historical perspective on

MENTAL RETARDATION
during the decade
1954–1964

a compilation of articles in children
Those articles from CHILDREN (1964–1964) dealing directly with mental retardation are found in the first section entitled Mental Retardation. In addition, two other groups of articles are included: those on maternal and child health and crippled children's services since these areas, too, are on the threshold of expansion as a result of the 1963 Maternal and Child Health and Mental Retardation Amendments to the Social Security Act.
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MENTAL RETARDATION
during the decade 1954–1964

a compilation of articles in CHILDREN

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
WELFARE ADMINISTRATION • Children's Bureau • 1964

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Foreword

THE DECADE 1954–1964 was of historic importance in the Nation’s efforts to do something about mental retardation, particularly as it affected children.

Beginning early in the fifties, the Children’s Bureau was hearing a rising clamor from citizens and public officials alike about the problems of mentally retarded children.

For the Children’s Bureau, the decade began and ended with a landmark. In 1954, the Children’s Bureau took a major step forward in service to the mentally retarded when the Bureau made its first special project grant from maternal and child health funds for a diagnostic clinic.

The decade closed with President Kennedy signing the 1963 Maternal and Child Health and Mental Retardation Amendments to the Social Security Act.

From the vantage point of 1964, these articles seem vital and important as a historic record of the decade that put new meaning for retarded children into the words a “fair chance for every child” regardless of race, creed, color, economic status, or physical or mental handicap.

KATHERINE B. OETTINGER
Chief, Children’s Bureau
WELFARE ADMINISTRATION

Provided by the Maternal and Child Health Library, Georgetown University
The Children's Bureau has long been concerned with the health and welfare of mentally retarded children. In fact, it was almost at the time of the Bureau's founding in 1912 that attention was focused directly on these unfortunate members of our population. In the broad mandate that instructed the Bureau "to investigate and report upon all matters pertaining to the welfare of children and child life among all classes of our people," all children were included. And so it was natural that in its very first year of life, the Bureau began studies of children with special problems. Among these children were those called in the parlance of the time "feebleminded," or the "mentally deficient."

The Bureau knew that by making efforts to aid those who were abnormal or subnormal or suffering from physical or mental ills, it could advance the health and welfare of normal children. As has so often been the case in the Bureau's activities, a citizens' committee played a large part in getting this first study of mentally defective children underway. A group of about 40 persons organized under the leadership of the "Monday Evening Club" requested a study of the problem of "mental defectiveness" in the District of Columbia. These citizens in the Washington community realized that there was no special provision made for the care of these mentally handicapped individuals who, more often than not, were unable to care for themselves.

The need for some sort of custodial institution was seen by other groups as well. The District Board of Charities reported that the District of Columbia was forced to send its mentally defective children to institutions located in Pennsylvania, New Jersey, and Virginia. The Board of Children's Guardians reported "* * * the same unsatisfactory condition as a year ago and for many years preceding. While bills have been pending in Congress for several years intended to establish a training school in the District of Columbia for feeble-minded children, none has been enacted." The superintendent of the Home for the Aged described the difficulties of making a home-like atmosphere for the elderly when the institution was forced to house many persons not because they were old, but because they were mentally infirm and there was no place else for them to go. The superintendent of the National Training School for Girls, looking to the future, recognized that without proper care, these girls would become "helpless mothers of successive illegitimate children."

Clearly, then, citizens were aware of the need for appropriate care for the "feeble-minded." And, clearly, any information regarding the extent of the problem would be a great impetus in obtaining the goal of a proper institution. In rising to meet this need, the Children's Bureau, through a research study, brought evidence to bear on many phases of the problem—the individual suffering and degeneration, the burden to families, the handicap to the school system, and the danger to the whole community from the lack of proper provision for those suffering from mental defect.

The Bureau published its findings under the title Mental Defectives in the District of Columbia in its series on dependent, defective, and delinquent classes. In this publication, we see the early definition of what we now call mental retardation. It was quite different from today's. These early pioneers in the
field were seeking to make a distinction between insane persons and mentally retarded persons. Thus they wrote:

The term "mental defect" implies congenital defect occurring in early life as contrasted with "insanity," implying a diseased condition developed in later life.

The author of this early study, Emma O. Lundberg, social service expert for the Bureau, also tells us that the term "feeble-mindedness" was then largely used in the United States as a generic term applied to "all persons who because of mental defect are incapable of normal development." We also learn that it was the American Association for the Study of the Feeble-Minded who, in 1910, adopted the classifications used in this field for many years.

Although it was impossible to make individual tests of mentality, the investigators made great efforts to enumerate the number of mental defectives in the District of Columbia who might be assumed to be proper cases for institutional treatment. Allowing for error in omission and inclusion, a figure of approximately 800 mental defectives was reported. Of this figure, 273 were under 15 years old. It was strikingly revealed, however, that the institution population at that time was composed mainly of older individuals, rather than of children of the age when training would be profitable.

Since there was no institution designed especially for these unfortunate persons, a number of them were found in reformatories, hospitals, homes for dependents, the Government Hospital for the Insane, and private homes totally unequipped for their care. A typical, poignant case is a woman, 72 years of age, who was confined to a hospital for the insane for 60 long years because there was no place else for her.

* * * She has been unnecessarily subjected to the restraint and conditions surrounding the insane. Had she from childhood been in an institution in which she could have received the training and education her mental condition made possible, she would have spent the years of her institutional life in useful occupation that not only would have made her happier but would have yielded some return to society.

The study also revealed that the so-called special schools in the District were really not equipped to handle severely defective children, yet such children were found in attendance—again, because there was no other place for them.

The report also covered the extent of State provision for mental defectives, the kind of institution adapted to their care, and treatment and economic aspects of the problem. Most important, the author constantly brought out the possibility of training these individuals for a useful life. The appendix to the study offered concrete illustrations of various phases of the problem of mental defect.

Thus was the Bureau's struggle for aid to the mentally retarded begun. Though this first published report was only in reality a brief social survey, it brought the problem to light and forced recognition of the fact that a child with a mental defect has his right to special and appropriate care just as much as a child who is blind or who is born without an arm or a leg.

But the work of the Bureau was not to stop here while its attentions were turned elsewhere. It was found, in fact, that through its other concerns, more information about mental defect was to be gained. By its studies of dependent children, the Bureau learned much about the number and needs of mentally defective children. Moreover, juvenile courts were able to provide a good deal of fact because of the close relation between delinquency and defective-ness. In Chicago, the juvenile court employed a physician who devoted his entire time to the mental examination of children coming before the court. Other courts in other States picked up this idea, and it was thus that in reporting delinquency cases to the Bureau, States were also able to report upon mentally defective delinquents. Also adding to the Bureau's knowledge on the subject of the mentally defective were the studies on illegitimacy and feeble-mindedness. By acting as a sort of clearing-house on legislation, the Children's Bureau was able to provide States with information as to what their neighbors were doing to aid the feeble-minded.

The year 1917 again saw attention focused directly on the mentally defective. Miss Emma O. Lundberg undertook the study of the social conditions and needs of mentally defective persons in New County Castle, Delaware. The study was part of a general survey of educational and social needs in Delaware in which the Bureau of Education and the Public Health Service were also engaged. It afforded general evidence as to the social injury and personal suffering caused by the presence in any community of mentally defective persons who lacked suitable
mentally defective. The idea that a child who could in another way help our mentally defective children not have proper parental care and guardianship was not known how such public responsibility was recognized or expressed. By finding out, the Bureau could in another way help our mentally defective children.

The next published study dealing with mental defect came in 1919 and was again done in cooperation with the Public Health Service. Mental Defect in a Rural County was a "medico-psychological and social study of mentally defective children in Sussex County, Delaware." In her letter of transmittal to Secretary of Labor Wilson, Julia C. Lathrop, then Chief of the Children's Bureau, noted that "the study demonstrates the importance of combining medical and psychological investigations in a study of the prevalence of mental defect."

At that time in a rural district such as Sussex County where living conditions were primitive, families needed to be socially and economically independent. For those who could not remain independent, such as the severely mentally defective, there was the Sussex County Almshouse—the only public institution in the county. The study noted that mental defect was coming to be regarded by more and more persons as a medical problem and one requiring scientific study. The difference between mental defect and mental illness as we know it today was beginning to be recognized. It was pointed out in this introductory material that psychoneurotic individuals who make childlike emotional adjustments, or individuals with retiring and "shut-in" tendencies and who may eventually develop dementia praecox, might be mistaken for a high-grade mental defective. Use of the Binet scale to determine the mental age of the child was mentioned for the first time in this Children's Bureau study.

The findings of the researchers were again just what one might expect. There were a high number of mental defectives and most of them were uncared for. As in other places throughout the country, the feeble-minded in the public schools benefited not at all from regular classes and, in fact, only disrupted them. In the section "Social Study of Mentally Defective Children," the study takes on new proportions and becomes more definitive than previous studies. Investigators looked at the types of homes in which the children lived, the adequacy of care they received, the social and intellectual status of the family, characteristics of the children themselves, children not living in their parental homes, children in the almshouse, children with no home, children with mental defect who were working in industry (on farms and in canneries and the like), mental defectives as "offenders against social standards," and also the recurrence within families of mental defect.

During the years that followed this study, the Children's Bureau continued to act as a clearinghouse of information on trends in the States and thus focused attention on the problem. Early recognition of defect in a child was known to be of vital
importance. With this in mind, the Bureau helped demonstrate a mental clinic for preschool children in Boston. This idea of attempting to understand a child's mental difficulties at an early age, as well as his nutritional, postural, and other physical needs, was a big step forward in the field.

Later, in 1923, the Bureau undertook a study of the work histories of minors who had been pupils in special classes for mental defectives. They picked 7 cities and obtained work histories of 1,000 minors who had been in these special classes. They also obtained information on special facilities offered, on vocational training, placement, and supervision in industry of boys and girls of subnormal mentality. The great majority went into work of an unskilled or semiskilled type that required little; if any, preliminary training. More than half were in manufacturing and mechanical industries. Others were in transportation as truck and taxi drivers, telephone and special delivery messengers, and delivery boys. Most girls were factory workers, and the next largest number were in personal and domestic service. Many were salesgirls. Seventy-eight percent of the boys performed their jobs satisfactorily; for eighty percent of the girls, this was true. The study, published under the title Employment of Mentally Deficient Boys and Girls, seemed to indicate that there is a place for subnormal boys and girls in industry.

As an index of what the Nation was doing regarding mental defect, Grace Abbott, second Bureau Chief, noted in her annual report of 1927 various legal enactments in the States. Much of this activity was, of course, stimulated by Bureau interest and concern, so that it was "heartening to see the country attempting to begin to meet the needs of these children." In Arizona, a bill provided for the creation of a children's colony for the care and education of mental defectives. Kansas enacted a law requiring boards of education to ascertain the number of children in public schools who are 3 or more years retarded in their school progress and to establish special classes for them. Minnesota, Indiana, Pennsylvania, and Nebraska all passed laws that year relating to the feeble-minded. Many other States either passed or had before their legislatures bills for sterilization of the feeble-minded. (This was then thought to be a useful way of controlling the problem.)

By 1931, many more States were making efforts to care for the feeble-minded. Connecticut authorized their comptroller to pay towns $150 annually for each mentally subnormal child attending, for the full year, special classes provided by such towns. Provision was also made for State payment to the county commissioner for special classes established in county temporary homes. Illinois broadened the act that created their State colony for epileptics to include mentally retarded children. Indiana provided for a special school census to discover school children retarded by 3 years or more attending public school or of school age. Some States were even changing the names of their institutions for the feeble-minded, dropping the word "feeble-minded" to avoid undesirable connotations. Massachusetts was attempting to establish supervision for retarded children outside of school hours. And many other States were passing laws relating to support of mental defectives and to their admittance to institutions.

The year 1935 marked the passage of the Social Security Act, important to our Nation in so many ways. It was important to the field of mental retardation because it allowed a gap in health services to these children to be partially filled. The law provided the Bureau with the added responsibility of administering Federal grants for maternal and child health, crippled children, and child welfare services. And it emphasized the principle that everyone, through the Federal Government, shares with the State and local governments the responsibility for helping to provide community services that children need for a good start in life. Through demonstration programs in maternal and child health, the Bureau hoped better health services could be provided by the States for mentally retarded children.

This, however, was not enough. It was still the case that severely damaged infants did not survive, and the general feeling about those who did was that little or nothing could be done for them. A common way of handling the problem was to hide it. But, between 1940 and 1950, many changes took place in the American way of life that had a dramatic effect on the problem of mental retardation. The United States had the biggest baby boom in history. As the population increased, so did the number of mentally retarded. Better care of all mothers and babies and medical advances resulted in the survival of more babies, and hence more retarded babies who might have died in earlier years.

Mothers and fathers of retarded children banded together to seek help for their children. Reports began to appear showing what some retarded children could achieve if help were provided. By 1950, organized groups of parents undertook two major tasks. They set out to learn how their long-
neglected children could be helped, and what was needed to help them. In their efforts, the parents enlisted a variety of resources, including the Federal Government. Among the Federal agencies who responded early to the pleas of these parents was the Children's Bureau.

During the early 1950's, the Bureau set out to discover in detail what the States were doing. By 1954, the Bureau could report that maternal and child health activities in behalf of mentally retarded children and their families were extremely limited. Many local public health nurses were reporting in their caseloads children suspected of being mentally retarded, but for the most part they had few or no resources for establishing a diagnosis. Consultation and guidance as to how to deal with these children and their families generally were not available. Some children who were functioning below the normal expected level of development were being followed in well child conferences, but adequate developmental and diagnostic appraisal was usually unavailable. Nor was there any continuing guidance for parents once a diagnosis had been made.

As a result of what it had learned and in response to the rising clamor from citizens and public officials alike, the Bureau now took a major step forward in service to this group of children. In 1954, with a special project grant to California from maternal and child health funds, a diagnostic clinic for mentally retarded children was set up at the Children's Hospital in Los Angeles. In 1955, grants were made to Hawaii, the District of Columbia, and Washington to set up special projects which would demonstrate how clinical services might be developed in the community. The following year, 1956, Federal funds became available which were earmarked specifically for mental retardation. By that time, the Bureau knew enough to state succinctly the principal needs in services for mentally retarded children. Dr. Martha Eliot, then Chief of the Bureau, told the Congress:

- We must find these children early.
- We must provide a complete evaluation of each case.
- We must interpret the findings to parents.
- We must use these findings as a basis for ongoing help and care.

Studies had shown that the biggest gap in services was in relation to infants and preschool children. The basic needs of these children were and are, indeed, only an intensification of the needs that all children have for preventive health services, child health supervision, and good parent-child relationships.

Congress responded to the testimony it heard by providing that $1 million of grant funds should be used specifically for special projects in the field of mental retardation. With these funds, the Bureau could now aim direct efforts at providing proper care for these children. The Division of Health Services approved 26 special demonstration projects in the States. These projects, operated as part of State health department programs in maternal and child health, were each designed to:

- Provide early case finding, evaluation, diagnosis and treatment, planning and followup care, particularly for preschool mentally retarded children and their families;
- Evolve patterns of service and methods of providing services which all State health departments could use;
- Provide training and orientation for a variety of professional workers.

The Bureau was quick to point out that while it might seem that a major portion of staff would be devoting large amounts of time for a specialized group, the results of their efforts would benefit all children. For example, by studying how toxic agents, complications of pregnancy, nutritional deficiencies, etc., can result in mental retardation, it was possible to promote improved prenatal care, obstetrical services, and well baby care and thereby improve the general health and well-being of all mothers and children.

During the time the Bureau's central office and regional staffs were working hard to develop this program, the Children's Bureau through its consultant on mental retardation worked directly with health departments on such important problems as methods of financing comprehensive care, relationships between State governments and nonofficial groups and agencies working in mental retardation, desirable State legislation, and educational programs for professional personnel.
States began to evaluate critically their respective programs and existing legislation and regulations affecting this group. They saw that it was more than just a medical problem. Child welfare agencies began to include mental retardation as a separate category requiring the same special attention as day care, adoption, or licensing of agencies and institutions.

The States were quick to report their social service activities in the field, thus enabling the Bureau to once again act as a clearinghouse of information. The fact that the public was beginning to grow in its understanding of the capacities and special needs of mentally retarded children, and the fact that community resources to meet these needs had been expanded, were major factors contributing to the emphasis on rehabilitation services for this group. As more children were able to remain in their own homes or foster homes, professional casework help in facilitating the social and emotional well-being of the total family was being widely recognized as a vital need. The trend was away from long-time custodial care, and institutions were coming to be regarded as training resources for those who need temporary segregation from society.

In 1956, the Bureau, as part of its series of folders on handicapped children, published The Child Who Is Mentally Retarded. Addressed to parents, this publication explains briefly and simply about mental retardation and offers some encouraging notes for parents who often know very little about what is wrong with their child.

In 1958, maternal and child health programs continued to expand in the area of mental retardation. By then, 36 State health departments were offering special services to the retarded. And in the regions, the Bureau sponsored biregional conferences for professional workers to share experiences and ideas. In addition, the Division of Research developed a report form which was sent to States operating mental retardation clinics to accumulate service data. For the calendar year 1958, a total of 7,097 applications for admission to clinics were handled in 37 States, an average of 192 for each State.

At the same time, a great surge of interest in mental retardation occurred in schools of social work. Two institutes for faculty were held at the Universities of Utah and Tennessee in March. Child welfare workers in the States were attempting to expand preadmission and post-discharge services for children in State institutions, indicating a growing acceptance of local responsibility. Consultation was offered to the States by the Bureau to help them modify their licensing requirements in light of increased services to the mentally retarded. Moreover, State agencies were actively considering the social services required by other members of the family as well as by the mentally retarded child himself.

By this time, it was widely recognized that many of these children could be cared for in the home. However, little material was available to parents to help them in caring for their retarded child at home. In light of this, the Bureau published in 1959 a manual for parents titled The Mentally Retarded Child at Home. Written with warmth and understanding, the booklet offered some answers to the heartache and frustration that comes from not knowing how to provide what is best for these youngsters. Practical information about day-to-day care was given. Most of the manual was devoted to ways of helping the young child attain his maximum independence.

Programs under maternal and child health auspices continued to enlarge in 1960. Considerable progress was made in joint planning on the part of official State agencies, but little success was gained with respect to work with voluntary agencies. In the States, much activity was being carried on. New projects were being started, old ones carried on, new clinic facilities were being established, legislatures were allotting more money for facilities and services, and many evaluation centers were opening.

By the start of the 1960's, conferences, symposiums, training courses, and institutes were being carried on in many places in order to train workers for these programs.

Meanwhile, the Bureau continued to provide consultation to the States on such problems as costs, inservice training, personnel resources, and the relatively new and fast increasing problem of retarded delinquents.

To help professional people working in the field, the Bureau's Clearinghouse for Research in Child Life published in 1960 a special issue on Research Relating to Mentally Retarded Children. This booklet included research projects since 1949 and separated these studies into easily recognizable categories, such as mongolism, intelligence, and personality.

By the middle of 1960, the Bureau had information which showed that increased efforts should be made to reach more new cases and spread services to broader areas. The Bureau urged the establishment of new clinics, greater geographic coverage in the clinics already established, and some new ap-
The demonstration projects had proved their worth, and it was now time to let local health departments use what they had learned.

To call attention to the metabolic disorder, phenylketonuria, the Bureau published *Phenylketonuria: An Inherited Metabolic Disorder Associated With Mental Retardation*. Written by two doctors for doctors and public health workers, it describes approaches to screening, early detection, and treatment. Publication of available information at that time did much to promote interest and action in this area. States began to move ahead with plans for the detection and followup of the disease.

By mid-1961, the Bureau was involved in a broadscope screening program for the detection of phenylketonuria. Financed by Children's Bureau grant-in-aid funds, the program was gotten underway in hospitals in 26 States. It was designed to test the effectiveness of routine screening of newborn infants as a regular part of hospital procedure. At this time, the Bureau completed and published *An Inventory of Children With Phenylketonuria* as a basis for its followup study of the effects of dietary treatment on the mental development of PKU children and the influence of such factors as age at which treatment is initiated, duration of treatment, and problem of dietary control.

In 1961, the Bureau issued a progress report, *Health Services for Mentally Retarded Children, 1956–1960*. It showed how the States used the special maternal and child health project funds and described the special demonstration projects in the States. The Bureau also compiled lists of special clinical facilities for mentally retarded children and published them from time to time. Initially developed to facilitate the exchange of new ideas, approaches, and techniques among these special programs, the listing has also been of use to some agencies and programs as a partial directory of specialized clinical services for this group of children.

Between 1958 and 1961, public institutions for the mentally retarded increased from 99 to 111, while private institutions more than doubled from 182 to 400. However, studies indicated that the addition of new facilities had not reduced waiting lists. This brought out the fact that more selective criteria in admissions were needed as well as expanded community services in foster family care, group day care, and other social services.

The establishment of the President's Panel on Mental Retardation increased the Bureau's role in the field. Katherine B. Oettinger, Children's Bureau Chief, was asked to serve as co-chairman with Mrs. Eunice K. Shriver for a seminar on therapeutic recreation for retarded children. Other Bureau staff met many times with Dr. Leonard Mayo and other President's Panel members to discuss areas of mutual concern.

Another gain for mental retardation services came in 1961. In July, appropriations for both maternal and child health and crippled children's services were increased to $25 million, the full authorization for each program. Of that money, $1 million was earmarked for mental retardation. At that time, 46 States were providing some special direct clinical services to retarded children and their families. Over 12,000 such children were served in 1960; some 4,500 medical students received training through use of the special clinics; and over 25,000 public health nurses received some orientation in working with mentally retarded children and their families.

The Children's Bureau was also focusing attention increasingly on children with multiple handicaps. A sizeable number of children in pediatric hospitals and on State crippled children's caseloads were found to be suffering from physical as well as neurological handicaps. Many of them had conditions so complex that a high degree of professional skill and specialization by several disciplines was required for treatment and rehabilitation. Because these children could not be adequately cared for by the family physician, the Bureau was constantly urging States to set up their clinics and medical centers accordingly.

The year 1961 also saw new funds through legislation to accelerate development of social services. Money was made available to States for research and demonstration projects in child welfare. Particular attention was directed in the area of day care for retarded children. Representatives from the Bureau worked with the National Association for Retarded Children on an ad hoc committee to consider programs and issues regarding group day care for these children. Working together in this manner offered an excellent opportunity to define and interpret the objectives of day care and to consider criteria for the admission of retarded children to these programs according to standards of good child welfare practice.

During 1961, a workshop on Mental Retardation for Social Workers in Maternal and Child Health
Projects was held which offered many ideas for social workers in mental retardation programs. So that this wealth of information would not be confined to those attending, the Bureau later published some of the speeches given there under the title Child Health Projects for Mentally Retarded Children: The Role of the Social Worker.

During 1962, screening for phenylketonuria was in effect in 29 States and Puerto Rico. About 181,000 newborn infants had been given the Guthrie blood test and PKU was confirmed in 18 of these infants, a figure nearly double the number anticipated on the basis of estimated incidence of this inborn error of metabolism.

The clinics and special projects supported by the maternal and child health programs served approximately 25,000 children and their families in 1962. Despite this increase in the total number served, the requests for these services continued to mount. Since 1958, there has been an increase of 145 percent in applications that could not be served in the year in which they applied and which had to be added to a waiting list. Approximately 77 percent of the new cases admitted were under 9 years and 75 percent of those under 6 years had a variety of physically handicapping conditions in addition to their mental retardation.

State crippled children's programs were developing services designed to increase mobility and self-care activities of retarded children. An excellent example of a successful project was in Minnesota at the Faribault School for the Mentally Retarded. A Mayo Clinic physician had conducted monthly with the child and the parents as well; social group work with both the parents and the child; and types of care, planning and guidelines for ways of training these children.

A report entitled Institute on Nutrition Services in Mental Retardation Programs relates how nutritionists, dietitians, and allied workers met to explore their functions in services for this group and to consider ways of strengthening and extending the nutrition component of clinical programs.

In order to take into account the most recent research and investigation, the Bureau brought up to date its bibliographies on phenylketonuria and on galactosemia. These bibliographies cover all the major aspects of research and select the kind of references that will direct the reader into more intensive study of a given aspect if he wishes to pursue it.
racy of reporting and, in addition, preparation was begun of a 5-year statistical summary of services provided by medically directed clinical programs.

The report of the President's Panel on Mental Retardation included recommendations relating to research and manpower, treatment and care, education and preparation for employment, legal protection and development of Federal, State, and local programs for the mentally retarded. The report showed that mental retardation affects some 5.4 million children and adults and involves some 15 to 20 million family members. Cost of care was estimated at $550 million a year, plus a loss to the Nation of several billion dollars of economic output because of the underachievement, underproduction, or complete dependence of the mentally retarded.

The report found that epidemiological data from many reliable studies showed a remarkably heavy correlation between the incidence of mental retardation, particularly in its milder manifestations, and the adverse social, economic, and cultural status of groups of our population. This was especially true for low income groups who lived in slums where the mother and the children received inadequate medical care, where family breakdown was common, and where individuals lacked opportunity and adequate education. In short, the conditions which spawn many other health and social problems are, to a large extent, the same as those which generate mental retardation. Therefore the panel concluded that "to be successful in preventing mental retardation on a large scale, a broad attack on the fundamental adverse conditions will be necessary."

In the report's comprehensive analysis of factors relevant to mental retardation and its survey of programs and resources in this country and foreign lands, central themes permeated and guided the report: (1) retarded persons have potentials for productive living beyond those heretofore recognized; (2) responsibility for the mentally retarded must be shared by Federal, State, and local governments and voluntary groups and organizations; and (3) a real possibility exists of preventing mental retardation on a large scale through a broad assault on adverse environmental conditions in our society. This report, which embraced many dimensions of the problem—research, prevention, clinical and social services, education, vocational rehabilitation and training, residential care, legal aspects, planning and coordination of services, and public awareness—represented a monumental contribution toward stimulating program development and advancing public understanding.

In his message to the Congress calling for remedial legislation, President John F. Kennedy said that we must seek out the causes of mental retardation and eradicate them * * * strengthen the underlying resources of knowledge and, above all, of skilled manpower which are necessary to mount and sustain our attack on mental disability for many years to come * * * strengthen and improve the programs and facilities serving the mentally ill and the mentally retarded. Emphasis on prevention, treatment, and rehabilitation will be substituted for a desultory interest in confining patients in an institution to wither away * * * For too long the shabby treatment of the many millions of the mentally disabled in custodial institutions and many millions more now in communities needing help has been justified on grounds of inadequate funds, further studies and future promises. We can procrastinate no more. The national mental health program and the national program to combat mental retardation herein proposed warrant prompt Congressional attention.

And on the same day, February 5, 1963, Representative Wilbur Mills, Chairman of the House Ways and Means Committee, introduced the "Maternal and Child Health and Mental Retardation Amendments of 1963" (short title of the bill), which carried out the recommendations of the President for legislation on this subject.

Between the time the bill was presented to Congress and its passage, the Children's Bureau ended its Golden Anniversary year. As a fitting way to close the year, the Citizens' Committee for the Fiftieth Anniversary of the Children's Bureau called a conference of 75 leaders in the field of child care to consider the implications for children of the Report of the President's Panel on Mental Retardation. This conference was held in Washington, D.C., on April 9, 1963.

In conjunction with the Children's Bureau itself, the anniversary committee had invited a varied assortment of leaders to review and discuss and, most important of all, to determine "desirable next steps" to assure translation of the recommendations of the President's Panel into action. Individuals represented such organizations as the Child Study Association of America, the American Legion, the Urban League, the American Medical Association, the Salvation Army, and the National Congress of Parents.
and Teachers. There were also specialists in public health, psychiatry, obstetrics, pediatrics, nursing, education, social work, religion, and representatives of governmental and voluntary agencies.

The scope of the meeting was both broad and deep. In a full day of speeches and panel discussions, the conferees made incontrovertibly clear the size and infinite complexity of the mental retardation problems. A small pamphlet, *The Steps Ahead*, written by Dorothy Barclay Thompson, was published about the conference.

The mental retardation bill became Public Law 88–156 on October 24, 1963. At the time of the signing, President Kennedy called this new act “an important landmark in our drive to eliminate one of the major health hazards affecting mankind.”

It was true that by this time as a nation, we knew enough to make important inroads against some of the causes of and contributors to mental retardation. To this end Congress amended the Social Security Act to assist States and communities “in preventing and combating mental retardation through expansion and improvement of the maternal and child health and crippled children’s programs, through provision of prenatal, maternity, and infant care for individuals with conditions associated with childbearing which may lead to mental retardation, and through planning for comprehensive action to combat mental retardation, and for other purposes.” The act authorized a 5-point grant program of $265 million over a 5-year period.

It doubled the annual authorization for Federal grants for maternal and child health services administered by the Children’s Bureau under Title V, part 1, of the Social Security Act over a period of 7 years in steps of $5 million, from the present $25 million to $50 million for 1970 and subsequent years.

It provided identical increases in the authorization for Federal grants for crippled children’s services, administered by the Children’s Bureau under Title V, part 2, of the Social Security Act.

It authorized a new 5-year program of grants to State or local health agencies for projects to provide necessary health care for expectant mothers who have, or are likely to have, conditions associated with childbearing that increase hazards to the health of the mothers or their infants.

It authorized appropriations not to exceed $8 million for any fiscal year for grants, contracts, or jointly financed cooperative arrangements for research projects to improve maternal and child health and crippled children’s services.

It authorized a one-time appropriation of $2.2 million for grants to States to assist in developing plans for comprehensive State and community action to combat mental retardation. The Federal share is limited to 75 percent of the cost of the State’s proposed planning and related activities. It was decided that this aspect of the legislation was to be administered by the Public Health Service.

The annual grant appropriation authorized for the fiscal year 1964 is $5 million. This authorization is increased to $15 million in fiscal 1965 and $30 million for the next three fiscal years. Appropriated money will be available to State agencies for providing up to 75 percent of the cost of any projects. Money for planning grants is also available. These grants will enable States to develop public awareness of mental retardation as a problem and of the need for combating it; to coordinate State and local activities relating to the various aspects of mental retardation and its prevention, treatment, or amelioration; and to plan for other activities leading to comprehensive State and community action.

Research supported by this program is applied research directed toward the improvement of services. Examples might be the methods of assessing a mentally retarded child’s potential for progress that can be applied in the office of a pediatrician or a general practitioner, or a long-time followup of cases of children with PKU who have been on special diets to determine the results of treatment.

The ability of public child welfare agencies to serve retarded children and their families had already been strengthened by the 1962 amendments to the Social Security Act. Through the Bureau, the act provided for gradually increasing the ceilings on child welfare authorizations from $25 million over the succeeding 5 years, so that by 1970 these authorizations will amount to $50 million a year. Through these funds, the Bureau is able to promote group or family day care, special foster family care, licensing standards, and consultant services so badly needed for these children.

On any one day in 1962, public welfare agencies were providing child welfare services to about 30,000

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mentally retarded children. Nearly half of these were in foster care.

About one-fifth of the States in 1963 were providing day care services for mentally retarded children in day care centers or family day care homes. State and local public welfare agencies were giving attention to the needs of the mentally retarded child, particularly those whose retardation grows out of cultural deprivation. They were searching for ways of protecting these children from emotional and moral neglect, for methods of providing them with mental stimulation, and giving help to parents in giving more adequate care for these children. Special attention was being given to developing small group homes, special foster family care, and day care for many of these children. Public agencies were developing licensing standards and consultant services for voluntary facilities to provide improved services and care for these children.

The enactment of the 1963 Maternal and Child Health and Mental Retardation Amendments represented a major breakthrough for mentally retarded children.

The Children's Bureau would now be able to put its long years of experience and knowledge about these children to work in their behalf.

Early 1964 found the Children's Bureau busy helping States plan for the best use of the Federal funds available under the new legislation.

For the Bureau, this was the beginning of a new era.
Mental Retardation
Factors in Mental Retardation
A Program for Mentally Retarded Children
Home Training for the Mentally Retarded Child
Some Pointers for Professionals
What Hospitals for the Mentally Retarded Can Achieve
Home Training for Retarded Children
Community Clinics for the Mentally Retarded
Child-Welfare Service for the Mentally Retarded
Atypical Children With Communicative Disorders
Research Trends in Mental Deficiency
Counseling Parents of Retarded Children
Care of the Mentally Retarded in Sweden
A Home Economist in Service to Families With Mental Retardation
Mental Retardation in the Soviet Union
Minimal Brain Damage in Children
Guardianship for the Mentally Retarded
Orientating Parents to a Clinic for the Retarded
The Doctor and the Handicapped Child
A Proposed Program to Combat Mental Retardation
Mentally Retarded Teenagers in a Social Group
The Physician and Parents of the Retarded Child
The Public Health Nurse in a Program for the Mentally Retarded

Maternal and Child Health
Maternal and Child Health
Maternity Care Looks to the Future
Helping Mothers Handle Emotional Problems
Child-Health Services Since 1935
Twenty Years of Maternal Care
Changing Emphases in School Health Programs
Prenatal Nutrition and Infant Health
Teamwork in Helping Families to Launch a Life
Perinatal Casualties
Improving Maternal and Child Health Through Statistical Studies

Articles

Health Services—Accomplishments and Outlook
Hospital Consultation to Improve Maternity Care
A Broad View of Maternity Care
Deterrents to Prenatal Care
Moving Ahead Against Mental Retardation
Role Playing in a Maternity Home

Crippled Children
Crippled Children
A Nursery School for Cerebral-Palsied Children
When Children Are Born With Defects
Stabilizing Influences in Helping Handicapped Children
Services to Crippled Children, 1935–55
Treating Young Children for Hearing Impairment
Evaluating Care of the Orthopedically Crippled
What Affects Blind Children's Development
Therapeutic Group Work With Handicapped Children
Coordinating Health Services for Handicapped Children
Helping Parents of Handicapped Children
Parents of Children With Congenital Amputation
The Family Approach to Feeding Chronically Ill Children
The Dental Problems of Handicapped Children
A Nursery School for Cerebral Palsied Children
Blind Children With Developmental Problems
The Influence of Handicapping Conditions on Child Development
Group Education for Parents of the Handicapped
Communicative Disorders in Children
Adoption Opportunities for the Handicapped

The New Threshold
Accent on Prevention Through Improved Service

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MENTAL RETARDATION
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MENTAL RETARDATION

The many articles on mental retardation that appeared in CHILDREN during the decade 1954-64 varied over a wide range—from an article portraying the reaction of a mother to her mentally retarded child and the ways she found of helping him to a whole series of articles directed to the highly skilled professional people working with these children and their parents. The first article, Factors in Mental Retardation, by Dr. George A. Jervis, in a sense forecasts the developments of the decade. The last article, Accent on Prevention Through Improved Service, by Dr. Arthur Lesser, in a sense forecasts the next decade.

These articles, even the older ones, are still of great value to workers in the field.
What can be done for children who are mentally retarded? The question is being urgently pressed today by parents who are not willing to assume the long-accustomed attitude that children thus disadvantaged should be hidden away in shame; and by others who believe that all children, even those whose capacities are extremely limited, should receive opportunities for achieving their maximum potentialities.

CHILDREN plans to explore this question in a series of articles in forthcoming issues by persons engaged in various aspects of work with mentally retarded children and their parents. Because an understanding of any problem is a prerequisite to an intelligent consideration of efforts toward its solution or alleviation, the series is being introduced with this article defining the phenomenon of mental retardation—insofar as it can be defined—and presenting its known and suspected causes.

FACTORS IN MENTAL RETARDATION

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VARIOUS SCIENCES have contributed to our present concept of mental deficiency. For a long time sociologists have observed that there are individuals who, since childhood, have been socially incompetent and incapable of adequate self-support. Psychologists, coming later, have noted that this social incompetence is often associated with defective intellectual development. They have discovered ways of measuring the degree of intellectual deficit and of establishing certain correlations between intellectual endowment and social attainments. Then as medical science advanced physicians became increasingly aware that some diseases occurring during fetal life or in infancy may result in lesions of the brain with consequent mental defect. Finally, with the advent of the science of human genetics the relevance of genetic factors in determining deviations of intelligence emerged.

Mental deficiency may be defined as a condition of arrest or incomplete mental development existing before adolescence, caused by disease or genetic constitution and resulting in social incompetence. This definition includes both the sociological concept which stresses the social inadequacy of the defective, and the psychological concept which is considered in the term "arrested" or "incomplete" mental development. The biological viewpoint is embodied in the mention of genetic factors and diseases.

Intellectual impairment developing after adolescence is not usually known as mental deficiency but as dementia, a customary differentiation for more than a century in both legal and medical thinking, in spite of its dubious validity.

Thus defined, mental deficiency is not a single condition, but a symptom common to diverse conditions of disparate etiologies and of various manifestations.

In the recognition of mental deficiency, the results of psychological examination play the leading role. The mental age (MA) is determined by psychometric tests and the intelligence quotient (IQ) calculated as...
the rapport of the mental age to the chronological age (CA): \( \text{IQ} = \frac{\text{MA}}{\text{CA}} \times 100 \). Other factors besides intelligence quotient are taken into consideration, such as educational attainment, emotional reactions, general behavior, and social adjustment. The information from both familial and personal history is carefully evaluated. Finally, a complete medical examination is performed, using modern techniques of clinical and laboratory medicine. It is upon the evidence thus collected that the diagnosis is made.

Considerable difficulty is often experienced in diagnosing the borderline cases between “subnormality” and mental deficiency. The criterion of social adjustment is decisive in these instances.

**Incidence and Classification**

In estimating the incidence of mental deficiency, a great deal depends upon the criteria of diagnosis used in the assessment of defective individuals. For instance, if the criterion of social incompetence is adhered to, the incidence will be higher in a strongly competitive urban environment than in rural communities. If a purely psychological criterion is adopted, the test used and the arbitrary point of demarcation between the defective and the nondefective individual will determine to a large extent percentage figures. If one accepts an IQ of 75 instead of one of 70 as the lower limit for the nondefective, the percentage of defective population will be over twice as large. Estimates based on institutional censuses are obviously inadequate and always too low, since only a fraction of the mentally defective population is institutionalized. Those based on large-group testing of school children have their limitations and are perhaps too high. Accurate surveys using modern techniques of securing data and uniform criteria of evaluating intellectual and social development have been few in number and limited in extension.

On the basis of scattered and incomplete data collected from many sources, it may be assumed that the incidence of mental deficiency in the general population is around 1 percent, using IQ below 70 as the criterion. This figure yields a total of 1,500,000 mental defectives in the United States.

Defectives are usually classified into three groups—idiots, imbeciles, and morons, but the corresponding terms of low-grade, medium-grade, and high-grade defective are to be preferred. Defined in sociological terms and in the language of the English Mental Deficiency Act (1927), idiots are persons whose mental defectiveness is of such degree that they are unable to guard themselves against ordinary physical danger. Imbeciles are persons whose mental defectiveness, though less extreme than in idiots, still prevents them from managing themselves or their affairs, or, in the case of children, of being taught to do so. Morons are persons whose mental defectiveness, though not amounting to imbecility, is yet so pronounced that they require care, supervision, and control for their own protection or for the protection of others, or, in the case of children, appear to be permanently incapable of receiving proper benefit from instruction in ordinary schools.

In more precise psychological terms, an idiot is a person having a mental age of less than 3 years, or, if a child, an intelligence quotient of less than 20. An imbecile is a person having a mental age of 3 to 7 years, inclusive, or, if a child, an intelligence quotient from 20 to 49, inclusive. A moron is a person having a mental age of 8 to 11 or 12 years, or, if a child, an intelligence quotient from 50 to 70 (or 75).

Although of considerable value in dealing with practical problems of defectives, both sociological and psychological classifications present limitations, being purely descriptive in character. More comprehensive are medical classifications which follow mainly etiological criteria, grouping patients according to the cause of the defect. While this type of classification may offer considerable difficulty in individual cases, because of scanty and contradictory etiological data or the fact that more than one etiological factor may be responsible for the defect, it does bring about a better understanding of the problem in relation to preventive measures.

Etiologically, mental defect can be divided into two large groups—endogenous or primary, and exogenous or secondary. In the exogenous group the defect comes chiefly from environmental factors. This group can be subdivided into types according to the causative agent—infec tious, traumatic, toxic, and endocrine. On the other hand, an endogenous defect is determined mainly by those hereditary factors known as genes. The group includes conditions due to the combined action of many genes each of which alone would have an insignificant effect, or to the action of a single dominant or recessive gene.

**Hereditary Defects**

Multiple genes. Mental defects determined by multiple genes are “undifferentiated” in that they carry no specific physical distinction and are “aclinical” in that they show no clinical manifestations.
other than intellectual impairment. This group has also been designated by other terms: "residual" because it is composed of individuals who are left after a classification of specific forms; "subcultural" because so many of its members originate from low cultural environments; "familial" because of the high frequency of the condition in the patients' families. Since these cases can be diagnosed only by psychological and social adjustment criteria, differentiation between high-grade morons and dull-normal individuals may be difficult. While antisocial behavior and psychopathic traits occur in the group, they are far from universal.

Estimates of the incidence of undifferentiated mental defects run between 30 and 75 percent of all the mentally retarded, the lower figure probably running nearer to the facts. It includes defects of all grades, but high-grade morons predominate.

While the etiological factors determining the large number of undifferentiated cases of mental deficiency are still in dispute, it seems likely that they are similar to the factors responsible for general intelligence—in other words, genetic constitution. It seems reasonable to assume that most of these undifferentiated cases represent merely the lower part of the normal frequency-distribution curve of intelligence, known to statisticians as the Gaussian form. This means that a certain number of individuals are bound to appear in the range below the line indicating IQ 70. They are an integral part of the population as a whole, just as are individuals with superior intelligence with an IQ above 130. According to the curve, the majority of undifferentiated defectives are in the moron classification with IQ's between 50 and 70, and only a very few at the idiot level, with IQ's below 20—a picture which corresponds to observed fact.

Genetic constitution, however, is not the only source of all undifferentiated defectiveness, for environmental factors, such as subcultural milieu and poor hygienic conditions, undoubtedly play a causative role. The task of tracing the source of the defectiveness in individual cases is not easy, particularly when malnutrition and deprivation have been in the picture.

**Single genes.** Some differentiated defects are determined by the presence of a single dominant gene transmitted from parent to child. Such defects are always traceable in the family history unless of a type that prevents reproduction. Frequently they turn up in severe form in alternate generations occurring in the intermediate generation only in incomplete form. Sporadic occurrences in families with no history of the defect are probably caused by a new mutation in a parental germ cell.

Data collected at Letchworth Village indicates that dominant genes probably account for only about 1 or 2 percent of all mental defects. These are always characterized by some physiological changes which make them classifiable into specific or clinically recognizable diseases. Among them are tuberosclerosis, neurofibromatosis, and neyroid idiocy—diseases in which mental deficiency is accompanied by skin lesions—and several forms of mental defect characterized by changes of bone structures.

There are also clinically recognizable defects caused by the presence of two similar genes, known as recessive genes, one from each parent. Since persons of blood relationship are more likely to carry similar genes, such defects occur more frequently among the offspring of consanguineous marriages than in the general population.

In the great majority of the recessive cases the parents themselves are normal, being merely carriers of the gene, or, in genetic terms, heterozygous for the gene. The defect is characteristically distributed among 25 percent of the sibs, and is sharply distinguishable. While such defects are on the whole rare, they include a number of specific diseases: amaurotic family idiocy, a progressive and fatal disease accompanied by blindness which, according to type, may show up in infancy, childhood, or adolescence; gargoylism, a disease characterized by mental deficiency and grotesque bone changes; phenylpyruvic idiocy, the result of an inborn error in metabolism of an amino acid; hepatolenticular degeneration, a progressive form of mental deterioration caused by degeneration of nuclei at the base of the brain; and some forms of diffuse sclerosis, also a progressive disorder causing brain damage.

**Environment-Produced Defects**

A large but not yet clearly determined proportion of defectiveness comes from factors outside the hereditary constitution including infections, trauma, poison, glandular disorders, and physical or emotional deprivation. Rough estimates, based on unpublished data from a number of institutions indicate that such factors may account for at least half of the mentally retarded population in the country.

**Infection.** Brain damage resulting from infection from the nervous system may occur in the womb or during infancy or childhood. The type of infectious agent, the severity of its attack, and the age of
the child when attacked determine the degree of damage.

One of the most prevalent of such infections used to be syphilis, transmitted during gestation from an infected mother through the placenta to the fetus and resulting in brain damage to the fetus and later mental defect in the child. While syphilis still is responsible for a small percentage of all defectiveness, the proportion of infected children has already been reduced by venereal-disease control programs and undoubtedly will be further reduced in the future. Especially effective has been the increasing adoption of routine serological tests of pregnant women, prescribed by law in many States.

One form of severe mental deficiency comes from rubella infection (German measles) in the mother during the first 3 months of pregnancy. Besides the intellectual impairment resulting from fetal brain damage the rubella virus's attack on the fetus often produces congenital deafness, anomalies of the heart and eyes, and microcephaly (undersized head and brain).

Facts about the effects of other virus infections of the mother on the fetus are not so definitely established. It is possible that some other viruses may act in a manner similar to that of the rubella virus.

Brain fever is estimated to be responsible for the mental defects of 10 to 20 percent of all institutionalized defectives, according to Letchworth Village data. Caused by one of the encephalitis viruses or by a bacteria, such as the meningococcus of meningitis, it often strikes in infancy and childhood. While many children recover from it completely and others die, some recover with permanent impairments, the most common of which is mental defect. Measles, scarlet fever, chickenpox, whooping cough, influenza, and other communicable diseases common in childhood also occasionally leave brain damage.

Patients whose mental defectiveness has resulted from acute attacks of these diseases are usually referred to as post-encephalitics. The degree of mental defect among them varies considerably with the individuals. Many of them exhibit a peculiar behavior pattern marked by episodes of overactivity, restlessness, impulsiveness, assaultiveness, and wanton destruction.

Trauma. While accidents resulting in injury to the brain may sometimes occur in infancy or early childhood they are insignificant in comparison to injuries at birth or in the neonatal period as a cause of mental defect. Cerebral trauma during birth has been variously estimated to cause from 10 to 50 percent of all defectiveness. However, the incidence in institutionalized defectives does not seem to be above 20 percent. According to data gathered by the United Cerebral Palsy from one-half to two-thirds of the children in the general population showing evidence of birth injury are not mentally defective.

Difficult labor and prematurity are the most frequent causes of brain damage during birth, the former because of the risk of mechanical injury and the latter because of the immaturity of the brain. An immature brain is more prone to damage.

Brain damage at birth comes either by asphyxia or by hemorrhage. Asphyxia, which must be present for a relatively long period to produce irreversible damage, may result from premature separation of the placenta, cord complication, overdosage of the mother with analgesic drugs, or delayed breathing by the newborn. Hemorrhage, which may be within the brain or its envelopes, comes from direct injury during delivery—by forceps, or by a tearing of the tentorium, one of the membranes of the brain, in compression of the head during its passage through the pelvic canal.

Toxic causes. Little is known about the effects of toxic factors transmitted from mother to fetus during pregnancy, but evidence exists for suspicion that there are several ways in which fetal poisoning, resulting in malformation and mental defectiveness, may occur. Eclampsia, a severe intoxication of obscure origin suffered by some pregnant and delivering women, may affect the child detrimentally. Some toxic drugs taken by a pregnant woman may also damage the fetus but what these are and how great the dosage must be to be damaging are still mysteries.

X-rays, on the other hand, are definitely known to be damaging to the developing central nervous system. Several cases are on record of mothers who after receiving deep X-ray therapy to the abdominal region during pregnancy have produced microcephalic children or children with other congenital abnormalities, including mental defect. However, improved knowledge of the effects of X-rays has resulted in the routine testing of women of child-bearing age for pregnancy before radiation, and thus in the reduction of defects from this cause.

Blood incompatibility between mother and child also has a toxic effect upon the child. This comes about most frequently as a result of the Rh factor, an entity present in the blood of about 85 percent of the population, but absent in the other 15 percent. When an Rh negative mother (whose blood possesses
no Rh factor) carries an Rh positive baby, toxic substances develop which may cause damage to the fetal blood, liver, and brain. However, this condition is responsible for less than 1 percent of low-grade spastic defectives, as fortunately only 5 percent of Rh-positive children of Rh-negative mothers develop the disease, while some who do develop it recover completely.

Mongolism, or mongoloid idiocy, a condition with a characteristic physical appearance, may also be toxic in origin, although little is definitely known about its etiology. Some authorities believe that the condition appears in the fetus before the third month of pregnancy as a consequence of a variety of toxic conditions inherent in the mother and associated with advanced age, endocrine disorders, or pathological lesions of the uterus. Mongoloids comprise about 5 to 10 percent of all defectives. Their IQ usually runs between 15 and 40. Because these children are prone to infection, they have a higher mortality rate than other defective children.

**Endocrine disorders.** While a certain percentage of mental defectives suffer from some glandular dysfunction, the proportion of defectiveness caused only by endocrine disorders is small. Cretinism is a form of mental defect definitely traceable to hypothyroidism or impaired function of the thyroid gland, either because of its lack of development or early destruction. This disease, which is also distinguishable by physical appearance, is endemic in areas where goiter is also prevalent, but it also occurs sporadically elsewhere. Dysfunction of the pituitary gland also causes mental defect, the most common type, Fröhlich’s syndrome, being characterized by obesity, underdeveloped genitalia, and mild intellectual impairment.

**Deprivation.** Emotional deprivation, frustrations, and insecurity may not only bring about a condition among normal children resembling mental defect but may cause incorrect estimate of the intellectual abilities of high-grade defectives, especially those also physically handicapped. Pseudo-feeblemindedness is produced in normal children so deprived by an emotional blocking which responds to psychiatric treatment.

The most severe form of pseudo-feeblemindedness, infantile autism, is dramatic, if rare, evidence of the importance of emotional factors in the development of intelligence. Children so affected behave like idiots, do not talk, respond to stimuli, nor engage in any activity requiring intelligence, even though their intellectual capacity may be normal or better than average. Psychiatric examination shows that their apparent defect is a form of withdrawal.

The classical case of Kaspar Hauser exemplified the degree to which deprivation of the means of learning could impair intellectual development. Such extreme cases are not likely to occur today. Nevertheless, deprivation of cultural stimulation in some isolated communities still plays a role in producing the apparent low level of intelligence among the populace. More tragic are the effects of such deprivation on patients with disabilities interfering with academic learning. False diagnoses of feeblemindedness too often occur among children whose only impairments are in hearing, reading ability, word comprehension, minor motor handicaps, or other disabilities. In these children emotional factors are undoubtedly also contributing to the picture of apparent intellectual defect.

**The Individual**

In spite of the growing knowledge of the causes of mental defects few specifics are available for their treatment or prevention. As the foregoing shows, mental retardation is not an entity itself, but a characteristic of a variety of conditions, each with a different cause. Moreover, in each form there is a wide range of intellectual ability.

Prevention for some forms may lie only within the scope of eugenic measures, though more scientific knowledge in the field of human genetics would be required before such could be confidently prescribed. Greater possibilities for preventing the exogenous forms through medical and public-health measures may be expected to be realized as knowledge of intrauterine life and development increases.

While treatment in the strict medical sense can be applied only to a small number of mentally defective individuals, in the broader sense of care and training it can be applied to all. But such a wide variation of conditions exist among children with mental defects that what kind of care and treatment each receives must be determined individually in line with a prognosis based on an accurate diagnosis of the case. While the goal can rarely be cure, it can almost always be improvement or the achievement of the maximum intellectual and social functioning of which the individual is capable.
A PROGRAM FOR MENTALLY RETARDED CHILDREN

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RECENT YEARS have brought slowly changing views of community responsibility toward the mentally handicapped. Earlier attitudes based on a preoccupation with their limitations, ignorance of their capacities for growth and development, and inadequate knowledge of those who lived at home, are stubbornly giving way as more scientific data become available.

While medical treatment of mental retardation is still in its infancy and cannot cure or regenerate damaged neural tissue nor correct faulty neural integration, the functioning of the mentally retarded child is subject to favorable or unfavorable influence and is often amenable to training measures. Moreover, psychological and sociological factors play a significant role in influencing the nature and degree of mental retardation afflicting a million and a half of our children.

In this context we must focus our attention upon the improvement of the condition through habilitative and rehabilitative measures.

The fundamental needs of mentally retarded children are the same as those of other children. Briefly, the requisites are: a stable, financially secure, and accepting family group; appropriate school and recreational facilities; and preparation and training for productive work. Naturally, the material necessities such as proper diet, housing, and medical care are as important to these children as to all others.

For the child with special problems or afflicted with a special handicap access to these necessities is so difficult that special provisions must be made.

Many mentally retarded children can become valuable assets in their homes and in the community if they are given the proper help and training. This involves not only early detection and diagnosis, but also appropriate school placement, suitable home management, speech therapy and remedial reading, and stimulating social experiences. As the child grows into adolescence, vocational education and guidance, job training and placement, appropriate social outlets, and suitable living arrangements become important.

Rehabilitation or more correctly the habilitation of the retarded child is a many-sided undertaking cutting across the responsibilities of many disciplines: medicine, education, psychology, and social work. The cost and the necessary array of facilities
involved in a total rehabilitation program put it beyond the means of the vast majority of families of retarded children. Therefore the community has a responsibility to consider the varying degrees of handicap in making existing services available for such children as well as establishing the additional services that may be required. Only then can the 75 percent of the retarded group who, according to Surgeon General Leonard A. Scheele, are capable of being rehabilitated become productive, contributing members of the community.

The Families

The families of mentally retarded children deserve special consideration. The maintenance of healthy family relationships is not an easy job for any family these days, even those where handicapped children are not present. But the additional strains and stresses placed upon the family of a retarded child can lead to many serious personal disruptions and contribute to family disorganization.

To each parent the experience of having a retarded child has an individual meaning and often a staggering impact. Moreover, the mother and father's ability to manage their child is subject to the influence not only of their own personality structures and the nature of the child's handicap, but also of the attitude of society. If the child and family are held up to public ridicule and scorn and approached with fear and suspicion, the parents' feelings of shame, guilt, and anxiety will be aggravated.

Anxious and overwrought by their child's condition, many parents of retarded children have also had to bear the callous rebuffs of professional persons who may have falsely reassured them that "Billy will outgrow his slowness—don't worry so much," or the nonprofessional advice of "friends" to "put him away now before you get too attached to him" for "Billy will never amount to anything."

The slow-developing toddler not only saps his mother's physical and mental health but often because of his complicating health problems drains the family pocketbook. Waiting patiently for Billy to outgrow his condition parents become painfully disillusioned as his differences from normal youngsters become more strikingly apparent with the passing years. Withdrawing Billy from contacts with strangers to protect him from hurt does little to ease his problems and creates many more for his parents. Often the accompanying overprotection retards Billy's functioning further.

Family tensions mount as disagreements between Billy's parents about how to deal with him increase in frequency and intensity. Tense and overwrought they may come to regard him as the cause of their misery.

Kanner, Sheimo, and others have written in detail about the complications of the parents' anxieties and perplexities. Siblings of the retarded child also become involved in these difficulties.

Family-service agencies can make a distinctive contribution to the maintenance of healthier family life by offering counseling, financial aid, homemaker, and other services to parents of retarded children. However, for too long they have, with a few notable exceptions, kept their doors closed to these harassed people. Only recently have they more generally begun to take an interest.

Special Clinics

Closely tied in with the need for family counseling is the need for special diagnostic and treatment clinics. Most parents have found it impossible to get the diagnostic and prognosis help necessary to proper planning for their child's care. Child-guidance clinics have tended to confine their services to children with problems not involving mental deficit. Most clinics dealing with mentally retarded children do so solely in connection with institutional commitment.

Special clinics for retarded children staffed by personnel from several interested disciplines can be of immeasurable assistance to the parent and to the community in providing basic diagnostic and treatment services, and in initiating the type of rehabilitative services essential to the child's well-being.

Such clinics are also useful for training personnel as well as for research and investigation into the lesser known aspects of mental retardation. Dr. Joseph Wortis in reviewing the experiences of the Morris J. Solomon Clinic for the Rehabilitation of Retarded Children in the Jewish Hospital of Brooklyn has pointed to the promise in this work.

Once you get accustomed to the slower pace of the retarded child, you find that these children have the same variety of charming, affectionate, and happy, or morose, difficult, and neurotic or psychotic traits that are encountered in work with other children, although the incidence of more disturbed children is unfortunately greater among them, partly because of faulty neural integration, but mostly because of the many frustrations these children experience. These children grow and develop, learn new things, and in a great many cases, with proper help and training, are capable of growing into happy and useful adults.

Since variations in the severity of mental handicap come about as a result of the complex interaction and timing of biological and environmental influ-
ences, the determination of the degree of mental handicap is a complex problem and cannot be quantified adequately on the basis of a mere test score. It must include a careful estimate of the medical aspects of the condition; a thorough estimate of the whole of the child's social experience; his family life, schooling (or lack of it), and social contacts, and must weigh the effects of other complicating factors such as speech disabilities or sensory and motor defects.

The goals of treatment should be individual and realistic. Some will require short-term and some long-term planning. Such goals should be based upon a careful evaluation of the child's handicap as well as his assets and capacities.

In one case the plan may be to improve the child's self-care skills—feeding, washing, toileting, dressing—through a combination of occupational therapy for the child and social casework for the parent. In another case the goal may be to prepare a child for special-class placement through weekly group-play therapy sessions. Or a parent may request help with concrete home-management problems. Another child might require medication to control his convulsions while a remedial tutor helps him to increase his meager reading abilities. Many children require speech therapy. Many parents require guidance. Still other children need a chance to develop socially in a well-structured group setting. In all cases the aim should be practical, should involve the parents in planning, and should attempt to use any community resources that might be helpful.

**School Services**

School services for retarded children have been in existence both in institutions and in the community since the early 1900's. Special classes have been geared to those retardates considered "educable"—children functioning in the borderline to moderately retarded range. Generally, the criteria for admission to public-school special classes exclude children under 7 years of age or with IQ's under 50, but even so there are insufficient classes to meet the needs of the "qualified." It has been estimated that not more than 20 percent of all retarded children of school age were enrolled in special classes for the school year 1952-53.

However, enrollment of mentally retarded children in special schools and classes in public-school systems in this country increased by 30.5 percent in the 5 years between the school years 1947-48 and 1952-53. This growth is more than 1 1/2 times as great as the increase in general public-school enrollment.

The schools are placing increasing emphasis on services to children with IQ's below 50. In 1952-53 this group represented about 4 percent of the retarded who were given special educational service in the public schools.

Until very recently almost no provisions had been made for severely retarded but "trainable" children. Now, however, a few States, including California and Ohio, and some local communities have set up programs, some in cooperation with parent groups. In other States the parents' groups themselves have organized such classes. A survey of these programs and of the educational problems of the severely retarded child, made by the U. S. Office of Education, has indicated that many children in the lower ranges of mental development can benefit greatly from an educational or training program suited to their needs and appropriate to the degree of their handicap.

The survey has shown too that the determination of who can benefit from classes cannot be based solely on a test score but must include an evaluation of the child's medical condition, his potential for social adjustment, his capacities for learning self-care, and other factors.

For the preschool-age retarded child the chances of obtaining nursery school or day-care services are very poor. The child is usually socially isolated and often rejected by his peers.

Only in a few scattered instances has any attempt been made to provide such care through a community service. At the Morris J. Solomon Clinic a program quite similar to that offered in day-care centers and nursery schools is operating on an experimental basis. We have also been successful in placing several youngsters in private nursery schools and have been delighted, as have parents and often the surprised school personnel, at the progress these children have made. Many severely retarded youngsters cannot be integrated into a normal nursery-school program but can benefit from a training program more appropriate to their needs.

**Group Experience**

Along with the inadequacy of school services for retarded children is a dearth of facilities available to them for recreational and group experience. The need for such experience is most acute for children and adolescents who are not attending school. Leading relatively sedentary, isolated lives, these children are ill-prepared to mingle socially or to face alone the trying demands of adolescence.

Many borderline and mildly retarded youngsters...
could be successfully integrated into the services for recreational and group experiences now in existence, with little modification of program. Since social skills represent the greatest growth potential for most retarded children, to deny them help in this area means crippling their chances for successful social integration and prolonging their dependence on others. Some national organizations, including both the Boy Scouts and the Girl Scouts, have already demonstrated in some areas the possibility of adjusting eligibility to admit retarded children to membership. If community centers could also see their way to welcoming retarded children, enormous benefit would result.

Residential Treatment

Consideration must also be given to needs of those mentally retarded children living in institutions. While some require institutional care, all too frequently the necessity for placement has arisen from: the lack of other community facilities and special services; the attitude of professional persons who regard institutionalization as the only way to deal with the problems of the more obviously retarded child; family problems involving tensions and disruptions or economic and social considerations. Too seldom is the child's actual condition the determining element in the placement decision.

The reluctance of most parents to place their child in an institution, even when such care seems best, is aggravated by the very real inadequacies of many institutions—overcrowding, sparse training facilities, staff shortages.

The institutional crisis continues to grow. In 1948 the 92 State institutions reported a resident population 14.4 percent above capacity, an increase in overcrowdedness from the year before. The institutional problem is further aggravated by the expanding life span of institutionalized retardates, and the many new demands for placement coming at earlier ages than formerly.

Such overcrowding makes it impossible for State schools to offer much more than custodial care and forces them to neglect educational and training programs. Parents whose children need placement face the intolerable dilemma of long waiting lists or of plunging themselves deeply into debt to pay for private care.

The expansion of community facilities would no doubt decrease some of the pressures now facing State schools, and would enhance their ability to improve their treatment, education, and rehabilitation programs. New Jersey, for instance, has found it possible to eliminate some children from its institutional waiting list through a program of training parents to help their children at home.

Other Needs

Camping facilities for the retarded are virtually nonexistent, as are foster homes and temporary shelters. A critical need also exists for guidance and counseling for the retardates themselves, especially the adolescents. Vocational guidance and job training opportunities are usually closed to them.

However, even if our communities should provide a well-rounded and integrated program of services for mentally retarded children, as these children grow into adolescence and adulthood, they are unlikely to find their productive capacities put to use, unless more sheltered workshops or industrial cooperatives are available in which they can produce under noncompetitive conditions. Our society has become so specialized and so highly competitive that the handicapped person's needs are not accorded recognition. It is highly unlikely that the efforts of voluntary agencies alone can fill this void.

Prompted by social rejection and humiliation, and the desire to secure more humane treatment for their children, parents of retarded children have in recent years banded together to help themselves. In self-help groups many of them have been able to overcome a sense of isolation and, thus strengthened, to initiate some of the services for their children that they have been long searching for in the community—special clinics, school groups, and recreational clubs. Their forceful espousal of their children's needs has also served to reawaken the interest of professional persons and others in the community.

Organization of the parents of mentally-retarded children is a comparatively recent development paralleling similar developments in other areas of need and sparse services, such as cerebral palsy, epilepsy, and muscular dystrophy. In the space of a few short years these local self-help groups have grown rapidly. In 1950 they joined together to form the National Association for Retarded Children whose membership spans the country, numbering many thousands.

Much of the good work of these parents' groups needs to be brought to the attention of the community as a whole and specifically to the taxpayer, the legislator, and professional persons, including workers in community planning and in health and welfare agencies. Unfortunately some professional persons
have hesitated to work with these groups because of what they regard as boisterousness, lack of sophistication about community planning and fund raising, and “emotional involvement” in the problem.

While these views may have some factual basis, parents' groups represent a social phenomenon whose existence cannot be denied and whose influence is growing. As their long pent-up energies and boundless enthusiasm are channelized in constructive and creative fashion these organized parents are doing much to inject into the field of community health and welfare services a new spirit of hopefulness, of creativity, and of closeness to the recipient of services.

Steps Ahead

The problems of the mentally retarded child must be faced and solved as competently as possible, not only for humanitarian reasons, but for the very practical benefit of society as a whole.

We are paying for our neglect of these children not only by having to maintain and to support large and costly institutions for their permanent care, but also through loss to the community of their potential social contribution. Following are some suggestions of measures that might help to alleviate current chaotic conditions:

1. Reevaluation of intake policies of voluntary and public health and welfare agencies with a view toward serving the retarded child as well as his family.
2. Application of the skills of group work and recreational agencies to groups of retardates and the inclusion of the mildly retarded in the already existing programs and centers.
3. Extension and improvement of school services for “educable and trainable” retarded children through support from public as well as private community sources.
4. Establishment by communities of special diagnostic and treatment clinics for retarded children where comparable facilities are unavailable.
5. Broadening of Federal and State programs serving the physically handicapped to include the mentally handicapped.
6. Voluntary and tax-supported subsidization of job training centers and sheltered workshops.
7. The granting of earmarked funds for research in preventative, treatment, and rehabilitation techniques.
8. Establishment of curricula in professional schools to offer courses of study in work with the retarded.

In all of these endeavors professional persons can look to the parents of mentally retarded children for encouragement and support.

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New Jersey's pioneering program builds parental skills and confidence through . . .

HOME TRAINING FOR THE MENTALLY RETARDED CHILD

VINCENTZ CIANCI, M. S. Ed.
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New Jersey Department of Institutions and Agencies

The Mother of a retarded child, speaking of the need for parent counseling and home training, at a conference on retarded children, described the happy lot of parents who do not have these special problems. "Parents who are bringing up normal children," she said, "have so much help in knowing what to expect of their child and what to do for him. They have the other children in the neighborhood. They have their own nephews and nieces. And besides this, they have all the baby books with their charts and tables and good advice."

She went on to mention the toy manufacturers, who produce educational toys for specific age groups, and the record companies and book publishers, who know so much about the needs of normal children and have designed their products to meet these needs. And finally there are the schools, which most parents can look forward to, where trained teachers will help them in the education of their child.

Parents of normal children do receive a great deal of accurate information and good advice from a great many sources. They know in general what to expect of their child, physically and mentally, and they know how other people are handling the problems that arise in their own family. The parents of retarded children do not have such support. As a rule, they have to face their problems alone. Or, if help is offered, it is likely to come from well meaning people with little or no experience, whose advice only adds to the distress, confusion, and misunderstanding which confronts these parents on every side.

The term "mentally retarded" covers a wide range of disability, from the mildly to the very severely handicapped. It includes individuals who, under ordinary circumstances, can lead fairly independent lives, others who require social protection of some kind, and still others who will always be dependent on their relatives or the community for physical care. Mildly handicapped children have the benefit of the public schools. In many places, there are special classes designed to meet the special needs of these children. State residential schools give custodial care and some training to the most severely handicapped. But there are a great many children who do not come within either of these groups. Some are so severely handicapped that they would be admitted to the residential school if there was space for them. Some are so capable that they would be admitted to the public schools if there were classes for them. In many places today, these are "forgotten" children, living at home, without the help which our modern techniques in medicine, psychology, and social work could bring to them.

The Home Training Program

New Jersey's Department of Institutions and Agencies maintains four institutions for the care and training of mentally deficient children. But these institutions have long waiting lists and many children, who should be receiving training of some kind, are forced to remain at home. In September 1943, the Department decided to set up an experimental

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Provided by the Maternal and Child Health Library, Georgetown University
program, to be called "Home Training," which would bring some of the services and techniques of the institutions to children living in their own homes. The first purpose of the program is to guide and counsel parents in understanding and training their retarded child so that he can take his rightful place in the home and community or, if this is impossible, so that institutionalization can be postponed with the minimum damage to the child. Early referrals to the program were from the waiting lists of the institutions. As the program became better known, children were referred by physicians, social workers, educators, and even parents themselves. Most of the children referred had, as a rule, I.Q.'s below 50.

A program of this kind, which aims at better community understanding of the problem of mental deficiency and better home and family adjustment, utilizes many kinds of professional skills and it is difficult to say which of these should be given first place. The New Jersey program was placed in the State Department of Public Instruction. A similar service, established in Massachusetts a few years earlier, had been placed under the Department of Mental Hygiene. The Massachusetts program was carried on by social workers, the New Jersey program by persons trained in education, psychology, and guidance. But both programs have had the same goal—to bring what knowledge we have about the mentally retarded into the homes where these children live.

**Effect on Parents**

The first result of a home training program of this kind is that parents acquire a feeling of social support, of "belonging" to the community again. Too often, the parents of a retarded child are burdened by unnecessary doubts and fears. When these are intensified by the indifferent, or even hostile, attitude of the community, the members of the family feel compelled to withdraw from all social and neighborly contacts. According to reports from a New Zealand home training program, the greatest needs of the parents of retarded children are for recognition and moral support. This New Zealand program was carried on through correspondence. A teacher in Wellington found that even through letters she was able to give a woman living on an isolated island the strength she needed to work with her retarded child.

In New Jersey the home teacher frequently finds that she is the only contact the mother has outside her immediate family. Some of these families have lived in their communities for years without knowing that there are other families with retarded children living not far from them. The fact that there is someone besides themselves interested in their child goes a long way toward dispelling fears and tensions. The teacher's visit sometimes takes on almost the quality of a social event. Soon grandmothers and aunts drop in to hear what she has to say. And before long neighbors are asking about the child's progress.

The home teacher encounters little or no resistance on the part of parents to her offer of assistance and guidance. This may be due to the fact that no matter what the source of the referral, the teacher always contacts the parent before visiting the home, explains that she had been asked to visit the home, and requests confirmation from the parent. The fact that the home training program is not forced on the parent but in every case is requested by the parent, results in opening the door to the teacher and welcoming her aid.

One of the first things the teacher can do for a mother is to help her understand her child's limitations. Parents very often, in their anxiety to have their children learn, try to push them beyond their abilities. This can only lead to a feeling of futility and defeat. The parents who insist that their child could talk "if he weren't so lazy" are only deluding themselves. A true understanding of the situation relieves the pressures placed on the child and makes for happier living all around.

Many times parents, in attempting to compensate for a child's deficiency, buy toys which he cannot use and does not need. They may buy the most expensive doll carriage, only to discover that their little girl does not know how to play with it, because such play requires imagination. The teacher can be of great service to parents in helping them select toys that are suitable to the mental and physical development of the child and that have teaching as well as play value. Manipulative toys, such as the ring pyramid, bang peg, large peg and board, nest of blocks, and others, are as suitable for retarded children as they are for normal children, except that the retarded child may use them with better result at a later age.

**The Teacher's Role**

The teacher must also show parents how to teach. It is always difficult for a mother to assume a teacher's...
role, and sometimes it is impossible. The first time a child pulls a chair to the door and removes the latch it is very hard for the mother, who must think of some other means to keep the door locked, to see this as a real accomplishment. But she can learn from the teacher of many situations in the home which can be turned into learning experiences.

A mother can be taught the importance of pointing things out to her child and naming them, so that even if he can’t name them himself he will be able to recognize them. Mothers sometimes do very little to encourage speech development in their child because they have been told that he will never speak. When a mother realizes that for her retarded child “speech” may mean making his wants known by gestures, single words, or phrases, she will do as much as possible to widen his experience and enrich his environment. She will make books for him with pictures of clearcut objects. Later she will buy colorful books and sit with him, telling him the story in simple words that he can understand. She will buy him appropriate records and he will learn to distinguish tunes and sounds. She will take him out to a few familiar places so that he will come to know some things outside the home.

Fathers, too, can be of great help, especially on these outings. One father takes his little boy out every evening, alternating between a visit to a pet shop and a visit to the park. Another takes his little girl on a regular round every Sunday morning. This includes picking up brother at church, going to the bakery, visiting grandmother, and stopping to see the ducks. The world is full of wonderful things to see and hear and know, and retarded children can learn to enjoy many of these things if they are introduced to them gradually.

Parents of retarded children, at some time or other, have to consider placing their child in an institution, or at least taking the necessary legal steps to make this possible. This is a very difficult and painful decision for a parent to make. But in the case of children who are so severely retarded that they require physical care, or so extremely distractable that their presence disrupts the home, institutional care is almost a necessity.

Although a home training program is established primarily to help parents train their child so that he can remain at home, the teacher must not close her eyes to the fact that some children’s needs cannot be met outside an institution. She must prepare the parents of such children for what is inevitable, so that when the day comes for the child to be admitted to a residential school, the parents will be ready for it.

There are a great many questions about institutional placement which, when answered to the parents’ satisfaction, put their minds at ease and help them to arrive at a solution. Parents contemplating placement are always concerned about the care and treatment their child will receive. Much unnecessary worry can be avoided if they are able to talk over their problems with someone who understands them. If it is clear that the decision will have to be to send the child to an institution, the teacher must realize that this cannot be accepted immediately, that the parents need time to adjust themselves to the idea of parting from their child. The teacher can ease this process by helping them to see the need for such a solution. Sometimes a parent feels that his child is being placed in a residential school because the home training has been a failure. The teacher can assure the parents that this is not true and that everything that has been done for the child at home will help him to live a happier and fuller life at the school. A visit to the school or a talk with another parent who has a child there can do much to dispel the apprehension which a parent naturally feels regarding such placement. The institutions, on their part, encourage visitors, especially parents, for they are concerned with the happiness of the children put in their care.

Joan and Robert

Parents of retarded children have a great many other problems, which may be extremely complex and which cannot be resolved quickly. Some parents need only a few visits from the teacher to see how to go about handling their problem. In such cases the teacher will not be needed again unless circumstances change. But for the home training program to be effective a long time contact of some sort must be maintained with the parents. They must know that the teacher is available if they need her.

In home after home, the teacher finds parents facing the same problems. One case history differs from another only in its superficial aspects. In any one of them, the problems which have just been discussed abstractly can be seen in their concrete, human form.

Joan was a little girl of ten when the teacher first visited her home. Her mother, Mrs. K., was concerned about the lack of training facilities for the
child and had been pressing for her admission to an institution. The teacher had been sent to the home in response to this appeal for help. Then, as now, there was a long waiting list and little chance of the child's being admitted to the institution and it was hoped that the teacher could help the parent train her child at home.

The teacher found Joan to be a pleasant child, of mongoloid type, with a mental age between three and four. She was the third in a family of four, well behaved, and secure in the love that surrounded her. The mother had done a remarkable job in training her in habits of self-help, so that she was quite self-sufficient.

After a few visits the teacher discovered that Joan was being taken out very rarely. Mrs. K. said that at one time she did take the little girl on excursions to town. But she had found it increasingly difficult to brave the stares and glances of curious people and had gradually stopped taking Joan anywhere. It was obvious that this experience had left its stamp of bitter resentment on Mrs. K. and had created anti-social attitudes toward her neighbors and society in general. Not all the people that Mrs. K. met were motivated by morbid curiosity. There were some, certainly, who were filled with sympathy and compassion because they, too, had a little Joan at home. But there was no way for Mrs. K. to know what was in the minds and hearts of her neighbors, because no one spoke of his problem and no one mentioned the words "mentally retarded."

The day the teacher announced that she was going to take Joan to the home of another little girl was a memorable one for Mrs. K. The family talked about little else for a week and when the day arrived everyone was out to see Joan go off with the teacher. Other visits followed, and these trips served a double purpose. Joan learned, among other things, the joy of having a friend of her own. And Mrs. K. herself soon got the strength and courage to take Joan out in the community, visiting friends or family, or merely shopping.

As time went on, the teacher was able to tell Mrs. K. many things which relieved her anxieties and gradually gave her a new outlook on life. She learned that Joan was not the only child in the community who was retarded, that there were many others who were living at home and receiving no instruction from any source. She learned that Joan could profit from home training and that the success of the program depended principally on Joan's mother, on how much time she was willing to devote to it. She learned that the needs and feelings and emotions of retarded children are very like those of other children. Eventually Mrs. K. realized that she was the key person in the situation, that she carried the major responsibility, and that her attitude toward the child could affect not only the attitude of the whole family, but that of neighbors and friends as well.

At first the teacher made weekly visits to this home. Joan learned to cut, color, sew, and do other craft work. No academic work was undertaken. Instead, emphasis was put on the types of activity which would help her fill her days. Joan made and sold pot holders, enjoyed making scrap books, learned a simple embroidery stitch, and made a great many mats. All very simple things—but accomplishments which were the result of many hours of patient guidance on the part of both mother and teacher.

Inevitably, the time came when the family no longer needed such service. The teacher, aware that this time would come, began preparing the mother for it in advance. She did this by gradually lengthening the time between visits. They decreased from weekly to monthly, and finally became yearly.

Joan is now twenty and at home. Her days are filled with the kind of activities that are satisfying to her. She makes little demand on the family and at the same time makes her own contribution by sharing in household chores. Although the teacher no longer visits the home, the mother and family know that the service of a home teacher is always available if circumstances should make this necessary.

Such circumstances sometimes arise. Robert was 5 years old when the teacher first visited his home. He was well developed physically, but slow in speech development and self-help habits. The mother's chief concern at this time was to develop these habits. The teacher made weekly visits to the home for 2 years and then succeeded in placing the child in a day class.

For the 2 succeeding years the teacher had little or no contact with this family. Then the father died suddenly. The mother, knowing that the teacher had always been there, ready to help her, did not hesitate to call on her. In this particular case, the best plan was to place the child so that the mother could work to support her two other children, and this was done.

**Working Outside the Home**

A home teacher's work inevitably extends beyond
the home. The retarded child needs the companionship of other children and the teacher is in a position to bring these children together. This leads in time to friendships among the parents and to the growth of classes and centers for both the children and the parents.

In New Jersey, the teacher is active in organizing play groups for young mentally deficient children which are staffed with volunteers. There are now three such groups in the North Jersey area and another is being planned. The children attending are usually on the list of the home teacher, and are either preschool or too severely retarded to attend special classes. The home teacher is present at all sessions of the groups and guides the work of the volunteers. In this way she can follow the progress of 10 or 12 children at the same time and so make her services more widely available. She acts as a liaison between the group and the home and so is always in touch with the parents.

Perhaps one of the greatest forces in the whole area of mental deficiency has been the phenomenal growth of parent groups for retarded children. The teacher must take an active part in the work of such groups. She must always be ready to share her knowledge with anyone interested in helping retarded children and to do what she can to promote sound principles and philosophies.

New Jersey's association of parents began in 1947 when 43 parents who were being seen by the home teacher met together to discuss their problems. Today there are 14 units of this kind in New Jersey and 375 throughout the United States, with more in the process of being organized. A bond of understanding and fellowship permeates these meetings. Parents, dedicated to helping their children, visualize and plan projects which sometimes take years to realize. These have included summer camps, sheltered workshops, discussion groups, nursery groups, and new legislation to open public schools to their children. One of the first classes for severely retarded children was established in Ridgewood, N. J., in September 1948. It has been in continuous session for 7 years and has contributed to the well-being of 60 children. Projects of this kind become realities because parents are willing to make the necessary sacrifices and because other civic-minded people are also ready to give of their time and their money.

This school had to turn to the community for help. The parents could not meet the total cost but the community responded generously. The YMCA and YWCA opened their swimming facilities to the retarded children and provided individual instructors. The Nursing Service supervised the health program. A church provided the housing. And a civic organization donated funds.

Much the same thing has happened in California, Connecticut, New York, and other places. The little town of Point Pleasant, N. J., boasts 100 percent participation of all civic organizations in its "Little Carpenter School." This town is determined to provide training for every retarded child. Fresno, Calif., is planning an even more ambitious project called Kalso Village. This will be a center which will include every kind of facility needed in the care, training, and education of retarded children.

The Ideal Program

These activities which have already been undertaken for retarded children are modest in scope, but they show that a total program is possible. The total program, which we hope some day to see in operation everywhere, will have four distinct parts or aspects.

First of all, there will be a home service for mothers of very young children or of children who are not eligible for centers or special school classes. Here a teacher will bring the parents the information they need in order to care for their child properly. She will guide them in training the child, in choosing toys and in selecting appropriate activities for him. She will help the parents to develop the child's abilities to the fullest. She will inform them of all the resources available in the community and the State so that they can plan the child's future intelligently. And she will also give the parents the strength and support that they need so much when they first realize that their child is not normal.

In the second place, a complete program will maintain community play centers. The present play groups in New Jersey and elsewhere have proven their worth. These should be made available to preschool children and to all others who, for any reason, are unable to attend public schools.

Thirdly, the program will maintain special classes under the auspices of a public agency. In New Jersey, the recent passage of the Beadleston bills made it possible for severely retarded children with I. Q.'s below 50 to be admitted to the public schools. California, Wisconsin, Minnesota, Connecticut, and Ohio have passed similar laws. In Ohio 115 classes for severely retarded children were established within a 3-year period after the passing of such a law in that State. This is progress of which Ohio can be justly
A mother of a retarded child suggests...

SOME POINTERS FOR PROFESSIONALS

LETHA L. PATTERSON

Member, National Association for Retarded Children

ONE of the most heart-warming aspects of being the mother of a retarded child these days is in being a part of a profound partnership which is developing between lay and professional people.

Of all life's problems, those presented by a handicapped child (and particularly a mentally handicapped child) require the utmost in teamwork within professions, among professions, and between professional and lay people, especially parents.

All over the country we parents are attempting to assume responsibilities appropriate to the partnership through helping to define our separate roles and in heightening our communications in order to save other families from unnecessary trauma.

Dr. Martha M. Eliot, Chief of the Children's Bureau recently said:

"When officials of public agencies ask what kinds of services should be provided for retarded children, my advice is 'ask the parents'... [they] are often best qualified to say what help they need, though professional persons will have to provide the hows."  

Thus, we laymen and professionals are indispensable to one another in our efforts to make up for past neglect of this serious medical, emotional, social, and educational problem.

Perhaps I can bring together for the readers of this journal for professionals some of the written and spoken insights which have come my way from both professional workers and parents. These, I feel, are relevant for those of you who find it your task to help families face this heartbreaking problem—whether you are physicians, psychologists, social workers, nurses, teachers, or administrators. On the basis of these and my own experience I urge:

1. **Tell us the nature of our problem as soon as possible.**

When I said this to a class of students of child psychiatry at the University of Minnesota Medical
School, I was asked by an alert student, “But Mrs. Patterson, what can the physician do when he is not sure himself and doesn’t want to worry the parents?” “Just be honest with us,” was my reply.

It takes great sensitivity and intuition to take a mother’s couched remarks and detect that they spell “worry.” Often we parents are concerned just as early as our practitioner, but we are reluctant to put our fears and worries into words. However, we give plenty of hints that we want our professional counselor to help us get them into words, to lead us on the proper course—whether that means waiting a while or consulting with specialists immediately. It is a wise counselor who knows when he does not have the answers and is willing to admit it.

One of my psychiatrist friends put it this way: “When I am faced with a worried mother or father *I have got a problem.* Either there is something wrong with the child, or something wrong with the parents, or both. And if I can’t identify the trouble, then I am obligated to get this family to someone who can.”

2. **Always see both parents.**

Fathers are parents, too, and all professional workers need to be reminded of this. Both parents should be present whenever possible, and at least on first consultations regarding a child’s handicap.

It is very difficult for a mother to go home and restate, interpret, and answer questions about a problem she does not clearly understand herself. Often the problem, with its fears, has brought about a lack of communication between mother and father. This is particularly true in a young marriage or when the retarded child is the first child. Establishing adequate communication is difficult in any marriage. Finding the words to support one another in this problem has been impossible for some of us. We have needed an objective person through whom to talk.

Unfortunately, all husbands (and wives) are not like the one who, when he learned that their little daughter would not progress like other children, said to his wife: “Honey, we don’t know what lies ahead of us—but whatever it is, we can handle it because we are strong people.”

Many of us can find this strength, however, if you will help us.

Another reason for seeing both parents is that both need to be pulled along together in their understanding and acceptance. I have seen too many mothers who realized the need for institutional care and were ready to “place” a child while the fathers trailed behind ignoring reality, not to recognize the great need for a common understanding. Sometimes it is the mother who will not admit that something is wrong and insists that her child stay in regular school classes when a special course of study is indicated, while the father suffers along in silence, afraid to precipitate the issue. If you but knew the isolation that can exist behind our four walls!

3. **Watch your language.**

Parents need to understand the implications of their problem, but too often we are given professional gobbledygook, or at the other extreme, plain talk of an obnoxious variety. Words like “idiot,” “moron,” and “feebleminded” used to be excellent and descriptive clinical terms but they no longer apply to our retarded children. Unimaginative writers and purveyors of so-called humor have polluted the meanings with connotations of social or moral deficiency in the mentally normal.

On the other hand, there was the doctor at a residential institution who wrote to two parents stating that their son was ill with “cervical lymphatic adenitis.” The worried family did considerable research to find that the child simply had swollen glands of the neck.

The child psychiatrist, into whose capable hands my husband and I finally could put our problem, was very sensitive in his use of words. He avoided “moron,” “feebleminded” and even “mental retardation” by encouraging us to evaluate our child’s developmental status. And when he confirmed our findings, we felt quite pleased with ourselves. He always referred to our boy as “your son,” “your lad,” or “Stephen” with a voice filled with great compassion so that we started thinking more about Steve’s problem and less about our own hurt egos.

4. **Help us to see that this is OUR problem.**

One way, of course, is by example—by not taking the problem over for us.

Too many well-meaning professional people in the past have thought they knew what was good for us and have recommended, even insisted on, institutionalization. We know, now, that denial of the existence of the child is not the solution for either child or parent, that abandonment is not the answer, and that it is psychiatrically unhealthy to rob parents of their responsibility for planning. Only as we parents are helped to work through our
problems can we find any peace of mind. If we have not planned for our child ourselves, if someone else has made the decisions, we have not really made up our own minds and so must keep going over the ground again and again. We may never be at peace with the solution which was reached for us.

Administrators of institutions tell us that the best help for families in adjusting to their child's placement is the fact that the parents themselves have decided—with adequate professional guidance, of course—that placement is best for the child in relation to the total family welfare.

There is another reason for showing us that this is our problem. You have no idea how much unprofessional, unsolicited, and untried advice we get from well-meaning people—our neighbors, relatives, friends and even strangers standing on street corners. When, with your guidance and example, we realize that this is our problem, we can shut our ears to the static and rely on our own judgment. But we need your professional support in helping us to feel competent in making these decisions, your confidence that we will ultimately make the proper decision for care in our particular case, your assurance that there is no failure if we change our plan when circumstances change—life situations and retarded children present different problems at different times. You can help us explore the possibilities for meeting our problem; support us in adjusting to our decision; act as a continuing sounding board against which we can bounce our own thinking; and give us a good, sturdy shoulder on which to lean when we get dizzy going through the maze of decisions.

5. Help us to understand our problem.

Parents differ in the quantity and quality of information they can absorb during different phases of this problem. What they want and need depends greatly on the individual, but many of us have had to search for the knowledge we needed in order to understand our child.

Six years ago, when I began my search, a severe scarcity existed in printed material on the subject of mental retardation. Today, there are many fine and helpful publications in this field. One of the best that I have seen for new parents is Jacob's "New Hope for the Retarded Child," which is inexpensive enough to be used as a handout. Many other books, bibliographies, journals, and pamphlets provide excellent sources for parents.

Regardless of what we parents are able to read and absorb, we will always have questions to ask. We will continue to need support from someone, whether our child is at home or away—particularly in those days which follow the confirmation that mental retardation is our problem.

One medical counselor asks parents to come back several weeks after he has given them the bad news, knowing that they will have questions which could not come to the surface during the emotional strain of hearing the verdict. Moreover, he sees to it that the parents get to a social worker and he also urges them to join an association for retarded children.

Frequently he turns their names over to the local association's "parents counsel committee" requesting that some mature couple—a mother and a father—call on them. He has found that parents who have successfully faced their problems can offer a special kind of help to new families which transcends his professional services. Further, he has seen the therapeutic effects of parents working together in organizations to improve the lot of the retarded and their families. Incidentally, he was initially one of the "pros" who were afraid of this "lay" movement.

6. Know your resources.

In referring to services, Dr. Eliot has called the retarded child "nobody's baby." Certainly there is evidence in most States that services are disjointed and uncoordinated. Rarely is there any one place which can put parents in touch with the resources that are available.

In Minnesota, where the county social worker is the local resource for parents, a booklet, "You Are Not Alone," telling parents where and how to seek help, has been distributed to members of the State medical association, county welfare boards, clergymen of all faiths, family and welfare services, clinics, public-health nurses, associations for retarded children, and newspaper editors in the hopes that the booklet (or the information) will be passed along to parents. It was produced by the statewide Conference Committee on Mental Deficiency, a professional-lay body.

California has started meeting this problem with information centers for the parents of retarded children, set up in Los Angeles and San Francisco by the State department of mental hygiene. The psychiatric social workers assigned to this task have a variety of functions—counseling individual parents, putting them in touch with resources, providing information to public and private agencies, and serving
as consultants in community planning.

Other States are developing a network of clinics with built-in social services for the sustaining help which is so necessary.

Anyone who has carried a handicapped child from one waiting room to the next in an effort to gather resources into one piece, will appreciate the significance of these several efforts to avail parents of the services that do exist.


All parents make mistakes in raising children. Those of us who have a retarded child are bound to make errors, but we should not be made to feel guilty about them.

One day I said to my medical counselor: "You know, of course, that I was angry at you for a good long time for 'confirming my diagnosis,' but never once have you put me on the defensive about it or any of the mistakes that we have made in relation to Steve."

"Why should I?" he countered. "How do I know I could have done any better than you, had I been in your circumstances?"

He went on to give this definition of "good parents":

"Parents are good parents, when to the best of their ability, understanding, and circumstances, they meet as adequately as possible the needs of their children."

8. Remember that parents of retarded children are just people.

This has been my most amazing discovery. We are just people with a serious problem, a great sorrow—a living sorrow. We have the same strengths and weaknesses as others in the general population. We have the same problems, the same handicaps. But when the burden of mental retardation is heaped upon us, often these problems and defects are magnified and we, in turn, create problems for those of you who must deal with us. But as a group, I do not think we should be considered abnormal, particularly in view of the poor cultural attitude towards our problem, the lack of interest and services, and the fact that some parents have made great personal and family sacrifices to carry this "cause" to the public conscience.

You cannot generalize about parents of retarded children any more than you can generalize about retarded children. Gifted, average, or limited, any of us can find our problems complicated by our own emotional makeup. Professional people working with us must learn to appraise these variables in our intelligence and emotional stability.

Apropos of this are the technical articles which some of us read. Why do we always face such words as "anxieties, hostilities, frustrations, guilt-feelings," and other emotionally charged words to describe our reactions? Such pseudoscientific certainties merely serve to make parents feel even more inadequate, it seems to me.

You should take seriously the comment of a New Jersey parent: "... Is not what appears to be 'guilt feelings' to professionals, merely concern with the child's welfare, mingled with grief over his handicap?"

"All parents experience some feelings of guilt about illness in their children..." Dr. Julius B. Richmond, pediatrician, of Syracuse University has said. If outward manifestations of these feelings persist in us after you have assured us that "no act of omission or commission" on our part has been responsible for the condition of our child, perhaps our feelings might be more aptly described as "regret." We are bound to feel regret if we have rejected this child, if we have struck out at him and created problems for him. With this regret we very likely feel anger at not having had the proper guidance at the times we needed it.

Might not some of our hostility be nothing more than righteous indignation over the neglect of our problem? Actually, if some of the pioneers in the parent group movement had not become "mad" in the early days, our problem would still be largely ignored. Who can say, on the basis of present knowledge, when anxieties are neurotic overreactions, if parents must ask: "What will happen to this child after we are gone?" "How can we pay for expensive care outside our home?" "Where can we hire a sitter so that we can take a vacation?"

Whatever labels we use for these feelings, they have added up to a great determination—you might call it "compulsion"—for some of us to see to it that new parents coming along can walk a smoother path. And there is considerable evidence that many of these new parents are avoiding some of the emotional scars which some of us bear.

Dan Boyd, a New Jersey parent, has described three stages in the growth of a parent of a mentally retarded child: (1) Why did this happen to me?
The fact that a parent is working in an organization “to help all retarded children” does not necessarily mean that he has grown with his own problem. Some can be stage-3 leaders, without having graduated from stage 1. Such self-pitying parents are the hardest to help. It often takes a long wait and the greatest skill on the part of professional counselors and their parent counterparts to help them to begin to make realistic plans for their own child.

Most parents, however, mature quite rapidly under the stimulus of the group. Self-pity fades when they find that they are not alone. Soon they are seeking to learn from and emulate the parents who have met their problems successfully. And before they know it, they are experiencing the healing that goes with helping another family. Some move on to be eager for all parents to have access to the organization which has rescued them from desolation.

Even these mature stage-3 parents can slip back, temporarily, into stage 2, when a problem arises at home or when previous decisions must be reviewed. During these times we can be very difficult. Then you must support us, while feeling “nothing but plain, simple, humble reverence before the mystery of our misfortune,” to use the words of John Cowper Powys.

This means that you must look at your own feelings about us and our children. If you do not have a natural feeling of concern for the mentally retarded, if you feel indifferent to or repelled by children who are not mentally normal or by parents under great stress, then you should not be dealing with us at all.

9. Remember that we are parents and that you are professionals.

Some of us are becoming so well-informed in certain areas of this problem and we are associating with you in so many different pursuits that, at times, it must be difficult to remember that we are parents and, as such, will always be emotionally involved with our own problem and our own child, regardless of the “objectivity” we may have about the problem generally, or another family’s problem, specifically. In communicating with us you must be clear as to whether you are speaking as counselor to client, adviser to organization member, coworker, or personal friend. In this we expect you to use professional judgment.

For example, don’t in front of us: belittle or countermand the opinion of one of your professional partners; make critical remarks about other parents and their handling of their child; jump to conclusions about our case without adequate clinical study or knowledge of the facts. And, of course, don’t try to do a job that is outside your professional discipline.

When we see so much that needs to be done, we have little time for professional jealousies, or for the individual who uses mental retardation as a ladder to personal success. It does not take long for us to pigeonhole a “problem professional” whose own emotional difficulties are getting in the way of our efforts.

10. Remember the importance of your attitude towards us.

Sometimes I think your colleagues place too much emphasis on “objectivity” and not enough on “loving kindness.” Certainly we expect you to be objective about our problem. But about us? Never! A really gifted professional person cannot help feeling—being subjective, attempting to stand in our shoes and to look out at our problem through our eyes—in the process of helping us. Psychiatrists call this “empathy.” It is only through empathy that you can divine the proper words and acts to help us.

There are greater depths and breadths in helping parents of retarded children than many of you have realized in your initial attempts. It has been as exciting for some of us parents to watch professionals grow as it has been rewarding for professionals to watch some of us parents grow. We can help each other become more effective people through our partnership.

You are obligated, it seems to me, to “feelingly persuade” us as Shakespeare said, to help us find “what we are.” We have many strengths. If you can help us convert our problem into good for mankind, help us find the sweetness in the uses of our adversity, you will find a far more precious jewel in your professionalism than you ever thought existed.

And you will be professionals in the most noble and magnificent sense of the word.

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WHAT HOSPITALS FOR THE MENTALLY RETARDED CAN ACHIEVE

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The two things that institutions for retarded children have in common are long waiting lists and a wide range of problems. Otherwise they vary considerably in their function, approach, and remedial techniques, and even in the type of population they serve. Many include only a small segment of the multitude of diagnosed conditions and complicating handicaps found under the uniform label “mentally retarded” or “defective.” Nevertheless, even in these, the range of conditions among the patients is broad.

In almost all institutions, public or private, there are patients with relatively high and extremely low endowments. There are patients with superimposed neuromuscular or skeletal abnormalities, those who suffer from epilepsy, those with physical stigmata, and those who differ little in appearance from other children. Though deviant from the normal in many respects, all are human personalities with needs at least as complicated as those of children everywhere.

In the not too distant past, the severely retarded child had but a slim chance to survive to school age. His need for specialized medical care went unrecognized and he remained at home, except in the most unusual circumstances. Institutions had no plans for him; in many States he was actually excluded from programs. In those days the majority of institutional residents came from the mildly or moderately retarded groups. A pessimistic outlook on prognosis frequently resulted in their lifelong seclusion from society.

Recently, however, a shift has been taking place in the composition of institutional populations. Advances in diagnostic methods, greater knowledge of disease control, the discovery of life-saving drugs, have all contributed to an increased life expectancy for the severely defective child, while the process of urbanization with its more crowded living conditions and growing employment of mothers has added to the difficulty of caring for him in the family unit. As a result, doctors and others have tended to recommend his separation from his parents by way of institutional care. Under this pressure the institutions have had to revise their programs to take greater cognizance of the severely retarded. In the meantime other developments have lessened the need for institutionalization of the mildly and even moderately retarded.

A psychiatrist who heads a large public institution presents some thoughts on . . .
New trends in the philosophy of public education have contributed to this change, at least in some areas. Most public schools used to limit admission to children of average or greater intelligence, and children with mild or moderate mental retardation had to be placed in institutions, if they were to get any schooling at all. In recent years a more liberal interpretation of children's educational rights has brought about programs for the mildly and moderately retarded in many school systems, so that such children do not always have to leave the family circle for schooling.

This shift in intramural populations toward the more severely retarded, more physically handicapped, and younger children confronts institutions for the mentally retarded with the necessity of reviewing their philosophy, purposes, goals, and therapeutic techniques. Institutional programs in a number of places today are beginning to reflect some of the thinking produced by this challenge. In each place the emphasis and direction have inevitably been influenced by the individual character of the institution, its population and its staff as well as by the degree of concern throughout the State for what happens to the mentally retarded.

No institutional administrator can bring about a Utopian program by merely designing a blueprint. Always he will be surrounded by barriers of costs, professional shortages, and scientific unknowns that can only be partially surmounted.

As a psychiatrist in charge of an institution presently housing about 2,700 mentally retarded children and adults I have arrived at certain conclusions of what an institution for the mentally retarded should be. These were influenced by my experiences and orientation. In presenting them I do not claim that they represent the only way of meeting the needs of the mentally retarded. Nor can I pretend that we have realized all of them at Pacific State Hospital, nor that what we have achieved has not been achieved elsewhere. If I use illustrations from that institution it is because its program is the one I know best. If I refer to adult patients, too, in this journal focused on children, this is because the very nature of mental retardation—which keeps children from becoming adults—makes it impossible for age to be a criterion in plans for the mentally retarded.

Basic Concepts

My first conclusion is that the proper role of an institution for the mentally retarded is to serve as a hospital for those whose condition requires psychiatric or somatic therapy, constant nursing care, or close observation. Education, social work, psychology, the rehabilitation therapies, and several other disciplines play an important role in the total therapeutic approach. They are also a part of the program, in order that the child who can profit by them is not denied advantages he would, but for his hospitalization, get in the community. Such a hospital needs specialized medical facilities with carefully developed programs, selected tools, techniques and especially trained personnel. Ideally, all treatment and program is directed toward one goal—helping each patient to reach the maximum of achievement and independence his mental capacities will allow.

The criterion for admission to such a hospital is the condition of the child in relation to the ability of his parents and the community—emotionally and physically—to provide him the care he needs. This does not limit the hospital to care of the severely or moderately retarded for the difficulties of being even a mildly retarded child at times produce emotional disturbances which in some cases are more amenable to treatment in a hospital.

Certain general psychiatric concepts need to be kept in mind in the care of the mentally retarded child. His emotional needs are essentially the same as those of other children. To develop the maximum of his personality potentials he needs the benefits of a warm parent-child relationship. For this, early institutional care is at best only a substitute.

On the other hand, emotional problems in the family can become a strong negative force in personality development. The birth of a defective child often acts as a trigger to many conflicts within or between the parents, resulting in strained family relationships. In some instances, separation of such a child from the family may be better than the uncritical maintenance of family unity—for in tense situations he is likely to be submitted to overprotection or overt rejection, either of which can greatly hamper his development.

Proper decisions as to whether or not separation is in order can only be made with the understanding of the forces that operate within the family. Here is where the hospital's own out-patient clinic becomes a necessity. In helping parents reach a decision the clinic, having a clear knowledge of the intramural program, can weigh the disadvantages of hospitalization against the problems of home care and can view the emotional climate of the family relation to
both factors.

Mentally retarded patients are suffering from a chronic condition. Therefore their hospitalization usually is prolonged. This carries with it the danger that a routine, protective, and pathology-oriented milieu may act as an arrestive, or even regressive force. In daily living overemphasis of the handicap must be guarded against lest it become a psychological barrier forever in the way of maturation.

The hospital which acccents achievement will find it necessary to revise many patterns inherited from custodial institution days. It will insist on trained and competent staff from the professional specialist to nursing personnel. It must find ways of selecting persons with a wholesome, warm, and understanding attitude toward the mentally handicapped and of training ward personnel within the institution. At Pacific ward "psychiatric technicians" receive a year of in-service training.4,5

In a large hospital patient grouping is important since much of the therapy—environmental, physical, social, and even psychiatric—must be applied to a number of patients at once.

At Pacific we have found the most effective groupings to be functional rather than either diagnostic or age-based. The chief criterion is the answer to the question: What is the immediate goal of achievement? For the year-old, moderately retarded child and the bedridden, older child it may be the same—ambulation, to learn to get about in some manner. For others, adolescents or tiny tots, it may be toilet training; for still others, more advanced, to learn how to dress themselves, or even to learn to read and write. At Pacific the classification for placement in the 30 some wards takes into consideration the following criteria in order of priority: ambulation, habit training, sex (except for small children), and other factors. These, of course, are often interrelated.

Functional groupings help keep the accent on achievement, and thus provide a stimulus for both the staff and the patients. At Pacific this stimulus is kept alive by weekly case conferences on each ward of the personnel concerned with the ward program. This team includes the physician, social worker, psychologist, nurses, technicians and others.

We have found that achievement can be a goal for even the most helpless patient, for whom ambulation or toilet training may never be goals. Getting such patients out of bed each day and putting them near each other has shown us that they can become interested in their surroundings and one another. Some even learn to move about.

The Hospital Community

Schools in hospitals for the mentally retarded are of crucial importance. They must provide the kind of learning opportunities that retarded children can use. Classes should therefore be available for children of the various age and maturation levels who can profit by them. Some may concentrate on such simple things as how to button a button and tie a bow, while others teach children to read and write, and to develop vocational skills. The aim is to give the patients the scholastic, vocational, and social skills which will help them to live as independently as possible whether in the community at large or in a sheltered setting.

Heavy emphasis should be placed on teaching patients the elements of living in society which are not a part of working—what to do with leisure time, how to make friends, how to budget money. Unless this is done, discharged patients who succeed vocationally may get into trouble and have to return to the hospital.

Within the institution social exchanges and the development of warm interpersonal relationships should resemble those experienced elsewhere. If the patient is to cope with living in a less sheltered setting, he must learn during his years of development how to meet temptations, challenges, and frustrations as well as to exercise choices. The hospital that provides an environment which is entirely artificial can hardly expect a patient to assume even a semi-independent role later. Complete separation of age groups or sexes may decrease administrative problems but is not likely to contribute toward the future independent adjustment of the patient. A community center with recreational and musical activities, a library, movies, dances, a beauty parlor, radio, and television, can greatly help to broaden interests.

With this in mind our program at Pacific includes a Rehabilitation Therapy Department which, with a strong groupwork emphasis, focuses on the provision of normal recreational and social experiences for the patients in a community center.

We also have a campus card system which enables a large percentage of patients to move about the grounds at will when not scheduled to be elsewhere. Since this means intermingling of the sexes on the grounds and in the community center, the inauguration of the system met with some warnings of trou-
ble, which, however, have failed to materialize. We of course exercise more supervision than would be found in the normal community. We have also established a small store to give the patients a chance to exercise choice and practice in the use of money.

Work assignments within the hospital can be one of its most important therapeutic aspects if the emphasis remains on the therapy rather than on institutional maintenance. The therapeutic value comes from the feeling of usefulness the performance of the task brings as well as from the vocational preparation that might be involved. Assignments must, therefore, be individually selected as part of the patient's total program. We have found at Pacific that patients experienced in maintenance tasks can take their first step toward community living in paying jobs in private institutions. With the help of an industrial therapist appropriate job assignments are made and exploitation is avoided. All patients with job assignments have regular days off and are included in recreational programs.

One type of work assignment, currently being tried at Pacific, has a two-edged therapeutic purpose—to give nonambulatory young children the mothering they need and to give the moderately retarded young girl an outlet for her mother instincts. Each girl in this program is assigned one or more children who may be severely retarded, to feed and care for. The girls grow extremely fond of "their babies," even of those with gross physical manifestations of their defects, and cuddle and play with them with real spontaneity.

Religious opportunities are a part of normal life, and as such must be part of the hospital's program. Like many other institutions we have chaplains of the three major faiths at Pacific who not only conduct religious services but also participate in the total therapeutic plan.

Even in the healthiest hospital communities patients should not live in isolation from the outside world. This can be avoided by arrangements for group and individual excursions into the outside community, as well as by visits of outsiders to the institution. Individual contacts are the most important to foster, especially between the child and members of his family. Visits home help the child to retain his interest and skill in home living, and are important for the parent as well. Last year, over 1,700 patients, with varying degrees of retardation and superimposed handicaps went out from Pacific on short visits home. Last Christmas more than 800 patients went home for the holidays.

Other individual contacts can be arranged through a volunteer program. Of the many contributions volunteers can make to an institution the most important is the demonstration their presence affords of society's continued interest. The 50 some volunteers engaged in direct service at Pacific come from 3 groups: parents of retarded children; other persons with a personal interest in retarded children; and clubs.

We have found that group excursions do not have to be limited to the mildly or moderately retarded. Last year we took 1,300 patients to the County Fair during its 2-week run, many so severely retarded or infirm that they had to be escorted around the fair grounds in wheel chairs. We also take patients to the public parks, picnic grounds, and for bus rides.

**Inpatient Therapies**

When the total hospital environment is made as normal as possible special therapies for the amelioration of the patient's handicap have a better chance of succeeding. Sometimes the focus of medical and nursing energies must be toward maintenance of life. At other times the child's condition calls for greater variety in programming and may include surgery, physical therapy, seizure control, and individual or group psychiatric therapy as well as regular "well-baby" medical care and dental services.

The hospital's total treatment program should be guided by medical philosophy and involve a close relationship between patient and attending doctor on whom the major responsibilities for the individual's program lie. In all respects the hospital's standards should satisfy the professional organizations. Up-to-date techniques in the various medical specialties—especially psychiatry, pediatrics, internal medicine, orthopedics, neurology, and physical medicine—should be available.

Psychiatric service is of particular importance for the mildly retarded patient, whose need for hospitalization generally comes from superimposed emotional disturbances manifested in rebellious behavior. Intensive treatment upon admission is often effective and may result in early discharge. Release of emotional tension has been known to lift some children clear out of the category of "retarded." Psychiatric observation of the relationship between parent and child can also be helpful in the staff handling of the severely retarded. Individual and group psychotherapy, play therapy, and the somatic treat-
ment methods should be freely utilized as part of the armamentarium of psychiatry.

Because of the close relationships between emotional disturbance, mental disease, and mental retardation, a hospital for the mentally retarded might well have a ward for the psychiatric treatment of mentally ill, but non-retarded children. We hope some day to have such a ward at Pacific in addition to one we already have for children whose condition does not seem to fall into any of the more clearly defined forms of mental retardation.

Outpatient Service

Many of the problems of retardation can be handled on an outpatient basis. In most instances, proper diagnosis can be made in a clinic without help of intramural observation. An outpatient clinic also gives the hospital physicians opportunity to make their special knowledge and experience available to the nonhospitalized. While the hospital needs an outpatient department of its own, clinic service can also be provided by community sources.

The contributions of the allied professions—social work, psychology, special education, physiotherapy, occupational, recreational and music therapy, dentistry, nursing, chiropody—should be well integrated into the program. Collateral treatment of the family is of primary importance in helping in the long term adjustment of the patient and assuring his reacceptance into the family circle.

In addition to the wards for the various age and functional groups, described earlier, the hospital needs a unit for infants. While it is generally agreed that group care is not the best kind of care for babies normally, many severely defective infants need hospital care in order to survive. For many, too, separation from their families is inevitable, and the question arises as to whether it might not be best for them as well as for their parents for this to come early.

Upon the establishment of the diagnosis a therapeutic relationship begins between the patient, the family and the hospital. The interpretation of the diagnosis to the parents, the working through of their conflicts around it, the acceptance of the implications of retardation, long-term planning and actual therapy may well be done on an outpatient basis. So may treatment of the early stages of emotional disturbances in mildly retarded children, with the avoidance of hospitalization a possibility.

An outpatient clinic for the retarded must provide a variety of services. Control of seizures, help with relatively simple child care problems, or assistance with somatic conditions may spell the difference between hospitalization and the continuation of home care.

An outpatient clinic can also help to lessen the length of hospitalization by extending services to patients after discharge. The possibility of the clinic following through with the efforts of the residential program can bring about earlier release.

To carry out this variety of services the outpatient clinic needs a professional team combining the skills of physician, social worker, and psychologist.

As a supplement to both hospital and clinic, a day-hospital program to give outpatients the opportunity for therapies available only within the hospital would make it possible for some retarded children to have the advantages of both hospital and home care. Its counterpart, a day-leave program, could help hospitalized patients to community adjustment. These objectives have not yet been achieved at Pacific.

Admission and Release

Usually when a retarded child is hospitalized the move should not be regarded as a permanent plan but rather as a new phase in his treatment program. The family and the patient, if possible, should know the reasons and purposes of admission and should understand the goals which are to be sought. Since separation is usually traumatic for both child and parents, they should be prepared for this.

Methods of admission have an important bearing on the early adjustment of patients and families. Court commitment seems unnecessary for most cases, and can be an extremely traumatic experience for the parents. Well-timed, voluntary admission, with parental consent and careful protection of civil rights is the best method of entry for most children.

New patients find the hospital a strange environment in spite of the best preparations. A receiving unit, staffed to give intense individual attention, can alleviate anxieties, expedite the final diagnosis and delineate the therapeutic plan. Its staff can also work intensively with members of the family who are disturbed by the impact of separation. At Pacific, where a central receiving unit is under construction, we have found that the period of adjustment usually lasts from 3 weeks to 6 months.

The hospital’s responsibility also includes planning opportunities to make release possible and the provision of continued support to help make it a
success. To be geared to the needs of the patients, release plans ought to encompass a variety of opportunities—placement at home, in a foster home, or on a job, as the situation warrants.

Developing a foster care program requires considerable skill and effort, but it can be successful. Currently 40 foster homes are caring for patients of varying degrees of retardation, from the Pacific State Hospital. Each cares for from 4 to 6 patients, carefully selected, with two criteria uppermost: the parents' readiness to accept foster home placement for their child; and the child's ability to benefit. Needless to say, such a program requires continued supervision and work with foster parents to see that the children get opportunities for play and stimulation.

A hospital's release and follow-up plans might be developed with the aid of an outpatient clinic or special staff assigned to community work. Job-finding, foster-home-finding, and follow-up supervision for the patients of the Pacific State Hospital are carried out by social workers from the Bureau of Social Work in California's State Department of Mental Hygiene.

Skills and Knowledge

A good clinical program cannot be maintained without a professional staff keenly interested and skilled in dealing with mental retardation, but not over-specialized in this area. It is important for staff members to have opportunities to keep their professional knowledge broad and up-to-date. An important medium for this, both from the hospital's and the community's point of view, is an all-purpose mental-hygiene clinic or a child-guidance clinic. Since emotional problems and mental retardation are closely related, part-time service in such clinics by the hospital's staff can be rewarding. At Pacific an outpatient mental-hygiene clinic on the grounds of the hospital provides such an opportunity. Affiliations with other institutions might bring similar opportunities to other specialists.

The serious shortage of personnel trained to work with the mentally retarded and the need among professional persons who serve the community at large for better understanding about mental retardation obviously put a responsibility on hospitals for the retarded to participate in the vanguards of professional training. Moreover, student placements within a hospital can have a stimulating effect on the program.

The Pacific State Hospital currently is serving as a setting for field placements for university students in medicine, social work, special education, and hospital administration. Two medical schools have undergraduate students in the institution. Graduate medical students specializing in psychiatry and pediatrics are also working there. Such a use of the institution in professional education may result not only in greater professional understanding but also in greater dissemination in the public at large of information about the needs of the mentally retarded.

Scientific knowledge in mental retardation is still in its infancy. If hospitals for the mentally retarded are to improve their programs they must also become centers of research. Their case material lends itself to a multitude of investigations, from methods of diagnosis or studies of etiology to problems in therapy. Furthermore, research is one of the best stimuli for professional growth. Its quality improves with administrative support, adequate funds, and the help of a nucleus of good research specialists. Its results may not only broaden knowledge in the field of mental retardation but may also shed light on a variety of medical problems, such as childhood diseases and schizophrenia, as well as on our general understanding of genetics, biochemistry, and other facets of human life.

The Future

All the suggestions made thus far could be incorporated into the traditional structure through which we now care for the person institutionalized because of mental retardation—the large centralized institution drawing patients from many miles around. Questions could be raised, however, about this structure. Is it the best setting for treating mentally retarded patients who must be hospitalized? Would it be better for such patients to be treated in units of general hospitals near or in their home communities?

There is no unqualified answer. There are pluses and minuses in both types of institutions. Smaller units in general hospitals would keep the patient closer to his family and could give more individualized attention. They would have another plus in bringing problems in mental retardation closer to other fields of practice in medicine. In such a setting opportunities for research and training and for university affiliations could also be more easily worked out. At the present time there are no uni-
versities in the country whose schools of medicine or social work offer a chair in mental retardation.

On the minus side of the smaller unit is the shortage of personnel with the skills, experience, and willingness to work with the mentally retarded. This makes centralization of professional resources almost a necessity. Researchwise too there is a possible minus in a small setting. With the scattering of patients sufficient case material may not be available in any locale. The larger centralized units can have a more concentrated case material. They can offer a more varied program to patients. They can utilize available human resources better, and the administrative cost is less.

Out of the current increased interest in the mentally retarded will undoubtedly come more and better trained persons willing to work in this field. When this happens institutional programs may develop locally. Then we will probably find that neither type of institution obviates the other—that the variety of children and problems in mental retardation demands both.


HOME TRAINING FOR RETARDED CHILDREN

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WHEN the District of Columbia Department of Public Health established a clinic for retarded children as a special project in its Bureau of Maternal and Child Health, it determined on two important features: geographic location outside of a hospital and the provision of continuing service to the family after diagnosis.

The clinic's professional staff includes a full-time psychiatric-medical social worker and a pediatrician, a clinical psychologist, a psychiatrist, and a child-development specialist, all on a part-time basis. Also participating is a part-time pediatric consultant public-health nurse. This staff functions initially as a diagnostic team, incorporating the findings of other specialists in building a picture of a child. For the diagnosis the clinic utilizes as needed the resources of the Bureau's Crippled Children's Services. These include neurology, electroencephalography, physical medicine, occupational therapy, ophthalmology, hearing and speech evaluation, and public-health nursing. The staff members of these services often participate in the treatment plan.

As part of its continuing service the clinic provides, on a selective basis, social casework services, short-term psychotherapy, home training, and referral to other community agencies.

The home-training program is worked out by the child-development specialist, who focuses on helping parents with the practical problems of daily living with a mentally handicapped child. The specialist participates with the team in planning the overall treatment program by giving reports on the child's behavior. Her reports are based on observations usually made in the clinic's playroom when the child is playing by himself, though occasionally they are supplemented by observations of the child's behavior with other children there or in his own home with his parents, his brothers or sisters, or adults other than his parents.

The child-development worker learns something of the ways in which the child relates to people and the anxiety or ease with which he accepts separation from his parents. She also notes how he handles his body and how he uses his sensory equipment, thus getting an idea of the picture he has of himself and of whether or not there might be a defect in his sensory endowment. She learns something of the degree of his social adjustment by observing his play habits, his ability to communicate, how he handles his own clothing, how he deals with aggression, and whether or not he has any understanding of the rights of others. She reports further information about the child stemming either from her own observations or from parents' reports bearing on such matters as feeding, toilet ing, and patterns of expressing affection.

At its evaluation conference the team sets up goals for helping the child and his family which may require a continuing relationship of the child-development worker with the family. This may mean planning with the family to help the child achieve specific skills within his area of competence such as
learning to pull off his shoes and socks or to feed himself.

The following cases portray the variety of activities included in a home-training program.

**A Severely Retarded Boy**

The mother of John, aged 2, came to the clinic in an effort to avoid having to “institutionalize” her son. He had already been studied carefully at the Johns Hopkins Hospital and was under private neurologic care for seizures. These, nevertheless, continued from 3 to 12 times a day in the form of mild loss of contact with his surroundings.

The family was referred by a private social agency, to which the parents had gone originally to discuss placement. As time went on, several factors had changed their purpose: a slight improvement in John who began to control his body movements; pressure from his grandparents who were shocked at the idea of “putting him away”; hearing other parents talk before and after committing a child; and finally, a visit to the institution under consideration.

Since the parents were now asking help in training, the clinic accepted the referral.

Medically, John was summarized as a child with convulsive disorder which showed up in a markedly abnormal electroencephalogram. When he was a year old a psychologist at Johns Hopkins University found him to be functioning at a 12-week level in most areas, with a stronger ability—about 16 weeks—in motor areas.

The home-training program consistent with such a diagnosis included:

1. Advice on ways of handling this heavy (35 pound) boy at home.
2. Study of feeding techniques.
3. Assistance to the mother in making a more accurate evaluation of the child’s potentialities. The mother had shown an understandable tendency to exaggerate progress, having pitted herself against medical advice to put the child in an institution.

The child-development worker carried out her services through visits to the home.

On the first visit the mother was feeding the child liquid food in a low “baby-tenda” from which lifting was difficult. He sucked the food in very fast, throwing his head back to swallow it without stopping to taste it. At the end of the meal the mother tried to demonstrate how her son handled a cup and a spoon, but he had lost interest and accomplished nothing. During this visit the worker stressed the values of the following:

1. A more convenient kind of seating arrangement (higher).
2. A more civilized rate of speed.
3. Self-feeding opportunities at the beginning of the meal.
4. The use of other food textures.

The worker later discussed these recommendations with the pediatrician, particularly those regarding food textures. The pediatrician suggested solid foods such as banana, cooked carrot, hard-boiled eggs, and zwieback, in rather large pieces which John could handle himself.

Revisiting the home a month later the worker noted some change. John brought his head toward the spoon. Also, the mother had slowed down the feeding process—a difficult achievement for her since the child’s dispatch in tucking away a large plate of pureed food was one of the few real satisfactions in her day.

On subsequent visits the worker discussed toilet training with the mother, suggesting that complete continence was an unrealistic goal and recommending cutting down on the amount of time the child was left on the toilet seat. She also recommended certain bathing techniques.

At each visit the mother made some comment either for or against institutional placement, as though she were arguing out the problem with herself in the worker’s presence. Eventually, she formulated the idea that she would “place” John when he learned to walk, which she thought would occur at about 3 or 4 years of age. Since this plan made it desirable to evaluate the child’s rate of growth, the worker made an appointment for him with the clinic’s psychologist.

The psychologist found John to be a child who “does little in coming to grips with materials.” She reported: “He is able, at 2 years and 2 months of age, to succeed in some items at the 2-month level, and had scattered successes through 5 months. Motor development is superior to other areas, and on the report of the mother he scored at 8 months largely because of this. He did not transfer objects from one hand to the other; he did not turn at the sound of a voice or the ringing of a bell. Left to his own
devices on the floor, he made active cooing and laughing sounds, scratched his clothing, and sucked his fingers.

These findings were interpreted to the mother by the clinic's medical director in the light of what could be projected for John in the future. By a comparison of this test with the previous one the parents were given some idea of the rate at which development was occurring. They finally had to face the question of whether or not John would ever be able to walk.

Meanwhile the mother continued to try to improve feeding techniques and to stimulate John to move about on the floor. At the end of 8 months John had made limited but nevertheless real progress. He showed less messiness in swallowing; he split less milk and reached for the cup to bring it to his mouth, although he still needed a guiding hand. He could carry a filled spoon to his mouth for 3 or 4 successive trips. He would drop the spoon, however, when it reached his mouth. The mother had become more relaxed with the boy and seemed to feel that since her efforts had produced some results she did not need to pad the picture to make the clinic understand her drive to keep him at home.

At one point the mother purchased a walker in order to get John to move about a bit by himself. However, the walker turned out to be too short for him and possibly too light. The worker suggested that a consultation with other mothers having similar equipment problems might be helpful. John's mother as well as several other mothers of heavy, non-walking, convulsive children, enthusiastically accepted this idea and decided to meet together regularly to discuss their problems.

At these group meetings with the child-development worker the mothers talked about walkers, where to buy rubber pants big enough for such children, what kind of a bed other than a crib could be safe for a child who might convulse at night, and how to build outdoor play yards, stronger and bigger than playpens, which would not require lifting the child over an edge. They talked about potty chairs versus toilets, how to build outdoor swings, where to buy clothes which did not look too old for children who still seemed like babies. The clinic's psychiatric social worker sat in on some of these meetings. From time to time the mothers discussed such problems as how to deal with typical manneristic behavior—studying the hands, rocking, weird noises—and how differently they felt about such behavior when it occurred at home or in public.

Toward the end of the series of discussions John's mother told the child-development worker that she was pregnant. Thereafter, her feelings toward her son began to change and she could say that sometimes she would look at him and "just be tired of him," though she would hasten to add that this was not all the time. At this point she began to consider institutional placement with an entirely different point of view. Because of this change the child-development worker referred her to the social worker for help in thinking toward this step. When she eventually committed the child she was invited to return to the clinic at any time she wished. She did not return, and the one time she phoned she announced that she felt all right about the commitment.

The experience of working under supervision to train her child apparently helped this mother to see his limitations more clearly and helped to free her to go ahead with her own life and family planning.

A Mongoloid Child

Not all of the children seen at the clinic need such elementary instruction in self-care as did John. For example, there was Sammy, a frail, spindly, 5-year-old Mongoloid boy. The team's study showed him to be a child who had achieved the basic self-help accomplishments but who badly needed social opportunities.

Sammy was referred to the clinic by a public-health nurse, who had known his family through her work at school where she saw his three older brothers. The mother, a tired, tense, thin woman, tended to two extremes in her way of looking at her youngest child. Sometimes she expressed the fear that he would stop growing completely and be just as he was for the rest of his life. At others she would reveal the hope that when he was able to go to school he would catch up with other children completely.

Both of Sammy's parents were foreign born. The father came from England, where he had been a valet...
Sammy's mother showed that she had a fine working understanding not only of the ways to teach Sammy, but also of how to select specific goals. Said she: "I wait for him to give me the things to work on." When he showed an interest in learning how to get upstairs, helping him with this became the most important activity of her day. When he became interested in taking off his shoes, she allowed him all the time he needed to unlace his orthopedic shoes, remove them, and place his socks inside them before he went to nap. Through her patient efforts she revealed that on a day-to-day basis she accepted her child's limitations.

During the worker's visits this mother also revealed an ambivalent attitude toward Sammy's condition by saying in one breath that she could not wait for him to go to kindergarten, and in the next, that she was afraid of having him be with big, normal children who would shove him around and knock him down.

During the next few months Sammy's tonsils were removed, thus freeing the boy from a tremendous drain of colds and infection. At a home visit after the operation the worker saw him eat three bowls of cereal with lots of milk and a bowl of applesauce for breakfast.

At this time, the family was having an unusually difficult time financially. Since the mother was continuing to buy a special vitamin-A milk for Sammy, though she could hardly stretch her food money to cover school lunches for the older children, the worker suggested that she come in for a conference with the Bureau's nutritionist, who could counsel her on how to choose less expensive, though nourishing, foods. She readily accepted this suggestion.

Sammy's lack of association with other children increasingly worried his mother. When he was refused admission to a nursery school for physically handicapped children, the worker suggested that the mother organize a small play group in her own living room to provide him with a not-too-demanding social opportunity and, hopefully, to lead him eventually into other living rooms. The mother commandeered three children almost at once, but after the first meeting complained that Sammy just watched while the others came in and broke his toys. The worker suggested that she cut back the size of the group to include just one other child, the youngest of the three original visitors, a little boy, aged 3.

At her next visit the worker helped the mother to see how to divide the morning into periods of free
play, a more quiet, organized activity, and solitary-but-adjacent doings. The worker also showed her how to read a story to young children, taught her some simple circle and finger games and discussed with her techniques of handling a small group.

Sammy now meets with two other children twice a week. So far the group has not left his living room. However, both Sammy and the young visitors show evidences of social growth and some understanding of the rights of others.

Here, while the skills of team members have contributed to a more comfortable situation in the family, the mother’s own devotion and patience have been primary factors in the retarded child’s growth.

A Potentially Normal Child

Another child with whom the child-development specialist has worked might be considered normal potentially. In this case the worker strove more to bring about a change in the parents’ attitude than to teach skills. The child, Joe, aged 5, was referred to the clinic for psychological testing after he had failed to adjust in his second try at attending kindergarten. Other specialists had noted that the parents were smothering Joe with overprotection and had recommended foster-home placement. At the clinic Joe underwent a complete diagnostic study, with his family’s consent.

This boy’s outstanding symptom was his difficulty in separating from his parents. At the clinic he could not accept their being in an office adjacent to the playroom with the door open. His parents reported the following:

He fed himself but was picky, disliking vegetables, fruits, and meats. He was afraid of the dark. He was very slow in dressing himself, could button but not tie, and was apt to get things on backwards. He made a lot of noise, talking mostly to himself in gibberish. His behavior was “flighty” and they could sometimes control him only with a strap. He was beginning to stop sucking his thumb, but had many temper tantrums during which he would hit his head and rock.

These parents said that they had felt “life was not worth living” after they had discovered that Joe was retarded. They were not clear about who had told them the child was retarded.

Psychological testing at the clinic scored this 5½-year-old boy with a mental age of not quite 4, but the test pattern indicated higher potentials. He showed unevenness and variability in functioning. Some of his behavior was negativistic while his responses showed immaturity in some developmental areas such as fine coordination. The psychologist’s recommendation included a “positive experience with an accepting adult and an opportunity to be with other children in a structured situation.”

Physical examination showed no medical problems or abnormalities.

The child-development worker’s visit to the home revealed that there Joe was in even less control of himself than he was in the clinic. He acted as though he resented his mother’s attempt to talk to the visitor and exhibited an extremely short attention span and very little common sense. The worker also noted that many of his play materials were fragile or too complicated for him. His puzzles, for example, would have been hard for an 8-year-old. Most of all he liked to get behind his bed and beat upon a drum.

During this visit the mother seemed somewhat less tense than she had in the clinic.

The staff program for this family included work with both the mother and the child. Coincidentally, the clinic at this time had decided to observe a group of children for a few weeks to see if they were ready for kindergarten. Joe became part of this group. The plan was for the psychiatric social worker to hold both individual and group conferences with the mothers of these children while the child-development worker worked with the children individually and in groups. The sessions were carried on in the clinic.

At the first of these an attempt was made to help Joe let his mother out of his sight for a very short interval. This was given up when it proved too distressing for him. On his second visit Joe arrived at the clinic in tears lest a separation occur. His mother assured him that it would not but in an aside to the child-development worker said that she would leave the playroom surreptitiously. This gave the worker an opportunity to discuss the desirability of a straightforward approach to the child, without cajoling or lying. No separation was attempted at this visit.

A few weeks later Joe seemed ready to play with another child but when he did so his behavior became so wild that he had to be removed from the room and kept away until he could pull himself together. The child-development worker’s discussion with the mother at this time centered on the importance of setting limits for the boy and giving
him a clear-cut notion of what was expected of him.

Six group sessions a week followed during which the prekindergarten program included activities organized by the teacher as well as some modified free play. Joe was able to participate in this program with special assistance from the teacher. Eventually he seemed ready for a regular kindergarten.

During the summer the family moved to a new neighborhood. In response to the clinic's interest in knowing how Joe adjusted to kindergarten, the family made an appointment to visit the clinic after school had begun.

At this visit Joe showed signs of having grown considerably in self-control, in his ability to face another person and talk directly to him, and in the quality of his play life and handling of materials. His mother reported that he no longer beat drums constantly. After Joe and his mother made two more trips to the clinic a conference with both mother and father was held to suspend the clinic's relationship with the family for a while. Both parents remarked that a miracle had occurred. Nevertheless, they were unable to see the cause and effect of their slightly modified ways in handling their child. They were continuing a pattern of overprotection in such ways as accompanying Joe to and from school, although none of the other children in the class had this kind of supervision. It seemed impossible to help these parents understand that Joe would need increasing independence.

The parents left the clinic's service with the understanding that the staff would recheck by telephone during the winter and review Joe's situation the following spring, when next steps might be formulated. Meanwhile, one can only hope that in the absence of more fundamental changes, the introduction into the social world which entering school has meant for Joe can assist him in continuing the healthy growth already observed.

An Experimental Program

These three cases point up the wide variation in types of help from which parents and children can profit through a clinic for the mentally retarded, involving problems ranging from those presented by the grossly damaged child who requires total care to those of the child without any apparent organic defect who requires help in becoming a functioning member of the community. So little has been done in the past in helping parents with such children, particularly those of preschool age, that the techniques for doing so are still largely in an experimental stage. The need for help, too, is so vast that it is doubtful whether an evaluation clinic could ever furnish all the direct service required. What a clinic can do at this point, perhaps, is to learn through such an experimental program what the methods and techniques are that are required and so build up a body of knowledge and skill which can be passed on, on a consultation basis, to the staffs of the referring public-health and social agencies, so that they can more adequately help families with such problems as they meet them in their work.
COMMUNITY CLINICS FOR THE MENTALLY RETARDED

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In the latter part of 1949 a group of parents in New York began to explore the possibility of establishing some special clinical facilities for themselves and their retarded children. Most of the parents in this group had done a good deal of "shopping" for help. It seemed to them that the existing clinics could not and did not answer their need. These facilities were too limited and too overtaxed with other problems. Their intake policies were too restrictive. Most of them lacked staff experienced in dealing with the mentally retarded. In most of them treatment was not available to the "less responsive" mentally retarded patients.

The few special clinics which were in existence for the mentally retarded at that time were largely limited to sorting and labeling the mentally retarded—to separating them from the normal and from other handicapped persons. They were used in certification and commitment procedures, in determining eligibility for special classes and in some research programs. Their function was a limited diagnostic one.

The parents in New York wanted special clinical facilities which had a much broader purpose. They wanted more than a labeling-and-sorting operation. They wanted some definite answers and some continuing help. As parents they wanted to know what was wrong with their children: Why had this tragedy happened to them? What had caused it? What could be done about it? They wanted the kind of help for themselves and their retarded children that they could get from a child-guidance clinic or medical clinic if their child had a behavior problem or an orthopedic condition—evaluation, diagnosis, interpretation of findings, and continuing guidance and management supervision.

In 1949, these parents were unable to find anywhere in the United States an example of the kind of clinic they had in mind. There was little guidance professionals could offer. No one had experience in providing the type of service they wanted. No one quite knew what it took or how best to design such a service. What the parents finally set up was an exploratory demonstration project, based on some judgments, a few guesses, and lots of hope.

Five years later, in 1955, the member units of the National Association for Retarded Children, in a survey of their activities, reported that 33 such special clinics for the retarded were either being operated directly by them or had been stimulated by them. According to this survey, 12 additional clinics were being planned for 1956.

The growth and expansion of such clinical facilities within the past year has been even more rapid. Many more have been developed by parent groups, hospitals, and private foundations. In addition, through congressional appropriations the Children's Bureau has assisted health departments in 24 States and Territories to establish special projects in mental retardation, all of which include some aspects of special clinical services to young mentally retarded children and their families.

While the definition of clinic varies, about 75 community clinical programs for the retarded in various parts of the country could be listed at the present time. In view of their increasingly significant place in the total program for mentally retarded, it is important to examine them critically. How have they...
been developed? What administrative and functional pattern have they evolved? Where have they failed? What have they proved? Which of them could serve as models for future developments?

While the enthusiasm of the parents' groups which stimulated these clinical programs created an extremely favorable atmosphere for experimentation and the evolution of new patterns of service, it also developed a negative aspect—a feeling of distrust of anything that already existed. What was known and what had been done had not met the need. None of it could be used. At times this feeling resulted in the discarding of basic principles of services to people and in losing track of basic human needs which the mentally retarded have in common with other individuals. Mental retardation was viewed as a specific subnormal condition of the intellect and the approach was to this subnormal condition alone.

**Clinic Patterns**

The effect of many of these positive and negative factors on the new special clinics is evident in their operation, functioning, and achieved results. Some of the problems created by the lack of clarity as to how mental retardation should be defined are also reflected in the operations. Some of these clinics have been unable to say who is to be included in the category of the mentally retarded as far as their own operations go. Some are still struggling with such questions as to whether mental retardation is primarily a social problem or whether it is a medical, a psychological, an educational or a psychiatric problem.

Naturally, the way a clinic answers these questions has a bearing on what it does and how. The answers will determine, for example, whether there is medical direction, whether there is a team approach, whether the child or the parents are the focus of attention in the helping process, what is included in evaluation, and what kind of help is offered.

The new special clinics which have sprung up since 1940 are variously organized. They include facilities patterned after the traditional pediatric outpatient service; the traditional child-guidance clinic; single-discipline guidance centers staffed only by psychologists or social workers; and various combinations of these patterns. They include facilities directed by pediatricians, psychiatrists, psychologists, social workers, nurses, educators, or others, with different program emphases resulting from different professional direction. Goals and purposes are variously defined. Indeed, in looking at this assortment of new clinics, one is at times struck by the fact that the only thing which many of them have in common is the kind of patients they serve—the mentally retarded. But even this diagnostic category is defined differently in different clinics.

Despite the varying concepts as to what a special clinic for the mentally retarded should be, much has been achieved through these experimental demonstrations.

New resources have been brought to bear on the problem. For example, the special projects of the Children's Bureau, developed by the maternal and child-health programs of the State health departments, have produced a public-health approach in the provision of clinical services to younger children. Directed by pediatricians, they provide clinical teams, usually consisting of social workers, psychologists, public-health nurses, child-development specialists, and consultant psychiatrists.

Experimentation in the clinics which have existed for several years has proved and disproved a great many assumptions and concepts about mentally retarded children. For instance, observations of mongoloid children living at home have demonstrated that these children do not necessarily follow the stereotyped behavior pattern, so frequently seen in institutions, of being sweet and docile.

These clinics have emphasized the individuality of the person who may be retarded. They have demonstrated the need of retarded persons for primary services in health, education, and welfare as well as for special help.

The achievements of some of the older clinics have not always been clear to the parents who have turned to them. From the point of view of these consumers there have been many shortcomings in services. Limitations of funds and staff, long waiting lists, and too little followup after evaluation have been responsible for some dissatisfaction. Financial and staff shortages prevent most of these clinics from dealing with all of the aspects of each problem presented. In some clinics certain aspects of evaluation and treatment are emphasized, depending upon the setting and the interest and orientation of the director. This emphasis may not fit in with the needs of each parent or child coming to the clinic.

A 2-year-old severely retarded child and his parents have different needs from a 12-year-old educable retarded youngster and his parents. They require different types of skills and services in different degrees of concentration, with individual variations, of course. Mapping out a program of
daily care for a severely retarded 2-year-old is not a psychiatrist's area of greatest competence. On the other hand, most pediatricians would not consider themselves equipped to deal adequately with a severe behavior problem presented by a 12-year-old retarded, but otherwise healthy, boy. The parents of the 2-year-old might require the assistance of a public-health nurse, a medical social worker, and some nutritional, occupational, and physical-therapy consultation; whereas the 12-year-old youngster and his parents might need a good deal of psychiatric help from a psychiatric-clinic staff, including guidance from a psychiatric social worker and from a psychologist.

**Differences Within the Category**

To serve mentally retarded children and their families well, planning for community-wide services takes into account the individual differences within families, the various causes and degrees of severity of retardation, the different ages of the retarded children, and the different behavioral expressions.

These differences call for a variety of clinical services, all of which have a place in an overall, balanced program for the mentally retarded. No one clinic can be designed to meet their total needs, any more than one clinic can take care of all the needs of normal people. We do not expect child-guidance clinics to provide well-baby care. We do not expect geriatric services to care for children.

Approaching the question of special clinical facilities in this manner, the kind of direction, approach, and staffing pattern utilized really would depend upon the kinds of problems, the functioning levels, chronological ages, and developmental stages with which the clinic was attempting to deal. As do normal children and adults, mentally retarded individuals go through certain developmental stages. Within each developmental stage certain needs are paramount. Clinics must be staffed and have their programs planned to meet the needs characteristic of each stage.

Taking these stages chronologically we come first to the prenatal period.

It has been estimated that approximately 90 percent of the known conditions resulting in mental retardation originate in the prenatal period. If this proves correct, special attention must be given to all known possibilities of prevention.

While a great deal of research still remains to be done, we do have some knowledge about the relationship of prenatal life to mental retardation. For example, we have some evidence of the adverse effect on the fetus of nutritional deficiencies and we know of certain complications of pregnancy, such as German measles occurring during the first trimester, or the Rh factor.

Preventive efforts depend upon the development of criteria for detection of conditions during pregnancy which might result in mental retardation and the better application of already existing knowledge of day-to-day prenatal and obstetrical care. These efforts should focus on alerting medical and other personnel, through refresher courses and other means, to recognize clinical signs of conditions in an expectant mother which could result in mental retardation in her unborn child. Such efforts would include making available to the medical practitioners consultation services from a variety of specialists and providing laboratory facilities to assist in the evaluation of suspect cases and in outlining specific treatment approaches. To be effective such consultation requires coordinated effort and a team approach.

Following delivery, the care and treatment of the newborn infant who is mentally defective requires experts with other skills. From the prevalence studies which have been completed, we might expect to identify approximately 2 mentally retarded children per 1,000 infants under a year old. Retardation to be detectable at this age has to be severe. Undoubtedly better casefinding methods will increase this rate. Also, as diagnostic techniques are improved, some less severely affected children might be recognized as mentally retarded at this age. Nevertheless, the known group would be made up largely of infants diagnosed at birth as being mentally defective.

**Care of Infants**

Diagnosis of mental impairment in infancy is based largely on the existence of one or more of a variety of congenital abnormalities generally associated with mental retardation. Such diagnosis rests with the physician, as does the primary responsibility for interpreting the child's condition to the parents. Since what has been diagnosed is a specific medical condition or a symptom picture, which it is assumed will result in mental retardation, the initial assistance provided to parents in meeting this impact should primarily come from the physician. Likewise, any treatment which might stop or reverse the progress of these congenital conditions must derive from medical prescriptions.

Pediatric services are of first importance for main-
taining the health of mentally retarded children, just as they are for the health of all children. Many of the infants in this group have a weak hold on life. Without skillful prenatal and obstetrical care many of them would not survive.

A program designed for newborn infants identified as being mentally retarded requires therefore pediatric direction. Its clinical services must be directed toward:

1. Prevention of further organic damage, particularly in such conditions as galactosemia and phenylketonuria.
2. Health supervision for the infant.
3. Interpreting the child's condition to the family, planning with them for the child's care, and helping them get the help they need.

Since most retarded infants are under the care of private physicians, consultation services to assist physicians in carrying out these functions should be part of the total planning.

The One to Fives

In the age range of 1 to 5 years the number of children identified as mentally retarded increases. Diagnostic instruments in this group become a little more sensitive so that some less severely retarded children can now be recognized. The prevalence rates in studies suggest that we might expect a rate of 4 mentally retarded children per 1,000 in the 1- to 2-year-old group; and of 6 children per 1,000 in the 3- to 4-year-old group.

Differential medical diagnosis is more complicated in this age grouping. Children who fail to perform like their peers in the expected sequence of development are frequently suspected of being mentally retarded. Visual and hearing difficulties, cerebral palsy, and other physical handicaps frequently interfere with functioning, and the resulting lag in development becomes apparent. Determining whether developmental lages are due to sensory defects, other disorders of physical and psychological nature, or mental retardation is an important aspect of service for children from 1 to 5.

The differential diagnosis, arrived at by the physician with such supplementary findings as he seeks, now requires a continuing contribution from the psychologist for a stage-by-stage evaluation of the rate, deviations, and strengths of the developmental process.

The reactions of parents who learn about their child's retardation during these years are different from those of parents told about their child's defect shortly after delivery. The parents of an older child who had assumed that he was normal, may slowly accumulate evidence that something is wrong, such as little or no learning from experience, or apparent incapacity to move from crawling to walking. These are the parents who are apt to shop around, driven perhaps by a mixture of disbelief and hope. The sooner they obtain definitive diagnosis and evaluation, the sooner they can turn their energies to productive activities on behalf of their child. They then are interested in some specific advice and guidance in such matters as training the child to crawl, sit, walk, talk, feed himself, dress, undress, go to the toilet, and perform other aspects of self-care. To provide parents with this kind of help a home training program becomes an essential element in the services of a specialized clinic.

Clinic services for retarded children of preschool age must be geared to serve the moderately retarded whose retardation may not be discovered until they are as old as 4 or 5. On the whole, these children will function at higher levels than those whose retardation was apparent earlier, and they will have had several years of comparatively "normal" relationships and experience in family life. Their retardation may show itself in slight deviations in specific areas of development, such as speech or play patterns. These children may be ready for their first supervised group experiences, which they might receive in play groups promoted by the clinic, by some other agency, or by a parents' group. Having had preliminary satisfying experiences with other children, a fair proportion of them are capable of participating in regular nursery programs. For example, a 5-year-old who looks and acts like a 4-year-old might be placed in a regular 4-year-old group.

The total group of children known to be mentally retarded swells in number during the first years of school attendance because it now includes those who have been identified as retarded because of their inability to cope with school demands. Severely retarded children come to represent only a small minority of the total group.

Behavior and emotional difficulties are both more prevalent and more prominent, bringing a greater need for psychiatric help. Community planning for this group centers primarily on providing educational facilities, and necessitates the gearing of clinical services largely to determining a child's readiness for school and providing diagnostic information.
to the schools to help them map out appropriate educational programs. The clinic would have to be staffed by personnel able to treat effectively the behavior problems of retarded children and to differentiate diagnostically between the children who are mentally retarded and those who are emotionally disturbed. Parents who first learn of their children's retardation during early school years face a different situation from that of parents who learned during their child's infancy or early childhood of their children's condition. Many parents of a school-age retarded child presumed, before he entered school, that their child was normal and enjoyed a few years of relationships with him unclouded by worry about his abilities. To readjust their concept of their child and still maintain a healthy relationship to him, as they vacillate between belief and disbelief following the school's detection of the mental retardation, often requires casework help spread over a long period.

Adolescents and Young Adults

In adolescence and early adult life, severely retarded persons continue to require special and separate facilities. So do those who are capable of functioning more fully but in whom mental retardation has become complicated by emotional deprivation and lack of training. However, most of the mildly retarded individuals who were defined as "educable" during their school years apparently no longer require special community services. They have become at least marginally self-sufficient and have apparently found a place in the community as earners.

With young adults the need to work and produce is a major drive. Those young adults whose mental retardation is of such a nature as to require continued community programming profit from vocational education, employment guidance, and job placement. Some require sheltered work opportunities. Social and recreational programs, which may have to be developed especially for such individuals, must also be an important element of planning. Psychiatric help should be available, of course, because of the inevitable strains on the mentally retarded even in the most protected situations.

Problems of sex, dating, and marriage present themselves in adolescence and adulthood. Many retarded persons are unable to cope adequately with these drives. Individual problems approximate a chronic pattern of withdrawal, regression, dependence, and isolation. There is preoccupation on the part of both the retarded adult and his family as to what will happen when the family no longer is able to provide supervision.

In general, clinical services for adult retardates also have a special contribution to make in evaluation of work potentials, supervision of health problems related to the retardation, and the reevaluative observation which would spot possible deteriorative processes. Among some retardates there is the breakdown of some physical functions and the emergence of some senile patterns at an earlier chronological age than is usual.

In addition to the kind of evaluation just described, clinical services for adult retardates must be prepared to offer supportive guidance and casework help.

The development of clinical services for people who are mentally retarded, therefore, is not a simple undertaking. Such services cannot be provided in the same way as services for specific organic disorders. The category of mental retardation is too broad and nonspecific. It includes too wide a range of human needs to make it practicable to attempt to meet all of them in any one clinic or with a set pattern of clinical specialists. Services people require at differing developmental stages should determine the staffing patterns at such stages.

The sequence in establishing the various units of clinical services to achieve a totally balanced program should be guided by community leadership decision on what degrees of retardation and what age groups require attention first.

2 New York State Department of Mental Hygiene: A special census of suspected referred mental retardation, 1955.
CHILD-WELFARE SERVICE FOR THE MENTALLY RETARDED

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CIAL WORKERS have long recognized that social phenomena are vital factors in child development and that a child’s problems and needs must be considered in relation to his environment—his family, his culture, and his community. Of these interacting forces, the child’s relationship with his family has the greatest significance, for in the family his basic needs for love, security, and physical comfort must be fulfilled. While other social institutions such as churches and schools may contribute much toward the child’s adjustability, their effectiveness depends largely on the extent to which their teachings are reinforced by the family. Since not all families discharge their responsibilities adequately, society has developed child-welfare services as one means of helping parents to provide their children with an opportunity for a satisfactory living experience.

In fulfilling these functions, public and voluntary welfare agencies have thus far largely neglected children handicapped by mental retardation. The needs of these children for diagnostic services, including pediatric, psychiatric, psychological and social services, special education, and training, comprise a major problem. This article will suggest some of the ways in which child-welfare services as part of a total community program can more adequately help mentally retarded children and their families. Many of the considerations to follow are also applicable to other social workers.

Who Are the Mentally Retarded?

The American Association on Mental Deficiency defines mental retardation as “that group of conditions which is characterized by: (1) inadequate social adjustment; (2) reduced learning capacity; (3) slow rate of maturation.” These conditions may be present singly or in combination. They result from subaverage intellectual functioning which is usually present from birth or an early age. The association further defines mental retardation as “basically a symptom complex resulting from a wide variety of conditions including not only defects of the central nervous system but also those in the psychological and sociological spheres.” It also points out that the psychological and social factors not only operate as causative mechanisms but may also play significant roles in influencing the degree and nature of mental retardation based on organic defect. This concept, in stressing the dynamic as opposed to the static elements in the condition, suggests that many mentally retarded children can be helped through treatment, education, or other thera-
peutic procedures even though the basic cerebral defect may not respond to remedial measures.

Because of the varying definitions used and the difficulty in applying the concept of social inadequacy, no accurate figures exist regarding the number of children or adults who may be classified as mentally retarded. It is safe to say, however, that those who fall into the lowest intelligence classification (persons incapable of achieving any degree of self-care) are a small minority of the total group. Comprising about 3 percent of all mentally retarded persons, many of them are physically as well as mentally handicapped. About 13 percent of all the mentally retarded are moderately retarded, semi-dependent, capable of self-care and the acquisition of simple work skills under sheltered conditions.

The remainder, or 84 percent of the retarded group, consists of persons who fall into the very broad and complex category of mild or borderline deficiency. Many of these children have no demonstrable defect of the central nervous system. In some of these children poor intellectual functioning is due to social and cultural deprivation, superimposed upon a subnormal intellectual endowment. Their failure to adjust socially results partially (perhaps even primarily) from personality and behavior disorders resulting from environmental inadequacy, insufficient guidance and the negative effects of undesirable association.

Mentally retarded children with cerebral defect are born to families from every socio-economic class in society. On the other hand, children whose deficient functioning comes from a combination of sociological causes and poor endowment generally come from culturally and economically deprived families. In many of these families the child's retardation may be but one of a host of problems.

The tremendous variation in conditions of mentally retarded children is illustrated in the following cases:

Randy, a severely handicapped 5-year-old, has never been able to sit unsupported, cannot feed himself, is completely unresponsive, and is unable to communicate in regard to his most basic needs. The extent of Randy's handicap, the result of a birth injury, has been known to his parents since his early infancy. They were told at that time that the child would not live beyond 2 years of age and were advised to seek institutional care. State care, however, was not available for so young a child, and the family's moderate income was not adequate to afford private residential care.

The parents are intelligent people from an average socio-economic background. The mother has a deep emotional investment in Randy despite his unresponsiveness. The burden of his care is a serious drain on her energies and she is unable to devote sufficient time to the needs of her other child. Her chronic fatigue and nervous tension is a serious threat to the stability of the home.

Freddy, a 10-year-old Mongoloid child, is the youngest of 4 children. Psychological tests indicate that he functions at a 4-year, 3-month mental age level, can benefit from social habit training, and can learn simple tasks. The rural community in which he lives does not provide facilities of an educational or recreational nature for children with this degree of mental limitation.

Freddy is in good health, is a behavior problem in the home, and is well accepted by his brothers and sisters. He has few opportunities for social relationships with children of his own age and occupies himself with simple household chores.

Freddy's father is a skilled laborer and earns an income adequate for the needs of his family. Although Freddy has not presented any unusual problems of care to this time, the parents are concerned about his approaching adolescence. They wonder, too, who will look after him in the event of their death.

Joan is an attractive, physically mature, 16-year-old girl, born out of wedlock. She has a history of petty theft and has occasionally demonstrated aggressive, hostile, and anti-social behavior. She lives in a deprived neighborhood with a high incidence of delinquency and associates with adolescents whose behavior is characterized by keeping late hours, drinking, and sexual promiscuity.

Joan's mother, who is of borderline intelligence, also has exhibited a degree of social inadequacy. She has entered into common-law relationships with several different men. Her work history is unstable so that she has had to receive public assistance funds for a number of years. She has close emotional ties and genuine affection for her daughter. Her awareness of Joan's limitations and need for supervision is, however, dim.

Joan attended special classes in the public school system from the age of 8 until her exclusion at age 16, on the basis of having achieved her maximum education potential. She is able to read and write satisfactorily on the 6th-grade level, but has not yet developed any work skills.

Social Diagnosis

An integral part of the casework function in child-welfare service is a skilled appraisal of the capacities, limitations, and resources of a child and his family. In instances of mental retardation, when psychological and social factors may further limit inadequacies due to cerebral defects or other causes, a careful social diagnosis is of paramount importance. Limited intellect is but one of many factors which cause social insufficiency. Many persons of subaverage intelligence are socially adequate, whereas others of good intellect but suffering from neurotic disorders, psychosis, or personality defects, are not. It is not uncommon for children with mild retardation to develop some form of emotional disturbance which
further depresses their level of functioning. Equating mental subnormality with social incompetency ignores the importance of other factors and is not in accord with current knowledge on the psychodynamic aspects of human behavior.

Clinical experience suggests that some children regarded as mentally deficient are more emotionally disturbed than mentally impaired. Thus, early identification and diagnosis of children not functioning well are essential from a standpoint of prevention of retardation as well as of treatment. The child who is slow to respond to parental demands, retarded in his physical development, and unable to compete successfully with children his own age is particularly apt to provoke feelings of anxiety and frustration. Parents of such a child are likely to have feelings of guilt and self-doubt. The resultant intrafamilial tensions present an unfavorable milieu for the child's healthy personality growth.

Helping such parents to recognize and accept the fact that their child is retarded does more than alert the family to the child's special needs in home training and management or for a nursery school experience. It gives the parents an opportunity to adjust their goals for the child in accordance with his actual potentials, relieves them of frustration based upon unrealistic aspirations, and facilitates the development of positive relationships between the child and his parents as well as between the child and other members of the family. In this manner, the child's incapacity for social living may be limited only by his degree of intellectual retardation rather than also by a complexity of social and emotional disturbances.

Child-welfare workers are frequently in a position to help in this identification and diagnostic process. They know of such children in the caseloads of public welfare agencies on the basis of problems not directly related to the child's deficiency. Some of them are referred to them by the school, the juvenile-court judge, other social agencies, a neighbor, or a parent because of behavior problems or apparent neglect or abuse. Social workers need training in recognizing deviations from normal growth and development and in identifying the many factors which may cause a child to function at a subnormal level.

Diagnosis in a clinical or social sense involves in most cases the combined efforts of several professional disciplines, working as a team. The physician must determine the child's physical limitations, the etiology of the disability, and the nature and degree of organic impairment; the psychologist must determine the child's capacity for learning, his special abilities or disabilities, the total personality configuration, and its implications for successful social adjustment; the social worker must determine, on the basis of the dynamics within the family, the extent to which family experiences have impeded or expedited social growth and the emotional and material resources of the family to meet the child's special needs. None of these factors can be readily determined on the basis of a single interview or examination. They emerge clearly only in a continuous form of evaluation.

So many factors may affect a child's rate of learning, maturation, or social competency that prognostic predictions, particularly during early childhood, are extremely hazardous. Many children identified as mentally retarded during their school years and thought to have limited potentials for economic productivity develop into stable and self-supporting members of the community. The child-welfare worker must maintain continuous contact with the family and keep abreast of its changing needs.

Problems of social and emotional adjustment may occur at every age and at every stage of development. Though other needs such as maternal and child-health services, special education, or vocational rehabilitation may assume primary importance for children in specific age groups or with certain handicaps, the family's need for help in providing the child with a successful social living experience arises in all groups and may play an important part in determining whether the primary service provided is effective.

**Social Treatment**

The major purpose of diagnosis is, of course, to offer a basis for the formulation of a sound treatment plan. What can the child-welfare worker contribute in a total service program?

The birth of a defective child is an extremely traumatic experience for every normal parent. In a child-centered culture such as ours the meaning of parenthood has deep ego significance. Parents are prone to make strong emotional investments in their child even before it is born. It is extremely difficult for them to give up the emotional gratifications anticipated from the social and educational achievements of a normal child and to avoid the feelings of guilt and shame that are apt to arise when the child is retarded. Such feelings are natural reactions to intense ego frustrations, but the frequent tendency to
explain parental behavior on the basis of these emo-
tions alone is an oversimplification. Because all
parents react differently to their children no matter
what specific abilities or disabilities the children may
have it is important to understand the parents' life
experiences as children, adults, and parents, for these
determine their reactions to their children, whether
normal or retarded.

Parents are often susceptible to well-meaned, but
ill-founded, advice because of their own ungrounded
fears and misconceptions regarding mental defi-
ciency. They are frequently advised that other chil-
dren in the home will be adversely affected by the
presence of the retarded child. They may be told
further that as the child matures into adolescence
and adulthood, his child’s mind will be unable to
control the urges of sexual drives. Undoubtedly,
many cases can be cited to support such contentions,
but any approach to the mentally retarded as pro-
ducts of a single mold has little validity. The child’s
social competency depends a great deal upon the
social demands made on him by his family and the
community. Research regarding the social nature
of mental deficiency indicates that in underdeveloped
countries the mildly retarded are able to adapt to
the social and cultural value system of their society,
which is less demanding than ours.3

Adapting the Environment

One of the responsibilities of the child-welfare
worker is to help create for the child as far as possible
an environment in which the social demands made
upon him are within the realm of accomplishment;
where he is protected from situations dangerous to his
welfare, yet not overprotected to the point where de-
pendency is unnecessarily prolonged; where the atti-
dudes of his parents and his brothers and sisters are
accepting and understanding yet not overly sac-
rificing.

The child-welfare worker can help to create this
therapeutic environment in the following ways:

1. Casework interviews with parents. These
may be directed toward (a) interpreting the child’s
abilities as well as his limitations; (b) relieving par-
ents of the anxieties, conflicts, tensions, and frustra-
tions the child’s condition arouses; (c) helping par-
ents to solve marital or family problems that might
be distinct from the child’s handicap but which may
impede emotional development.

2. Concrete assistance when needed. This may
include making arrangements for financial aid to

3. Arrangements for homemaker services. This
is another resource the worker can call upon to pre-
serve family strengths and unity. In many in-
stances, freeing the mother from the burden of con-
stant care and supervision of her retarded child, thus
enabling her to meet the needs of other family
members, may prevent family disorganization. In
some families with retarded children homemakers
may also be used effectively in a teaching capacity—
demonstrating better methods of home management
and child care to immature, inadequate, or retarded
mothers who without such guidance may be unable
to function satisfactorily as parents.

4. Arrangements for day care. Placement of the
child in a day-care center, a family day-care home, or
a nursery school appropriate to his needs often re-
lieves pressures in the home. The mother may need
help from the child-welfare worker in accepting such
an arrangement as providing opportunities for
growth for the child as well as relieving her. Fre-
quently the child with mild retardation can be in-
cluded in a group of normal preschool children.

5. Foster-family placement. This may have to
be considered for some children whose parents, for
varying reasons, cannot adequately fulfill their
parental functions and responsibilities. While a
child’s sense of security is more likely to be main-
tained in his own family, in some circumstances re-
moving the child from home is undoubtedly the
wisest course. Where this means must be resorted to,
the child is more apt to find emotional security in an
intimate relationship with substitute parents than
in the comparatively impersonal atmosphere of an
institution. In addition to providing obvious ad-
vantages over institutions for social and emotional
growth a good family atmosphere may stimulate the
rate of learning in some retarded children.

Many retarded children have been placed in foster
families by child-care agencies, but frequently the

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Developing Social Competency

Along with the responsibility for adapting the environment, as much as feasible, to the needs of the retarded child the child-welfare worker has responsibility for seeing that the child receives help in developing greater social competency. The first step in this direction for the preschool-age child is through the development of motor skills, coordination, and other abilities that may eventually permit a reasonable degree of self-care. Helping the mother to further such developments is the function of a public-health nurse, occupational therapist, physical therapist, or child-development specialist. However, the effect of parent-child relationships on such training and the possible need to help siblings of retarded children with their feelings and attitudes about the child may call for direct service or consultation by a child-welfare worker.

Many retarded school-age children, particularly those with mild retardation, can profit from direct counseling services to themselves or their parents. Some of them cannot make maximum use of their school experiences because of unfavorable home conditions, emotional disturbances, or hostile community attitudes. In such instances, the child-welfare worker, by virtue of his intimate knowledge of family dynamics, can provide the teacher with valuable insights regarding the child’s behavior and learning problems, thus making it possible for her to plan an effective educational approach.

Since the success of a school experience for many children may also depend upon the degree to which knowledge and habits learned in school are reinforced at home, the child-welfare worker may need to serve as a liaison between the school and the family. She can help the family be aware of the teaching methods used, the abilities of the child uncovered at school and requiring continued development at home, and the forms of discipline to which the school has found the child to be most responsive. Not every child requires this special assistance, but where the emotional climate in the home is impeding the child’s capacity to learn, the skills of the social worker as a “family specialist” can contribute a great deal.

Retarded adolescents in particular present a challenge to the caseworker. Many of them come to the attention of child-welfare agencies because of delinquent behavior or the need for protective services. The theory that a person cannot be helped unless he initiates the request for help himself does not hold up in work with retarded adolescents. The social or moral judgment of some of these young people, as well as of their families, may be so impaired as to prevent them from making wise decision, particularly under stress. A child-welfare worker may sometimes need to be a retarded adolescent’s superego, setting limits, offering advice, or making direct decisions. Though not made in reference to the retarded, Charlotte Trowe’s comment regarding “aggressive casework” is relevant:

“We no longer refrain from the use of authority, sometimes actually in the form of judgments as to right and wrong. To the extent that we use this authority in response to the client’s need and his incapacity to appraise and regulate himself, rather than out of our own need to be authoritative, we are finding it a helpful measure. We support the client in many instances, more frequently than formerly, with advice and guidance, in response to his capacity to use it, or his incapacity to function without it.”

Assuming such responsibility for another person is a weighty obligation. It requires the caseworker...
to have an understanding of the child's total personality, his special needs, the nature of his defenses, the social attitudes of the community, and his interaction with the environment in which he lives.

Retarded children need to be protected against exploitation, but they also need help in accepting the consequences of their own decisions, if they are able to make decisions and to profit by mistakes. In working with them a child-welfare worker must understand his own attitudes toward mental retardation and must guard against the pitfall of overprotection. He must help parents realize that the development of good judgment does not result from the passive acceptance of failure, but from facing up to unpleasant consequences. Michael F. Grapko has said of normal children: "The persons who succeed in avoiding unpleasant consequences denies himself the opportunity for learning and growth." This also applies to the retarded.

The child-welfare worker can also help the retarded adolescent in developing good social relationships with the opposite sex, in finding opportunities for vocational training and employment and in budget management. Mildly retarded young adults may also need a social worker's help with the social-adjustment problems of moving into new living arrangements, working with persons with whom they may have little in common, and adapting their living habits to the authority of an industrial setting. Not all of the retarded can make the transition from school to employment, but professional guidance can help many to be assimilated into the general population.

**Coordination and Research**

Child-welfare workers can also stimulate and participate in community planning and social research in respect to the mentally retarded. There is an urgent need for better coordination and utilization of existing resources in health, education, and welfare under public and private sponsorship. There is also a need for evaluation of ongoing programs, and stimulation of professional and citizens' groups into social action to eliminate gaps in services.

In collaboration with persons of other professional disciplines, child-welfare workers can also investigate the nonmedical aspects of mental retardation so that training and treatment techniques may be based on scientific facts rather than opinion. Greater concern in these areas by social workers and by schools of social work may spread interest in the potentialities of the retarded and provide a basis for more enlightened social attitudes and planning.

Thus, child-welfare workers and other social workers can play an important role in alleviating some aspects of the social component in mental retardation. Although medical research into the possibilities of preventing retardation has made notable progress in determining the causes and possible solutions in certain types of cerebral defect, for the present we must accept the fact that mentally handicapped children will be with us for many years to come. As with other health and welfare problems, social workers must deal with the present situation as well as the future in accordance with the best knowledge and resources currently available.

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ATYPICAL CHILDREN WITH COMMUNICATIVE DISORDERS

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WITHIN quite recent years there has been developed a powerful armamentarium with which to deal at the diagnostic level with the atypical child who has communicative disorders. Granted that much remains to be learned of the etiology and prevention of such disorders—particularly the facts of intra-uterine environment—the various techniques of measurement and description are becoming more refined and make more sense with each advancing year. However, with more and more children being brought through catastrophic perinatal events and maintained in good health, the numbers of multiply-handicapped children have been steadily increasing.

It becomes readily apparent to the student of epidemiology and biostatistics that a large proportion of the children who are atypical—that is, who need special help in development, in learning, and in social and emotional adjustment—have one combination or another of communicative disorders. Something is sufficiently wrong with their hearing, language development, or speech, alone or in combination, so that these disorders in themselves constitute fundamental difficulties in development, in learning, and in social and emotional adjustment.

It has been society’s bent to think of these children according to primary and secondary handicapping conditions, and therefore to begin therapy in terms of the so-called primary problem. In many respects, this is an unsettling idea that is only quasi-logical, and probably represents only one among many possible perspectives from which a child may be viewed.

From this perspective, however, one may see retarded children who are deaf, deaf children who have either the athetoid or spastic form of cerebral palsy, spastics with dysarthria (a neural breakdown in the motor speech system), athetoids with aphasia (an organic inability to use or understand words), aphasic children with crippling skeletal conditions, rheumatoid children with reading disabilities, aphasic epileptics, schizoid children with aphasia, and many other combinations. Apparently, this matter of labels may determine which of a number of dysfunctions is primary and which is secondary in the child’s condition. Again, this is an unsettling idea, particularly when viewed in the light of a general commitment about concern for “the whole child.”

A long step forward in clinical management is marked by the development in recent years of group diagnostic teams, wherein many paramedical disciplines are brought together for interaction around the central figure of the handicapped child.

The “integrated cleft-palate diagnostic group” is an example. A typical group includes representatives of pediatrics, plastic surgery, prosthodontics, orthodontics, dental surgery, otology, psychiatry, speech pathology, and social service, with none of these being either primary or secondary in the diagnostic task.1 Procedural steps in a particular instance result from group appraisal and consensus, all aimed at a single goal, the best development of the child, which means achievement of the best possible communicative status.

Similarly, “diagnostic centers for multiply-handicapped children” are coming into being in a few medical centers. The driving force of this development has been the realization that in many instances of interclinic referral the child may be lost in the shuffle of a busy medical center, with a confusion of followup records and extreme difficulty in checking out the necessary steps in examination and treatment.
of complex, multiple problems. The larger the hospital, the more apt this is to occur, particularly to children with chronic problems who must be handled at the outpatient medical-care clinic. This is the fault of nobody in particular; it stems simply from the fact that problems of interagency activity and referral, record keeping, distribution, and followup, scheduling or rescheduling, all involve a morass of paperwork and rechecking which busy clinicians do not have time to do. It also stems from the shifting nature of a residency staff, the lack of coordination among specialty consultants, the pressures of various acute problems, and a variety of other aspects of the complex of modern medicine.

**Complex Handicaps**

Like other children, the atypical child with multiple handicaps, including one or more of the communicative disorders, badly needs to be viewed as a “whole child.” What does such a view involve?

Child A exemplifies a common problem. She is 31 months old. Her mother had had 4 miscarriages prior to her conception, and during the pregnancy received hormones from the second month and was kept on frequent bed rest. Labor was prolonged; the cord was wrapped around the infant’s neck at birth; the baby was cyanotic and was kept in oxygen for 2 days. There were no postnatal infections or diseases.

As the child grew the motor developmental landmarks were somewhat delayed, but not drastically. At 2 years of age, she showed no problem involving balance, but exhibited a slight lack of coordination in handling things. Her parents were uncertain about whether she had responded to sound in early infancy, but had not really become concerned about her hearing ability until she failed to learn to talk. At 31 months she had achieved only a rudimentary gestural language, which was unstable, no understanding of verbal language, and no speech.

Testing gave clear evidence of normal auditory peripheral function, but showed unstable perception of both pitch and loudness. This indicated a disorder of the central auditory pathways with, in all probability, a receptive language problem, aphasia. An extensive neuropsychologic examination confirmed this impression and also produced evidence of lack of central visual coordination in respect to memory for visual patterns. In spite of showing deficiencies in hearing, language, and speech, the examination gave clear evidence of reasonably good intelligence. This was supported by pediatric developmental neurologic examination in which the child showed no obvious symptoms of retardation except in these various sensory-perceptive areas. An electroencephalogram (recording of the brain waves) showed no frank evidence of an epileptic disorder, but gave some indications of hemispherical asymmetry of the brain and a definite slowing of two types of brain waves, the theta and delta waves.

In summary: The child was in good health after a stormy perinatal experience. No symptoms relating to her ears were present; her peripheral hearing mechanism apparently operated within normal range. There was clear evidence of a central auditory deficit. Central visual functions were not normal. There were problems in memory. Language development was aberrant. The electroencephalogram did not present a recognizable diagnostic picture, but was not normal.

What is this problem? Any of the classical labels is scarcely pertinent. The child can hear, but is deaf; she is retarded, but is not basically mentally defective; she can see, but cannot remember visual patterns, nor can she remember auditory patterns in time; she frequently responds to sound, but cannot discriminate what she “hears.” Cortical function is obviously affected, but not in any classical form of “brain injury.” She shows a slight lack of motor coordination, but not enough to imply cerebral palsy. She has shown no emotional symptoms beyond what would naturally accrue from communicative deprivation. Certainly this child suffers delayed speech, but this term does not describe her problem.

Actually, she has many problems, involving deficits in sensory functions, in perception, in memory, and in learning. She is a multiply-handicapped child, who needs reassessment regularly, a carefully designed program of parent guidance, and, later, a regimen of skillful teaching based on the diagnostic findings. There is no school placement which can be ideal for a child with such problems, except one which includes eclectic procedures and extensive creative teaching.

Unfortunately, this child is not a rara avis. In a busy clinic for children with communicative disorders, hundreds of children with these and other related problems are seen each year. They are atypical children, in terms of classical description, and in terms of one another.

A vast amount of attention is being paid these days to cerebral-palsied children. Most if not all of them have one aspect or another of hearing, language, or speech disorder. Some types of cerebral
child to be retarded in several 'ways, for lack of either hearing, word comprehension, or sight leads to build on are questions rvith quite different answers for each. Many children are mentally retarded and deaf, or mentally retarded and aphasic, or mentally retarded and blind.

One would expect the deaf, or aphasic, or blind child to be retarded in several ways, for lack of either hearing, word comprehension, or sight leads inevitably to a large measure of communicative deprivation. It is most important that children who have been impeded in their development by communicative deprivation not be confused with children who are profoundly deficient in their capacities to learn. A vast difference lies between the potential of the child who is biologically deficient in capacity to learn, and that of the deaf or aphasic child who functions suboptimally because of sensory, perceptive, or mnemonic deprivation.

Another group of children with combined handicaps which are often extremely abstruse, are the so-called "emotionally disturbed." A principal diagnostic objective is the attempt to discern whether the obviously disturbed child has emotional problems which are fundamental aspects of personality and self-appraisal, or are sequels to sensory, perceptive, or mnemonic deprivation. Many deaf children become so communicatively frustrated by the time they are 3 years old that their emotional disturbance may overshadow the basic problem.

At one extreme of possibilities among emotionally disturbed children is the child with the Straussian syndrome—completely distraught by problems of perception. He simply cannot organize his world through the sensory and perceptive functions at his disposal.

At the other extreme is the schizoid child, whose world is relatively well organized in sensory and perceptive terms, but for whom this does not make any difference. He is away from it, in any sense of the direct relationship of ordinary values. He may carefully step over every toy in the room, while maltreating the instep of every adult present. He may commonly not respond to sound, not because he is deaf, but because sound is not an acceptable stimulus for him; he does not want it.

Between these extremes are many combinations and degrees of emotional states and communicative handicaps, resulting in; one or another aspect of the deviation from normal reactions called "disturbance." It is important for the clinician not to confuse lack of response with inability to respond, so far as the sensory systems are concerned.

Speech Disorders

Among the defined speech disorders (exclusive of stuttering, a speech dysrhythmia which is a symptom of an underlying anxiety state) perhaps 70 percent are usually grouped under the rubric "dyslalia" or "functional articulatory disorder" as distinguished from an impediment caused by cleft palate or some...
other clearly discernible structural inadequacy. Clinical evidence has been growing rapidly (though not experimental evidence) to indicate that many children suffer a natural inability to monitor their own speech output with precision.

The obvious disparities of the lispers and the lal-lers from normal speech indicate an inadequate kinesthetic development. This too may be a result, however, not a cause, the basic difficulty residing at the sensory-motor level in an inability to remember the details of sound-sequence from the speech of another person. An extreme form of this is a disorder called “cluttering.”

The clutterer may share with the stutterer the usual forms of perseverative or retardative dysrhythmia, but far from being burdened with an anxiety state the clutterer does not care what he says. He cannot monitor himself sharply, and simply bumbles along, expecting the world to do the best it can in making sense of his utterances. He is like the trained mule; he can perform well if one can get him to pay attention to the demands of the occasion. The mule may require the ministrations of a club; the child needs speech training by a sergeant major.

At another extreme, an aphasic child in early infancy may have shown clear auditory orienting reflexes, but later, not being able naturally to learn and remember verbal symbols, may have inhibited the reception of sound, commonly enough all sound, environmental as well as verbal. The young epileptic not infrequently goes through a similar represive stage. The problem of these children is not that they do not hear. The problem lies at a higher organizational level, an inadequacy in memory for the symbols of sound and a resultant failure in ordinary reflexive responses to sound of any kind. In some respects, it may well be that these children learn “not hearing” as a kind of defense or adaptation to a confusing world.

The Listening Mechanism

This commentary would be incomplete without reference to the organic listening mechanism. Current experimental evidence quite clearly demonstrates the existence of a neural network, including not only afferent fibers but a complex set of efferent fibers which compose a central alerting system for the hearing end organ, the ear. It seems obvious that many of the clinical entities which entail sensory and motor disparities, auditory and otherwise, may involve this alerting system at any point from the cortico-thalamic tracts to the peripheral structures. Children with involvement here need consistently to be alerted to sound and to be taught to attend to it, so that the various complexes of environmental sound may become sources for learning and for normal relationships with the social world.

We have, then, not a simple straightforward picture of hearing in terms of a black-and-white, you-do-or-you-don’t kind of behavior. Rather, the various communicative disorders represent some form of breakdown in a sensory-motor continuum. Hearing, language, and speech are not unrelated operations. Naturally, they may be studied as though they were, but the studying does not make them so. On the contrary, in developmental terms, these various aspects of receptive and expressive behavior are inextricably bound together in a kind of feedback loop of relations between the individual and his environment. A child hears, learns to listen, learns language, learns to talk, learns to hear himself, listens to himself in comparison with what others say, and so on. Any serious interference with or breakdown of this self-monitoring loop may profoundly upset its integrity.

Because of the nature of common causes and effects, a large proportion of atypical children have real difficulties in hearing, in learning language, or in speaking. A historical label—the deaf child, the child with delayed speech, the retarded child, and so on—does little justice to the complex of the communicative disorder, or to the effect on “the whole child.” The point is not that some deficit in a child is primary and another secondary, but that there is communicative confusion in the way the child can relate to his world. The various confusions in this regard require insightful recognition and handling, not as entities but as part of the total picture of the child with multiple problems.

Increased knowledge about causes, more refined diagnosis, and more effective treatment may result from . . .

RESEARCH TRENDS IN MENTAL DEFICIENCY

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ONLY A FEW years ago persons engaged in research showed little interest in the problems of mental deficiency. While there were exceptions, most research workers were unable to see any direct connection between their work and mental deficiency. They might express interest and recall having heard a lecture on the subject but this was about the limit of their familiarity with this field of research. Sarason and Gladwin,1 in concluding their survey of psychological and cultural problems in mental subnormality, noted the disappointing quality of research being done in institutions for the retarded and the "disinterest of behavior science departments (psychology, anthropology, sociology, psychiatry) in the area of subnormal functioning."

To put it crudely, one might say that mental retardation simply was not popular. Funds, thinking, and personnel have been engaged in other directions. While the desirability of research was recognized by institutional staffs, their geographical isolation from universities and their budget limitations forcing them to focus on pressing service needs have combined to stunt the growth of research and training in the field.

In the past 5 years, effort on the part of the parents affiliated through the National Association for Retarded Children has resulted in considerable stimulation in all aspects of the field, clinical and research alike. It is to their credit that they have recognized the need for research even though they know this implies commitment to a long-term and, more often than not, unspectacular grind. It is well recognized that the complexity of the factors involved in mental retardation requires research in many disciplines if a more adequate understanding of treatment, cause, and prevention is to be developed.

An immediate result of this stimulation has been an increase in the number of projects under way involving the mentally retarded. These range in a broad sense from efforts to provide more trained personnel for work in the field as at George Peabody College2 to the special diagnostic clinics supported by the Children's Bureau.3 As part of this general stimulation the National Association for Retarded Children, the National Institute of Neurological Diseases and Blindness, the National Institute of Mental Health, the Association for the Aid of Crippled Children, and the New York Foundation have jointly supported surveys of biological, psychological, and social problems in mental retardation.4 A project on technical planning in mental retardation being conducted by the American Association on Mental Deficiency, now in its third year, has involved a variety of activities designed to stimulate improvement in research, training, and program development.5

These general projects have underscored the necessity of closer association of the institutions with universities and medical schools in order to break down the isolation of the field and to bring in those whose interest in basic research problems will revitalize the concepts used in mental deficiency. Such
The Behavioral Sciences

In the behavioral sciences an interesting shift may be observed away from concentration on the use of psychological test-score patterns used to delineate subgroups toward studies designed to tease out the specific difficulties which may exist with respect to some achievement, or to determine how a particular treatment may affect individuals in order to know better how to proceed educationally and vocationally.

Woodward and her coworkers at the Lenox Hill Hospital in New York City have reported on their 3-year study of preschool children, emphasizing the importance of psychogenic factors in inhibiting mental growth. Whether or not their efforts at treatment will prove to be successful is not known, but they do focus attention on the necessity for early identification and treatment in children without detectable organic defect. A somewhat similar project being carried on by Kugel and his associates at the University of Iowa is briefly reported in the Here section in this issue of Children. (See page 35.)

Griffith and Spitz have studied the process of abstraction in high-grade retardates. When such youngsters are asked to give the property common to three nouns they tend to be successful when they have independently been able to define two of the three words in terms of a possible abstraction. That is, if they define chair and table when these are presented in a vocabulary list as “furniture,” they may later be able to recognize that chair, table, and bed when presented together are all “furniture.” The authors suggest an application of their work in the training of retardates through the teaching of a common description for several types of social behavior. For instance, meaning for the term “bad” might be developed from the association of “bad” with “punishable,” or “cause for being returned to the institution” while these terms in turn are related to the specific items “fighting,” “lying,” and “stealing.”

The importance of taking specific handicaps into account in program planning is illustrated by Hunt and Patterson’s study of retarded children with visual or auditory perceptual difficulties. When a brain-injured child with a difficulty in auditory perception is asked to sort out a series of pictures so that they illustrate a story to which he is supposed to listen he tends to concentrate on the pictures and blot out the auditory cues. This work has obvious implications for teaching methods and class composition. [See pages 13-16 for further discussion of mentally retarded children with perceptual defects. Ed.]

A method of measuring activity level has been described by Foshee who used it to measure drive strength during simple and complex learning.
While the implications for program and treatment in this study are not immediate, the long-term results from the study of motivation and learning in the retarded should be considerable. McPherson has again reviewed the experimental literature on learning in the mentally retarded. She reports 14 studies meeting her criteria for inclusion since 1948. While this represents a number larger than that reported in the original review, which extended back to 1904, it remains a very small number when it is compared with the mass of studies reported in the general psychological literature. From her review it is apparent that our knowledge of the learning process in the retarded remains fragmentary and confused.

**Quantity and Quality**

The studies briefly mentioned here can only indicate the diversity of work now being done in the field. Other investigators are evaluating the effects of socio-economic conditions and language barriers in school performance, the effects of the loss of the mother in infancy on growth patterns, and the self-picture of the retarded child in relation to his goals and level of aspiration. This diversity and quantitative improvement does not necessarily mean that better work is being done. However, there are signs of a qualitative improvement both in the kinds of questions being asked and in the experimental designs.

In general, instead of the comparison of groups on some psychological test score or pattern, more effort is being expended to investigate the psychopathology of mental deficiency. With a more specific knowledge of what is amiss in the learning, thinking, problem solving, personality, and socialization of the mentally retarded, it should be possible to make better predictions about success in education and rehabilitation than can be made at the present time from a knowledge of the I. Q. or of the fact that the individual is considered “brain-injured.”

While this paper has focused primarily on the behavioral sciences, the same tendency observed there, the introduction of new concepts, and the relating of experimentation to current theory may be seen in other disciplines. Lippman’s paper on the significance of heterozygosity for hereditary metabolic errors may be cited as an example of this. This suggests how the application of modern genetic theory and techniques of investigation may shed light on the etiology of retardation in those people who at present are classified as “familial” or “undifferentiated.”

With time, it seems inevitable that concepts and theories which have been found fruitful in the laboratories or in other populations than the retarded will be applied to research with the retarded. This in itself will do much to reduce the gap between university and institutional research workers and increase the useful knowledge about mental deficiency.

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An important process in treatment in a mental retardation clinic is . . .

COUNSELING PARENTS OF RETARDED CHILDREN

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In all services directed at helping children, treatment necessarily includes, besides the child, another person who is directly responsible for the child and closely affected by his condition. This person is usually the mother, and though not a patient, is always a client of the agency. This is particularly true in clinics concerned with mental retardation. Treatment of mentally retarded children has to be primarily aimed at reduction of secondary difficulties and improvement in tolerance of the condition and in ability to handle it on the part of the persons carrying responsibility for the child. The problem of retardation is always a family problem, and diagnosis has therefore to be a family diagnosis focused on the total situation. Thus, parent counseling becomes one of the most effective treatment tools.

"Parent counseling" is used here primarily to describe a process of casework treatment, based on diagnostic findings and aimed at ego support and adjustment to reality. It is an enabling and helping process based on the understanding of the dynamics of personality and it uses relationship as a vehicle.

"Diagnosis" as used here will include medical, social, and psychological diagnosis of the child’s condition, of the needs of the family as a unit, of the parents’ personalities, and of their ability to use available services.

Many of the problems that occur in connection with mental retardation are common to families of handicapped children in general. The parents have to understand the nature and extent of the child’s condition, face their own feelings of guilt and rebellion, and learn adequate modes of handling the afflicted child. In such families other children may be neglected and normal life experiences curtailed for either the healthy or the handicapped members, or both. Family breakdown may result from the parents’ own withdrawal from normal activities. In the family with a mentally retarded child additional factors of social shame, embarrassment over the child’s behavior, and bafflement over the child’s uneven capacities, often must be dealt with.

In contrast to other medical conditions, treatment of the retarded child’s condition rests primarily with the parents rather than with a professional worker, even if the youngster attends school or a day care center. It usually consists of helping the child to achieve optimal development and maximum use of his capacities. To do this effectively parents need help in working through their own feelings and adjustments as well as practical advice in regard to their everyday problems.

Relationship and Timing

Development of a good professional relationship is one of the main prerequisites for successful work with parents. Parents tend to reject painful information that comes from a seemingly uninterested or unfeeling source. If the diagnostic process in the clinic is an un hurried one, parents have time to understand step by step what the clinic personnel are attempting to do, to prepare themselves to accept

*Supported by the Children’s Bureau and the Pennsylvania Department of Health.
the diagnosis and a treatment plan, and to develop a workable two-way relationship with the clinic personnel based on trust and respect. Much of the frantic "shopping around" in connection with chronic conditions may be caused by attempts on the part of clinicians to shortcut the diagnostic processes. The team approach in diagnosis gives the parent an opportunity to work through negative feelings that emerge in one or the other contact and to clarify interpretations. "Shopping around" can often be avoided by permitting parents to use the various team members for comparison of opinions.

Parents' previous experience with other facilities have to be dealt with directly at the time of first contact. If the new clinic does not want to be just one of a growing list of clinics in the parents' experience, client and workers must clearly understand the reasons for dissatisfaction with the previous agencies and what the client's present expectations are.

At the Mental Retardation Unit of St. Christopher's Hospital for Children the diagnosis may extend over several weeks. The clinic is staffed by a team representing a variety of professional disciplines. Cases are screened for admission by the pediatrician and most of the team members are involved in the diagnostic work-up. This is terminated by a team conference in which plans are worked out with full consideration of the child's needs, family wishes, and available facilities. The team delegates discussion of such plans with the family to the person who has developed the most workable relationship with the family and who will have to carry the main responsibility for helping them carry out or modify the suggested plans. This is frequently the social caseworker.

In regard to mental retardation there is sometimes a strange notion that establishing diagnosis is identical with giving treatment. Diagnosis is an essential step toward understanding treatment needs, but it is not treatment. The parents' expectancy and readiness for help is necessarily being aroused during the diagnostic process. If this is not followed up promptly with an actual treatment plan, their readiness to involve themselves in a treatment process may be lost.

The parents' most crucial need for service occurs at the time when they first learn of the diagnosis. It is then that they need support in handling their emotions, help in clearly understanding the diagnosis and its implications, and assistance in planning for their child.

Considerable anxiety is usually aroused by a diagnosis of mental retardation. If this is not handled promptly, parents may develop rigid defenses which are not easily amenable to change. A caseworker can help parents set up the kind of defenses that will cushion reality adjustment rather than paralyze functioning. Even the most stable parents have to cope with a certain amount of personality disorganization in reaction to severe stress and shock. Professional casework services at this point work as a "catalyst" for helping parents to recognize their thoughts and reestablish ability to function.

**Casework Approach**

The parents who come to a mental retardation clinic are as a rule quite aware of the fact that they have a problem. They may, however, deny its nature. Parents should clearly understand the findings of the clinicians in regard to their child's difficulty. However, they need not accept these findings immediately and fully in order to work toward relief of their problem. Diagnosis of mental retardation is not likely to change, and the parents' acceptance may come gradually as a result of treatment.

If a parent persists in calling his child "slow" instead of retarded, the worker may do the same. If the parent continues to express conviction that the child will eventually "catch up," or does not belong in this "terrible" special class, the worker need not contradict him but can patiently help him face the truth. Parents can be helped gradually to see the diagnosis not as a "dead end" verdict, but as a starting point from which to approach much of the problem.

Parents often spend considerable effort in trying to prove to the worker that the child is normal. If they really believed this, they would not continue with the clinic. They often try to push the worker into an argument in order to convince themselves. The worker does well not to be drawn into such an argument. In time the parents draw their own conclusions.

We found most of the parents seen at our clinic very eager to find and use services. Many cooperate far beyond their own need and show good grasp of the value of their contributions to the understanding of the problem. However, as in any clinic setting, some parents withhold information or try to manipulate clinic personnel and time. Such behavior has to be discussed quite directly with the clients and limits should be set.

Service cannot be effective without the full and
voluntary participation of parents. The parent who cannot respond to efforts to help him and who continues to try to manipulate the clinic will manipulate treatment goals. Neither he nor the child will in the end profit from treatment. However, the amount of responsibility for initiation and continuation of contact that can and should be put on the client should be determined on the basis of the psychosocial diagnosis rather than on rigidly established clinic procedures.

Through social-casework counseling, parents of retarded children can be helped to develop:

1. Some understanding of the meaning of the term “retarded” as it applies to their child.
2. Understanding of the degree of their child’s handicap and what this will mean in the future.
3. Ability to understand their child’s assets, his needs, and his difficulties.
4. Appreciation of the effect the presence of a handicapped child has on family life in general, on their other children, and on themselves as parents, and on adjustment of the family within the neighborhood.
5. Understanding of the fact that the child’s retardation and his behavior are separate entities and that behavior can be influenced at least to a degree by educational approaches.
6. Ability to judge whether neighborhood reactions are caused by the child’s behavior, appearance, or mental ability.
7. Techniques to use such understanding constructively in order to help the handicapped child, the entire family, and the community.
8. Knowledge of available resources relating to their own situation and to the problem of retardation in general.

While needs differ, time for consideration of these areas has to be provided in planning. The “one shot” approach is rarely helpful.

**Patterns in Counseling**

In spite of the uniqueness of each case, definite patterns emerge that may serve to guide program planning. Contacts fall roughly into four phases: (1) the initial period, encompassing the diagnostic process, clarification of the situation and needs, establishment of treatment goals, and selection of treatment methods; (2) treatment, consisting of more or less intensive counseling, individually or in groups; (3) tapering off, a time when goals being achieved, contact becomes less frequent and is eventually stopped; (4) followup, consisting of occasional contact either as needs arise or as children are brought to the clinic for other appointments.

**Initial period.** It is neither feasible nor necessary to offer counseling services to all parents who come to a clinic for diagnosis of their child. By the end of the diagnostic period it should be possible to estimate fairly accurately the parents’ need for counseling services, their amenability to this type of service, and the feasibility of intermediate as well as long-range goals.

Selection of appropriate treatment methods should be made after consideration of a number of factors:

1. **Ego strength**—the parents’ maturity; emotional stability; capacity to accept their roles as parents, as marital partners, as members of their community; their intellectual endowment and the use they make of it.
2. **Family strength**—the quality of interrelationships between the different members of the family, and the kind of emotional and practical support parents can count on from other family members.
3. **Environmental and cultural influences**—the presence or absence of other irritants in the home or in the neighborhood and the influence of cultural and religious factors on the family’s acceptance or rejection of the problem.
4. **Degree of handicap** and the parent’s understanding of it. It is considerably more difficult for the parents of a moderately retarded child who is physically healthy and attractive to accept the diagnosis than to see him as plain stubborn, lazy, or spoiled. The parent of a severely retarded child with external stigma is less able to avoid the problem.

**Treatment goals.** In mental retardation, treatment is aimed at increased comfort of all people concerned with a trying situation.

Problems have to be analyzed so that partial solutions can be found as the need arises. Tension and frustration in parent and child may be reduced by cathartic experiences for the parents, and by help with practical problems such as learning ways of handling unacceptable behavior, and planning for school or other types of placement. If problems are
met as they occur, many retarded children can live happily within their own family groups and make their contributions to family living, at least during their childhood years. Where placement away from home is indicated, the parents can be helped to see that this has advantages for the handicapped child as well as for the rest of the family.

Level of Treatment. In general, the level of treatment remains in the area of reality adjustment, ego reintegration, and development of techniques for daily living. Intensity and depth of treatment vary greatly within the range of clinic function. If the parents have prominent personality disturbances or many problems in addition to their child's retardation, they may have to be referred to more appropriate agencies.

Treatment Techniques. Treatment techniques most often used are clarification, supportive counseling, and environmental reorganization. This does not preclude the use of insight therapy, but where such therapy is of paramount importance, referral becomes necessary. Though the counseling focuses on the problem of mental retardation, parents may be enabled by treatment to translate the help they got for one problem to others as needed. This happened in the case of the A family.

The A’s were referred by their family physician, who was struck by the intensity of the negative parent-child relationships. The oldest child, Tim, retarded because of an organic condition, was extremely hyperactive and lacked concentration. The parents’ severity in trying to control his behavior had led to violent negativism on his part. The younger brother, Don, considerably brighter than Tim, got vicarious enjoyment out of teasing his older brother into temper outbursts resulting in actions for which Tim eventually was punished.

During the contact here, explanation as to the organic basis of some of Tim’s behavior was given to both parents. They were helped to evaluate their own approach to the children, to consider the differences of their children’s needs, and to try new ways of meeting these needs.

The parents became aware of the teasing of the younger child and of the effect on both children of their own impatience and high standards. They also became aware of their own strained relationships and how these resulted in their undercutting each other’s effectiveness with the children. Gradually the whole family situation calmed down. When a new baby was born, both parents were able to avoid many of the mistakes they had made at Don’s birth which had created such intense jealousy and difficulties between the boys.

Treatment Methods. The caseworker may counsel either in individual contact or in groups. It has been hoped that the development of group techniques might prove more economical of the worker’s time than individual contacts. This has hardly been the case as far as economics of time and professional efforts are concerned. The economy lies in the fact that the more appropriate treatment is the more effective one.

Individual Counseling

At the St. Christopher’s clinic individual counseling has been offered to the parent with highly individualized needs, strong emotional dependency, intense masochism with certain types of passive-aggressive adjustment, or clearly psychotic tendencies. We found such parents poor group risks, since they tend to be disruptive to group processes because of their urgent need for attention, the intensity of their relationships, or their need to act out. In individual contact the worker can adjust the process to the individual and can control the gratification of his particular needs. This was the method used in the B case.

The B’s had accepted the diagnosis of their only child’s retardation before coming to the clinic, but they felt strongly resentful of the doctor who had given the diagnosis. They interpreted his statements as meaning that no limits could be set for the boy’s behavior. They joined a parents’ organization and used the group to project their anxiety about their own problem.

In individual contact, the B’s were brought back again and again to their own problem of handling their child’s behavior. They were helped to face their misinterpretations of what they had been told. They also came to realize how much they acted out their own discouragement by proving time and again that they were not able to set limits for their child, while other people were able to do so. As it became necessary, the caseworker allowed them to forget discussion of the child and his problem and focus on their general discouragement and disappointment, of which the child was only one factor.

The caseworker saw the parents in separate interviews and helped them work through some of their rivalry in their positions within the family so that a common approach could be established.

Group Counseling

In group counseling we are not concerned with intensive group therapy, but with casework counseling in groups. Goals are: personality reintegration and adjustment to reality. Group processes and teaching methods are combined to afford the individual relief from tension, understanding of children’s behavior, and techniques for handling specific problems.

Group processes are helpful to basically mature parents whose functioning is temporarily impaired by the overwhelming nature of their problem; to parents with a tendency toward projection and intellectualization; to parents with pronounced though well-controlled feelings of hostility, who can find relief through limited acting out; and to parents with dependency needs which may be met through group identification and support.

In selecting members for groups at St. Christopher’s we have not found it particularly necessary
The case of Mrs. C. illustrates several of these points.

Mrs. C. was unable to make effective use of individual contact when it was offered. She covered up her intense feelings of hostility by complete denial and adopted an attitude of subservience. In the group she quickly assumed a certain amount of leadership, which the group kept from going beyond bounds. She used the group constructively to gain better understanding of her own problems, to learn from other parents' techniques of handling situations, and to get gratification for her need to dominate.

After the series of group sessions ended, a second attempt at individual counseling, made at Mrs. C's request, was no more effective than the first. But in another series of group sessions the again used the group experience constructively.

**Length of Contact**

Length of time necessary to achieve intermediary or long-range goals varies greatly, depending on the kind of emotional or reality problems to be worked out and the complications encountered in the process. Length of contact may be in inverse ratio to the severity of the actual handicap. An obviously severe handicap often allows for clearer diagnosis, less parental resistance, and fewer alternatives. On the other hand, parents of a more salvageable child may be in need of longer periods of service to achieve an acceptance of the retardation and evaluate a variety of possibilities for the child.

At the St. Christopher's clinic cases that receive short-term services only fall roughly into three groups.

Group 1 includes parents who during the diagnostic process or previously have learned to understand and accept their problem and are basically able to handle it on their own. Usually only one interview following the diagnostic period is needed to clarify that the clinic stands ready to help them whenever necessary. Such parents use the clinic as they need arise.

Group 2 includes parents who are not accessible to continued treatment even if they are in need of it. They either have not accepted the diagnosis or are unable to mobilize themselves sufficiently to involve themselves in treatment. The caseworker alerts other team members to these problems so that the parents may receive some help when they bring the child in for followup visits to the physician or the psychologist and may be referred to the caseworker at a later date if feasible. In the interim the caseworker seeks opportunities for casual contact with the parents in the clinics.

Group 3 includes parents already known to community agencies, which usually continue service to the family, often in collaboration with clinic personnel.

Intensive casework treatment over a longer period is offered parents with complex problems either of their own personalities, environmental situations, or difficulties with the child. We have found it most economical and helpful to offer intensive, frequent interviews at the very beginning of the treatment period and then to gradually decrease contacts as parents become able to manage on their own.

Recently we have begun to experiment with a more extensive than intensive approach consisting of a cooperative effort between the public health nurse and the social worker. Two groups of parents have been included in this program: (1) basically stable parents whose problems of child management are caused by the child's severe handicap; (2) immature, anxious parents who have management problems with their children caused at least in part by their own insecurity. No attempts are being made with either group toward too strong involvement in the parents' own problems. Explanations are given for the child's behavior and new approaches to handling are suggested. The public health nurse visits the more immature parents to demonstrate ways of handling the child. It is too early to say how helpful such an approach may be. However, considerable relief of upset has been achieved in a few of the families in this experiment.

All tapering off of long-term treatment should be on a planned basis. Unplanned "fizzling out" devaluates the treatment received and may leave the parents with a feeling of dissatisfaction. As treatment goals are gradually realized, parents themselves usually begin to express a lessened need for contact. Increase in problems and anxiety may occur as wider spacing of interviews begins. If the caseworker permits the parents to set their own pace, the frequency of contacts will decrease.

One advantage of casework at a clinic is that cases can be followed over extended periods of time without maintaining intensive or regular contact. Parents often use scheduled followup visits to the pediatrician, psychologist, or speech pathologist as opportunity to bring the caseworker up to date with their present stage of affairs. The caseworker also may schedule followup interviews at certain stages in the child's life, for example when he is getting ready for
a nursery school experience, camp experience, or school placement.

Parents' Organizations

Parents' organizations such as the Association for Retarded Children should be used as a resource in planning with parents of mentally retarded children. These organizations provide such parents with strong emotional support and valuable outlets for the constructive channeling of their anxieties, frustrations, and tensions. However, referrals to such groups should be made on the basis of diagnostic considerations, and should include preparation of the client and the organization as in any agency referral.

The timing of such a referral is important. These organizations properly expect their members to promote understanding of the problem of mental retardation. To do this effectively and without harm to themselves parents have really to understand and accept the nature of their own problem and they have to be ready to identify with a large group. Otherwise they may use activity in the organization to avoid facing their own problems and working through their own anxieties and difficulties. We have found that parents who have joined large organizations of parents without preparation often accept mental retardation as a community problem, but do not really acknowledge their own problems in relation to their own mentally retarded child.

Parents who are well prepared for group membership can offer a great deal to these organizations in their work to spread understanding of the needs of the mentally retarded.

However, this type of activity cannot substitute for the emotional and practical help needed by parents at crucial points to maintain their own and family stability in facing the problems presented by the fact of their child's retardation. In offering such help, the goal of casework counseling, whether to individuals or groups, is to help parents achieve their optimum functioning to meet their own responsibility for the treatment of their child.

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THE NEED for care and training of mentally retarded children and adults poses for each society problems in which the basic concepts of public responsibility for all its children, on the one hand, and protection of its weaker members of whatever age, on the other, are paramount. Pearl Buck has observed that a civilization can be largely judged by its attitudes toward these questions. Inevitably these attitudes express themselves first in the legal and judicial protection afforded to the individual, and secondly in the types of services which may be provided by law at public expense, of which free public education for all children is an example.

In the United States, although the foundations of law as well as the majority of social institutions stem from the British tradition, there is a close kinship with the philosophy of the Scandinavian countries where there is also interest in the rights of the individual and belief in equality of opportunity. It is not surprising, therefore, to find in the United States and Sweden many parallels in the histories of concern for the mentally deficient. Today several States of the United States have legislative commissions studying the legal status of the individual who is mentally retarded and in need either of special training or of guardianship. Such studies inevitably involve examination of the structure of the various governmental agencies which could have responsibility for providing services to the retarded. In 1954 the Swedish Parliament enacted a major revision of the national laws pertaining to both these facets of the problem of mental retardation.

Sweden is divided into 24 Provinces and 6 independent cities. In regard to services the independent cities have the same status and responsibilities as the various Provinces. The population of Sweden is somewhat more than 7 million, the Provinces having on the average about a quarter of a million people each. The Province of Stockholm, which excludes the independent city of Stockholm, has a population of about 400,000, whereas the city itself has a population of a little over 800,000. Thus from the point of view of the population base it is fair to draw an analogy between the country of Sweden and its Provinces, on the one hand, and one of the more populous States of the United States and its counties, on the other. From a political point of view the analogy is also useful, since most of the health, education, and welfare responsibilities which in the United States are vested in the State governments are in Sweden a function of the National Government. For this reason it should cause no confusion if in this discussion we adopt the European custom of referring to a national government as "the state." As in a State of the United States, the state may in some instances carry out its responsibilities directly, and in others it may delegate them by mandate to a political subdivision—in Sweden, a Province or a municipality—the state retaining the responsibility for establishing and maintaining standards of service.

Functions of the State

There are ten departments in the Swedish National Government, two of which are particularly concerned with the mentally retarded—the Department of Interior and Health and the Department of Education and Religion. The Department of Interior and Health previously was a part of the Department of Social Welfare. About 10 years ago the Department of Social Welfare was reorganized, and the responsibilities for the mentally deficient were transferred to the Department of Interior and Health.
Before 1944 the problem of mental retardation was regarded solely as a medical problem. That year the Swedish Parliament enacted a law emphasizing the importance of the educational aspect of help to retarded persons, and transferring the major responsibility for services to them from the Royal Board of Medicine, Department of Interior and Health, to the Royal Board of Education, Department of Education and Religion. Under the new law enacted in 1954 the responsibility for programs for the retarded is divided between the two boards, the Royal Board of Education and Religion having the principal responsibility for directing their education and the Royal Board of Medicine for directing the medical and protective care. The combined service is lodged in the Department of Interior and Health.

Scope of Provincial Authority

The 1954 law placed the principal responsibility for actual education and care of the mentally deficient in the Provincial government, which is required to establish a “central board” for the administration of the program. There are certain exceptions to this delegation of responsibility. In principle, the state retains responsibility for the mentally retarded who have seriously complicating conditions such as blindness, deafness, or severe behavior disorder, providing separate institutions for them. For the defective delinquent, for example, there are two state institutions and two state-supported, state-supervised private institutions. The state is also expected to take responsibility for the very destructive or disturbed, and the most severe cases. In practice, however, this provision has been interpreted to require the Provincial authorities to provide interim care for such individuals while waiting for placement in a state institution or elsewhere.

With the exceptions noted above, the Provincial authorities are expected to take responsibility for mentally retarded children and adults of all ages. The definition of “mentally retarded” in Sweden, however, does not include the uppermost educable group or “slow learners.” The dividing line generally speaking is an IQ of 65 or 70. The slow learners—children with an IQ of 65 or 70 up to 80 or 85—are educated in special “help classes,” which are a part of the regular public schools, operated by local school boards much like those in the United States.

The Provincial central board for the mentally deficient has responsibility for those retarded children of preschool age who, for one reason or another, cannot be cared for at home, for children of school age who are not eligible for the “help classes,” for young people of postschool age, and adults who are not socially competent. For the state or Provincial services any person “registered” as mentally deficient is eligible without fee, regardless of his financial circumstances.

Each Provincial governing body must establish a central board for the education and care of the mentally deficient and also submit a plan for approval by the appropriate agencies of the National Government of Sweden for schools, institutions, and extramural care. Two or more Provinces may combine their services. With respect to the division of authority and administrative responsibility, the relationship between the state agency and the Provincial boards responsible for the mentally retarded in Sweden is not unlike the relationship in the United States between State departments of education or of welfare and local boards of education or county welfare boards, except that in Sweden there is a somewhat higher degree of state control over standards than is usual in the United States.

Legislative Provisions

There are two major principles around which Sweden’s legislation for the retarded is centered. The first is that no child should be placed in an institution unless there is absolutely no possibility of his remaining either in his own home or in a suitable foster home. For the child who cannot remain in his own home the central board is required to secure foster family placement if at all possible. The second principle is that a strong distinction exists between the educational program and the protective care program, though there is administratively little distinction between the residential and the day programs in these areas.

The law provides that the Provincial central board shall appoint a director of the educational program and a director of the care program. It sets up certain qualifications for each of these positions and it further provides that the director of the educational program may also have responsibility for the care program, but not vice versa. The majority of Provinces take advantage of the opportunity to combine the two programs under one director, an educator.

Facilities

In Sweden a child is eligible for a special school program if he has an IQ somewhere between 35–40 and 65–70. When the child has been so classified,
he must attend a school. He is subject to compulsory attendance from the age of 7 to at least 16, and thereafter up to the age of 21 at the discretion of the director of the program and the central board as described later. The expenses, whether for day or residential school or for foster care, are entirely borne by the public.

The emphasis is on day schools. Special day classes may be set up within the public schools by arrangements between the Provincial central board and various local school authorities. When such arrangements are made, there may be an agreement between the director of the educational program for the retarded and the school principal or superintendent concerning the supervision of these classes. However, the ultimate responsibility for supervision always rests with the director. Special day schools may be established under the supervision of the director, and day classes may also be set up in any residential institution for children who live near the institution. The law requires that any community having a total population of 25,000 or more shall have access to a day program. Such day programs may be provided in the community itself or in an adjacent area which is accessible to the children.

The law also provides that separate units (under a single administration) shall be provided of the following types:

1. Adult occupational residence centers. These are for the adults who may have been educated in the special schools or classes but who are not capable of handling themselves in the community. The law specifically requires that they be given work to do to be kept occupied.

2. Residential old-age centers. The age at which "old age" sets in is not specified, but generally speaking these institutions are for the accommodation of individuals who may have been in the occupational residence centers or in extramural placement (own family or foster family) and are now too old to work.

3. Child care homes. These are for children who are not eligible for schooling. Simple self-help and sense training, physical and speech therapy are provided as appropriate.

4. Institutions providing residential care for adults. These are for the same individuals later in life. By law children and adults must be separated in the care program. As a result, in some Provinces the care homes for children under the "care" program have been placed near the residential schools for children rather than near the centers for residential care of adults.

5. Day care centers for children over 4 and adults who are living in the community and not attending any other school program. Suitable occupational activities must be provided in these centers.

Admissions and Discharges

The general principle behind the admission and discharge procedure is that enrollment in the school program is compulsory for eligible children of school age, but enrollment in all other programs is voluntary. A child who is not subject to compulsory school attendance may be placed away from home without the consent of his parents only when the usual judicial proceedings, applicable to children generally under the child welfare code, have been instituted and where the guardianship of the child has been transferred from his parents to the board of child welfare. The circumstances under which this is possible are comparable whether the child is of normal or of retarded mentality.

In general, it is expected that parents will take the initiative in applying to have their children "registered" as mentally retarded. If a child is of school age and is thought by the authorities of the regular schools to be eligible for education in the special program of the central board for the mentally retarded and the parents fail to apply, the schools are obliged to see that an application is filed. In any case the parents are required to state in writing whether or not they concur in the application. When a child is "registered" it becomes the Province's responsibility to provide for him through its central board.

The board's first responsibility is to determine in what part of the program the child should be placed. If the parents concur in the application and proposed plan, there is no need for judicial proceedings. If they do not agree to the proposed plan, then a special committee headed by a judge and composed of from two to four members of the central board adjudicates the issue, after reviewing all the evidence. This committee must also be available to review transfers from the school department to the "care" department.

When a child who has been in the school program reaches the age of 16, the director must determine whether or not he may be discharged or should continue in the school program, and if continued whether this be in its day or residential aspect. The reasons for the director's decisions must be
Procedures for Classification

When an application is to be made for a child to be "registered" as mentally retarded, whether for the school program or the care program, certain forms, including a record of medical and psychological examination, must be completed. In most cases the medical and psychological examination is made at the child guidance center in the Province, where a qualified child psychiatrist sees the child. Subsequently both the director and the psychiatrist of the central board's educational program must concur in the proposed plan for the child. If they disagree, the matter must be referred to a special judicial committee even though the application may have been a voluntary one. Under the law the central board's child psychiatrist cannot be the examining doctor who supports the application, since the same doctor cannot act as both proponent and reviewer of the case.

In general, applications for registering children for protective care are voluntary on the part of the parents. The only exceptions are the cases in which the child welfare board has seen fit to intervene. In such a case the child welfare board must first obtain jurisdiction over the child. Then it may act in loco parentis in applying for admission of the child to the services of the central board for the mentally retarded for either day-care, foster-family, or residential placement.

The law also provides for trial placement of children for observation up to 6 months, or in special cases up to 1 year. Children so placed are not considered to be "registered" until a final decision has been made. This provision makes rapid placement of children possible in case of an emergency in the family such as a parent's death.

If it is decided to transfer a child from the educational to the care program, the procedures must be instituted anew, practically on the basis of a new admission. A child can be transferred from the protective-care to the educational program by the director, with the physician's approval, without renewed application.

It is important to note that with the exception of mentally retarded persons subject to the compulsory school-attendance laws—that is, those considered educable, between the ages of 7 and 16—there is at all times the opportunity for a parent or guardian or even the mentally retarded person himself to arrange for discharge from the school or care program. Even the severely retarded adult has a guardian other than the authority operating the program. So far this provision for voluntary withdrawal of a child or adult from the program by his parents or other guardian has rarely been misused either to the disadvantage of the child or of the community.

Parent counseling for parents of children of preschool age as well as older children is provided at child guidance clinics associated with provincial hospitals. The parents' organization cooperates in counseling and advising parents on the home care of young and very severely retarded children. Thought is being given in the Province of Stockholm to inaugurating a more formal home training program with well-qualified visiting teachers, who would each assist about 20 families.

A well-supervised foster home program for children of all ages is already underway.

Basic Program Concepts

In visualizing the application of all these provisions it is important to bear in mind that everything is done on a smaller and more intimate scale in Sweden than in the United States. For example, the Province of Stockholm has less than 600 insti-
tutionalized children and they are divided among 4 separate institutions, 1 a residential school and 3 custodial homes for protective care. A dozen children in one cottage or home living unit is considered a large number. Swedish visitors, as well as visitors from Japan, Holland, Great Britain, and elsewhere, have observed that the vast American institutions, with some “cottages” housing a hundred or more children, are incompatible with their concepts of human dignity and of the principles of good child care.

Whereas in the United States the trend has been away from county responsibility in the institutional field as being inefficient, in Sweden small units, close to the citizenry served and locally administered, are looked upon as desirable. The evils of lower standards, fear of which leads many in the United States to advocate concentrating operational responsibility at the State level, are combated in Sweden by firmer imposition of state standards for Provincial (county) programs, combined with a greater emphasis on and acceptance of public, as distinct from voluntary, responsibility for care of the afflicted, regardless of the family’s economic status. This point of view apparently makes possible the expenditures needed for the construction and appropriate staffing of small living units and schools and the provision therein of a high quality of professional service at per capita cost greater than would be tolerated in the United States at the present time.

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A multidisciplinary team in an Iowa research project uses . . .

A HOME ECONOMIST IN SERVICE TO FAMILIES WITH MENTAL RETARDATION

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FOR THE PAST YEAR a home economist at the State University of Iowa has been a member of a research-oriented multidisciplinary team providing services to a selected group of families in which at least one parent and one child appear to be mentally retarded. The families are being “saturated” with a variety of services in an effort to determine the relation of social, economic, and educational deprivation to familial mental retardation—retardation occurring throughout a family without any apparent organic cause—a phenomenon which seems to be peculiar to families of low socio-economic status. In this study, known as the Pine School Project, an attempt is being made to learn whether the alleviation of deprivation through services brings about improvement in the measurable intelligence and functioning of the members of such families.

The author acknowledges the cooperation of the other members of the child development clinic in the preparation of this manuscript. They include: Robert B. Kugel, pediatrician; Theron Alexander, psychologist; Marlin H. Roll, educator; Harry B. Brown, social worker; June L. Triplett, public health nurse.

Provided by the Maternal and Child Health Library, Georgetown University
The project is a cooperative undertaking involving two State agencies, the health department's division of maternal and child health and the welfare department's child welfare division, and the following units of the university: the child development clinic in the department of pediatrics, the department of home economics, the college of education, the Iowa Child Welfare Research Station, the department of psychology, and the school of social work. It is being conducted by the staff of the child development clinic. (See CHILDREN, January-February 1959, page 35.)

These children and their families were initially seen in 1957 by the clinic's staff, which at that time consisted of a physician, a psychologist, a social worker, and an educator. They were provided with a complete team evaluation and followup care. Gradually it became obvious to the staff that in the followup services large areas of family life were being neglected, such as interpersonal relationships, methods and attitudes of child care, family feeding, money management, homemaking, and health and cleanliness practices. Therefore, a home economist and a public health nurse were added to the staff.

The home economist was charged with finding ways of helping the families to improve their home life and of studying the effects of the methods she devised. The assumption was that these families could be motivated to improve their conditions, that they could be encouraged to learn methods and techniques for doing so, and that the mentally retarded children would benefit from the efforts of their parents to achieve an improved home environment, especially if these efforts were successful. The home economist's services were envisaged as primarily supportive and educational, with the goal of teaching mothers to recognize and to solve their homemaking problems.

The Families

At the beginning of the study 18 children of preschool age, diagnosed as being familialy retarded, were enrolled in the project's experimental day school, the Pine School. They were selected from nine families meeting the following criteria:

1. The child and at least one of the parents must be diagnosed as mentally retarded, with no apparent organic involvement, the child's IQ being somewhere between 50 and 80.
2. The family's status in society must be in or near the lower socio-economic group.
3. The families must reside in Johnson County, Iowa.
4. Parents must be living together at the onset of the study.

The Families making problems.

The first step in working with these families was an effort to establish rapport.
To accomplish this, she visited each family with the social worker and told the mothers about the kinds of services she had to offer. She followed each initial visit with three more "get acquainted" calls, a week apart, during which she tried to learn something of the mothers' interests and abilities as possible levers for motivating them to improved functioning.

Two facts became apparent from these early meetings: (1) that these mothers were lonesome people, cut off from society, and (2) that they wanted to learn how to make their homes more livable.

Some of the mothers showed immediate enthusiasm when the home economist offered to teach them to sew, clean, plan meals, and prepare food. Others expressed mild interest, and one was almost totally unreceptive.

As soon as the home economist achieved rapport with the mothers, she found her services in demand. Two other members of the staff—the public health nurse and the social worker—were also receiving heavy demands for followup services from the families. Therefore, these three staff members decided to divide the responsibility for maintaining regular contact with the families. Under the plan each family would receive at least one home visit a week from one of these workers. If an emergency arose requiring the skill of a worker not assigned to the family, that worker would be called in.

Several times during the ensuing year all three workers found themselves concentrating on a particular problem of one family. At other times two of the workers were doing so. When the special problem was solved, the responsible worker continued calling on the family every week.

This plan to coordinate the efforts of nurse, social worker, and home economist created no professional jurisdictional problems. The home economist often found herself listening to a woeful story involving a health or social problem, but she made no attempt to deal with it on the spot, except to say that she would send the social worker or the public health nurse out to call. After a staff conference the appropriate staff member would go into the home and try to help solve the problem. Each discipline represented remained distinct; each worker had more than enough to do.

The loneliness of these families was unmistakable. They did not participate in groups such as parent-teacher associations, women's clubs, or church groups, either because they felt inadequate or because they had tried in the past and had a painful experience which they did not wish to repeat. Most of them had no close friends; their relationships were principally within their immediate families.

The staff believed that a group organization might fill the mothers' need for companionship and also serve as a teaching medium for the home economist. Therefore, the home economist took a two-pronged approach—individual and group—in providing services.

**Work With Individuals**

Three families were assigned to the home economist. Each had asked for help on many homemaking problems. The home economist visited each family once a week at unscheduled times—unscheduled to stimulate the mother to keep her house in order at all times. She began by attempting to find out what problem in homemaking was causing the mother the most concern and to help her make plans for a solution that would not require a large outlay of money and that seemed to be achievable. She gave the mother suggestions but left her with the responsibility for carrying them out, calling back at appropriate intervals to discuss progress, and to lend her support and encouragement.

Once—but only once—the home economist made the mistake of taking up with the mother a community criticism of the family. The mother immediately withdrew and became defensive, and the good rapport the home economist had so painstakingly established was nearly lost.

**The Greens**

The first family selected for the home economist's concentrated attention, whom we shall call the Green family, consisted of a mother, a father, and 10 children. The father, who was employed on the section gang of the railroad, was considered a reliable and willing worker. However, he drank heavily on week ends and gambled. Ever since his marriage he had been sent to the county jail three or four times a year because of drunkenness and for mistreating his wife. The mother was overweight, but otherwise pretty. From the time she was 6, when her mother died, she had been in one foster home after another, never being fully accepted or loved. At 16, she had been persuaded by her father, who did not approve of her current love affair, to marry a man much older than herself. She has never forgotten her teenage love.

The Greens had received help from the county welfare department most of their married lives, as
had their parents. They lived near the railroad tracks in a dilapidated dwelling, inadequate in rooms, furnishings, and health accommodations.

In 1957, the Greens’ 10 children had been made wards of the court, and shortly afterward the two older boys were sent to different State institutions for the mentally retarded. The four girls still lived at home and were attending the public schools, but two of them were failing in their school work, and the other two were in special education classes. Of the remaining four children, all boys, three were attending Pine School, and the youngest, who was subject to convulsions as well as being retarded, did not attend school. All the children were attractive looking, but they were always dirty, ragged, and unkempt.

On her first visit to this home the home economist found living conditions almost unbelievably bad. Food-encrusted dishes were on the tables; food which had previously been spilled on the floor had been allowed to accumulate and spoil; broken pop bottles and beer cans were sitting about; the furniture was broken and covered with dirty quilts. Two windows were broken and, since there were no screens, the house was full of flies. Dirty clothes were scattered in confusion about the rooms, and a fetid odor permeated the house.

Without making any reference to these conditions, the home economist called on the family at least once a week as she looked for strengths to build upon and established a relationship with the mother—a process that took four visits. As Mrs. Green gradually realized that the home economist was not going to find fault with her or demand something from her, she began to show an interest in food purchasing and preparation. The home economist used this interest as a strength to build on, and with consultation from the social worker, tried to formulate simple, realistic goals that Mrs. Green could be encouraged to meet. Since Mrs. Green had exhausted her credit at the small, expensive neighborhood store where she bought her groceries, a discussion of food buying and planning was selected as a starting point. In a very short time Mrs. Green asked that the home economist help her to plan her meals for a week and to make out a market order. The social worker and the nurse, both of whom were also visiting the family, also supported Mrs. Green’s efforts to plan. Now she plans by the week and purchases at a supermarket most of the time.

After some time the staff could not help but notice the improvement in the mother’s housekeeping. When the home economist arrived on her unscheduled visits, dishes were usually done, the floor scrubbed, and the dirty clothes put out of sight. The interest being shown in the family by the staff and their noncritical attitude seemed to motivate the mother to greater effort.

Whenever Mrs. Green mentioned the possibility of improving some area in her home, the home economist showed an immediate interest. When the mother expressed a desire to paint and fix up the living room, she arranged for the paint to be purchased through a gift fund available to the child development clinic. Mrs. Green painted the room herself and was very proud of her accomplishment. She then saved and bought some plastic curtains for the windows and replaced the broken window panes. This show of interest and activity was a great surprise to everyone.

This family has been served by the project for 2 years, and the home shows definite signs of improvement. There are periods of backsliding, especially when Mr. Green is on one of his periodic drunks, but in general, the family does not go back as far as the state of apathy it was in when first visited by the project workers.

The two boys who were enrolled in Pine School are now attending public schools. While the next-to-youngest boy still needs to attend Pine School, he has learned to talk and express himself, which he could not do before. While these children are still retarded, the project staff believes that they can see some improvement and will be able to see more in the next 3 years.

The Marnes

The second family selected for the home economist’s concentrated help—called here the Marnes family—consisted of a father, a mother, and five girls. The youngest girls, twins, attended the Pine School. The older girls, 8, 9, and 10, attended the public school special education classes. This family had the kind of housing and equipment usual in lower middle-class families, but their attitudes and income defined them as of lower socio-economic standing.

Mr. Marnes, a responsible foreman in an ice cream factory, had become an orphan at an early age and had been passed from one home to another, finally ending his childhood in the city orphanage. He joined the Navy as soon as he had finished the eighth grade, and had never gone back to school. Mrs.
Marne also had had a very deprived childhood. Her parents had had a large number of children and had frequently received public assistance. They had worked their children very hard around the home and had taught them the elements of cleanliness but little else. Mrs. Marne took the same attitude toward her own children. The girls were attractive looking, but often unkempt and shabbily and inappropriately dressed.

The relationship between Mr. and Mrs. Marne was stormy. Although Mr. Marne made a steady income, he would not trust Mrs. Marne with any of it.

Mrs. Marne was immediately receptive to the home economist's offer of help. There were so many things she wanted to learn that the home economist had difficulty pinning her down to one achievable goal. However, she eventually decided to learn to clean house for others, so that she might have some money of her own to spend.

Realizing that the houses in which Mrs. Marne might find work would be more elaborate than her own, the home economist took her into her own home once a week to teach her a variety of housekeeping skills. Mrs. Marne obviously wanted to learn, and she did learn rapidly although her intelligence test had produced one of the lowest scores in the project. After 6 weeks of this arrangement, the social worker suggested that Mrs. Marne be encouraged to seek employment as she now had the skills she had set out to learn and was in danger of developing a dependency relationship to the home economist. Though the home economist helped her find her first job, at present she has several cleaning jobs which she secured by herself and which fit her children's school hours. The reports of her work are good.

Mrs. Marne also asked for help on planning and marketing for the family's food. Breaking into tears she told the home economist that Mr. Marne was tired of her routine fare and refused to come home for meals. The home economist responded by helping her to plan a week's menu and market order built around the kinds of foods her husband liked. Learning that Mrs. Marne did not know how to use a cookbook, although she owned three, she also showed Mrs. Marne how to follow a recipe. Mr. Marne now seems to enjoy eating at home and Mrs. Marne is continuing to try new dishes.

After 2 years of service the Marne family shows great improvement. Through contacts made in her housekeeping jobs, Mrs. Marne has become aware of how other people live. Consequently, the children are now having their hair brushed and combed, and their dresses altered to fit them. Their mother has encouraged them to join the "Brownie" Scouts, to attend Sunday school, and to have parties. The two youngest girls have moved into a public school and seem to be doing well. In spite of her low IQ, Mrs. Marne has a tremendous drive to improve her family.

**Group Meetings**

Because of the obvious loneliness of the women being served in the project, the home economist decided to try to get them together in group meetings. She saw the possibilities of using the meetings not only to alleviate the mothers' loneliness but also to help them learn more about meal preparation and food planning, sewing, child care, housekeeping, and personal cleanliness. Approaching some of these subjects with groups rather than with individuals would be less likely to wound personal feelings. If the women took turns in having the group meet at their homes enough competition might arise to serve as a motivating factor for "sprucing up" their homes. The meetings might also be used as a means of introducing the young children of these families to one another and giving them some opportunity for social interactions. The home economist hoped that each time a woman had a meeting in her home and had to cope with the various problems of entertaining, the experience would add to her ability to accept responsibility.

Because of her energetic, outgoing nature, Mrs. Marne was asked whether she would like to form a social group of the women whose children went to Pine School. When she responded enthusiastically, it was suggested that she bring the idea up at a Pine School PTA meeting. Meanwhile, the home economist also planted the idea of a social group with other mothers in the project. Thus, when Mrs. Marne made the suggestion at the PTA meeting the mothers accepted it readily because they were familiar with it.

There was never any difficulty in selecting a meeting place, as each woman in the group seemed anxious to entertain.

At each meeting the hostess furnished the necessary dishes; another member of the group brought refreshments having volunteered to do so. These have ranged all the way from good and attractively decorated sandwiches to a poor pumpkin pie. Before each meeting the home economist checked early
in the week to see if she could be of assistance to the
hostess and to the woman bringing the refreshments,
and to make sure that they had not forgotten that
they were to serve. She also sent notes to all the
mothers reminding them of the meeting. No one
ever forgot.

These meetings were obviously very important
to these mothers. Only once, at a time of extremely
bad weather and a measles epidemic, was more than
one mother missing. Each meeting day, the public
health nurse and the home economist made the
rounds in their cars, picking up children and their
mothers who had no other way to get there, and tak-
ing them to the home of the party hostess. Only one
woman in the group could drive a car at the begin-
nning of the program. Since then, four women have
learned to drive.

With suggestions from the public health nurse
and the mothers themselves, the home economist has
planned the program for these meetings. For the
first meeting she selected an activity that would be
fun without posing any threat to the mothers. She
brought dried weeds to the meeting for the mothers
to paint and to make into winter bouquets. At first
the women were diffident about trying, but soon were
painting away enthusiastically. The bouquets were
in evidence in some of the homes all winter.

At the next two meetings, the mothers decorated
quilts for naptime use at the Pine School. Activi-
ties at subsequent meetings have included a recipe
exchange, a demonstration by a mother of how to
make baking-powder biscuits, a discussion of wash-
ing techniques, a demonstration by the home econo-
mist of sewing techniques, and a discussion of how
to get inexpensive ascorbic acid into diets. This
last subject was chosen because nutrition surveys
showed the diets of these families to be low in
ascoorbic acid value.

The Pine School staff had found that many of
these mothers were not able to tell when a child
was too ill to attend school. Therefore, one meet-
ing was devoted to simple health instructions. The
public health nurse showed the mothers how to read
a thermometer, told them what a temperature meant,
and gave suggestions on how to tell whether a child
was too ill to attend school.

One meeting followed a showing of a child de-
velopment film at the Pine School PTA meeting and
was devoted to a discussion of child rearing. The
women were shown government bulletins on child
care for different ages and were given those in which
they were interested.

In spite of these serious discussions, the meetings
are essentially of a social nature. The time devoted
to discussion has purposely been kept short because
of the shortness of the mothers' attention spans and
because the children are likely to be noisy.

A Sense of Status

Being a member of a group has given these women
a sense of belonging. Probably the most important
outcomes of the meetings for them have been the
attainment of friendships and the development of a
sense of status within themselves. As they have
gained in stature in their own eyes, they have tended
to become more adequate. The competition that is
usually found among the members of any group
has begun to appear. The women have tried to
dress as well as their friends, have the house as nice
as their friends' houses, and be as clean as their
friends.

One of the most unreceptive women in the project
has learned through the group meetings to accept
the services that the project staff has to offer. She
has attended each of the meetings, accepted medical
assistance, and asked for help in learning how to
sew. Both she and her husband have begun to at-
tend the Pine School PTA meetings and have made
friends there. She has exchanged babysitting serv-
ces with other women in the group. This woman
and her husband had once had their 10 oldest chil-
dren removed from their home by court order for
being incompetent parents.

Another woman, who used to be described as
slovenly, now takes great pride in her appearance
as well as in the appearance of her children and her
home. She and her family have moved from a
dilapidated shack in town to a larger, more adequate
house in the county, which she has fixed up with
donated curtains and a few purchases. Her hus-
band has been able to work out the rent by helping
the farmer who owns the house. The family keeps
the home neat and tidy, despite the fact that the
mother must carry water for some distance.

A closely knit group can be a powerful force
in an individual's life. Such a group might be
difficult to organize without a nucleus to start with
such as the Pine School PTA. To the home econo-
mist it seemed important that the idea of a group
organization should develop through one of the
mothers, and that transportation to the meetings
should be provided since they were afraid of a new
experience. Other ways might be tried and found
to work equally well.
How much the awakened interest of these parents in their homes has affected their children is difficult to judge. However, we can make one observation: When six of the younger children of the Pine School project reached the age of eligibility for attendance at the school and their psychological tests were given, only one of them tested low enough to meet the criterion for admission. This is merely an observation, but it raises the question: Could there be a relationship between the stimulation of the parents and Pine School brothers or sisters and the fact that these children had higher IQ scores than their older siblings?


MENTAL RETARDATION IN THE SOVIET UNION

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During a recent 7-week visit to the Soviet Union under a grant from the National Institute of Mental Health, U.S. Department of Health, Education, and Welfare, I had an opportunity to visit eight cities and to make a number of observations and inquiries on various aspects of child care and psychiatric practice. Because of my special interest in mental retardation I gathered as much information on this subject as I could, and supplemented it with further study of the Russian literature. Although my visit coincided with the summer vacation period, so that I could not observe the schools, I was able to learn enough to describe briefly the main features of Soviet work in respect to retardation.

In the Soviet Union, mental retardation is viewed basically in the same way it is viewed here: as a problem involving both biological equipment and educational opportunity. Human intelligence—or the lack of it—is not regarded as a simple matter of genetic endowment, but as a complex phenomenon, implicating inborn peculiarities of nervous structure or function, diffuse or focal brain damage, sensory or motor defects, fatigability, educational development, psychological interest or incentive, capacity for attentiveness, distractibility, and a number of other related factors. There are, however, important differences in approach and emphasis among Soviet psychologists and educators as compared with those in this country.

In the Soviet Union a child’s performance on a series of standardized tests, such as we employ in psychometric examination, is not regarded as a measure of intellectual capacity. Prof. A. R. Luria, whom I met at the Moscow Institute of Defectology last summer, said to me:

An IQ of 65 might mean quite different things in four different children: the first might have a congenital brain defect; the second might be suffering from a general weakness of the nervous system due to fatigue, general debility, malnutrition or some other weakening condition correctable later in life; the third might have some motor or sensory defect, such as a partial hearing loss; and the fourth might be a perfectly normal child who lost a lot of time at school because of some protracted illness. An IQ is always a merely quantitative thing; it tells us little or nothing about the qualitative causes of the bad performance.

For these reasons psychometric testing is not used in the Soviet Union. It is not now the basis for diagnosis of mental deficiency nor for special educational placement.
For a period after the October revolution of 1917, Western psychometrics enjoyed considerable vogue in the Soviet Union, and both backward and gifted children were sorted out by the psychometricians, called pedologists, for special educational placement. It was soon discovered, however, that the gifted child tended to come from the displaced upper classes, while a disproportionately large number of the backward children came from workers' and peasants' families, or from certain undeveloped national groups. Many complaints and criticisms and much theoretical discussion ensued, leading finally in 1936 to a resolution of the Communist party castigating the psychometricians for labeling an excessive number of normal children as defective, abolishing the whole profession of pedology, and inviting the pedologists to become teachers if they wished.

One consequence of this sweeping resolution was to give the educational system back to the teachers—called pedagogues in the Soviet Union—and to elevate pedagogy to a level of a serious and systematic science. To this day almost all psychological work is conducted in pedagogical institutes and its reports are published in pedagogical journals. The leading research institute on mental retardation, the Moscow Institute of Defectology, comes under the aegis of the Academy of Pedagogical Sciences, which is the planning and coordinating agency for scientific educational work.

The Institute of Defectology is staffed by about 50 scientific workers, of whom some 10 or 15 are psychologists, seven or eight neuropsychiatrists, while 20 or more could be described as scientific pedagogues, whose work differs very little from that of the psychologists. There are only one or two pediatricians on the staff. This research institute is associated with a small school, which is used for training and research purposes, but its own activities are limited to research on the development of diagnostic, analytic, and teaching techniques for the educationally handicapped, including the retarded. Its current budget is 10 million rubles a year, a very large sum, when one considers that the salary of a skilled scientific worker may be 30,000 to 60,000 rubles a year, and that of a laboratory assistant 7,000 to 15,000 rubles.

Many research projects are being carried out at the Institute. They include a series of studies designed to correct faults in attentiveness associated with asthenia or fatigability or faults in plasticity. These studies and others reveal a concern for correctable physiological malfunctions of the brain—in contrast to the common assumption in this country that brain dysfunction necessarily means anatomical defect. Professor Eugene Sokolov, an associate of Professor Luria at the University of Moscow, is doing remarkable work in the measuring and recording of attentiveness by studying a number of physiological variables, especially shifting changes in the caliber of the blood vessels of the scalp and fingers. By means of these methods it is now possible to record the response of children to words related by sounds or by meaning, and thus to study the steps through which language development proceeds in both normal and defective children. This has important implications for the analysis of the thinking processes and for corrective education. Professor Luria has for a long time been interested in the organizing role of speech in the development of thinking and of abstract concepts in children.

One result of research carried out at the Institute is the development of an ingenious pencil-shaped photoelectric scanning device that emits distinctive sounds when passed over printed letters, so that the blind can learn to read by ear.

Definition

Soviet workers in the area of retardation tend to narrow the field to those types of retardation presumed to be due to cerebral defects or inadequacies, and to regard types of intellectual or educational backwardness due to social, educational, or psychological causes as problems of general pedagogy. The preferred term for mental deficiency is oligophrenia, which has connotations of a medical nature. Dr. Pevsner, the author of a recent textbook on oligophrenia and a member of the Institute's staff has described it as “a kind of underdevelopment of the complex forms of mental activity which arises as a result of an organic lesion of the central nervous system at different stages of the intrauterine development of the fetus, or in the very early period of the child's life.”

The diagnosis of oligophrenia, Dr. Pevsner told me, should be limited to those children who can be presumed to have suffered an actual brain injury in intrauterine, perinatal, or early infant life. She said it was reasonable to assume that the main pathological lesion in such cases was a diffuse injury or defect of the cortex, though she acknowledged that certain other associated factors may be encountered, mainly of two kinds: She said that hydrocephalus seemed to be a common associated factor in mental deficiency.
and that a superimposed focal lesion may complicate a diffuse brain injury.

Dr. Pevsner also expressed the opinion that the crucial physiological factor in the pathogenesis of mental deficiency was the inertness or immobility of the feebleminded child's reactions. Acknowledging that the element of anatomical defect must be considered too, she said that this may well express itself by contributing to the physiological inertness or lack of plasticity, and hence to an incapacity to shift or modulate in the learning process. She pointed out that the mammalian brain, in its evolution, has constantly gained plasticity and that the lack of plasticity could be regarded as a lower evolutionary stage of brain development.

From a clinical point of view, a leading symptom among mental defectives is their lack of capacity for abstraction or conceptual generalization. Dr. Pevsner described three types in which the lack of plasticity could be encountered: (1) those having a weakened capacity for both excitation and inhibition; (2) those in which the inhibitory functions are weak—the restless or excited children; (3) those in which the excitatory processes are weak—the torpid, indolent children.

Special Education

Children having these various types of defects are not segregated according to type or diagnosis but are mingled in special schools. The Soviet pedagogues regard it as undesirable to have a school group consisting only of children with one type of symptom—hyperactivity, for instance. The teachers are instructed in the specific difficulties of each child and are then expected to individualize their understanding and approach to the educational problem the child presents.

For example, the hyperactive child is first taught inhibition by external restraint. A teacher may actually hold a hand over the child's mouth or restrain his mobility. At a later stage the child may be expected to impose his external restraint upon himself by clapping his own hand over his mouth, and still later the restraint may become internalized, an important gain for the child.

The proportion of boarding schools among these special facilities is high: in the Russian Federated Republic, out of 301 special schools, 130 are boarding schools. In Leningrad, three out of eight special schools are boarding schools.

The more severely retarded children—imbeciles and idiots—are dealt with outside the school system, in special hospitals and day centers. These are under the control of the Ministry of Social Welfare. I do not know how many children are so placed.

J. Tizard, a British visitor to the U.S.S.R. a few years ago reported that the education of defective school children includes solid groundwork in reading, writing, and arithmetic, and elementary instruction in the natural sciences, geography, history, civics, drawing, singing, and physical education. During the last 5 years of training increasing emphasis is placed on vocational training. Tizard also reported that over 90 percent of the young people who complete special schools become employed in ordinary work. Prof. Zurabashvili and his staff in Tiflis told me that graduates of special schools go to work in regular factories or on collective or State farms, where special and appropriate tasks can be assigned to them. I unfortunately have no information on the number who fail to meet the curriculum requirements of these special schools, but I suspect their number is small.

Because of the Soviet distrust of psychometrics, and their special concern about the possibility of social and psychological reasons for retardation, children are ordinarily not placed in special education facilities for the retarded until they have spent a year in a normal class. The decision to transfer the student from the public school to an auxiliary school can be made only by a special commission, and only after it has been established that the public school has taken all necessary measures over an extended period of time to improve the child's success, without obtaining positive results; and after child psychiatrists have also concluded that the cause of the child's inability to pursue the public school studies is a mental deficiency due to an organic brain defect or disease. If there is no special school in the child's region or city the child may be sent to a school elsewhere. The regulations require that each student shall be accorded an annual review of his status by the pedagogical soviet of the school to determine the possibilities of his return to a regular public school.

There are no waiting lists for any of the special educational facilities, and all are fully staffed. Tizard describes a typical day school for 250 educationally subnormal children (all high grade defectives except for 20 imbeciles) which is generously staffed with teachers, and in addition had a physician and two fieldshers (physician's assistants) in attendance. He also described a residential institution for 60 trainable, physically healthy imbecile children, aged 8 to 17, which had a staff of 32; and
another larger one near Leningrad with 210 children (75 high grade imbeciles, 80 low grade imbeciles, and 55 idiots, including 23 cot cases) and a staff of 107.

There is much medical activity with these children, a great deal of it preventive in nature—frequent examinations, massage, exercise, special diets—as well as conventional medical treatment. There is also some psychotherapy, speech therapy, and physiotherapy.

Teachers of the retarded get a special 5-year course of training in the defectology department of the teachers’ training colleges. This is 1 to 2 years longer than the regular teacher training course. A regular teacher who wishes to work in this field must acquire additional training. Teachers of the retarded get 25 percent more than the regular teachers’ salary of 800 to 1,100 rubles a month.

Incidence

Though statistically reliable comparisons are not possible, and will not be for some time, there are indications that the actual amount of true mental deficiency in the Soviet Union is less than it is in the United States.

The strict policies on admission to special schools, Professor Luria told us, are partly responsible for the low percentage of children in special classes, a proportion he estimated roughly as less than one percent. After further inquiry and investigation I made an estimate which I believe to be more accurate. The result is even lower. In the Russian Federation Republic, which has a population of 113,000,000, there are 30,000 children in special classes for defectives, and an estimated additional 18,000 mentally retarded children still in the regular school, not yet diagnosed or placed, making a total of about 48,000 children regarded as suitable for special classes. Since a little more than 16,000,000 children are now attending the 10-year schools (corresponding to our primary and secondary schools), this would mean that one child out of every 350 children of school age, or less than one-third of one percent, is regarded as suitable for placement in the special classes for the retarded. These figures include children in special boarding schools.

Even if these rough estimates were doubled to make allowance for children outside the school system, the proportions would be considerably lower than the usual estimate of mental retardation in our population—3 percent. But it is, of course, not possible to get an accurate idea of prevalence from the numbers receiving services.

It is interesting to conjecture whether the apparent low rate of mental retardation in the Soviet Union may bear some relationship to the fact that the Soviet population is given free and comprehensive medical service—much of it preventive—from the womb to the grave. This attentive medical care, associated with liberal maternity leave policies and benefits (4 months leave with full pay, starting with the 8th month of pregnancy), may contribute to the health of offspring.

For example, the amount of prematurity (based on a birth weight of 2,500 g. or less) in the city of Kiev is reported as 4.9 per 100, compared with an overall rate of 9.4 per 100 reported in the city of New York in 1959, and over 16 per 100 for the Negro population in some districts of the city. The prematurity rates in Kiev and New York may, of course, be based on dissimilar reporting methods or varying completeness, but the differences are probably real.

The so-called psychoprophylactic or natural method of childbirth, which is used in 90 percent of the births in the Soviet Union, minimizes the use of drugs and may reduce the chance of brain damage.

The Cesarean-section rate is said to be generally around 2 percent in Soviet obstetrical services, and is reported as above 4 percent in many hospitals here. The many children we saw all over the Soviet Union impressed us as being unusually vigorous and robust.

Conclusions

On the basis of my observations and studies, which were necessarily limited, I think I can fairly make the following general statements:

- The overall picture of mental retardation services and research in the Soviet Union compares favorably with our own, and is in some respects superior.
- The rejection of psychometric testing, the exclusion of social and psychological problems from the concept of oligophrenia, and—possibly—the comprehensive health services combine to reduce the incidence of diagnosed and recognized mental deficiency in the U.S.S.R. But valid statistical comparisons are difficult to achieve.
- Russian research in this field is more neurophysiological than is our own and tends to be more intimately related to educational practice.
- Vocational placement of the retarded adult seems to create no difficult problems in the Soviet Union.
- Special education is regarded as a branch of science. The teachers enjoy considerable social prestige.
Continued contacts between American and Soviet scientists and other professional persons, mutual interchange of information and personnel, and cooperative research undertakings promise to be mutually rewarding.

An interdisciplinary problem, medical, paramedical, and educational . . .

MINIMAL BRAIN DAMAGE IN CHILDREN

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M ANY PROCESSES, both environmental and biological, contribute to an individual’s overall development. It is generally accepted that in the child who is without intellectual deficit, most deviations in behavior and performance are determined primarily by psychocultural factors. Less emphasis is apt to be placed on the importance of the integrity of the central nervous system through which behavior and learning are mediated and monitored.

In our clinic, a multidiscipline diagnostic clinic for handicapped children, operated by the University of Maryland in Baltimore, and the Maryland State Department of Health, we have evaluated 525 patients and have encountered a surprisingly high number—19 percent of the total group—in whom, after exhaustive examination and assessment, the final diagnosis was minimal cerebral dysfunction or minimal brain damage without intellectual subnormality.

This clinic population is not by any means a representative segment of handicapped children, but is a highly selected group of children referred to the clinic from various places throughout the State of Maryland over a 3-year period. It seems likely, however, that other pediatricians have encountered youngsters with the same perplexing problems.

The subject of minimal brain damage involves considerable controversy as to whether or not this is a diagnosable clinical entity. The dispute is not unexpected, however, for several reasons:

1. The subject matter deals with inherently complex functions which are difficult to measure.
2. The clinical techniques available to assess brain function are relatively crude and, in general, not designed to elicit subtle deviations in higher cerebral performance.
3. In an era in which the importance of environmental stresses in the causation of abnormal activity has been emphasized strongly, it has become somewhat unfashionable to diagnose organic cerebral pathology in the absence of specific neurological signs.

General Considerations

The brain is an organ of enormous complexity, some of the more delicate functions of which are not readily assessable by the usual neurological examination. Among these functions are perception, cognition, judgment, concentration, impulse control, visual and auditory memory, perceptual motor function, and symbol organization. Injury to or mal-development of the cerebrum may interfere with these higher brain functions and contribute to certain behavioral deviations, language disorders, and learning disabilities in the absence of specific neurological signs of mental retardation.

When cerebral dysfunction exists and the clinical neurological examination is normal, the term “minimal brain damage” or “minimal cerebral dysfunc-

Based on a paper presented at the 1961 spring meeting of the American Academy of Pediatrics.
tion" is used in designation. The conduct disturbances associated with minimal brain damage are termed "organic behavior disorders." The language problems and learning disabilities that are related to neurological impairment are classified as neuropsychiatric learning disorders.

The clinical manifestations of this kind of neurological deficit vary with the age of the patient and severity and location of the abnormality. Such disorders may not be apparent in infancy. Not uncommonly they present themselves as developmental deviations in the preschool years. Most frequently such disturbances are first noted in the early school years. Characteristically, adjustment and academic problems occur between the ages of 5 and 11 years.

As components of a continuum, behavior disorders and neuropsychiatric learning disabilities caused by minimal brain damage usually exist together in varying combinations, though they may occasionally appear independently. Characteristic of this impairment is absence of specific neurological signs, although minor degrees of motor incoordination, nonspecific awkwardness, mixed laterality, time and spatial disorientation, or adiadochokinesis (inability to perform rapid alternating movements) can usually be detected. Delayed speech development, mechanical speech imperfections, echolalia (meaningless repetition of others' words), strabismus, visuo-motor impairment, and abnormal electroencephalograms are found in greater numbers than in control subjects.

**Organic Behavior Disorders**

It has long been known that persistent disturbances in personality may be noted in a child who has suffered epidemic influenzal encephalitis or severe head injury.\(^1\)\(^2\) Behavioral deviations similar to those associated with postencephalitic and posttraumatic states are also found in children in whom no convincing evidence of cerebral insult can be elicited. Frequently noted in the histories of these children are maternal pregnancy complications, prematurity, and perinatal difficulties.\(^3\)

The borderline between that which is normally active behavior and that which is pathological is not easy to define. In extreme cases, however, if familiarity with the pathological condition has been established, the difference may be recognized without difficulty.

There are no pathognomonic signs for minimal organic impairment of the central nervous system, but it is possible to describe in general terms those characteristics which are frequently noted in children with such impairment and to point out trends which suggest neurological impairment, based on objective but inferential observations. Similar characteristics are at times noted in children who are healthy and normal. However, when they occur in greater frequency, with greater severity, and in combination, and persist through the various stages of development, they can be regarded as related to cerebral dysfunction.

Hyperkinesis (hyperactivity) and distractibility are the two most striking features of organic behavior disorders. The child is constantly in motion. More important, however, than the degree of hyperactivity, is the quality of his overall performance. Because of excess distractibility he cannot ignore the countless inconsequential visual and auditory stimuli which the normal child selectively screens out. As his interest and attention are directed first to one object and then to another with little design or apparent intent, his overall demeanor may assume a bizarre character—disorganized, disruptive, and unpredictable. Cohen\(^4\) described this kind of childhood activity in detail over 20 years ago and used the term "organic driven-ness" to denote the apparent surplus of inner compulsions.

Whatever its causation, this non-goal-directed, semiwillional, seemingly irrational deviation from normal patterns is extremely difficult for others to tolerate. The child's classroom adjustment is apt to present a major problem. The task of learning becomes extraordinarily difficult, due, at least partially, to restlessness and the inability to exclude irrelevant sensory impressions.

Impulsiveness, perseveration, emotional lability, lowered frustration tolerance, inappropriate and sometimes overwhelming anxiety further contribute to the child's anomalous adjustment.

It was Strauss\(^5\)\(^-\)\(^7\) who first presented a systematized approach to the psychological assessment of the brain-injured child and stressed the disturbances in perceptual and conceptual functions. He pointed out the importance of the differential diagnosis to determine whether a younger with bizarre behavior is neurotic, psychotic, brain-injured, or mentally retarded.

Additional and important contributions to our understanding of children with these perplexing symptoms have been made more recently by Bradley,\(^8\) Eisenberg,\(^9\) Laufer,\(^10\) Rogers,\(^11\) Knobloch,\(^12\) Bender,\(^13\) and others in this country, and Luria\(^14\) in the U.S.S.R.
It was Pasamanick who first presented convincing evidence of the high incidence of pregnancy and perinatal complications in the histories of hyperkinetic children. He postulated that certain organic behavior disorders are reproductive casualties related to cerebral palsy, epilepsy, and mental retardation.

One of the conspicuous characteristics of the child with subclinical neurological impairment is the manner in which he relates to people. This may take one of two extremes: an inappropriate and unselective display of affection to total strangers; or a pronounced and continued disregard of people, similar to the responses of patients with early infantile autism, whose regard for individuals is not unlike their regard for furniture.

However strong the observer's organic orientation might be, he will find it difficult to ignore the strikingly high incidence of psychopathology in the families of these children, although this is not a universal phenomenon among them. While neurological dysfunction, from whatever cause, contributes to only a small fraction of all conduct disturbances in children, in brain-damaged children there seems to exist a lowered emotional threshold as a result of cerebral disorganization and thereby a predisposition to embarrassment by environmental stresses—stresses under which the non-brain-injured child might manifest no compromise.

Eisenberg in his classical paper on the psychiatric implications of minimal brain injury has stressed the psychobiological background of this syndrome and its expression as a physiological disorganization of adaptive behavior.

Cohn has referred to the syndrome as “social dyspraxia,” a splintered, apparently aimless, searching demeanor which is other than merely a reaction to environmental stresses.

Importance of Diagnosis

Differential diagnosis in the child who may be neurotic, schizophrenic, autistic, or brain-injured is of more than academic importance. The usual psychotherapeutic approaches may need modification to assist the child with cerebral dysfunction effectively. Parent counseling, with the object of helping the parent understand why this child has been so hard to rear, might be carried out in a significantly different manner than with parents of a child whose basic difficulty was emotional disturbance.

In the assessment and management of the disturbed parent-child relationship, either as cause or effect of the child’s disorder, it seems pertinent to recognize whether the child’s environmental needs are excessive because of neurological disturbance. Parents who would be well-equipped to satisfy the needs of a healthy normal child may be incapable of meeting the requirements of a child who is brain-injured, so that the child is left in a state of relative environmental deprivation. For, the needs of the brain-injured child are excessive: for understanding, acceptance, affection, guidance, and well-directed, consistent, firm, and early discipline.

Although the organic background of hyperkinetic behavior seems certain, the point of view that this is not amenable to psychological therapeutic intervention cannot be justified. Organic drives can be modified by environmental influences although this may be a difficult undertaking.

Drug therapy has been of significant value in decreasing the hyperactivity, distractibility, and extreme anxiety associated with brain injury. Many pharmacologic agents have been used. Encouraging and at times dramatic results have been obtained with dextro-amphetamine, benadryl, and, notably, dilantin.

If secondary emotional complications have been avoided, the long-term outlook of the hyperkinetic child with adequate intellectual endowment is favorable. As he matures, the child often develops the ability to compensate for perceptual distortions. In most such children, hyperactivity and impulsivity can be expected to show significant resolution shortly after puberty, either with or without medication.

Learning Disorders

The language and learning disorders associated with cerebral dysfunction cannot be ascribed merely to shortened attention span and poor classroom adjustment. They represent specific disabilities which are related to high cortical functions. As such they are extremely difficult to diagnose.

It is well known that the schools contain many children who seem destined to be educational casualties—bright children whose school life is burdened because of inordinate difficulty in mastering the basic academic skills. A characteristic of most of these children is delayed acquisition of reading ability. They may also have a similar difficulty with arithmetic, spelling, and writing. If the child is a nonreader, he eventually encounters difficulty in all academic processes which require comprehension of written language. The usual presenting complaint is overall academic deficiency.
Often when the ordinary investigations reveal no apparent physical cause for such learning difficulties and when psychological testing indicates average ability or better, these children are categorized as lazy, poorly motivated, or emotionally blocked.

In the most severe cases, their disabilities may derive from:

1. **Auditory agnosia**, a condition in which sound is received by the brain, but not interpreted, and so has no meaning attached.

2. **Motor aphasia**, in which there is interference with ability to express a meaning in language.

3. **Dyslexia**, in which there is impairment of the reception, integration, and utilization of visual symbols, and so, an inability to read.¹⁹

The milder forms of psychoneurological learning disorders may be manifested only as inconsistent auditory comprehension, mild articulation defects or difficulties in word finding, or slight delay in the acquisition of reading skills.

Failure to recognize the neurological background of these problems may lead to serious psychic trauma, to which the child is already predisposed because of a coexisting lowered emotional threshold. The constant, and seemingly inevitable, day-to-day failures these children experience produce feelings of inadequacy and eventually lead to anxiety, hostility, rebellion, and schoolphobia, thus further aggravating their unsatisfactory school adjustment and academic achievement.

It is unlikely that all, or even most, specific language and learning disorders are due to tissue injury. The high incidence of such disabilities in the families of children presenting these difficulties and the predominance of males among them suggests the possibility of a genetic inheritance in a significant number. This has evoked the concept of cerebral dysmaturation—or developmental deviation—not related to native intelligence, but involving specific centers or pathways of the brain.²¹ However, the exact location and nature of these defects has not been described.

It is necessary to recognize that the constellation of behavior and learning disorders described here represents highly specific if often ill-defined disabilities. They constitute only a small percentage of all adjustment and academic problems among children.

Children with the symptoms described here appeared in our clinic and were studied conscientiously by competent professional workers for many months before a gradual awareness of the complex psychobiological background of these disorders evolved.

**A Interdisciplinary Problem**

Out of our study and experience we have arrived at the following observations:

1. Some educators, neurologists, psychologists, and audiologists have been aware of the significance and importance of minimal brain dysfunction for many years.²²

2. The inherently complex nature of the problems of children with this disability crosses many professional boundaries, but the professional workers have not learned to complement each other effectively in their efforts to help. They have not cultivated the interprofessional communications and exchange of ideas which are necessary for our mutual understanding of these complex problems.

3. Many children, the nature of whose handicaps are not well understood, are being treated in child guidance clinics, remedial reading centers, speech correction classes, and special educational settings, although they have never been adequately studied and have not responded well to long-term and intensive intervention.²³,²⁴

4. Brain-damaged children are being treated for schizophrenia or autism and presumed environmental deprivation without consideration of the fact that their detailed developmental history often reveals that they were never healthy, normally responsive children even in earliest infancy.

5. Speech therapists are treating children for mechanical speech defects when, in some instances, a profound central language disorder exists.

6. Known bright children with specific reading disabilities have been managed for long periods of time on the presumption that they were poorly motivated, emotionally blocked, or neglected at home.

7. Intelligent children with reading disabilities are being considered mentally retarded on the basis of group intelligence tests which presuppose the one skill which is notably impaired.

8. Hyperactive children have been excluded from schools as antisocial without recognition of the nature of their handicaps and without provision of appropriate educational facilities and techniques to meet their special needs.

9. The usual neurological examination is sensitive to less than 50 percent of brain function, yet many clinicians have excluded the possibility of any central nervous system pathology on the basis of this type of examination alone.
10. The skills and techniques of the clinical psychologist, audiologist, and speech pathologist may detect neurological impairment in the absence of classical neurological signs.26

11. The electroencephalogram can be expected to yield significantly valuable information about central nervous system function even in the absence of clinical seizures. It is abnormal in over 50 percent of children with hyperkinetic behavior, specific reading disabilities, and language problems.26-28

The current controversy over the implications of minimal cerebral dysfunction does not promise to be resolved in the foreseeable future. The full significance of this type of impairment is not yet known and must await the time when the medical, paramedical, and educational disciplines have learned to communicate with and complement each other.

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GUARDIANSHIP FOR THE MENTALLY RETARDED

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PARENTS of normal children generally can look forward to the time when their children will achieve some measure of financial security and social prestige. For many of the retarded, however, in spite of the considerable expansion of educational and training resources that has taken place in recent years, these are still unattainable goals. For those among the retarded who are chronically dependent or semidependent persons, a lifetime plan of guidance, care, and supervision is needed.

The trend toward keeping mentally retarded children in their own homes and integrating them wherever possible into community programs and functions has focused attention on the need for long range planning for them. Many parents have demonstrated remarkable ingenuity and adaptability in meeting the immediate needs of such children. Yet even among the most adequate parents, today's successes are often marred by tomorrow's uncertainties. "Who will look after my retarded child's interests when I am gone or can no longer do so myself?"

The deep concern and anxiety reflected in this oft-repeated question is well founded. Parents of retarded children—perhaps better than anyone else—fully realize the self-sacrifice and dedication often entailed in their care. When because of parental effort, the retarded child is happy, content, well-adjusted, and in many ways a contributing member to family and community life, the parents are apt to be reluctant to accept institutional care as the ultimate living arrangement for him. They cannot expect, nor indeed are many willing, to burden other members of the family with the often trying responsibilities of caring for and supervising a retarded adult. They hesitate to seek the assistance of friends for this purpose and fear that strangers may lack understanding of what their children need and how these needs may be fulfilled.

With advances in the medical sciences, the survival rate of damaged infants has been increased and their life expectancy prolonged. More and more, parents are faced with the likelihood that their retarded children will survive. With machines displacing men from jobs and many families moving from one community to another, life in our society has become more complex. These changes sorely tax the capacities of the handicapped adult for independent functioning and social usefulness.

These developments have brought into sharp focus the need to re-examine existing measures for safeguarding and promoting the welfare of the retarded in case of parental death, disablement, or inadequacy. Sometimes the need for guardianship stems not only from the incapacities of the retarded person, but from the inadequacies of his parents who are still living. In some cases, parents are unable to meet the physical, emotional, or behavioral problems of their retarded child and are unresponsive to professional efforts to help them. Where these conditions prevail, society, through its established agencies and social institutions, has a responsibility to protect the child's interests and rights and to provide opportunities wherein he may develop to his fullest potentialities. Though the legal rights of children may vary within States, this fundamental value in our culture is an inherent part of our social system as
it is expressed in our customs and in our laws.

Current practice in relation to guardianship and the concepts and philosophy underlying these practices vary greatly. A few States encourage guardianship arrangements under public welfare departments for all retarded persons, whatever the family's status and capacities and the individual's living arrangements. Most widespread, however, is the practice of vesting legal custody and sometimes guardianship responsibilities for the retarded in the superintendents of State institutions, but only for those persons who have been admitted to the institutions—approximately 4 percent of the mentally retarded population. Unfortunately, many families with retarded children at home, who do not plan for institutional placement, do not recognize the need for future guardianship arrangements.

Complexities in the present systems of guardianship are thus formidable obstacles in the long range planning many retarded persons need. Happily, the National Association for Retarded Children and its State and local affiliates are actively exploring different ways of planning for the future of the retarded. It has already launched upon a group insurance program. Among other techniques being considered are arrangements for guardianship.

**Forms of Guardianship**

The needs of the mentally retarded for protection have long been recognized in the legal systems of many countries and in all the States of the United States, and various methods have been developed to safeguard their welfare and protect their financial and personal interests. Traditionally they have been grouped with the mentally ill and with minors as being mentally incompetent to conduct their own affairs or to perform adult functions such as making wills or conducting litigation.

Various forms of guardianship have been utilized in efforts to promote their interests. These are of four kinds: guardians of the person; guardians of the property; general guardians (of person and property); and guardians *ad litem*, appointed solely in connection with court actions.1

In the main, there are relatively few instances of considerable property belonging to the mentally retarded just as there are in the population at large. Usually, the need for guardianship exists more in the area of personal concern and interest in their well-being than in relation to property. Therefore, the appointment of general guardians should probably be made more frequently than separate guardians of the person and of the property for the same individuals. A general guardian could well exercise the necessary fiscal care of moderate amounts of property and at the same time evince the degree of personal interest and concern which is so vital to the welfare of the mentally retarded. In any event, the capacities of the mentally retarded person's natural guardians for this role should be considered paramount. Others should not be substituted for natural guardians during the natural guardians' lifetime unless they are unable to fulfill the responsibilities inherent in guardianship.

Parents are recognized as the natural guardians of their minor children and of their mentally retarded children who reach the age of adulthood and have been adjudged incompetent. However, the existence of mental defect in an adult, no matter how apparent, does not automatically confer guardianship responsibilities on his parents. Although in many instances, controversial issues regarding the management of the retarded adult or his estate are not apt to arise, it may be a wise precaution for parents to seek an adjudication of their child's incompetence while they are living. In this way arrangements for future guardianship can be expedited and continuous protection of the child assured.

This concept of the need for a continuation of the natural guardianship functions for the adult retarded child is expressed in provisions of revenue laws concerning dependency exemptions, in social security legislation, particularly regarding eligibility of handicapped dependents for social insurance benefits, and in decisions regarding medical and other forms of care.

**Individual Need**

Mentally retarded persons—by definition—lack the intelligence and social competency to manage their own affairs with ordinary prudence and judgment. Within this broad definition, however, the range of incapacity is great. A fairly large proportion of the mentally retarded are only identifiable as such and actually function on a defective level only during their school-age years when the expectations and demands of a normal life exceed their abilities. At the age of majority, many of them become self-supporting, and need guidance and supervision only when confronted with situations of serious social stress. For these persons, guardianship may not be necessary.

However, the more severely handicapped or the
less socially adequate, lacking the capacity to act for themselves, need someone who can act in their behalf. Whatever their chronological age, they cannot be expected to behave responsibly in certain situations, to negotiate contracts, or to be liable for their misdeeds—especially in instances where they lack the intelligence to distinguish right from wrong. Even as adults they need social and legal protection against exploitation and also personal guidance toward social adjustment and training.

Retarded persons whose intellectual deficits stem primarily from social and cultural factors often differ markedly from persons who are retarded from other causes in many respects and have a greater capacity for self-direction and self-maintenance as adults. Hence the need for guardianship provisions in these cases is not always apparent. The need should be determined by careful interdisciplinary evaluation and subjected to periodic review, not only of the retarded person’s capacity for self-reliance but of the environmental circumstances which may have dictated the need for guardianship in the first place.

**Functions and Responsibilities**

Much confusion exists in the public mind regarding the functions and responsibilities of legal guardians and how they differ from those of parents. For this reason, some parents hesitate to plan for such arrangements, and at times persons who could be potential guardians are somewhat reluctant to act in this capacity.

In many respects, guardianship and parenthood carry similar responsibilities. Like the parent, the guardian becomes responsible for the care, custody, and control of the child. He is entrusted with authority to make important decisions regarding the well-being of his ward that may affect the individual’s whole life. These decisions may involve medical care, employment, consent to marriage, and entry into the armed forces—all of which may be considerations for many of the retarded and problems about which they cannot be expected to exercise sound judgment.

Judicially appointed guardians, on the other hand, are subject to certain limitations to which parents are not subject. These stem from various legal aspects of guardianship. Guardianship—where minority is the basis for appointment—automatically terminates when the child attains his majority. This does not apply in cases based upon mental incompetency. In any case, while the guardianship is in force, the relationship is subject to continuing supervision and review by the court. The wide discretionary powers of the guardian are, in contrast to those of parents, exercised under court direction—at least in theory.

**Aids in Planning**

Planning for care, education, and treatment, or regulating behavior of the mentally retarded is often complicated by lack of resources and facilities, negative social attitudes, or limited opportunities. In many other instances, the most suitable plan for a retarded ward cannot be carried out because of very limited or totally unavailable financial assets. The guardian has no duty to support and educate the ward except from the ward’s own estate, nor does he have any right to the ward’s earnings and services.

Guardians cannot always be expected to have the special knowledge to handle effectively the sometimes complex situations involved in the care of a handicapped person. However, they can be helped to discharge their responsibilities toward a retarded ward more effectively when the supervision of the court is supplemented with skilled social services, competent advice, adequate safeguards of the ward’s interest, and a plan suited to his special needs.

State laws generally define the conditions relating to the value and kind of property under which a guardian of property must be appointed to hold a fiduciary relationship to the ward. At times, the same person is appointed to act as guardian of the person and estate and is thus called a general guardian. Though this is often a highly desirable practice, where the property involved is not extensive, clarification is essential as to the respective powers and duties of each office. The guardian of the property’s activities are confined primarily to the “prudent and economical management” of the estate entrusted to him and these activities are subject to court direction and periodic accounting to the court.

As fiscal responsibilities are better understood, especially as social insurance programs are expanded with wider coverage and larger benefits, parents may become more conscious of the various alternatives available to them in long-range planning for their retarded child. Already, as noted earlier, extensive efforts have been undertaken by parents’ associations to familiarize their membership with group life insurance plans and other techniques for the future care and support of their retarded offspring.

Guardianship of mentally retarded children and adults then, particularly in the assumption of certain parental functions, is a weighty responsibility. It is
incumbent upon the courts therefore, and upon the parents who may designate their choice of guardians through last will and testament, to use the best judgment in their selections. Equally important, such appointments call for the availability of skilled social services to the court and guardian.

What happens when both parents die and no provision has been made for guardianship? Much will depend on the age and capacities of the retarded person himself. However, even the obviously retarded person who needs someone to protect his interests is not likely to come to court attention unless an action for dependency or institutional commitment or probate of an estate is initiated. These actions do not ensure that a guardian of the person will be appointed. Therefore, when a retarded person is bereft of his parents it is important that relatives, friends, neighbors, or others concerned with his welfare petition the court to appoint a guardian who will have responsibility for him. Where the welfare of the retarded person is in jeopardy, the public welfare agency has a responsibility for initiating the necessary protective measures, of which guardianship may be a crucial component.

Properly used, the guardian-ward relationship can serve to establish an atmosphere of affection, security, and recognition for the retarded person and contribute to his social growth and development.

**Institutional Guardians**

As already mentioned, in certain sections of the country it has become customary to replace natural guardians of the mentally retarded with institutional superintendents appointed to serve as guardians for those persons who are involuntarily committed by courts to institutions. Even in many instances of voluntary admissions, such guardians are appointed. The rationale behind such appointments, or the appointment of State welfare directors as guardians of noninstitutionalized persons, is that the appointees can make necessary decisions and promote the interests of their wards.

In practice these systems of public guardianship tend to become routine and stereotyped. The individual is easily lost sight of in these large-scale guardianship systems which are apt to become bookkeeping arrangements rather than socially significant efforts to aid the mentally retarded. Where a single guardian is responsible for hundreds or thousands of retarded persons, he cannot be expected to keep abreast of the individual’s changing circumstances and needs. Often whatever action is taken is in response to emergencies or situations of stress, rather than to a positive plan for meeting anticipated needs. Furthermore, complicated legal and supervisory problems may arise when the retarded person is transferred from the institution to some other facility or is returned to the community on family or work placement. These are additional arguments for a one-to-one guardianship arrangement.

Moreover, the appointment of guardians, when parents would like to continue exercising their full responsibility and have demonstrated capacity to do so, is often a disservice to the retarded persons and to the parents themselves. In effect, the parents of children with institutional or State guardians are, or can be, precluded from manifesting a substantial interest in the welfare of these children in regard to many areas of life planning—placement in and release from foster care, special medical service, marriage. This exclusion of the parent militates against a strengthening of the natural ties between institutionalized persons and their families. Such an involuntary estrangement can weaken family relationships and impede the ultimate return of the mentally retarded person into family living. Hence the guardianship can result in a prolongation of the very problems the court action sought to alleviate.

Then too, when public guardians are appointed society is lulled into the belief that all the interests of the retarded are being protected, whereas in reality in many cases only a modicum of protection is afforded.

One of the objectives of guardianship for persons in institutional care, whether this be undertaken by a public guardian or a private citizen, is to facilitate their rehabilitation and return to community life. This objective is interfered with when commitment is accompanied by real or presumed loss of the retarded person’s civil rights.

**Recruitment and Termination**

Guardians for the mentally retarded can be recruited by utilizing the specific interests of various groups of people. One of the principal sources might well be organizations of parents of the retarded where there is a common concern and background of meaningful experience in dealing with the mentally retarded. Many of the members might be encouraged to function productively as guardians. Such parents, particularly those who have resolved their personal conflicts about having a retarded child, possess a unique understanding, sympathy, and feeling for the mentally retarded. Consequently, they
could bring to bear a sympathetic interest which could not be duplicated easily by others.

Local bar associations might be another source of recruitment. The legal training and experience of members of the bar would be a valuable asset in a guardian. Moreover, having bar association members act in this capacity should enhance the interest of these organizations in the retarded.

Another recruitment source might be service groups—men’s clubs, women’s clubs, civic organizations, and the like. Many such groups are already actively engaged in volunteer work with the retarded and in the sponsorship of social and recreational programs.

An essential component in the productive functioning of guardians appointed from such sources would be cooperation between them and social service agencies within the community. By pooling their understanding of the mentally retarded, by joint planning, by interpretation of special problems and needs, they could accomplish much for the welfare not only of the mentally retarded but of the entire community. Local social agencies would seem to have a particular obligation to help recruit such guardians and to give them guidance and stimulus in their efforts.

Sometimes guardians appointed for the mentally retarded continue on long after the need for such guardianship has disappeared, as, for example, when the retarded person has achieved a degree of social competency where he can reasonably manage his own affairs. Thought should be given to arranging for a periodic review of guardianships in relation to individual circumstances and with regard to the manner in which the duties are carried out. As soon as it is shown that a person can function adequately without guardianship, the arrangement should be terminated. Where the responsibilities of guardianship are not being competently discharged, a successor guardian should be appointed. Generally, courts are required to supervise the activities of judicially appointed guardians. However, the extent to which supervision is exercised and the methods employed vary considerably. There is reason to believe that in practice there is more supervision of guardians of property than of guardians of the person. The vital role of the latter warrants greater community effort and concern in promoting the best possible safeguards.

**Legislative Suggestions**

It is perhaps time for States to review their laws and administrative practices regarding guardianship and other provisions for the mentally retarded. This can be done by the use of statewide citizens’ committees charged with specific responsibilities for both study and report to the State legislature. Many statutory provisions need reexamination in the light of modern developments in psychology, social services, medicine, and other fields.

In such reviews special attention should be given to the clarification of judicial and administrative functions in respect to the mentally retarded and to the provision of services and legal protections which will improve the condition of mentally retarded individuals and promote their well-being.

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ORIENTATING PARENTS TO A CLINIC FOR THE RETARDED

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IN THE OPERATION of a clinic for retarded children, the following questions are repeatedly raised:

- How can the waiting list be cut down?
- How can the interest of parents be maintained pending the beginning of the study?
- How can parents be kept from breaking clinic appointments?
- How can parents be best informed about the work of the clinic?

Confronted with these provocative questions, the staff of our clinic set up a system of group orientation meetings in March 1960 for parents at intake as a method for improving the service of the clinic. The problems presented by the long waiting list and failure of parents to understand the clinic’s services are now handled more effectively. Broken appointments in a multidisciplinary clinic involving the team approach especially had long been a matter of grave concern, since a broken appointment affects several staff members simultaneously, thus wasting the service of the clinic and allowing fewer children to be served.

The meetings, which are held in the evening, were organized and conducted by the chief social worker for parents of children on the waiting list. These are parents who so far have not been interviewed at the clinic. They have either telephoned the clinic to inquire about the possibilities of service for their child or have come to the clinic’s attention through a telephone call from a doctor or another professional person. In either case the clinic has received little information about them other than identifying data. During the meeting, each parent is given a schedule of individual appointments with the social worker, clinical psychologist, physician, child development specialist, and speech and hearing specialist.

Since March 1960, the meetings have been held at regular intervals and are now attended by the pediatrician-director who acts as a medical resource consultant to the group. The parents are seen in groups averaging about 10 couples each. The individual appointments for each child and parent are spread over a 6-week period, the first parent coming to the clinic with her child a week after the meeting for the beginning of the study.

The group meetings provide the staff with a chance to find out which parents are still interested in the clinic service and to obtain from them signed forms permitting the staff to send for pertinent medical and social information in advance of their individual interviews. The meetings’ most important advantages for the staff, however, lie in the opportunity they afford for observing the parents and gaining insight into each couples’ attitudes toward their child, toward each other, and toward other parents with a problem similar to their own.

The rationale of this approach is to meet the parent’s need for service at the time of the request. The parent who has contacted the clinic has already overcome one hurdle by beginning to accept the fact that his child may be retarded. Therefore, it is vital to provide service to him at a time when he is still searching for help for his child, before he has had much of an opportunity to become resigned to the child’s problem.

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Parents usually find some therapeutic relief in learning about the detailed diagnostic procedure the clinic has to offer and in being assured that their child will be seen and assessed by a team of specialists in work with children. The clinic's structure begins to have some meaning for them as they have an opportunity to see and inspect the different examining, testing, and play rooms where the study of the child will take place. Often they express relief at learning that the study is not to be conducted in a hospital atmosphere and that the children will not have to stay overnight.

Nervous tension is often aggravated in a family by the presence of a retarded child. In these discussion groups, tensions are often relieved when parents learn that mental retardation is not necessarily inherited. Some parents also find relief in learning that in comparison with others their child is not so badly handicapped. Parents are also often relieved to learn that their child can acquire self-help skills even though this can be accomplished only through a slow, tedious, training procedure, requiring repetition, relaxation, and routine.1

We hear much about parents who shop around from one clinic to another. This is not necessarily as unwise as many persons assume. Since there is considerable variation in medical practice, a parent may want confirmation of a diagnosis of mental retardation just as he might of any other medical diagnosis. Thus our clinic serves parents who may be known to other diagnostic clinics as well as those who are making their first clinic appointment. They are also widely different in educational and economic background, although families from the low-income groups predominate.

In order to help parents sense quickly what they have in common despite their wide differences in background, the group leader always points out that each has come to the meeting because of a deep concern about his handicapped child and that it is important for them not to blame themselves for the handicap. This does not mean that the parents are regarded as a homogeneous group or that they all feel the same way about their retarded child. However, at the time of the meeting they are all expressing their concern as parents of handicapped children. Recognizing this fact creates a sympathetic feeling toward one another and creates interaction among them. Mutuality of interest is more important to the members of such a group than are differences in their socio-economic, cultural, or educational background.

The social worker, through a permissive attitude, attempts to provide a "safe" climate for frank discussion among the parents. In the first part of the meeting she describes the clinic's services and what is expected of the parents. She also introduces some mental health concepts, pointing out that the clinic staff is as much concerned about the social adjustment of the child as with his physical condition. She also presents the concept of mental retardation as a symptom of biopsychosocial malfunction.

She encourages the parents to think of their child first and the handicap second, so that it becomes more than a difference in words when they say "my child who is retarded," rather than "my retarded child." Another point she stresses is that the mentally retarded child has the same desire to belong and be accepted by others as the nonretarded, and that in general his emotional needs for recognition, companionship, and a sense of usefulness are the same as those of the normal child.

Orientation Techniques

Many parents of retarded children deny the fact that their child is different from normal children before they finally accept reality. In these group meetings the social worker does not try to convince a parent that his child is below average for she realizes that while the discussion may be helpful in modifying the parent's attitudes, time will be the most important factor in this regard.

In describing the clinic, the social worker points out that it has been set up as part of the city's health program to provide complete diagnostic study and evaluation for any child under 18 who is a resident of the District of Columbia, and in whom there is a question of mental retardation. The parents are given a description of what goes into the diagnostic study and followup services, and of the work of the various staff members who participate: a pediatrician-director, two social workers, a psychologist, a child development worker, a nursing consultant, and a psychiatric consultant who have at their disposal various other consultants from the health department's staff including specialists in speech and hearing, neurology, electroencephalography, physical and occupational therapy, orthopedics, ophthalmology, and cardiology.

The social worker compares the clinic team approach to a family, telling how each member contributes his particular skill in order to help the other team members to do a better job as well as to help the retarded child. She also stresses the informality
and friendliness of the team members in order to help the anxious, hard-to-reach parents to become more relaxed so that they can become active participants in the study.

**Focus on the Child**

The second part of the meeting can be described as a group-intake interview through parent discussion. Social workers who have had responsibility over the years for individual intake interviews generally acquire considerable skill in quickly assessing the client's problem. This skill can be transferred to a certain extent to a group-intake setting. Of course, when a group is present the social worker cannot do as much interpretation of individual problems nor pick up immediately on some of the emotionally charged clues which emerge from the discussion. However, these clues often point the way to the focus of the subsequent individual interview.

What makes the intake interview so challenging, whether in an individual or a group setting, is that at this time, as the client presents his problems, the social worker is in a position to receive the full impact of his personality and his reactions to his problems. Later as the relationship continues and more detail complicates the picture, it is often more difficult for the worker to identify the trends which are significant for the assessment of the handicapped child in relation to his family.

As the parents describe their child's behavior, it often illustrates the child's social maladjustment. Problems in behavior such as short attention span, hyperactivity, temper tantrums, and a high degree of distractibility are described rather than examples of slow intellectual performance. It becomes evident that the children referred to our clinic are like the children at the Edenwald School of the Jewish Child Care Association of New York—"a group with retardation, emotional disturbance, and organicity all mixed up in a complicated dynamic pattern." 2

When the parents are stimulated to think of mental retardation as a cause of their child's social dysfunction, impairing his ability to adapt, their overemphasis on the possibility of a physical basis to the child's difficulties tends to diminish. For example, the chief complaint of most parents is that their child is not talking, even though he may be several years old. Often parents assume that the child has some defect in his speech mechanism which treatment would alleviate. The social worker tries to help these parents understand that slowness of speech is often one of the characteristics of retardation and that a child usually understands more than he can communicate.

Although parents listen with interest and often ask questions in the part of the meeting devoted to an explanation of the clinic's services, their participation intensifies considerably when the focus shifts to their problems with their child. The social worker refers to this second half of the session as "their" part of the meeting for it is their opportunity to introduce themselves, to tell about their child, his age, his characteristics, and his relations with his siblings, and to state what they want and expect from the diagnostic study.

To get the discussion going, the leader invites the parents to volunteer to talk or to take turns in the order of their seating arrangement, as they wish.

At this point, the parents' interest turns quickly from the group leader to each other, as each parent describes the condition and individual characteristics of his child. The parents generally relate to each other quickly, gaining mutual support and sympathy. Rarely has a parent decided at the meeting that he does not want his child to go through the clinic study, although a few have decided afterward that they would wait a while before having the study made.

**Mutual Support**

The following example illustrates the way the parents find support in each other. A mother of a little Mongoloid baby had brought in a picture of her child for the clinic personnel to examine. This woman had a great need to deny that her child looked like a Mongoloid. As the discussion progressed, she passed the picture around to the other parents and a number of the parents reacted to it immediately. While some of the parents agreed with the mother that the baby did not look like a Mongoloid and others thought they saw some Mongoloid characteristics, the whole discussion seemed to develop a bond of sympathy and understanding in the group.

Often the group interaction has a more therapeutic effect than the explanations of the group discussion leader. This was true with Mrs. O, who described her 6-year-old daughter in somewhat critical terms by saying: "Mary knows what to do but she won't do it. She will repeat what I tell her to do but will go ahead with her play and ignore what I have said. Punishing doesn't seem to help. When she is asked why, she replies, 'I don't know.'"

Obviously feeling irritated and frustrated at Mary's behavior, Mrs. O added, "I want this study
to show me how I can make her do what I tell her to.”

Very quickly a father spoke up, saying, “It’s pretty hard to make anybody do anything for very long. Maybe it would be better to have someone tell you what might be the reason for Mary’s acting up.”

Mrs. O nodded at this and the discussion continued.

Sometimes the social worker gets clues to be followed through later. A mother described her slow child as being the smartest one in the family about getting her own way. She said her child could run circles around anyone by coaxing, demanding, or making a fuss. Some other parents agreed that they had the same trouble. The social worker made a mental note that these parents needed help in modifying their children’s manipulative behavior.

The parents’ feelings of guilt do not come out in a group as often as might be anticipated. However, one very articulate, uninhibited father suddenly blurted out:

“Say, I have a sister in a mental hospital; do you suppose that’s why my little girl is slow in developing? Would it be my fault since it’s on my side of the family?”

Before there was time for the social worker to answer, another parent said: “It is like the lady said earlier: it’s not to your credit if your child is bright and it’s not your fault if your child is slow.”

There have been times in the meetings when mothers have wept as they described their retarded child, but when this has occurred the group has accepted it calmly. One mother who was telling how difficult it is for a woman to handle a handicapped child alone said in a shaky voice: “My husband left me and now my little girl frequently runs away because she wants to find her daddy.” The group was very silent as she struggled for self-control.

Another distraught and somewhat hostile mother of a retarded and emotionally disturbed 10-year-old boy said bluntly: “I want my child sterilized because I don’t ever want to be responsible for rearing any of his children.” The other parents looked stunned at first, and then began talking of their own fears of what the future would hold in the way of social relationships for their handicapped children. The social worker pointed out that many parents worried about this and that society does not provide a pat answer to the problem. She stressed the fact that each child is entitled to a thorough individual diagnostic study before any recommendation is made for his treatment.

Individual tape recordings of 12 of the parent group-orientation meetings have been made with permission of the parents. (They are available upon request to the clinic.) Demonstrating vividly the dynamic interaction which occurs as the parents discuss their children, they reflect both agreement and disagreement about suggestions made by the social worker as well as by the parents themselves, and show how the social worker uses opportunities to comment, interpret, or recommend a “let’s wait and see attitude.”

Patterns and Values

Over the months we have been able to detect certain patterns in these meetings.

We find that a group of from 8 to 10 couples usually promotes more interaction among the parents than a larger or smaller group.

We find that fathers often take the initiative in describing in detail their child’s problems. And, contrary to our expectations, we have often found that fathers are readier to accept a diagnosis of retardation than some mothers. For example, fathers sometimes attend the meeting alone, their wives having stayed home as babysitters, and when this happens such statements as the following are not unusual: “I see this child as very different from other children in the family, but I wouldn’t dare say this if my wife were here because she would hit the ceiling.”

We find that parents want the support they get from other parents. Often at the end of the meeting parents ask about the possibility of having further opportunities to talk together about their common problems. These parents usually become the nucleus of further parent discussion groups to which parents are invited after the diagnostic study has been completed, the evaluation conference held, and the interpretation given.

The feeling of mutual support engendered in self-led parent groups, such as those sponsored by local parents’ organizations, is partly the reason why such groups have grown so in strength and numbers during the past 10 years. However, we have found that some additional advantages are provided when meetings are led by a professional staff person as part of the total diagnostic and treatment procedure of a clinic. This makes it possible for the meetings to—

• Be “treatment-oriented” instead of solely supportive and informative.

• Help parents consider their child’s accomplishments and strengths as well as his limitations.

• Help parents, when necessary, to keep from re-
revealing themselves too openly. (When a parent begins an emotional “confession” or starts bringing family skeletons out of the closet, the leader can intervene with a comment which universalizes what has been said or otherwise puts it into an impersonal framework.)

- Make it possible for every parent present to participate in the discussion. (The leader can, when necessary, tactfully terminate the discussion of a dominating member of the group and encourage a less articulate one to express himself.)

- Provide for intervention when the discussion gets blocked on an emotional level that only feeds the members’ self-pity.

- Help parents become better informed of community resources which have programs for retarded children.

Although each meeting does not result in all of these advantages, some are always achieved.

The group orientation procedure also saves considerable staff time during the diagnostic study by reducing the parents’ need to ask questions at this time. We find especially that parents who have met and talked with other parents who have similar problems do not so frequently ask, “Why did this happen to my child?”

The group-intake procedure also gives the staff opportunity to observe how husbands and wives react to one another, to other parents in the group, and to the social workers, thus gaining some indication of the quality of a couple’s marital relations and of their other interpersonal and community relations. It also gives the staff an opportunity to learn about the parents’ attitudes toward their child.

Since the clinic recommends but does not require both parents to be present for the diagnostic study appointments, the parent group-orientation meeting often provides the staff with the only opportunity to see the father. This is true even though a visit by the social worker to the home is regularly included as part of each child’s diagnostic study.

By providing a means of seeing parents more quickly, the group-orientation procedure avoids anxiety-producing delays not only for the parents but also for the staff. We find that staff morale has improved now that appointments with parents and children can be scheduled well ahead, thus permitting orderly planning and acceleration of clinic work.

However, although the parent group meetings at intake have an educational and an orientation focus, their chief goal is to increase the parents’ understanding of their child’s problem. Unless the family is helped, factors contributing to the child’s problem remain unchanged. When parents are helped through group discussion or individual casework treatment, or both, much can be done to relieve the effect of retardation and help the child to develop to his full potential.

As the parents listen to each other talk about their children, they often gain new ways of looking at their own problems, feel less isolated, and gain emotional support. Treatment actually begins at the parent group-orientation meetings.

*Scher, Bernhard: Help to parents: an integral part of service to the child. American Journal of Mental Deficiency, July 1955.*


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THE DOCTOR AND THE HANDICAPPED CHILD

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The physician plays a primary part in the development of the child who is handicapped. While he may never have a direct part in the occupational, physical, or speech therapy, or special education the child ultimately receives, he can set the stage for the successful use of these services by the way in which he helps the parents and child accept and work with the handicapping condition. This responsibility rests on the doctor because he is usually the first person to define for the parents the nature and extent of the child's handicap. This important event often occurs in the hospital at the time of birth, if the condition is immediately recognized, or later when the child is admitted to the hospital for observation.

What the doctor tells the patient or his parents about the handicapping condition is certainly important. How he tells them and how he and the hospital staff act toward the child or his parents can be critical. We are constantly expanding our medical knowledge about the causes of various handicapping conditions, and for some conditions we have ameliorative surgical and medical therapy. However, for most handicaps we can only offer partial improvement in the actual physical condition, and for many we have no corrective therapy.

In the latter instances, the child, his parents, and the doctor ultimately have to face the fact that the handicap will be permanently present in some degree and will interfere with the child's normal developmental progress. Obviously this is extremely difficult for the parents and the child, but, perhaps not so obviously, it is also extremely difficult for the doctor. He has to admit that within his chosen profession he is failing because he cannot heal the patient. For this reason, some doctors find it difficult to give up various surgical and medical procedures that often consume a great deal of the patient's time, energy, emotions, and money, and lead to very little functional change in the handicap.

The physician who can accept the fact of his inability to remove the patient's handicap can help the child and his parents to accept it. Then everyone's time, energy, and emotions can be directed toward the best possible adaptation of the child to the everyday world. Some physicians handle this task exceedingly well and others make no effort to cope with it.

We know that doctors often fail to get the parents and their child started in the right direction when the handicap is first recognized. We know this from the reports of parents' complaints. For example, Dr. Koch and associates at the Los Angeles Children's Hospital in a study of the attitudes of parents of retarded children to the medical care received found that parents were critical of what they were told, such as "put the baby away and forget about him," or "there is no hope," and of what they were not told. "My questions about the baby's development were ignored" was a frequent complaint. Dr. Koch found that parents were also critical of how they were told about the baby's condition: for example, "The diagnosis was fired at us," "He told us in a cold way," "He was blunt," and "He tried to help, but wasn't interested in the child."

Such statements indicate not that the doctors
involved were cold, but that they were very emotionally involved because they felt helpless.

These feelings on the part of the doctor have been illustrated by Wilma Gurney in a report written in 1961 of the Child Amputee Prosthetics Project of the University of California at Los Angeles, for which she was then chief social worker.

An obstetrician who delivered one of the babies now in the Child Amputee Prosthetics Project contributed to our understanding. He described his feelings as being very strong and personal, feelings of revulsion and of somehow not wanting to be around the mother. He found himself not wanting to see her or talk with anyone about it.

"After all," he said, "obstetricians don't like this sort of thing. Why do you think we chose this specialty? We don't like stillbirths or abortions, and especially we don't like anomalies."

He went on to compare serious anomalies with other devastating chronic long-term illnesses, saying they were much harder to face than cancer. He explained his thoughts this way:

"Death is really not so terrible. It's the living death that some people have to endure every hour of every day for years that is so devastating. This couple will have to watch their little girl grow up deformed and will be reminded all the time of the heartbreaking difference between her and other little girls."

It is apparent that the feelings about anomalies are strong in doctors as well as parents and can paralyze effective action. Nevertheless, how the doctor talks to the parents and how he conducts himself affects the child's future. Nonverbal is as important as verbal communication.

When Communication Fails

We physicians know that we have failed with parents and their handicapped children when we find that they are not able to accept or use the help of various specialists or special equipment that would be to their advantage. Such children and their parents are still trying to solve the initial crisis of accepting the fact that a permanent handicap exists, of recognizing that hiding from it or having magic dreams will not send it away.

Miss Gurney in another report of the Child Amputee Prosthetics Project at UCLA found that the parents could be divided into three groups:

1. Parents who have sufficiently coped with the traumatic experience of having given birth to a child with an anomaly to be able to discuss the disability realistically; who realize and accept the child's need for both independence and dependence; and who have so freed themselves from self-blame that they can communicate understanding to the child and be helpful to him with his own problems of being different from other children.

2. Parents who are bewildered by the problems that are created by a child who is different; who continue to be troubled by a feeling of having caused the anomaly; who express concern about the reactions of strangers, friends, and relatives to the amputation and to a prosthesis; but who have the strength to look at their reactions and concerns and to make use of help.

3. Parents who have attempted to absorb the child in their own needs and conflicts, or who have isolated the child through avoidance of communication or insistence upon complete self-sufficiency; or who have withdrawn from close association with the family by illnesses or flights into activity, and who in defense deny the need for help.

The children in the first group of families are usually ready to accept a prosthesis immediately and will proceed promptly to learn how to use it. The children of the second group may not yet be ready for acceptance of a prosthesis. Often it is deemed advisable to defer prescribing one for such a child until he has a better understanding of his handicap, but everyone is optimistic that the child and his parents are accessible to help. On the other hand, the children of the third group almost never accept a prosthesis or try to use one correctly. Furthermore, the parents and children tend to reject help with their emotional problems. They are so hard to help at this point that the wisest course is to take steps to prevent this point from being reached.

Dr. Call, a UCLA child psychiatrist, in his report of group meetings with parents of cerebral palsied children, found much the same types of parents' responses to children's handicaps as Miss Gurney. He emphasized the close emotional tie that some mothers developed with their handicapped children, a symbiosis that precluded the child's independent action and self-identification.

We have noticed in working with blind children that when some of them reach the age of 18 months or 2 years, they are still very infantile in behavior, having lacked stimulus from their parents toward any development of independence. Apparently frustrated by their inability to cope with the environment, they have begun to withdraw within themselves. By 4 to 6 years of age, some blind children appear severely retarded and are placed in State institutions where their downhill progress continues. Other blind children have received help early enough to bring them out of this early autism and have gone on to successful school careers. However, many parents of blind children could be helped to avoid letting the children get into such a state. The child has to be accessible to be able to benefit from educational programs for the blind.

What can the doctor do to help prevent some of these problems? He must, of course, define for the parents as clearly as he can the nature of the handicapping condition. Sometimes this is easily done, but sometimes, especially in regard to mental retar-
dation and cerebral palsy, the doctor cannot clearly see the prognosis. He must in any case try to explain, from a medical point of view, why the condition occurred. Sometimes he can do this; most often he cannot. He can, however, listen attentively to the parents’ question, “What did we do wrong to cause this?”

And as parents describe some of the ways they feel they might have brought about the condition, the doctor can help them see that these were unlikely causal factors.

Next the doctor must provide the parents with some ways of dealing with the problem over an extended period of time. He must give them ideas and information that will permit several courses of action. The family needs to come to decisions of their own, in due time and in the quiet of their own home. Any abrupt suggestion to “put the child in an institution and forget about him” is ill advised.

Whatever information and help a doctor tries to give the parents should be given unhurriedly. They can only assimilate a small amount at a time. There should be opportunity for daily discussions between the doctor and the parents while the child is in the hospital. The parents and child (if an older child) should feel that they are not alone with their problem and that the doctor is ready to give them encouragement and moral support.

The type of handicap a child has is important in determining not only the management of the child but also the attitude of the parents toward the problem. The age at which the handicap is clearly defined is also important in these respects and carries with it certain similarities for all types of handicaps.

Handicaps Noted at Birth

Physical handicaps noted at birth are for the most part obvious deformities such as congenital amputation of the arms or legs, deformities of the spine (spina bifida), and deformities of the face, including cleft palate and cleft lip, and the more general and sometimes more subtle physical signs of Mongolism.

The parents of the child with an obvious physical defect know immediately that the child will be handicapped in some measure and in the case of congenital amputation are aware that surgical and medical reconstruction will be of partial help only. Such a handicap has a rather sudden finality about it, bringing a crisis for the parents which is immediate and severe. The mother is usually informed of the anomaly before she sees the child, as she should be. But this means she often becomes filled with feelings of self-pity and guilt before she has held her child in her arms and learned to know him as a person. The mother of a child with a cleft palate and cleft lip may have similar feelings, but she usually knows that the condition can be ameliorated by surgery. The mother of the Mongoloid child is, of course, similarly shocked by the knowledge that her child is imperfect, but the deformity is less obvious to her. The probability of mental retardation is only a prediction that she can temporarily disbelieve until time forces her to face the facts.

The common factor in all of these situations is that the mother is told that she has a deformed child before she and the child have had any interpersonal interchange. This confounds the problem of establishing a strong, healthy, mother-child relationship. Miss Gurney has illustrated this:

What happens to parents following the birth of an abnormal baby? Parents describe this period as living in a night- mare, with only the hope that it is a nightmare from which they will awaken. For those who are not permitted to see their baby, the nightmare is prolonged, making it difficult and even impossible to start dealing with reality. For those who are shown their baby in ways that reveal revulsion on the part of the staff at the sight of incompleteness or deformity, there is an imprint of rejection by persons who should have the greatest understanding of such conditions. For those who are left alone there is the sense of being outcast, of uncleanliness. For those who are fortunate, there is someone who recognizes their sorrow, who handles their baby with tenderness, who says by actions that though this is a disappointing and devastating thing that has happened, the parents are not going to be left to deal with it alone. Universally, parents feel they are alone with a problem that is hopeless.

Fortunately many mothers overcome this difficult emotional situation by virtue of their own emotional strength. Their children develop into successful participants in a prosthetics program, speech therapy class, or special education class. The important point is that many other mothers who might otherwise flounder in their mothering can be helped to establish a strong, healthy relationship with their babies.

It is the seemingly little things that are done in the hospital by the nurses and the doctors that can make the difference. The doctors and nurses who work in the newborn nursery enjoy that pleasant glow that is reflected by the happy mother with a healthy newborn baby. Everyone is upset when a deformed baby appears. The anxiety and depression that affects the staff is transmitted to the mother. This situation is hard to avoid, but there are constructive and destructive ways of handling it.

A common form of destructive behavior is the acting out by members of the hospital staff of their
own anxiety in efforts to “protect” the mother. The mother is not allowed to see the baby until she is “stronger,” and no one talks to her about the child’s deformity. The baby is placed in a special room and is often overtreated with the use of unnecessary incubators or special feeding techniques. Such behavior emphasizes the enormity of the problem for the mother.

Recently a baby with bilateral cleft lip and palate was born in the UCLA hospital. The inexperienced intern on duty in the nursery was justifiably upset and started to act out his anxiety by overprotecting the mother. We more experienced members of the staff urged him to get the mother and baby together as soon as possible and let the mother give the baby most of the feedings. He was hesitant at first, arguing that the baby weighed only 5 pounds and, therefore, needed special care in the premature nursery, and furthermore, because of the defect in his large palate, the baby would have to be fed by stomach tube.

We pointed out that since the baby was vigorous he would not need an incubator or other special premature care and that many similar babies nursed well from an ordinary nipple. We told him that many mothers consistently cut the rubber palate flap off of the special cleft palate nipples after they get home. The intern deferred to our greater experience, and the mother began giving her baby feedings on the first day, using regular bottles with ordinary nipples. We were all amazed at the ease with which this mother accepted the facially deformed baby and at the skill which she demonstrated in taking care of him.

In this instance we at least did not stand in the way of the development of a good mother-child relationship. We took one further step to try to avoid future problems. We know that this baby will be seen by many doctors and other professional persons in his childhood, such as the pediatrician, plastic surgeon, otologist, orthodontist, audiologist, and speech therapist, and that in a university clinic a patient can become lost in a maze of appointments and a confusing variety of advice. Therefore, we ask the social worker of the pediatric clinic to become acquainted with the mother in the hospital, and to become the mother’s liaison with the rest of us. In private practice, the family doctor should play this role, and at UCLA we hope to train doctors to be able to do this well.

What we hope we conveyed to this mother is the idea that she can take care of her child better than anyone else. We also want her to feel that she is not alone and that we will always stand by to help her when she needs us.

**Handicaps Noted Later**

In such ways the doctor can help the parents of infants whose handicapping conditions are apparent at birth and in doing so help the child. But what about those children whose handicaps only become apparent sometime later during the first 18 months of life? Such conditions as blindness, deafness, mental retardation, cerebral palsy, and some types of handicapping congenital heart disease fall into this category. Because such conditions usually are unsuspected when the baby is in the newborn nursery, it is often possible for the mother and child to have a good and reasonably natural beginning together. But in these instances it dawns on the mother gradually that something is wrong. She then becomes disturbed in her management of the child because he is not following anticipated patterns of behavior. She blames herself for mismanaging the child or the child for misbehaving.

Often when the handicap is finally diagnosed and the mother learns from the doctor of her child’s true condition, she is naturally resentful of the time she spent in unnecessarily tormenting herself or her child. She becomes angry with the doctor who did not discover the condition at the onset and with the doctor who did discover the condition but was too abrupt in telling the parents about it. It is a time of many recriminations.

The hospital staff, doctors, nurses, and social workers have to be prepared to accept the overflow of the parents’ emotions, including anger, guilt, self-pity, and rejection. The parents need acceptance with all their troubles just as the child does. Too often we who deal with such parents are in a hurry to tell them that the child will do all right if they would only stop acting silly and use some rational common sense. This is desirable but takes time.

There is a natural tendency for such parents to act out their sorrow and feelings of guilt by doing everything for the child, and since the child at this age is still very dependent he has little chance to free himself. A concept to get across to these parents is that they should not prolong or exaggerate the child’s dependence on them.

Children who become handicapped when they are older, through accident or illness, present an entirely different problem. They have had several years of normal relationships with their parents, siblings, and
friends. If all has gone well in these relationships, they have a firm emotional background to help them cope with the new crisis of being handicapped. Parents, friends, and doctors are often amazed at the skill with which such children can adapt to a handicapping condition. On the other hand, if the child is already emotionally disturbed and his relationship with his parents is distorted before he acquires the handicap, the new problem only adds fuel to the distorting forces.

In such instances, persons in a professional position must avoid focusing on the handicap in searching for a solution to the child’s adjustment problem and must try to keep the child and parents from doing the same. These parents and their child need help with the problems they had before the handicapping condition developed.

The hospital staff can help the child by letting him know by their attitudes that he is just as acceptable with his handicap as he was before. They should accept his sorrow, depression, and anger with understanding, but without indulging in these emotions themselves. The doctor especially needs to represent an understanding and sympathetic pillar of strength that can withstand all emotional onslaughts. From this position, he can help the child and his parents deal with the handicapping condition constructively and keep it in its proper perspective.

**In Summary**

To recapitulate, no matter what handicap a child has or when it is first recognized, the physician is in a strategic position for preparing the child for later special therapy and education because he is the first to define the nature of the handicap for the parents and the child. The skill with which he deals with this critical moment is of paramount importance to the success of the future adjustment of the child.

In the newborn period, the primary goal must be the development of a healthy mother-infant relationship. The doctor must try to convey to the mother the idea that she can take care of her handicapped child better than anyone else.

In early infancy, the chief problem is the parents’ tendency to act out their sorrow by exaggerating and prolonging the dependency of the child. The physician must help the parents see the need for letting the child grow toward independence.

In later childhood, the principal difficulty is to avoid attributing to the handicap problems that existed a long time before the handicapping condition was acquired. The doctor can help the child to understand that he is as acceptable in his handicapped condition as he was before, and to sort out those problems related to his handicap and those related to other factors.

In transmitting healthy concepts to the child and his parents, the physician must be helped by the attitudes and behavior of the entire hospital or clinic staff.

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On October 16, 1962, a distinguished group of experts presented a report to President Kennedy on the problem of mental retardation in this Nation. The document, entitled "A Proposed Program for National Action To Combat Mental Retardation,"\* was presented to the President by Leonard W. Mayo, chairman of the group. It represented a year of intensive study, conferences, and public hearings by a panel of 28 outstanding physicians, scientists, educators, lawyers, psychologists, social scientists, and citizens concerned with mental retardation. They had been called together a year before at the White House and asked to make a broad study of the scope and dimensions of the various factors that are relevant to mental retardation and to explore ways to prevent and deal with this problem. The panel was specifically asked to make recommendations with regard to:

1. The personnel necessary to develop and apply the new knowledge.
2. The major areas of concern that offer the most hope.
3. The present programs of treatment, education, and rehabilitation.
4. The relationships between the Federal Government, the States, and private resources in efforts to eliminate mental retardation.

The panel's report includes over 90 recommendations. It presents the problem of mental retardation as a major national health, social, and economic problem, affecting some 5.4 million children and adults and involving some 15 to 20 million family members in this country. It estimates cost of care for those affected at approximately $550 million a year, plus a loss to the Nation of several billion dollars of economic output because of the underachievement, underproduction, or complete dependence of the mentally retarded.

The program of action proposed by the panel derives from conclusions arrived at on the basis of its study. Numerous facts are presented to document its statement that: "Mental retardation is a complex phenomenon stemming from multiple causes;" and to show that many of the specific causes are known and can be prevented or their results treated.

Equally well documented is the conclusion that for the bulk of mental retardation cases, a specific cause cannot yet be ascribed. Nevertheless, as the report points out, epidemiological data from many reliable studies show a remarkably heavy correlation between the incidence of mental retardation, particularly in its milder manifestations, and the adverse social, economic, and cultural status of groups of our population. This is especially true for low-income groups who live in slums where the mother and the children receive inadequate medical care, where family breakdown is common, and where individuals lack opportunity and adequate education. In short, the conditions which spawn many other health and social problems are to a large extent the same as those which generate mental retardation. Therefore, the panel has concluded that "to be successful in preventing mental retardation on a large scale, a broad attack on the fundamental adverse conditions will be necessary."

A Broad Attack

From these basic conclusions the panel has recommended a "broad spectrum" attack on many fronts to focus not only on the specific causes of mental retardation but also on the root problems in the social, economic, and cultural environment which nourish the specific causes and seem to have a direct causative influence of their own.

Fundamentally, the panel's recommendations call for the allocation of

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more resources for services to help the youth of the land achieve health, education, and training, for community reconstruction and renewal, and for improved employment and social services—with special attention to improving opportunities and services for distressed groups in the population. The panel warns that its recommendations will be costly to implement.

The major recommendations of the panel are grouped into eight categories. While it is impossible to comment on all of these here, presenting a few from each category may indicate the breadth of the report, a little of its detail, and some of its flavor.

Research. The panel has made 19 recommendations concerning research into the causes of retardation and into effective methods of care, rehabilitation, and learning. These include recommendations for developing research centers on mental retardation at strategically located universities and at institutions for the retarded, and for a Federal program of collection and analysis of statistics on the incidence, prevalence, and socioeconomic characteristics of the mentally retarded.

In view of the importance of basic research on learning to the achievement of national goals as well as to the special needs of the mentally retarded, the panel has proposed the establishment by the Federal Government of a national research institute of learning to include an intramural as well as an extramural program.

Prevention. The section on prevention contains 11 specific recommendations, all of which are far reaching in their impact. Major stress in the report is given to the recommendation for a greatly strengthened program of maternal and infant care. This is to be directed first at the centers of population where prematurity, which is closely associated with retardation, and the rate of "damaged" children are high. Protective measures against such known hazards to pregnancy as radiation and harmful drugs are recommended, as is the development of genetic counseling services. The report also recommends that communities undertake long-range programs to improve social, economic, educational, and health opportunities in the slums as well as specific measures to offset the adverse effects of deprivation of intellectual stimulation on the children and youth living in such areas. Among the latter are suggested increases in public health nursing and social casework services to deprived families, day-care centers, guidance and employment services in the schools, parent education services, and homemaker services.

The panel has estimated that the full application of existing knowledge in taking action on a broad front to correct adverse community conditions, as well as in taking more specific preventive measures, would prevent perhaps half of all new cases of mental retardation. Moreover, the panel points out, such action would also reduce the incidence of other health and social disabilities.

Clinical and Social Services. The panel’s approach to the subject of clinical and social services is based on the assumption that the richer and the more easily available all general services become, the less need there will be for special services for the retarded. Viewing retarded persons as part of, rather than apart from, the general population, the report calls for the removal of all barriers blocking their access to such general services. It points out, however, that the various services that should be available in this array must be marshaled in different ways and in different combinations for different people in accordance with their needs at different times.

To implement these basic tenets, the panel’s recommendations range from providing continuous child health supervision for all children to the extension and improvement of clinical services for the mentally retarded. Additional Federal funds are recommended for the crippled children’s program so that physically handicapped children who are also mentally retarded can be served more fully by this program. A “fixed point” of referral and information to which parents and professionals in every community can turn for help is suggested as essential.

The concept of the “continuum of care” which the report spells out in this section merits careful study and consideration. As used by the panel, “continuum of care” involves the selection, blending, and use, in proper sequence and relationship, of the medical, educational, and social services required by a retarded person to minimize his disability at every point in his life span. Thus, “care” is used in its broadest sense, and “continuum” underscores the many transitions and liaisons within and among various services and professions through which the community attempts to secure for the retarded the kind of help he requires. A “continuum of care” permits fluidity of movement of the individual from one type of service to another while a sharp focus is maintained on his unique requirements. The ongoing process of assuring that an individual receives the services he needs when he needs them and in the amount and variety he requires is the essence of planning and coordination.

Education and Training. The section of the report dealing with education, vocational rehabilitation, and training is based on the premise that both public and private school systems have an obligation to provide appropriate educational opportunities for all mentally retarded children who can profit from training. The panel points to the need for 55,000 more teachers trained to work with the retarded; calls for the improvement of special education programs, and suggests that centers for instructional material be developed. Other recommendations call for increased State vocational rehabilitation appropriations, the strengthening of school counseling services, the establishment of educational diagnosis and evaluation services, sheltered work opportunities beyond the traditional workshop setting, and recreational activity centers for severely handicapped adults.

Residential Care. The challenge which the panel presents to the Nation in the section on residential care is how to accelerate the change from large isolated facilities to smaller units close to the homes of patients and to the health, education, and social resources of the community. To help residential facilities achieve this pattern, the panel recommends Federal grants to State institutions for support of demonstration projects in the areas of rehabilitation and care, inservice training and education of personnel, and research.

The panel also presents objectives which the administrative authorities of residential facilities can implement. These concern such areas as admission and release policies, treatment goals, diagnosis and evaluation prior to admission, and extension of services beyond the campus.
Perhaps one of the more important recommendations in regard to residential care is that calling on the States to redirect funds earmarked for expanding large institutional facilities to developing the type of facilities there are in some European countries. These include a wide range of diversified residential arrangements in local communities—small units designed in program and structure to meet the needs of specific groups such as infants, the senile, or young adults.

The Law. A refreshingly new legal concept of the retarded is presented in the section on the law. The approach is based on the assumption that "the richer and better the services concerned with their welfare, the less need there is of coercive intervention to provide care." Says the report: "Indeed in dealing with problems that arise with the retarded in the community, formal legal intervention should be regarded as a residual resource and should not occur where social or personal interests can be adequately served without it."

The panel calls for a differentiation between guardianship of the property of a retarded person and guardianship of the person. The development of a limited guardianship of the person is called for, together with periodic review by the courts of the need for continuation of any form of guardianship. Judicial review, every 2 years, of the need for continued institutional care for all retarded adults is recommended. The panel also calls for new approaches in the treatment of mentally retarded criminal defendants.

Organization of Services. The recommendations in regard to the organization of services underscore the panel's basic finding that the problems of the mentally retarded are not and cannot be the responsibility of any one discipline or agency; that rather they must be important concerns of several departments and agencies; that, therefore, they require a multiple, but coordinated, attack. Thus, the report recommends that States set up arrangements such as an interdepartmental committee, a council, or a board to coordinate the efforts of the dispersed services in the community. To encourage the development of such machinery, the panel has recommended that the Secretary of Health, Education, and Welfare be authorized to make grants to the States for comprehensive planning of efforts to combat mental retardation.

Grant-making bodies, both public and private, are urged to give priority to joint enterprises which might provide improved coordination of research, training, and service. Programs of interdisciplinary training are recommended. Models of pilot demonstrations of successful patient management coordinated with training and research are suggested. The section also includes a whole series of recommendations to encourage the U.S. Department of Health, Education, and Welfare to provide greater leadership in stimulating comprehensive planning on Federal, State, and community levels to combat mental retardation.

Public Awareness. The strategic placement at the end of the report of a section on public awareness clearly conveys the panel's feeling that without an expanded program of information and education on mental retardation for the general public and for professional organizations, little progress will be made in implementing any of the recommendations. The panel calls specifically for the use of the mass media of communication to reach a variety of groups with information on different aspects of retardation. The panel again warns in this section that to be effective, none of the agencies concerned can discharge their obligation alone, and recommends that all work in close liaison through a planning and coordinating committee.

Next Steps

On reviewing this report, one may well ask how some of its broad objectives for the retarded differ in kind or degree from desirable goals for other groups with special needs. The panel has answered this by stating that while its recommended objectives for the retarded do not differ fundamentally from what others need, the retarded do not presently receive either the attention or the services accorded to others.

An effective way to achieve results beneficial to many, moreover, is to seize the handle presented by an important segment of the population which has been neglected and lift that group to a higher level without losing sight of the needs of all. If, for example, research in learning is spurred by the urgent and specific needs of the retarded, the chances of gaining information of a generic nature will most certainly be enhanced.

No doubt there will be a great deal of discussion of this report, some in praise and some in criticism. Many people will complain of its unevenness from one section to another in terms of depth. Others will object to the lack of specificity in some of the recommendations. It must be remembered, however, that this report is only one step in achieving the kind of total program which is needed. We have reached this step through a slow beginning of interest in the mentally retarded coupled with a growing dissatisfaction with inadequate salvage efforts. The appointment of a body—the panel—charged with study, review, and the production of a comprehensive report was a tremendous move forward.

The most important step is yet to come. This will no doubt be the most difficult, the longest, and, as Dr. Mayo has indicated, the one with the least amount of glamour. It must consist of a careful examination of the report to determine how the recommendations can be carried out and what this will take. On this phase of activity will hinge the success or failure of the panel's efforts.

The U.S. Department of Health, Education, and Welfare took action in this direction shortly after this report was presented to the President. Through the Departmental Committee on Mental Retardation and in conjunction with the Bureau of the Budget, it analyzed the report in an effort to delineate which of the recommendations involving Federal agencies can be carried out under existing authority, which require new authority, and what would be necessary to implement them. As about half the recommendations relate in some way to responsibilities of the constituent agencies of the Department, or require some type of national stimulation or coordination, such action is a real beginning toward the panel's proposals.

A similar process will need to take place on the part of State and voluntary agencies, private foundations, and religious and professional groups which are involved and concerned. Only through such efforts will the recommendations of the panel eventually be realized.
MENTALLY RETARDED TEENAGERS IN A SOCIAL GROUP

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CHILDREN LEARN to live with others only through experience. However, the retarded child is often caught in a vicious spiral that is negative and limiting to his social development. The lack of social experiences leads to social retardation and ineptness in chronologically appropriate social skills, accompanied by emotional difficulties arising from feelings of rejection and deprivation; and the lack of social skills further limits the opportunities the retardate has of participating in social experiences.

Mentally retarded children must be taught many things which normal children learn spontaneously or incidentally. Often they must be taught to play and to be helped in developing creative qualities that give them fun and pleasure. When this has been achieved the retardate can gain the same satisfactions from participating in social activities as other people. These satisfactions derive from: (a) being recognized and accepted in the group situation; (b) a sense of accomplishment in activities in which he is successfully interacting with his peers; (c) the experience of self-expression, especially when making positive contributions to the group's activities; (d) the enhancement of self-esteem; (e) and the feeling of "belonging."

To give young retardates these opportunities, the New York City Chapter, Association for the Help of Retarded Children has conducted a group work, recreation, and camping program for mentally retarded children, teenagers, and young adults for the past 11 years. At first the program was directed by a social caseworker, but for the past 5 years it has been the responsibility of a professional social group worker who spends full time on the job.

The program was developed on a decentralized basis in whatever facilities were available in neighborhoods throughout New York City—churches, synagogues, schools, park buildings, housing projects, and veterans and union halls. It includes groups of elementary school-age children, teenagers, and young adults. In placing individuals in the groups, chronological age, previous social experiences, and social adequacy and functioning are considered together. Trained group workers are used as group leaders, assisted by a nonprofessional person of the opposite sex who may be a staff member or a volunteer.

The purpose of the program is to provide:
1. A medium of enjoyment for mentally retarded children and youth.
2. A setting which will aid them in social adjustment—one which provides a small, intimate, face-to-face experience with others of the same age, including members of the opposite sex.
3. Experiences to help them develop simple, useful skills that they can carry over to the home, to the community, and perhaps to employment.
4. Experiences to help them accept themselves and the limitations imposed by their retardation, as well as to utilize their capacities to increase their feelings of self-worth.
5. A means of freeing parents for a few hours weekly of the supervision of the retardate and of helping them to carry over into the home and community attitudes that will promote increased independence in their children.

One of these groups is the Queen's Teens—a coed social club of adolescent retardates 12 to 15 years of age, one of 12 such groups throughout the city. The group meets each Wednesday evening from 7:30 to 9:30 p.m. in the basement recreation room of a large cooperative housing project in a middle-class neighbor-
neighborhood in the borough of Queens. The location of
the meeting place is far from ideal—neither having
the facilities of a community center nor offering
potential contact with other children, but it is
adequate.

The membership of the Queen's Teens reflects
the socioeconomic character of the middle-class
neighborhood.

The New York City Chapter, Association for the
Help of Retarded Children provided the overall pro-
gram structure, supervision, and administration,
which in this instance included the paid male leader,
special interest and holiday programs, and program
supplies. A women's auxiliary affiliated with the
New York City Chapter supplied two female volun-
teers a week, refreshments, and occasional special
program needs.

**Composition of Group**

Members were referred to the group by the New
York City Chapter after their application had been
processed through intake. The intake process in-
cluded an interview by the director of group work
services with the young person and one or both par-
ents at the office of the Association. Before the inter-
view, information about the child's development and
his family situation was obtained from school rec-
ords, clinic material, and other sources. Criteria
for membership in the Queen's Teens were: (a)
membership of the parents in the Association for the
Help of Retarded Children; (b) chronological age,
12 to 15; (c) the ability to participate at the level
of the group; (d) the capacity to derive benefit from
the group experience. Eligibility in relation to the
last two criteria was determined only after the teen-
ager had participated in several group meetings.
The final decision was made by the Chapter's direc-
tor of group work services, the leader of the group,
the parent, and the teenager himself to the extent
of his ability to understand.

Within the 8-month period on which the observa-
tions in this paper were based, a total of 19 teenagers
were referred to the group. While the aforemen-
tioned criteria identified this as a “formed” group,
it contained some elements of a “natural” group in
that its members referred to it some of their class-
mates from school. (Most of the young people at-
tend special public school classes for the retarded.)
The group became stabilized at 10 members, with
an average attendance of 8 or 9 youngsters at each
meeting. Of those who did not continue: one
was found by the leader to be functioning at a higher
level than the group; another chose not to come be-
cause he himself felt the group was too young for
him; one child had no means of transportation;
three teenagers never attended because their mothers
were not interested in the group after visiting the
meetings; one youngster was asked not to come be-
cause his attendance was irregular, averaging less
than once a month, and his behavior when present
was disruptive to the group.

The teenagers who remained in the group came
regularly to meetings not only because of interest in
the group and the program, but also because the par-
ents assumed the responsibility for bringing them.
Only two of the members lived within walking dis-
tance, the others being scattered in a 5-mile area.

The children's IQ's ranged from the forties to the
seventies. This information, however, was found
to be of little use in planning recreational activities
for the group, for it did not give any indication of
the young people's ability to function in a social
group. What was of greater importance in program
planning was the youngsters' ability to relate to
adults and peers, to work and play with others, and
to use program materials. At present there is no
meaningful measure of this type of ability available.

A scale rating the children on the nature and ex-
tent of their social functioning and adequacy would
be of great help in the selection and placement of
individuals in social groups. There appears to be
a distinct difference in the individual's intellectual
level, his chronological age, and his social function-
ing. We found that the child who had previous
positive social experiences functioned better in the
group, regardless of his intellectual level.

**Program Structure and Content**

In programming for the “QT's” the emphasis was
on the provision of both social and learning expe-
riences which to the participants would be regarded
as exciting, satisfying, and full of fun. The group
worker and the volunteers worked with the young-
sters in an uncritical and supportive manner in re-
gard to their participation while attempting to fur-
ther their development in the areas of self-care, use
of program activities and materials, interaction with
their peers and adults, and self-expression.

The group was called a “club” on the assumption
that the term would have status significance to the
adolescents. The group worker took the responsi-
bility for planning a program and modifying it to
both the group's and the individual's readiness at the
time of the meeting.
The activities relied upon were the kinds common to recreational groups—loosely organized games, square and folk dancing, singing, arts and crafts. In addition, activities involving the retardate in learning a functional task related to everyday living were included and were especially popular. These activities included (1) short trips in and around the immediate community; and (2) preparation of refreshments. The trips included shopping in the supermarket, buying sodas and cakes in a local cafeteria, walking to the park, riding the subway, and eating lunch in the automat. The supermarket and cafeteria trips provided the basis for later role playing as waiters, clerks, and customers.

The volunteers were responsible for selecting and bringing refreshments that the children could prepare for themselves. They started with caramel apples and popping corn and moved to chocolate and tapioca puddings, pizza pies, vegetable salads, hot dogs, and stuffed celery. The parents were especially impressed by the skill their children developed in these activities.

Special projects—puppet making, mad-hatters ball, birthday parties, and celebration of holidays—were also successful.

Each 2-hour meeting was planned to allow for individual participation both in choosing and leading activities. The breakdown and approximate time involved in each session were as follows:

1. **Premeeting (15 minutes)**. While the group was gathering for the evening, the teens moved about the room playing with various games and equipment. During the period of initial development these were set up before the young people arrived. Later the young people helped the worker to get the room ready for the evening.

2. **Meeting (15 minutes)**. The group worker would call the members to come and be seated around a table. The “meeting” opened with a set of seated circle games used regularly from week to week. After this opening the group worker asked the members to tell about their individual experiences during the week and encouraged them to talk about their other interests, with the purpose of engaging the individuals in informal conversation, allowing for and stimulating interaction between the members themselves and the adults. In addition, the evening’s activities were planned at this time.

3. **Major activity (30 to 45 minutes)**. The theme of the evening was developed and carried out during this period—parties, walks in the snow, games, or arts and crafts.

4. **Refreshment period (30 to 45 minutes)**. While the members ate the refreshments which they had helped prepare, the group worker and volunteers engaged them in individual informal conversations. Afterwards the members helped in cleaning up.

5. **Closing period (30 minutes)**. The program ended with singing, dancing, or a game or two. Then the group worker made an announcement about the following week. Before going home the young people helped to put away the program equipment and made a game of folding and stacking the chairs. The group worker and volunteers always greeted the parents as they arrived to pick up their youngsters.

**Some Observations**

From the experience with Queen’s Teens one could draw some general observations on group work with the retarded:

1. **Retardates, like other individuals, can be expected to react differentially to group experiences.**

Contrary to a common belief that retardates tend to be passive and conforming, the group worker found evidence among the Queen’s Teens of a normal range of behavior. For example:

   Mary, Jane, and Alice can be counted on to do whatever the group wants to do or what the leader suggests. They always vote as the others and never do anything on their own or in disagreement with the others. They seem too insecure to express their own wishes. Yet, when a decision was left up to the three of them and nobody else, one of them came forth with a suggestion that the others followed.

   * * *

   In contrast, Bob, Jim, Dick, and Lottie act completely independently, participating in the group activities only when they want to. They seem to regard the meeting as an opportunity for individual self-expression. Jim, for example, entered the room one evening saying, “Leave me alone tonight; I don’t want to play.” He then moved away from everyone and began walking around the room by himself. When he got tired of doing things by himself, he came back into the group and participated in activities with the others for the rest of the meeting.

Thus, some of these young retardates found in the group experience a chance not only to do things with the others but also to express their individuality by choosing when and where they would participate. As long as an individual’s expression of independence was not disturbing or limiting to the others in the group activity, it was respected and encouraged by the leaders.

2. **The individual’s needs take precedence over the group’s needs.**

The group worker found that often the actions of an individual were more important to deal with than to keep the group activity going—for example, when Larry threw a tantrum because he was not
allowed to dominate the group in playing a game; or when Bob kept running around screaming.

However, in such instances, after the group worker stopped the group's activity in order to deal with the individual he would involve the entire group in the discussion of the situation. In that way the problem of the individual was woven into the program of the group.

Often independent actions were expressive of creative urges or moods rather than the acting-out of hostility or anxiety. Thus, Bob rushed to the piano and banged away loudly while the group was singing *She'll be Coming 'Round the Mountain*, and at another time Jim listened quietly to a phonograph record while the group played tag.

At such times, the group worker adapted the group's activity to involve the independent individual in a positive and encouraging manner: With Bob—"Let's join him at the piano and sing while he plays," applauding his efforts when the song ended. And with Jim—"Jim, will you help us play musical chairs by turning the record on and off while we play?"

In both these instances the individual moved with the group into the next activity after such an approach.

When it was not possible to adapt the group's program to an individual's independent behavior, the individualist was asked to stop what he was doing but with the condition that later on he could come back to finish what he had started. In essence the group worker was saying that he thought the individual was as important as the group.

3. Program is planned to provide individuals with opportunities to experience success.

It was assumed that a successful experience in participating in the group's program would loosen the individual's inhibitions and give him the security to participate in the program more fully. Therefore, games were modified so as to give everyone a chance to win. Arts and crafts projects were always admired if the individual himself liked what he produced. The group worker made a practice of informing each parent—in front of the child—that their child had done quite well that night in the group.

In playing "choosing" games sufficient control was provided by the group leaders to assure each teenager a chance to be both chooser and chosen.

4. Expectations of the level of an individual's performance must vary in relation to the intellectual, social, and emotional aspects of behavior.

Among the Queen's Teens the group worker assumed an uncritical role in relation to a child's intellectual performance. However, when it came to cleaning up, putting on coats and hats, getting chairs, he was more demanding. The level of expectation of course differed for each child, according to the child's physical and motor coordination. When the child did not respond as expected, the issue was dropped and taken up at a later time when the child seemed more cooperative. For example:

Laura, who is almost blind, was given a record to place upon the phonograph. (Her mother had mentioned earlier that she had never done this at home.) Because of a spastic condition, Linda had very poor motor coordination, but she was able to get herself to the record player, place the disk on the turntable, and almost get the needle in the right groove. She exhibited great pride in this accomplishment.

**Alfred, an obese and overprotected child, was afraid of going out into the snow. He said he would catch cold or he would slip and break a leg. It was a difficult task to get him outdoors—one which involved seeing him through three tantrums—but after this was accomplished, he became more amenable to other trips away from the building.

5. Group activities must be carefully selected to suit the functioning level of the group.

For the Queen's Teens the group worker chose familiar games which the young people knew and liked. New games were also introduced but modified to suit the group and allow for successful play. Among them was a clapping rhythm game that is popular with adolescents generally. It took 3 months for the group to learn this game, but they did learn it and liked to play it so well that they made it part of the opening portion of each meeting. Regardless of the type of activity, the presentation was always geared to the level of the group members in order to minimize frustration and provide for satisfying participation.

**Group Worker, Individual, and Group**

While the retardate benefits from experience in a social group, he evidences a slower than normal development in social skills. It is up to the group worker to remain "enthusiastically patient" during the long, slow process of gradual improvement. While enthusiasm and warmth are important factors in work with any group, they are even more important in work with retardates. Parents and teachers of retardates, because of the demanding nature of their responsibilities, may at times have their enthusiasm worn thin. Yet, like everyone else, the retardate needs people around him who are stim-
In spite of the necessity to suit the activities to the group, it is not necessary to "talk down" to the retarded. The leader talks to them in the same manner as he would to other adolescents.

On the other hand, because the retardate is limited in social experience, it is necessary for the leader to have a highly structured program plan that remains similar from week to week. As the participant becomes more accustomed to the pattern, he begins to anticipate what will come next, deriving much satisfaction from this accomplishment.

Experience with the Queen's Teens, and other groups of mentally retarded formed by the Association, indicate that while individuals change within the group, there is some group movement toward higher levels of activity. Individuals, however, do learn to participate in activities with their peers, and in social adequacy appear to move closer to the social expectations of their chronological age.

The Queen's Teens is now in its third year of existence. In this third year we have noted some movement toward subordinating individual needs to that of the group; in the ability of the group to carry out a short "business" meeting; in the individual's ability to take on more responsibility for his own behavior and for planning together with the other members; and in the ability of the group leader to lessen the active nature of his role in the knowledge that the group could take more responsibility in regard to simple activities.

The Association, in extending its program to serve additional groups in different parts of New York City, has found that variables such as previous group experience, religion, culture, and socioeconomic and minority group status have an impact upon a group experience for the retarded adolescent, although there are still many unknowns in this regard. In some families of low socioeconomic status, retardation of a child may be only one of the many other serious problems affecting the family and is not therefore always perceived as a crisis situation, as it is apt to be in middle-class families. Many retarded adolescents in such families, who are in the higher functioning range of retardation, seem to have much in common with their normal contemporaries and to have acquired some social skills in the process of daily living. Barring gross stigmata, their intellectual deficit or perceptual difficulties are the most obvious signs of their retardation to the group worker.

In the group situation, these young people need a great deal of help in planning and following through on responsibility for program development, as did the Queen's Teens, and again structured program is helpful. However, relationships are formed more readily between the members who are of the same socioeconomic or cultural background in view of their having similar experiences in school and in the neighborhood. The members also relate more easily than those in such groups as the Queen's Teens to other young people who use the group service agency, as they generally share a similar background. These young retardates also seem to have greater interest in energetic activities, especially athletics, and less fear of risking injury. They have had more exposure to group experiences with their peers, both retarded and normal. This is probably due to less maternal overprotection.

As additional experiences are accumulated with such groups and analyzed, the findings may not only help to refine social group work method with the mentally retarded, but bring to light additional information about social development patterns and the use of leisure time and about what kind of interaction patterns occur between retarded and normal individuals as well as between retardates.
DURING the last 12 years much progress has been made in assessing the potential ability of the retarded child, and applying this toward the development of community programs to help him realize this potential. Sparked by the National Association for Retarded Children and given major impetus by programming and funds from the Children's Bureau, a mushrooming of multidisciplinary clinics devoted to diagnosing and planning for the retarded child has occurred throughout the country. These clinics examine the child from medical, social, psychological, and educational points of view, interpret to parents the nature and magnitude of the condition, and attempt to set up a comprehensive plan for future management of the child.

However, many children are taken long distances to clinics for the mentally retarded by their parents, and after confirmation of the diagnosis return to their homes where professional persons who have specialized in work with retarded children may not be available. Thus it remains to the family physician or pediatrician to counsel and advise the parents as their mentally retarded child grows older.

What can the family physician or pediatrician do when presented with a child obviously mentally retarded or one suspected of being so, if in his community such specialized services are not available? Does helping the parents and child require a vast body of information which he cannot hope to have at his command? Must he take extensive refresher courses in mental retardation to answer the inevitable and seemingly interminable parental questions about the child and his future?

When the retarded child is passing through the first few years of life, it is most difficult for any person to answer the questions of ultimate prognosis uppermost in parents' minds. Nevertheless, these early years are crucial for the child, since during this period of life his basic personality patterns begin to emerge. If in addition to a delay in development the retarded child must cope with a liberal dose of parental anxiety and feelings of helplessness, his entire adjustment can be channeled into areas of behavioral abnormality which will lead inevitably to early institutionalization.

The pediatrician or family physician who sees retarded children can and must play an important role during these early years. By virtue of his training and experience in normal child development, he can contribute to the normal personality development of the retarded child, especially if he already has an established relationship with the family and has gained their respect and confidence. Through his knowledge of the home atmosphere he can anticipate problems that may arise and can give the parents many practical suggestions for managing the child. Many parents who, because of their feelings of guilt and anxiety, would not be able to seek help from a child guidance clinic or social agency can lean on the strength of their family physician or pediatrician, and thus accomplish many changes in their behavior toward the child even though they do not gain any real insight into their own feelings. Direct suggestion, even when it conflicts with basic parental feelings, can often be accepted.

The birth of a child is a momentous occasion in the life of a family. Long before birth, parents idealize the child and make elaborate and often fanciful plans for his future. Many parents see their child as an extension of themselves and as an opportunity to live out their own fantasies and wishes. While many normal children do not live up to the often unrealistic expectations of their parents, who therefore must gradually relinquish their cherished plans, par-
ents who receive a diagnosis of Mongolism at their child's birth or mental retardation early in life have their dreams and fantasies brought to an abrupt end. Thus, when a diagnosis of mental retardation is made, it is the parent who suffers a blow rather than the child. Consequently parents who seek help for a retarded child are usually in a state of heightened emotions. They frequently expect and fear the worst, and are already calling forth the usual feelings of shame or guilt which people suffer if something goes wrong in connection with the birth process. One recent study of the initial subjective reactions of a group of parents whose children had been diagnosed as mentally retarded has shown that about half expressed feelings of rejection toward the child associated with shame or guilt, and a large proportion of the others worried about reactions to the child of their other children, relatives, and friends. Some parents are unable to overcome their frustration and disappointment at the child's inability to attain their ambitions for him; he remains a source of irritation to the family and may even precipitate its disruption.

**Diagnosis**

When the physician first suspects Mongolism in a newborn infant, he may want to seek confirmation of his diagnosis by consultation with a colleague. His next step must be to interpret the diagnosis to the parents during the neonatal period or shortly thereafter, preferably to both of them together. After the initial shock has subsided, the parents will inevitably deluge him with questions concerning the "why" and "how" of it, and having to do with the child's chances for health and adjustment in later life. In addition to talking these problems over with them in considerable detail, he may find that providing them with a copy of the booklet "The Mongoloid Baby," which answers the questions most frequently asked by parents on this subject, is a great help to them.

In the case of the nonstigmatized retarded infant, the diagnosis is usually one gradually suspected, frequently not until after the child is a year old. The physician then has the difficult task of deciding whether a developmental aberration is a physiological variant or is, in fact, true mental retardation. Perhaps the most pertinent finding in early diagnosis is the observation, as recently noted by Illingworth, that the child who is mentally retarded from birth or shortly after birth is behind in all fields of development except occasionally in the gross motor

**Telling the Parents**

When the physician tells the parents about a diagnosis of mental retardation, he frequently meets with denial, and then sometimes becomes the target for parental criticism and hostility. This is particularly true if he presents the diagnosis only, giving no suggestions as to how the child should be handled or what kind of plan should be made for him. In a recent study, Koch and his co-workers have commented on the frequent dissatisfaction of parents with the way pediatricians and general practitioners deal with the problem of the mentally retarded child and on the parental bitterness toward what they regard as the cursory nature of the examination and presentation of facts. In the case of the non-Mongoloid child, who seldom exhibits recognizable physical abnormalities, parents and physicians fre-
behind the phrase "he'll grow out of it." When the diagnosis is eventually made, the parents often express animosity toward the physician who did not listen to their fears.

Some physicians react to the diagnosis of retardation in a child with an abrupt recommendation for institutionalization. While this may be indicated in some situations, the recommendation is a far-reaching one and should be made only after such factors as attitudes of the parents toward the child, the social background of the family, the welfare of the child's siblings, the economic status of the family, and the availability of satisfactory institutions have been taken into account. Such a recommendation is often made without considering the possibility that the retarded infant may profit considerably from the mother-child relationship in the first years of life and that his presence in the family is not likely to interfere seriously with the normal emotional development of older or younger siblings. Studies such as those of Schippers and Saenger have emphasized the good adjustment of many retarded children and young adults living with their families.

Helping parents face up to the diagnosis cannot be done quickly. For example, at the District of Columbia Clinic for Retarded Children, which provides continuous followup services to retarded children and their parents as long as they are requested, the initial interpretation may take as long as an hour to an hour and a half. During this time the parents are encouraged to express their feelings of hurt and disappointment as well as to ask any and all questions concerning the child's future potential. And the clinic's services to parents do not end with the initial interpretation. Many parents receive brief or continuing social casework in order to work out their feelings; the child development specialist sets up home training regimens; parents are seen in groups so that they may explore their mutual feelings toward their children and how to deal with problems of behavior and development; brief psychotherapy is made available to selected children; and a variety of other services are given. Parents are encouraged to contact the clinic at any time the child exhibits a developmental crisis or at any time educational or training plans are indicated.

Thus, the actual evaluation is both a learning and a therapeutic experience for parents since they have a chance to air their views of the child's deficiencies and to compare his development with the development of normal children. Rarely after this is a parent unable to realize, at least intellectually, that his child is retarded.

However, we have found subjective parent reaction at the time of interpretation at the clinic to vary from complete acceptance of the clinic's findings and whole-hearted cooperation in planning for the future life of the child to one of complete rejection and subsequent "shopping" to other agencies. Some parents persist in their fantasies that the child will "grow out of it" and that the retardation is not as severe as the clinic has found. They frequently use the interpretation session to criticize one or more aspects of the evaluation and to ignore many of the findings.

Counseling and Time

Curiously, during this often very emotional session, parents seem to be directing their comments to the world at large rather than to any specific clinic member—their reason tells them what their feelings will not allow them to believe. Particularly is this true of fathers, who frequently cling to the hope of future normality. It is at this time that counseling, whether given by a trained social worker or by any other professional person with the ability to listen, sympathize, and respond wisely, is most valuable.

It is this author's impression, however, that even following a careful evaluation and continuing followup service by skilled personnel, the most important factor in the ability of parents to plan realistically for their child is time. Many parents, while initially rejecting the diagnosis, after a period of time in the home, where they can appraise the child and compare him to his normal siblings and playmates, are able to see and to say that their child is abnormal. An important element in the effects of time is the fact that the retarded child of preschool age passes through the same stages of development as do normal children, even though at a slower rate. For instance, when a parent has been able to observe his child's attainment of a particular self-help skill such as toileting, he is able to say to himself that the problem is not after all hopeless. Being more hopeful, he is at the same time more able to admit that his child is retarded.

Many parents who have initially rejected the diagnosis of mental retardation return to the clinic a year or so later proudly demonstrating the recently learned skills of their child. Some parents who are
unable or unwilling to talk of their disappointment or guilt at having produced a retarded child are able to focus on their accomplishments and plan ahead for his future life. It is most important, therefore, that the “pot be kept boiling” during the early developmental years when the child who ultimately will have great difficulty in school can be compared more favorably with his normal siblings.

**Anticipatory Guidance**

How different is the retarded child from normal children in the preschool years? In one sense he is no different. For, while his rate of neuromuscular development is delayed, the stages through which he passes are the same. As the normal child does, he will sit before he crawls, crawl before he stands, and stand before he walks. At the time of walking he is most likely to respond to attempts to toilet train him. Thus, the physician with even rudimentary knowledge of child development can give the parents “anticipatory guidance” by applying this knowledge to interpret the next step in the training of the child. He can supplement his interpretation by giving them easily obtainable and readable booklets on normal child development which deal with many of the needs of parents of a retarded child in the preschool years.

The frequent contacts with parents and child provided by ordinary well-child visits provide a natural setting for discussions of developmental problems. In these, the physician need only provide continuing sympathy, support, and encouragement to the family. While advice should be geared to the level of parental anxiety, it should always be presented in terms of normal stages of development. The parent can compare his child’s progression in these stages with those of normal children, especially if the child has older, normal siblings, and see that after all this is first and foremost a child—a handicapped child, to be sure, but a child nevertheless.

The services of public health nurses are invaluable in helping parents of retarded children, especially when they visit the home and provide practical advice and demonstrations of how to set up self-help routines—self-feeding, toileting, dressing. This not only helps the mother in managing the child but also indicates that someone is interested in her problem and is willing and able to help her meet it. Information contained in such booklets as “The Mentally Retarded Child at Home” also proves quite useful in this respect.

In talking with the parents it is not necessary to use scare words such as “brain damage” or highly scientific phrases which the parent may misinterpret or not understand. Parents should be encouraged to watch their retarded child grow and to enjoy him just as they would a normal child, treating him in terms of his mental age and allowing him to progress at his normal rate of speed. “Behavior problems” encountered in the preschool period are most often characteristic of the developmental stage for the child’s mental age or a reflection of abnormal pressures applied by parents who are treating him as a child of his chronological age. The younger a retarded child when diagnosed and the earlier the physician is able to help the parents set up simple regimens in the home, the greater is the likelihood of a child’s developing a healthy personality and being able at school age to adapt to and enjoy the school setting for which he is qualified.

The occasional hyperactive, distractible, retarded child whose retardation has an organic basis presents special problems in management by virtue of his speeded-up pace of living and requires a modified approach involving firmness and limit setting, techniques often alien to many parents. The paradoxical effects of such central nervous system stimulants as dextroamphetamine and methylphenidate are frequently very useful for quieting the hyperactive behavior of such a child.

During his contacts with the family the physician must continue to remember that the parents’ acceptance of a child’s mental retardation will be gradual. Whether or not it proceeds at the rate he thinks it should, the important thing to watch is whether the parents are following through with plans for training in self-help skills and are treating the child in a way that will foster a healthy personality development. Each parent must find his own way to this acceptance, and there are as many different ways as there are parents.

The physician should be prepared to keep his own plans for the child flexible. For example, he may feel that a young child’s place is with his mother in the home all day, failing to realize that the presence of a child who remains an infant for a long period of time may be a chronic source of physical and emotional strain on the mother. A substitute mother in a daytime foster family home or day-care center can allow the mother the breathing spell she needs. Should the physician at any time become aware of increasing parental tension or inability to deal with the child in the family, referral of the parents to an
appropriate community family service or child welfare agency for counseling or planning for institutional placement is indicated.

As the child grows and approaches the age at which children need group experience, the physician should try to help the parents find a nursery school in the community which will accept retarded children, to help prepare the child for entering a specialized class in the public school. Helping the school-age retarded child more and more becomes the responsibility of the educator and vocational rehabilitation worker as the child grows older, the physician's role becoming one of normal health supervision. With optimal care and training many retarded children as adults become productive members of society, and when they do the physician can look back with pride at his role in fostering their normal personality development in the preschool years.


6 ———: The development of the infant and young child, normal and abnormal. E. S. Livingstone, Ltd., Edinburgh, Scotland. 1960.


THE PUBLIC HEALTH NURSE IN A PROGRAM FOR THE MENTALLY RETARDED

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THREE YEARS AGO a demonstration project was carried out in Long Beach, Calif., which has had far-reaching effects on the nursing services provided to families and children by the Long Beach City Department of Public Health. This was the provision of services for one year by the Traveling Diagnostic Clinic of the Children's Hospital of Los Angeles.

Operated by the hospital's child development clinic staff, the Traveling Diagnostic Clinic, a clinic for the mentally retarded, is a project supported with Federal funds from the Children's Bureau and sponsored by the California Department of Public Health, Bureau of Maternal and Child Health. Its purposes are to demonstrate the multidisciplinary approach to the problems of mental retardation, to interest and educate professional personnel in the field of mental retardation, and to stimulate communities to develop resources and facilities for the care of the retarded. The clinic team consists of pediatrician, public health nurse, social worker, and psychologist.

The Long Beach City Department of Public Health serves a population of 357,000. The nursing division has a staff of 17 public health nurses, 3 nurses assigned to clinics, 1 licensed vocational nurse, 2 nursing supervisors, and a director. The major emphasis in the nursing service is on maternal and child health programs with approximately 70 percent of nursing time spent in these programs.

The department has long provided public health nursing service to families of mentally retarded children upon request of families, physicians, and social and health agencies. However, as time went on, it became evident that a more coordinated community approach was necessary if families were to receive the guidance and support they needed to help the children achieve their maximum potential. If hospitalization of the child was recommended, years of waiting for admission often ensued because of the overcrowded conditions in the State hospitals. Therefore, it seemed necessary to place greater emphasis on helping the family to maintain the retarded child in his home whenever feasible. As a spur to developing this kind of service, the health officer, after consultation with representatives of the State Department of Public Health and of local community groups, made the request for the Traveling Diagnostic Clinic.

Included in the groups consulted and kept informed of the plans were the Long Beach Children's Clinic, a nonprofit voluntary agency; the Family Counseling Service, also a voluntary agency; the
Exceptional Children's Foundation, an organization of parents of retarded children which maintains a school for the retarded; the public schools; a speech center; and the local pediatric society.

The Long Beach Children's Clinic provided space for the clinic and the first clinic session was held in May 1961.

Prior to the first session, a series of six orientation meetings, conducted by the staff of the clinic team, were held with the professional people of the community, including the health department staff. These meetings focused on the problems of mental retardation and their medical, social, psychological, and nursing aspects.

There was also preclinic planning within the nursing division of the health department. The nursing consultant from the traveling clinic team, the department's nursing director, and the nursing supervisors met to discuss the public health nursing aspects of the program and to arrange the necessary administrative details.

The Nurses' Functions

One nursing supervisor was assigned overall responsibility for the nursing division's participation in the clinic program. She attended all clinic staffings. This nurse assumed the team nurse's role after the demonstration project was completed and a community clinic established. Each nursing supervisor supervised her regularly assigned group of field nurses in regard to this program as well as the department's other programs.

Each public health field nurse was immediately involved in the evaluation of the clinic's patients from her district by contributing an assessment of each patient based on observations made in home visits. This assessment consisted of two parts:

1. The nurse compared the child's performance level with the performance level expected of normal children of his chronological age in order to gain an impression of his use of the intellect.

2. The nurse observed the problems of care and management the child was presenting to the family, forming an opinion of how well or how poorly the family was handling the child.

The second portion of the evaluation interrelated with the first, for the nurse often would be able to point out how parental management methods influenced the child's performance in either a positive or adverse way.

An important part of the nurse's first visit to the patient's home was her interpretation of the clinic service to the family. She also prepared the family for their visit to the clinic, explaining the various professional disciplines which would be represented there and the reasons why the parents would be expected to present the child before the group.

In order to demonstrate the public health nurse's role as a team member, the nursing consultant of the traveling clinic's team conducted each nurse's first evaluation visits with the public health field nurse acting as observer. After the visit, the team nurse and the field nurse discussed the content of the visit and then the team nurse prepared the written report, which she presented at the clinic with the field nurse observing. Thereafter, the field nurses conducted the visits to new patients on their own and presented their own reports at the clinic. The nursing supervisor assisted the field nurses in the preparation of their reports and was available to them for consultation. After the clinic evaluation of a child, the nurse who had made the initial evaluation continued to visit the family, basing her service to the family on the clinic's recommendations.

Over and over the field nurses were impressed by the way parental management influenced the child's performance.

For example:

The team nurse and a field nurse visited Peter, aged 4, who had very little speech. During the visit, Peter displayed hyperactive and wildly undisciplined behavior. According to the mother's presentation of his development and level of self-care, the child seemed to perform at no higher than the 18-month level. He was not toilet trained, still took a bottle, and could barely feed himself dry foods with his fingers. Yet, during the course of the visit, the nurses watched the child take three parts of a vacuum cleaner, assemble them, plug in the cord, and turn on the switch—all evidence that the child had more intelligence than would be thought from his general performance. Investigation of the parents' methods of management revealed these to be so inappropriate and inconsistent that even a normal child under the same circumstances would have difficulty learning and adjusting.

In this case, the nurses who visited the home were able to list for the clinic many mismanagement factors relating to Peter's poor performance. Their findings were blended with those of the other team members to form a diagnosis of mental retardation less severe than first assumed, with an emotional overlay.

Staffing Sessions

Children under 6 years of age were admitted to the clinic's service on referral from a professional source. There was no financial screening during the
demonstration period. The referrals were made to the health department's director of maternal and child health, who arranged for each child to have a nursing evaluation. Prior to the clinic's staffing session, the child was also seen at the clinic's Long Beach headquarters by the team's psychologist, and the parents by the team's social worker. Reports of these interviews, along with the nursing assessment, were made available to the clinic for the staffing conference.

The staffing sessions took place once a month and lasted for a full day. Four patients were scheduled for each session. The sessions were attended by a large number of people, including the family physician, representatives of the health department, the Long Beach Children's Clinic, the schools, the nearby State hospital for the retarded, and various social agencies and other professional persons acquainted with the families of the children to be presented. As many as 20 persons might participate in planning for one child.

The following case of a 4-year-old child referred for evaluation to the clinic by his pediatrician illustrates the usual clinical conference routine:

Before the parents and child came in, the clinic's pediatrician opened the discussion by presenting the medical history, including the birth record and all prior medical and laboratory reports. Then the public health nurse, the social worker, and the psychologist reported on their observations.

The public health nurse said that the family lived in a substantial house, particularly suitable for caring for a retarded child because of an intercommunication system in the bedrooms and a fenced-in play yard. She assessed the child's general performance as at the 3-year level. She said she thought the family gave good care, but that the mother was so anxious that she was permitting the child to manipulate her. For example, the mother was feeding the child although he had the ability to feed himself. Noting other problems of discipline, the nurse expressed the view that the mother needed further help with management and the child group experience.

The social worker reported on the personality structure of the parents and the strengths and weaknesses of family functioning. She told of old unresolved problems which had been aroused at the time of the child's birth and were contributing to parental anxiety. Some initial counseling had been done. The psychologist, reporting on his findings, stressed the moderate degree of the child's retardation.

The parents and child then were asked to enter the room. The psychologist had the child demonstrate his ability to perform various developmental tests. The parents were further questioned about the child's history and drawn out about their view of his problem. As the doctor examined the child, he pointed out his findings for the benefit of the parents and the group. The family then withdrew.

In the discussion which followed the pediatrician reviewed all the findings and indicated the prognosis from the medical point of view. The etiology of the problem was still unknown, but the degree of retardation present was moderate enough to allow for envisioning future placement of the child in a special class, perhaps eventually in a job. It was decided to recommend training class experience for the child, counseling for the parents from the local Family Service Agency, and continued public health nursing service. Representatives from the Family Service Agency and from the training class were present and helped make the recommendations. The family's physician agreed to continue to provide the child's health supervision.

The parents returned to the room. The team's pediatrician gave a review of the medical problem and the present medical findings. The psychologist told of his findings and recommended the kind of training experience the child should have. The representative from the training class described for the parents the kind of program that could be offered the child. The social worker suggested further counseling to the parents and the representative from the Family Service Agency briefly described the service that the agency could offer. The nurse commented on what the child ought to be able to do for himself as indicated by his mental age and suggested a few ways in which self-feeding might be encouraged. Further questions by the parents were answered, and the group members commented positively on the parents' efforts on behalf of their child.

After the family left, the pediatrician led the group in further discussion of the case and its implications.

Forty-four children were seen during the demonstration period. Of these, 27, or 62 percent, were referred for public health nursing followup. Problems most commonly identified as needing nursing assistance were: feeding, training, discipline, and seizure control. Nursing also was recommended to offer emotional support and to help families utilize other community resources. Carrying out these recommendations involved home visits and conferences with other agency workers.

During the second half of the year of the demonstration (1961-62), a number of nursing staff meetings were held to discuss the progress of the patients served in the light of the findings and recommendations made at the clinic. The meetings were attended by the director of maternal and child health and the health department's social work consultant as well as by the department's nursing staff. The discussion revolved around the management problems of young retarded children. These meetings gave the nurses a chance to express their feelings and gain support from the other staff nurses in regard to cases in which progress of child and family was slow.

The demonstration convinced the Long Beach community that a multidisciplinary approach is necessary for helping families with retarded children. At the end of the demonstration period the visiting team withdrew and a community clinic for retarded children was established under the Long
Beach Children's Clinic. It continues to offer the same kind of service offered by the Traveling Diagnostic Clinic through the participation of pediatricians, social workers, and psychologist from the participating community. The health department provides the same nursing service as it did during the demonstration period, with the field nurses serving as team members. The patients are referred by a professional source, and a fee for the service has been established on a sliding scale.

**Problems and Values**

The introduction of any new program into a nursing service always poses administrative problems. This program has been no exception. There has been an increase in our nursing caseload of retarded children. We have found that more nursing time is needed for this service than for other maternal and child health programs as home visits are longer and recording is more detailed. More contact with other community agencies is necessary because the family problems are more severe. Most of the families referred for nursing followup need intensive and prolonged service, and the inability to provide the quantity of followup visits needed because of other work pressures has been frustrating to the nurses.

One of the biggest problems was finding enough clerical time to handle the correspondence and records, especially the time involved in obtaining medical histories and reports from previous medical sources. This was solved by obtaining part-time clerical help with funds allocated by the State from the Federal maternal and child health grant. Additional public health nursing staff was also obtained through this grant.

We also found that the nurses suffered an emotional impact in working with these families that they had to work through. This was similar to the emotional impact they experienced when we started visiting families of mentally ill patients. A considerable amount of supervisory time was devoted to listening and providing support to nurses as they vented their feelings about specific family situations. As one supervisor noted, "The nurses come back from clinic either in the clouds or in the depths, but in either case they have to talk about it."

Some of the nurses found it difficult to be a team member of the clinic—to make a nursing assessment of the child's development and performance and be prepared to defend it at the clinic staffing. This was partly due to their own anxieties about their knowledge of mental retardation and their inability to see themselves as contributing valuable information in the assessment of the child.

While the field nurses already knew much about normal growth and development and a great deal about sound child-rearing practices before the demonstration, they had considerable shyness in offering an assessment of the material they observed. They tended to equate assessment of the developmental level or performance level with diagnosis. Some of the nurses would have preferred to bring in the facts and let the pediatrician or psychologist draw the conclusions. When asked to place a value judgment on the child-care practices of the families seen in clinic and relate this to the patient's performance level, the nurses were even more hesitant. However, as the nurses observed in clinic, then later participated in staffings, their confidence grew as they saw their contributions welcomed by the other team members and put to use in the recommendations made.

In spite of all these problems, the benefits brought to our nursing service by this work with the mental retardation clinic have far exceeded the negative aspects. The greatest benefit has been that our total maternal and child health program has been enhanced by the nurses' increased knowledge and understanding of growth and development. The nurses' interest in parent-child relationships and their relationship to development has been stimulated considerably. As a result, there is earlier casefinding of deviant behavior. There is evidence in the nurses' child health records of more attention being given to problems of discipline and management, and more realistic counseling of parents in relation to the child's developmental level.

There is still much to be learned about nursing service to families of the retarded—the kind of nursing care that is needed, the techniques of home training and counseling which are most effective, and the preparation and staffing necessary to provide it. There is a wealth of data available from nursing records but research personnel and funds are needed to make the necessary studies.

However, as a result of our experience, we are convinced that more emphasis on normal growth and development in basic nursing education is needed. We also believe that nurses generally need more preparation for helping families in crisis, not only in relation to mental retardation but in other nursing care problems—alcoholism, mental illness, suicidal tendencies. And we have learned that they need supervision in facing the emotional impact of these situations—to help them react with empathy rather
than identification. Nurses especially need help in accepting the retardate's slow progress.

We believe that the nurse must have freedom to participate as a team member, not only in programs for the mentally retarded but also in other programs where the problems are equally as severe. In order to do this, she must be able to conceptualize and convey to other disciplines the nature of the nursing contribution.

Through this demonstration we have learned that field public health nurses have the potential to make good team members. With assistance they can learn to participate effectively in team evaluation. The nursing contribution can be defined and separated from the contribution of the other disciplines and plays an important part in the evaluation process.

1 Children's Hospital of Los Angeles, Child Development Clinic: Child development project annual report, 1961-62. Los Angeles, Calif.
MATERNAL AND CHILD HEALTH
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One fact was clear in 1964. The keystone to further progress in maternal and child health programs lay in the broader distribution of services to groups of mothers and children who are barely or inadequately reached.

The 1963 Maternal and Child Health and Mental Retardation Amendments would make it possible to make real progress in the expansion of these important services and thereby contribute to the reduction of infant and maternal mortality and morbidity.

These grants put the States in a better position to meet the increased demands for these services as the child population continues to increase. More mentally retarded children can be found early and served through special diagnostic clinics for these children under State maternal and child health programs. In 1962, over 25,000 children, as compared with 12,000 in 1960, received services through the 76 clinics supported with Children’s Bureau funds and 36,000 children were served in all clinical programs of this type. Despite this increase, applications for these services far exceed the resources of the clinics; the 1963 amendments represented a major advancement in the availability of such services for mentally retarded children.

Mental retardation occurs more often in those population groups where maternity care is inadequate. The rate of premature births is also higher among these groups, and premature infants are more likely to be physically handicapped, mentally retarded, and brain damaged than are full-term infants. Women who receive little or no prenatal care, and who have complications of pregnancy, come predominately from families with low incomes. The tragic fact is that increasing numbers of these women, especially in our larger cities, are receiving inadequate maternity care.

The 1963 amendments authorized a 5-year program of grants to States, to be administered by the Children’s Bureau, to provide essential maternity care for those who are unlikely to receive this care since they come from families with low incomes or for other reasons. This health care is provided mothers during pregnancy and following childbirth and for their infants and is available particularly for prospective mothers who have conditions associated with childbearing that increase the hazards to their health or to their babies, including those which may cause physical or mental defects.

The history of the development of the maternal and child health programs from their beginning in the early 1920’s is told in Five Decades of Action for Children: A History of the Children’s Bureau.

The articles in CHILDREN during the decade 1954–1964 show, in addition to the many articles on mental retardation, a heavy emphasis on maternity care, school health, and helping parents with child rearing problems.

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a distinguished obstetrician asks how more mothers can get better care in child-bearing, and offers, for discussion, one proposal

MATERNITY CARE LOOKS TO THE FUTURE

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THE RECORD OF MATERNITY CARE during the past few decades has been one to evoke gratification and pride. But in this rapidly changing world, maternity care must anticipate the future if it is to continue to serve the best interests of womanhood.

The greatest problem which maternity care will face in the next decade is personnel. Even today there is cogent evidence pointing to a shortage of physicians. In the last 30 years the output of physicians has merely kept pace with the growth in population. Meanwhile, the demands for medical services have soared. The expansion of public health programs, of industrial medicine, of mental hospitals and of research, plus the pressure of military requirements, have reduced the number of actual practicing doctors, in relation to population, to a figure lower than it was either in 1940 or 1949. Even a cursory survey of our 7,000 hospitals will show that only a small minority can secure an adequate house staff; many have none whatsoever. According to a recent report of the Council on Medical Education and Hospitals of the American Medical Association, there are about 3,000 more approved internships in the United States today than there are interns. In a certain large municipal hospital, a fourth of the babies are born without benefit of medical attendance, simply because three lone interns cannot handle 4,000 deliveries a year.

The forecast for the future is still more worrisome. On the basis of an expected population of some 171,000,000 in 1960, the Commission on the Health Needs of the Nation predicted that 30,000 more physicians than the anticipated supply in 1960 will be required to give reasonably comprehensive care to the entire civilian population and to meet the pressing needs of the public health services, industrial medicine, mental and tuberculosis hospitals, faculties of medical and public health schools, and the armed forces.

In view of the dearth of physicians predicted for 1960, those interested in maternity care will note with concern that in the late 1960's a sharp rise in birth rate is probable. In the mid-forties any overworked obstetrician could have warned his Commissioner of Public Schools to expect a huge increase in first grade pupils around 1953; and exactly this has happened. By the late 1960's these same first graders will be reaching marriageable age and it can be forecast with reasonable certainty that the marriage bureaus of that decade will be just as overcrowded as are the school houses of today. This means of course more babies and more maternity work. Some idea of the extent of this increase may be visualized from the following figures: the number of young persons who will attain the age of 20 in the late 1960's will exceed by more than one-third those who are reaching that age during the present decade; the number of young persons who will reach their sixteenth birthday during the single year of 1963, it so happens, will exceed by more than two-thirds those who attained that age during the year of 1953.

But these are not the only factors to be considered in evaluating the future adequacy of maternity personnel. Of the number of doctors who will be avail-
able, what percentage will elect to practice obstetrics? Will the proportion be more or less than today, or perhaps about the same? Although this question cannot be answered with certainty, the evidence suggests that the percentage will not be more and may be less. Those of us who have given our lives to obstetrics and who list it high on the roster of essential medical services will admit with reluctance that it is not a popular specialty. But this is the truth. Many general practitioners will tell you that they continue obstetrical work solely because it engenders good family relationships and so contributes to the development of their practice in other fields. A surprising number of obstetric and gynecologic specialists, when they get to be about fifty, decide to "graduate" (so they say) into straight gynecology because of the long, irregular and unpredictable hours which obstetrics imposes. As the ranks in other specialties start to thin, can obstetrics still attract its present quota of practitioners? It is conceivable that this question may be answered in the negative.

Although the outlook for adequate obstetric personnel over the next decade is therefore discouraging, there is no reason for outright pessimism provided immediate steps are taken to meet the threat. Even if these dire forebodings do come to pass, it will not be the first time that obstetrics has faced a shortage of physicians. In World War II, as their younger colleagues went into uniform, a large number of obstetricians confronted the onus of delivering 700 and more babies a year. This means, on the average, two deliveries a day in addition to miscarriages. It means, on the average, one patient in labor all the time, day and night, 365 days of the year. When account is taken also of the irregular spacing of these deliveries plus the huge amount of prenatal and postnatal care entailed, the magnitude of the assignment would appear more than any one person could possibly manage. Nevertheless, it was managed and, by and large, managed safely.

How was it done? To the credit of these obstetricians let it not be forgotten that the most important factor was ceaseless work on their part to the point of physical collapse. But, another factor also proved indispensable and helped greatly to save the day: to wit, the assistance rendered by nurses trained to a certain extent in clinical obstetrics. After a suitable period of instruction these nurses were prepared to perform, if need be, the following functions: in prenatal care, history taking, blood pressure determinations, venipunctures, abdominal palpation, fetal heart observations and attention to the more common complaints such as nausea, heartburn, constipation and excessive weight gain; in labor, they were trained to carry out, in addition to the procedures just mentioned, rectal examinations, emotional support of the patient and, indeed, pretty much the entire conduct of labor except actual delivery. The latter they undertook only as an emergency. If, at any time, the slightest abnormality developed, the obstetrician was notified. Actual analysis of the case records of obstetricians who followed this pattern of maternity care, reveals that at the first visit, the patient was always examined and interviewed by the physician; on subsequent visits she was examined by the obstetrician once in every three visits perhaps but brief interviews might be more frequent. The number of examinations carried out by the physician...
in the course of labor and the time he spent at the bedside varied with the exigencies of the moment.

This, then, is a program of maternity management in which the obstetrician relies heavily for the minutiae of care on specially trained maternity nurses. They act, as it were, as "obstetric assistants" and constitute an important part of a maternity team. It is an arrangement which has saved untold hours for obstetricians and which, in actual practice, has worked, and worked safely.

Questions will of course be raised about the dependability of these nurses' observations, both in prenatal care and in labor; but anyone with much experience in obstetrics will probably agree that the errors and oversights of such a nurse would be fewer in the long run than those of a hurried, harassed and exhausted obstetrician. In all likelihood they would be just as reliable as those of an intern, probably more so; but there will be no question of competition here with interns because, if the prognostications set forth in the first paragraphs of this article are correct, a huge number of hospitals will have no house staff.

If the utilization of skilled maternity nurses with advanced clinical training has proved helpful when obstetricians in private practice have been faced with a shortage of medical personnel, the same general principle would seem applicable to other areas of maternity care, for instance, to vast sections of the South where about one-half of the nonwhite births occur in the absence of either a physician or a nurse. But, at this juncture, let us be absolutely certain that this "general principle" is clearly understood. It entails the use of highly trained maternity nurses who work under the direction and control of an obstetrician. Any thought of resurrecting the independently operating midwife is out of the question. That is why the terms "Advanced Maternity Nurse" or "Obstetric Assistant," long and clumsy as they are, may be preferable to "Nurse-midwife." But, no matter what appellation is decided upon, the prerequisites to success of any such plan are (1) that a physician examine and screen all patients at the onset of prenatal care, and, through the nurse, assume indirect responsibility for such normal gravidae as are turned over to her; and (2) that the obstetrician, by a pre-arranged and well organized plan, be available for consultation throughout pregnancy, labor, and the puerperium. As for the workability of this plan in underdeveloped rural areas, a very similar program proved highly successful on the Eastern Shore of Maryland during World War II and, as everyone knows, this general arrangement constitutes the pattern of the Frontier Nursing Service whose record in certain isolated areas of Kentucky is enviable.

In both the Maryland and Kentucky programs, home delivery was the rule except in complicated cases. The concept of maternity care which is here envisaged for underdeveloped areas postulates hospital delivery by these specially trained nurses. That, at least, should be the goal because home delivery, quite apart from other drawbacks, is the most extravagant form of maternity care in its expenditure of personnel. Thus, a team of physicians and several maternity nurses can give continuous care during labor and delivery to many women in a hospital during the time demanded by a single labor at home. Moreover, from the viewpoint of the safety of mother and child, it is preferable that a patient be delivered in the hospital even though she has to be sent home within 12 hours. This idea of maternity nurses delivering babies in the hospital is a new one in the United States but is part and parcel of this program recommended to meet the shortage of physicians. The development of such programs should be a joint enterprise between the local health department, on the one hand, and the local medical society or university department of obstetrics and gynecology if available, on the other.

But attention to our own mothers is not the only responsibility of the United States in maternity care. As the bonds between free nations become closer, agencies throughout the world, especially in Asia, are beseeching us for advice and personnel to promote their own maternity programs. Since about three-fourths of the world's births occur in Asia, the magnitude of the challenge is staggering. Here again the chief need is personnel. At a meeting of the Expert Committee on Maternity Care of the World Health Organization, held at Geneva in November 1951, the global aspects of maternity care were discussed in detail and it was agreed that the overwhelming need was facilities for the training of native midwives. A pattern for maternity care, under the conditions existing in Asia, has been developed in China by Dr. Marion Yang on the basis of some forty midwifery schools scattered throughout the country. That experience has served to stress the essentiality of the midwife in all public health programs for underdeveloped areas. To a greater extent than any other public servant she enjoys the affection and confidence of the populace, has an entree to their homes and,
if properly taught, is our most efficacious agent in enlightening the masses in regard to the rudiments of general hygiene as well as maternity and child care. The World Health Organization is seeking American nurses with advanced maternity and public health experience to help organize schools for the training of native midwives throughout the world. It is American nurses who are sought for the purpose, not midwives in the ordinary sense of that word, because it is believed that a broad background in nursing, in public health, and in social outlook is essential. But to equip these young women for such service it is mandatory that they receive advanced training in maternity care. They must know practical obstetrics.

Although the potential openings for American nurses with advanced maternity training are thus legion, two questions at once pose themselves: Where can nurses who wish to embark on such careers obtain training in clinical obstetrics as part of a program in maternity nursing? Can the necessary number of nurses be recruited?

Opportunities for such training in obstetrics, as part of a program in advanced maternity nursing, are practically nil in the United States. To develop them will require fortitude, because the whole scheme is contrary to orthodox thinking in this country. It will demand patience, because this is a pioneering effort in which misunderstandings are likely to develop and in which trial and error, at the start at least, must be the policy. It will necessitate furthermore, on the part of most obstetricians and some nurses, a complete revision of their attitude toward the functions of the nurse in obstetrics. But, in the light of the personnel shortage facing maternity care, and our changing concepts of the kind and quality of care required, who can name a feasible alternative?

What sort of training program is contemplated? It goes without saying that all candidates must be graduate nurses, matriculated in advanced programs of maternity nursing. The duration of the course in obstetrics which is included in this comprehensive maternity nursing program should not be less than 6 months. It should be under the direction and control of the obstetric staff of the hospital and with the cooperation of the nursing group. The number of students should be limited to such an extent that each student conducts not less than 30 deliveries during the course. The program of training would resemble an internship in obstetrics with certain exceptions: (a) The clinical work would be complemented, especially during the first months, by intensive coverage of the whole field of practical obstetrics, especial emphasis being laid on prenatal care, the conduct of normal labor, and signs of the abnormal; (b) a number of procedures, such as forceps delivery and general anesthesia, would not be assigned to the students. In order to make the training as useful as possible, however, she should be instructed how to repair spontaneous lacerations, to perform episiotomy and repair, to administer pudendal block anesthesia and should be allowed, under “scrubbed supervision” to deliver a few multiparous breeches. Yes, much of this is contrary to established custom.

Since March 1953 an experiment has been under way at the Johns Hopkins Hospital the purpose of which is: (a) to study the feasibility of training nurse midwives in a university obstetric clinic; (b) to evaluate the specific contributions which well trained nurse midwives can make to maternity care; and (c) to ascertain the role which nurses so trained can most advantageously play on the obstetric team.

The project is being carried out in cooperation with the Division of Nursing Education, Teachers College, Columbia University. The trainees have appointments as “obstetric assistants.” This designation was chosen because it more nearly connotes than any other the main function which we would envisage for such nurses; namely, the rendering of skilled assistance to obstetricians. In vast rural areas of this country and in understaffed hospitals, this skilled assistance may also include the conduct of normal deliveries but never without the supervision and control in absentia, of a readily available obstetrician.

In the first 6 months 2 nurses were selected who had completed the course in Advanced Maternity Nursing at Teachers College, Columbia University and the course in Nurse-Midwifery at Maternity Center Association, New York City. These nurses gave complete antepartal, intrapartal, and postpartal care to 85 mothers, under the supervision of the obstetric staff. Our experience during this time was so gratifying in every respect that a 6 months’ course was begun on October 13, 1953, for nurses who had completed the course in Advanced Maternity Nursing but who had not had previous midwifery training. The students receive instruction and guidance from the 2 obstetric assistants who continue to work under the supervision and control of the obstetric staff.

Although we still consider that this program is in the experimental stage and avow that we have

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much yet to learn, we are convinced, on the basis of close observation, that nurses with this type of advanced training have unique and urgently needed contributions to make to maternity care. Quite apart from the expected shortage of physicians, mothers everywhere stand to benefit from the meticulous, sympathetic, and highly personalized attention which such nurses are able to render throughout pregnancy, labor, and the puerperium. By training, temperament, and outlook, they are singularly fitted for this important mission. This is their transcendent raison d'être.

The problem of recruiting a sufficient body of qualified nurses to make this project worthwhile, may or may not prove difficult; and limiting the group to eligible candidates from the advanced maternity nursing programs will involve less rapid expansion, but their competence will be recognized and the quality of care safeguarded. Despite this country's 365,000 active nurses, there is a critical shortage; and it is estimated by the President's Commission on the Health Needs of the Nation that the shortage for the country as a whole in 1960 may exceed 50,000. On the other hand, this figure means that the ratio of nurses to population in 1960 will be a little higher than we have at present. Moreover, the program envisioned for these maternity nurses offers such unique responsibilities and such rich opportunities in various spheres that it promises to attract a full quota of well prepared candidates. As in other clinical fields such as psychiatry, the profession of nursing will maintain its position by qualifying its members for increasing responsibilities.

Many other problems facing maternity care now and in the future will doubtless come to mind, but most of these center, in the last analysis, on this same crucial issue of personnel. For example, more hospital beds are urgently needed since ideal maternity care demands a 10-day hospital stay. To attain this objective in many localities, new hospital construction will be necessary; but in countless other areas, where the shortage of maternity beds may be equally dire, large maternity units are closed down because of insufficient professional personnel. There are plenty of beds, but no doctors or nurses. In this connection it is important to recall that the maternity nurses of the type we have in mind can function, if need be, as competent members of the clinical obstetric team as well as administrators, supervisors, or teachers, of maternity nursing care.

The most prevalent criticism which European obstetricians and midwives level at American maternity care is our assembly-line method of managing patients, especially the fact that they are often left alone throughout most of labor. This lapse is even cited as evidence in favor of home delivery. It is pointed out that parturients at home are never left alone and that they are amid familiar faces and surroundings with the result that apprehension is minimized; and as apprehension is minimized, labor becomes more physiologic with a lower incidence of uterine inertia. There can be no question about the general validity of this criticism. The lesson to be drawn from it, however, is not that we should elect to go back to home deliveries but that the psychological advantages of home delivery should be brought to the hospital. This emphasizes again the need for the type of maternity nurse which we have visualized.

Given competent personnel in sufficient quality and quantity other problems dwindle in significance because such personnel can be counted on to resolve whatever other difficulties arise. The vast strides made in maternity care during the past few decades are attributable to many factors, but the transcendent factor has been a network of thoroughly trained obstetricians and nurses. This army of workers did not develop by chance but was the purposeful and far-sighted creation of various agencies intent on meeting the recent needs of maternity care. Let us hope that the crucial problem of future personnel will be handled with equal wisdom and success.
Helping Mothers Handle Emotional Problems

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For many years one of the major tools of the maternal and child health program has been the child health conference or clinic. Increasingly these clinics are places where parents may receive help with the early social and emotional difficulties of their children as well as with their physical health.

The Bureau of Maternal and Child Health of the District of Columbia Department of Public Health put this concept into action very early in its work with mothers and children. The medical staff of that Bureau recognized that social difficulties within the family often threatened the care given the child or created emotional tensions and problems within the child which interfered with the normal process of growth.

For this reason, the Bureau, shortly after its establishment in 1936, added medical social workers to its staff to help with these problems. From almost the start of the program, casework services from a medical social worker have been available to these clinics, first intermittently, later on a regular basis.

During the years, the Bureau and its staff have greatly increased their understanding of the effect that social and emotional difficulties within the family have on the growing child. This article shows the types of emotional and social difficulties encountered in the clinics and how the medical social worker helps the mother with these difficulties—help which in turn benefits the child.

The emphasis of the medical social worker in the child health clinics of the District of Columbia is primarily on helping with those social and emotional problems that interfere with the normal, healthy development of the child. Her activities may include direct social casework services to parents and children and consultation with other staff members and other community agencies. She merges her services with those of other professions in maintaining the physical and emotional health of the child.

The District has 15 neighborhood child health clinics offering health supervision to preschool children. The Bureau of Maternal and Child Health has a small staff of medical social workers headed by a director of medical social service; one medical social worker is assigned to these centers. This means, of course, that coverage is limited, but referrals for social casework services are made to this worker from all the centers.

A large majority of the families using the child health clinics are in the lower socio-economic group and have all the problems usually present in this group, such as substandard housing, and inadequate and frequently irregular incomes. Many are individuals with a long history of deprivation. Often these mothers come from broken homes and have never had an opportunity to develop a warm enduring relationship with another person or to develop their innate potentialities.

In these centers, the physician's health appraisal includes a developmental evaluation of motor, adaptive, and social behavior, language development, and personal habits. The physician evaluates whether or not behavior and development are within normal limits for the child's age and discusses this with the mother when this seems desirable. The public health nurse also sees all the mothers and discusses these things with them. Through this educational process many mothers become well informed about what can be expected of a child at various age levels. But as valuable as instruction is, it does not meet the
problems of mothers who are upset about personal difficulties or have problems in their families that make it impossible to absorb the information available to them or even to use the knowledge they have.

There are many ways in which medical social workers help these mothers. They help the mothers with their use of the services in the clinic, with difficulties in family relationships which are affecting the development of the child, and with the early recognition of tensions in relationships. They also identify deepseated difficulties and assist mothers in accepting help if such help is available on a sustained basis. Through such help to the troubled mother, stresses and strains are eased, solutions to some problems are achieved, and, in the long run, the child's situation is improved.

In some instances the mother's and child's needs are such that service from another community resource is essential, if they are to have help. In the District the usual social agencies present in large cities are found. As in most social agencies in the country offering skilled services there are long waiting lists, not enough funds to cover all needs, and not enough trained workers. As a result, the best than can be attained is some improvement in the situation.

What are the problems mothers bring to these centers—problems to whose solution medical social workers offer help?

Sometimes an insecure, upset mother may respond to advice regarding the care of her child as if she were being criticized for what she is doing or failing to do. For example:

One young unmarried mother was referred to the medical social worker because her child was malnourished and was not gaining weight despite the efforts of the center to help her with this. The medical record showed that the mother was usually very upset in the clinic and frequently cried. She had said that she could not afford to buy the foods recommended for the child by the center. She was on the verge of tears when she came for an interview with the medical social worker. Although she had been referred for assistance with financial problems, she said she did not need such money and remained totally uncommunicative about what was really troubling her.

Finally the worker commented that something must be wrong since she seemed so upset. The mother started crying and between her sobs revealed that she did not want "to be bothered all the time." "What is it here in the clinic that bothers you?" the worker asked. Eyes cast down, the mother said slowly, almost in a whisper, "They keep telling me that the baby isn't doing well; I know he isn't doing well, I know that, but I don't want to be told this all the time. I'm doing everything they tell me."

The worker asked if the recommendations had sounded like criticisms to her. "My friends keep asking me why I come since the people here keep saying things to me all the time," she replied.

"It isn't that I haven't had the money to do it—and I've followed the doctor's suggestions in feeding him. It isn't my fault that he doesn't gain."

Evidently the mother had construed the suggestions made by physicians and nurses as criticism of her care of the child. Her way out apparently had been to say that she did not have the money to follow through on these recommendations so they wouldn't think she was an inadequate mother.

The worker commented, "The doctors and nurses are concerned and want to help you. You seem worried and upset and perhaps this makes it difficult for you to care for the baby—and he may be reacting to the way you feel, too."

This last remark seemed to free the mother enough to talk about things that were bothering her. She started to talk about the father of the child—and immediately became quite choked up with feeling. He was living in another State and was showing no interest in her or the child. At this point the mother was unable to go on.

Because this mother was so deeply disturbed and unhappy the worker knew that many months would be required to help her feel less anxious.

In preparation for the mother's next clinic visit, the worker talked to the doctor and the nurse about the mother's feelings and her need for reassurance and encouragement.

On the next clinic visit two weeks later, the child showed an appreciable gain in weight for the first time in 3 months, and the mother was commended on the child's improvement. The clinic recommended that the child get a special, rather expensive type of milk and the mother accepted financial help with this for one week. Later she arranged to take care of this responsibility herself.

The next visit showed the child had continued to gain weight and the mother expressed surprise and pleasure with this improvement. She seemed much more relaxed and listened carefully while further recommendations for the child's care were discussed. She was very proud of the child's improvement and the staff's recognition that she was responsible for it.

During the last two interviews and the ones that followed, the mother was able to talk more freely. She stated that she was very hurt that the father did not marry her after she became pregnant. Since she had been talking with the worker, she was feeling better than she had for a long time and she thought it best that she try to forget about him. This affair had "messed up" her life and ruined her plans for an education. She had returned to school after the birth of her child but was unable to continue because
she had no one to care for the baby.

The worker wondered whether it might not be possible to work out plans in the future for the mother to go on with her education. The mother brightened at this possibility and said she certainly would appreciate any help the worker could give her with such plans.

Although all the mother's problems had not been resolved, she had been freed to talk about the things that prevented her from giving good care to the child. The worker's non-blaming and understanding attitude had relieved her tension and made it possible for her to be less tense with her baby. The baby in turn responded to the changes in his mother and gained weight. The worker would continue the interviews with the mother until she gained more confidence in her ability to meet her own problems and plan for the future.

Many mothers are concerned about thumb sucking, nail biting, masturbation, feeding problems, aggressiveness toward a younger child, whining, and negativism. The worker can evaluate the behavior with the mother and help her determine whether the behavior is within normal limits, in which case the mother feels reassured by the interview and feels that "talking it over has helped me," as one mother commented after an interview concerned with the symptoms of jealousy her 2-year old was showing.

Most mothers understand jealousy when it is expressed directly through overt action, for example through the child's attempting to push the baby off the mother's lap or wanting to be held whenever the baby is held. But they do not always understand so well a child who shows his jealousy indirectly by regressing in toilet training or wanting a bottle again after having been weaned without difficulty some months previously. Sometimes they are not quite sure how they should handle a child who shows love for the new baby 1 minute and the next minute wants to hit him in the face.

Some mothers may not recognize a behavior difficulty or may be reluctant to admit to themselves that any exists. Others may express concern about the behavior and seek some simple treatment in the form of easy-to-follow advice that will clear up the situation. Even when mothers recognize the symptoms, often they have not yet reached the stage where they consider the behavior serious enough to be seeking help and may not have thought of the clinic as a place where emotional as well as physical factors are considered.

Behavior problems of children in the child health clinics have ranged all the way from the relatively common but sometimes excessive jealousy an older child feels toward a new baby to the psychotic behavior of a 4-year-old who finally had to be admitted to a mental institution. The latter, of course, is exceptional. Most of the problems encountered are excessive manifestations of a normal trait of behavior at a given age which might be considered abnormal at a later age, if no help were given.

Often behavior which in itself may not seem grossly abnormal may be indicative of serious disturbances in the life of the child. For example:

Three-year-old Mary was whiny and apprehensive in the clinic, constantly clinging to her mother. The mother reported that Mary had a poor appetite, did not sleep well, and complained of pains. Upon examination the doctor found no physical basis for these symptoms. Suspecting that the root of the difficulty lay in the home situation, the doctor referred the mother to the medical social worker.

The mother said that Mary is an only child, so has no playmate in the home. She is not allowed to play much with other children because her parents say that she does not get along with them and sometimes they hurt her. She cries if her parents leave her with someone while they go out, so the father refuses to go anywhere unless Mary can go with them. Mary is the center of attention at home and her parents can hardly let her out of their sight. They have her sleep in their room because they do not want her too far away from them. The mother said that the father is critical of her if Mary hurts herself slightly, saying that she should have watched Mary more closely.

The mother seems almost as protective of Mary as her description of the father but is beginning to feel very tied down. She expresses some resentment about the father's attitudes toward Mary and herself. The mother said she felt the father was losing his interest in her. He was concentrating entirely on the child and giving her all of his attention. The mother was doing everything she could for the child and was really trying to care for her the way the father wanted her to. But no matter what she did, her husband was still critical of her.

She admitted a good deal of dissatisfaction with her own life, too. Before Mary came, the mother had held a fairly responsible job—and her husband had seemed proud of her and interested in what she was able to do. She says that she does not have enough to do now and the responsibilities she does have are not stimulating enough. Because she had come from another State fairly recently, she has few friends and is practically without interests outside her home. Financially she does not need to work but she is thinking of finding a job to occupy at least part of her time. At this point the worker asked, "Is this really why you want to go back to work?"

The mother thought for a moment and came back with, "I really don't know! When I think about it, I know I really have enough to do at home. Ac-
tually I'm busy all the time." The worker asked, "Do you think your husband would have more respect for you if you worked?" The mother looked a little startled; then said, "Maybe so." "Perhaps this is why you feel tied down and resentful of your husband's attitude toward Mary. It must seem to you that he thinks Mary is more important than you are," the worker said. The mother didn't answer but seemed to be busy with her own thoughts.

The worker asked whether she thought children Mary's age really needed their mother's care and whether this responsibility was an important one. The mother nodded her head in agreement.

As the worker and the mother went on discussing young children and the possible causes of Mary's behavior, the mother was able to say that she thought Mary was responding as she was because of the way she and her husband had been handling her; maybe Mary's difficulties went back to the relationship between them. The mother guessed that she, herself, had been holding Mary too close because she was unhappy in her relationships with her husband, and Mary bore the brunt of this. For the first time, the mother seemed to be able to look at Mary and her needs as a growing child.

The mother, once having recognized the situation for what it was, could accept responsibility for it and do something about it. At a later interview, the mother reported that she and her husband had talked things over. She had decided not to go back to work. These were important years in her child's life and in the lives of her parents. They were trying to give Mary more opportunities to play with other children. They had invited a neighborhood youngster into the home to play and Mary seemed to get great enjoyment from this. Clearly Mary's problems were not all solved but progress had been made and the way was open for further work with the mother.

Another 3-year-old was referred to the medical social worker by the physician because the mother was concerned about his behavior.

Johnny sucked his thumb, masturbated, and had a speech difficulty. She thought Johnny's difficulties dated back to the time when she had had to return to work because she had separated from her father.

She had had a child prior to her marriage to Johnny's father and had always felt quite guilty about this. "The bottom just dropped out of everything" when she learned she was pregnant and she had never really been quite happy since. The grandmother had always cared for this older child.

After her marriage to Johnny's father, the mother soon found that she would not assume financial responsibility for the family as she thought he should. By the time Johnny was born, they were separated. She returned to her mother's home and was quite miserable because she felt she was a burden. At first she had been getting public assistance but this was stopped when the father had indicated he wanted a reconciliation. The mother, feeling that he had not changed fundamentally, did not wish to go back to him.

The father had not supported them adequately while he was in the home and, since the separation, had given only a small amount toward Johnny's support and then only after she had taken court action. She was resentful and disappointed in her husband and upset because she could not give her children the supervision and companionship she felt they needed. Everything seemed quite hopeless to her.

It is at this point she decided that the only thing she could do was to get a job. Immediately Johnny seemed upset, would not eat, lost weight, and became quite withdrawn. Because she suspected that Johnny was not getting enough attention, she arranged to have an aunt who was fond of him care for him. She thought that his behavior had improved some since this arrangement was made but she still was not entirely satisfied. She did not completely approve of the way he was being handled by the aunt. She felt that neither his aunt nor his grandmother had much understanding of a young child's needs.

Johnny was the only boy on the mother's side of the family and all his adult associates were women. As the only boy, he had received a great deal of extra attention; but not all of this was helpful. Sometimes it took the form of teasing about his being different. The mother was aware of these problems but did not know how she could control them completely.

Because of the undesirable effect this type of social situation was having on the boy and because he needed companionship with children of his own age, the worker suggested that nursery school would be a good experience for him—and the mother agreed. The worker helped the mother make arrangements for Johnny to attend a nursery in one of the settlement houses.

The worker, realizing that nursery school placement would not solve all of Johnny's problems, offered continuing services to the mother. She and the mother would see how Johnny responded to nursery school. If this did not work out satisfactorily, some other arrangements would have to be made. His mother will need sustained casework help in coping with her heavy parental responsibilities alone and in working out some of her own difficulties.

Occasionally, of course, medical social workers find mothers who are faced by situations so difficult that good care for the child is practically impossible for them to attain. For example:

Peter who was doing very poorly was referred to the medical social worker with the suggestion from the physician that if the home situation could not be substantially improved, perhaps the child should
be placed outside the home temporarily so that he could be built up to the place where he might be able to get along. All efforts to help the mother improve the care to her children had failed up to this point.

The mother was a somewhat limited individual who might have been able to manage her home and children satisfactorily under less difficult circumstances, but an interview with the worker showed that she was overwhelmed by her responsibilities. The family's housing was deplorable, which made care of the children very difficult. The mother recognized that Peter was malnourished and poorly cared for but was too discouraged to do much about it. She had a large family of six children and the father was not able to earn enough to support them at a decent level. Her own responsibilities in caring for the children seemed too much for her to handle and she was resentful toward the father for not recognizing this and helping her during his off hours.

She said she actually had had "three babies" to care for during the last few weeks. Peter, the child referred by the doctor, was about 6 months old; the 6-year-old child had recently broken his leg so he was in a cast and an 8-year-old girl was so retarded mentally that she was completely helpless. There was no money to pay for even part-time help for the mother.

A recommendation that the retarded child be placed in an institution had been so bitterly opposed by the father that no application had been made. The worker suggested that perhaps things would be easier if Peter were out of the home for a while. The mother agreed that with Peter out of the home, she could start making arrangements for placing the little girl in an institution. Even though she gave the impression of being fond of her children and wanting them with her, she was willing for Peter to go away temporarily. She said that it seemed the best thing to do because she could not give him the care he needed.

The worker was able to arrange through a child-placing agency for Peter to go to a foster home for 3 months where he gained weight rapidly and otherwise made good progress. During this time, the retarded child became ill and died.

The worker encouraged the mother to talk about her feelings about this, realizing that the sense of guilt many parents have about an abnormal child may be intensified when the child dies, particularly if the care the child received was not the best. The mother admitted she felt guilty about the child's death and resentful toward the father. Perhaps if he had permitted the child to go to an institution, she might still be alive. The mother felt that he was blaming her because she didn't do a better job in caring for the children. She had done the best she could under the circumstances. During the interview she said that perhaps it was better that the child had died because she knew the little girl's condition would never have improved.

While Peter was out of the home, the 6-year-old child's cast was removed so he was able to walk again and thus relieve the mother of extra care. After this, the mother was able to make some improvements in her home situation. She found much more satisfactory living quarters which made her housekeeping responsibilities lighter. Shortly thereafter she got a part-time job to supplement the father's income and a relative moved into the home to care for the children while the mother worked. When Peter was finally ready to leave the foster home, the mother was enthusiastic about his returning home. She felt she was now in a position to provide for him. Later clinic attendance showed that he was doing well.

For whatever reason a mother or child is referred to the medical social worker, the worker in the child health clinics is sensitive to the mother's emotional reactions and the ways in which she expresses or disguises her feelings about the child. While working with the mother the worker observes the child's behavior and his relationship to the mother. In all her interviews she is alert to any family and other interpersonal relationships which may affect the child's development.

In the course of her study of the mother, the child, and the family, the medical social worker contributes her knowledge of their social needs to other members of the staff so that these can be taken into account when planning for the care of the child and when carrying out that plan.

Through social casework, the medical social worker gives the mother a feeling of acceptance and understanding which may increase her ability to care for the child. She accepts the mother's attitude which may involve hostility or indifference toward her child. She tries to show the mother that she is aware of the many difficulties confronting her and to help her with them. She considers what there is in the mother's marital and family relationships and in the mother herself, that must be taken into account before the services offered by the clinic can be truly helpful to her and to her child.

In many instances, the medical social worker recognizes that the mother's and child's needs can be met only through the collaboration of other community agencies—she then uses her knowledge of community resources to help the child and his family.

Some of the developments in the child health centers of the District of Columbia give evidence of the ways in which medical social workers can contribute to child health clinics in providing services to meet the emotional and social needs of mothers and children.
The Social Security Act of 1935 established a new landmark in the development of health services for the mothers and children of the United States. One section especially, Title V, was of direct significance in the development and expansion of child-health services in the various States and Territories. This title authorized Federal grants to be made each year to the various States, through the Children's Bureau, to help them extend and improve their maternal and child-health and crippled children's services.

Although the Maternity and Infancy Act of 1921, commonly known as the Sheppard-Towner Act, had previously set a precedent for Federal grants for child-health purposes, the Social Security Act went beyond the provisions of the earlier legislation in several important respects. Services under the Sheppard-Towner Act had been confined to those relating to the maternity cycle and early childhood, whereas those under the Social Security Act raised the upper age level of eligibility to 21 years. Title V also authorized, for the first time, grants-in-aid for medical and related services for handicapped children.

Of most significance, however, was the fact that the grants under the new act were not conceived as temporary measures with a specific termination date. Many of the gains made with the support of Sheppard-Towner grants were lost in the early 1930's following the termination of the act in 1929. On the other hand, the size of the appropriations for both maternal and child-health and crippled children's services under the Social Security Act has been increased on several occasions since 1935.

The Federal grants have played a significant role in most States. In those with the lowest per capita incomes the grants established a means for financing child-health services. These States, generally with higher birth rates and more acute health problems, received proportionately greater Federal grants, often exceeding the proportion of taxes they paid into the Federal Government. The result was a much higher level of child-health services than they could otherwise have attained.

Even the more well-to-do States that had developed basic child-health services without Federal aid could point to tangible benefits from the grants. While they might have been on the short end of the stick in the exchange of Federal taxes and funds, the availability of Federal grants affected the further development of their child-health services. For them, the Federal funds often took on the semblance of an "extra," which State officials controlling the purse strings were more willing to use for experimental or demonstration programs or for special studies than they were in the case of direct State funds. The Children's Bureau's administrative decision to encourage the States to set aside a portion of the grants specifically for demonstration projects and broad training programs further paved the way for new departures in the child-health field.

An Era of Development

Passage of the Social Security Act came at the threshold of an era of unprecedented development bearing, directly or indirectly, on the health of mothers and children. During the next 20 years changes in the overriding concepts of health and of child rearing, the spectacular scientific advances in medicine and related fields, the broadening responsibilities of a number of professional disciplines in the health field, and changes on the social and legislative scenes all had significant impacts on the way services developed. Many of these changes were in turn affected by the direction in which child-health services were developing.

In the two decades since 1935 there has been increasing acceptance of health as a positive goal, and
Our population now includes 12 million more children than it did in 1935, and a much greater proportion of children than then in the 5–9 and under 5 years groups.

not simply the elimination of overt disease. This understanding was codified in the World Health Organization’s definition of health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. During this same period there was a sharp swing away from rigid concepts of child rearing and toward a more permissive attitude that looked upon the infant and the child as a person whose emotional and physical needs should be met on an individual basis. The potential damage to the emerging personality from prolonged institutionalization, especially during infancy, was clearly established, with a resulting emphasis on placing young children in suitable foster families when they cannot be with their own parents. There has also been increasing realization of the possible emotional trauma resulting from hospitalization of young children, even in the absence of surgery, and a trend toward adequate preparation of children for the experience of hospitalization.

In 1935, the Nation was starting an upswing toward a prolonged period of higher living standards which accelerated rapidly after 1940 in spite of the dislocations of war and inflation. In the ensuing years the birth rate rose steadily and sharply until it reached and maintained a relatively high plateau during the past decade. The trend toward smaller families was reversed and the middle-class “ideal family” with two children gave way to a family of three, four, or more children. Even in the face of a high incidence of divorce and separation, family disruption on the whole was markedly reduced as a result of an even greater decrease of disability or death of one or both parents.

During these past 20 years new technical developments have come thick and fast in medical and related fields. First, the sulfa drugs, and later the antibiotics, accelerated the already rapid decline in mortality from infectious diseases during the perinatal period and childhood, and made possible the control of rheumatic fever and the kidney disease, acute nephritis. The availability of an improved vaccine has been a major factor in eliminating whooping cough as a public-health problem. Now the advent of an effective vaccine against poliomyelitis promises to accomplish similar results with infantile paralysis.

New developments in the use of blood and blood derivatives have had lifesaving applications in unexpected fields. A striking recent example has been the use of gamma globulin in infants and young children who suffer serious infections because of a low level of gamma globulin in their own blood. Advances in pre- and post-operative management and in surgical techniques have made surgery safe during the newborn period, and have made many previously hopeless conditions of the heart and blood vessels and other systems of the body amenable to surgical correction or alleviation. Lessons learned in physical medicine and rehabilitation during and after the second World War have been rapidly applied to the care of children as well as adults. Progress in electronics has made possible new developments in audiology for the testing and training of children with impaired hearing and for the development of hearing aids suitable in size and durability for children.

In some instances, solution of old problems has introduced new difficulties, only to be followed by solution of the new problem as a result of intensified research.

Two striking examples may be cited. After the relationship of Rh incompatibility to erythroblasto-
sis fetalis, a generally fatal anemia of the newborn, was understood and applied, the improved survival rate following use of multiple transfusions appeared to be accompanied by an increase in the number of cases of kernicterus, a complication affecting the brain, with its frequent sequelae of mental deficiency and cerebral palsy. The development of exchange transfusions and of improved laboratory methods for determining proper indications for their use has reduced this problem to very low levels.

The rapidly mounting incidence of sight-destroying retrolental fibroplasia among premature infants caused some people to question the desirability of applying the expensive and time-consuming techniques which had been increasing the premature baby’s chances of survival only to have a blind child as the outcome. The urgency of the problem stimulated research in many medical centers and finally led to an understanding of the role of excessive use of oxygen in producing the retinal changes and irreversible stages of retrolental fibroplasia. As a result, it is likely that new cases of blindness from this cause will become a rarity in the near future.

**The Team Concept**

The past two decades have also seen increasing acceptance and use of persons from many professional disciplines as essential members of the health team—social workers, nutritionists, health educators, and physical therapists, to name a few. Rather than displacing physicians and nurses from their traditional roles in the provision of health services, they have made new contributions as a result of their own specialized training and experience. These have strengthened the services of the long-established disciplines. A basic concept of care has developed. In essence, this implies the pooling of the specific contributions of each discipline, the joint consideration of the information obtained, and the common development and carrying out of a broad plan of treatment.

This team concept has been most highly developed in the management of children with various handicapping conditions, in which the treatment plan has included, along with physical rehabilitation, consideration of the child’s emotional needs, adjustment of the child and his parents to the handicap, education, and, for older children, vocational testing, guidance, and training. Training of professional personnel has placed increasing stress on the team concept, especially in short-term training financed through

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**CHANGES IN CAUSES OF CHILD MORTALITY**

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Accidents continue to be a leading cause of death among children as deaths from acute diseases have dropped spectacularly. The figures for the 15-to-19-year-old group do not include deaths in the Armed Forces overseas.
special grants from Title Y funds. Teams from the different health disciplines in various combinations have been trained, for example, in the care of premature infants, in the management of children with rheumatic fever, and in the rehabilitation of orthopedically handicapped children.

For School-Age Children

Many changes have taken place in the provision of health services for children of school age. In the mid-1930's few voices had been raised to question the sterile program of regular health examinations of school children, with little attention to followup procedures to secure correction of adverse conditions found. The school physician was usually caught in the web of routine examinations, and little attempt was made to bring the family physician into the program. The emotional climate of the school and the management of the emotionally disturbed child were usually considered entirely apart from health services.

Today the routine cursory examination in the school is being replaced increasingly by more adequate, although possibly less frequent, medical examinations by the family physician or, when this is not possible, by the school physician. Screening tests for vision and hearing are being widely employed.

Greater emphasis is being placed upon teacher observation of individual children and upon frequent conferences between teacher and nurse on suspected health problems. Often these conferences are a prelude to special examinations by the physician, so that the physician devotes his attention to the children most urgently in need of care. The school physician is increasingly being regarded as a consultant in all matters pertaining to health in the schools.

True, these changes have occurred more in concept than in practice in all too many places. The longer history of school-health services and the weight of long-established practices have tended to retard progress more in this field than in other areas of child-health services. An added factor has been the divided and frequently unclear responsibilities of educational and health authorities in the administration of health services for school children. This problem must be resolved through joint planning and good will within the local communities.

Mothers and Infants

After a long period in which little headway was made in reducing maternal mortality, a dramatic change occurred in the mid-1930's when there began the steady, rapid decline in the maternal death rate which has led to the present low maternal mortality rates. Nevertheless, the rapidity of the decline has not led to complacency. There are probably more maternal-mortality conferences held under the auspices of medical groups and health departments, and more extensive maternal-health programs, than there were 15 or 20 years ago. The same techniques of investigation of maternal deaths, using the results of these investigations for professional education and to discover unmet needs in the community or State, have been applied to the still extremely important problem of intermediate and late fetal deaths and neonatal mortality.

Educational techniques aimed at better preparation for parenthood have also changed significantly. In 1935 classes for pregnant women, which had a tradition of well over a decade behind them, appeared to be on the wane. These classes placed a great deal of emphasis on preparation for home delivery and on the early diagnosis and care of serious complications of pregnancy. They were available mainly to low-income groups. In recent years a different type of class for expectant parents, often including fathers as well as mothers, has become prevalent.
Aimed at giving the participants a real understanding of pregnancy and childbearing, the modern classes have become important adjuncts to medical care, with participants usually being referred by their obstetricians. They convey important information on nutritional needs during pregnancy and on child care after birth. Most important, however, are the opportunities they provide expectant parents to express feelings and to ventilate anxieties in a group situation where they can see for themselves that their misapprehensions are common to many others. The resulting relief of anxiety about pregnancy and childbearing presumably helps establish a sounder base for later care of the children and for better family relationships.

Emphasis in child-health conferences has shifted from routine physical examinations, administration of immunizations, and advice on feeding to the mental-health aspects of child growth and development. The better child-health conferences provide ample opportunity for the mother to ask questions about the problems bothering her. The mother is kept informed of what to expect at each stage of her child's development, so that needless anxiety can be avoided and behavior problems prevented. In some instances the traditional functions of the child-health conference have become adjuncts to what is essentially an educational program, with child-study groups being formed by the parents of the children seen in the conferences.

**Preventive Programs**

In no field of child health has there been a more radical change than in that of dental health. In 1935 only secondary interest in children's dentistry was manifested by the dental profession. Even if all dental manpower could have been concentrated on the care of children's teeth, it would not have been able to clear up the backlog of dental caries and it probably would not have been able to keep up even with the increment of new caries. No preventive techniques were available which could be applied readily on a mass scale. There were few specific programs concerned with dental health, and there was little that such programs could offer. Such children's dental programs as did exist consisted largely of an endless treadmill of care for dental emergencies.

Today prevention of dental caries has come to the fore. Fluoridation of community water supplies, although still a subject of controversy similar to that aroused by pasteurization of milk and chlorination of water in the early days of these public-health procedures, is rapidly being applied across the Nation. By the spring of 1955, about 1,040 communities having a total population of 21 million were being served with fluoridated water. This is most impressive when one realizes that about one-quarter of the total population living in communities with water supplies lending themselves to fluoridation are already getting the benefits of this procedure. Children in these communities can look forward to having only one-third as many teeth affected by dental caries as have children in other localities and to the prospect of having simpler treatment to correct whatever dental caries develops.

For children living in areas where water fluoridation is not possible or practical, another preventive technique is available—the application of a sodium-fluoride solution to the teeth. A series of such applications at about 3-year intervals during childhood results in a reduction of about 40 percent in the number of teeth affected by dental caries. While such rapid strides as have occurred with water fluoridation cannot be expected in instances of topical application of fluorides, because of the number of trained dental personnel required, the use of this approach has spread rapidly.

Beyond this, courses in children's dentistry are now an accepted part of the curriculum of the dental student, and practicing dentists are showing a steadily increasing interest in children's dentistry. Many communities with fluoridated water supplies are now reaching the point where immediately available and interested dentists will be able to give adequate attention to the residual problem of dental caries.

With the sharp decline in the infectious diseases and other causes of mortality in infancy and childhood, death and disability following accidents have assumed relatively greater importance. Interest in the problem of childhood accidents has become widespread only in the past decade. Medical groups and voluntary health organizations, whose interests previously were focused exclusively on the diagnosis and treatment of disease and various disabilities, have promoted public-health education, legislation, and other measures designed to reduce the hazard of accidents to children. There has been growing appreciation of the dangers of leaving within children's reach common medicines such as aspirin as well as many household materials which are ordinarily not considered toxic. A recent development has been the organization of "poison centers" where persons who have taken toxic materials can receive emergency treatment and where information on the ingredients...
of various substances ingested by children can be provided to physicians and other persons on a moment's notice.

**Paths for the Future**

Much has been accomplished in the field of child health in the past 20 years. While we can be proud of our achievements, there is no room for complacency. Many needs must still be met. Meeting these needs will be a challenge to the ingenuity, energy, and devotion of persons in all fields bearing on the health of children. Future progress may be visualized as following three paths along which we must proceed simultaneously. These paths are: Research in the development of new techniques; the spread of available services to population groups not now reached; and increased depth of services to those already served.

Further research should be conducted in all fields of child health. In particular, intensified research is needed in what has been called the continuum of fetal wastage. The continuum starts with fetal and neonatal mortality, and extends through premature birth and through residual handicapping conditions, such as cerebral palsy, epilepsy, and mental deficiency, which are associated in varying degrees with disturbances of fetal development and delivery. The prevention of premature birth alone would cut the neonatal mortality rate in half and reduce to some extent the incidence of residual handicapping conditions. While much has been learned about the many factors which can produce congenital malformations in experimental animals, only a start has been made in applying this knowledge to the prevention of congenital malformations in man.

Mental health is another broad area for research. The possible relationship of controllable factors in emotional and social development to overt mental illness in later life still awaits clear demonstration. Similarly more needs to be known about the intrinsic factors of personality, the disturbances in intra-familial relationships, and the adverse community pressures which lead to delinquent behavior in children and adolescents.

The second path to further progress in child health is the broader distribution of services to population groups now barely reached. Regular health supervision, public-health nursing, and other basic health services are still lacking in many rural areas and in some socially and economically underprivileged groups. These are the very groups in which a concentration of health problems exists and which are hardest to reach for child-health services. Children in migrant families suffer all the handicaps of an unstable environment, usually with inadequate and temporary housing, poorly prepared foods of low protective value, and insufficient, constantly interrupted formal education. Only recently has thought been given to the development of an organized health and educational program for these children which will follow them from crop to crop along the stream of migrant labor.

Finally, depth must be achieved in many child-health services now lacking the essential elements of complete programs. Too many demonstration programs have remained simply demonstrations of what could be accomplished on a broad scale if sufficient personnel and funds were available. Programs for handicapped children which lack consideration of the emotional needs of the child and his family inevitably fall short of their goal of fulfilling the child's rehabilitation potential. School health programs that still place emphasis upon sterile, cursory health inspections at frequent intervals cannot be expected to reduce the prevalence of so-called physical defects nor to educate children in the value of good medical care. Child-health conferences which consist mainly of immunizations and advice on feeding miss the chief values of parent education and guidance in promoting optimal emotional development of children. Any child-health program lacking in depth is poor economy in the long run.

In this brief discussion, it has been possible to present only some of the highlights in child-health developments over the past two decades. Clearly the momentum gathered over the years will result in further expansion and improvement of health services for mothers and children. What will be needed more than ever is periodic critical reappraisal of these services to be sure that outmoded procedures are not allowed to reduce their effectiveness and that proven new knowledge and techniques are applied as rapidly as possible.
TWENTY YEARS OF MATERNAL CARE

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Commissioner, Massachusetts State Department of Public Health

IN THE 20 YEARS since the passage of the Social Security Act, a generation of Americans has grown to parenthood. Its children are being born into a different world. Twenty years ago 1 out of every 172 mothers died; today only 1 in 1,900 loses her life in childbirth. This dramatic saving of life is of tremendous importance, for of all tragedies perhaps the greatest is the loss of a mother's life. Yet it introduces other problems, for we can now turn to reduction of morbidity as a goal in itself. We can broaden our focus to see more in childbirth than the mere delivery of a living mother and a healthy child. Now that this basic essential can be assured, we can dare to look at our methods to find out whether some elements of value are missing—or even whether some have been lost in the process. Perhaps we may even accept maternal care in its broadest sense as part of every phase of a woman's life. In any event, at this 20-year mark a pause for reflection should be worth while.

In reviewing the developments of the past 20 years it is rather astonishing to realize that the entire history of any concerted efforts toward providing maternal care barely antedates the score of years preceding them. The first prenatal clinics were established in this country shortly after the beginning of the century. The development of modern maternal care has taken place in the United States within the last 50 years.

The first step was bold and brilliant. For centuries maternal care had begun with labor pains. The idea of preventing maternal diseases and obstetrical difficulties by anticipating them broke widely with tradition and made possible the future of maternal care. The prenatal clinic became a practical demonstration of the elimination of disease through organized means for detecting its earliest signs and symptoms. Gradually another fundamental principle was established—that obstetrical difficulties could be controlled through building a sound physique by measures of general hygiene. It seemed logical that maternal mortality could be conquered by a wide expansion of these clinics.

Great progress was made, but the results fell short of hopes. Apparently only a partial answer had been found.

As time went on closer inspection of mortality statistics brought out an important fact. Although the overall death rates had been reduced, the relative ratios of the three major causes—sepsis; hemorrhage, trauma, and shock—remained essentially the same. Any improvement, therefore, reflected advances against all the hazards of pregnancy and not against any one alone.

Broadening Concepts

Good prenatal care availed little if accouchement was delegated to poorly trained practitioners with poor facilities. Sepsis in the puerperium resulting from inept delivery could undo all that good technique had accomplished up to that point. Realization of this profoundly affected all future programs, for it brought realization that advance must be made along a broad front. To be sure, salients here and there could be pushed out, but the line eventually had to be straightened.

This concept at first seemed to supply all that was lacking to reach the ultimate goal—that no mother or child should die or suffer harm in childbearing. But another element was even then entering the picture—consideration of emotional stress and strain as factors of importance in practical programs designed to reduce maternal mortality. At the same time, under the stimulus of the great pioneer social workers, more and more attention was being directed to the effects of social and economic conditions upon people in general and on the family—and hence the pregnant woman—as the basic unit of our society.

The credit for this broadened view of the pregnant woman goes to no one group in particular. The physician, the social worker, the medical schools, the
nurse, the midwife, governmental agencies, and the people—parents and others—all had their parts.

By the time of the Social Security Act of 1935 the general outline of the years ahead was established. Like the Sheppard-Towner Act, which preceded it in making provision for maternity care, this legislation accepted the principle of local initiative and responsibility with financial and professional help from the State and Federal governments. Thus there could be three-way support in moving forward.

Reduction in Mortality

If 1935 rates prevailed in the United States today 24,000 mothers would die this year. Instead only about 2,000 will lose their lives. For the sake of the future this accomplishment deserves analysis.

The same major causes of maternal death have kept the lead throughout these 20 years. But all have been drastically reduced and changed, as the following table shows:

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<th>MATERNAL MORTALITY BY CAUSE, UNITED STATES 1935 AND 1952</th>
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The reduction in deaths from toxemia has resulted from generally improved prenatal care, for 20 years of research has not produced a specific cure for this disease of pregnancy. The greatest single factor in its control is constant watchfulness—continuous observation, examination, and hygiene teaching. This involves many tools, from the simplest readings of blood pressure, weight, and albuminuria, to complex socio-psychological studies. One of the most useful—since it is controllable—is optimal nutrition development through diet guidance, with motivation of the mother by a physician or a nutritionist. This has proved valuable both as a preventive and a therapeutic measure.

Of all the major causes of maternal mortality sepsis has yielded most to frontal attack by the sulfonamids and the antibiotics. The development of these antibacterial agents is the one most dramatic event of the last 20 years and one of the most dramatic in medical history.

Two important elements of care brought about the drop in deaths from hemorrhage, trauma, and shock. First, a tool, as valuable as the antibiotics in control of sepsis, was greatly improved—transfusion. Blood transfusion, of course, was used long before 1935, but in the past 20 years the techniques it involves have been improved to such a degree that it is now available almost wherever babies are born. Secondly, today’s obstetrician, general practitioner, nurse, and midwife all are better trained. They possess knowledge, technical proficiencies, and judgment that a generation ago were the prerogatives of their teachers alone.

In 1935 the general category of “other causes of death” contributed only 10 percent. Today this percentage has risen to 16—due to the great decreases in the three major causes. This miscellaneous group now demands the attention it has been denied in the past. Fortunately, various specialists have become increasingly interested in these problems.

It would be unfair to judge the past 20 years alone on the basis of mortality, for they also have included other great steps forward.

Morbidity has fallen. There has been a vast improvement in the condition in which the postpartum mother now is returned to her nonpregnant state. An increasing realization of the impact of disability in the mother upon the entire family has brought about an appreciation of the close relation between the physical and social elements in maternal care.

Efforts to improve the nutritional status of pregnant women through diet control have been an important factor in the reduction of morbidity as well as in the management of toxemia. As standards have been established and studies conducted to test their application, practical programs for nutritional betterment have become recognized as a vital part of general pregnancy care.

Changing Methods

The past two decades were also years of great change in anesthesia and analgesia. All forms of inhalation agents were tried, and spinal and local techniques were developed. Although certain clinics formed a preference for one type as a routine, most interpreted their experience otherwise, using each type according to its distinctive value. Studies also brought out the important fact that obstetrical anesthesia had definite problems and peculiarities of its
own and so could not be considered just another phase of general surgical anesthesia. One of the major differences lay in the necessity of considering the effect of maternal anesthesia on the fetus. Inevitably a group of specialists arose who devoted their full time to obstetrical anesthesia with great benefit to the safety of both mother and child.

The year 1935 was very close to the first major revaluation of the earlier "twilight sleep." Many efforts were made to find analgesic drugs that would relieve the pain of labor without adverse effect upon the child. The aim was a labor if not without pain at least without memory of pain. Many drugs and combinations were tried with varying success, all falling short of the ideal.

Paradoxically, these same years also brought almost violent reaction to the search for a perfect analgesic. The proponents of "natural childbirth" set a goal which was the exact opposite—a complete awareness of the experience of childbirth. Unfortunately, this became equated with "childbirth without fear" and "childbirth without pain," thus focusing on the very element to be eliminated. Nevertheless, these pioneers served womenkind well, for they showed that neither analgesia nor anesthesia were necessary elements of childbirth and, therefore, could be eliminated if desirable. The next 20 years will see this method assume its proper place in maternal care.

In close association with "natural childbirth" has come a move toward "rooming-in" or keeping the baby in the same room or near the mother. The two systems go together rather well but are not necessarily linked. They have also paralleled a gradually revived interest in breast feeding. Many clinics have established elaborate facilities and teaching routines for rooming-in. However, it has become apparent that the spirit that motivates the hospital staff is more important than either physical setup or schedules.

All these developments have been part of a steady march toward the concept that maternal care should support the normal physiology of pregnancy and reduce interference to a minimum.

Another major development in the last 20 years has been a steady increase of hospital deliveries. While in 1935 only 37 percent of all deliveries in this country occurred in hospitals, the proportion had risen to 90 percent by 1951. Much discussion has occurred over the question of whether this is for the best. At least it has coincided with the reduction of maternal mortality to the lowest figure on record.

Changes have also taken place in academic obstetrics. Surprisingly little actually was known 20 years ago of the physiology of reproduction, the profound physiochemical reactions that take place during pregnancy. But the ensuing years have been an era of greatly expanding research, bringing to the study of pregnancy some of the best researchers in all fields of medicine. As a result, the pregnant woman has emerged in a new light, as a totally different person—not as one whose nonpregnant state has been interrupted by the addition of pregnancy, but as one who is now in the pregnancy phase of her life. The obstetricians have themselves worked in these new

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**DROP IN MATERNAL MORTALITY 1935-52**

Deaths of mothers in childbearing have dropped rapidly since 1935, but the death rate among nonwhite mothers is still more than twice as high as among white mothers.
areas. They have also found new resources in the increasing number of related professions and have thus been able to make wider distribution of their own talents. The differences between urban and rural service have constantly lessened.

During this period the obstetrician and the pediatrician have gradually drawn closer together so that the division between maternal care and infant care tended to break down. At the same time infant mortality has dropped. But a residuum has remained which has failed to respond, at least by comparison. This is the perinatal group of deaths—the stillbirths and the neonatal deaths of infants under a week old. Clearly the conditions underlying this loss of life are obstetrical, and, if the pediatrician is to help, his influence must be felt long before delivery; or, in reverse, the obstetrician's responsibility must carry beyond birth.

Socioeconomic Influences

The most significant development in maternal care began to take shape toward the end of this 20-year period. It came from a series of questions forced to the surface by the growth of pregnancy care.

Can continued improvement in the technical means of care eliminate the residue of maternal mortality? Or are there other indirect, perhaps more subtle influences with which we must reckon? Is it enough to deliver a healthy unharmed baby from a healthy uninjured woman? Or are there other responsibilities the physician must assume as a part of good maternal care? The answers to these two groups of questions lay in the facts of modern life.

Over the years it has become clear that many social, economic, and psychological conditions engendered by society today are reflected in the well-being of mothers and children and even in seemingly specific causes of death.

Many of the most difficult problems of maternity care in this country in recent years have had their roots in the changed status of the family and more particularly of the woman. In earlier times almost every woman had home building as her career, but in recent years social and economic forces have both led and forced many women into a new world apart from the home, a world in which they must compete in traditionally masculine work yet retain their own attitudes. Since these forces have changed neither the physiology nor the psychology of women, the mother remains still the one best agent for infant care. By diverting her attention from this role these forces strike directly at the heart of the family.

That the effects of socio-economic factors in childbearing are not just theoretical was demonstrated by the recent work of Baird in Aberdeen. He found that he could divide women in his study on the basis of height as a variant both to social status and nutritional state. Women over 150 centimeters tall showed a more "female" type of pelvis and had fewer difficult deliveries, while those under this height tended toward the male or android structure. Other studies in England and Wales, Scotland, Sweden, and Holland have demonstrated a relationship between the incidence of stillbirth, premature birth, and neonatal mortality, and the socioeconomic classification of the family.

The problem of the unmarried mother also stems deeply from sources within the economic and social structure. The social and economic factors associated with illegitimate birth are almost always unfavorable.

Emotional Factors

The importance of psychological pressures have also been increasingly recognized. Many of the economic forces have, in fact, produced their effects through emotional strain. The economy of the marginal income may be sufficient to provide an adequate diet, but the fear and worry of the constant struggle to make it do so may be devastating. The mental anguish of the mother who would choose to stay home
but is forced into employment by sheer economic necessity is very real.

There has also been much emotional maladjustment of mothers to their families and to their place in the community that does not derive from economic conditions. Modern education often trains women for work outside the family rather than for a position as the center of the household. When a woman’s training conflicts with her basic urge toward motherhood emotional stress appears.

In these days of “mechanization” of so many of the processes of our daily lives it has been natural that similar methods should have been tried in maternal and child care. The growth of great clinics has brought the best of medical service to large numbers of women who otherwise would not receive it. However, this approach may have eliminated a vital and necessary child-mother relationship be developed in an institution. If not, how can the confidence—indeed, the faith—of the mother be secured by relative strangers in this important period? How can a professional person give support to a mother-to-be who suddenly realizes that her whole life is now to be changed? Such questions have led to increased attention to the slow psychological preparation of the wife, the husband, and their other children for the baby’s arrival.

These emotional stresses may be working for the good of the mother and her child, but they can also be threatening in their possible influence. Guiding her safely through them takes sensitivity and sagacity on the part of those dealing with her.

**Today’s Advantages**

Such sociological, economic, and psychological influences already have affected profoundly the maternal-care programs of our country. In fact, the American woman herself has changed for the better under their pressures to a very great degree. Her physique unquestionably has improved as standards of living have risen in the past 20 years. Better living conditions and better nutrition have certainly played their parts in equipping her better for childbearing. This generation of mothers is the first to have gone through the teens without facing the hazards of disease which threatened their mothers and grandmothers—chlorosis, typhoid, and tuberculosis, for example. Emotionally too, the American woman has changed. She has a greater knowledge of her own physiology and of what factors actually do influence health and prevent disease. Childbirth is no longer a mysterious phenomenon. She can look upon it in an intelligent, objective way.

The mother of the present also has the advantage of a better environment. To be sure, it is a complex environment filled with frustrations, stresses, strains, and pressures, but at least it is one in which these factors are recognized. To reduce them as much as possible is beginning to be accepted as a responsibility of maternal care.

The physical environment in the hospital has changed for the better. The emergency maternity and infant care program of World War II did a great deal to improve hospital procedures and facilities. Recently more adequate obstetrical facilities...
have been provided under the Hill-Burton Act, while the development of hospital licensing authorities by many States has also added to the improvement of hospital care for maternity patients.

These improvements have come none too soon for the increasing birth rate has placed a tremendous load on hospital facilities. A hospital built for 2,500 deliveries a year ago is now caring for more than 5,000 maternity patients each year. Although the shorter hospital stay tends to eliminate overcrowding to some degree, the problem still remains.

More important than the physical facilities available in today's environment are the professional people surrounding the mother who are trained to serve her throughout this period of her life.

First, of course, is the physician, who must take the ultimate responsibility for the care that the mother receives. He is far better equipped for this task than was his own professional father 20 years ago. Although the general practitioner remains the backbone of maternal care and services, more specialists are now available to him. There is also better distribution of well-trained men throughout the country. The physician of today also recognizes the help that he may obtain from workers in the ancillary medical services. He is beginning to appreciate the fact that each of these workers has a unique contribution to make to the mother and to her family. True, it has taken time to establish the team concept. The realm of maternal care has so long been a relatively personal patient-physician relationship that the idea of several people being involved has been hard to accept. It has taken time also for the other team members to gain their professional rings in this particular field and to find their proper relations to one another.

The nurse remains as the doctor's first helper but with a much wider application of her skills. She is a member of a group who must somehow provide continuous care though her time is divided among office, hospital, and home. If she is in addition a midwife, as many nurses are, she has even further responsibilities.

Social workers, nutritionists, mental hygienists, and health educators are more recent additions to the medical team and have created a demand for their services far beyond the number of trained workers they can furnish.

The pediatrician's role as a specialist in this team has already been discussed.

The final "member" of the team is actually the community or the State. Because so many of these valuable ancillary services are difficult to provide, the State inevitably must come into the picture in helping to furnish them. This is particularly necessary since the general practitioner, who in this country is the principal accoucheur, is overworked and in need of help. It is the community's responsibility to see to the provision of consultations for him in all necessary areas.

Nevertheless, in spite of all that the State can provide most of the deliveries will continue to take place with a minimum of personnel. While no one man could be expert in all of the areas of specialty required, the practitioner can and must recognize the areas that need to be covered and to the best of his ability cover them or seek help elsewhere.

Lest one become complacent about the accomplishments of the past 20 years, two very sobering facts must be underscored which stand clearly between the present and the future in maternal care. First, it is now possible to add as part of maternal care services which specifically support the social, emotional, and psychological values lying at the heart of the family. Second, low though our maternity mortality is, 50 to 75 percent of all maternal deaths that occur could still be prevented if the full benefit of modern medical knowledge were available to all maternity patients. Implicit in these two facts are responsibilities.

The future must seek answers to two major questions: How can the utmost of technical proficiency be secured and maintained? How can the emotional and social values of the family be preserved? These must be answered within the structure of a social and economic world that is growing more and more complex. Those who would attempt answers must state them not only in terms of physical conditions, but also, as Sir James Spence would put it, in terms of "courage, gaiety, self-confidence, and sympathy." Only through the mother, the father, and the family can this expression take place. Those who are dedicated to help must be the first to appreciate this. Their task, therefore, becomes doubly difficult for the future. They must continue in their efforts to save lives—for no mother should die—but they must also play a big part in making better living.

Changes in the major health problems besetting children call for...

CHANGING EMPHASES IN SCHOOL HEALTH PROGRAMS

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The Partnership of education and medicine that is essential for a school health program has been expressed in many ways but hardly more simply and directly than in a report of the Joint Committee on Health Problems in Education of the National Education Association and the American Medical Association. The report lists these functions of a school health program:

1. To appraise the health status of pupils and school personnel.
2. To counsel pupils, parents, and others concerning appraisal findings.
3. To encourage the correction of remediable defects.
4. To assist in the identification and education of handicapped children.
5. To help prevent and control disease.
6. To provide emergency service for injury or sudden sickness.

Each of these components is broad and may have varying interpretations as well as applicability. Their applicability is affected by the kinds of health problems that are predominant today. These are different from those of a generation ago and vary among our communities and even from neighborhood to neighborhood in a city. How to carry out these program functions and what meaning they have for school health personnel will differ widely. Basically they have extensive usefulness.

The Need for Change

However, differences in communities and in health problems are not the only factors which determine the content of a community's school health program. Often these programs continue practices which, though appropriate several decades ago, hardly are effective today since they fail to meet the major challenges of the present generation.

When school medical services started in this country (the first is reported to have begun in Boston in 1894) the control of the spread of contagious and nuisance diseases was the principal objective. This led to medical inspections of children in school. Subsequently major emphasis was placed on examinations for the discovery of physical defects and procedures designed to show parents the need for having these defects corrected. This continues to be the major emphasis in school health services. Such examinations are considered of importance not only for case-finding purposes but also for their usefulness in teaching children basic facts about health and in helping them to develop good health habits. In fact, for many schools, health education is considered the principal reason for having school health services.

Probably the most extensive evaluation of a school health program is the study done in New York City in 1942, known as the Astoria Study. This study...
not only pointed out that much wasteful repetitive work was going on, which, year after year, resulted in the recording of more defects, often involving the same children, without adequate follow-up activity, but it also showed the way to a more effective program. The conclusions and recommendations of this study have been widely influential. They are particularly significant for teamwork in that the study demonstrated the effectiveness of the teacher in case finding and the importance of her relationships with the nurse and physician as a member of the school health team.

While not all of the findings of the Astoria Study have equal applicability in all of our communities, several basic questions do. These include:

1. What are the major health problems of children in our community?
2. What priorities should be established in providing health services?
3. What are our community health resources and how effectively do we use them?
4. What is the most productive use of the time of the school doctor, nurse, and teacher?
5. For what children should the school provide physical examinations?
6. How can the effectiveness of follow-up services be increased?
7. What is the relationship of the school guidance program to the school health program?

Answers to such questions as these must be sought both within the school in its policies and administrative procedures and in the relationship of the school to the rest of the community. One administrative question has lately been given increasing attention—that is whether nurses in these programs should more appropriately be employed by schools or health departments.

Many people feel that most school health programs are badly in need of review with respect to their content, procedures, and objectives. Large sums of money are spent in these services, with varying effectiveness. Not enough recognition has been given to the ways in which our health problems have changed. Communicable diseases and other acute conditions are now less important. More attention must be given to the problems accompanying growth and development, adolescence, and handicapping conditions of childhood. This will require increased attention to the functions of the school health team and the most effective use of the team members' time.

Medical Examinations

A brief recapitulation of the history of school physical examinations will illustrate how concepts of school health services have changed, as well as some different points of view regarding them. Twenty-five years ago annual medical inspections of all school children were customary. Subsequently, as education became effective in increasing the public understanding of the importance of controlling communicable and nuisance diseases and of securing medical care early and seeking health supervision for children, the value of medical inspections diminished sharply. Some form of frequent health examination was still considered important in many places, however, and has not yet been given up. As recently as 1945, a law was passed in one State which provides for Statewide biennial medical and dental examinations of all pupils in public and private schools. Examinations of such frequency and such large numbers cannot be done adequately, are wastefully repetitive, and may give many parents as well as school administrators a false sense of security.

School health studies have demonstrated that effective case finding at less cost can be achieved by having 3 or 4 routine examinations during the 8 school years, with parents present, and using various screening tests and the teacher's observations and her conferences with the nurse for selecting children at other times for referral to the physician. The teacher has been shown to be a good case finder. Moreover, the more parents rely on their own physicians for their children's health examinations, the less will be the need for the school to provide it. The extent to which they do this varies considerably, however, and is related to the family's income.

Such a plan for health examinations has been shown to be effective and less wasteful. It enables the school doctor to serve as a consultant to the school and the school health team to concentrate on the more important health problems and on securing adequate care for the children who need it.

Limiting the frequency of school health examinations in this way has led many people to the conclusion that this means that school-age children need a health examination only three or four times. Actually what it means is that it is not practical...
or efficient for the school to provide such an examination more often.

Studies have been made in Rochester, N. Y., of the value of the examination of first-grade children. Most of these children had had physical examinations in kindergarten, either at the school or in their own physicians' offices, so that little new was discovered. The value of the routine first-grade examinations was, therefore, questionable so far as Rochester was concerned. In other communities the examination on entering school is often the first a child has had in several years.

In Washington County, Md., 1,103 examinations were done in the school health clinics in a 2-year period. The most prevalent health problems were upper respiratory difficulties and behavior problems. A number of serious conditions were discovered which were unsuspected. These included 5 children with rheumatic heart disease, 4 with congenital heart disease, 3 with acute rheumatic fever, 1 with malignant but curable kidney tumor, and a variety of others. The discovery among 1,100 children of more than a dozen with serious diseases would certainly bear out the value of the school health examination program for this county.

Another aspect of the school health examinations has received insufficient consideration. The scope of the medical examination when done in school has limitations imposed on it by the unavailability of laboratory tests as well as the physical surroundings. It is essentially a medical screening examination. Those children who need further diagnostic services and treatment must seek this elsewhere. Would it not be more practical to have these examinations done in a clinic rather than in the school? If the child does not go to his own physician for examination, the clinic can schedule immediately any laboratory studies or further visits, thereby insuring more prompt and effective follow-up.

**Screening Tests**

What other health services should be provided in the school? While most people feel that ideally the periodic health examination ought to be done by the child's own doctor, screening tests of vision and hearing are best done in school where children are in groups. Visual acuity in childhood often changes rapidly and, therefore, vision tests should be done annually. The Snellen test and the Massachusetts vision test have been demonstrated to be efficient screening tests that are carried out most economically and rapidly with groups of children. Hearing testing should be done every two years routinely, with repeat tests on children who do not pass.

These two tests are of great importance for many reasons, among which is the fact that a child needs to see and hear reasonably well in order to progress in school. Another reason, especially valid in public health and education, is that large numbers of children are involved. Moreover, with adequate attention, progression of hearing loss can frequently be prevented and normal hearing may be restored. Between 5 and 10 percent of children fail to pass audiometry tests. These children are in need of further attention. Because defective vision and hearing are so prevalent and can be readily discovered by screening tests and corrected or improved, screening examinations are of utmost importance.

Other screening tests may be of value in the school health program. Periodical measurements of height and weight may be useful when interpreted properly, and are, of course, one of the oldest procedures in school health. Consideration should be given to making routine hemoglobin determination at intervals as a measure of nutritional efficiency. There are now simple rapid urine tests for diabetes, a condition, however, which is not common in childhood and, therefore, questionable for inclusion in a mass screening program. Routine testing for tuberculosis, especially at puberty, should be employed much more widely than at present.

Another screening device as yet little used in school health programs is the pupil's health history as provided by a parent. In medical education much stress is placed on learning to take a good history, because such a history often provides much useful information. In school health work the history does not receive much attention. In reviewing the Pennsylvania school health program recently, the medical advisory panel stated that "a medical history can be devised that will be useful in detecting a number of different ailments, including allergies, epilepsy, diabetes, infected tonsils, rheumatic fever, mental illness, and orthopedic defects." Such a history was developed for adults by Cornell University Medical School. Known as the Cornell Medical Index, it is being successfully used in the outpatient department of the New York Hospital. A similar history, filled out by the parent, was tested in the California school health program, and found to be reliable and useful to the doctors and teachers, who were very favorable in their evaluation of it.
**Points for Review**

School health examinations include periodic health appraisal, screening tests, and continuous observation by the teacher, with referrals to nurse and physician. This part of the school health program needs objective review so that the most productive use is made of the time of the school health team, and activities of comparatively little value can be reduced or eliminated. The problem of dental caries is an illustration of this:

Dental caries is a condition which is very common and has received a great deal of attention in school health services. Probably 90 percent of children have dental caries. That being so, little is accomplished by frequent dental inspections. It can safely be assumed that every child ought to go to a dentist at least once a year for dental care. Efforts should be directed to getting this done rather than to provide repeated dental inspections.

It is possible to reduce dental caries in children by 40 to 60 percent by adding sodium fluoride to the water supply or by applying it to the teeth periodically. The reduction in the size of the problem through fluoridation, and attention given to education in dental hygiene and helping children get under dental care would be far more productive than repeated dental inspections. Yet for various reasons there are many delays in changing over to this kind of a program.

School health services staff devote a large part of their time to the follow-up of children who are found to be in need of further diagnostic work and care. Much of this responsibility is assigned to the public-health nurse. This is often one of the weakest parts of the program. How productive the procedure actually is varies considerably and should be analyzed by each program regularly. It is the repeated finding and recording of defects about which nothing gets done that has led to much current concern about school health programs.

Since not all defects are of equal significance, it would seem to be possible to devote time to follow-up on the important ones rather than to all that are recorded. Studies of administrative procedures have resulted in more efficient follow-up. But for the most part the school is dependent on the parents, the child's physician, and other outside resources to provide what is necessary. The extent to which such resources are available and the relationship of the school to them is crucial in this phase of the program. In Philadelphia, of 74,940 reported remediable defects in 1951-52, only 30 percent were treated over a 2-year period. Yet Philadelphia is a city where there are many community health and medical facilities.

It is important that the school health program be administered in close relationship to other health programs in the community and not isolated from them. In Washington County, Md., the program is a joint responsibility of the department of education and the department of health and is regarded as an integral part of the county's organized health service. This has enabled the county to develop a program in which there is a continuity from preschool health services to services in the school and to several specialized public-health programs. The fact that the Washington County health department has a well-organized hearing-conservation program undoubtedly accounts for the fact that recommendations for follow-up care of 430 children with ear, nose, and throat problems were carried out for 92 percent of the children referred. Of 293 referrals for tonsillectomy and adenoidectomy, 195 were carried out by the conservation-of-hearing program and by private physicians. High rates of successful referrals were achieved with other children as well.

Thus, it is possible to achieve considerable success in follow-up care if this is regarded as sufficiently important to expend time and money to do it, in a program which is closely coordinated with other community agencies. Studies have been done which demonstrate that the financial status of the family, the availability of community resources, and the level of education of the parents are significant factors in the parents' carrying out the recommendations of the school.

**For Handicapped Children**

Perhaps in no other aspect of school health work is the need for genuine teamwork so evident as in services for handicapped children.

Many children have disabilities, often of a chronic or permanent nature, which may create problems in obtaining an education. These are the children who are orthopedically handicapped, children with poor sight and hearing, children who have cerebral palsy, heart disease, epilepsy, allergies, diabetes, and other conditions. Most of them can be educated as readily as other children. But many will need some modification of their educational programs if they are to benefit from educational opportunities. It is generally estimated that about 10 percent of children require special education. These include the physi-
cally, emotionally, and intellectually handicapped. There are, of course, many more who do not need special education, but do require special attention from time to time.

In 1930 the White House Conference on Child Health and Protection made this recommendation: "A State program for crippled children should be built upon the rights of individuals to an equality of opportunity, especially from the educational viewpoint. Academic education and prevocational and vocational guidance and training adapted to crippled children should be available to them at all times in which they are physically able to receive the same, regardless of the location of their residence. Physical care and education designed to produce self-supporting and useful citizens should be carried on together."

Most handicapped children can be educated in regular classes or in special classes in regular schools. The trend is clearly in this direction. Special classes in day schools are becoming increasingly common. Flexibility in school administration is, of course, requisite. Such schools must have adequate health and guidance services and teachers with training in the education of exceptional children.

Schools can make a further contribution by making some provision for education in the preschool years. Children with cerebral palsy and children with impaired hearing can benefit greatly by early education. Many so-called deaf preschool children, with a proper diagnosis, a hearing aid, auditory and speech training, and training in lip reading, will get much more out of school if they have the advantages of special training in a nursery school. Such children today are often subjected to needless segregation in a residential school.

Epileptic children on the other hand are commonly excluded from school altogether. Most of them do not need special education, but they do need a chance to go to school with other children, which they usually are able to do. About 75 percent of epileptic seizures can be controlled by medication. Even if a child does have a seizure in class no one is harmed by this if the teacher is calm and helpful. The teacher's attitude will set the stage for the attitudes of the children.

The placement of children in special classes requires expert medical and educational judgment and should be done only after careful diagnostic work. Children who are in special classes should be examined periodically to see whether such placement is still necessary. A review of children in special classes done in New York City revealed that 58 of 182 in sight-conservation and Braille classes, or 31.9 percent, were inappropriately placed. Fifty-four of these were reported to belong in regular classes. In the same study, of 74 children in cardiac classes, 87.9 percent "probably did not require placement in the special classes." The report further states that "modifications of the school program should be individualized in terms of the changing needs of individual children. The primary objective should be to return as many children as possible to regular classes in as short a time as possible."

Another aspect of school health which is receiving increased attention is that of the social and emotional development of children and the problems which sometimes develop. These may be more common today or we may be more interested in them. The teacher is in a good position to recognize attitudes and behavior in younger children which may be suggestive of the later development of delinquency.

More adolescent children are reported by the juvenile courts to be in difficulties than in the past, and this places on us a responsibility for dealing with these problems. The school social worker, or visiting teacher, is concerned principally with children whose behavior, attitudes, or family situation are such that they require special attention if they are to benefit from their educational opportunities. The school social worker is frequently able to assist the school staff in improving the child's school adjustment. When the pupil is to be referred to community social agencies or comes under the care of the juvenile court, the social worker is involved. This aspect of the school health program is taking on increased significance in many urban areas. Although often considered a part of the guidance program rather than the school health program, little reason exists for continuing to separate them.

For Adolescents

The problems of adolescents are especially pertinent to the health programs in secondary schools. There is a greater interest in adolescence than ever before. In fact some people believe that just as the period of infancy and early childhood formerly received a concentration of attention in pediatrics and public health, so we are now moving toward the adolescent and devoting more time to his problems of growing up and seeking independence in our ever more complex society. In adolescence psychological
problems take on greater significance. As teenagers are apt to look elsewhere than to their own parents for guidance, the schools through counselors and others often have an opportunity to be helpful to them.

Many parents are unprepared to cope with the various phases of adolescent development. For many years health workers have emphasized anticipatory guidance for parents of preschool children, but only recently has it been suggested that similar guidance might be offered to parents of pre-adolescent children.

An obstetrician, Dr. Samuel Kirkwood, Commissioner of Health in Massachusetts, recently stated, "Of all times in the life span of a woman, most difficult is this jump from girlhood to womanhood and the responsibilities of physical reproduction. Literally overnight the young girl becomes a totally different person. She is no longer the same to herself. Her position in the family is as changed as her place in the community. She looks at no one, and no one looks at her, in the same light as before the event of puberty. Our civilization places great restrictions upon her and we give her at best little help in this trying time. Only intelligent, sympathetic support can resolve the conflict of necessary dependence and equally necessary self-assertion which marks this time of life." 5

The concern of the previous generation of health workers was directed to the problems of maternal and infant mortality. A more positive purpose is expressed by Dr. Kirkwood in his concern for healthy children and healthy families. Many obstetricians and pediatricians today believe that the most strategic time to prepare for satisfactory childbearing and childrearing is during the period of adolescence. In accepting this opinion health services, health education, and health counseling must be coordinated in more effective ways to capture the interest of adolescents in preparing to meet their responsibilities of the future.

Dr. Roswell Gallagher’s adolescence clinic in Boston represents a pioneer effort to deal more constructively with the young adults of this age period. Similar clinics are in the process of development elsewhere. Problems of adolescence may well be the major challenge of our generation, just as infant mortality was for the previous one.

PRENATAL NUTRITION AND INFANT HEALTH

GENEVIEVE STEARNS, Ph. D.

Research Professor, Department of Orthopedic Surgery, College of Medicine, State University of Iowa

In the United States the past 50 years have brought a gratifying decline in the number of deaths occurring in babies under one year of age. In 1956 only about one-fourth as many babies died for each thousand babies born alive as had died in 1915. But the number of babies dying at less than a week of age has not declined nearly as rapidly as the death rate in older infants. Babies who die before they are a week old now make up the largest share of all infant deaths under a year of age. A majority of these early deaths occur in infants born prematurely.

There are many causes of early infant death; some of them we can as yet do little about. We can try to find out why babies are born prematurely and work to eliminate these factors. Every baby is entitled to his full time in his mother’s uterus; it is his best insurance for a healthy infancy. Not only are premature babies apt to be frail babies, but the danger of birth injury is greater for them.

Careful study in many countries and with many types of investigations makes it seem certain now that one big factor concerned with premature delivery is the poor state of the mother’s nutrition and health even before she is pregnant. Poor nutrition during pregnancy itself only makes the situation worse.

The great tragedy is that much of this poor nutrition among mothers and mothers-to-be is unnecessary. Better judgment in buying the family food often would provide good nutrition for the entire family at no increase in cost. Stuart and Burke in Boston observed that when nutrition during pregnancy was inadequate, the fetus suffered to a greater degree than the mother. Mothers whose protein intake was low gave birth to smaller and lighter-weight infants than did well-fed mothers. It is well known that strong babies are easier to care for than are weak babies.

Poor Food Habits

Studies of food habits of low-income pregnant women in Iowa showed that, in that State, very few pregnant women did not get enough food. A far higher percentage of these women ate too much, yet were poorly nourished because of poor choice of foods. They became fat, yet were malnourished. Their food habits were such that the normal amount of calories had not provided enough of the necessary nutrients, so they felt unsatisfied—the “hidden hunger” of the malnourished.

Unfortunately, we humans do not know instinctively what foods we need most, so we eat more of the same foods we are accustomed to. Thus in Iowa some pregnant women were getting enough of each nutrient studied, at the expense of getting fat from too many calories. Many others just got fat, but were still malnourished, because even double the amount of the foods they liked to eat did not provide the essential nutrients.

Very few of these pregnant women got enough calcium for their own bones, not to speak of getting enough for the baby’s. Almost as many ate far too little protein. Of the common vitamins, riboflavin and vitamin C were in short supply for many. A quart of milk a day would have given the great majority of these women sufficient added calcium, protein, and riboflavin to have made their supply
of these nutrients ample. More fruit or fruit juices and salad vegetables would have improved their vitamin-C intake. Unfortunately, they turned to more baked goods to satisfy their hunger, often at much greater financial cost than the milk and fruit. Only because the flour was enriched the women got sufficient iron and thiamine and some riboflavin from the large amounts of breadstuffs they ate.

All of these women were eating the same foods as they had eaten since childhood. They had not altered their general diet pattern. That is generally true. Meal patterns tend to go on in families for generations, modified a bit in each generation by the likes and dislikes of the husband. Unfortunately such modifications are usually downward. Foods not liked by either member of the young family are omitted and often no substitution is made. So the number of foods eaten grows steadily less and the family nutrition suffers.

But that is not all of the story. Studies of school-age children show that grade-school children can be taught what foods they need to eat and they will learn to eat them both in school lunches and at home. High-school boys will generally eat almost every food available. High-school girls, however, are socially conscious, afraid to eat for fear they will get fat or have poor complexions, yet torn by the urge to go with the crowd and eat as the crowd does in its special "hangouts." The boys will go home after such snacks and still eat a full meal at home, but the girl tends not to eat her meals at home if she has snacked after school. Then she is hungry again before bedtime and snacks again. Unfortunately such snacks rarely provide much besides calories and the girl's nutrition suffers at the time she most needs a good diet to complete building her own body.

Effects on Pregnancy

If she follows a nutritious diet over several months, such a girl can achieve good nutritional status. But if her poor eating habits continue, she does not really complete building her own body until many years after growth has stopped. Many girls marry and start a family at a young age. With their own bodies incomplete, they have to build both a new body and also sufficient muscle and other tissues in their own bodies to carry the fetus and to deliver it. The young mother tries to do this without changing her food habits, except in regard to quantity. It is no wonder that many come to grief.

In the Iowa study of pregnant women, it was observed that the well-nourished women delivered pre-maturely only when they had twins, or had had five or more babies at closely spaced intervals. In either case, the babies were usually in good condition and only a pound or so under the weight which marks prematurity. All the babies thrived.

On the other hand, in the same study the group whose diets were poorest were most apt to deliver prematurely, and most of them were young mothers, delivering their first to third child. All of these babies were single births; there should have been no excessive load on the mother had she been well nourished. Since premature delivery might be nature's way of sparing the mother a burden beyond her capacity, it seems that these young women's bodies were poorly equipped to provide nourishment for a new life.

The study also showed that the prematurely born babies of the poorly nourished mothers were smaller and weaker than those prematurely born to better-nourished mothers. Several of these very small babies were not strong enough even to live, despite modern care and feeding. Some of the babies were malformed. There are many causes of malformation. Poor nutrition is one cause, difficult to prove for humans but well known in animal studies. Though poor nutrition is not yet proved as a cause of congenital malformations in human infants, the likelihood that it does cause malformation is so great and the preventive is so simple that no mother should take the risk. Had the young mothers of our study been better nourished, more of the babies probably would have been carried to term and would have lived; those who lived would have been stronger; and it seems possible that some, at least, of the deformities could have been prevented.

Studies of adolescent girls in Iowa showed that previous nutritional status affected their ability to utilize nutrients when they were given a good diet. Girls who had been well fed through midchildhood were able to retain ample amounts of the nutrients provided in good diets. Girls who had been poorly nourished through midchildhood were unable to utilize the nutrients of a good diet, especially such nutrients as calcium, which are not easily absorbed. Several months of good feeding were necessary to make these girls as efficient in use of their food as were the well-nourished girls. Once they achieved that improved efficiency they maintained it easily. Both groups of girls were adversely affected by emotional disturbances. Retentions dropped sharply when the girls became overexcited.

Many girls have their first child in mid-teens,
while they are still unstable emotionally. It seemed probable to Iowa nutritionists that added emotional problems of marriage and early pregnancy could only worsen the nutritional state of a girl already poorly fed. Therefore we studied the ability to retain nutrients of girls of 14 and up who were illegitimately pregnant. The majority of the group came from homes wherein an illegitimate pregnancy would cause emotional concern. However, two of the girls, who were socially immature and of low intelligence, showed no signs of distress about their pregnancy. Both of these girls had been poorly fed before the study; yet both were able to retain ample nutrients for their infants and for themselves. The girls who were worried or distressed over their circumstances did not utilize their food as well; one girl, almost despondent over her situation, lost nutrients heavily from her own body and ended her pregnancy with her own skeleton having lost twice the minerals needed by her infant.

These findings suggest that: (1) if the young mother is emotionally stable, she is apt to be in an excellent position to improve her own nutrition, as well as her baby’s, by eating a good diet during her pregnancy; (2) the favorable effect of pregnancy hormones on increasing the absorption and storage of needed nutrients by the pregnant woman can be wholly nullified by serious emotional problems in the pregnant mother.

Using a different approach, a group of obstetricians in Aberdeen, Scotland, studied the effects of the lifetime nutrition of the mother on the physical state of her baby. They started with the assumption that girls who had been poorly fed since infancy would be more apt to be stunted and would not be as strong as girls who had always been well-nourished. They divided all the mothers of first-born children born in the city in one year’s time, about 3,500 of them, into three groups according to height, and subdivided each group according to general health. Then they listed the result of pregnancy among the women of each group.

In the study the lowest rates for prematurity (32 per 1,000 live births) and for deaths during the first week of life (19 per 1,000 live births) were found among the infants of the taller women in good general health. Infants of mothers in each group studied showed steadily increasing prematurity and death rates as the height and health of the mothers decreased. The poorest group, women under 5 feet 1 inch, who were in unsatisfactory health, had the highest rates (152/1000 and 64/1000, respectively) for premature delivery and early death of infants. Poor nutrition throughout the mother’s life had increased the chance of prematurity in her infant five times, and more than tripled the chance of his death before one week of age.

### Changing Habits

The evidence is strong that the best insurance any baby can have for life and health is to be born of a mother who has been well nourished all her life. Thus, improvement in nutrition of prospective mothers at any age, if maintained, will result in improvement in infant health. Certainly it would be easier for a young woman to drink a quart of milk and eat more fruit and vegetables during pregnancy than to care later for a frail baby, susceptible to infections and difficult to feed.

Malnutrition is, of course, not the only cause of premature delivery by a mother. It is, however, easily preventable at moderate cost. Daily ingestion of adequate amounts of nutritious foods by girls and young wives would decrease strikingly the incidence of prematurity in their infants. The foods

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**FOOD RECOMMENDATIONS FOR WOMEN**

**Nonpregnant and Pregnant**

Excerpted from

Described for the maintenance of good nutrition of healthy persons in the United States. Allowances are considered to apply to persons normally vigorous and living in temperate climate.

<table>
<thead>
<tr>
<th></th>
<th>Nonpregnant, age 25, weight 128 lb, height 64 in.</th>
<th>Pregnant (2d half of pregnancy)</th>
<th>Lactating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calories........</td>
<td>2300</td>
<td>+300</td>
<td>+1000</td>
</tr>
<tr>
<td>Protein (gms.)</td>
<td>58</td>
<td>+20</td>
<td>+40</td>
</tr>
<tr>
<td>Calcium (gms.)</td>
<td>0.8</td>
<td>1.5</td>
<td>2.0</td>
</tr>
<tr>
<td>Iron (mg.)</td>
<td>12</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Vitamin A (I. U.)</td>
<td>5000</td>
<td>6000</td>
<td>8000</td>
</tr>
<tr>
<td>Thiamin (mg.)</td>
<td>1.2</td>
<td>1.5</td>
<td>1.7</td>
</tr>
<tr>
<td>Riboflavin (mg.)</td>
<td>1.5</td>
<td>2.0</td>
<td>2.5</td>
</tr>
<tr>
<td>Niacin 1 equivalent (mg.)</td>
<td>17</td>
<td>+3</td>
<td>+2</td>
</tr>
<tr>
<td>Ascorbic acid (mg.)</td>
<td>70</td>
<td>100</td>
<td>150</td>
</tr>
<tr>
<td>Vitamin D (I. U.)</td>
<td>. . . . . .</td>
<td>400</td>
<td>400</td>
</tr>
</tbody>
</table>

1 Niacin equivalents include dietary sources of the preformed vitamin and the precursor, tryptophan.
needed include milk (or dry nonfat milk solids), organ and other meats (the cheaper cuts of meat are just as nutritious as the more expensive ones), cheese, eggs, fruits, and vegetables, including salad and other greens. Such foods can be purchased as cheaply as the cakes, pie, and fancy rolls too often purchased instead.

No one wishes to change his or her settled food habits; the advantages of change must be made very clear. The greatest advantage is most obvious to the young pregnant woman—the health and vigor of her coming baby. Then, if ever, the young mother will be interested in improving her diet. She finds this easier and has a better foundation on which to build if she has had good food habits in her early life.

However, the most difficult problem is to reach the adolescent girl. Appeal must be made to beauty, not health, for these girls, and nutritious foods must be made as easy, or easier, for them to get as are foods of poor quality. If fried starchy foods and soft drinks only are available at the teen-age "hangout" those are the foods they will eat, to the exclusion of more nutritious foods served at home. Yet it is most important that the adolescent girl be maintained in good nutrition, if she is to arrive at pregnancy with her own body completed and with sufficient stores to provide ample nutrients for her infant during the critical first weeks of pregnancy when the separate organs are forming.

No discussion of improvement in nutrition of mothers-to-be is complete without mention of the role of the young father-to-be. When the young pregnant woman is given dietary advice, the common answer is: "I can't. I'd have to cook two separate meals, for my husband eats so few of these foods." Sadly enough, they speak the truth. Though foods are so plentiful in this country, children are allowed to grow to maturity eating only a few foods, and those cooked in one or two ways.

A potent argument for the young husband is to remind him that the coming baby is his, also. It is his wife's duty to eat what she needs to bear a sturdy infant and it is his duty to see that she does. Taking this responsibility will not injure him in any way, and it may even help the next baby. If an expectant father is asked to become guardian of his wife's diet, he usually assumes the responsibility, though it forces him to taste and to eat many foods he has never tried to eat before. After several months of eating well-balanced meals, the two young people have learned that they both feel better and are stronger than with their old haphazard ways of eating. Another family has started on the road to good nutrition.

Priceless gifts for a family to pass on to a child are a strong, well-nourished body and good food habits. A new family tradition of food habits, this time habits of choosing foods that lead to good nutrition, can be started best when a new family is starting. The mother who teaches her boys as well as her girls the wisdom of good nutrition, the proper rating of different foods according to their nutritious qualities, and the value of learning to eat a wide variety of foods to insure adequate intake of all nutritional essentials is upgrading the nutrition of her community and that of its unborn children.

7 Jeans, P. C.; Stearns, G.; et al.: Unpublished data.
THREE artificial separations complicate most efforts to provide health services to child-bearing and child-rearing families. These are:

1. The schism between obstetrics and pediatrics, resulting in the care of the mother being separated from the care of the child.

2. The consideration of the mother or child apart from the father and total family.

3. The separate functioning of the many professions which have something to contribute to total family health.

During the years 1950 to 1956 a clinic known as the Family Health Clinic at the Boston Lying-In Hospital attempted to find out how these artificial separations might be minimized. This clinic was supported in major part by a grant from the Association for the Aid of Crippled Children. Members of the regular staff of the department of maternal and child health of the Harvard School of Public Health, and of the Boston Lying-In Hospital, took part in the experiment. Analyses and preparation of the accumulated data were made possible by special grants from the Charles H. Hood Dairy Foundation of Boston, and the Milton Fund, Harvard University.

This paper will review some elements and implications of the pediatric experience.

The clinic was organized under sponsorship of the department of maternal and child health of the Harvard School of Public Health, the Boston Lying-In Hospital, and the Children's Medical Center of Boston, as a pilot study to explore the use of a multiprofessional approach in a single obstetric-pediatric clinic. Patients were selected from the hospital's regular outpatient clinic, criteria being that they be primiparous married women, free of unknown pathology, and living within accessible distance of the service. The clinic was open to mothers, fathers, and children, and offered family-focused service throughout the entire period of pregnancy, and for at least a year afterward.

Over the period of 6 years prenatal, postnatal, and well-child health supervision was supplied to 116 families having their first babies and 25 of the same families during subsequent pregnancies.

**Clinic Operation**

The Staff. The clinic team gave service of the various kinds pertinent to present-day maternal and child care. Obstetricians, pediatricians, nurses, nutritionists, and social workers provided direct service to patients and consultation to each other. A psychiatrist served as mental-health consultant to the rest of the team.
Method. Prenatal services began early in pregnancy for the majority of patients. Pediatric-clinic visits began when the baby was about one month old, and proceeded at monthly intervals during the first year. Both obstetric and pediatric services were provided with considerable flexibility and frequency, varying with the disciplines involved and with needs of individual families. As far as possible, families were cared for by the same personnel throughout their experience in the clinic. However, the pediatrician started initial contacts with the families as a member of the prenatal service team.

Usually the patients were seen in each visit by 3 or 4 staff members who assembled their observations into one record. Teamwork was facilitated by pre- and post-clinic case conferences of total staff, by casual or planned individual conferences between staff members, by administrative staff conferences, and by additional case conferences with the mental-health consultant.

Premises of Operation. The obstetric and pediatric care was given on the premises that:

1. Pregnancy, child bearing, and child rearing comprise a continuum.
2. These natural processes tend to intensify the problems of daily existence and to introduce new problems posing challenges that can literally make or break a family.
3. The way in which each new challenge is met has immediate and long-range effect. Mastery tends to move the family on to further success, whereas failure tends to move the family in the opposite direction.
4. Logical services consist of timely measures enabling families to master the crises of pregnancy and child rearing and in doing so not only to prevent complications but to derive strength from the experiences.

The project experimented with methods of providing these services as an integrated function of several professions working together.

Pediatrics In the Clinic

The clinic goal was to launch a life, and with that life new dimensions in the life of a family—not a 9 months’ task, but one extending throughout childhood—a continuum without a real end point even at the elected time of ending well-child care.

It made an effort to seek out and utilize the powers of growth and development for the benefit of child and family—the fetal growth and development, the parental maturation that takes place during and after pregnancy, and the subsequent growth and development of the child.

The pediatricians were participants from the beginning of the prenatal period onward. They tried to get acquainted with the parents during the pregnancy and to be of informational assistance and a source of relaxation and comfort by stressing that the parents would have their continued support after the child arrived. After the child was born, they proceeded with standard child-health supervision practices, with every phase of care geared to the growing and developing parents as well as to the growing and developing child. They used the usual tools of well-child supervision to avert death, prevent disease, and prevent distorted parent-child relationships. They stressed promotion of child and family health by channeling services through the parents as well as the child.

The pediatricians made steady, systematic search for parental strengths and tried to help parents become aware of those strengths, pointing out to them in visit after visit actual evidence of how they themselves were growing, developing, and functioning in their parenthood. Parents were helped to understand how the quality of parenthood gradually develops through interaction between themselves and the child and between themselves as husband and wife becoming also father and mother.

In Loco Parentis. As is so often the case today, the parents served lacked the supports that an extended family provides. Many were far from their own parents, and most grew up in small families where they had had little experience with child bearing and child care before they entered these adventures themselves. Many were very young. The family aspects of the Family Health Clinic were thus important in the sense of the staff’s working with the whole family, and also in that the clinic itself served as a sort of “family” for the patients.

Protection of Parents. Advice on child care, especially in the newborn period, was kept simple. A conscious effort was made to strip daily routines of nonessential practices that might confuse, fatigue, or even overwhelm inexperienced parents. New routines of care were introduced gradually and were adapted to the parents’ confidence and competence to carry them out.

Specific recommendations were made for maternal rest and for parental recreation. The fact that few
parents included recreation in their planning seemed closely related to a paradoxical time-outlook many of them manifested. While they tended to regard the baby and the demands of parenthood as an immediate crisis calling for an all-out effort on their part even to the exclusion of physical rest, recreation, and adult companionship, at the same time they looked on babyhood as an interminable and demanding period of dependence. The clinic's pediatricians attempted to free them from such unrealities by gearing child-care advice to simple essentials and helping them set a comfortable pace that they could have some hope of maintaining throughout their child's growing and changing childhood. In these efforts the pediatricians attempted to convey the sense of the moment and the sense of motion.

The Sense of the Moment. At each clinic session the pediatricians elucidated the transitory phenomena of infancy, using every opportunity in the examination, in the interview, and in anticipatory guidance to present the brief, lovely moments of infancy and early childhood. This was done because many developmental phases last only a few days yet are momentous milestones and should be made visible to nurturing parents so that they can find enjoyment and encouragement in them as does a gardener with the first spring crocus. The purpose was to help the parents to become progressively perceptive and increasingly aware of the child as a separate and unique individual. Thus, the child would be encouraged to become increasingly independent and the parents to become less dependent on the clinic.

The Sense of Motion. In striving to convey the sense of motion, the pediatricians during the physical examinations, history taking, and anticipatory guidance always linked the immediate visit with the preceding month and the month to come, so that the parents could perceive the dynamics of the baby's progress and their own development. The clinic record was employed as a tool of parental development. Notes made of parental comments and their concerns of the moment were judiciously used at subsequent visits to illustrate progress.

Fathers. Fathers were not in the clinic as much as the staff might have wished, since the hours conflicted with most of the fathers' working hours. However, such paternal attendance as did occur convinced the clinic group of the desirability of arranging services to encourage father participation.

The clinic staff saw the father's role as the stabilizing, nurturing head of the family. This view was supported by the fathers' responses when the examination of a child was conducted in the presence of both parents and with their collaboration. Time and again paternal cooperation proved a facilitating force in the growth of family strengths and unity. Conversely, in some situations in which fathers were unable to come to the clinic, well-meaning wives used the clinic as a threat to bring the husband to their own way of thinking, thus converting the potentially unifying influence of the clinic into a source of family conflict.

Siblings and Other Relatives. Additional pediatric values were inherent in the fact that in many instances the clinic served more than one child in the same family. There was not only a salutary carry-over from pregnancy to pregnancy and child to child, but also benefits derived from seeing brothers and sisters at the same time. For example, in helping a family simplify child-care practices, it was better to plan for the family as a whole than to drift into prescriptions of overelaborate attention to one child. In helping families whose children had behavior problems and in which emotional interrelationships were strained, the fact of knowing the various members personally helped the pediatricians to custom-fit their counsel.

The overall family approach included consideration of the influence of a number of relatives—the babies' grandparents, aunts, and uncles. Sometimes these were members of the household, or neighbors. Often they lived far away, but entered the family scene in visits of momentous influence. Clinic experiences indicated that the family's relationships with these relatives were almost never neutral, and that whether they turned out to be of a strengthening or destructive nature could be influenced considerably by the clinic.

Shared Perceptions

In parent-focused pediatrics, the better the pediatrician comprehends the parents the better work he can do. In this clinic, the pediatricians' comprehension was facilitated by getting to know the parents during the prenatal period, by working with the whole family, and by knowing its members not only through pediatric contacts but through the selective perceptions of various colleagues of other disciplines. Case conferences provided the pediatricians with additional information on family progress from other workers and with an opportunity to convey their own findings to their other colleagues for use in further parental support.
Analysis of clinic records reveals that individual staff members gained quite different impressions of the parents, and that the pooled impressions were often different from any of the single ones. The nature of the impressions seemed to be molded by the interpersonal relationships between the patients and the staff members and to be influenced and altered by numerous other factors: the staff members’ professional discipline; the sex of the worker; the personalities of workers and patients; and what and how much the workers and the patients had in common.

The patients seemed to make their own distinctions in the kinds of material suitable for presentation to one worker or another. For example, they might talk freely with the social worker about financial hardship but not even mention the subject to another worker, or they might tell the pediatrician about their fear of a possible congenital anomaly without mentioning this fear to anyone else. The pooled perceptions gave the pediatricians many clues concerning subsequent developments in child care in specific families and as time went on impressed them with the inestimable value of such predictive “previews.” They found that they could start work with a newborn child already better acquainted with that child and his family than they could ordinarily hope to become within several months’ time in separate practice.

Case analyses indicate that these shared prenatal observations gave the pediatricians from 6 to 40 pertinent clues per family. Families were identified who could best make use of a structured, highly scheduled type of infant care, as were families who were likely to do better on a more relaxed regime taking their cues from their child from day to day.

In addition to these positive possibilities, the team’s shared insights provided danger signals varying from useful clues to impending minor pediatric predicaments to warnings of potentially serious family strain to which a pediatrician might otherwise have unwittingly added.

**Values of Teamwork**

Every staff participant in the clinic undoubtedly benefited from the privilege of working with other professional disciplines and with medical colleagues of various specialties, but the pediatricians seemed unusually favored. In the first place, pediatrics shares to a high degree the specific concerns of each of the disciplines and specialties which were represented on the team. Like the nutritionist, a pediatrician is characteristically concerned with feeding. In working on a team with a nutritionist, the pediatricians had an opportunity to increase their competence in advising on feeding practices. One happy aspect of this collaboration was the development of feeding practices geared to stages of children’s motor, social, and adaptive development.

The teamwork between the pediatricians and the team’s nurses was established with relative ease because of their traditional pattern of working together. The effects of their relaxed attitudes were noticeable in conversations in which they examined their former practices with new viewpoints.

Pediatric benefits from association with the social workers can best be likened to “depth perceptions.” Through the social workers’ explorations and understanding of the patients’ situations, the pediatricians could better comprehend the place each child occupied within his family. Such comprehension is always a prerequisite to pediatric diagnosis and planning, but generally one which the pediatrician has to manage to get as best he can through his own data gathering and insight. With the privilege of social-work collaboration, the pediatricians not only had a wealth of data at their fingertips but had benefits of the kind of perception and interpretation made possible by social-work training.

As always, the representatives of each discipline saw a situation through the eyes of its own profession and pulled out data which might not have been visible to or impressed an observer of a different orientation. This enabled fellow workers to view their own findings in a different light.

For instance, in the course of maternal interviews the nutritionist often became aware of the mother’s attitudes toward her own diet—attitudes which frequently affect the way a mother feeds her child—and could let the pediatrician know and thus be able to reckon with influences which might distort specific infant-feeding practices. Thus, pediatricians were alerted when a mother known to have restricted her own diet to a monotonous range of foods seemed reluctant to introduce new foods, tastes, and textures to her baby.

The pediatricians were continually impressed with the pediatric good that nonpediatric workers accomplished when these workers added a few per-
their own work as they gradually incorporated new points of view and methods acquired unconsciously by working with colleagues of several disciplines. Their interviews with parents, for example, were considerably affected by an awareness, consistently stimulated by the mental-health consultant and the social workers, of the stresses the parents were experiencing.

Staff members of the three medical specialties represented in the project—obstetrics, pediatrics, and psychiatry—found in working together that they could do their own tasks better because of something gleaned from their colleagues' contacts with the patient. As the project went on, each became aware that in addition to giving them the advantages of being with other professions the clinic was providing them with an unusually pleasant form of postgraduate medical education.

The values of the pediatricians' working with the obstetricians have been mentioned in terms of the unification of the obstetric-pediatric continuum. Another type of unity also occurred. In a partnership composed solely of obstetricians and pediatricians conspicuous differences between the two specialties might stand out. However, in this experiment, in which both groups worked with many other professions, they found themselves strongly allied by virtue of their shared common medical background. Time and again they interpreted and reinforced each other's clinical roles to other members of the staff. The act of serving each other in this regard seemed to diminish the differences in viewpoint between these medical specialties. The same situation held true between these physicians and their other medical colleague, the mental-health consultant.

The psychiatric consultant was thoroughly versed in the chief attributes of normal family mental health, and so able to direct the team's attention to the many healthy phenomena appearing from the prenatal period onward. While they were alert to signs of incipient trouble, their principal contribution was an awareness of signs of strength. In a review of the cases one is struck by how astutely the psychiatrist identified strengths in the parents in the majority of cases and guided the rest of the staff in the judicious nurture of those strengths.

Perhaps the major obstacle overcome in this multidisciplinary project was the gradual effacement of some of the stereotypes that representatives of the various disciplines have of one another. For example, the physicians had opportunity to see at first hand how social caseworkers use techniques of "ego support, clarification, and modification of environment," as well as educational methods. The social workers, for their part, saw that pediatrics is not limited to advice on the mechanics of child care, but shares social work's concern with the reinforcement of family capacities to cope with stress. All the disciplines became aware that each profession has ethical standards respecting patients' privacy.

The consensus of the participants as the project ended was that the clinic's advantages were greater than its problems. The majority of the latter had to do with the development of methods required by a multidisciplinary group learning to work together and with whole families, and could largely be met by administrative provisions.

Pertinence to Public Health

A clinic of this sort might be a helpful adjunct to a public maternal and child-health program as an excellent service to a group of families, and as a means of raising standards of care in the rest of the program and perhaps elsewhere. Possibilities would depend on how much the participants function elsewhere, and how much the project could be used for preservice and inservice training.

One of the most important features is the carry-over of insights gained in the experience into the participants' other functions, for the participants undergo personal and professional maturation which makes itself manifest in more effective functioning wherever they are.

As for carryover of method into another setting, this could be as little or as much as the other setting permitted. It could vary from a single improvement such as record linkage making the mothers' prenatal and obstetrical records available in the child-health work, up to a full-scale duplication of the clinic's total approach.

5 Bernstein, R.; Cyr, F. E.: A study of interviews with husbands in a prenatal and child health program. Social Casework, November 1957.
PERINATAL CASUALTIES

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The period of human existence between the end of the 19th week of gestation and the end of the first month of postnatal life presents a greater hazard to the individual than any other period from then until old age. The magnitude of the problem is illustrated by the fact that deaths of viable fetuses and newborn infants make up about 10 percent of all deaths occurring in the United States today.

As great as these losses are, they represent only a part of the total problem of casualties associated with birth. It is now abundantly evident that the factors responsible for dead fetuses and infants and those responsible for damaged infants are very much the same. Thus, there is an aftermath or "continuum" of the birth process that is of grave concern. Infants with sublethal injuries may develop a number of potential and real neurological sequelae, including epilepsy, mental deficiency, cerebral palsy, and even abnormal behavioral patterns appearing in later childhood.

Any definition of casualties connected with birth process must be sufficiently broad to encompass a wide spectrum of events, including fetal death in utero at all stages of gestation, death of liveborn infants during the first month of life, malformation, and permanent disability because of some type of injury before, during, or immediately following the birth process. The period of time covering the total birth process is referred to as the perinatal period, and mortality and morbidity incurred by fetuses and infants during this span of human existence are designated as "perinatal casualties."

The concept of a perinatal period is useful in many ways, but because it has been only recently widely employed there has been confusion about the time period involved. The definition proposed by the American Medical Association—from the 20th week of gestation through the 28th day of life—is receiving wide acceptance.

In a total appraisal of reproductive wastage, however, it is necessary to consider the loss of products of conception at any stage after the union of the two pronuclei in the fertilized ovum, as well as the antecedent genetic and environmental background of the mother. Patients who have experienced reproductive failure frequently have a similar etiologic background with patients showing infertility, pathologic manifestations of menstruation, and other gynecological disorders.

The recurring nature of these interrelated problems explains the fact that about one-fourth of all patients experiencing reproductive losses account for nearly two-thirds of all the losses. The incidence of previous gynecological symptoms in these women is high, indicating that preconceptional care is an integral part of obstetric care. Such care or its lack has a direct influence upon the incidence of perinatal casualties, both immediate and remote.
Clearly then, any thorough appraisal of the problem of perinatal casualties requires a multidisciplinary approach. Attacking the problem of fetal and maternal welfare must be part of the general health program and cannot be relegated to any single group of medical scientists. The problem is primarily one of community health. It involves medical scientists, clinicians, nurses, and public or community health workers; and through its relation to socio-economic status, it becomes the concern of demographers, nutritionists, sociologists, economists, political scientists, and, of course, the general public.

**Extent of Problem**

Perinatal casualties do not lend themselves to precise summation, but they are believed to exceed 900,000 annually in the United States. This estimate includes disability immediately or subsequently apparent as an aftermath of the birth process as well as the mortality in the perinatal period.

Since reliable figures on morbidity and remote sequelae do not exist, advances in coping with the problem must be judged from mortality statistics, available from the Public Health Service's National Office of Vital Statistics. Between 1933, the first year for which such statistics are available for the Nation as a whole, and 1956, the infant mortality rate (deaths under 1 year of age) dropped 55 percent. All age groups shared in the reduction but in differing degrees, the greatest reduction occurring in the age group 6 to 11 months and the least in the group under 1 day, at 1 day, or 2 days old.

Despite reductions, deaths in the perinatal period still represent an enormous loss of human life. Today deaths of viable fetuses and newborn infants come to about 165,000 each year in the United States. An even larger number of deaths, approximately 425,000 annually, occur as spontaneous abortions in the previable stages of pregnancy. There are indications too that the sharp decline in perinatal losses which took place during the years 1935 to 1945, an era of rapid medical and social progress, has gradually leveled off during the present decade.

Although premature birth occurs in less than 10 percent of all pregnancies terminated after the period of fetal viability, prematurity is associated with more than one-half of all perinatal deaths. In New York State at the present time about 60 percent of the fetal deaths of more than 20 weeks' gestation and about 75 percent of the 6-day postnatal deaths occur in fetuses or infants weighing 2,500 grams or less at delivery. In upstate New York, during the period 1945–54, the neonatal mortality rate adjusted for birth weight declined by more than 30 percent, but the greatest decline occurred among the larger infants. No decline occurred among infants weighing less than 1,000 grams.

**Role of Vital Records**

Many public health agencies are attacking the problem of perinatal loss, through the continuing analysis of the data available from fetal, maternal, and infant death certificates and livebirth certificates. A major objective in such analyses is to show where knowledge is lacking in order to stimulate further research and study. Although there are important sources of data in hospital material, or from obstetrical-statistical cooperatives, a multidisciplinary attack on perinatal losses requires the exertion of every effort to correct deficiencies in the procurement and tabulation of data from vital records.

Indications are that the quality of death certificate data for perinatal deaths could be improved by a more intensive study of available clinical records and by use of data on pathological conditions, especially in assigning causes of death during the neonatal period. A recent study found that in 40 percent of the fetal and infant death certificates submitted to the Baltimore City Health Department by a hospital, the cause of death given failed to agree with the cause given on a special certificate based upon careful study of the findings on clinical and pathological conditions and the comments of a committee of medical experts.

A comparison of the percentage distributions of the causes given on the special and other certificates showed the following:

1. Fetal deaths were ascribed to causes and conditions in the mother about twice as often on the special certificates as on the others.
2. The frequency of causes determined in fetus, placenta, and cord was about the same on the different sets of certificates.
3. Fetal deaths were ascribed to unknown or ill-defined causes less frequently on the special certificates than on the others.

For neonatal deaths agreement between the special and original certificates was only 46 percent, excluding the rubric, hyaline-like membrane disease, which was not used when the original certificates were coded. Infection of the newborn was also found more frequently on the special certificates than on the others.
To evaluate properly the frequency of specific causes of perinatal death or to compare perinatal mortality rates, one must know the incidence of such multiple factors as race, parity, age, economic class, and the proportion of maternal complications in the respective population samples. These factors are highly interrelated and are associated significantly with the infant's birth weight as well as the general reproductive outcome.

The Etiology

The determination of the causes of perinatal death is subject to peculiar difficulties. All methods of classification thus far devised have failed in one way or another. Present knowledge concerning maternal, fetal, and placental factors is not sufficient in all instances to identify and separate the specific causes. Almost one-third of all perinatal deaths are unexplainable through current study techniques.

The underlying cause of perinatal death often does not reside within the infant's body and so cannot be determined by autopsy alone. It may reside in the mother or in the placenta.

In recording each death every effort should be made to determine the underlying cause. If the cause is indeterminable, it is preferable to ascribe the death to unknown causes than to the ultimate clinical or pathologic condition. Certain fetuses and infants with insignificant pathologic findings may have been insulted by anoxia or trauma over a short period of time without being left with detectable signs. It is especially difficult to classify such cases when the clinical records are deficient. Any measure of success in determining the primary pathologic cause of death depends upon the correlation of a detailed pathologic examination with a reliable obstetric and pediatric history.

The initial stages of standardization of techniques, clarification of definitions, and classifications of death are indispensable to the task of reducing perinatal losses. Granting that there are serious limitations in our current classifications, they have nevertheless exposed the problems that need concentrated study.

Classifying Causes

Several large independent studies of perinatal mortality have pointed out the same major causes of death and have estimated their incidence in relatively the same order of importance.\(^7\,^8\,^9\,^10\)

The opinions concerning the relative frequency of various specific causes of perinatal mortality expressed in the following paragraphs are derived in large measure from the studies of Nesbitt and Anderson,\(^*\) carried out on clinical and pathological material from the Johns Hopkins Hospital.

Anoxia. Anoxia is responsible for more deaths in the perinatal period than any other etiologic factor. It may be considered the primary cause of death when interference in the supply of oxygen from mother to fetus has produced structural changes in the fetus or infant visible at autopsy. It may be derived from a variety of factors—the placenta, cord, maternal diseases, difficult labor, and other complications.

One-third of all perinatal deaths in obstetric departments that care for a high percentage of indigent patients are attributable to anoxia. Moreover, anoxia is the principal common denominator between dead and handicapped infants, only a matter of degree and duration of insult determining whether the infant is killed or merely damaged.

Birth Injury. Deaths from birth injury include deaths of fetuses and infants who die as a direct result of injury during the mother's labor or delivery, usually intracranial injury, and of those who die from intracranial lesions initiated by anoxia. Such injury is the cause of slightly less than 10 percent of the total number of perinatal deaths. In about three-fourths of such cases there has been some type of significant maternal complication. Intracranial lesions and hemorrhage attributable to anoxic injury are much more common in premature than in mature infants.

Malformation. Malformations incompatible with life are responsible for about 9 percent of all perinatal deaths. The incidence of malformations as a cause of death is much more common in premature than in term infants. There is a close etiologic relationship between malformations and a variety of reproductive problems, including fetal death, both early and late, certain neonatal complications, premature birth, and habitual abortion. Available evidence suggests that a faulty maternal organism is the common factor that creates an unfavorable intrauterine environment for the fetus. Only a small minority of these abnormal obstetric events seem to be genetically determined.

Abnormal Pulmonary Ventilation. The problem of respiratory insufficiency in liveborn infants in the first several days after birth includes immature lung tissue and hyaline-like membrane disease. Hyaline-like membranes in association with pulmonary
atelectasis (imperfect expansion of the lungs) are found in a large group of cases with abnormal pulmonary ventilation, which ranks high as a causative factor in neonatal death, particularly among premature infants. Nearly one-fourth of all deaths of premature infants during the neonatal period are attributable to pulmonary pathology.

A number of obstetric factors are associated with the incidence of hyaline-like membranes in the newborn. These factors are premature birth, maternal diabetes, and delivery by Cesarean section. The incidence is also increased in association with breech delivery, multiple delivery, and maternal toxemia, but it seems likely that a high incidence of premature birth in these conditions may account for this finding.

Infection. Considerable attention must be directed to all clinical and pathologic findings in ascribing infection as a sole cause of death, since infection, particularly pneumonitis, is a terminal finding in many infants dying of other conditions. Deaths that are properly classified as caused by infection should have infection reported as the underlying cause, not merely as an ultimate complication. Infection as a primary cause of death assumes major importance as a cause of death in the postneonatal period, but it accounts for only about 5 percent of the total perinatal deaths.

Pneumonia occurring within the first few days of life as a result of intrauterine infection is a rather frequent finding in term infants. Long labors, prolonged rupture of membranes, particularly when the fetus is of term size, and intrapartum fevers are often associated with contamination of the amniotic fluid with bacteria.

Septicemia also occurs in infants on rare occasions. Although still a relatively minor cause of perinatal mortality, outbreaks of infections due to penicillin-resistant staphylococci are becoming more frequent.

Erythroblastosis. Hemolytic disease of the fetus and newborn infant, caused by Rh factor incompatibility in the parents, is a relatively minor specific cause of perinatal death because of its comparatively low incidence. Moreover, there are striking differences in the incidence among the races. It is responsible for only one perinatal death in about 1,500 births in obstetric clinics caring for large numbers of Negro patients. In hospitals where the clinic population is predominantly white it occurs approximately three times as often or about 1.8 per 1,000 births.

Other Conditions. Apart from the major categories of perinatal death, there are occasional conditions which counted together are responsible for less than 1 percent of all perinatal deaths. They include such unrelated conditions as advanced ectopic gestations, fetal hydrops (accumulation of fluid) of unknown cause, congenital tumors, marked increase in intracranial pressure without evidence of intracranial lesions at autopsy, placental infarction, and complications of the umbilical cord.

No Abnormal State. After classifying perinatal deaths in accordance with these major categories, there remains a substantial number of deaths, perhaps as many as 30 percent of all, without demonstrable lethal factors to explain them. The great majority of such cases are fetal deaths in utero, usually occurring before labor. About one-fourth of these fetuses have been delivered of mothers having significant maternal disease, usually toxemia or diabetes. Improved techniques for the study of tissue antibodies (fluorescent microscopy) and of viral infections may decrease the number of unexplainable perinatal deaths.

Prematurity and Abortion

Prematurity should not be listed as a specific cause of perinatal death, although certain of the aforesaid causes of death are more commonly seen in premature infants. The major factors in perinatal death of premature fetuses and infants, in descending order of importance, are placental complications, abnormal pulmonary ventilation, toxemia, birth injury, malformation, and infection. However, the impact of the factor of prematurity upon neonatal mortality is evident in all of the specific causes of death. When birth weight is taken into account the death risk of liveborn infants born to mothers with placenta previa is 2½ times that of liveborn infants born to mothers with no obstetric complications, whereas if birth weight is not taken into account the risk is 13 times as great. Similar observations have been made in regard to abruptio placentae.

Although much is known of the physiology and pathology of early abortion, an understanding of the etiologic factors involved has lagged far behind advances in other areas of obstetrics. A multiplicity of mechanical, clinical, physiological, psychological, and endocrinological factors have been implicated as causes of repeated abortion. These factors may be considered under the rather broad heading, "faulty maternal environment." It has become increasingly apparent that faulty environment for the developing ovum and fetus may be a factor common to a broad spectrum of specific types of fetal wast-

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age, including early and late fetal death, premature birth, and malformation. Thus, it is important to subject patients who have demonstrated any one of these specific types of reproductive failure to careful study.

Great voids obviously exist in the understanding of many of the basic principles involved in perinatal loss. Autopsies must continue to be energetically sought, and emphasis must be placed upon the acquisition of better clinical materials.

Morbidity

The factors responsible for dead infants and the factors responsible for live but damaged infants are very much the same. Most studies show that premature birth, birth injury, third-trimester bleeding, placental complications, advanced maternal age, and intrapartum infection are frequent antecedents to delivery of infants with permanent neurological damage.

Eastman and DeLeon report that 78 of 96 cerebral palsied infants subjected to careful study were born to mothers who had significant maternal complications. This study tends to add additional support to the growing opinion that anoxia incurred perinatally is a major cause of cerebral palsy and other neurological sequelae. Current and prospective studies should offer a clue to the precise etiologic factors and to measures for prevention.

Factors in Prevention

The prevention of perinatal casualties is a joint responsibility of several health disciplines, including obstetrics, pediatrics, anesthesiology, nursing, hospital administration, and public health. The adoption of a multidisciplinary approach to the problem of perinatal casualties represents the initial step in its solution.

The second major factor in prevention is the wider application of what is now known about patient care. It is not always necessary to know the finite causes of disease or death in order to take effective measures to control them. Maternal toxemia is a classic example. It has been stated that meticulous prenatal care is likely to eliminate toxemia as a maternal complication before its precise etiology is understood.

Statewide statistics do not make clear the fact that some counties within the State may have rates far in excess of the mean perinatal mortality rate for the State. Such differences call for a look at differences in services.

The third major factor in prevention is the elevation of living standards among the underprivileged classes. Low standards of obstetric care, low standards of living, and ignorance go hand in hand. Measures directed toward providing adequate facilities, personnel, and lay education have a positive influence on perinatal losses. Better nutrition and housing, good sanitation and adequate financial resources to ensure a decent livelihood, equal opportunity for education, and expanded social rehabilitation are necessary tools in the reduction of premature birth and to greater fetal and neonatal salvage.

Preconceptional Care

There is reason to believe that correction of all demonstrable medical, endocrinologic, and other kinds of defects, including emotional problems, prior to and during pregnancy, will enhance the probability of fetal salvage. The outlook for patients who have a recurring factor responsible for a high rate of reproductive waste, particularly habitual abortion, may be considerably improved by appropriate therapy prior to conception. Thus, a fourth factor in the prevention of perinatal casualties is preconceptional care.

Specific and supportive therapy in chronic illness, attention to the patient's diet, hygiene, habits, and psychological status, and the correction of endocrinologic and anatomic defects are important. Public health agencies should support this broadened concept of obstetric care by developing community "preconceptional" clinics set up to evaluate women who have demonstrated reproductive problems.

Professional and lay education is a fifth major factor in prevention of perinatal losses. Public health agencies can assist the obstetrician immeasurably by offering courses of instruction, medical films, teaching aids, and a continuous educational program for expectant mothers. Medical centers can join with other health agencies in providing professional programs of postgraduate education for practicing physicians, intramurally or extramurally. A technic which has proved valuable is the perinatal conference, in which fetal and neonatal deaths are discussed by obstetricians, pediatricians, pathologists, anesthesiologists, and other interested physicians.

A continuing analysis of perinatal mortality and morbidity at the local level is imperative. Since the problems associated with reproductive wastage vary greatly from one community to another, effective preventive health programs in one area may not be directly applicable in another. Thus, the establish-
ment of perinatal mortality conferences on a community-wide basis is desirable.

**Obstetric Management**

A **sixth major factor** in prevention is the evolution of a clinical attitude in obstetrics which emphasizes conservative techniques of management as a means of avoiding anoxia and trauma.

Fortunately, in the majority of cases, the obstetrician can anticipate the underlying problem of intrauterine anoxia and so prevent or minimize it by proper obstetric management. When the fetus is subjected to anoxia from unavoidable maternal complications, an avoidance of multiple insults to the fetal respiratory center should be the primary objective during labor and delivery.

Space does not permit a detailed account of the management of specific obstetric complications. Suffice to say that dissemination of current knowledge concerning conduct of premature labor, judicious use of analgesic and anesthetic drugs, antepartal prophylaxis against toxemia, prompt recognition and treatment of medical illnesses, attention to and supplementing of diet, proper attention to iso-immunization, induced labor prior to term in selected cases, surrounding patients with safeguards of blood replacement and appropriate chemotherapy, proper evaluation of the pelvis, judicious use of uterine stimulation, and expert resuscitation and care of the newborn infant will do much to assure optimal perinatal salvage.

With few exceptions, the longer the fetus can remain in the uterus the better are its chances of extrauterine survival. Certain medical advances in the management of specific medical illnesses, such as heart disease, diabetes, infectious diseases, and tuberculosis, have made it possible for some patients under therapy to proceed further in pregnancy than formerly. However, it is likely that the major part of the problem of premature birth—untended by maternal complication in about 60 percent of the cases—is specific in nature and lies in the basic mechanisms of the smooth muscle cell and its metabolism as well as its neurologic and endocrinologic control.

The obstetrician must acquaint those entrusted with newborn care with any antecedent obstetric factors which may conceivably lead to intracranial injury through anoxia or trauma. The ultimate prognosis for the infant during the ensuing days, months, and years may in large measure depend upon the effectiveness of management during the critical minutes following birth.

Public health agencies should assist private organizations in providing clinic facilities for the prolonged followup of infants who responded poorly at birth or who were born under circumstances likely to terminate in remote sequelae.

**More Knowledge**

The **seventh factor** in planning for prevention of perinatal casualties is the continued acquisition of knowledge. Fully one-third of all deaths in the perinatal period are unexplainable through our current techniques of study. A very large segment of the combined fetal and maternal mortality in the United States is due to functional disorders of the uterine muscular structure. Yet, when we look into these problems of uterine dysfunction, we find that we are ignorant of much of the basic pathophysiology involved. Even a basic understanding of maternal-fetal-oxygen relationships, and the precise effects upon the fetus, both immediate and remote, are fragmentary.

Broad areas of research must be encouraged in regard to levels of human reproduction and comparative physiology. Application of the knowledge gained to the betterment of perinatal welfare will inevitably follow. But the problem must be solved ultimately through the coordinated activities of multidisciplinary groups.

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In following up clues provided by vital records, North Carolina demonstrates ways of...

IMPROVING MATERNAL AND CHILD HEALTH THROUGH STATISTICAL STUDIES

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While in recent decades maternal and infant mortality rates have dropped dramatically, the downward trend has apparently halted in both infant and maternal mortality. Figures from the National Office of Vital Statistics show that for the Nation as a whole in 1957, for the first time in two decades, the rate of maternal and infant deaths failed to decline. Moreover, the major causes of maternal mortality and their relative proportion as a cause of death has remained the same.

More intensive basic and clinical research as well as continued improvement in obstetric care is clearly indicated if we are to save mothers' lives and make significant headway with such morbid states in children as cerebral palsy, mental retardation, and other conditions associated with damage suffered before, during, or shortly after birth. Epidemiological studies are equally important, sometimes even more so. By pinpointing the location of a health problem, they help us to see not only the nature of problems that still need solving but also where modern knowledge and skills have not penetrated sufficiently to prevent needless tragedies. The effort to locate health problems was in fact one of the main reasons behind the development of vital statistics.

How epidemiological studies can be used to bring about needed improvements in maternal and child health programs may be illustrated by some of our experiences in North Carolina.

In North Carolina the law requiring the reporting of vital statistics, passed in 1913, resulted almost immediately in recognition of the tremendous mortality associated with childbearing. This in turn led to continuous and successive steps toward correction. For example, an early followup of vital statistics records showed that most of the women who had died in child birth had had no prenatal or other medical care and had been delivered by untrained midwives whose ability was suspect even in those days. Such revelations led to the establishment of prenatal clinics and licensing and training of midwives.

Today a number of studies concerned with finding the reasons for maternal and infant deaths are underway which have been initiated and are primarily supported by the North Carolina State Medical Society, with varying degrees of assistance from the North Carolina State Board of Health, the county health departments, local hospitals, and physicians. Others have been initiated by and are largely supported by the State Board of Health, with the support and cooperation of the various branches of organized medicine. Still others have been initiated by local health departments which call upon the State and medical society services as needed.

In 1945 the North Carolina State Medical Society
established a committee on maternal welfare to study any problem related to obstetrics and, more specifically, to review all the maternal deaths in the State. The findings of the committee have been widely used for presentation to medical students, medical societies, and, to some extent, lay groups. Another committee of the State medical society, the committee on child health, has been conducting a study of neonatal deaths in hospitals having a hundred or more deliveries each year. This committee has not yet published any of its data, but is preparing to do so in the near future.

In 1954 the State Board of Health initiated a study of perinatal deaths under a grant from the Children's Bureau. This, a continuing study, now is being made in six hospitals, three of them associated with medical schools. Reports on the methods of collecting and analyzing data and on some of the clinical findings have been used in the teaching programs of the State's three medical schools as well as in presentations before local and regional medical groups.

Vital Statistics Services

The State Board of Health provides active assistance to these studies. Its section on vital statistics locates death certificates, performs any necessary cross-matching with birth certificates, and tabulates and prepares data. County health officers and county public health nurses follow up the statistical work by procuring detailed information concerning each maternal death—an activity which has stimulated some county health departments to examine their own maternity and infant programs more carefully.

The section on vital statistics provides two other services, invaluable in helping county health departments and hospitals see where and how they need to bring about improvements. The first and oldest is the issuance of annual reports of the health activities of each county, prepared jointly by the State Board of Health and the county involved. These reports include population data, income data, number of professional people practicing in the county, natality, mortality, and morbidity figures, health department activities, health programs, and other items of interest and importance. If the county utilizes its annual report it can readily evaluate its own health situation and take needed steps for improvement. The section on vital statistics also publishes other, more specialized, annual reports which can be used as supplements.

The other service, now 6 years old, is the annual provision to the hospitals in the State of a summary of the data concerning perinatal mortality in the hospitals. Each hospital is assigned a code number, known only to those handling the data and to the hospital itself, so that the hospital can find its own standing in comparison with the others.

The hospitals, particularly the larger ones, have evinced considerable interest in these reports. Many have requested State consultants, especially the obstetric consultant, to be present at staff discussions of the report. A better response from some of the smaller hospitals can be anticipated as they develop separate clinical departments to which the reports can be transmitted rather than to the hospital superintendent.

A County Study

In spite of the meagerness of facilities and the superabundance of routine work in most of the county health departments in North Carolina, several important studies have come from county health departments, conceived and carried out locally with little or no outside consultation.

One young health officer began a series of projects designed to lower the high infant mortality rate in his county. Finding severe nutritional deficiency among maternity patients, he and his nutrition consultant devised a simple method of scoring diets which they used as an aid in evaluating their ob-

<table>
<thead>
<tr>
<th>Diet scores:</th>
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<tbody>
<tr>
<td>Good</td>
<td>3</td>
</tr>
<tr>
<td>Fair</td>
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<td>Poor</td>
<td>84</td>
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<table>
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<th>Amount of milk:</th>
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<tr>
<td>3-4 cups daily</td>
<td>4</td>
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<tr>
<td>2 cups daily</td>
<td>7</td>
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<td>1 cup daily</td>
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<tr>
<td>½ cup daily</td>
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<tr>
<td>None</td>
<td>71</td>
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<table>
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<tr>
<th>Hemoglobin:</th>
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<td>70 percent and over</td>
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<td>60-69 percent</td>
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<td>50-59 percent</td>
<td>9</td>
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Table 1—REVIEW OF DIET RECORDS, 300 PRENATAL PATIENTS, Halifax County, N.C., June—November 1956

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Provided by the Maternal and Child Health Library, Georgetown University
stetric patients. They then secured basic foods from Federal surplus commodities for those patients who had poor obstetric histories or a low dietary score.

Originally the plan called for a control group, but it soon became apparent that this would be impossible to secure. However, the planners went on with the program on the theory that any improvement observed in the mortality rate and in the general condition of the mothers and infants would be convincing evidence of its value. The practical training in nutrition prenatal patients are receiving as a part of this project may be even more important than any immediate benefits from the surplus food provided.

Outcome of Prematurity

The nurse consultant of the State Board of Health’s maternal and child health division has been encouraging county health departments to keep a registry of all infant deaths. Following an examination of the death certificates with the matching birth certificates, the county public health nurses interview the mothers, attending physicians, and others, obtaining considerable information not provided by the certificates.

As a result of this procedure, the nursing staff of one county health department initiated a continuing and intensive evaluation of its maternity program including an analysis of neonatal and infant death rates. By matching infant birth and death certificates, the department found that the problem of prematurity was greater than that shown by the usual vital statistics summaries. This led to an interest in the outcome of those premature babies who survived.

In the succeeding 7 months the nurses conducted a survey of school-age children who in infancy had been cared for under the North Carolina State program for premature babies. Of the total of 139 children, 106 were located and seen. The gross preliminary findings on these 106 children were quite startling, even when allowance is made for the fact that because of the demand for bed space the premature infants admitted to the State program were generally smaller than average and from families of low socio-economic status. Only 54 percent of these children were considered to be free of serious defect by their parents, teachers, and the examining nurses. Thirty percent of them presented severe impairment such as cerebral palsy, mental retardation, and major congenital anomalies. The remaining children exhibited a variety of auditory, ocular, and speech defects.

After obtaining this picture the county health department requested consultation from the State on two points: (1) How could the department improve its contact with premature infants after they were discharged from the hospital? (2) Would further followup study on these children be desirable, and, if so, how it could be carried out? The result of the second question was the formulation of plans to subject the children to intensive physical, psychological, and social examinations. A group of children who were comparably premature but had not been in the State program for premature babies, and a group of children who were full-term infants will be selected as control groups.

During the discussions concerning the desirability of such a study, it was pointed out that large-scale and expensive studies of premature infants have been carried out in other parts of the country. However, the decision was to continue with the study because of the value of replication and because of the importance of having specific local information. A local study, it was pointed out, would have more influence with the county commissioners, welfare workers, physicians, and other local people than would data from a medical center elsewhere.

Program Changes

A most successful study from the viewpoint of program planning has been carried out in a large rural county populated by Caucasians, Negroes, and Indians in about equal numbers. This county has over the years had high mortality rates of all kinds, including high infant mortality. Traditionally a large percentage of women have been delivered by midwives, whom the health authorities have had difficulty controlling.

In 1954 the health educator and nurse supervisor of this county’s health department began cross-matching infant birth and death certificates. Subsequently, the public health nurses interviewed the mothers or relatives of all the deceased infants and accumulated pertinent information from other sources such as hospitals, attending physicians, and birth records. The interviews were conducted as soon after the death of the infants as possible.

After the first year the information collected was summarized and certain patterns became apparent. Table 2 presents a summary of the infant deaths according to the attendant at delivery, the place of death, and the attendant at death.

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Provided by the Maternal and Child Health Library, Georgetown University
The study revealed that the infants of the mothers delivered by midwives had little or no medical care during their terminal illness, and that many of these babies were ill for some time prior to death. Their mothers had had little or no medical care prior to delivery in spite of the fact that medical care was available in the county for all pregnant women, including the indigent, as prenatal clinics were held by the health department on a monthly basis in eight different communities. Many of the families, moreover, could have afforded private medical care.

As a result of these findings, the local health department requested simultaneous consultation from the local physicians and staff members from the State Board of Health. It seemed to these consultants that the local women were simply not oriented to the need for good medical care. After a long meeting the consultants came up with the following conclusions:

1. A centralized maternity clinic which would meet on a weekly basis and would provide the best quality of obstetric care was imperative.

2. Some effort to arrange for many, if not all, of the clinic patients to be delivered in hospitals under proper medical supervision should be made. This would require further consultation with hospital management, the local department of welfare, and the county commissioners.

3. The need for a better followup plan between the hospital and the health department in respect to premature infants was the major pediatric problem, but one that could be solved without too much difficulty.

4. Since infant diarrhea or gastroenteritis was the major cause of infant deaths, changes in feeding techniques appeared to be sorely needed.

5. A well-baby clinic similar to the maternity clinic was sorely needed.

The plan to hold a single maternity clinic in the county health department building instead of the monthly clinics in eight different communities throughout the county brought considerable protest from the profession personnel, as well as the communities where the clinics had been held. Therefore, the centralization was begun slowly by closing down one clinic, but when it was discovered that the patients would go to a central clinic just as readily as to a clinic in their own community, the remainder of the clinics were closed, except for the centralized clinic at the county seat. While coming to the centralized clinic entails considerable travel for some patients, our experience with it has confirmed our conviction that the quality of the service rendered is far more important in the maintenance of clinic attendance than the distance which the patients have to travel. Subsequent experience in other counties has reinforced this belief.

A second consultation in this county, this time including representatives of the county medical society, the hospital, the local welfare department, and the county commissioners, produced some vital results. The physicians, who agreed to rotate through the clinic, were assisted in promoting the hospitalization program, since they were not anxious to provide prenatal care to patients who would be subsequently delivered by midwives. Moreover, there was the possibility, which became a fact, that medical students and a house officer from a medical school might be assigned to the hospital if a sufficient number of patients and adequate supervision were available.

The administrator of the hospital, a nonprofit institution, saw a financial advantage in admitting patients for simple delivery and a short post partum period while they had no complications instead of running the risk of getting them later as seriously ill obstetric patients; he also saw the possibility of collecting a portion of the cost of hospital delivery if the hospital's contact with the patient could be established in the ante partum clinic. The local department of welfare offered to assist, defraying as much of the expense as its financial limitations would

Table 2—INFANT MORTALITY ACCORDING TO ATTENDANT AT DELIVERY AND DEATH AND PLACE OF DEATH
Robeson County, N. C., 1954

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<thead>
<tr>
<th>Number of infant deaths</th>
<th>Attendant at death (percent)</th>
<th>Place of death (percent)</th>
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<tr>
<td></td>
<td>physician</td>
<td>Home</td>
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<tr>
<td></td>
<td>midwife</td>
<td>Hospital</td>
</tr>
<tr>
<td>71</td>
<td>100.0</td>
<td>100.0</td>
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<td></td>
<td>23</td>
<td>95.7</td>
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<table>
<thead>
<tr>
<th>Attendant at death (percent)</th>
<th>None</th>
<th>Physician-day of death</th>
<th>Physician before day of death</th>
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<td>100.0</td>
<td>19.7</td>
<td>26.8</td>
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<tr>
<td>100.0</td>
<td>74.0</td>
<td>8.7</td>
<td>17.3</td>
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permit. The county commissioners suggested the possibility of some financial assistance from the county if the demand did not become too great.

Results

In practice the plan has worked well for the past 2 years. At the doctors' request no patient is admitted to the clinic without a note from her physician, but the doctors have willingly provided such notes to patients who could not afford private care. However, the plan does not completely solve the problem of getting patients to seek early prenatal care, and the public health nurses, health educators, physicians, and others have continued all of their usual activities toward securing earlier medical care for this group. All of the people associated with the clinic feel that the high quality of professional care has helped in getting these patients into the prenatal clinics earlier.

The physicians also take turns making hospital calls on the clinic patients who have been admitted to the hospital. The clinic records are taken to the hospital after each clinic meeting and kept there until the next time the clinic is held, so that prenatal records are always available in the event the patient is admitted to the hospital in the interim. Attempts are made to train the mothers in proper feeding technique before they are discharged from the hospital—an activity not possible when mothers are delivered at home.

While there has been no significant change in the number of new patients admitted to the clinic as compared to the number admitted to the eight clinics previously operated, the average number of prenatal visits per patient has increased from two to five. Hospital deliveries have risen and midwife deliveries have fallen, continuing a trend which had begun even before the inauguration of the program. The perinatal mortality rate, however, has not improved as much as had been hoped, but in the past 2 years, the State as a whole has experienced a slight rise.

Many patients have paid a part of the cost of their hospitalization. Since the amount which they have paid is far below the actual cost, the county commissioners, without any formal agreement, have reimbursed the hospital for the difference. Teaching the students has been a tremendous stimulus to the private physicians participating in the clinic management. Student nurses from the nurses' training school associated with the hospital also attend the prenatal clinics.

In this county the study of maternal and child health problems and designing a program to correct them involved many lay organizations. The wide interest aroused is likely to promote better maternal and child health in the years to come.

In addition to the three specific programs described, other counties have utilized the techniques of matching infant death certificates with the birth certificates, to begin improvements of their maternal and child health programs. This technique is simple and inexpensive and can be utilized by even the smallest health department.

A pervasive theme expressed throughout the 1960 White House Conference on Children and Youth was the need for planning to meet problems brought about by the rapid and complex social changes taking place in our country. The extraordinary progress that has been made in the protection of the health of mothers and children during the past 25 years is a source of great gratification. But a few cracks in the structure of our health services have appeared recently which should remind us that the progress made can be lost unless society is responsive to these changes.

In 1957, for the first time in 22 years, the infant mortality rate (deaths of infants under 1 year per 1,000 live births) increased to 26.3 from 26 the year before; it increased again in 1958 to 27.1 and, according to provisional figures, declined only slightly in 1959 to 26.4. Large numbers of pregnant women are reported as coming to delivery with little or no prenatal care. In a paper given at the White House Conference, a professor of maternal and child health told of a study which showed that 34 physicians serving child health conferences in one city spent an average of 4 minutes with each child. The resources in that city as in so many others have not been increased to keep up with the increase in the child population.

A study conducted in California a few years ago indicated that the health supervision of 20 percent of the infants in the State involved no more than one visit, if any, to a physician, and that 36 percent were considered adequately immunized against diphtheria, pertussis, and tetanus.

Paralytic polio in recent years has become predominantly a disease of preschool children of low-income families, but only about one-half of the preschool population in this country is adequately immunized against it.

Showing Progress

We have made little progress in decreasing perinatal mortality and in preventing handicapping conditions among children which may be traced to prenatal or natal causes. We have the information, however, which, if applied, would reduce the number of such perinatal casualties. We know that premature birth is more apt to be accompanied by neurological damage to the infant than full-term birth. We know that there is an association between inadequate prenatal care and premature labor. In the District of Columbia, for example, where the incidence of prematurity is about 10 percent for the city as a whole, it is 22 percent for women who give birth without having had prenatal care. What we know about preventing unfortunate outcomes of pregnancy is not being adequately applied. We may actually be losing ground in our preventive health services for mothers and children.

What are some of the factors which are making it essential to consider what must be done to hold our gains and make further progress? The most outstanding are: (1) the increasing child population; (2) social changes having a bearing on public health; (3) the increasing costs of medical care; and (4) changes in the practice of medicine and public health arising from the findings of recent research.

Population Changes

According to Bureau of the Census estimates, in 1935 there were 48,500,000 children under 21 years
of age, in 1960 there were 73,300,000, and by 1970 there are expected to be 91,300,000, or 42.3 percent of the population. By 1970 we may be having about 5,600,000 births annually, an increase of about 30 percent from 1959. The aging population is also increasing rapidly. The slowest growing group is in the age range 25-64 years.

This means that children and the aged who lean most heavily upon our tax-supported and voluntary resources are increasing more rapidly than the segment of the population which earns the money, is the source of tax revenue, and bears the major responsibility for child rearing. The outlook for working adults is greatly increased child-rearing responsibilities and increased financial demands.

In the coming years the budgets for our health services must increase appreciably merely to keep up with the growth of the child population. We must also anticipate an increase in the proportion of infants attending public child health conferences— from approximately 13 percent at present to 17 percent in 1970. More children will also mean an increase in the number of handicapped children. During the next decade if State crippled children's programs just keep up with the increase in child population and grow no more rapidly than during the decade 1950-59, the number of children for whom they will be providing medical services will nearly double—from 325,000 in 1958 to over 625,000 in 1970.

The estimated costs of the maternal and child health and crippled children's programs through 1970 consistent with the expected increase in the child population and assuming no more than the recent rate of growth of these programs are shown in tables I and II.

The changes in the population composition of large cities are creating new social and public health problems. While related to the more general and familiar phenomenon of the increasing size of metropolitan areas, the problems of large cities are distinctly different from those of the surrounding metropolitan counties. As middle-class families move to the suburbs, low-income families remain and others move in. Thus an increasing proportion of the resident population of most large cities is in the low-income group which is dependent upon community agencies for health supervision and medical care.

For example, only 40 percent of the resident mothers who gave birth in the District of Columbia last year were delivered by private practitioners; 60 percent were delivered by hospital service staff physicians. Of the women who gave birth at the District General Hospital, 45 percent received no prenatal care at all. Because of the increased number of deliveries at the District General Hospital, mothers and infants are often sent home within 24 hours after delivery to make room for other patients. Because of long waiting lists for admission to the city's well-baby clinics, babies in their first year are given priority. Some 16,000 children of preschool age are not receiving health supervision.

In Baltimore attendance at well-baby clinics during the past 10 years has increased 50 percent, and at prenatal clinics 75 percent.

In New York City one-third of the city's infant population receives its well-child supervision at the city health department's well-baby clinics.

The New York Academy of Medicine estimates that by 1965 one-half of all deliveries in Manhattan will be of medically indigent patients, and adds: "The omission of prenatal care in this borough is rising about 2 percent per year. This reflects the marked increase in the number of individuals who are seeking care and who are unable to find it in a satisfactory manner."

Similar examples can be found in large cities all over the country, many of which have not been able to respond adequately to the growing volume of dependency in their populations.

To a considerable extent, the readiness of children to enter school is influenced by the health supervision they have had in the first 6 years of life. Such supervision falls off sharply after infancy so that a large proportion of children begin school with health problems requiring attention. School health services have expanded considerably, but whether such expansion is effective in improving the health of school-age children is debatable.

Reducing Infant Mortality

Despite the great progress which has been made in improving the health of mothers and children in rural areas, rural counties have higher mortality rates than urban areas. Thus, in 1957, maternal mortality was 5.3 deaths of mothers per 10,000 live births in nonmetropolitan counties and 3.3 in metropolitan counties, a difference of 60 percent. There is, however, less difference in infant mortality rates—27.8 in nonmetropolitan counties and 25.4 in metropolitan counties.

CHILDREN • JULY–AUGUST 1960
As infant mortality declines, the rate of reduction can be expected to decrease. But infant mortality in the United States is far from having reached an irreducible minimum. The range of difference among States is considerable—20.9 per 1,000 live births in Iowa to 39.4 per 1,000 in New Mexico in 1957. Other countries have achieved lower rates than the United States.

Further progress in reducing maternal, fetal, and infant mortality and morbidity could be made through the provision of—

- Adequate prenatal care for all expectant mothers, with particular attention to women with present or past histories of complications of pregnancies and to women at either extremes of the child-bearing period. Such care may require the attention not only of doctors and nurses, but also of other professional staff such as nutritionists and medical social workers.

- Hospitalization at any time for women with complications of pregnancy, including those which predispose to premature birth, and provision for care at home when appropriate with the help of medical and other home care staff.

- Consultation from obstetricians and other specialists, when needed, for all pregnant women. The New York Conference on Perinatal Mortality has stressed the importance of making specialist consultation available day and night and cited four specific conditions in which it should be mandatory: abnormal presentation, operative delivery, bad obstetric history, and medical complications.

- Hospital care for small premature infants and for full-term infants in need of specialized care, in units equipped and staffed to meet their needs.

- Home care from medical and nursing personnel when hospitalization for delivery must be brief. The use of a multidiscipline team as an extension of hospital services into the home would help to provide the needed continuity of care.

Continued progress in maternity and newborn care is dependent not only upon adequate financing but also upon the availability of professional manpower. Though the number of annual births may increase by nearly 30 percent by 1970, the number of physicians is expected to increase by only about 18 percent. How then will adequate care be provided? A few obstetricians have suggested the use of nurses who have had special training in midwifery in hospital obstetric departments. The function of the nurse-midwife is a subject of controversy in the United States. Only through demonstrations and studies can the feasibility of this suggestion be determined.

The Mentally Retarded

Since 1957, when the Congress first earmarked $1 million of maternal and child health funds for grants for special projects for mentally retarded children, services for these children have rapidly increased. Forty-four State health departments now provide such services, including the 31 supported by these earmarked funds. Approximately $2 million in Federal maternal and child health funds is being used for this purpose. During the calendar year 1958, 38 States reported the provision of health services for 6,700 retarded children. About 75 percent of these children were under 9 years of age.

The objectives of the program for mentally retarded children are the same as some of those of the entire maternal and child health program: health supervision, preventive health services, the fostering of good mother-child and family relationships; the promotion of an understanding of the processes of growth and development. The provision of these services to meet the special needs of the mentally retarded child requires establishing a diagnosis of the child’s condition and an evaluation of his potentialities for growth, such as can be provided in a special clinic for the mentally retarded.

The staff of the mental retardation clinic usually includes a pediatrician, who is generally the director, a psychologist, medical or psychiatric social workers, public health nurses, and in some clinics a child development specialist, a speech therapist, and a nutritionist. The services of psychiatrists and other medical specialists are provided on a consultant basis. With the diagnosis completed, a more or less continuous relationship must often be maintained with the family by the social worker if the family is to be helped. But many families live far from the nearest clinic and cannot attend regularly. One of the problems encountered in these programs is how to secure continuing counseling and social casework services for families in small cities and rural communities.

What is most meaningful to the parents is the help they receive in home training in regard to everyday living with their retarded children. Public health nurses can help the parents of these children in their own homes in the same way that they help the parents of normal children in the maternal and
child health program, since the processes involved in guiding many mentally retarded children to achieve degrees of self-help are basically the same as in normal children. The nurse's contribution, however, is dependent upon a thorough evaluation of the child and his family and the maintenance of a continuing relationship with the clinic staff. Most of these programs are offering public health nurses consultation and inservice training in mental retardation and in growth and development.

A number of projects are located in teaching hospitals and are being used for the training of medical students, interns, and other professional personnel, thereby incorporating into basic professional training present-day concepts of mental retardation and its medical, social, and educational implications. The possibility of preventing mental retardation in children with certain disorders of metabolism such as phenylketonuria has stimulated much interest among clinical and research physicians as well as among health departments and institutions.

During the next few years some of the following features of health services for mentally retarded children should be explored:

- Expansion of community programs for mentally retarded children to provide diagnostic, evaluative, and preventive health services and social services for the family.
- Greater development of the child health conference as a means of early case finding and supervision.
- The use of school health services as a means of bringing medical diagnostic skills into the identification of children requiring special classes for the mentally retarded.
- Development of standards and licensing practices for the growing number of nursery and day care programs for young mentally retarded children.
- Development of home assistance programs for parents who are caring for retarded children at home.
- Development of standards for residential facilities and methods of promoting closer relationships with community clinics.
- Development of specialized services for retarded adolescents.

The Physically Handicapped

Significant changes are taking place in the State programs for handicapped children, quantitatively as well as in scope and concepts. Some 325,000 children received medical services in these programs in 1958—or 4.8 per 1,000 of the children under 21 in the United States. This is twice the 1937 rate.

The proportion of children receiving hospital care in these programs has been decreasing, constituting 16 percent of the caseload in 1958 as compared with 27 percent in 1937. The duration of hospitalization has also declined, from 44 days in 1937 to 23 days in 1958, the shortest average hospitalization since the establishment of the programs.

In part the decrease in hospital care is attributable

<table>
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<tr>
<th>Year</th>
<th>Total</th>
<th>Federal</th>
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<th>Average amount per child (cents)</th>
<th>Estimated civilian population under 21</th>
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<td>63,833,176</td>
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<td>48,880,241</td>
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<tr>
<td>1970</td>
<td>156,910,000</td>
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<td>170</td>
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</table>

2 For 1954–57, estimates are those used in apportionment, as prepared by the Bureau of the Census and the Children's Bureau. Estimates for 1958 are from Bureau of the Census, P-25, No. 156, adjusted to include Territories and possessions (+2.4 percent).

Table I

EXPENDITURES FOR MATERNAL AND CHILD HEALTH SERVICES

Reported for Fiscal Years 1954–58 and Projected for Fiscal Years 1965 and 1970

Provided by the Maternal and Child Health Library, Georgetown University
to the changes in the predominating diagnoses in these programs. Initially they consisted almost entirely of orthopedic service, but in 1958 orthopedic handicaps constituted a little less than 50 percent of the diagnostic conditions reported. Major changes since 1950 include: epilepsy, up 596 percent; congenital malformations, all types, up 94 percent; congenital heart disease, up 451 percent; hearing impairment, up 105 percent; mastoiditis, down 43 percent; osteomyelitis and periostitis, down 47 percent; poliomyelitis acute, down 89 percent; paralytic poliomyelitis, down 10 percent.

The increasing number of children who are receiving only outpatient services and their many different kinds of handicapping conditions call for more attention to the quality of outpatient care. The trend toward ambulatory care is paralleled in pediatric care generally, as physicians increasingly treat children in their offices for conditions which hitherto required hospitalization. But work on standards of hospital care has been concerned almost entirely with the inpatient service. It is time that recommended standards for outpatient services were developed with attention to the organization of services for handicapped children.

Research during the past two decades has produced many dramatic developments in medicine. Some, for example the production of antibiotics, have had a revolutionary and widespread effect upon medical practice and public health. Those that particularly affected crippled children's programs include—

- The reduction in the incidence of rheumatic fever and the prevention of recurrent attacks.
- Drugs that control epileptic seizures to an increasing degree.
- The Salk polio vaccine.
- The diagnosis and surgical treatment of congenital heart disease.
- The electronic hearing aid and its use in childhood.
- The new functional artificial hand.
- The drug treatment of tuberculosis.
- The increased understanding and application of the principles of physical and emotional growth and development.
- The extension and improvement of community programs for the care of handicapped children.

Developments such as these are bringing about changes in the composition of the diagnoses among the children seen in both the outpatient and inpatient departments of hospitals and in pediatric practice generally. A growing proportion of these children have long-term illnesses and handicapping conditions. In some teaching hospitals children with congenital anomalies or congenital heart disease constitute between 30 percent and 50 percent of the inpatients. If such proportions are widespread, this has major significance for the design of hospitals, for medical teaching, and for the future of pediatrics and the crippled children's programs.

While we have evidence that the composition of the diagnoses in both inpatient and outpatient departments has changed greatly, this is for the most part impressionistic. Studies are needed to give a clearer picture of the children being admitted to hospitals now in comparison with those of previous years.

Albert Snoke has pointed out many other ways in which these changes are affecting hospital requirements:

- Experience throughout the country indicates steadily decreasing occupancy in children's convalescent units and general hospital accommodations. Children are being treated at home rather than in hospitals, as there are a greater number of well-trained pediatricians and fewer children's diseases requiring prolonged hospitalization. . . . All this requires fewer children's beds, smaller hospital pediatric units, greater flexibility in the use of hospital beds, and a corresponding increase in facilities for the ambulatory care of children.

- Newer concepts of the needs of the child in the hospital, such as the necessity for a homelike atmosphere, liberalization of visiting rules and allowing parents to remain with children in the hospital are causing not only complete rethinking of the medical and nursing staff but also replanning of pediatric divisions to accommodate the parents and visitors comfortably and efficiently.

- Especially significant for future planning are those centers for handicapped children which are attempting to meet the needs of children with single or multiple handicaps within one organizational unit of the hospital. Through such units all the information needed about a child can be brought together in one place with one physician responsible for the patient, despite referrals to a variety of the hospital's departments.

Pediatric education up to now has been principally concerned with medical rather than surgical or physical problems. However, with pediatricians being called upon increasingly to participate with surgeons, public health nurses, social workers, psychologists, audiologists, and others in clinical services for physically and mentally handicapped children, some reorientation is needed in medical education to give greater emphasis to the problems of handicapped children. As an editorial in the Journal of
Pediatrics has pointed out, the pediatrician must “be equipped by training and interest to supervise and plan the general problem of the care of handicapped children. . . . He cannot simply consider his responsibility is over by referring the child to the orthopedist, ophthalmologist, or other specialist . . . .”  

**Major Problems**

While the incidence of certain handicapping conditions, such as paralytic poliomyelitis, rheumatic fever, osteomyelitis, mastoiditis, and tuberculosis, can be expected to continue to decline, other problems are coming to the fore. The widespread use of antibiotics has resulted in the survival of many children with hitherto fatal illnesses, some of whom will be handicapped all their lives. As research provides new methods of treating handicapping conditions for which no treatment was previously available, children with these conditions are coming to State crippled children’s agencies for care.

Of increasing significance is the collection of handicapping illnesses known as inborn errors of metabolism. While the number of children with any one of these conditions is not large, in the aggregate they are considerable. Thus far, 48 diseases have been identified in which a hereditary biochemical defect has been demonstrated. These are disabling illnesses for which “the union of biochemistry and genetics offer a rational approach to diagnosis, prevention and treatment.”

Congenital anomalies, comprising a large proportion of handicapping conditions of childhood, seem to be increasing. While this may be due in part to the more frequent survival of premature infants and term infants born with serious impairments, some authorities believe that the increase may be in part attributable to a rising level of mutagenic agents.

**Congenital Heart Disease**

Developments in relation to congenital heart disease illustrate how the application of productive research brings about major changes in crippled children’s programs. Between 30,000 and 50,000 children are born each year with this condition. Hardly more than 15 years ago there was virtually nothing that could be done for them. With development of the “blue baby operation” in 1945 and, more recently, open heart surgery, the outlook has completely changed. It is now reported that surgery can result in cure or improvement in 80 percent of children with congenital heart disease.

The number of children with congenital heart disease receiving care in the crippled children’s program increased from 2,200 in 1950 to more than 12,000 in 1958—from 1 percent of the total caseload to 4 percent—and we are probably just at the beginning of the rise in request for services.

The waiting lists at the few hospitals doing open-heart surgery are long, and they grow longer as more babies are born with conditions requiring this operation, for the number of patients that can be accepted for surgery each week is small. While the number of hospitals doing open-heart surgery is slowly increasing, more than one-half of the States as yet do not have hospitals adequately equipped and staffed for this purpose. The Association of State and Territorial Health Officers recently adopted a resolution urging State health departments interested in obtaining services for children with congenital heart disease to consult the American Heart Association’s “Standards for Centers Caring for Patients With Congenital Cardiac Defects.”

The cost of care for children with congenital heart disease makes considerable inroads in the financial resources of State crippled children’s agencies. In a number of States this has led to a depletion of crippled children’s funds before the end of the fiscal year, so that in 1959 Congress made a supplemental appropriation of $1,500,000 to be used only for services for children with congenital heart disease.

In at least one large State the health department pays for 80 to 90 percent of the open-heart surgery done in the State. This is an excellent expression of what is probably one of the basic reasons for the existence of State crippled children’s programs—making available to all children the productive results of years of research.

**Looking Ahead**

A review of the progress made in services for crippled children over the past 25 years suggests that the future will bring the following developments:

- Further broadening of the definition of “crippling” until all State crippled children’s programs will serve children with any kind of handicapping condition or long-term illness.
- Closer ties with maternity care services to increase the effectiveness of early casefinding of handicapped infants.
- The removal of unreasonable barriers to eligibility for services such as State requirements for
court commitment, residence status, and means tests which do not reflect the great variations in the cost of medical care.

- Extension of the programs to urban areas. The need is indicated by the fact that hospitals in large cities are increasingly requesting full payment for all patients.

- Changes in the design of pediatric inpatient departments reflecting the changes taking place in the diagnostic composition of inpatients, new concepts of diagnosis and care, and knowledge about the effects of hospitalization upon children.

- The development of new standards for outpatient and inpatient care.

- The development of outpatient centers for handicapped children which are organized and staffed to provide the comprehensive services needed by children with all types of handicapping conditions, thus bringing together the services presently being provided in many separate clinics.

- The development of home care programs for the aftercare of hospitalized children and for the care of homebound children.

- The development of inpatient and outpatient facilities appropriate for adolescents.

- The increased use of psychiatric services and greater attention to the social and emotional aspects of handicapping and long-term illness.

- The provision of special services for children who are both deaf and blind.

- Increased coordination of medical care, special education, and vocational counseling.

- The coordination with teaching and research centers of multidisciplinary services for children with multiple handicaps.

- The development of demonstration centers for the early care of children with paraplegia and quadriplegia brought about by accident or disease.

An intimate relationship must exist between the maternal and child health and crippled children's programs if they are to achieve their objectives. The increasing problems emerging in the crippled children's programs make it necessary to look to the maternal and child health program for help in prevention and early casefinding. Thus may be prevented the handicaps imposed on some children by premature birth, congenital malformations, exposure to radiation in utero, Rh incompatibility, metabolic disorders, poor nutrition of their mothers during pregnancy, their mothers' attitude toward pregnancy or toward themselves, or other factors. This underscores the importance of extending and improving the basic preventive health services for mothers and children.

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Table II

EXPENDITURES FOR CRIPPLED CHILDREN'S SERVICES

Reported for Fiscal Years 1954-58 and Projected for Fiscal Years 1965 and 1970

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Amount (dollars)</th>
<th>Federal</th>
<th>State and/or local</th>
<th>Average per child (cents)</th>
<th>Estimated civilian population under 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>1954</td>
<td>836,136,251</td>
<td>811,081,792</td>
<td>825,054,459</td>
<td>59</td>
<td>41</td>
</tr>
<tr>
<td>1955</td>
<td>39,884,931</td>
<td>10,821,280</td>
<td>29,083,651</td>
<td>18</td>
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<tr>
<td>1956</td>
<td>43,610,850</td>
<td>14,928,641</td>
<td>28,682,218</td>
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<td>1957</td>
<td>48,561,384</td>
<td>15,208,556</td>
<td>33,357,828</td>
<td>23</td>
<td>50</td>
</tr>
<tr>
<td>1958</td>
<td>52,660,949</td>
<td>15,311,930</td>
<td>37,349,019</td>
<td>22</td>
<td>54</td>
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<tr>
<td>1965</td>
<td>100,076,400</td>
<td>120</td>
<td></td>
<td>165</td>
<td>83,400,000</td>
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<td>1970</td>
<td>152,295,000</td>
<td>130</td>
<td></td>
<td>92,300,000</td>
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</tr>
</tbody>
</table>

2 For 1954-57, estimates are those used in apportionment, as prepared by Bureau of the Census and the Children's Bureau.
3 Estimates for 1958 are from Bureau of Census, P-25, No. 193, adjusted to include Territories and possessions (+2.4 percent).

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How the licensing program of a State health department provides . . .

HOSPITAL CONSULTATION TO IMPROVE MATERNITY CARE

GOLDIE B. CORNELIUSON, M.D.
Director
Maternal and Child Health Division, Michigan Department of Health

FANNY H. KENYON, M.D.
Chief, Hospital Consultation and Licensing Section

IN MICHIGAN'S population of almost 8 million persons over 200,000 births occur each year, more than 99 percent of them in hospitals. To protect the lives of the new babies and their mothers, as well as of other hospital patients, the Michigan Department of Health gives consultation to over 260 hospitals, licenses the 230 that give maternity care, and evaluates them and about 30 additional hospitals in relation to certification to the State department of social welfare for the care of public assistance recipients. Special consultation service is also given to State mental hospitals and to tuberculosis sanitoria.

Some basic convictions under which the department administers its hospital consultation, licensing, and certification are that:

1. Hospital administrators, staffs, boards, and auxiliaries are as concerned about good patient care and facilities as is the State department of health.
2. It is much more satisfying to both the hospital and the health department when a hospital improves its practices or facilities as a result of good consultation or education rather than as a result of "big stick" action.
3. Hospital consultation calls for teamwork of the highest order on the part of mature individuals who are dedicated to a cause and who have the ability to give consultation, to utilize consultation, and to learn as well as to teach.

4. Leaders among hospital administrators, practicing physicians, and nurses are eager to work with a governmental agency in the development of standards which will be administered by the governmental agency.

A Look Back

Our maternity hospital consultation program began in the late thirties when Alexander Campbell, an obstetrician highly respected by physicians throughout the State and dedicated to the task of bringing about improved maternity care for all women, joined the maternal and child health staff of the department. He was employed under a special Kellogg Foundation grant to give consultation in behalf of obstetric patients in doctors' offices and in hospitals, especially in rural areas, and, in cooperation with the maternal health committee of the Michigan State Medical Society, to stimulate formation of maternal health committees in county medical societies.

When conferring with doctors in hospitals, Dr. Campbell took advantage of opportunities to make recommendations regarding improvement in hospital facilities as well as in patient care. During the next few years the hospital consultation program was strengthened by the employment in the maternal and child health division of a pediatrician and two nursing consultants—one trained and experienced in maternity care and the other in pediatrics. In addition to giving individual consultation to hospitals, the maternal and child health staff conducted regional institutes on maternity and newborn care.
and prepared two manuals, “Recommendations for Hospital Nurseries” and “Recommendations for Hospital Maternity Departments,” which had wide distribution. The division also collaborated with leading pediatricians in the State and with industrial engineers in the development of an inexpensive, efficient incubator.

In the mid-forties, the wartime Federal Emergency Maternity and Infant Care program gave impetus to the State’s hospital consultation program by devising a sliding rate of payment whereby the per diem rate paid any hospital for the care of EMIC patients was based on the hospital’s compliance with certain requirements considered basic to the safe care of mothers and newborn infants. These requirements were: individual equipment for mothers and for infants; terminal sterilization of formulas (sterilization of the milk after bottling); adequate hand washing facilities; and adequate maternity department staffing.

A major change occurred in the hospital consultation program in 1951 when the responsibility for licensing hospitals with maternity departments was transferred to the State department of health from the State department of public welfare. Although the maternal and child health staff was somewhat afraid that the licensing responsibility might interfere with the excellent relationships which the department had built up with hospitals throughout the years of consultation, these fears have not been realized. On the contrary, the licensing function has strengthened the hospital consultation program while the department’s years of experience with consultation has helped to play down the “policing from above” which is too often inherent in licensing programs.

When the licensing program began, the department decided to give the hospitals reasonable periods of time to comply with the rules; and to increase gradually the number of rules requiring “immediate compliance” for full license while providing advice on how to meet the requirements efficiently as well as economically and practically.

The Michigan “Rules and Minimum Standards for Hospitals” include 180 individual regulations. With the advice and guidance of the health commissioner’s hospital committee the rules have been divided into three categories: (1) those requiring immediate compliance; (2) those requiring compliance within a planned period; and (3) those with compliance time undesignated. These last will be placed in the planned or immediate compliance categories at times when this seems reasonable for the majority of hospitals.

In 1951 in order to qualify for a full license hospitals had to comply immediately with only four rules. These required individual equipment for mothers, individual equipment for babies, running water in the nursery, and provision for sterilizing the babies’ formulas. During this first year of licensing only 56 percent of the hospitals in the State qualified for a full license. Eight years later, in 1959, although the list of 180 rules included 124 requiring immediate compliance, 90 percent of the hospitals in Michigan had full licenses.

The Program

At present major responsibility for hospital consultation, licensing, and certification in Michigan is carried by the hospital consultation and licensing section of the State health department’s maternal and child health division. This section consists of a physician director, four nursing consultants, two part-time sanitary engineers with master’s degrees in their specialty, and two clerks. While the section is small, it has available at all times the services of the large number of specialists on the department’s staff who have a variety of responsibilities within the department’s total program—epidemiologists, pediatricians, obstetricians, laboratory scientists, dietitians, ventilation and radiological engineers, statisticians, and others. The section’s staff has been stable and has achieved good rapport with the hospitals. We have found it important for the team to be directed by a physician, preferably one with experience in private practice as well as public health, because a physician not only understands hospital problems and what patients in hospitals need but also has status with the administrators and medical staffs of hospitals.

For administrative purposes the section has divided the State into four regions, with a nurse assigned to each region. All of the nursing consultants have master’s degrees but in different specialties: maternity nursing; consultation, with emphasis on maternity care; pediatric nursing; and nursing administration. They also have all had years of supervisory experience in hospitals, which helps them to understand hospital administrative problems. The differences in the nurses’ specialties help them to function as a team, for they all receive the benefit of the others’ counsel, informally in staff meetings, and, in field consultations, when they call
each other into their respective regions for assistance with special problems.

As nursing consultation regarding patient care, hospital facilities, and equipment demands highly specialized skills, our hospital nursing consultants give direct service to all hospitals without any assistance from the nurses of local health departments in all areas except Detroit. In Detroit a nurse employed by the city health department works in close cooperation with the State consultant assigned to the metropolitan area.

However, since many of the problems in hospital sanitation are similar to the problems local health departments help other large institutions to solve, qualified sanitary engineers on the staffs of all the large local health departments and a few of the smaller departments have accepted major responsibility for the sanitation consultation and annual licensing visits to hospitals in their jurisdictions. The State sanitary engineers give individual and group consultation to the local engineers and take responsibility for direct service to all hospitals not served by sanitary engineers of local health departments.

In our program the different consultants usually visit hospitals separately for the annual evaluation or licensing visits as well as for special consultation, but the physician, a nursing consultant, and the sanitary engineer also make joint visits frequently to discuss situations needing adjustment with the hospital administrator and staff. When infection breaks out in a hospital, the department's epidemiologist heads the study team and has top priority for the services of the regional nursing consultant and the sanitary engineer.

The length of consultant visits varies from a half hour to a week or more. A licensing visit usually takes a day, involving as it does a detailed evaluation of the hospital to determine compliance with the State's 180 rules or minimum standards. When infection has been reported in a nursery for newborns, the nursing consultant dons her uniform and goes into the hospital, often to spend several days observing the techniques used on all three shifts. A visit in response to a new hospital's request for help in setting up procedures and routines may last a week and may involve two nursing consultants, one working in the maternity department and another helping in central supply or another department.

Annual licensing visits are made by appointment only but many followup visits and some consultation visits are made without appointments. Hospital administrators and supervisory personnel often ask the nursing consultant to stop by whenever she is in the area. Such casual visits are often the most productive, especially when the nurse happens to come at a critical, and thus opportune, moment and is bombarded with questions and requests.

Consultants discuss their observations with the hospital administrative personnel before leaving the hospital and later prepare a written report for review by the section chief and transmittal to the hospital administrator. Included in the section's annual evaluation summary for each hospital is a listing of (1) violations, if any, (2) recommendations, and (3) improvements noted since the previous visit.

The consultation team informs the hospital administrators and staffs of services available from other consultants in the department. As a result, the department receives requests for help of various kinds—with the development of obstetric policies, educational programs, or record forms, with planning kitchen layouts, or with the solution of ventilation problems.

A Cooperative Venture

We have found that leading practicing physicians and hospital administrators and nurses will give eagerly and generously of their time and ability to help a governmental agency with the development of standards for hospital care.

The department's document, "Rules and Minimum Standards for Hospitals," was drawn up by the staff of the hospital consultation and licensing section and revised according to suggestions from the maternal and child health division. Selected sections were prepared in cooperation with, or cleared by, the directors of the department's other divisions or its specialists in sanitary engineering, acute communicable disease control, chronic disease, laboratory services, nutrition, health education, public health nursing, records and statistics, and industrial health. After clearance by the office of the State health commissioner, working drafts of the document were sent to about 100 persons: All members of the commissioner's hospital committee; the Michigan State Medical Society's maternal health and child welfare committees; the trustees of the Michigan Hospital Association; the Michigan Osteopathic Association and the Osteopathic Hospital Association; departments of obstetrics in the two medical schools within the State; schools of nursing

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Provided by the Maternal and Child Health Library, Georgetown University
in three State universities; and local health departments; as well as to many individual physicians, hospital administrators, and nurses. The suggestions received were correlated, and most of them adopted.

As a result of this procedure:
- The department received the benefit of advice from Michigan authorities in the field of hospital care.
- Organizations and individuals shared in the development of standards for their work.
- The final standards were higher than those which the State health department had originally thought feasible.
- Representatives of medical, hospital, and nursing organizations, and other individuals in influential positions in their professions, read the rules and standards word for word. Because they were thoroughly familiar with them, they later served as the best interpreters of them and of the State health department's objectives in setting them up.

In order to answer questions that hospital staffs had raised about the program's rules and minimum standards and to indicate various ways of complying with an individual rule, the maternal and child health division prepared a hospital manual. When the division was not able to keep up with the demand for copies of the whole manual or parts of it, many hospital administrators and nursing directors had sections of the manual duplicated for their use. An appendix including 40 exhibits has proved to be especially helpful to the hospitals. It includes information on many subjects, among them illumination, laundering, sterilization equipment, dishwashing, food, sterility tests for infant formulas, control of infection, eye prophylaxis, methods of formula preparation, suggested policies for obstetric departments, nursing and dietetic personnel, maternity and newborn record forms, and many other subjects, with a suggested bibliography.

Educational Emphasis

The major emphasis in Michigan's program for achieving a high quality of hospital care is placed on education.

Scholarships financed with Federal maternal and child health funds are made available to hospital maternity and pediatric nurses for accredited training at the graduate level and for non-accredited training at universities outside the State, such as short courses on premature care at Cornell University or the University of Colorado.

The maternal and child health division annually co-sponsors short courses with one or more of our three State university schools of nursing on subjects such as premature care; emotional aspects of hospital care of children; better care of maternity patients through better teaching of patients.

Each year the maternal and child health division holds several regional 2-day conferences for professional and practical nurses and nurses' aides working in hospital maternity departments. One hospital serves as host to personnel from a half dozen neighboring hospitals. Leading local physicians and nurses and State health department physicians, nurses, and sanitary engineers serve as the faculty.

The section's staff and other appropriate consultants also review plans for all hospitals to be built with Hill-Burton funds within the State as well as for many other hospitals.

The physician in charge maintains close working relationships with the children's division of the State department of social welfare in checking on any hospital participation in adoption procedures.

Staff members of the maternal and child health division and the statistical methods section work with hospitals on perinatal mortality studies. Improvement in maternity department records and an increase in the percentage of autopsies have been noteworthy results of these studies.
IMPROVEMENTS in the health picture of this country in the past 50 years can perhaps be no more dramatically illustrated than with statistics on maternal and infant mortality. Deaths of women in childbirth dropped, for example, from 60.8 per 10,000 live births in 1915 (the earliest year for which such figures are obtainable) to 3.7 in 1959. Deaths of infants within the first year of life dropped from 99.9 per 1,000 live births in 1915 to 28.4 in 1959.

Behind these statistics is a story not only of unprecedented advance in medical knowledge but also of its application through the spread of services, a story in which the Children's Bureau has been intimately involved.

But within these statistics there is also another story—of the unevenness of progress between the less and more advantaged groups of the population, as revealed when the statistics are broken down between white and nonwhite groups of the population, and of a slowing down of progress in recent years, as shown particularly in the statistics on trends in perinatal mortality.

Moreover, the accumulation of knowledge and rapidity of medical advance in themselves have added tremendously to the complexity of maternal and infant care, while the problem of providing care has been further complicated by the steadily increasing demands of an expanding population.

No longer can the clinician in the field of maternal and infant health limit his concern to the perfection of diagnostic, therapeutic, and followup techniques in patient care. He must of necessity be concerned with personnel shortages, social upheavals, changes in the socioeconomic composition of the population he serves, gaps in services, rising costs, and above all challenges of pregnancy wastage and the handicapping conditions which are a continuum of reproductive loss.

Clinicians cannot cope with these problems alone. Future improvements in maternal and infant health must develop through close liaison between clinicians (obstetricians, pediatricians, and generalists), pathologists, social scientists, and public health specialists—epidemiologists, researchers, biostatisticians, health educators, and medical economists. They also will depend on a closer relationship of these physicians and scientists with nursing, nurse-midwifery, social service, and rehabilitation personnel.

Five and a half million births a year in the United States are expected by 1970 as against the present 4½ million births in 1960. This look into the future is predicated upon the assumption that the birth rate of 24 per 1,000 population in this country will be maintained—and the chances are that it probably will. Serious consideration must therefore be given to the problems of providing good maternity care to all the childbearing women who will be a part of this population explosion. This will require that health supervision of all pregnant women be carried into the postpartum period, that it begin even before conception, and that it include attempts to prepare them and other members of the family for parenthood. Such continuity of care is appropriately called “perinatal care,” and characterizes the modern concept of complete maternity care.

It is questionable that we shall have the necessary medical and nursing manpower to assure the total health supervision of all pregnant women in 1970. H. D. Kruse has pointed out that to keep up with
the expected population growth, by maintaining the current physician-population ratio, would require increased enrollment in existing medical schools and the establishment of 20 to 24 new schools.

As of May 1959, there were 5,853 obstetricians certified by the American Board of Obstetrics and Gynecology. There are no data available on the types of physician performing deliveries, but obviously the number of certified obstetricians cannot possibly handle the current 41/2 million births. Probably most deliveries in the United States are performed by physicians in general practice. Yet all indications are that there will be a smaller proportion of generalists as well as certified obstetricians available in relation to the expanding population by 1970. How can we face up to this potential manpower deficit?

In New York City recently, the Obstetric Advisory Committee to the Commissioner of Health created a subcommittee on nurse-midwifery which has recommended that nurse-midwife training programs be supported both locally and nationally. Envisaging thus a greater supply of nurse-midwives than is currently available, including apparently nurse-midwives trained for teaching, the committee has suggested that nurse-midwives could act as expert teachers of obstetrical nursing, could provide expert obstetrical nursing supervision in hospitals, and as assistants to practicing obstetricians could assume many of the responsibilities of antepartum care and patient observation during labor. In this latter role, according to the committee, the nurse-midwife could provide great service in enabling obstetricians and general practitioners to provide more and better obstetric care to more people in the years to come.

The report emphasized, however, that as obstetric assistant the nurse-midwife should always be under medical supervision and should never practice independently except in those remote areas of this country, and elsewhere in the world, where no doctors are available.

The development of nurse-midwifery training programs and the integration of nurse-midwife services into the total maternity care program of this country could be expected to do much to relieve the pressures of an anticipated shortage of physicians—if there were not a personnel shortage in the total supply of nurses, from which the nurse-midwives would presumably be recruited.

Unfortunately there are not enough nurses today to carry out all the other nursing functions required for the health care of the population as a whole, including the important function of maternity nursing. Therefore, it is doubtful whether sufficient nurse-midwives to relieve the pressure on obstetricians and general practitioners could be achieved in the near future.

Greater use of the team approach with the obstetrician serving as consultant and teacher to a clinical team composed of general practitioners, maternity nurses, nurse-midwives, and social workers and carrying direct responsibility for complicated cases, is being suggested by some concerned persons as a means of spreading the services of highly skilled personnel more equitably among the population. Another suggestion is for the more widespread use of group practice among obstetricians, helped out by a common team of auxiliary personnel. Group practice among general practitioners with an obstetrician available as a consultant has also been suggested. This would help doctors who have not specialized in obstetrics to deal more successfully with high risk cases. Refresher courses in obstetrics are of course a must for all professional persons who become involved in maternity care.

The possibility of using simpler facilities than the large general hospital for maternity patients and infants not requiring special care might also be considered—an approach which might not only be less expensive but more psychologically satisfactory to mothers than a setting geared to the care of the acutely ill.

Problems of the Cities

Economic and social problems connected with the population explosion also have a bearing on the prospects for good comprehensive maternity care. Such factors as the adequacy of family life, housing, education, preparation for family life, and family planning must be considered.

The great metropolises of this country have experienced dramatic changes in population composition in the past 10 years, which complicate the problem of seeing that all expectant mothers receive comprehensive maternity care. Many of our large cities have experienced an influx of low-income unskilled persons, many of them Negroes from rural areas of the South, while losing large segments of middle-income groups to the suburbs.

In 1950, 56 percent of all live white births and 51 percent of all nonwhite live births in the United States were to mothers living in metropolitan counties. In 1959 these proportions rose to 60 percent and 61 percent, respectively, reflecting the shifts of populations to urban areas. While in 1950, nonwhite
births represented 13 percent of all births in metropolitan counties, in 1959 they represented 16 percent. In New York City this experience has been accompanied by a similar, but much greater influx of immigrants from Puerto Rico—many of them also from rural areas and unskilled in the kind of work available in the city.

The swelling of the cities' populations of low-income, unskilled, relatively uneducated people, whose problems of securing adequate housing and jobs are complicated by racial discrimination, has been accompanied by a rise in social problems—dependency, juvenile delinquency, illegitimate pregnancies—and an interruption or reversal in some cities of the past 50 years' downward trends in maternal and perinatal mortality (deaths of infants in the first 28 days of life and fetal deaths occurring after the first 20 weeks of gestation). New York City, for example, has experienced a rise in maternal mortality from 6 per 10,000 live births in 1955 to 6.9 per 10,000 live births in 1960, and a 2-percent rise in perinatal mortality from 1950 to 1960.

**Maternal Mortality**

While in the United States as a whole the maternal death rate reached an all-time low in 1959—3.7 per 10,000 live births, this was primarily due to the very great progress in reducing the mortality rate among white mothers, from 6.1 per 10,000 live births in 1950 to 2.6 in 1959. However, among nonwhite mothers the death rate in 1959 was about 4 times as great—10.2 per 10,000 live births, a rate that has not prevailed among white mothers since 1948. Progress in reducing the rate among nonwhite mothers is approximately a decade behind progress in reducing the rate among white mothers. The differences are much larger today than they were in 1915 when the rate for nonwhite (105.6) exceeded the rate for whites (60.1) by only 75 percent, as compared with today's 292 percent.

The chief causes of maternal deaths in the United States today are toxemia (not connected with abortion), hemorrhage, and abortion (spontaneous and otherwise), each with a rate in 1959 of .7 per 10,000 live births. The rate for toxemia in which abortion is not a factor, represents a 76-percent drop from the 1949 rate of 2.9. The rates for hemorrhage and abortion (including abortion with toxemia and sepsis) represent less spectacular decreases—53 percent (from a rate of 1.5) and 36 percent (from a rate of 1.1), respectively. The 36-percent decrease in the rate of maternal deaths associated with abortion was, in fact, smaller than the decreases in the rates for all other causes.

Obviously, current reliance on antibacterial therapy, blood transfusion, corticosteroid support, renal dialysis and even hysterectomy is insufficient to reduce the mortality from septic, endotoxic or bacterial shock secondary to abortion sepsis. Other means of prophylaxis against abortion deaths in addition to medical-surgical must be developed, including

**U.S. TRENDS IN MATERNAL MORTALITY 1915-1959**

While the maternal mortality rate has dropped sharply among both white and nonwhite groups, in 1959 the rate in the nonwhite group was as high as for white mothers over a decade ago. Fluctuations before 1933 reflect expansion in the birth registration area which became complete that year.
programs for early, meaningful sex education, preparation for parenthood, family planning, and special efforts to reach newcomers in the cities with early prenatal care. Thus, the social scientist should be consulted by the obstetrician-gynecologist.

In addition, the cause of every maternal death must be carefully scrutinized in obstetrical staff conferences in hospitals, and there must be no relaxation of the activities of maternal mortality committees of county and State medical societies. Since 1929 such committees have been helping to reduce puerperal loss by pointing out avoidable factors in maternal death studies and suggesting improvement in teaching and practice which make for improved maternal care. They should be encouraged to expand their activities to promote standardized terminology and definitions in maternal death studies, develop uniform labor, delivery and puerperal records for use in hospitals, and contribute to community postgraduate physician education by setting up local institutes, seminars, and congresses devoted to maternal mortality control.

**Perinatal Mortality**

Perinatal mortality has notoriously failed to keep pace with the marked improvements in maternal and infant mortality over the years. During the 1950's national progress in reducing perinatal losses was slower than in the preceding decade. From 1952 to 1959 the perinatal mortality rate decreased from 37.4 per 1,000 total births (live and still) to 34.6, or a decrease of 2.8 deaths per 1,000. In contrast, during the years 1942-49, the rate was reduced from 50 to 40.4, a decrease of nearly 10 deaths per 1,000. Again we find a lag in progress in the nonwhite as compared with the white group. While the perinatal death rate among whites decreased from 1950 to 1959 by approximately 13 percent, the rate among nonwhites went down from 58.1 to 53.5—a drop of only 8 percent.

These significantly higher rates in the nonwhite group not unexpectedly go hand in hand with a higher incidence of premature births (or births of infants weighing 2,500 grams or less), since perinatal loss varies with weight grouping, being much higher in the premature than in the mature infant in all ethnic groups.

In 1959 the major causes of neonatal deaths were immaturity unqualified, postnatal asphyxia and atelectasis (collapse of lung), birth injuries, and congenital malformations, which together accounted for 74 percent of all neonatal deaths. They also produced an unknown quantity of neonatal morbidity resulting in such handicapping conditions as cerebral palsy, malformations not incompatible with life, epilepsy, mental retardation and behavior problems. Such problems represent a major public health challenge which can only be met by delineating etiologic factors.

In 1956, the National Institute of Neurological Diseases and Blindness embarked upon an intensive collaborative study on cerebral palsy and other neurological disorders of infancy and childhood, making grants to 15 major investigational centers throughout the country for a multidisciplined attack on these handicapping conditions. The purpose of the study is to correlate factors affecting the parents with the occurrence of abnormalities in their children. Such factors as the course of pregnancy, labor and delivery, environmental influences including psychologic and emotional stress within the family, the family's socioeconomic state, and the mother's age, parity, medical and obstetric history and genetic background are under scrutiny in a sample group of births, as are any abnormalities appearing in the children at birth.

**CHANGES IN PERINATAL MORTALITY**

Perinatal mortality in this chart includes fetal deaths in pregnancies of 20 or more weeks and deaths of infants before 28 days of postnatal life. The "color" differences reflect differences in socioeconomic and other factors. The year 1947 is the first year for which such data is available by color.
or during infancy and early childhood. Much vital information on etiology is expected to accrue.

Available evidence suggests that anoxia of intra- or extra-uterine origin is probably the major underlying cause of perinatal mortality and morbidity. Of deaths in the first week of life in the United States in 1959, 26 percent were attributed to postnatal asphyxia and atelectasis.

Current research is supplying increasing knowledge as to the role anoxia plays in perinatal loss. Intrauterine anoxic stress at specific periods of the development of the fetus have been shown to produce fetal anomalies. The state of the fetus in utero is being evaluated by estimations of gaseous exchange between fetal and maternal blood in the placenta, as well as by electrocardiography and phonocardiography. Electrolyte metabolism of the infant at birth is also under scrutiny. Means to prevent premature labor associated with an incompetent cervix have been reported. Currently under study is the relation of the incidence of prematurity and perinatal mortality to asymptomatic bacteriuria (the presence of bacteria in the urine) during pregnancy.

Prematurity

The high incidence of prematurity should be a cause of grave concern. While the proportion of white infants weighing less than 2,500 grams at birth dropped from 7.2 to 6.8 percent of live births from 1950 to 1959, the proportion of such premature infants among nonwhite births rose from 10.4 to 12.9. In some large cities, for example, New York, the rate of immaturity for the total population went up during the decade.

Prematurity incidence is intimately associated with the quality of prenatal care. One major criterion of good prenatal care is the time of its introduction, the earlier in pregnancy, the better. Yet the problem of patients receiving late or no prenatal care prior to delivery is still to be overcome. Baumgartner and associates, reporting on prenatal care in New York City in 1951, showed that approximately 20 percent of all women whose pregnancies terminated in live births had late or no care, and that the highest incidence of such inadequacy was found in the lower socioeconomic population groups, in those patients delivered on the general ward service of the voluntary hospitals, and in the municipal hospitals.

The picture had not changed significantly by 1960. In the municipal hospitals, where the obstetric patients were of low income status, 42.5 percent had received late or no prenatal care. On the general ward services of the voluntary hospitals, where the patients are also of low economic status, 34.3 percent had had late or no prenatal care. In contrast, at the proprietary hospitals and on the private service of the voluntary hospitals, where the patients were of higher economic status, only 5.3 percent of the patients received late or no care prior to delivery.

Similar reports have come from other cities. For example, Oppenheimer has reported that in 1956, 57, and 58, in Washington, D.C., 47 percent of the women delivered at D.C. General Hospital, the tax-supported hospital open only to low-income families, had had no prenatal care. In 1957 in this hospital 21.5 percent of the mothers with no prenatal care gave birth to premature babies as compared with 10.2 percent of those who had had prenatal care. In 1946, neonatal mortality among the hospital's deliveries which were not preceded by prenatal care was 41.6 per 1,000 live births as compared with 23.9 for the District's total population.

Thompson has reported that at the Grady Hospital, a large municipal hospital in Atlanta, 23 percent of the patients who had come to the hospital for delivery during a study period had had no prenatal care, and only 11 percent had received prenatal care in the first trimester of pregnancy.

Socioeconomic Factors

Thompson has accumulated evidence indicating that the major factors involved in the rate differences in maternal mortality, perinatal mortality, and prematurity among the racial groups are socioeconomic in nature. He cites studies showing that:

1. A smaller proportion of Negro than white patients in both urban and rural areas are delivered in hospitals.

2. The incidence of toxemia has been found to be higher among patients in lower economic brackets.

3. Prematurity is more frequent among mothers who work outside the home; among those who have had inadequate prenatal care; among women who have poor diets; among women who become pregnant at an early or a late age or who are large multiparas, conditions found most frequently among low-income groups.

How to reach more pregnant women of lower socioeconomic population groups earlier in pregnancy is a pressing and continuing problem. Community programs for early case findings, health ed-
CAUSES OF NEONATAL DEATH
United States 1959

Over three out of four deaths of children under a month old are from causes arising either before or during birth.

It is also important to study procedures in the prenatal clinics in relation to their likelihood of encouraging or discouraging women to come for early and continuous prenatal care. How long do the patients have to wait to see a doctor? How comfortable are they made while they do wait? Has anyone inquired into the possibility of helping them make arrangements for the care of their other children while they attend the clinic, or are evening clinics held so that the woman may attend the clinic while her husband is available as a babysitter? Is the patient assigned a doctor of her own with whom she might build a doctor-patient relationship or is she likely to see a different doctor every time she attends? Is she encouraged to ask questions and express her fears?

Providing the public clinic patient with the kind of continuity of care and personal interest available to the private patients of obstetricians is not an easy problem for cities plagued by financial problems, staff shortages, and increasing caseloads. But experiments must be attempted if the task of assuring good maternity care for all mothers and infants is to be achieved. A few such experiments are underway.

For example, in New York City, attempts are being made through the cooperative efforts of the departments of health and hospitals to relieve the overcrowding in the clinics of the municipal hospitals by referring patients to the less crowded facilities of voluntary hospitals in the same health districts. The city has also begun to pay the doctors in the municipal hospital clinics, hoping in this way to alleviate personnel shortages.

The Philadelphia Department of Health has also been trying to relieve overcrowding in its municipal hospital clinics by contracting with voluntary hospitals to accept patients for care, and by establishing prenatal clinics in some of its neighborhood health centers.

In the District of Columbia, neighborhood prenatal clinics, closed for several years for budgetary reasons, were recently reopened when the health department produced figures showing a downward trend in prenatal care.

Perinatal mortality is higher in out-of-wedlock births in all ethnic groups. Pakter and associates recently called attention to the increasing number of births to unmarried mothers. In New York City the incidence of out-of-wedlock births increased 16.7 percent from 3 percent of births in 1946 to 8 percent in 1959. Nationally they increased by 39 percent, from 3.6 percent of all live births in 1947 to 5 percent in 1958. The rates were highest among the less advantaged groups of the population.

The solution to this problem obviously is linked in a large part with the social and economic reforms sorely needed in large urban areas. All community resources including churches, schools, and welfare, housing, and health agencies, together with the mass media of communication and entertainment must be involved in efforts to strengthen family life.

Analyses Needed

In addition to the specific steps already suggested for reducing perinatal mortality and morbidity, broader concepts must be put into operation in an attack on the problem. One important approach is through perinatal mortality and morbidity studies. The Committee on Maternal and Child Care of the
Council on Medical Service of the American Medical Association is providing the lead in this direction.

In October of 1960, the committee created the American Medical Research Foundation which sponsored a pilot project to study about 100,000 deliveries at about 100 hospitals in the United States, by computer methods. The goals are to encourage physicians and hospitals to maintain good records; to provide a technique that will be useful in investigating the problems of the perinatal period to encourage physicians to recognize the value of statistical studies; and to encourage local hospitals in self-analysis and evaluation of techniques, procedures, and results. The success of this pilot project may pave the way for uniform adoption of such control techniques by all hospitals.

In the meantime, the technique of self-analysis through the local perinatal mortality conference sponsored by hospitals, county medical societies, or health departments must be expanded. Such a conference brings together a multidisciplined group consisting of generalist, obstetrician, pediatrician, pathologist, biostatistician, public health physician, nurse, nutritionist, and other specialists to discuss errors of omission and commission in a given case, so as to prevent a recurrence in similar situations in the future.

The need also exists for more pathologists trained in perinatal pathology. Too few autopsies are being performed to provide physicians with sound anatomic information as to cause of death. The placenta is also being neglected. Strauss recently pointed out the widespread lack of information on the nature and significance of structural alterations of the placenta and membranes, particularly with respect to their relation to perinatal loss and morbidity, and urged that placental examination become an integral part of perinatal study.

Limitations of space prevent discussion of other important problems requiring thought now and in the future. We are living in an era of nuclear as well as population explosions. What do we do about radiation fallout? How do we develop protection of our genetic future? What are safe limits of diagnostic radiation in maternal and child health perspectives? What about the emotional well-being of parents-to-be in such an era? Are we sufficiently concerned with psycho-emotional preparation for childbirth? Are we ready truly to plan our families and our futures?

All disciplines concerned with maternal and child health practices must share the responsibility to work out the right answers to such questions. Only then can we achieve the goal of maternity care spelled out by the World Health Organization: "to ensure that every expectant and nursing mother maintains good health, learns the art of child care, and bears healthy children."

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16 Committee on Maternal and Child Care of the Council on Medical Service of the American Medical Association: Supplementary material for the study of perinatal mortality and morbidity, 1960.
Five studies in California reveal some...

DETERRENTS TO PRENATAL CARE

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THE ASSOCIATION of adequacy of prenatal care to outcome of pregnancy has been well established by studies which have shown significant statistical association between lack of prenatal care and prematurity and infant mortality. But why, in a State with widespread clinical services, should any expectant mother fail to have sufficient prenatal care?

This question has been bothering public health authorities in California during the past decade and, as a result, a number of studies of the extent of and deterrents to prenatal care have been made under various auspices in a number of counties.

In California, the 58 counties are the strongest units of local government, with considerable autonomy and control—jealously guarded by the county boards of supervisors—in regard to public health and welfare policies and the administration of county hospitals. While city health departments exist in some highly developed urban areas, there are no city hospitals or city welfare departments. While all counties do not have county health departments or county hospitals, those that do not have them make other contractual arrangements with community hospitals for the provision of appropriate hospital services, including maternity care.

Of the five studies of prenatal care to be described here, one was made by a county health department and county hospital, one by a county hospital, two by a city health department and a county hospital, and one by the State health department with the cooperation of the county health departments. All of them found that a considerable portion of women of lower income groups were either not getting any prenatal care at all or were not getting care as early as the medical profession deems necessary.

The State health department first called attention to the need for such studies in 1952 when it sponsored two working conferences of State and county public health personnel to consider ways of preventing prematurity. The State did not complete its survey, begun in 1954, until 1956, and by this time several local health agencies were already conducting their own studies. With the exception of the statewide survey, all of these studies were concerned with the coverage of prenatal care rather than with its quality.

One of the first of these local studies was carried out in Alameda County by the local health department's bureau of maternal and child health. This was focused on finding out what happens to expectant mothers who are ineligible for county hospital clinic care, and yet cannot afford private care.

Cooperating in the study were representatives from three local health jurisdictions within the county, from the county hospital, and from the county medical society. For the 6-month period from March 1 to August 31, 1953, a survey of 134 patients ineligible for county hospital outpatient prenatal care was conducted involving a complete followup of 123 of them by public health nurses through the 6-week postpartum period. All 134 ineligible women had been referred by the intake workers of the county hospital to appropriate local health departments within Alameda County, but information on 11 was not available at the time of followup. While information obtained during the home visits constituted the basis of the survey, some
additional information was obtained from the birth and fetal death certificates.

The data show that most of these women were ineligible for county prenatal care on the basis of too much income or lack of residence; 59 percent were not eligible because of their income; 13.5 percent because they lacked the required length of residence in the county; and 14.2 percent for a combination of these two reasons. Of the 123 patients, more than half (66) had received either inadequate or no prenatal care. Inadequate care was considered to be care begun after the second trimester. Of 106 patients who ultimately obtained some prenatal supervision, either through private or semi-private sources or eventually at the hospital clinic, half were delivered as emergencies at the hospital.

This suggests that patients who were ineligible for county care and referred to other medical care resources do not, in the final analysis, obtain sufficient care. Knowing that under the law the hospital has to accept them if they come to delivery as emergencies, many of the women make no other arrangements for care.

**In Los Angeles**

In connection with an inquiry into the eligibility of its obstetric patients, the Los Angeles County General Hospital briefly reviewed the prenatal care histories of all women who gave birth there during one week in April 1954 and found that one-third had received no such care. Since prenatal care was being offered in 32 health department clinics in the Los Angeles area for women financially eligible under the standards of the Los Angeles County Department of Charities, the State Department of Public Health was interested in knowing why care was not obtained. Therefore, a social work consultant on the State staff interviewed 413 mothers about two days after delivery to find out how much prenatal care they had received and why certain mothers had received little or none. These interviews took place from mid-February to mid-May 1956. Each mother was asked to give information about race, marital status, education, and the amount of prenatal care received. Each mother who had gone to a doctor or clinic no more than once, or not at all, and one-third of the mothers who had gone more than once—199 mothers in all—were asked a further series of questions geared to reveal their attitudes toward prenatal care. Those who had not seen a physician were asked why not.

Some of the highlights from the summary of this study were: 51 of the 413 mothers interviewed, or 12 percent, had not been to a doctor or clinic for prenatal care during the current pregnancy; 39, or 9 percent, had made only one visit. Of those who had had some prenatal care, one-third began care in the first trimester of pregnancy, and about one-fourth waited until the third trimester; 65 percent who had received care had attended a health department clinic, and 16 percent had visited both clinic and private doctor. There appeared to be no difference in classifications according to ethnic groups, residence, or marital or employment status as to number of prenatal visits made or the time prenatal care was begun. The mothers who did not get prenatal care consisted largely of the less educated, the older aged, the users of public transportation, and women who lacked prenatal care in a previous pregnancy.

Among the 51 mothers who had had no care, four were having their first child; 22 had had no care during a previous pregnancy; and 9, some of whom had had several pregnancies, never had care in any pregnancy. Three-fourths of the mothers who had had no prenatal care were delivered previously at the Los Angeles County General Hospital. Of the 21 percent (90) who had no care or not more than one visit, 52 said there were times during pregnancy they would like to have seen a doctor.

Responses of the 199 mothers to the attitudinal questions indicated over three-fourths of the mothers who received care were pleased with it. Over half had no criticisms of the care they had received; one-fourth made some qualifying comments. One-fourth did not respond to the question. In this group, attendance at a prenatal clinic appeared to be influenced adversely by a low educational level, language problems, employment, and problems of caring for other children.

In her report of this study, the social work consultant pointed out that her observations underscored the importance of the prenatal clinic's first contact with the expectant mother. She also reported that the fact that the pregnant woman had a medical problem or was worried about the impending birth did not always motivate her to seek care.

**High Risk Groups**

Another survey of prenatal care was done in the San José city health department. This survey was carried out by a social worker at the University of California School of Social Welfare, Berkeley, as part of her training in a project sponsored by the
Bureau of Public Health Social Work, California Department of Public Health. Briefly, it sought to determine the reasons why 435 of the 3,948 San José residents who gave birth to live babies during 1958 had had no prenatal care or had deferred seeking care until the third trimester of pregnancy. These mothers were found more often to be teenagers having their first babies, grand multiparas (women who had already had 4 or more children), and mothers over 40 years of age.

Social Factors

The study attempted also to determine whether a relationship existed between the trimester in which prenatal care was begun and such social factors as established residence, knowledge of resources, educational level, religion, and ethnic group. A sample of 30 mothers were selected for individual interview.

Among the women in this sample, the average length of San José residence was 11 years, the average educational achievement was ninth grade, and the average family income was $3,100 per year. Their housing was for the most part “adequate to meet family needs” but few were equipped with telephone, radio, or TV. Most of the husbands were unskilled seasonal laborers. Two-thirds of the women in the sample belonged to minority groups. Over half were of Mexican origin, a cultural group not accustomed to seeking early prenatal care.

Of the 30 mothers interviewed, 4 had had no prenatal care; 5 were ineligible for service at the county hospital, but later were admitted for delivery as emergencies. Three mothers said they did not know they were pregnant until late in pregnancy; 2 said they had not wanted to go for care but gave no reason; 10 said they had no one to care for other children while they were gone; 5 said they saw no reason to go for care since they were not sick; 5 said they put the beginning of care off to save money for delivery by a private physician. All expressed satisfaction with their hospitalization.

Of these 30 mothers, 5 were receiving public assistance through the aid-to-dependent-children program; but the 25 others had had no social agency contact. Twenty of the mothers had contacted both the health department and county hospital in seeking obstetrical care. Except for 3, all were markedly dissatisfied with the hospital’s prenatal clinic. Their complaints in the order of frequency were: (1) “Social workers don’t talk nice to you”; (2) “Can’t see a doctor right away”; (3) “Wait in the clinic is too long”; and (4) “Too hard to get there by bus by 8 o’clock when you have to get someone to stay with the children.”

The survey concluded that the financial factor seemed to deter the majority of these mothers from getting prenatal care. While they were ineligible for such care from the county hospital they had inadequate funds for obtaining private care. Of the 20 mothers who had delivered at the county hospital, 15 were billed and were trying to work out arrangements to pay. This problem, the social worker suggested, might deter these mothers from seeking early care in future pregnancies.

A second important deterrent was the problem of finding someone to stay with younger children. Other deterring factors were chiefly emotional or related to poor understanding: fear of doctors; not knowing of pregnancy; dislike of the clinic; or deeming prenatal care to be unnecessary.

Briefly, the major deterrents observed in this study were a combination of external obstacles, inadequate perception of what prenatal care involves, and dissatisfaction with the clinic’s procedures. The social worker who carried out the study suggested that it might be easier to minimize the external obstacles—for example, by liberalizing intake policies at county hospitals with respect to residence and financial eligibility—than to overcome the attitudinal deterrents. She pointed to the need for greater efforts by health departments and medical societies to publicize the importance of health supervision for the three high risk groups; and added that identifying the grand multiparas and pregnant women over 40 is not so difficult as finding the pregnant teenager, usually primipara and therefore without a prior health department contact. Once these expectant mothers are located, the social worker suggested, more time and effort with each by the clinic staff to determine her perceptions of care and to overcome obstacles might be effective.

A Wider Study

In 1958, the Los Angeles City Health Department conducted a survey to determine the extent of prenatal care among County hospital maternity patients and “to identify the geographical areas and sociocultural groups where unmet needs are greatest.” Nearly one-fifth of all city resident births in 1958 occurred at Los Angeles County Hospital.

The motivating factors for this survey were: The hospital’s perinatal mortality rate was 60 percent higher than the rate in the rest of the county. Furthermore, the infant mortality rate for nonwhites,
who are predominant among county hospital patients, had risen steadily since 1954.

The survey was based on a sample of 928 residents of the city of Los Angeles who gave birth at Los Angeles County Hospital or at the University of California Los Angeles Hospital as nonpaying patients. It was conducted by public health nurses located at 16 health centers throughout the city. The nurses completed questionnaires in the course of routine postnatal visits to the maternity patients.

The study revealed that 7 out of 10 county hospital maternity patients had received insufficient prenatal attention, and 2 out of 10 had received no prenatal care at all. For the purpose of study prenatal care was defined as “adequate” if the first visit took place in the fourth month of pregnancy or earlier, and if at least five visits to the doctor or clinic had been made. While the city health department had provided some prenatal care to nearly 60 percent of the patients, most of them had sought care late in pregnancy or had made less than 5 visits for prenatal attention. The least amount of care was received by women with Spanish surnames—a reflection, perhaps of the cultural attitudes of Mexican women toward prenatal care.

As in the 1956 study, the proportion of maternity patients under 20 at the county hospital was greater than for the State as a whole. The data also suggested that many mothers who had adequate prenatal care during their first pregnancy did not obtain it during subsequent pregnancies.

The fact that a woman was married and living with her husband seemed to be a significant motivating factor for seeking prenatal care, since mothers who were not with their husbands had on the whole received less prenatal attention. Established Los Angeles residence, though not a requirement for receiving prenatal care in the local health department clinics, seemed to be a factor influencing the receipt of care, since those patients who had been in the county less than a year had had less care than those who had been there longer. Three out of 10 of the women who had received less than adequate care had not reached high school. Patients with high school or college education were apt to have received more care. However, mothers who had had a junior high school education had received less care on the whole than those who had had only elementary education—a finding for which no reason could be determined.

The public health nurses had identified factors that seemed to be the obstacles to adequate care. Among these were the mothers' attitudes: 25 percent of the mothers who had made fewer than 5 prenatal visits for care said they did not feel prenatal care was important; 19 percent had said they did not know about the free clinics. There were also external obstacles: 25 percent cited care of children and 10 percent cited employment as reasons they had not gone for care more often; 34 percent named a variety of other obstacles too vague to be categorized. The nurses who conducted this study expressed the opinion that some reasons for not seeking care cited by the mothers were closer to being rationalizations of their behavior rather than real obstacles which could not have been overcome by greater motivation.

The social worker who carried out the San José study expressed a similar opinion. She believed that if the mothers had thought prenatal care to be really important, the external obstacles to their securing care might have been surmounted. In the San José sample, only 10 percent of the mothers said they understood why care was important.

The report on this Los Angeles study suggests that “no single attack on the problem of inadequate care is likely to yield a solution. An approach on a wide variety of fronts will be required.” However, it points out that the high rate of inadequacy of care revealed by the survey indicates “that existing programs and education techniques are not successful in motivating mothers to obtain adequate prenatal care.”

The Statewide Study

One of every eight newborns in California is delivered in a county hospital. At the time when the State department of health was first contemplating its statewide survey of the prenatal care received by obstetrical patients in county hospitals, these hospitals were showing prematurity rates that were 50 percent higher that the rates in private hospitals, infant mortality rates that were 60 percent higher, and maternal death rates that were 200 percent higher. The added costs to the counties for the care of premature infants were estimated at $3½ million a year, exclusive of the social costs. These facts were behind the concern which prompted the 1954–56 survey. In this survey an attempt was made to find out something about the quality of care as well as about the quantity of prenatal attention the mothers were receiving.

The data were collected through personal visits by a physician and a social worker from the State health department to every local health department, county hospital, and local welfare department.
having a medical care program. Information was obtained from a total of 93 prenatal clinics.

The net result of the study was the documentation of three major unsolved problems: the inadequacy of the quality of prenatal care received by the patients of county hospitals; the obstacle of eligibility requirements for prenatal care; and the failure of many expectant mothers to seek prenatal care.

The actual quantity of prenatal attention which the mothers had received could not be determined since many of the clinics had no such information. However, the county hospitals estimated that 10 to 40 percent of their obstetrical patients had had no prenatal care. The quality of care was also difficult to measure, since at that time there were no State standards for prenatal care. A few minimum criteria were used to measure quality, however, including the number and kind of professional staff present in the prenatal clinics; the amount of time allowed for the doctors and nurses to discuss patients together; the clinical procedures used; and the degree of restrictiveness in eligibility policies.

The survey revealed that clinic physicians spent from 3 to 45 minutes with the patients per visit. Often the patients were seen only by interns, resident physicians, or general practitioners, with little supervision from obstetricians being provided. The clinic nurses spent from 2 to 41 minutes per visit. In some counties, public health nurses also visited each mother at home at least once during the pregnancy. Nutritionists participated in the prenatal program regularly in 5 counties and provided consultation in 18. Social workers—training unspecified—regularly participated in 17 counties and were available as consultants in 9 others.

The procedures for medical examinations, laboratory tests and the like varied among the counties although those regarded by the State staff as most important had been carried out at least once on all patients. Written nursing manuals on clinic policies were available in 15 hospitals and 7 health departments. Special nutritional advice was given in 31 hospitals and 8 health departments.

Rules in regard to eligibility for care varied considerably, and were available in writing in only 60 percent of the agencies having them. Variations in residence requirements were great. Some counties adhered to them strictly and others gave greater attention to the patient's need for care and to the likelihood of the delivery occurring at the county hospital.

Among the disqualifying factors for free prenatal or obstetrical care were: coverage by health insurance; failure to waive the Statute of Limitations in regard to future suits for payment for medical care; failure to accept a lien on property; seeking care too early or too late; being a primipara; income over a fixed amount; and failure to provide blood for the hospital bank. Eligibility factors related to financial need also varied. In 42 percent of the agencies, budgetary standards used were the same as in the aid-to-dependent-children program; 58 percent obtained no prior medical diagnosis before eligibility determination so that complications or other diseases requiring special care were not taken into account.

Followup

The findings of this first overall study of prenatal care in California led the California State Advisory Committee on Maternal and Child Health to make the following recommendations:

1. That the State Department of Public Health develop standards and recommendations for good prenatal care, and provide consultant teams to local agencies seeking to improve their services.

2. That all eligibility policies be written and be made known to all community agencies and professional personnel who serve these families, and that consideration be given to the development of statewide basic policies of eligibility for prenatal care and for hospitalization for complications of pregnancy. Statewide policies are still being worked on.

3. That local health departments find out, if they do not already know, the extent of the deficit in prenatal care in their communities and the reasons why certain mothers either do not seek or do not obtain adequate care, and use the facts to plan appropriate improvement of local prenatal care.

The State health department has already carried out the first of these recommendations with the publication of a booklet entitled "Standards and Recommendations for Public Prenatal Care." The introduction of this booklet points out that these standards while directed to county hospitals and clinics "may also be helpful to physicians in private practice and to staff of non-tax supported prenatal care facilities." They are presented as minimum standards only.

In addition to spelling out approved medical procedures, these standards take into account the social aspects of good prenatal care, emphasizing the family-centered approach to the patient. They included not only a recommendation that a socioeconomic history be part of each medical history, but also a plan for counseling which emphasizes the need to have certain things explained to the expectant mother on her first visit to the doctor. This suggests that as a minimum, "Every expectant..."
mother needs an opportunity to discuss the effects of her pregnancy on herself and her family." The booklet also describes the functions and responsibilities of each member of the prenatal care staff.

The California State Department of Public Health is continuing to study problems related to prenatal care, especially in relation to prematurity. In order to understand more fully the types of families having premature births as well as to obtain information regarding other types of perinatal loss, the Bureau of Maternal and Child Health is carrying out a project of matching certificates of births and neonatal deaths, a repetition of a study done in 1949. This will provide data on the socioeconomic and demographic factors in relation to prematurity and maternal complications and what changes, if any, have occurred in these data in the past decade.

The department's Bureau of Maternal and Child Health is also considering a study of the characteristics of Negro families having an infant death. This study proposes to include examination of parental knowledge of facilities and attitudes toward use of medical care. Also under consideration is a study comparing prenatal care and hospital care received by patients of the county hospital and a voluntary hospital in Los Angeles.

The Bureau of Maternal and Child Health is also planning a followup statewide survey to determine what, if any, changes there have been in the quality, quantity, or availability of prenatal care since its 1954-56 study, and to determine the impact on prenatal care as a result of its publication of standards.

Another project in Los Angeles is aimed at the improvement of obstetrical records to provide complete information on prenatal, delivery, and postpartum care, and on the newborn. This is being carried out by the Los Angeles city and county health departments and the county hospital. It is hoped that ways will be found of using the newly developed records to facilitate communications between the health department prenatal clinics and the county hospital. The information should also be useful for research purposes, especially in evaluating various types of patient care.

In Los Angeles also, nurses and health educators are experimenting together with different ways of counseling expectant mothers, individually and in groups.

The California studies described here indicate that many expectant mothers do not get sufficient prenatal care. For the most part, they come from the groups of society which are disadvantaged because of discrimination against minorities, low income, lack of vocational skills, poor education, and undesirable living conditions.

These facts underscore the importance of the maternal and child health program in a total public health program and the necessity of keeping such activities from being thrust into the background by the demands of the newer problems of modern "civilization"—air pollution, radiological hazards, the diseases of aging. Health departments must keep a balance in their programs and try to stimulate the raising of standards at every level of responsibility.

The studies also emphasize the importance of considering the psychosocial and cultural factors affecting expectant mothers in planning a program of prenatal care. Only a beginning has been made toward a look at such internal factors as attitudes, knowledge, and the values put on health maintenance. Information about both external and internal factors must be included if a precise picture is to be obtained of the deterrents to prenatal care.

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HOW TO MOVE ahead to carry out the recommendations of the President's Panel on Mental Retardation was the subject of an all-day conference held in Arlington, Va., on April 9, as the swan song of the Citizens' Committee for the 50th Anniversary of the Children's Bureau, which sponsored the Bureau's stock-taking birthday party on the same date a year ago. (See CHILDREN, May-June 1962, page 120.)

The 75 conferees included members of the Citizens' Committee, representatives of the President's Panel on Mental Retardation and its Task Forces and of the Children's Bureau staff, and specialists from the fields of pediatrics, obstetrics, and other fields concerned with the mentally retarded. Their point of departure was the panel's report, "A Proposed Program for National Action to Combat Mental Retardation," which was submitted to the President last October (see CHILDREN, January-February 1962, page 29). Featured speakers at the general sessions included: Secretary of Health, Education, and Welfare, Anthony J. Celebrezze; Leonard W. Mayo, chairman of the President's Panel; Mrs. Sargent Shriver, consultant to the panel; Edward Davens, deputy commissioner of health for the State of Maryland; Donald Stedman, associate director of research for the Joseph P. Kennedy, Jr., Foundation; and Gunnar Dybwad, executive director of the National Association for Retarded Children.

A considerable part of the speeches as well as of the deliberations in afternoon group discussions was devoted to the possibilities of pending congressional legislation for stimulating State and local action, both of a public and voluntary nature, to prevent retardation as well as to provide better services to the retarded. Prevention, it was generally agreed, necessarily involves activities beneficial to the entire population, such as research into fetal and neurological development to identify the points where damage occurs, efforts to improve and extend prenatal and postnatal care, and the provision of nursery schools and kindergartens to provide intellectual stimulation to children early in life.

Consideration of where to start in the development of a comprehensive program of prevention led to an apparent consensus that this must be with "high risk groups"—the women of low socioeconomic status who are not getting adequate prenatal care and the "culturally deprived" children of the same socioeconomic background. One conferee, however, remarked that in the slum cores of some large cities such "high risk groups" would consist of all the women and children in the area.

The conferees put considerable stress on educational efforts—to help the unmotivated, high risk groups appreciate the importance of preventive services, to help the retarded themselves to develop their capacities, and to help physicians, social workers, teachers, and the general public achieve a better understanding of the needs of the retarded and their families. Stress was also put on the importance of expanding professional education to help meet the manpower needs of an expanded program, and of training volunteers and middle-level auxiliary personnel to supplement the efforts of the highly skilled in the provision of services.

Concern about how to reach the "unmotivated" with appropriate services—especially prenatal care—focused largely on the way services are provided and the attitudes of the servers, with emphasis on the need for greater consideration of the dignity of the client as a human being. The enhancement of human dignity was, in fact, identified as the chief reason for providing special and basic services to the mentally retarded and for the President's proposals to Congress on February 5 this year that Federal funds be provided for the establishment of 10 research centers concerned with mental retardation and grants to the States for the construction of facilities for the retarded and for the development of comprehensive plans of action in relation to mental retardation.

"While all people are not born equal," said Melvin A. Glasser, chairman of the Citizens' Committee, "the very definition of democracy demands that they have equal access to opportunities for development."

—KATHRYN CLOSE

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ROLE PLAYING
IN A MATERNITY HOME

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TODAY MANY NEW forms of therapy challenge the social work field and the traditional treatment methods. One is group therapy, which is becoming a more widely accepted and an increasingly practical form of therapeutic endeavor. The staff of the Florence Crittenton Maternity Home of Detroit, Mich., after reviewing the literature in the field, has been trying to evolve a technique of group therapy specific to the unmarried mother while continuing to use the established treatment of individual casework interviews. We have found the techniques of role playing and group discussion to be valuable additions in our treatment program.¹

The Florence Crittenton Maternity Home of Detroit, a voluntary agency supported by fees from the clients and by the United Community Service of Metropolitan Detroit, provides a residence for 60 unmarried mothers, as well as an outpatient service. The entire program is treatment centered, with an interdisciplinary staff including persons from the fields of obstetrics, psychiatry, clinical psychology, social casework, social group work, occupational therapy, administration, nursing, and teaching. To these services were added the services of a group therapist in 1956. This was the psychologist, Rosemary Lippitt, who inaugurated and carried on the experiments to be described here. Since then three staff members trained in group therapy techniques as well as in social casework have continued them.

All of the unmarried mothers receive individual casework attention. The group living situation with its daily routines, the school, the medical care, the health programs, the group activities, psychological testing, and individual casework all are part of a total treatment program. The group therapy techniques were added on the theory that there are areas of universality in the problems presented by a maternity home’s clientele which might be covered by a group method in a more meaningful and timesaving manner. The goal of the entire program is to give the unmarried mother some insight into the reason why she became pregnant, to help her develop greater ego strength, to provide as much support as possible in facing up to her problems, and to help with her social readaptation.

The maternity home provides an ideal setting for trying out role playing and other group therapy techniques. The environment is controlled, structured, and homogeneous. The girls’ very presence indicates that they have common symptoms, common problems, and common needs specific to an unwed pregnancy.

There are, however, difficulties in setting up experimental situations for trying out role playing in a maternity home. One is the ever changing complexion of the population. In our home this population undergoes a complete turnover every 3 to 4 months. Another difficulty is presented by the wide age range. While 55 percent of our girls are under 17 years of age, the ages range from 11 to 38 years. Variations in intelligence have not been much of a problem since...
most of our girls have average intelligence. Differences in religious, racial, and socioeconomic background—which in our home covers the range found in the general population—do not present difficulties when the focus is on a problem common to all.

Early Methods

Because role playing as a technique for helping unmarried mothers with their specific problems is generally new in a maternity home, our techniques have been continually in a process of development with no distinct transition point between our early and newer methods. During the first year especially, various methods were used in an effort to find out what would be applicable to our particular clientele. Both in staff sessions and with the girls we attempted to define and discuss the technique of role playing, to take a census of the problems which might be approached through this method, to choose one problem for each group therapy session to work on, and to encourage the girls to participate in the activity. The simplest forms of role playing were introduced with film strips as starting points. Role playing for humor was used as one of the warming up techniques which have been advised "to induce spontaneous states." 2

When a central problem was chosen by the group for the focus of the session, a situation was devised by the group director to be spontaneously dramatized by the girls. In the early stages the girls took the parts of other people in the structured situation, and the part of the unmarried mother was played by a staff member. Now the girls play their own roles.

Our goals from the beginning have been: (1) to help the unmarried mother gain some understanding of her own problem; (2) to help her work out a better method of approaching her family, employers, and school after her experience in the home; (3) to evolve some specific group therapy techniques for helping unmarried mothers deal with some problems common to all unmarried mothers. The techniques worked out during the first year have changed but little in the past 5 years.

Our original group was the entire population of the home. Attendance was compulsory. The sessions lasted an hour, with a series of 12 sessions extending over a 3-month period. Two or three weeks elapsed between each series. Thus we were able to begin with all the girls by introducing them to what role playing is, helping them to develop skills in the activity, and gradually shifting the focus to a concentration on how one would act or feel when faced with a specific problem. Then to the "classical techniques" of role playing 2 we added some group discussion, generally focused on the solutions suggested in the acting.

We also devised a technique of having the entire audience participate as one of the principal characters in the scene. In order to do this the group director usually asked all of the girls to think in terms of a character being portrayed in a dramatic scene. Then the director would interrupt the acting from time to time to ask a member of the group if she would do it the same way or another way, sometimes asking her to change places with the actor immediately in order to reveal her thinking. After several such changes there would be a general discussion of the best way to handle the problem being worked on.

We felt that these sessions must belong to the girls themselves if they were to gain maximum benefits from them. So the leader permitted full freedom of expression in acting and discussion.

Reaction sheets were also used. On these sheets the girls expressed their reactions to the session and suggested questions for future dramatizations, thus revealing the problems that were worrying them. We tabulated these problems regularly and found that the same ones were repeated frequently and that these fell into a rather orderly pattern, going from the more simple and obvious practical problems to the more complex and intensive emotional problems. The same types of questions were repeated by each succeeding group. Those most often asked were: "How to act in front of the baby's father?" "How to handle suspicions of your neighbors, relatives, and friends who do not know where you have been?" "How to prove to your parents that you can be trusted?" "How to explain to your new employer where you have been for the past few months?" "Is it better to go out with your old crowd or to develop a new one?" "If I have not told the father of the baby, how will I feel when I see him again?" "How will I feel when I see my friend with her new baby, when I have just given up mine for adoption?" "To go to the same school or a different one?"

No matter with how many groups this method was used nor how many sessions were held, the gamut of problems remained the same. Because of this we eventually came to the decision that a more planned procedure needed to be developed to cover more adequately the total area of the girls' concerns.

This led to the formulation of the series of 12 sessions. We begin by using pictures which can be cut from any magazine. In the first session each girl is given a picture and asked to think out in a few min-
utes what the person portrayed is feeling and doing. The girls then take turns coming to the front with their pictures, pretending to be the person on the picture and expressing that person's feelings. This procedure has the purpose of helping the girls learn how to express a feeling. After this we present simple situations for role playing and progress to more complex ones. As the group works together, members gain skill in spontaneity and a feeling of cohesiveness. Just as a caseworker carefully proceeds toward a goal in individual therapy, we work carefully toward our group therapy goals. If the girls achieve insights into the nature of some of their problems more rapidly in this way than in individual therapy, there is greater attainment of our overall goals for them in the short time they are with us. When a girl acts out her thoughts and feelings about a situation, it becomes real to her, particularly if she is an adolescent. The part-taking gives her an opportunity for reality testing, which helps to strengthen her ego. Because the situations are the kind that all the girls are facing, she can mobilize and act out her hostilities, without fear of reprisals.

A tabulation of the checked responses and volunteered comments on 307 reaction sheets from the early days of the program indicates that on the whole the girls saw value in the experience. Among the checked responses were 154 that the meeting was "helpful;" 75, "very helpful;" 8, "extremely helpful;" 54, "a little help;" and 16, "no help at all." Typical of 102 of the volunteered comments was the statement: "I think it is helping me a lot to learn to work out my problems, instead of overlooking them." Among the other comments, 64 indicated that the respondents liked the discussion and acting out; 15, that they liked the friendly gathering with the other girls; 4, that they did not like anything about the meeting; and 4 suggested that the group be split into smaller groups. The rest contained no comments.

Present Methods

Over the years we have gained some knowledge, increased our skills, achieved new insights, recognized our mistakes, and so continually reevaluated and revised our methods and plans. Each role playing session is followed by a regularly scheduled staff conference, attended by the caseworkers, housemothers, psychologists, doctors, and a psychiatrist. At the meeting, the session's effects on individual girls and the group are discussed along with their implications for future sessions and the handling of individual girls.

We now work with the girls in three groups, instead of trying to deal with the total population as a group. When the therapy group consisted of the total population (usually from 40 to 55 girls) many problems arose. Sometimes there was difficulty in "warming up" or insufficient common interest. In other words the group director was dealing with a "crowd" and not a therapeutic community. Even our present groups may be too large. It would probably be better if we could have four instead of three. However, our three trained group therapists do not have sufficient time to take on a fourth group. The three groups consist of:

Group I: All girls who are new to the maternity home. The girls usually stay for three or four sessions in this group and then advance to one of the other two groups, according to age.

Group II: Girls under 18 who have had experience in Group I.

Group III: The more sophisticated girls who have had three or more sessions with either of the above two groups. This group is confined largely to girls over 18 so that problems of young adults can be discussed more freely.

This restructuring of the groups necessitated new subgoals for each group within the overall framework of the three major goals already mentioned. Our new goals now are:

Group I: Orientation or introduction to role playing to create ease and spontaneity. Insights into the girls' feelings about their problems may be gained.

Groups II and III: Strictly role playing focused on problems common to the group. Some insights into fears gained as well as social readaptation and social reorientation.

The sessions are still all unrehearsed and completely spontaneous. Prior to these sessions, however, plans regarding the focus of the session, the specific goal sought, and the degree of emotional intensity that can safely be allowed to develop are discussed by the staff in interdisciplinary conference. The procedures are similar to those which have been reported in use at the Pontiac State Hospital in Michigan where "plans are dependent upon the primary focus and the ego strength and personality of the patients concerned." However, the questions raised are specifically pertinent to the needs of unmarried mothers.

Generally, problems likely to be encountered by all unmarried mothers are still the focus of the ses-
sions, but the situation is designed to fit the need of one of the group members. Both real and make-believe occurrences are used as the framework for the acting. The make-believe situations help the girls develop a feeling of ease, temper their anxiety, and, because they are less threatening, hold their interest from one session to another. This is important where sessions are held only once a week. Make-believe scenes also bring about a greater degree of spontaneity and more ready participation, especially if the girl is fairly new to the group.

Usually girls are able to act out a situation in which they are intimately involved only after they have developed a feeling of security within the group. We have found, however, that generally actual situations can be approached more rapidly in the group setting than in the individual casework setting. As we work along with the group the members are able to devise their own situations. The group director, however, through questions and interruptions, directs the group's attention to what is happening in a way designed to have a therapeutic effect. She knows when and where to cut the scenes, not only to enhance the therapeutic effect but also to prevent damage from being done to the girl, or to her image in the group.

Whenever possible we have a staff observer or “co-therapist” attend the group sessions. This makes it possible for nonverbal communications to be observed more easily and for support to be provided a girl when none is forthcoming from the group. The co-therapist or staff observer, who may be the caseworker, the housemother, the doctor, the psychiatrist, or the psychologist, is also helpful in interpreting the session to the staff by giving an objective “third party” impression of how it seemed to go as well as by helping to evaluate the insights gained by the individual group members.

The Values

We continue to use “reaction sheets” and to tabulate the responses they contain. The problems expressed remain essentially the same. A tabulation of the check list responses on 305 reaction sheets from recent sessions gives the following evaluations: 66, “(a little helpful” and 30, “no help.” 68, “(very helpful” 109, “helpful” 66, “a little helpful” and 30, “no help.”

Some rather typical comments from these reaction sheets were:

“The small groups feel at ease—girls of the same age grow closer together and can express their feelings better.”

“We talk about things that sometimes we are scared to talk about.”

“We have been helped to solve problems we did not even realize we had.”

“This brings the situation into reality.”

So we have come to feel that role playing is of value in our program. It helps the girls not only to understand better how others feel about their behavior, but also to know how to handle constructively their own feelings and behavior. It gives them an opportunity to experiment with different kinds of behavior in an effort to find an appropriate procedure to use after they return home. It also helps them to develop a more understanding attitude toward their parents, relatives, and friends. Moreover, through the common sharing of a problem in a group the girls learn that it is not theirs alone and through this they are able to develop greater self-assurance.

The more a girl participates in role playing, the more proficient she becomes in it and the more confidence she develops about her ability to handle herself naturally when she is actually faced with the problem she has feared. We believe that this technique is particularly valuable for helping girls who have difficulty in expressing their feelings, and also for helping those who learn best from seeing and being. Girls who already had enough self-assurance to handle difficult situations are encouraged to participate in the role playing in order to demonstrate their ability.

We believe that these role playing sessions enhance our program and leave the caseworker free to use her time to a better advantage. They facilitate the treatment of a larger number of patients because the participants in the discussions spread their newly achieved insight throughout the entire group. The sessions also help the girl who is not immediately amenable to individual therapy through offering her the support of the group.

Thus, we are convinced that role playing as described here can be used as an effective supplement to casework and other forms of group work in a maternity home. Through the combined therapeutic team a unity of purpose in the treatment of the girl as a whole person, not only for herself but in relation to her particular world, is achieved.


CRIPPLED CHILDREN
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With the advent of the Maternal and Child Health and Mental Retardation Amendments of 1963, the crippled children's program stood on a new threshold.

The increased funds for crippled children's services under these amendments makes it possible for States to broaden their definition of "crippling" so that State crippled children's programs can serve children with any kind of handicapping condition or long-term illness including crippled children who are mentally retarded.

The development of comprehensive treatment centers for children with multiple handicaps—where coordinated services are related to their physical handicaps—is a high priority in a number of States. These centers provide treatment which is required by children who are retarded and who also have other types of handicapping conditions.

The history of the development and growth of the crippled children's programs is recounted in Five Decades of Action for Children: A History of the Children's Bureau.¹

The articles relating to crippled children appearing in CHILDREN during the decade 1954–1964 ranged over a wide variety of subjects: cerebral palsy, birth defects, helping handicapped children, hearing impairment, the orthopedically crippled child.

They all reflect the growing and broadening concept of services to handicapped children so characteristic of this decade and this developing program.

A NURSERY SCHOOL FOR CEREBRAL-PALSIED CHILDREN

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THE MICHAEL REESE HOSPITAL nursery for cerebral-palsied children, established in 1944 as an experimental and demonstration center, provides a social, educational, and treatment program for 14 handicapped pre-school children.

A cerebral-palsy clinic open to children of all ages developed as an outgrowth of the nursery. It provides medical supervision and specifications for equipment and takes responsibility for referring patients to treatment programs, but has no therapy program of its own. The nursery center includes the nursery proper and a treatment section with physical, occupational, and speech therapy.

In the nursery proper the fundamentals of a good nursery school are adapted for the child with a physical handicap so that the program can provide opportunities for him to function and develop to his maximum ability at his own speed. Each day’s activities require some special planning for each child because of the multiple handicaps presented by cerebral palsy. If Jamie cannot walk he need not be relegated to one location for long periods but can be taught to crawl or ride a bike, or helped to tumble with the more hardy children on the mats. Davie or Susie can join the group at crafts if given a sponge instead of a brush with which to paint. Each child receives the dramatic equivalent of some activities he may not directly experience because of his handicap.

The school has a well-trained and flexible staff of teachers and assistants, therapists, and a social worker, who help the children and their parents as a cooperating team. Medical specialists in the treatment center provide highly specialized medical care and consultation for defects in hearing, vision, respiratory function, mental retardation, aphasia, and other handicaps which may accompany cerebral palsy. An administrator coordinates the services of physicians and training staff into a secure working team concerned primarily with the welfare of each child and his family.

Activities

The children spend a major part of their time playing, because this is the way they learn, create, share, and mature. However, unlike many nurseries, Michael Reese does not segregate children into age groups. The teacher sets the stage for all kinds of activities adjusted to the ages and current interests of the children and their previous play experiences as well as their handicaps. She encourages the badly handicapped child who cannot walk to achieve experiences as near the normal child’s as possible by showing him how to use special apparatus or teaching him to roll or crawl. She listens to the boy or girl who cannot speak intelligibly and gradually learns to understand and communicate with him. She encourages the confused child who refuses any patterned toys to create with paints, clay, or sand. She tries to be sensitive to each child’s wishes at the moment as well as his needs in the long run.

Like any well-planned nursery the Michael Reese Nursery provides the children with four important
areas of experience: free play; group activities; regular routines; and special occasions.

Since preschool children work best in small groups of two to five, they need a program allowing each to get about on his own, choose his activity, play freely alone or with several others, and change to something else as his interest and attention span demand. The teacher sets the stage, indoors and out, with a variety of interesting toys and creative experiences. Some children ride together on built-up tricycles or specially adapted walkers, pushing a weighted doll buggy, descending the safety-rimmed slide, moving up and down a set of bannistered stairs, rolling on mats or crawling up the incline, or in some other way getting that gross motor activity so necessary to every young child. Another child lies flat on the floor, running small cars over the surface around him. Some children play “tea party” in the doll corner or load groceries in the school store, while others take an imaginary boat trip with lined-up chairs. One “reads” the pictures in a book.

Throughout the period the teacher guides and encourages each child according to his needs or sets limitations understood by the children themselves. Without neglecting anyone, she devotes special time to the badly handicapped child, helping him achieve a well-rounded day of play and group experiences.

Because they lack some of the normal child’s experience, young cerebral-palsied children usually need more definite information and direct guidance to orient them to the outside world and to stimulate creative play. The cerebral-palsied child may never have gone shopping with mommy or bought a newspaper with daddy or mailed a letter. He may have to be taken on a trip to see the trains or to be shown pictures of them before he will “play train” or attempt to draw one. Planting seeds, baking cookies, washing doll clothes are experiences which make books seem more realistic. The group of children around the craft table or in the block corner will need varying amounts of help but each child can initiate some part of his project to make it his own.

The nursery uses a variety of medically approved and individually adapted means of assisting a handicapped child to stand and move about on his own. Because a handicapped child resents being set apart by having to use a table or wheelchair the regulation nursery chair, with additional support built under competent supervision, is used for every child in the school. The conventional stand-up table, or the individual chimney support where a table is not needed, enables the child to be located near any toy or piece of equipment he chooses. Toys are carefully selected not only for durability and adequate function, but for continued interest and possibilities for growth. Blocks, puzzles, and formboards, patterned toys of all kinds help develop eye-hand coordination and recognition of color and shape. Packing boxes, boards, and mats provide opportunities to climb, jump, slide, or crawl in and out of something. Toy cars, boats, dishes, dolls, and animals set the stage for dramatic play.

Over a period of time, noticeable changes take place within the group. Children new to the nursery play mostly by themselves or grouped about the teacher, and rarely settle down to anything for long. Several months later, however, they enjoy more highly organized forms of activity. Two children playing together run trucks side by side or briefly enjoy a party or house play. Several sit around a table building a garage together or planning a bus or train trip with nursery chairs. The children have chosen friends, and are beginning to exhibit signs of community spirit.

Although the children spend much of their day in free play, some part of it is occupied in a teacher-directed group. Every day before lunch the staff groups them into younger and older sections for music, stories, and conversations. The younger ones learn to attend and to participate for short periods in very simple songs, games, or accounts of their doings at home. They may plant a seed, watch and talk about the ways of the pet turtle, or illustrate a song with simple movements or gestures. The older ones participate in prereading experiences. They note birthdays on the calendar, look for “long” or “short” or “round” objects in the room, talk about books and learn to look at them, notice signs and learn what they mean. They may present an oral “newspaper,” plant a garden, or plan a special event, such as building a drugstore with packing boxes. Such participation helps develop attention, self-expression, and group planning.

Special occasions include birthday celebrations, holidays, and seasonal events. A timid, handicapped child may bloom first at his own birthday party where he is the center of attention in a pleasant setting. The children may spend days getting ready for the annual Christmas party for parents, making gifts for Mother’s Day, or baking cookies for some occasion. Periodic trips to a farm or the zoo, or a market or business center, initiate all kinds of creative art, lively discussion, or imaginative
**Routines**

In every nursery school the staff helps the young child to learn to handle his natural requirements—the general routines of eating, sleeping, toileting, self-help, and cleanliness—by patient guidance, without pressure, after carefully watching for cues that he is ready to assume responsibility. The cerebral-palsied child usually needs extra help not only in the use of some special equipment but also in achieving a measure of self-help and independence.

Daily after lunch and nap the children at Michael Reese sit near their beds dressing and undressing. Their teachers and therapists without any nagging or punishment encourage them to take-off and put on wraps, lace and unlace shoes or manage braces, and use their own cups, forks, or spoons at table, alone or with the amount of help needed. The presence of other children also provides them with a strong though indirect social suggestion toward self-help.

As in other nursery schools the staff at Michael Reese helps the child understand and accept conformance to routines and certain standards of behavior such as sharing, recognition of the rights of others, and respect for property. Kind and flexible in placing limitations on a child, the staff members try to help him build up his own self-control.

They did this with Jennie. A passive, fearful child who spent most of her time alone, Jennie refused to wear her new body brace. Without any attempt at force, the physical therapist talked to her kindly about the brace and its use. After several days she quietly said to him, "Mr. John, I want to have a secret with you. When you take me on my trip tomorrow I will wear my brace for you.” And thereafter she continued to wear it.

**The Working Team**

The friendly working relationship among staff members at the nursery center is sensed by the children as well as by visitors. A well-defined working policy results in effective teamwork on overall problems and the problems of individual children.

The physical therapists in the nursery emphasize posture and locomotion not only through table work but in helping children use apparatus, carefully designed to meet the needs of each. The physical therapist also works with the teacher on plans to further the developing abilities in the group. These may involve a more active nursery program for the severely handicapped, including such activities as mat rolling, crawling, and the use of a specially adapted walker, tricycle, sliding board, or chimney support. Such activities prevent contractures and other liabilities due to continuous sitting or inadequate posture, bracing, or ambulation equipment. The physical therapist aids the individual child in a variety of ways, from helping to make him physically comfortable in his chair, periodically evaluating the amount of mechanical or human support he needs in walking or sitting, or helping him to acquire a new ability such as bike riding.

The speech therapist helps the child learn to talk or improve his speech in a treatment session and during his efforts at spontaneous expression in the nursery group. When her time allows, she cooperates with the teacher during the conversation and music periods or unobtrusively joins the children in free play around the sandbox or tea table, talking with them informally and evaluating their communicable speech. Her conversation with shy Teddy as she helps him dress after nap may be as beneficial as any direct "lesson.”

The occupational therapist centers largely on developing the child's independence in feeding, toileting, and dressing through direct function or indirectly through toys and games. Being present to help certain children take off their wraps on their arrival, she promotes hand function and encourages self-help. Her aid to Sandy at lunch may be as valuable as any "feeding" session in the treatment room.

At times the occupational therapist and teacher plan certain projects together such as finger painting, doing puzzles, or whipping cream to make butter. In this way the therapist not only helps certain children needing specific aid but encourages correct hand usage throughout the group. She also helps children individually—little Susan to keep her hands flat while finger painting, Dale to use both hands by building with large hollow blocks, Donna to use the left hand to assist the right. In her work during the children's activities she is careful not to dominate the group nor destroy its spontaneity. This work does not require her daily attendance in the nursery group nor a sacrifice of her own program of individual treatments, but it does enable her to use the daily nursery program to further her own efforts.

The nursery's social worker helps the parents understand the nursery's activity and treatment program in relation to their own children. She also helps them with their personal and family problems. In addition she confers with other staff members, in meetings and individually, in an effort to bring about
more effective coordination of the child’s home and school experiences.

The teachers at the Michael Reese nursery are selected not only for their background in child development and techniques in handling young children but also for their warmth and friendliness. Their job requires encouraging the children to express their feelings, pleasant and unpleasant, and to accept the unpleasant ones. They help the children redirect their hostile expression into acceptable channels, and in the long run, to grow into acceptable behavior. They do this not by nagging or scolding but by analyzing each child’s particular problem and attempting to help him grow on the basis of his needs.

For instance, instead of reproaching listless, badly handicapped Martha for her continual wetting, her teacher and therapists set about helping her to hold her own cup, feed herself with a special spoon, ride a tricycle, color and paint in her specially built chair, and play with the other children. In time she proved to be one of the most imaginative children in the school. As her happiness grew, the teacher explained to her how she would try to help her keep dry. Soon after this, Martha stopped wetting.

The teacher at Michael Reese helps the children build up wholesome attitudes toward their own bodies. She handles their questions about differences in sex or their “crippled” condition openly, casually, and reassuringly, yet realistically. She provides opportunities for the child’s social adjustment, helps him maintain his own rights and feelings and respect the rights and feelings of others. While she is not at the hub of all activities, there are times when she must guide or intervene. At other times, after carefully setting the stage, sheretires somewhat into the background to watch and listen. She adapts the daily program, supervises her assistants, evaluates each child and his progress, and works with each according to his needs.

One of the most difficult problems faced by the teacher of young cerebral-palsied children is how to concentrate attention on the needful child yet spread her energies over the group. Judy, who cannot put a puzzle together, pick up the crayons as she draws, or accomplish any hand function alone, must have special attention. But the teacher must also attend to the group as a whole, redirecting children temporarily bored or steering them into some purposeful activity, quieting the boisterous ones before rest time, helping plan a particular craft project, protecting certain children from their aggressions, and performing a variety of other services.

The teacher must be careful, however, not to force the child who flits from one choice to another, unable to settle into any pursuit, into some purposeful activity before he is ready for it. He may be too disturbed to play constructively or he may have had no previous experience with other children or with play materials. He will need gradual encouragement.

The nursery teacher at Michael Reese is interested in the children as developing personalities and not as “cute little darlings” to be exploited or merely played with. Sensitive to the difficulties of the immature child with little social experience beyond the mother-child relationship, she helps him bridge the gap in forming other relationships. She encourages shy children to express themselves and to take their own part and tries to protect the aggressive ones from too much guilt over their attacks. She guides each child according to his stage of development.

Parent-School Cooperation

The nursery’s physicians and training staff, with the help of the social worker, work individually with parents to help them further their children’s development. The therapists teach the parents how to apply and care for braces or how to help the child use some ambulation equipment or a built-up spoon to feed himself. They encourage parents both to talk and to listen to their child, thus furthering his efforts to communicate. The teachers encourage parents to widen their children’s experience by taking them on trips to the park, the firehouse, a parking lot, a farm or a store, thus giving them a background for understanding the world in which they live.

Parents are encouraged to visit the center to observe or to talk over problems with teachers and therapists. This not only furthers their understanding of the nursery’s aims for their child but also provides the school with helpful information. Parents also are invited to carefully planned medical reviews, where they can talk informally with physician and staff about their child’s progress.

Every spring and fall informal workshops bring staff and parents together to mend, paint, and decorate books, toys, and furniture, and generate a feeling of friendly cooperation. In addition, fathers and mothers meet once a month with the director for parent-centered discussions. She encourages them to express their feelings and helps them make suggestions for resolving their own problems.

Does It Help?

Each child admitted to the nursery is carefully se-
lected from the applicants with an eye to all his needs and his likelihood of benefiting from the program. The parents’ ability to cooperate is considered as a factor in the child’s potential success or failure.

After the nursery accepts a child, the social worker helps prepare both mother and child for what may be their first separation. Mothers attend school for the first week or more to help their children in their initial adjustment. Well in advance of a child’s discharge from the nursery the social worker plans with the parent for his future, taking into consideration the child’s abilities, his family’s wishes, and the opportunities available in the community for his education and training.

How do we know whether the school has helped the child over the months or years? There is no exact formula, of course, only certain clues, for evaluating a child’s growing maturity. As we live with these children and care for them day after day we compare each one’s growing maturity with his past behavior. Is he increasingly happy and outgoing? Is this dependent little boy becoming more self-reliant and successively able to direct his own activities and interests? Is he more resourceful in solving his own problems with less appeal to the adult for help? Is the retarded or confused child growing more interested in colors and shapes, objects and experiences in the world around him? If a child is developing in some or all of these ways, if he is becoming more creative and imaginative, with ever-growing and more mature interests, he is probably advancing on a par with his possibilities. No nursery school can expect more.
An interprofessional panel considers ways of helping parents . . .

WHEN CHILDREN ARE BORN WITH DEFECTS

VICTORIA SHANNON

Medical Social Worker, Division of Crippled Children,
Connecticut State Department of Health

MOST OF US who are engaged in health and welfare services have seen families which include a child with a congenital defect. We have seen the parents burdened with the extra tasks that caring for such a child demands and even more with the conflicting feelings they have about themselves and their child. We have wondered how they reacted to the child’s birth. Could professional people have been more helpful? Can we learn to be of more help in the future?

To stimulate thought about helping parents in the period shortly after the birth of a child with a congenital defect, the Connecticut Branch of the American Association of Medical Social Workers sponsored a panel on the subject at its annual meeting held in conjunction with the 1954 meeting of the Connecticut State Medical Society. While problems of adjustment occur from the child’s birth throughout life, the panel concentrated on ways of helping parents in the shock of their first knowledge of their child’s anomaly. Since the most effective help to the child and his parents comes when physicians, social workers, and nurses work together, representatives of these three professions were each invited to contribute to the discussion.

Because of her studies of patients, the social worker in a prenatal clinic usually has knowledge of value to the physician considering how to help the parents. She may know the answers to such questions as: How did the parents feel about each other at the time of pregnancy? Has the marriage abounded in hostilities? Have the parents been accepted by their in-laws? Have the parents had to struggle with feelings of guilt over sexual activity or over their reaction to the pregnancy? Have cultural differences enriched their marriage or complicated their adjustment? Do they use religion as a source of support or a threat of punishment? Are there environmental difficulties which could be lessened? She has learned these answers in her efforts to build a relationship which may help support the woman not only during pregnancy but also after delivery.

The support given to the expectant mother by the nurse during pregnancy and good nursing care at the time of hospitalization are important in any

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<th>PANEL MEMBERS</th>
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| **John C. Leonard, M. D., moderator**  
Director of Medical Education and Clinical Director  
Hartford Hospital |
| **Katherine Davis, R. N.**  
Administrative Supervisor of Pediatric Service  
Grace-New Haven Community Hospital |
| **Alberta de Ronge**  
Medical social worker, Bureau of Maternal and Child Hygiene  
Connecticut State Department of Health |
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| **Paul Molumphy, M. D.**  
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Assistant Clinical Professor of Pediatrics  
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CHILDREN • JANUARY-FEBRUARY 1955

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pregnancy. The warmth of a good nurse can add much to a mother’s feeling of confidence in her own abilities as a mother. This comes from both public-health nurse and clinic or bedside nurse. In addition nurses increasingly are becoming aware of the emotional implications of the patient’s behavior and of the effects of personal problems on the patient’s health and are bringing this understanding to bear in their handling of their patients.

The physician is the professional person of most importance to expectant parents. A significant part of his medical care is the reassurance that everything is going well or being watched and that he will be making the delivery safe. Since he appears as one who instills courage and strength he often engenders the kind of positive feelings formerly reserved for the husband.

Many physicians have found that most pregnant women have a suppressed fear of giving birth to a defective child. When this actually happens, “fantasy and reality appear to meet.”

The discussion of how the hospital team might help to lessen the nightmarish quality of this experience opened with a summary of a case known to the State division of crippled children. The baby, Jane, had a variety of congenital defects which made her anything but a picture baby. She received surgery in the general hospital shortly after birth and again at 4 months. She remained in the same hospital till she was 7 months old and was then transferred to an orthopedic hospital for children.

The mother was discharged at about the usual time after delivery. She rarely visited Jane either at the general hospital or at the orthopedic hospital. “I was so knocked out by the baby’s condition that I hadn’t the strength to get out of bed,” she told the medical social worker when the family was referred to the division of crippled children.

This mother had been ill at home for over a month after her discharge from the hospital. Her upsetting experience was intensified by the attitude of her own and her husband’s parents, her own refusing to see the baby and her husband’s saying that she should not have had a child because she was too young to know how to take care of a baby.

Nevertheless Jane’s mother was at this time in the fifth month of her second pregnancy and was terrified at the possibility of the coming baby being like her first. She hated to go to sleep because she always dreamed of deformed babies. All this came out after she had bombarded the social worker with questions about Jane—“How big is my baby? Does she sit up? How much does she weigh?”

Both the mother and father received enough emotional support from the social worker to become able to visit Jane and to move toward feeling themselves to be more loving parents and, therefore, better persons. In addition, they were relieved of the financial obligation they had incurred for Jane’s care, even though they had not been able to see how they would meet it. Pressure for payment of overdue bills had aggravated the difficulty these parents had had in visiting their baby.

Mothers’ Fears

After this case was reviewed the obstetrician pointed out that at the moment of birth a mother often fears that her child will be dead, injured, or defective. A mother may express this fear by asking, “Does it have all its fingers and toes?” Knowledge of a defect should not be kept from a mother when she asks, “How is my baby? Is he alive?” If the mother is to continue to trust the doctor, she should receive a frank answer. If she is told that the child is normal at this time her difficulty in eventually accepting the truth about her child’s condition will be greatly increased. She may even insist that the defective child cannot possibly be hers. Learning that she was given false reassurance in the delivery room may provoke such resentment in both herself and her husband that neither may be able to establish good relationships with physicians in the future.

In the delivery room at the time of the birth of a defective child the doctor faces three immediate decisions: whether to tell the mother about the anomaly, to show it to her, and to discuss its prognosis. The panel obstetrician advised that in such a situation the mother must be told both about the anomaly and its degree of severity and should be shown the child unless it is greatly disfigured.

A more difficult decision, he said, is what to do if the anomaly is major and disfiguring. Usually the father wants to help. The mother’s desire to see or not to see the child should be respected. Often the nature of the defect is less severe in reality than in the mother’s imagination. Its prognosis should be discussed in general, leaving details in the hands of the appropriate specialist or a pediatrician.

The physician may find it very hard to tell the parents about a defect. The panel moderator mentioned how, as a young instructor, he had to force himself as well as the resident physicians to face this painful task. Some physicians may be especially
reluctant to discuss the possibilities of mental retardation. Nevertheless in cases of brain damage it is unfair to the parents to let them continue to have false expectations, the moderator said.

The panel members questioned whether efforts to conceal the existence of a defect would always be successful. One told of a mother of low intelligence who said of her child: "I knew something was wrong. Nobody smiled or said anything; and he was blue, not like my other babies."

Another mother had been told only that her baby boy, who had a cleft lip, was alive. She had not been allowed to see him for 2 months while he recovered from surgery. Later when the child was 10 years old she told a social worker that at the time of his birth she had overheard people whisper the word "hare." Concluding that her baby was completely covered with a thick growth of hair she had refused to see him when she was at last given the opportunity to just before he was placed in a boarding home. The decision to place the child outside the home had been made by her family physician and her husband without consulting her. Her delay in seeing her baby and her exclusion from all planning had fixed in this mother the belief that her child was a monster.

Experience with mothers of infants with cleft lip has shown that they appreciate the skill of the physician more fully if allowed to see their children before surgery. More important, seeing the baby at once helps the mother accept him as an individual personality.

The Nurse’s Role

The nurse pointed out that in dealing with a newborn child it is essential for all nurses coming in contact with the patient and family to know:

Whether the family knows the child is not perfect.

What information the physician has given the family.

How much information the physician wishes the nurse to discuss with the family.

Whether immediate corrective surgery is planned or whether correction will be postponed and for how long.

Old wives’ tales often help to aggravate a mother’s disturbed feelings—particularly a sense of guilt about her own responsibility for the defect. Nevertheless, she may hesitate or forget to ask her physician about the validity of what she has heard from her neighbors or elsewhere. The nurse has an opportunity to develop close rapport and learn some of the mother’s concerns—sometimes these come out only while the mother is caring for or feeding her child. The nurse can reassure the mother and work with her and with the social worker and physician in planning ways of helping both mother and child.

Anxious parents frequently misinterpret a physician’s remarks or cling only to the encouraging ones, so that they fail to face the facts. The nurse, who may be seeing the child and parent more frequently than either physician or social worker, is in a position by her own acceptance of the baby to help the parents to accept their child’s limitations.

If the child is to undergo surgery the nurse should know what the physician has told the family concerning the operation, how many stages are involved, and what the possible complications may be. A reassuring experience for the family at this point may be to see a child who has had successful surgery for a similar condition, for example, cleft-lip repair or a heart operation. In the postoperative stage the nurse may help to reduce parents’ fears concerning their child’s condition when oxygen tents and other equipment unduly frighten them.

The Pediatrician

During the discussion, the pediatrician pointed out that a pediatrician if chosen before delivery can be of help to the obstetrician and the parents when the latter are informed of their child’s defect. However, he warned against too much initiative on the part of the professional staff in urging the mother to see the baby. Emphasizing the importance of proceeding very slowly with parents, who naturally need time to learn gradually to accept their baby’s abnormality and to become relaxed in the face of it, he pointed to the need for patience in dealing with them.

“We can be most helpful,” he said, “by letting the parents talk about the child’s handicaps, and how it affects them personally and as a family, how hard it is to feed the baby, how difficult it is to answer other children’s questions, how they haven’t been able to go out. These everyday problems are all important. As the parents relate these experiences and their feelings about them to the doctor, they learn that he is interested in them as well as in their child.”

Each family must be understood individually by the pediatrician, who must see them regularly and plan his care in terms of months and years rather than in days and weeks.

“The parents are quick to notice impatience on the part of their doctor,” the pediatrician added.
“When they feel that they are being rushed, they cannot be free and comfortable in discussing the problems, nor can they work towards making definite plans for the care of the infant.”

Only when the parents realize that the pediatrician accepts them with all their mixed feelings and attitudes about their child, will they be comfortable with him. When they are, he may be the person with whom they will raise the question of whether they dare have another child—especially if they have any feeling that the obstetrician may have been at fault.

Future Pregnancies

The question “What about having other children?” is always asked sooner or later. When another child is on the way the mother and the father of a defective child will be seeking reassurance that misfortune will not strike again. In such instances, said the panel obstetrician, the obstetrician consulted must know about the parents’ past experience in as great detail as possible, with particular emphasis on the manner in which the parents were handled by the medical personnel in attendance, what they have been told about the etiology and prognosis of the defect, and what their reaction has been to it. Only with these facts in mind and with a careful appraisal of the parents, based on close questioning, can he do his best to help with the parents’ emotional problems. While there is some increased incidence of abortion, prematurity, and congenital defects in subsequent pregnancies among individuals who have had a congenitally defective child, it is not so great as to prevent an obstetrician from honestly expressing considerable optimism regarding the outcome of another pregnancy. “Such reassurance is extremely important,” the obstetrician maintained.

Another case discussed involved the mother of a boy with a serious cardiac malformation. When her baby was about 3 months old, this woman had said, “It isn’t fair for any baby to have so much trouble,” and was very emphatic about never wanting another child. Two years later she became pregnant again. When she first talked to the clinic social worker, she was feeling very guilty about not wanting another child and had postponed talking to her husband and relatives or making any plan for obstetrical care. She said that her former physician had been very critical of her reaction to the birth of her boy, including her desire not to have another baby. Nevertheless she was thinking of going back to him again in spite of her resentment—perhaps to punish herself.

When the social worker helped her think of alternatives that would be more satisfying, her self-confidence increased and she was able to discuss with her husband some of her feelings. Together husband and wife worked out plans for medical care and took other steps to make everything about this pregnancy as different as possible from the previous one. However, this mother is still far more anxious than she was before she had a child with a defect and will continue to need the support of the pediatric clinic team even though her next baby is normal.

The obstetrician introduced another problem:

During pregnancy clinical signs and X-ray examination or both may disclose some weeks before term the presence of a major anomaly, especially hydrocephalus or anencephalus, gross malformations of the head and brain. This puts the obstetrician in a position of either deliberately concealing this knowledge from the parents, or of divulging the information to one or both of them. Frequently he handles the situation by informing the father about the anomaly, perhaps with the recommendation that it is up to him to decide whether or not to inform his wife. The obstetrician and the father may thus become partners in deliberately concealing the truth from the mother, a fact which may later be resented by the mother and have far-reaching repercussions. The father’s emotions in relation to such a deception ought to be considered as well as how this will affect the wife’s future feelings about her husband, the obstetrician said.

“On the other hand,” the obstetrician added, “the mental state of the mother who knows that she is carrying a defective child is unfortunate and may possibly be reflected in difficulties in the further course of pregnancy or labor, depending on her personality and her deep feelings concerning childbearing, as well as on her past experience. We do not have in this situation the favorable maternal psychology which makes acceptance of knowledge of congenital anomaly relatively simple in the actual delivery setting.”

The responsibilities imposed on the physician by foreknowledge of a defect are tremendous. The obstetrician cited a case in which a young husband was told of an expected hydrocephalic child. The father became greatly disturbed and told his mother. Promptly all the relatives became involved, each family blaming the other.

Sufficient knowledge about the family, the marriage, and the couple’s feelings about the pregnancy might help the physician decide when and with whom
he would talk. Such information would probably be known to the social worker or in some situations to a public-health nurse or to a medical student or physician who had had the time necessary to get such information and had learned how to use it.

The social workers suggested that a father told of an expected anomaly might gain emotional support from being able to talk over his problem with a social worker. The latter might help him to express his real feelings about whether to share this knowledge with the mother. A social worker might also help the father to realize how his handling of this crisis might affect the marriage. This clarification of the husband's feelings could be brought to the physician and used by him as a basis for further joint planning.

At this point in the discussion the pediatrician suggested that perhaps it was unfair for the obstetrician to unload his prebirth knowledge of defectiveness onto either parent before delivery. "There is too much emotional adjustment at stake to put the whole burden of knowledge on the father alone," he said. The pediatrician and obstetrician agreed that this whole area needs much further study.

**The Social Worker**

In discussing the making of long-term plans for families with defective children, the panel members maintained that the feelings and wishes of the family must be respected and that the parents should be the ones to consider the various ways of caring for their child. For example, advice to have a child placed in an institution may be disastrous to the parents if they are not ready to accept it.

Many parents have guilt feelings about having produced an imperfect child. Through the casework relationship the social worker often can help the parents to change their feelings about themselves so that they no longer blame themselves for their child's condition. Conflict between parents and among relatives over the child can then be reduced.

The same questions and problems may crop up again and again before real understanding and acceptance of the child are achieved. Some parents may need help in raising questions, such as whether their first reaction to the pregnancy affected the development of the fetus, or in asking about their child's prognosis or whether they should have other children. The social worker and other members of the professional team may also facilitate cooperative relationships among the various hospitals or clinics that may be involved in the case.

In some instances the pediatrician or family physician may have the interest, time, and skills to help the parents with their planning. Because of the length of time involved, and the complexity and cost of the services required, many physicians refer their patients to the local unit of the State division of crippled children, where the child can receive coordinated care from a team of medical specialists, nurses, social workers, and speech, occupational and physical therapists. Other private, voluntary, or tax-supported resources are drawn in on the patient's behalf.

Frequent communication between the various professional persons involved is essential in working with families of children with congenital anomalies. For example, if the child has cerebral palsy many persons will have different services and points of view to offer—all needed by the patient at one period or another. If the family is to participate there must be such close working together of the professional people that the family will see unity in approach and goals, even with variety of personnel and method. Spending time in a case conference can save time by increasing the effectiveness of work with the patient.

As the professional personnel involved we also need to learn much more about our own feelings concerning parenthood, the processes of pregnancy and childbirth, persons with defects—and how these feelings affect our work. We need to learn much more about the meaning of these experiences to other people so that we can understand different parents' reactions to them.

In our daily work with expectant parents, we need to make use of our opportunities to help build their confidence and move toward more effective adulthood. When a child is born with a defect we need to accept his parents' feelings, and to realize the individuality in each situation. We must assist such parents from the beginning in understanding what is involved in their child's treatment and prognosis—that several operations at different periods of a child's life may be needed, that training of a special sort may diminish a handicap, that help can be given them in relation to their own feelings. In short, we need to use our professional skills with the greatest understanding of which we are capable.

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Experiences in a hospital school have revealed some . . .

STABILIZING INFLUENCES IN HELPING HANDICAPPED CHILDREN

KATHARINE L. FOSTER

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The greatest allies of persons dealing with the problems of handicapped children are the stabilizing factors that often exist within the child himself in his family or other personal relationships, or in outside circumstances. What these are and how they affect the child’s progress have been amply demonstrated by the patient-students at the Massachusetts Hospital School for Crippled Children, a resident school for the orthopedically handicapped child of normal mentality, operated by the Massachusetts State Department of Public Health.

The Hospital School admits severely handicapped children whose disability prevents them from attending regular public school, whose medical treatment would interfere with continued schooling for a period of one or more years, or whose poor adjustment to their handicap has interfered with their progress in school. The patients range in age from 3 to 21 years, but a child of 3 or 4 is admitted only if the medical need seems to be so important that delay might constitute a threat to his life or hinder his progress by establishing fixed abnormal muscle patterns of position and function.

By orthopedic surgery, physical therapy, and occupational therapy the School helps the child to attain maximum power and efficiency within the limits of his physical disability, with the aim of returning the child to his own home and community as soon as possible.

Now that educators are giving increasing consideration to the exceptional child, the educational needs of the less severely handicapped child are being met more and more by regular school systems, thus enabling the Hospital School to transfer children to their community school after they have achieved certain goals. However, many patient-students with physical handicaps severe enough to preclude the possibility of their ever attending public school remain at the Hospital School for completion of academic and vocational training. Comprising the major portion of the enrollment they include children seriously disabled as a result of accidents or traumatic illnesses such as poliomyelitis; congenital conditions such as malformations, spina bifida, and cerebral palsy; or familial diseases such as muscular dystrophy. Of the institution’s 131 patients, 72 are paraplegics, who because of paralysis are able to
walk, if at all, only with braces and crutches, and often are incontinent of bowel and bladder.

The problems of helping children with such handicaps to a positively oriented existence are clearly evident. Everyone working with these children is aware of the negative aspects. Their seriousness cannot be denied, but it is possible also to point to positive factors with which and by which constructive goals can and have been reached.

**Parental Support**

Foremost among these factors may be the family’s attitude. There was at the Hospital School a few years ago a severely handicapped boy with cerebral palsy who when he came at the age of 19 on referral from a treatment center had had no formal schooling and was completely dependent upon his family. He walked with a laborious, hitching gait, but he could get around fairly well with a large tricycle. His speech, always with grimaces, was unintelligible except to those who were with him constantly. His athetoid movements seemed to defeat any practical training. On the surface this boy, Frank, seemed to present an insoluble rehabilitation problem to the School.

The Hospital School’s social worker visited Frank’s home and learned from his mother that she had been following the treatment center’s recommendation to encourage him toward as much independence as possible. Previously whenever Frank had gone out on his tricycle some member of the family had followed along after him. Though feeling almost desolate the mother had taken her courage firmly in hand and had allowed him to go alone, even when this evoked the criticism of her neighbors. She told of watching out the window while Frank worked at least half an hour by trial and error to unlock the padlock to the shed where his tricycle was kept. She spoke with pride of his persistence, thus exhibiting not only her courage but also her unconditional love and respect for her son. Other members of the family also showed their love for Frank by welcoming the social worker with enthusiasm when she visited.

Such warm backing from his family assured Frank’s progress. Despite his athetoid movements, he continued the training in weaving he had started at the treatment center. He also managed to get as far as the sixth grade in his school lessons. Now he sells his weaving products in his home town, advertising them himself as he rides around on his tricycle with a placard in front and on back. Although his weaving does not bring him great financial returns Frank in a sense represents total rehabilitation, for he has learned to use his limited capacities to their fullest extent and has become an accepted member of his community.

Realizing the importance of maintaining the child’s close relationship to his family, particularly with those children who must remain away from home many years, the Hospital School encourages visiting on both Saturdays and Sundays and gives liberal vacations to the patients, including a long summer vacation. But some parents cannot accept their children enough to take advantage of these opportunities.

We have known a number of children much less severely handicapped than Frank who have been totally rejected by their families. In such instances we try to help the members of the family toward more acceptance of the handicapped child by patience, sympathy, and understanding of their own needs. But what if we fail? Then we must rely on a situation which is perhaps characteristic of any inpatient institution, wherein a variety of persons know the children and have an opportunity to become somewhat of a parent substitute to one of them. Thus an attendant, a man on the farm, a housemother, a teacher, while not actually filling the place of a child’s mother or father, may at least become a confidant, a special person in the youngster’s eyes. Or we may, if we are very lucky, find someone outside the hospital environs who takes the child home on vacations “just like the other children.”

**Rejected Children**

Although the grossly rejecting families are not many—currently 10 out of our total population of 131—their rejection is such a tragedy for the individual children involved that for the social worker it looms as a large and serious problem. The parent substitute helps to dilute this problem by providing a stabilizing factor for the child. Usually the close relationship involved has arisen spontaneously between the child and a member of the institution’s personnel. Occasionally the social worker has taken an active part in fostering such a relationship, and has provided interpretation of the child’s needs to the parent substitute and supportive help to both the parent substitute and the child. Sometimes the child may have been so badly hurt psychologically and needed so much help in relating to another person that the parent substitute may have to be the social worker herself who may use her training and experience to
help the youngster form a relationship which may provide him with a constructive experience.

One of the school's fairly recent graduates was a youngster who had been caught in an intolerable family situation. Even prior to the onset of her physical difficulty she had been the victim of rejection by a mother who did not want to be bothered with children, and had been placed in a foster home. Her parents were finally divorced and subsequently both were remarried.

The girl, Beth, was intelligent and attractive in appearance. She was wheelchair bound, but had good upper extremities. She was not disliked by others but neither was she popular, as she lacked warmth and was caustic in manner. Her way of meeting people's curiosity about her handicap was to glare at them. She never went home for vacations and was not invited by others, partly because of the severity of her handicap and partly, perhaps, because of her caustic attitude. During each vacation Beth came to the social worker's office and wept bitterly and uncontrollably.

Beth's mother visited perhaps twice a year with many promises which were never fulfilled. Therefore, the girl was alternately lifted up with hopes of her mother's love and interest, and let down to miserable suffering. After several years of this, and as Beth became older, the social worker felt that if the girl could understand her mother's inability to fulfill the role of a mother, her own hurt would be lessened. She tried to give her that understanding but at that time felt she had achieved little success.

During the following years the social worker and Beth discussed Beth's family situation; what went into making friendships; the advisability of accepting a person's curiosity regarding her handicap and of meeting new people at least half way; plans for the future; and various other topics. They began doing something together each vacation, for this was a time when Beth needed a parent substitute even more than a social worker. Sometimes they included Beth's younger sister who had also been rejected by her mother and lived in a foster home.

The constant support available to Beth when she needed to let her loneliness spill over during those years and later in the first critical weeks after she had left the protected environment of the Hospital School to take a job, enabled her to become a self-supporting, competent young lady. Last summer she was able to go on a vacation by herself to a place where she was the only girl with a physical handicap. She found that she was well liked, possibly because she no longer had to glare at the world, but was meeting it smilingly and with courage.

The important stabilizing factor in Beth's development was not whom she turned to for support but that there was some one person able to gain her confidence in her terrible loneliness and insecurity.

**Inner Strength**

In many instances the stabilizing factor is the patient himself. We have all seen the patient who seems to have all the odds against him, but because of some stamina, some strength of character, will be able to win through. Sometimes this is so obvious that everyone who knows the patient is sure of this. But in other instances it may be hidden from view so that even though we believe we know the patient well we are unaware of his underlying strength.

The patient-students at the Hospital School included for many years a boy, whom we shall call Bill, who was a paraplegic and had all the complications of that condition. He did not do well in school. He tried all of the vocational courses and failed or was disinterested. Moreover, he never followed instructions in caring for his own personal needs, although he had been taught patiently over a period of years.

Bill's mother and father were divorced and his father's whereabouts was unknown. His mother visited him occasionally but as she lived in a rooming house she was never able to take him for vacations. Bill talked to the social worker and over and over again, pleading for a chance to live on "the outside," a term used by the patients for any community outside the institution. This raised a number of questions: What would he do? Where would he live? How would he care for himself? Would people tolerate his lack of personal hygiene? The social worker suggested that he might use his last year at the Hospital School to prove he was able to care for himself. But he did not change. Bill's desire and difficulties were taken up with his mother, in the hope that she might offer to get an apartment for him, but she became hysterical, crying that if the personnel of the Hospital School wanted to take the responsibility of letting Bill out it was up to them, but she knew unqualifiedly he belonged in an institution.

On the other hand a psychiatrist, consulted by the social worker about Bill, reported: "I can certainly understand the misgivings about him in view of his past performance and I realize that this just give a chance' cry is often the prelude to failure. However, I believe that the odds are good enough to
warrant the trial. If he is the sort who cannot play his best unless the chips are down, he will make the grade. On the other hand, if he is a psychopath he will never make it no matter what is done. Unfortunately, with the circumstances under which he has lived so far, there is no clear-cut way to make an absolute prognostic differentiation. My advice would be to make the trial if at all possible. There is more to gain than to lose.”

So with things not looking very promising plans were made. No one really expected them to work, but the staff agreed that Bill should be given a chance. A room was found, temporary help from the public welfare agency was arranged, and the State Division of Vocational Rehabilitation agreed to make plans with him.

Everything went completely to pieces within 5 weeks. Bill was put out of his room because of his lack of personal hygene; he refused to go to the sheltered workshop on the grounds that the Division of Rehabilitation was giving him the “run-around,” and he turned to the Hospital School for help. This was denied him as he had been given his chance, and he was advised to accept permanent institutional care.

Then, when he was completely up against it, Bill found himself a job and found a boardinghouse in which to live. He is still with both 3 years later. He has been responsible for four other physically handicapped boys getting placed in the same factory, has bought a car and has turned into a steady, reliable young man. As the psychiatrist sensed, he turned out to be the kind who “plays best when the chips are down.”

**Community Spirit**

The fact that a hospital school is a community of people with similar problems and interests can be a supporting factor in rehabilitation. If a handicapped child can manage at home and in a public school where he has more normal living, a hospital school has nothing to offer. However, if the severity of his handicap, his family’s or his own poor adjustment to it, or a combination of factors necessitates his admission to a hospital school, the spirit of the community can be of tremendous value. There the sympathy he will get will not be maudlin; in fact, quite the opposite. He will have to stand with the other children on the strength of his personality—on what he is. But he will not have to face the reaction of others to his physical difference for he is expected to have one. Such casual acceptance of his disability may help him to accept it himself. As he learns to do more for himself within his own limitations, and as he becomes more mature, he can then begin to take the next step toward fitting into a world of nonhandicapped people.

An integral part of this community is the help the students can and do give each other. Their freedom of expression is not hampered by self-consciousness about their handicaps. They discuss their mutual problems and work them out in their own ways. They joke about their differences, saying amazing things to and of each other. They can also cut through barriers that a person who is older or without a handicap cannot do. One girl told a friend: “Go on, feel sorry for yourself, it will get you nowhere but you can wallow in it if you want.”

Sometimes such forthright treatment by a contemporary does more for a child than any older person could do. The children also see their friends going into the mysterious “outside” and doing well. All this bolsters their courage.

Something of this spirit at the school must have had a hand in building up Bill’s determination to make good on the outside. In spite of all the uncertainties of the staff he had never had any doubts.

Another example of the value of the institution’s community atmosphere can be found in the case of a girl who was referred to the Hospital School with a fairly mild type of disability. Although she could get around well she walked with a mild spastic type of gait which was awkward and noticeable. She had been in public school and had done well until she reached high school when her marks dropped drastically for she had become aware of her difference and was desperately unhappy. At the Hospital School, however, everybody had a “difference”. Her adjustment there was rapid and her school marks immediately improved. She continued on at the Hospital School until she was graduated from its high school. By that time she had regained her confidence enough to enter college. In her first year of college she has not made a spectacular record but has done well and, more important, she has been able again to feel comfortable in a group of predominantly nonhandicapped people.

Time can be another stabilizing factor. Certainly the medical profession depends upon and recognizes its value in allowing nature to heal. Time, or more correctly, what can take place as time passes, may also heal social ills. Frequently families who have paid little attention to their children in their early days at the Hospital School have eventually renewed their
interest and have even become supportive and helpful. This has not always come about spontaneously, but often as a result of the social worker’s understanding attitude toward parents, her gentle but constant prodding, and her reports on their child.

Time as a Healer

When a child is born with a handicap the shock to the parents is severe, arousing feelings of helplessness and hopelessness, and sometimes feelings of guilt. But after time goes by and the child develops personality and learns to do more for himself, the hopelessness lessens. If the parents can be persuaded to take the child home they sometimes find, to their surprise, that he is accepted by their neighbors with much less difficulty than they expected. As they find others responding with affection to their child and themselves become proud of what he can do, they may gradually take up the reins again.

There is a little boy at the Hospital School who was born without any arms and with one leg shorter than the other. His father’s devotion has never varied, but his mother was so hurt psychologically by this shock that she could deal with it only by avoiding him. Her reaction to him made it necessary to place him in another institution until he was old enough for transfer to the Hospital School.

During his year at the Hospital School, this mother has gradually become less disturbed. While the boy’s first visit home was difficult and he cried to come back with “the kids,” his periods at home have gradually increased, the last one being 2 weeks long. The other children in the neighborhood play with him; he is part of their gang. This boy has learned to do amazing things with his toes, and his mother just recently said with pride—“he can do almost everything.”

No pressure has been put on her. The social worker agreed with her when she suggested that if the boy stayed home too long he would have difficulty readjusting back at the Hospital School, although it was evident it was really too hard for her to keep him any longer. Nevertheless progress is being made as her hurt is lessening.

Sometimes when hope seems very dim, an unexpected factor enters in to bring stability—call it chance, coincidence, or fate.

Until a few years ago Eleanor, a girl severely handicapped with diffuse arthrogryposis, a congenital condition of joint deformities and muscular weakness was a student at the Hospital School. She had been born out of wedlock and placed in a foster-family home where, because of the severity of her handicap, care could not be maintained. She was therefore admitted to the Hospital School at the age of 2 years, although today the school would be more adamant about such a young child’s need for the individual love and care of a family home. At the age of 15, Eleanor was found to be incapable of further education and unable to profit from vocational training because of poorly functioning hands. Wheelchair bound, she was worrying about the future and fearing transfer to another institution.

Little else seemed to be in store for Eleanor because her mother had rejected her almost completely, writing only rarely from her home in another State. However, her mother did ask Eleanor in a letter where she would go when she had to leave the Hospital School; and Eleanor in answering named another State institution to which she would probably be transferred. Her mother immediately came up to the Hospital School, greatly concerned. She told the social worker she had been deserted by her own mother when she was 7 years of age, and because of her need for medical treatment had been sent to the institution Eleanor had named, and had lived there for several years. Eleanor’s mention of the institution brought back vividly the unhappiness and loneliness of this experience, and with these memories came the realization to this mother, perhaps for the first time, of what she had done to her own daughter.

After some months of planning, Eleanor finally went to her mother’s home in the faraway State. The adjustments were bound to be many, between Eleanor and her mother and stepfather, for they did not know each other. But at least there was a chance for this young girl to live outside an institution for a while and to hope for a brighter future.

A Philosophy

The Hospital School has not always been as fortunate in finding solutions to children’s problems as in the cases presented here. There have been failures—the family who did not come to accept their child in spite of time, patience, and understanding; the student who failed to respond to any kind of appeal or therapy, preferring to remain dependent; many others representing struggle, suffering, and defeat for child and hospital personnel alike. Nevertheless, the Hospital School’s philosophy persists—never to give up, while a child is under care, the effort to seek out and build on the stabilizing factors which can sustain his future.
THE FOLLOWING REVIEW of developments in the care of handicapped children during the past 20 years has been compiled from comments of directors of State crippled children's programs in various parts of the country. A request to all State directors for a "few paragraphs" on what they would like to see emphasized in an article brought 25 replies.

These comments were impressive in revealing the quality of the directors' ideas, their obvious concern for extension and improvement of total care of handicapped children, and an indication of nationwide ferment toward better integration of services. The feeling that crippled children's programs are still in a stage of dynamic growth came through very strongly. Undoubtedly the programs are riddled with unsolved problems and glaring omissions. Nevertheless the communications from the States provoke a thrill of pride at the vigor and vision with which these are being attacked.

Many of the letters pointed out that some State crippled children's programs preceded the passage of the Social Security Act, in a few instances by many years. All, however, acknowledged that the act gave "tremendous impetus to the broader development of services for children, particularly in rural areas," through its three-way partnership arrangement involving local, State, and Federal governments.

Twenty years ago the purpose of the program was set forth in the Social Security Act, title V, part 2, section 511, as follows:

"... enabling each State to extend and improve (especially in rural areas and in areas suffering from severe economic distress) as far as practicable under the conditions in such State, services for locating crippled children and for providing medical, surgical, corrective, and other services and care, and facilities for diagnosis, hospitalization, and aftercare, for children who are crippled or who are suffering from conditions which lead to crippling . . ."

While the Federal Government has increased its share of the expenditures for crippled children's services threefold since 1940, when it spent $3,700,000 on the program, State and local governments have in the same period increased their contributions sixfold—from $5,600,000 in 1940 to $29,800,000 in 1954. However, approximately 40 percent of the State and local share in 1954 was raised and spent in only four States. Some States, with comparatively low incomes, appropriate very little more than the amount necessary to match the Federal dollars, while one or two are not putting up enough to draw the full amount of Federal aid due them.

Basic Philosophy

Any program of medical services for crippled children needs guideposts to point direction and goals. These vary somewhat from State to State but on the whole derive from an underlying philosophy which may be stated in four basic principles:

1. The program has a humanitarian basis growing out of a normal concern for the well-being and happiness of children. This is widely recognized and accepted. Less well understood is the tremendous economic saving to the State in dollars and cents associated with transformation of potentially lifelong handicapped, dependent, unemployed persons to useful citizens. Increase in manpower resources and the consequent gain in national security is an additional consideration.

2. Primary emphasis should be directed toward application of the increasing numbers of preventive

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measures which medical science is providing. Programs for crippled children should never be allowed to become mere salvage operations to patch up disabilities which need never have occurred.

3. Every service needed for the total medical care and rehabilitation of the crippled child should be employed. All available private resources should be utilized and the balance financed from public funds. Continuing effort should be made to encourage individual initiative and the assumption by parents, within their ability, of responsibility for the care of their handicapped child.

4. The effectiveness of a State crippled children’s program depends upon the degree to which its activities are correlated and integrated with the medical and allied professional groups, medical schools, hospitals, voluntary health agencies, and various social and educational agencies in the State and local community. A program is not and cannot be made a self-contained unit.

In applying these principles it must be remembered, as Eliot has recently reminded us, “that physically handicapped children are particularly exposed to discrimination, isolation, and rejection by the community and even sometimes by their own families.” Said Dr. Eliot:

“We know only too well that any child who is rejected or who feels himself deserted by his family will find the road to a healthy personality a most difficult one.

“Handicapped children then, even more perhaps than normal children, need the bulwark of family trust, affection, acceptance, and support if they are to avoid overt aggressive behavior, even delinquency, on the one hand, or the building of walls of defense by retreat within themselves on the other. This places a great burden upon all of us who have a part in guiding the future development of this program to continue to look at our procedures and practices. We must make sure that everything is being done that can be done to bring complete health to the children under care.”

Coverage and Priorities

The most consistent trend nationally, as revealed in the letters from the State directors, has been the broadening of the definition of a crippling condition. During the early years of the program most States concentrated on providing services for orthopedic handicaps in conformity with the then current definition of the term “crippled.” Disabilities amenable to plastic surgery such as cleft lip and palate were soon added. About 1941 several States, stimulated by Federal funds for “special projects,” began to set up demonstration programs for children with rheumatic fever, rheumatic heart disease, and hearing impairment.

Then cerebral palsy, previously included under orthopedic conditions, began to receive special attention in several States, which developed projects designed to further integrate medical and educational services by providing physical, occupational, and speech therapy and medical, psychological, and social supervision simultaneously with the education of the child.

Recently this integrating trend has accelerated and has been extended to a host of new handicapping conditions. In addition to those already mentioned conditions receiving special attention in State programs today are sight conservation as well as eye disorders amenable to surgery, speech disabilities of all types with the point of reference being “communicative dysfunction,” congenital heart disease, epilepsy, nephrosis and nephritis, diabetes, asthma, severe orthodontic defects, and even the clinical aspects of specific reading disability.

These trends have been accompanied by concern over what one State director described as “the emotional factors involved in not only the impact of sudden disability and the disturbance of normal growth and development of the personality by congenital or early disability, but also the physical expression of emotional disturbances which require careful and complete evaluation.” As an example of the latter he cited efforts toward the detection of functionally deaf or hard-of-hearing children.

Practically all of the responding State directors stressed the insufficiency of appropriations to meet the needs of at least some types of conditions.
program director pointed out that “not only has the cost of medical care per individual unit gone up tremendously within the past decade but furthermore the amount of medical care per person has also increased so that at the present time we are faced with a serious problem in meeting the financial cost for such improved care.”

As a matter of fact, funds, personnel, and facilities for crippled children's services will probably always be limited in relation to actual need. This means that program directors, staffs, and advisory groups must think about spending available funds in a way to achieve the greatest benefit for the largest number of children at the least cost. In developing a balanced array of services, increasing attention is being given to priorities of emphasis stemming from sound public-health criteria rather than from sentiment. Basic criteria are:  
1. The number of children affected.  
2. The severity or potential severity of the handicap.  
3. The amenability of the handicap to medical therapy and preventive measures.  
4. The likelihood of the child’s becoming, if untreated, dependent, unemployable, and a permanent public responsibility.  
5. The unfavorable effect of the handicap on the emotional, economic, and social status of the child and his family.  
6. The extent of interference with satisfactory progress in school and future employment.  
7. The cost per child to secure maximum benefit.  
8. The progressiveness of the condition.  

Standards and Distribution

Undoubtedly the most significant and enduring contribution of the State crippled children's programs has been the way they have carried the torch for high standards of medical care.

For the past two decades the persistent insistence on a high quality of care has been notable. It has paid off large dividends in terms of qualifications of professional personnel; high standards of facilities used; and organization of services so that children can be moved freely from rural areas to medical centers and back, from hospitals to long-term institutions, from hospitals to their homes with all of the needed resources and services available to them at each point.

The concept of total care provided in orderly continuity and directed to the whole child within the family unit is a brilliant achievement. The development of administrative operations with sufficient flexibility to carry it out is an equally important accomplishment.

A large part of the credit for these achievements should go to the orthopedic statesmen who had the vision and drive to insist on high standards back in 1935 and before. History will also surely chalk up several points on this score for the Federal Children's Bureau. As one State director put it, “Children’s Bureau consultative service to the States has promoted establishment and maintenance of standards of medical care and has indoctrinated State staffs in new and broader concepts of care of children.”

In this connection another significant result has been the tendency of private agencies to adopt the standards of care set by State agencies for both treatment facilities and personnel.

Of first importance in the elevation of standards and in the development of new programs has been the use of a portion of the Federal grants for providing opportunities for special training. Federal money has been used to support courses in pediatric nursing, cleft-palate surgery, audiology, the care and treatment of epileptic or rheumatic-fever patients, and various aspects of physical therapy, as well as to provide for medical social work field practice in agencies for crippled children.

One of the outstanding characteristics of medical practice in the past 50 years has been the trend towards specialization and urbanization with a consequent maldistribution of personnel and facilities, especially for complex diagnostic problems and long-term care. Medical specialists, diagnostic facilities, laboratories, and the other impediments of modern medicine have congregated in large metropolitan centers resulting in a geographic roadblock for the crippled child who lives in a rural section.

“One very certain value of crippled children's services has been their ability to reach children in rural areas who otherwise would be neglected,” was but one of a number of such comments from the program directors. Nevertheless, the inherent difficulties imposed by long distances in providing complete and continuous care continue to be formidable. Said one comment from the West:

“Many of our children are 400 miles away from the closest center. If your children in Baltimore had to travel halfway to Chicago for treatment, you would
get some idea of what we are up against. The problem of followup from the center is difficult and we are finding that most of our followup must be done through public-health nurses who have received in-service training in this field. The problem of distance in the Western States has never been satisfactorily solved. The travel costs for the State board of health personnel are very large and the time consumed cuts down on the efficiency. Since we have no medical school in the State, we use several out-of-State for postgraduate training.”

Some States are attacking this problem through the establishment of regional and district offices.

**Interprofessional Approach**

Nearly all of the communications from the States produced emphatic evidence that the team approach is perhaps the dominant trend at the moment in organization of services.

State after State described plans for bringing together a group of specialists to work as a team in a crippled children’s clinic or center. More and more we find a pattern in which a medical specialist, such as an orthopedist, and the pediatrician, medical social worker, public-health nurse, and physical therapist work together to evaluate the problem and formulate a plan of continuous care. In many instances a special educator, either in person or through appropriate communication, becomes a member of the team. For older children the vocational counselor from the State Vocational Rehabilitation Service joins in the task of making a long-range plan.

The postclinic conference is rapidly becoming a popular and effective way of reaching a deeper understanding of all the problems imposed by the disability and helping parents to plan to use all community resources in their solution.

As community mental-health organizations and child-guidance clinics increase in number, a close relationship is being established with them by crippled children’s centers and clinics. Thus they can bring the skills of a team of psychiatrist, clinical psychologist, and psychiatric social worker to bear on the problems of those crippled children in whom difficulty in accepting needed treatment or excessive emotional disturbance compounds the underlying problem of physical handicap.

In the case of the subtle and complex problems associated with hearing impairment and speech disorders, the ball is now usually being carried by a skilled and smoothly functioning trio of otolaryngologist, clinical audiologist, and speech therapist, who work closely with the pediatrician, the public health nurse, and the medical social worker.

The field of sight conservation still seems to be lagging behind this trend. Better teamwork needs to be worked out between ophthalmologist and optometrist before the great bulk of the difficulties can be overcome, especially in rural areas.

Many of the directors’ letters expressed great enthusiasm for the new approach to total care of infants with cleft lip and palate. Nearly half the program directors referred to the development of an integrated cleft-palate clinic. One rather detailed comment illustrates how far interprofessional collaboration has advanced:

“The speech pathologist begins counseling the parents of the cleft lip and/or palate child at the time of the first application to the Crippled Children’s Division. He sees the parents on the same day that the child is examined by the plastic surgeon, which is usually the day before hospitalization for the primary closure, with the emphasis usually being on the problem of the child’s future speech. Contact is then made by the Division’s medical social consultant and the on-going care begins.

“At the age of about 4 years, the child is sent to the university dental school for dental X-rays, head plates, and wrist films, at which time molds of the mouth are also made. At this time the child is also seen by a pedodontist. By then the speech pathologist has made his evaluation, the medical social consultant has followed the case closely, and the plastic surgeon has seen the child yearly to suggest any operative procedures that may improve the cosmetic effect.

“After the age of 5 years the child, accompanied by his parents, is examined by the plastic surgeon, speech pathologist, representatives of the dental school who had performed the original examination, plus an orthodontist and prosthodontist from private practice. A pediatric examination is given and after each specialist has had an opportunity to study the patient’s history, examine the patient, and review the dental films and molds, a case conference is held at which time the orthodontist, prosthodontist, plastic surgeon, pediatrician, nursing consultant, and social worker discuss with the speech pathologist any method at the disposal of the respective specialist which may improve the child’s speech. There is a free flow of ideas among all of the specialists to determine what surgery, orthodontia, or prosthodontia
may be necessary to give a good cosmetic effect and normal alinement of the teeth, as well as any type of device which will improve the child’s speech.

“For the next 15 years the parents are instructed from time to time by the medical social worker on how best to coordinate all the services. The nursing consultant sends the composite data to the public-health nurse in the child’s own community. She then coordinates the followup care and urges the family to get all necessary work done so that the orthodontist and prosthodontist may properly carry out their function.”

**Accent on Prevention**

The people who wrote Title V of the Social Security Act back in 1935 had the vision to see the great importance of applying the principle that an ounce of prevention is worth a pound of cure. This idea is incorporated in this section of the act by the wording “or who are suffering from conditions which lead to crippling.”

In the early years of the program relatively little attention was paid to preventive possibilities possibly because of the preoccupation with taking care of the backlog of severely handicapped children. Even in 1955 much remains to be done in putting into day-by-day practice the close relationship which should exist between maternity, infant, and preschool, and school health programs on the one hand and crippled children’s programs on the other.

In recent years, much more attention has been focused on the preventive aspects of crippling, partly because of stimulation from the Children’s Bureau through a variety of “special projects.” The concept of different levels of prevention is now widely accepted. “Primary” prevention for example would be pasteurization of milk to reduce the possibility of bone tuberculosis; smallpox, diphtheria, and other active immunizations to prevent various disabilities; the provision of cod-liver oil to avoid rickets; and a host of other procedures. “Secondary” prevention refers to the planned and systematic application of early case-finding techniques, prompt and definitive diagnosis, and arrangement for treatment and meticulous followup so that the “condition which leads to crippling” is taken care of before handicap results or becomes severe. Early diagnosis and care of rheumatic heart disease and hearing impairment are typical examples of this approach. Such preventive efforts require careful organization of services, constant effort to follow through each case, and close and cordial collaboration between the crippled children’s program and the maternal and child-health and school health programs, voluntary health services, medical schools and teaching hospitals, and other community services.

Perhaps the greatest challenge facing crippled children’s programs at this time is subtle, sustained, and complex cooperative community action needed to realize fully the goal of “secondary prevention.”

**New Treatment Methods**

State crippled children’s programs have been responsive to the many new discoveries in medical diagnosis and treatment which have become available.

Rickets as a cause of crippling was already on the way out in 1935. Improved case-finding procedures and additional treatment facilities as well as pas-
urization of milk and new antibiotics have dramatically reduced bone tuberculosis. Chemotherapy and antibiotics have also greatly reduced both the number and the severity of cases of osteomyelitis, an inflammation of the bone marrow. The new Salk vaccine promises to control poliomyelitis.

In the field of childhood cardiac disability the advent of sulfadiazine and penicillin have made possible the control of rheumatic heart disease, while the development of remarkable new operative techniques have opened the way to habilitation of over half of the cases of congenital heart disease.

During World War II many remarkable new ideas and procedures were developed which have boosted the whole field of rehabilitation. One of the most remarkable examples is the creation of a new medical specialty, clinical audiology, which has practically revolutionized previous thinking about "deaf" children and made it possible to provide auxiliary methods of communication to nearly all youngsters with impaired hearing for whom treatment is started early enough and maintained with the necessary intensity.

One of the most exciting recent developments has been the improved approach to upper- and lower-limb prosthesis, resulting from research spearheaded by the National Research Council and characteristically based on the team approach of orthopedist, physical therapist, and prosthetist.

Other exciting examples could be added to this list. But there is also another side of the coin, for sometimes the wonder drugs and improved methods of obstetrics and care of premature infants result in the survival of severely disabled infants. Nearly all program directors expressed concern about the increasing numbers of children in the categories requiring custodial care or institutional type of habilitation services. The solution to this problem would seem to be a "must" for the next decade.

**The Ideal Program**

Of necessity this cursory survey has simply highlighted certain significant advances. Crippled children's services still have far to go to reach the goal intended in the basic enabling legislation. Currently the Child Health Committee of the American Public Health Association is developing a number of "Statements on Recommended Practices in Programs for Crippled Children." When published these will be helpful in crystallizing current thinking on the best approach to the several types of handicaps.

Meanwhile Kobes has recently offered us a definition of what a program should be:

"An ideal crippled children's program is one which has the broadest possible range of high-quality medical care and related services available to meet the needs of children who have a broad spectrum of medical diagnoses. These medical categories should perform those which are characterized by long duration of the effects of the handicapping condition and thereby cause an undue amount of strain on the family's energies and economic resources. Adequate payments should be made to all who render services, whether they be full-time staff members or part-time consultants giving clinical services. All families should make payments toward the cost of care within their ability to pay. All personnel should meet the highest possible standards of professional ability and performance. The health and medical-care services needed to obtain the best clinical results for each child should be made available, and the social, emotional, educational, and vocational-training aspects of each child's needs should also be the concern of those who have the responsibility of administering the State's crippled children's program. Whenever it is necessary to do so to insure a wide range of capable services, the State should provide training programs to help fill any gaps which may be present. Existing resources should be used to the fullest extent and without duplication of services. They should be improved whenever necessary to meet the most desirable standards of care, and only when existing resources are definitely proved to be lacking should completely new facilities be constructed. There needs to be sharing of resources among communities, even to the extent of working out interstate arrangements when it seems undesirable to make available for one State a service which may be used but rarely. Only when we know that we have a program which will bring the maximum number of physically handicapped children into our society as useful, productive members can we feel that our job is nearing its highest level of success and accomplishment."

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The child with impaired hearing presents a special challenge in diagnosis and treatment, and, when disability is permanent, in development and training. Because of the close relationship between impaired hearing and behavior, the earliest possible diagnosis is indicated. Hearing disability inevitably promotes deviant behavior, with varying consequences to the individual's welfare.

The etiologic pattern is diffuse. The great majority of infants and young children with hearing handicaps suffer from injuries to the auditory nerve, or central damage, rather than from the middle-ear conditions resulting from upper-respiratory infection, common in school-age children. In the past 5 years approximately 2,000 children under 6 with hearing difficulty have been examined in the Hearing and Speech Center of the Johns Hopkins Hospital. In a small number of them the impairment is clearly assignable to familial traits; in a large number it belongs in the category of undeterminable etiology. Some of the latter have had no contributory medical histories, while others have had such agglomerate histories that precise determination of cause is impossible. The remainder, about 75 percent of all, can be subsumed etiologically as:

1. Ultra-virus infection of the mother in the first trimester of pregnancy—the causal factor in a high percentage of hearing impairment among young children.
2. Prolonged or severe anoxia at birth.
3. Birth injuries and prolonged labor with instrumentation.
4. Erythroblastosis, an anemia connected with Rh incompatibility of mother and fetus. This is a prevalent factor in auditory impairment among atheixed children.
5. Severe viral infections in the first 6 to 8 months after birth, damaging to the hearing structures.
6. Meningitis, particularly influenzal meningitis of the very young.

Types of Impairment

The incidence of hearing impairment or relatable language dysfunction among preschool children is rapidly rising. This may be attributable to the fact that modern obstetrics and pediatrics are saving more and more defective children who formerly might not have survived. All the classical types of hearing impairment have been found among this age group but the proportion of pure conductive lesions is small.

Nerve-type or perceptive impairments are caused by atrophy or underdevelopment of the cochlear nerve, or organ-of-Corti cells, in the inner ear, or to lesions somewhere along the central auditory pathways. High tones are commonly more affected than low tones. However, when the hearing loss is severe, whatever the cause, both high and low tones are involved. The effect is not only of lessened intensity but also of acoustic distortion so that understanding as well as hearing is impaired.

In general, no adequately demonstrated treatment for perceptive impairment exists. However, total
nerve-type deafness is extremely rare in this age of early diagnosis and advanced chemotherapy. The fact that a child does not appear to respond to the ordinary limits of sound does not mean total impairment. It is a rare child, indeed, who does not have some residual hearing. The determination of how much is a matter for clinical testing.

Conductive impairment results from interference with the mechanics of audition in the external canal or in the middle ear. The effect is the dampening of the transmission system, thus diminishing the intensity of sound. While this never results in total deafness, it may cause great difficulty in communication. Children with conductive impairment are apt to live in a world of "muddy" sound wherein clear distinctions are difficult to make, thus hampering their ability to pay attention. In the very young child this penalty is particularly severe and commonly causes considerable retardation in both language development and social maturity. In many children with conductive impairment, hearing, and therefore behavior, fluctuates greatly, to the confusion of their families.

Conductive-type hearing impairment in a very young child is usually amenable to treatment, when diagnosis and followup action are promptly undertaken. A conductive-type impairment involving midline adenoid tissue and obstruction of the Eustachian tubes often complicates a basic nerve-type impairment. This can be relieved by medical and surgical therapy, to achieve a permanent baseline of hearing.

A psychogenic hearing impairment also exists which presents no symptoms of otic pathology but affects normal functioning. By no means rare in children, this usually presents a difficult diagnostic problem.

Another problem evidently rapidly increasing in incidence is only apparently one of hearing. A child fails to respond to sound although he has a normal hearing end-organ. The core of the problem is at a higher level, in the cerebrum, and involves not the reception but the perception of sound. Sound penetrates to the brain, but lesions there or developmental lacks prevent a normal association of it with meanings and therefore interfere seriously with the development of appropriate responses and of the structure of the verbal symbolism called language.

**Hearing Evaluation**

Evaluation of a small child's hearing acuity and potential is not a simple process. It requires a careful case history with special attention to prenatal and natal events which could be causal factors, the time parents suspected a hearing loss, possible contributory data in postnatal history, and the degree of normality in the child's physical and social development as well as a careful study of his reactions to sound, including direct observation of the child and inquiry of the parents. It also involves careful observation of the child's play activity, his adaptation to new situations, his motor development, attention span, and social maturity.

Otherwise normal children with impaired hearing soon become highly visually-oriented; by the age of 24 to 30 months they will have developed an extensive gesture language. Those with a fair amount of residual hearing will be using their voices quite consistently in babble and will have made definite attempts to communicate verbally. Very deaf children will not continue to babble freely, for they cannot monitor their own vocal attempts well enough. Those with central disorders, wherein the trouble lies in the cerebrum rather than in the end-organ, will commonly ignore sound or respond only sporadically.

A thorough diagnostic work-up involves a complete otorhinologic examination, including careful inspection with a nasopharyngoscope. Important, too, is careful pure-tone audiometry. A difficult procedure with most young children with impaired hearing, this usually requires the services and facilities of a special clinical center. However, general physician can find out a lot about a child's hearing provided that the sounds he uses for testing are of known values of intensity and pitch.
The early detection of hearing impairment in young children depends largely on the astuteness of the pediatrician and the general practitioner in interpreting the developmental history and in observing the degree of language development.

A child talks because he hears and as he hears. Gradually, with much imitation and reiteration, he begins to relate sounds to meanings and to develop language comprehension; only then does he start to talk. If the child’s hearing is severely impaired, ordinary sound is meaningless to him; very loud sound will capture his attention but will not continue to do so until and unless it becomes a daily, hourly experience. If he has a moderate-to-severe impairment, with fairly good residual hearing for low-pitched sounds, he will respond to a variety of sounds if paying attention to them is worth while.

Some children, with severe acoustic distortion—good acuity for low pitches but rapid deterioration as pitch increases—learn very soon to ignore sound. Hearing something of everything but not enough of anything, they have little opportunity to learn to discriminate between father’s voice and mother’s voice, or the telephone bell and the tinkle of the Good Humor man. In a world wherein most sound is very much alike, they will stop making the unrewarding effort toward an impossible differentiation. Consequently, many are mistaken as mental defectives.

A similar sequence may be implicit in the behavior of the brain-damaged or cerebrally maldeveloped child. In him sound penetrates the analytical structure of the end-organ but is not translated readily into meaning at the cerebral associative levels of differentiation and recall. Thus the development of normal language symbolism is blocked. These children need special training which is very different from the kind needed by the deaf child.

In plain terms, children with severe hearing impairment do not develop naturally as do their peers with normal hearing. Lacking a fundamental component of the natural means to communicate, they find learning a slow and complicated process. Moreover, many of those who come to clinical attention present a combination of defects—auditory, intellectual, and psychological. The diagnostic problem frequently resolves itself into a determination of whether hearing impairment plays any part in the deviant development.

Between the ages of 2 and 6 years children are highly absorptive and responsive and at their peak as natural language-learning mechanisms. Therefore, medical or surgical measures to correct hearing loss should be carried out as early as possible. Children with permanently impaired hearing must have a careful evaluation of its degree and the relation of this to general development and behavior, so that plans can be made for habilitation or rehabilitation.

Few children are totally deaf; most can gain some material benefit from the use of a wearable hearing aid. Once the picture of the child’s hearing loss and potential is obtained, effort should be made to put his residual hearing to use as an adjunct in learning language. For children with profound hearing defect, vision must be the basic stimulus, with audition an adjunct. For those with a relatively large amount of residual hearing (down to about 65 decibels below normal), audition can be basic, as it is normally, with vision adjunctive in language learning. Many children whose hearing impairment is moderate or severe can be brought to normal functioning with training and the use of a hearing aid.

**A Communicative Dysfunction**

Deafness is a dysfunction not only of the ears but of the listening mind. Many children with quite good potential levels of auditory acuity become functionally deaf because they have never had the opportunity to learn to hear. A recent diagnostic analysis of 572 preschool-age children suspected of hearing impairment because they did not develop normal language and speech, revealed that 116 had normal auditory end-organs. Their developmental lacks were caused by a variety of factors, from mental deficiency to behavioral pressures. In this study

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**Figure 2.**

The frequencies in cycles per second include 128, 256, 512, 1024, 2048, 4096, and 8192 cycles. The hearing loss in decibels ranges from 0 to 110 decibels, with 0 being the right (R) and 110 being the left (L) ear.
speech-hearing potentials were generalized from pure-tone audiograms obtained by a special measuring technique, galvanic skin-resistance audiometry. In this procedure a very young child responds to sound with an involuntary reflex.

Over 2,000 preschool-age children with hearing difficulty have been tested by skin-resistance audiometry in the past 5 years. Only 27 percent were found to be profoundly deaf. Apparently only about 30 percent of educable children with hearing impairment are educatively deaf, that is, require special residential or day-school training.

All children with handicapping hearing impairment require special help at both preschool and school ages; how much and what kind depends on the child's particular needs and capacities. Those with mild or moderate impairment are well within reach of a wearable hearing aid and, other things being equal, can be expected to function within normal hearing range. Those with severe impairment require a great deal of careful analysis and special help. Whether eventually they will emerge as "hard-of-hearing" or as "deaf" children depends largely on the way they are handled and how society helps them meet their problems.

The 2-year-old with a severe hearing impairment does not belong in school; he is not yet ready to learn in any formal regimen of teaching. Once the clinical picture is clear, his parents must be taught every possible insight into his needs and ways to meet them, how to help him discriminate between sounds and to learn language, usually with the constant use of a wearable hearing aid, and eventually to develop understandable speech. This as well as the determination of hearing loss and potential is an important aspect of clinical audiology.

Some Case Histories

The following cases illustrate the importance of early case finding.

Figure 1 shows the audiogram of a 6-year-old whose hearing impairment was caused by toxemia in her mother during pregnancy. When she was first seen at the clinic at the age of 2 her hearing for tones below 1,000 cycles was much less than this audiogram shows. After retest was done by galvanic audiometry she was fitted with a wearable hearing aid at the age of 26 months. She developed language and speech well. The dark lines are actual threshold measurements of her speech-hearing ability. With her hearing aid, she functions well within normal range. Now 7 years old, she is in a regular second grade at school and is leading a normal life.

In contrast is Figure 2, the chart of a young woman graduate of a conservative State school for the deaf. She was 19 when she was first seen at the clinic. Her speech is extremely limited. Communicatively and psychologically, she is a deaf person, although her unaided speech-hearing threshold is only a few decibels below the first child's. She has grown up in a world of silence. With a hearing aid she too could perceive simple speech within normal range. She does not know the hearing world, however, and does not want to know it. The mind becomes deaf when the ears are not helped to convey sound.

Figure 3, the chart of a 9-year-old boy with nerve-type hearing impairment, illustrates the same point. Audiometric testing puts him at the level where ordinary conversation would not penetrate without a hearing aid. He has had special help at home in language and speech training since he was 3 years old. He has always attended a regular school, where he is doing superior work. His life is entirely normal; he is fully oriented to the world of sound; he is not deaf in any sense of the word, but he would be lost without his hearing aid.

Figure 4 shows the audiogram of a child with severe acoustic distortion. This boy's hearing impairment was caused by chickenpox at the age of 2 months. He is normal in all respects except in hearing ability and language development. Now 5, he has worn a hearing aid since he was 3 years old. Slowly he is making progress in language differentiation. His mother works with him daily. He has also had considerable help from a speech-hearing
therapist attached to the school system in which he has been attending a class for normal preschool children. He needs daily school work in language, audition, and speech, but this is not available.

Figure 5 shows the audiogram of a child who is educatively deaf. His impairment is of undeterminable origin. The heavy line represents mathematically his threshold potential for speech-hearing derived from the pure-tone audiogram. Now 5, he has been wearing a hearing aid for 2 years; sound is meaningful to him, but his impairment is so great that sound can never be the foundation for language learning. What he hears is a most useful adjunct to what he sees. He is in a special class for preschool deaf children and demonstrates a rapidly developing language-mind. If this development continues, he should be able to communicate quite understandably by the time he is at a high-school level.

Figure 6 shows an interesting progression of development from awareness of sound to the emergence of language meanings. At 3 years and 2 months the boy whose hearing is charted here had a few unconnected words and some language understanding. He was aware of voice and toy-sounds at the level of 30 to 35 decibels below normal. When the examining otologist found clear evidence of a conductive element in his hearing problem, a tonsillectomy and adenoidectomy were done. The second audiogram, made 5 months later, shows definitely better thresholds for pure tones with quite normal levels in the low-pitch ranges. Awareness had been improved by 10 decibels. The boy was obviously more alert and responsive to sound of all kinds. A third audiogram, made about 18 months after the first, shows that the pure-tone acuity had remained stable. By this time it was possible to test the child's hearing for speech. The resulting 30-decibel level was not considered threshold as few 4-year-olds with distorted hearing can listen to a precise speech-hearing threshold. Auditory meanings were well on the way, however. Now, at the age of 6 years, this child is getting along well in a regular first grade. He wears a very light-gain hearing aid, with a specially adapted earmold.

Some Basic Concepts

A few generalizations can be made from our experience of the past several years in dealing with a large group of preschool children with hearing handicaps. These encompass 10 basic concepts:

1. Hearing rehabilitation is a many-sided cooperative endeavor involving the pediatrician, the otologist, the clinical audiologist, the psychologist, the teacher, and, above all, the parent, working as a team.

2. Communication ability in children with hearing impairment involves acoustic, linguistic, visual, behavioral, developmental sensory-motor, and social elements. Hearing, speech, and language cannot be isolated from one another or divorced from the overall developmental processes.

3. Treatment and training should be based on a full diagnostic appraisal including an early measurement of the amount of residual hearing, and, when possible, the child's ability to use it.

4. Treatment and training should be started as early as possible in the child's life, preferably be-
between the ages of 18 to 30 months. So far as tools of communication are concerned, the child's career begins in infancy.

5. With appropriate handling, many children having a profound impairment can learn to understand speech and to talk.

6. The majority of children with impaired hearing have a great deal of residual hearing and can make good use of amplified sound, providing this is started at an early age when sound can become an integral part of the developing mind. Even the child with a profound loss can benefit from amplification to some degree.

7. Wearable hearing aids provide the means for putting the child in contact with sound through all his waking hours. Children seem to make the best adjustment to them between 2 and 3 years of age, but the time for providing the aid must be set for each child according to his readiness and needs.

8. Some special handling is always necessary at home and at school for children with handicapping hearing impairment. Whether it should involve special work in a regular nursery school or elementary school or in a special day or residential institution is a task for careful audiologic-educative determination.

9. Most children develop best in a situation that is the closest approach to a normal setting, while meeting their special needs.

10. Parental understanding and parent guidance are the keys to working with children having severe hearing impairment. Progress with the child is usually made in direct proportion to the parents' understanding and acceptance of the problem they face. They need to understand how communication develops, and how they can and must stimulate it in the minute-by-minute experiences of their child. They must be shown how to communicate clearly and simply at short distance, using the same vocabulary over and over in a wide variety of situations, until meaningful associations are grasped and the child begins to relate and store them, and eventually to reproduce them in his own speech. They must learn how to anticipate communicative requirements and to expand the child's vocabulary.

Two Principles

This framework rests on two convictions which have special implications for medicine and education:

1. Although each child is a unique individual, with his own special needs in communicative development, generalized methods can be made to work as the professional team learns to work together.

2. The utilization of modern electronics makes possible an emphasis on hearing, not deafness, in the prospectus of the child's future.

A large group of veteran hearing-aid users under the age of 6 are now giving direct evidence that children with serious hearing impairment can and do learn language and speech if an appropriate program is launched early enough and is followed through in the formative years.

EVALUATING CARE OF THE ORTHOPEDICALLY CRIPPLED

Staff members of the Bureau for Handicapped Children
New York City Department of Health*

EVALUATION of the care currently being rendered to orthopedically handicapped children, still one of the largest diagnostic groups receiving crippled children's services, is important to program planning. It is useful, however, only if based on valid methods and reliable data. In New York City, where the program includes about 7,500 children with orthopedic handicaps, the Bureau for Handicapped Children of the city Department of Health, has for the past 4 years been developing methods for measuring the quality of patient care. Through these methods it has found weaknesses which it has already taken steps to correct.

The data studied came from the following sources: (1) live-birth certificates; (2) surveys of services given in hospitals and convalescent homes to orthopedically handicapped children; (3) the program's register of handicapped children; (4) the State-Aid Medical Rehabilitation (payment) Program; (5) the city's diagnostic clinic; (6) the school placement program for physically handicapped children; (7) other sources, such as national or local accrediting groups. Material from these sources is collated so that what comes from one source supplements what comes from another, thus rounding out the picture.

Case Finding

Birth certificates which include spaces for reporting congenital malformations and birth injuries produce data for measuring the effectiveness of case finding. The information they contain, however, is often incomplete, because the abnormality must necessarily have been found within a short period after birth, usually 48 hours, in order to have been reported on the certificates. While many obvious malformations and injuries can be ascertained that early, others cannot or are not. Possibly more complete material could be obtained from the records of hospital nurseries, or the investigation of certain groups of newborn infants who are potentially more "vulnerable," such as: those delivered prematurely; those delivered after precipitate or prolonged labor; those of high birth weight; those delivered by high or mid-forceps, by breech extraction or by Caesarean section; those delivered of women suffering complications of pregnancy; and those who fail to breathe spontaneously at birth.

Data relating to the age of children coming for treatment are also pertinent to the effectiveness of case finding. These are available from diagnostic and consultation-service clinics, from the register, and from the payment program.

In New York City, for instance, we found that of all the children with certain congenital malformations or birth injuries whose care was paid for by the State-Aid Medical Rehabilitation Program in 1953, only 4 percent were infants under 1 year of age, and only 32 percent were in the age group from 1 to 4 years. None of the children with clubfoot were under a year old. Only 5 percent of the children with congenital dislocation of the hip were less than a year old, while 34 percent of them were over 4. Only 17 percent of the children with spina bifida and meningocele were under 1, while 57 percent were over 4 years old.

Such an obvious indication of a delay in case find-
ing or in successful referral to approved medical-treatment agencies suggested a need for greater awareness on the part of physicians and public-health nurses of the importance of early case finding and of the need for more skill in recognizing the signs and symptoms of certain disabilities deriving from prenatal and natal influences.

**Diagnosis, Treatment, and Rehabilitation**

Information obtained from a study of hospitals, convalescent homes, and outpatient clinics—either directly through team survey or indirectly through payment for service—can assist in the evaluation of the caliber of care the children are receiving.

In New York City, the diagnosis, treatment, and rehabilitation of orthopedically handicapped children are carried on by hospital outpatient and inpatient services, by convalescent homes, and a diagnostic and consultation service provided by the health department in a large teaching hospital.

To obtain data for evaluation the Bureau surveyed these hospitals and convalescent facilities for information as to: (1) professional qualifications of the directors of their orthopedic, pediatric, physical medicine and rehabilitation, X-ray, laboratory pathology, and anestheisa departments; (2) the degree of responsibility and authority invested in these directors; (3) the policies they had established and the degree of supervision they gave; (4) the qualifications of personnel administering anestheisa; (5) the qualifications of physicians performing orthopedic surgery; (6) whether or not they contained organized departments of orthopedic surgery, pediatrics, and rehabilitation, and, if so, whether these had been approved by the respective medical specialty board for residency training; (7) the frequency of medical rounds and conferences; (8) the provision of other qualified professional personnel, such as nurses, social workers, therapists, psychologists, nutritionists, and the degree of medical guidance and assistance given them by the medical staffs; (9) the capacity and census of the children's orthopedic service, and the length of the waiting list, if any; (10) whether child patients were kept in the hospital longer than necessary and, if so, why; (11) the degree to which the various members of the professional team work together; and (12) how often children were reevaluated by this team.

Because of the importance of maintaining family ties while a child is hospitalized the Bureau also asked about the frequency of visiting hours.

Since only a small percentage of orthopedically handicapped children require hospitalization, outpatient departments provide the device for early case finding, for making an accurate evaluation and diagnosis, for school-placement recommendations, and for providing much of the treatment, supervision, and rehabilitation.

From orthopedic outpatient facilities the Bureau sought information on: (1) whether there is a separate children's orthopedic clinic; (2) whether qualified orthopedists and at least one pediatrician attend the children's orthopedic clinic; (3) the physician-patient ratio; (4) the type of patient history taken, physical examination made, laboratory and X-ray services and counseling given for the evaluation and reevaluation of the patient's condition and progress throughout the course of treatment; (5) the schedule of the patient's revisits to the clinic, and the clinic's follow-up of broken appointments; (6) the degree of supervision given to therapists; (7) the frequency with which children are admitted to the inpatient service for diagnostic procedures not provided for in the clinic; (8) whether or not the clinic completes X-ray and laboratory tests and makes cast changes on the day of clinic visit or requires revisits for the procedures; (9) how often children are reevaluated by the team; (10) the degree of privacy provided for counseling and guidance to the child and his parents.

In regard to nursing the Bureau looked for: (1) the presence on the staff of a qualified nursing supervisor for both the children's orthopedic and rehabilitation services; (2) the ratio of nurses to both inpatient and outpatient orthopedic and rehabilitation patients; (3) the percentage of nursing staff who are registered professional nurses; (4) the allocation of duties in relation to the personnel's degree of training and experience; (5) the nature of the clinic's program for counseling parents; (6) the degree of home followup and supervision of selected patients by the community public-health nursing agency; (7) the degree of integration of the therapy services and the nursing service; (8) the degree to which the nursing staff participates in team rounds and conferences.

The Bureau also focused on four aspects of social-service departments: (1) the administration, including the professional qualifications and the responsibilities of the director; (2) the quality of professional supervision made available to the casework staff, the size and quality of the staff and the assignments received; (3) the availability of medical social casework services to children and their
families; (4) comparison of the size of caseload with the actual number of children under medical care in hospital or clinic. It also considered the timing and nature of referrals to the social-service department; the content of medical social casework services provided to patients and their families; the extent of referrals to appropriate community agencies; the degree of medical social work participation in team planning on behalf of the child and the kind of social data made available for the medical chart.

In its survey the Bureau covered 25 hospitals providing orthopedic services—15 general hospitals, 6 predominantly for orthopedic patients, 2 for chronic disease, and 2 for communicable disease. Since some of these had very few orthopedic patients and none had a waiting list of child patients, some pertinent questions arise: How many hospitals in a highly specialized field can a community afford? Do children receive the better treatment when they are scattered in a number of facilities, or concentrated in a few?

Observations of these hospitals and of their 22 outpatient clinics indicate that while many of them provide some aspects of total patient care, only 2 provide all aspects of care; and many have not yet been able to bring what aspects they do provide together so that the various professional services function as a team for the total benefit of the child. However, the Bureau has found that this step of first hand observations by a team including an orthopedist, pediatrician, physiatrist, hospital nursing consultant, and medical social worker represents the beginning of an educational program effective in improving the quality of care.

During the course of the surveys, the team members found a number of children in hospitals who did not appear to require further inpatient care. Since overinstitutionalization is not only psychologically hazardous to the child, but also wasteful of community funds, the Bureau set up a committee in 1953, composed of members of the survey team, to review the record of all children who had been in any institution under the aegis of the payment program for a period of 1 year, all children in any institution designated by the team as a "problem institution" and all children with serious or complicated problems of care and rehabilitation.

During the first 6 months of its activities, the committee reviewed, at least once, the situations of 210 children, for whom the payment program had paid for a 120,683 patient-days of care. Of these children, 48 were recommended for discharge to their homes. Forty-seven were actually discharged shortly thereafter. In addition, 37 children with cerebral palsy were recommended for screening for possible admission to special classes in public schools. Of these, 7 were screened and 4 were admitted to special classes, one was placed on the waiting list for admission, and 3 were found to be too mildly handicapped for admission.

Some children in hospitals were recommended for transfer to a convalescent home and vice versa. Some were recommended for foster-family placement; some, for admission to a State institution for the severely mentally retarded, and one, for admission to a residential school for the blind. In general, the better institutions had fewer children who were "overinstitutionalized" than the substandard institutions.

The School-Age Child

Data on services for the school-age, orthopedically handicapped child are obtainable from: the school placement program of the crippled children's agency; the board of education; the records of patients in hospitals and convalescent homes; the diagnostic-clinic service; programs for homebound children or children in special schools or classes; and various organizations, such as parents' groups and parent-teacher groups.

Data from such sources can provide the following information: (1) the percentage of children in hospitals and convalescent homes provided with educational services; (2) the percentages of known orthopedically handicapped children on home instruction or in special schools or classes; (3) medical and health needs of homebound orthopedically handicapped children and of those in special schools or classes; (4) the appropriateness of assignment of children to a home teacher or to a special school or class; (5) the number of children on waiting lists of special schools or classes; (6) the number of children recommended for special schools or classes who are unable to attend because of inadequate transportation service; refusal of admission by school principals, unsuitable school plant, unsuitable housing at home, or other deterrent factors; (7) patient-days of absenteeism from school because of attendance at outpatient clinics; (8) provision of school opportunities for children with more than one physical handicap.

In New York City the evaluation of services to
school-age orthopedically handicapped children focused on those who were homebound and those who were in special classes in the public schools. As a result, concerned groups are now considering methods of providing them more adequate services.

After reviewing the cases of the 74 orthopedically handicapped children in Manhattan receiving home instruction, the team members recommended that 29 children remain on home instruction, that 37 return to school, and that 2 be admitted to a hospital for inpatient care. Home instruction was being discontinued for one who was past school age and for 2 who were severely retarded mentally, and plans for 3 were undecided. The team recommended that almost half the children returning to school be admitted to regular classes. Of the 37 recommended for return to school, 18 are now attending school; 15 of these are in regular school classes and are doing well.

The team made specific medical recommendations for 35 of the 74 children and initiated followup procedures. These recommendations included medical care and supervision, other rehabilitation services, the provision of equipment, and weight reduction.

The team also recommended additional social-service assistance for the families of 11 of these children and recreational activities for 17 children. In a parallel study of 49 eighth-grade children in special orthopedic classes, conducted by the Board of Education, an orthopedic surgeon recommended that 15 children be transferred to regular school classes.

Vocational Rehabilitation

Since one of the objectives of a program for handicapped children is the ultimate absorption of the patients into the adult employed community, the vocational aspects of care are part of the evaluation of total care. One criterion is the closeness with which the crippled children's agency works with the Vocational Rehabilitation Service. This closeness can be measured by the degree to which the crippled children's program is involved in: the direct referral of the teen-age handicapped patients to the community vocational agencies; the stimulation of medical-treatment agencies to employ vocational counselors and to refer patients to vocational agencies; efforts to persuade medical-treatment agencies to share vocational counseling personnel.

Data on the vocational rehabilitation of orthopedically handicapped young people may be collected through a variety of procedures: surveys of hospitals' orthopedic services for children; review of the situations of young people who are homebound or who are in special classes; analysis of sources from which young people have been referred to the community's vocational-rehabilitation agencies; analysis of orthopedically handicapped young people reported to the register; and analysis of public-assistance rolls for persons disabled by conditions arising in infancy and childhood.

Of the 74 orthopedically handicapped homebound children evaluated in New York City, 25 were 15 to 19 years of age. At least 11 of these were found to be in need of vocational guidance and were not receiving it.

Prevention

In a sense, data from a program for handicapped children can be an index of the effectiveness of the community's overall health program. For example, an effective tuberculosis-control program should result in the eradication of tuberculosis of bones and joints. An effective maternal and newborn program should result in a significant reduction in the incidence of cerebral palsy and of Erb's and brachial paralysis. An effective accident-prevention program should result in the reduction of disability due to trauma. An effective infant and preschool health program should result in the elimination of rickets as a cause of orthopedic disability. Improvement in the quality of medical and hospital care should result in the elimination of disability due to osteomyelitis. If preventive measures are effective, incidence figures on all these conditions should be decreasing if not disappearing entirely.

In New York City, the Bureau for Handicapped Children attempted to evaluate the preventable factors of birth injuries through an analysis of severe birth injuries reported in 1948. This revealed an association between the type of birth injury and the type of delivery. For example, low and midforceps deliveries were associated with facial paralysis; breech delivery with fractures; Caesarean section with intracranial injury; spontaneous delivery with brachial plexus injury (resulting in paralysis of the arm). An analysis of the type of accoucheur in these cases revealed that 60 percent of the midforceps and 85 percent of the breech deliveries reported occurring on the wards of municipal and voluntary hospitals had been performed by the house staff without a qualified obstetrician in attendance. In the private services of voluntary and proprietary hospitals, 40 percent of midforceps deliveries, 62 percent of breech deliveries, 38 percent of internal podalic
versions (turning the baby from a breech to a head presentation) and 25 percent of Caesarean sections were performed without a qualified obstetrician in attendance.

**Miscellaneous Aspects**

In addition to the type of information gained by the methods so far described other areas must be explored to complete a broad evaluation of services for orthopedically handicapped children. These include foster-family placement, housing, transportation, recreation, and custodial or residential care.

Necessary data for evaluating the foster-family aspects of the program include information on:

1. The number and type of orthopedically handicapped children in hospitals and convalescent homes who are medically ready for discharge and who for social reasons cannot return home;
2. The number and type of such children placed in foster families over a given period of time and the reason for placement;
3. The type of children selected for foster-family placement;
4. The caliber of the foster homes and their accessibility to medical-treatment agencies;
5. The degree of supervision provided to the foster parents;
6. The number of orthopedically handicapped children awaiting placement.

In New York City the Bureau for Handicapped Children has attempted to apply these suggested criteria on foster care in its total evaluation of the care of the orthopedically handicapped. However, so far its data are incomplete.

Criteria for determining housing needs include information as to:

1. The number of orthopedically handicapped children medically ready for discharge from hospitals or convalescent homes who cannot return home because of their families' unsuitable housing;
2. The number of homebound children who are prevented from either attending school, receiving continuous medical supervision and care, or becoming employed, because of the isolated location of their homes;
3. The number of families on waiting lists for low-cost housing who have an orthopedically handicapped child;
4. The provision in low-cost housing of special facilities for the orthopedically handicapped such as ramps, siderails, doors wide enough for wheelchairs, special gadgets, and elevators;
5. The length of time elapsing between application and the actual moving into such housing by families having an orthopedically handicapped child;
6. The degree of priority for low-cost housing given to families having an orthopedically handicapped child.

Criteria for evaluating the adequacy of transportation include information as to:

1. The number and types of orthopedically handicapped children requiring and receiving special transportation to school, to recreational services, and to medical treatment agencies;
2. The size of the waiting list for such transportation;
3. The costs of transportation;
4. The length of time spent by the child during transportation;
5. The type of transportation provided, the use of specially equipped vehicles, and the provision of attendant service.

Data supplying a view of the recreation opportunities for orthopedically handicapped children include information as to:

1. The number of orthopedic services in hospitals and convalescent homes employing trained recreation or group workers and their ratio to the children;
2. The number of regular or special recreational agencies and camps in the community which accept orthopedically handicapped children;
3. The number of orthopedically handicapped children on their waiting lists;
4. The caliber of services they provide;
5. The number of homebound children in need of a recreational program.

Criteria for determining the adequacy of residential care for orthopedically handicapped children include information as to:

1. The number of severely disabled children at home, or in hospitals or convalescent homes, who have no rehabilitation potential and no family or whose family can no longer care for them, who require long-term placement and who are too severely handicapped to be placed in a foster family;
2. The availability of residential services for such children, and the caliber of such services;
3. The number of children needing such care and awaiting placement.

**Comment**

These techniques for evaluating the care orthopedically handicapped children are receiving might well be applied with appropriate modifications to the care of other handicapped groups including those with rheumatic fever or heart disease, epilepsy, hearing impairment, visual impairment, and mental retardation. For children with any of these handicaps, as for the orthopedically handicapped, an important factor is flexibility of community services so that they can move from one to another as their individual needs change. Such flexibility requires the provision of the services already mentioned, frequent periodic reevaluation of the child, and a good understanding of children's needs by the staff members who serve them.
It also requires willingness on the part of an agency whose function is no longer needed or is being performed better by other agencies to change its interest to needs still unmet. Very likely many communities have adequate funds available to serve the orthopedically handicapped well. Whether such funds are always used to the best advantage for the maximum number of children requiring services will depend on the wisdom, understanding, and leadership displayed by administrators of both the official and voluntary health agencies, and by influential members of boards of the voluntary health agencies.

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WHAT AFFECTS BLIND CHILDREN'S DEVELOPMENT

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WHAT IS THE EFFECT of the handicap of blindness on the development of the infant and young child? What real limitations does it impose? Is retrolental fibroplasia only one aspect of a generalized brain defect? How can one evaluate the capacity of the blind child and in particular differentiate between the truly mentally defective child and one whose developmental progress has been disturbed by unfavorable environmental circumstances? Are specialized techniques needed to overcome the handicap? What kinds of services should the community be prepared to offer? These are some of the questions to which, for several years, the Project for the Study of the Development of Preschool Blind Children, at the University of Chicago Clinics, has been trying to find soundly based answers through its multidisciplinary research program.

In the brief space of this article one can do little more than highlight the material to be included in the detailed report of the project. Perhaps the most significant finding of the study is that the development of the blind child with no other major physical handicap can be expected to progress in orderly fashion so that by school age he is functioning well up to the level of his sighted peers. This development, however, takes place only to the extent that overall conditions have been favorable for him. This finding emphasizes the importance of getting skilled service to the parents at the earliest age possible if the child is not to become retarded in his development.

The project resulted initially from the broad approach of Dr. Arlington C. Krause, Professor of Ophthalmology at the University of Chicago Clinics, to the study of the problem of retrolental fibroplasia. The formal phase of the research program covers the 5-year period from August 1949 to August 1954. Actually the conclusions in the study are based on observations over a much longer time.

As early as 1942 doctors at the Clinics called in both psychologist and social worker to study with them every case of a blind child, whatever the diagnosis, and to help them in formulating appropriate plans of social treatment. The increasing number of cases of blindness from retrolental fibroplasia in prematurely born children soon created a problem of such magnitude that systematic research into the social and psychological factors in the child's development became imperative. Since many of these children were retarded in functioning according to
normal developmental standards, Dr. Krause believed that such research was essential first in contributing to an understanding of the nature of the disorder and secondly in providing a basis for treatment of the individual child.

In August 1949 funds from the Field Foundation and the Chicago Community Trust made it possible for a psychologist and social worker, already long familiar with the problems, to devote full time to the project. A second social worker was added in March 1951, through the support of the Tibbetts Foundation and later the Woods Charitable Fund, Inc. A research grant from the Public Health Service, U. S. Department of Health, Education, and Welfare, has also contributed to the project's support.

Principles and Objectives

The extensive preliminary experience of the project staff with children with retrolental fibroplasia provided the basis for formulating the general principles underlying the study. Most important were the following:

1. A longitudinal study with repeated observations of the child at regular intervals would yield the most productive results.
2. Such a study should, if possible, follow the child from the time of the diagnosis of blindness until he was of regular school age.
3. The study would require a teamwork approach involving continued working relationships within the University of Chicago Clinics as well as with key community agencies.
4. Service to parents in accordance with the objectives and methods of the research plan would be a necessary part of the research program.
5. The primary focus would be the overall functioning of the child in relation to his total environment. This would require observations in the home by both psychologist and social worker.
6. The study would be primarily descriptive in nature, with gathering and analyzing observed data as its first step.
7. The study should yield data indicating areas needing further investigation and suggest methods for carrying this out.

The objectives were defined as follows:

1. The primary concern of the psychologist was to establish more accurate developmental norms for blind children, which would provide a sound basis for clinical evaluation of an individual child and for social and educational recommendations for him.
2. The primary concern of the social worker was to gain a better understanding of the total development of the blind child with particular reference to the factors which promote or retard his optimal development.

Obviously there were overlapping areas where both psychologist and social worker could make significant observations.

While the project staff recognized the advantage of methods such as the use of a matched control group and a representative sampling of blind children, there seemed to be no way of achieving these. The staff, therefore, sought other safeguards. Since restricting the study to children known medically to the University Clinics might have introduced unidentifiable biases, a cooperative agreement was reached with the counseling service for blind children in the Illinois Department of Public Welfare by which all known blind children in the Chicago area meeting the established criteria were referred to the project between specified dates.

While it is not certain that this had the effect of bringing all children meeting the criteria to the attention of the project, it is believed that the constant efforts of the State Department of Public Welfare to make its counseling service widely known to hospitals, ophthalmologists, pediatricians, and others, combined with the publicity resulting from Parents' Institutes, were sufficient to produce a situation closely analogous to compulsory registration. Since referral to the project was made only on the consent of the child's physician, eye reports and other relevant medical data about the child could be obtained from the doctor.

Experience had demonstrated the importance of seeing the child in the early months of his development, preferably as soon as the fact of blindness became established. Intensive study by the project was therefore limited to children seen at or before 15 months of age. All "educationally blind" children in the Chicago area meeting this requirement and having no other major physical handicap received systematic study and casework service—"educationally blind" being defined as those expected by the referring ophthalmologist to require braille in their education. The psychologist's observations of these children were scheduled at 3-month intervals until the child was 2 years and 6 months of age and at 6-month intervals until age 5. Thereafter the observations were on a yearly basis. This intensive group included 66 children. The qualitative conclusions of the research project are based on the analysis by the psychologist and social worker of the combined data on these children.

A second group of children was followed systematically by the psychologist in order to provide a larger number of test observations at the various ages as well as to give some basis for comparison.
with the intensively studied group. It included “educationally blind” children who for one reason or another did not meet all the criteria for inclusion in the first group, for example, age first seen or residence in the Chicago area. For this second group the age requirement was raised to include children seen at or before 27 months of age. For these children the referring agency assumed continuing casework responsibility on a cooperative basis. This group included 77 children.

Finally, there was a third group composed of 152 children who did not meet the criteria for either of the above groups but for whom psychological-test observations and related social data were available. These were usually children seen on consultation, many of them at the yearly Institute for Parents held as part of the statewide service for preschool blind children carried on by the Department of Public Welfare. For most of these children only one or two psychological observations were obtained.

For research purposes home visits by the psychologist were usually more productive than office visits. This was the plan usually followed except in the third group.

As a result of this plan of study over 2,500 psychological-test observations of young blind children were available for analysis for the purposes of attaining the first objective: that of gaining a better picture of the developmental patterns of blind children.

The social worker’s concern was primarily with understanding the basic factors influencing the child’s total development (the second objective) and her work was limited in general to the intensive group. Her role followed no set pattern and was dictated by the research requirements and the needs of the individual cases as they were agreed upon in staff conferences, often with the help of the psychiatric or casework consultant or both. Throughout the study she had close working relationships with the ophthalmologist and the pediatrician, both in regard to individual children and in consideration of larger aspects of the program. Of particular value to the parents was the continuing interest of the ophthalmologist in the progress of the child and the problems they were encountering, long after the diagnosis had been made and when there were no further medical recommendations.

**Method of Study**

For both psychologist and social workers the basic method, observation of the child in his environment, involved highly subjective aspects of professional judgment-making. Recognizing the dangers in such a plan, they constantly looked critically at both method and findings in an effort to secure disciplined and well-documented evaluations. As the study progressed detailed guides for observation and analysis of data evolved.

The fact that the observations came from two disciplines provided a certain safeguard. Moreover, the fact that the same psychologist and the same social workers were gathering the data gave consistency to the factors operating in the judgments. Staff conferences and discussions with psychiatric, social-work, and research consultants were invaluable in bringing up points particularly susceptible to bias. Repeated observations over a period of time gave opportunities to test out and verify hypotheses.

The original plan had been to follow all children in both groups in the longitudinal study until age 7 when their school progress and evaluation by the school authorities would serve as a check against the project’s predictions. Unfortunately, a decision to shorten the duration of the project made the complete attainment of this objective impossible. However, the school experience of the older children served as partial confirmation.

In the intensively studied group the changes in test scores and rating of behavior and individual development in relation to changes in the child’s total situation provided a safeguard to subjective judgment. There were added checks in the facts that the final analysis of psychological data was made by a psychologist who had had no direct contact with the children and that the analysis of the social data was based on ratings made independently by the two social workers, from which all items producing significant differences of opinion had previously been eliminated.

Two general methods were used for analyzing the quantitative psychological data from the test observations of the children in the three groups: 1) an item analysis to determine the percentage of success on each item at each age level; 2) rating scales for each child at each age interval plus a summary rating of the child’s functioning level as measured by the quantitative test data.

Five-point rating scales were also developed to indicate the social workers’ evaluation of the “opportunities for learning” which the children in the intensive group had had and their prediction as to the level of functioning which could be expected from
of 16 carefully defined items with a summary item 17 expressing the overall evaluation as follows:

Extent to which the overall learning situation has been favorable to the child's total development with special reference to the degree of self-motivation, self-reliance, and active interest in the environment. Consider quality of relationships, appropriateness of expectations, opportunities for success (in relation to mother's evaluation of child's accomplishment), type and variety of learning experiences both within the family and the larger community.

The Prognostic Scale rated the child with respect to his degree of independent functioning, orientation, use of capacity, and extent of secondary handicap.

Each child in the intensive group was rated also on "degree of blindness" and "orientation."

Though only children expected by the referring ophthalmologist to require braille in their education were included in the study, there was a wide range of degree of blindness, from children who were totally blind to some who had a considerable degree of useful vision. Each child was, therefore, rated on his degree of functional vision as observed by the staff. "Orientation" was defined in terms of the child's ability to get about freely and independently and to relate himself to his environment.

The rating-scale technique made possible some useful comparisons of relationships between the child's functioning as measured by psychological-test data and the complex interrelated factors in his environment.

Summary of Findings

Data gathered in the 5-year study have contributed substantially to the attainment of the project's objectives and to providing a basis for answering the questions raised at the outset.

Analysis of the quantitative psychological data and school and other experience demonstrates clearly that the development of the blind child who has no other major physical handicap can be expected to follow an orderly progression in which he will be functioning up to the age level of the sighted group by the time he reaches regular school age. Probably even more significant, however, is the evidence from the study of the intensive group, that this orderly development takes place only to the extent that the total learning situation has been favorable for the child.

The extremely wide range in the functioning level of blind children has been noted repeatedly, but comparatively little systematic study has been directed to the difficult problems of identifying factors which determine the development of the individual child and of finding ways in which his capacity can be properly assessed. Equally significant with the wide range in functioning found among different children in the project are the extreme fluctuations in test scores of individual children shown in the data provided by the longitudinal study. Almost without exception these fluctuations are found to be related to factors in the child's overall learning situation.

The advantages of such records for an analysis of the factors contributing to the child's development are obvious.

But what then constitutes a learning situation which is favorable for the child's optimal development? Here our experience runs counter to many of the traditional views with which the parent is confronted as he tries to understand confusing and frustrating behavior. At the outset let me stress that we have found that blindness in and of itself is not the determining factor in the child's development. Rather, failure on the part of adults to know what to expect of a blind child or how to encourage his optimal development creates the problems.

As basic characteristics of "optimal development" the staff agreed that special attention should be given to the degree of self-motivation, self-reliance, and active interest in the environment displayed by the child. All three were areas that traditionally have been expected to present particular difficulties to the blind child. All three were useful in differentiating children who were doing well from those who were making only limited use of their capacity. "Opportunities for learning" also were considered in terms of their contributing to or delaying the emergence of these qualities.

For purposes of summarizing the staff's evaluation of the nature and quality of the child's experience the detailed Opportunities for Learning rating scale was used, summarized under the following headings: 1) quality of relationships; 2) appropriateness of expectations; 3) opportunities for success (in relation to the mother's evaluation of the child's accomplishment); and 4) type and variety of learning experiences both within the family and within the larger community. These ratings were then compared with the child's rating on intelligence and social-maturity tests and with the other variables being studied.

As with all children, the basic ingredient for encouraging the development of the blind child was
found to be the kind of comfortable relationship with his parents wherein parent and child both experience continuing satisfaction and enjoyment. Indeed the child's "psychological" development in the limited sense of the term is dependent upon this type of relationship. Yet in the blind child, who depends on it most, the physical handicap operates against achieving it. This happens not only, or even primarily, because of neurotic elements in the parents' attitudes but because of the realistic problems involved and the lack of sound guidance to give parents confidence in their ability to handle their child constructively.

There is real danger in failing to appreciate the realistic basis for the parents' anxiety or in assuming that problems must be due to some personality defect on their part. Moreover, there is too little recognition of the heavy demands which meeting the child's needs for optimal development imposes on the parents, demands which will tax all their resources of understanding, ingenuity, energy, and emotional stability for extended periods of time.

The blind child seems to be particularly sensitive to the feeling tones of the people around him even though his behavior often does little to suggest this to the inexperienced observer. This paradox highlights the importance of getting skilled counseling help to the parents as soon as the diagnosis of blindness is established so that they can better understand the youngster's often puzzling "lack of response" or "withdrawal" and learn how to encourage his reaching out to his environment, first to friendly persons, and through them, as he develops, to the world of things.

This reaching out, which is being increasingly recognized as basic in the development of all children, assumes particular importance in the case of the blind child, the very nature of whose handicap imposes a serious barrier to its achievement. All too frequently his development is tragically warped and restricted because of the tendency to assume that limited functioning is the necessary and inevitable result of his physical handicap. Rather the limitations are the response of the child who has been seriously deprived both of emotional satisfactions and appropriate experiences at the successive levels of his development.

**Expectations and Experience**

I have purposely avoided the use of the word "stimulation" throughout this discussion because of the connotation which it so frequently carries of “doing something to” the child rather than providing the kinds of opportunities which will motivate him to activity on his own part with encouragement and freedom to develop a mastery of his environment by the use of all his capacities. The children themselves have taught us much about how they learn and, conversely, how often with the best intentions in the world, we get in the way of their learning. Here the detailed records have been invaluable, and will serve to provide a better basis for determining appropriate expectations.

Even recognizing the disadvantages, of the pressure which comes from expecting too much of the child, we have come to feel that expecting too little in the early period is more prevalent and that this may be even more damaging to his development. Failure to observe and recognize the signs of readiness in the child's behavior and to capitalize on them by providing maximum opportunity for learning new skills is to place serious obstacles in the way of his orderly development. The inevitable frustration the child experiences is a major factor in creating emotional problems, often of great severity. This vicious circle is extremely difficult to break, whether the child's pattern be one of withdrawal or of more aggressive behavior, such as extreme tantrums.

The existence of inadequate expectations even among highly qualified professional persons was illustrated recently in a meeting of a parents' group. A prominent pediatrician, speaking on the development of normal children, said that most children begin to walk between 12 and 16 months of age but that an even wider age range for beginning could be called "normal." Unfortunately he added the comment that a blind child, however, could not be expected to walk before 2½ years of age. One can only conclude that he was generalizing from a limited experience. We have found that blind children can fit into the same pattern as sighted children and that some will walk at well under a year. Seriously delayed walking is usually only one result of conditions which are unfavorable for the child's progress.

Because of the poor motor development of many blind children we became particularly interested in trying to understand why some of the 4- and 5-year-olds in the intensively studied group were showing so much freedom and skill in their motor development and such a high degree of ability to get about independently and to orient themselves in new situations. These children were in marked contrast to the children whom we came to speak of as the blind blind children who showed little freedom or initia-
We found that the children with good motor ability and orientation had all had “favorable opportunities” for this type of development, as we have come to define such opportunities through the use of the rating scales, while the others had had serious limitations imposed in at least one important area. One can predict with confidence that the children who were able to get about freely will be adults who will travel independently, while we may have grave questions, so far as our present knowledge goes, as to the others. According to our findings, skill in orientation seems to bear little or no relationship to capacity as measured by the psychological tests or degree of vision.

There has been such consistent evidence of the close relationship between the functioning of the blind child and his total life experience that we have been forced to the conclusion that any sound evaluation of his capacity depends upon an intimate knowledge of these interrelated factors. For example, we have repeatedly observed children whose functioning was below normal at the outset but who have improved in this as the parents have been helped to understand the child and meet his needs more adequately. We have also seen extreme, temporary regressions when disrupting family problems have occurred, such as illness in the family, the loss of the father’s job, or the birth of a young child who absorbed the mother’s attention for a time. To take the child’s functioning at such a time as evidence of his capacity is tragic in the extreme.

Thus we have become convinced that retarded functioning in a blind child with no other major physical handicap should be presumed to be directly related to the complex social and environmental factors in his total experience until proven otherwise by intensive study. However valuable the various test instruments can be in the hands of a skillful clinician, they are useful only if regarded merely as guides for observation and tools in the study of the child and his family. There is no easy answer to the problem of differential diagnosis and no substitute for careful study by well-qualified staffs of all aspects of the problem—medical, psychological, and social—over an extended period of time if necessary. Unfortunately such diagnostic services are not available in most communities.

In regard to the basic medical question that started us on the research, the evidence strongly supports the theory that the retarded functioning seen so often in children with retrolental fibroplasia is not the result of a true mental defect but is evidence of extreme deprivation of appropriate experience or of emotional disturbance, or both, which has developed because of misunderstanding of the child’s basic needs and failure to provide a favorable learning situation for him.

Counseling Service

Are there then specialized educational techniques which are needed by the blind child in the preschool period? We do not believe that there are in the usual sense of the word, though the matter is by no means as simple as the statement “the blind child is first of all a child” would seem to imply. Further understanding of the blind child will come, we believe, as the best scientific knowledge of the development of all children is brought to bear on the study of the individual blind child, against the backdrop of the accumulating scientific knowledge of the developmental patterns of blind children.

One interesting aspect of the study has been the opportunity to work with leaders in the nursery-school field in placing blind children in regular nursery schools. Here the Nursery Committee of the Welfare Council of Metropolitan Chicago gave leadership, first in a study of the possibilities and then in accepting blind children into their own agencies. Substantial financial support from the Chicago Parents of the Blind and other interested groups has made placement in regular nurseries possible for any child ready for it. Through the combined efforts of the project staff and the preschool counseling service of the State Department of Public Welfare more than a hundred children in the Chicago area have enjoyed this experience.

The success of the plan has been found to depend on the continued availability of skilled counseling help both to the parents and to the nursery schools. We believe that such placement has great advantages for blind and sighted children alike when it is part of a long-range plan based on an understanding both of the needs of the individual blind child and what the particular nursery school has to offer. Nursery school without the necessary allied services both to the family and the school has, in our experience, been of doubtful value.

There is increasing recognition of the imperative need for skilled casework service to parents, from the time of diagnosis through the preschool period, by counselors who have understanding of the prob-
lems of blind children. Such service should make use of and coordinate all the varied community resources which may be needed. Particular responsibility for leadership in the development of services, we believe, rests upon the medical and allied professions, not only because of their contact with the family at the crucial time of diagnosis but also because of their position at the “growing edge” in extending knowledge and developing sound practices for prevention and treatment in the whole field of child development and mental health.

Development of adequate services depends, however, not only upon training personnel who can put into practice what is already known but upon the extension of research methods and the continued critical observation and evaluation of experience. There is urgent need for research into the problems of the multiply-handicapped blind child and for the development of services for the poorly functioning and the emotionally disturbed children for whom institutionalization is too often the only provision. The difficulty in finding effective ways for treating these severely—and in many cases unnecessarily—handicapped children is a compelling argument for providing the needed preventive services that will enable the parents to meet the total needs of the child at the successive levels of his development. Here our knowledge is far in advance of the application of it to meet the varied needs of individual blind children and their parents.

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**The isolation of a crippled child from his normal peers breaks down through . . .**

**THERAPEUTIC GROUP WORK WITH HANDICAPPED CHILDREN**

RALPH L. KOLODNY, M. S.

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MEDICINE, casework, and psychiatry have all made substantial contributions to the rehabilitation of physically handicapped children. They have not, however, dealt directly with the special problems of social adaptation that confront the physically handicapped child. Already sensitive to his handicap, such a child finds that other children of his own age show limited tolerance, at best, for his inability to participate fully in play.

Some handicapped children are able to surmount this difficulty and to win a place in the social life of their neighborhood. Even among them, however, what seems like a fairly good adjustment may sometimes actually represent over-compensation, an unwillingness to accept realistic limitations. On the other hand, many handicapped children, having their feelings of inadequacy reinforced by experiences of rejection by their contemporaries, tend to retreat from social contacts. Such children need special assistance to help them participate with security in the social activities of their peers.

To meet these needs the Boston Children’s Service Association gradually evolved the program now carried on by its department of neighborhood clubs.
Referrals of physically handicapped children for groupwork service come to the department from medical social workers, specialized agencies for the handicapped, and parents. Usually the department does not place these children in groups made up of others who are similarly handicapped, though in a few instances involving children needing special protection it forms groups of children with one type of handicap. Its normal procedure is to form a club around each handicapped child, the other members being drawn from physically normal children in the child's neighborhood. This gives the handicapped child an opportunity to participate in a kind of group experience that would ordinarily be inaccessible to him. This approach to group composition derives from the theory that association with normal children, under trained, professional leadership can provide many handicapped children with a corrective emotional experience. The goal is the integration of the handicapped child, insofar as his capacities allow, into the normal life of his peers.

The policy of not including more than one handicapped child to a group should perhaps be further examined. It is based on the theory that having more than one such child in a group can introduce intense rivalries which other members may not be able to accept.

Of the approximately 30 groups conducted by the department each year, about half come into being as a result of the referral of physically handicapped children. The department has formed groups around preadolescents and adolescents of both sexes, with a wide variety of handicaps—orthopedic, cardiac, urinary, auditory and others. They have included homebound children as well as those who are able to get about. Primary responsibility for the formation and leadership of groups is carried by the department's full-time staff of professional groupworkers, although some groups are led by second-year groupwork students or part-time paid leaders who are graduate students in related fields.

Most groups begin by meeting in the handicapped child's home. As soon as it is feasible, however, meeting-places are rotated so that the homes of other members are used as well. If a youth-serving agency exists in the neighborhood, meetings may be held there, occasionally at first and later regularly. The choice of meeting place and the process of movement to other meeting places depend upon a combination of factors: medical restrictions on the handicapped child's movement, his emotional readiness to leave his own home for meetings, the physical suitability of the home for meetings, the availability of neighborhood resources and the age of group members.

Limits on activities used in the group are set by the referred child's handicap. Within these limits the kinds of activities the leader suggests are determined by the interests and capabilities of the handicapped child and the other members. In a group formed around a hemophiliac confined to a wheelchair, for example, programs might include: informal dramatics, sedentary games of a type which allow the safe expression of aggression, crafts with blunt tools, and active games involving the use of the upper part of the body. The program developed is related primarily to the child's needs as a person, rather than to his handicap per se.

Preparing the Child

The groupworkers focus their efforts, primarily, on the group process itself. We are interested in structuring program and guiding interaction in such a way that the handicapped child as well as the other members of the group will find an increasing amount of satisfaction and mutual acceptance as they meet, play and work together. We learned early in our experience, however, that the use which the children make of the group and of their relations with one another depends largely upon how carefully the worker has prepared each member and his parents for the experience. The process and procedure of group formation, therefore, assume an importance which is no less vital than the actual process of working with the group after it is formed. If we do not first recognize and try to handle some of the anxieties of those most directly concerned with the group, including parents and family members as well as the handicapped child and other club members, we can vitiate our rehabilitative plans.

Any strikingly new experience, whatever the pleasures it seems to promise, can seem threatening to the individual. If a handicapped child is to be able to look forward to and enjoy a new experience he must know what to expect. His fears and those of his parents must be allayed.

Both the referring agency and the department take part in the process of preparing the child for a club. If the referring agency is a hospital social service unit, the medical social worker may begin the process. She introduces the idea of a club to the child and to his mother, pointing out the opportunities a group offers for activities and association with others, and explaining, in general fashion, the group-
formation procedures employed by the department. If the child and his parents express an interest in the club she gets in touch with our agency about them.

The referring agency's relationship with the handicapped child and his mother is of crucial importance throughout the referral period. If referral is carried out in perfunctory fashion, confusion and hostility are likely to result. Since formation of the group may take some time, and delay may be upsetting, the security provided by a continuing relationship with the referring worker can be of the utmost importance.

After referral, one of the department's group leaders, or his supervisor, makes a series of visits to the child's home. If possible, both parents and the child are seen at the first visit.

During these early pregroung interviews the groupworker begins the procedure which he follows in all his ensuing relationships with the parents and the child—leaving the initiative in decision making up to them, whenever possible. While he stresses the helpfulness and enjoyment a club experience can bring to the child he does not press for acceptance of the service. He presents it to the mother as a possible aid in her efforts with the child and as a process to which she can contribute some of her own skills and knowledge.

The groupworker attempts to reduce the child's anxiety over participating in a club by relating the experience to something with which he is already familiar. He encourages the child to talk about his interests and the activities he has engaged in when in the hospital or at home alone, explaining to him how he can use these interests and experience in a group.

Although the worker keeps his own questions to a minimum, he answers the mother's and the child's questions about the club as directly and as fully as possible. He does not belittle their expressed fears, some of which may have a realistic basis. A mother of a child whose condition is aggravated by respiratory infection may be anxious about the possibility of children coming into meetings with colds. In such an instance, the worker explains that adjustments in club procedures can be made so that the child's health will not be endangered, such as an agreement that no one will attend a meeting when he has a cold. Many handicapped children ask the question: "Suppose nobody wants to join?" Aware of the feeling underlying such a question, the worker points out concrete ways in which members have been brought into other similar clubs.

The worker takes up certain other difficult subjects quite directly, without waiting to be asked. He makes it clear to the parent and child that the other club members may come from different backgrounds than they and that the department's policy is to disregard ethnic, religious, and racial origins in forming groups. This can have beneficial effects. The worker's attitudes toward others who are "different" may help the handicapped child to sense the worker's acceptance of his own "difference."

Parental Anxieties

Few parents of the handicapped children categorically reject the idea of a club. Most of them realize the help which guided group association can offer their youngsters. However, because of the emotional pressures to which they have been subjected by their children's illnesses, they display varying degrees of ambivalence when presented with the possibility of such group association. Even the mother who has herself initiated contact with the department shows some ambivalence through various forms of resistance.

Some mothers openly resist the idea of sharing their child's care with an outsider. Some who do not show resistance at first later attempt to control the leader and to dominate the group. A few expect too much, asking to be relieved of their child's care for long periods of time.

Parents always hesitate at the thought of placing a severely handicapped child in regular contact with other children. The mother may be afraid that the child's membership in a club will mean that he will have to compete with other children, to his own and perhaps to her embarrassment. Some mothers have attempted to circumvent this problem by suggesting as club members other children who also suffer some handicaps. Some are afraid that the club membership will expose their handicapped children to "aggressive" children. On the other hand some parents of handicapped but ambulatory children, denying their child's need for special help, put pressure on the child to join "regular" groups, such as the Boy Scouts.

While there are some instances where resistance completely blocks the formation of a group, usually the initial resistance on the part of parents is not so profound as to make further work impossible. Ordinarily, their desire to have their child lead a less constricted life enables them to accent the service, despite their fears. They may continue to show anxiety through their behavior in relation to the
group, but generally, the groupworker is able to handle any difficulty by accepting their fears and hostilities and showing his interest in them as individuals.

However, some parental fears may remain strong despite the worker's understanding attitude. While a mother may seem to accept the idea of the club by permitting its formation, she and her child may be so bound to each other emotionally that they fear the separation entailed by the meetings or become upset when they are asked to carry responsibility. As a result, the child's attendance becomes sporadic. When this occurs the leader does not press either the parent or child but gives their anxiety a chance to subside. He also tries to offer some substitute gratification to the mother, such as increased attention, to make up for her partial loss of the child.

While alert to parental resistances and anxieties, the worker is careful not to lose sight of parental strengths. He encourages the mothers, and, if possible, the fathers to use their interests and skills in helping him to plan for and work with their child and his group, wherever this can be done naturally and in line with group needs.

**Group Formation**

The process of forming a group around a physically handicapped child may be carried out in several different ways. In every case, the worker first asks the referred child and his mother if they know of neighborhood children who might be interested in joining the club. This not only helps them to make a direct contribution to the alleviation of their own problems, but it may eventually bring together some children whom the child knows and with whom he wants to associate, so reducing his anxiety. If either the mother or child have suggestions for members the worker asks them to describe what these children are like, helping them to evaluate them in relation to their suitability for the group.

The general criteria he uses in attempting to weigh the suitability of a suggested member are:

1) The member should be about the same age as the referred child; 2) he should be able to accept a limited and sometimes sedentary type of program; 3) he must be able to control his impulsiveness; 4) he should not be deeply afraid that the handicapped child's condition is contagious; 5) he should not have displayed an excessively pitying attitude toward the handicapped child in previous contacts; 6) he should not have been consistently in conflict with the handicapped child in the past; 7) there should be some likelihood of his being enthusiastic about the idea of a club as something he himself might enjoy.

If any of the children described by the mother or child do not seem suitable for membership according to these criteria, the worker helps the mother and child to understand why they should not be asked to join.

The children's age often raises problems. Many ambulatory handicapped youngsters wish to include in the group children younger than themselves because they feel more comfortable with them. Explaining the advantages of associating with children of his own age, the groupworker also points out that younger children might feel ill at ease in the group and assures the handicapped child that he can continue to associate with them for free play. On the other hand, the worker also points out that any youngster who joins the group must be able to tolerate a restricted kind of program. This is a sine qua non of membership. A member who is easily frustrated by limitations in activity can disrupt the group and upset the handicapped child.

If the children suggested seem to be likely candidates for club membership the mother is asked to get in touch with their parents about the proposed plans. If she does not wish to do so herself the groupworker undertakes this task. In any event, the worker eventually visits the homes of all of the prospective members.

In some cases neither the mother nor the child knows anyone to propose as members. The worker then suggests that the mother visit the neighborhood school in order to enlist the help of the principal and teachers. Some mothers respond to this idea negatively, and the worker looks for other means of securing members, visiting the school himself or other neighborhood institutions. When a mother is willing to make school contacts the worker prepares her for her interviews with the school's staff. After someone at the school has talked with suggested children and advised their parents of the department's plan, the worker visits their homes.

In visiting the homes of prospective members, the worker explains the kinds of program activities the proposed group can carry out and what these have to offer in the way of enjoyment, but also points out the limitations that will have to be imposed on the group. He stresses the potential value of the group to all members. He also attempts to answer the prospective members' questions, especially those relating to the handicapped child and the nature of
his handicap, carefully avoiding the creation of undue anxiety in so doing.

During this first visit the worker attempts to determine the prospective member's suitability for the group. Except when a suggested child is clearly unsuitable for membership he is allowed to join the group if he indicates a desire to do so. While this policy sometimes leads to difficulties, a rigid screening system for membership would be impossible to operate. The use of diagnostic testing in order to evaluate suitability for membership, for example, would give rise to many complications. Even though parents were to permit such testing, which is unlikely, the procedure would lead to serious problems arising from the exclusion of some of the children tested. It might also inhibit the establishment of a warm ‘natural’ climate in the group. Moreover, the selection of members according to narrowly specific criteria is often made unfeasible by the limitations of the peer population in the neighborhood.

A club formed around a physically handicapped child usually contains from five to eight members. The smallness of the membership is dictated, in part, by the fact that meetings, in many cases, must be held in homes—in kitchens, basements, and bedrooms. It also derives in part from the fact that for some severely handicapped and isolated children, the experience of being exposed to relationships with more than a few new children can be overwhelming. The basic reason for keeping the clubs small, however, is to give the leader opportunity to work effectively with the members.

The Sense of Adequacy

The agency has certain general objectives as well as specific aims in its work with every club. A primary goal in working with a child whose role and status among his peers have been radically altered by illness or accident is to help him to recover a sense of his own worth. The approach is to help the child develop social and play skills which will enable him to take on status-giving roles in interaction with his peers. This is not an easy process since it is always complicated by previously existing emotional problems, either in the child or in members of his family.

Many methods are available to the worker attempting to restore a child's sense of adequacy. Individual workers use different adaptations of them at different times. The process as a whole needs to be studied more intensively before all of the nuances of technique can be identified. Four general steps are, however, clearly necessary:

1. Accepting the handicapped child's dependency and behavior.
2. Helping other members to react less resentfully to his dependency by giving them as much individual attention as possible.
3. Starting with activities which are well within his ability and for which he may have been especially prepared by the leader.
4. Later, gently challenging his tendency to cling to the familiar, through exposing him to carefully planned activities which are not beyond him but which do call upon him to extend himself.

These techniques were an important part of the worker's approach in the case of Sally, aged 14, a polio patient. In reality, they were not separate from other aspects of her approach to the girl or her stepmother or to the problem of group composition, though they will be discussed separately here.

Sally was paralyzed by polio when she was 13. When the group was formed a year later, her prognosis for walking was poor. She and an older sister were children of their father's first marriage. Their young stepmother was strict with both girls but tried to rouse Sally from her inertia.

In the hospital Sally had been difficult to work with and showed little desire to get better. When she returned home the family was unable to accept her poor prognosis and seemed to deny the implications of her illness. Since her shoulders were too weak to support crutches, she got about very little, and remained in bed most of each day.

A cousin and three other girls from the same street, all of them older and more sophisticated, visited her often at first. Upon referral from the hospital a groupworker from the agency initially worked with this “fun” club, although she had misgivings as to its value for Sally. When three of the girls lost interest, the worker set about forming a club with girls who were closer to Sally's level of maturity, from among those Sally had known in school prior to her illness. In this group the aspect of the groupworker's efforts aimed directly at Sally's feelings of inadequacy had to do with program activity.

As Sally had been skillful at handicrafts even before her illness the worker focused the group's attention on this type of activity. Fortunately, the other members also had an interest in handicraft. At first the groupworker visited Sally frequently in order to give her individual training in one craft, copper enameling. As a consequence Sally became very dependent on the groupworker. This development was counterbalanced in the girl by a rise in her
self-esteem as she became able to impart her knowledge of copper enameling to the others. She seemed very pleased at meetings when members asked for her help. The group had to depend a good deal on the groupworker at this time, for copper enameling requires a baking kiln which the leader must tend. Sally seemed quite able to share the groupworker's attention with others, perhaps because her skill in the craft enabled her to function more independently than they, thus bringing her a sense of status as well as satisfaction.

Undoubtedly, the others felt some hostility toward Sally because of her superior ability in the enameling work. They did not openly express this, however, perhaps because it was mitigated by their own interest in the work. Moreover, the leader was careful to introduce some other activities for which Sally had not had special preparation, thus making it unnecessary for other members to lag behind her in achievement and challenging her to mobilize herself for something new. She responded well to the challenge and received recognition from the other members in the process. All of these activities made it necessary for Sally to get out of bed and to sit at the table with the others.

While the groupworker allowed Sally to become dependent, she did not encourage her to remain dependent by expecting her to give something back in the way of affection or finished products. Rather, she gave her time and attention to Sally in a manner which stimulated the girl to act more independently in expanding her creative abilities, not in isolation, but in the company of friends.

Sally returned to the hospital for a prolonged period of observation and retraining after 6 months in the group. Nurses who knew her previously have commented on the change in her behavior. Instead of being inert from despair, she has been active in helping the other two girls in her room. Her use of occupational therapy has improved and she seems to enjoy new activities. She has developed a close relationship with a teen-age boy patient and visits him frequently. Generally, she seems now to be participating in her own treatment.

These changes could hardly be attributed solely to the club experience. The medical social workers at the hospital have undoubtedly had a great deal to do with it, as have some changes in Sally's circumstances. She is less sick than she was before. Her stepmother seems to be more accepting of her handicap. Her medical prognosis is better, giving her a chance eventually to walk. But in addition to these factors, the groupworker's approach in the club experience played a part in bringing about the girl's improved outlook and behavior. Through this Sally was helped to develop some of the social and play skills which enable her to use the changes in her situation advantageously.

Other Members' Needs

In every club formed by the agency the worker attends not only to the needs and interests of the handicapped child but also to those of the healthy members of the group. This is true not only in programming for a group but also in planning for its termination.

One worker discovered during the second year of a group's existence that the needs of the handicapped child were beginning to conflict with some of those of the other members. He was having to control program and relationships rather tightly and to use activities focused primarily on the handicapped child's needs. Therefore, for the sake of all the members he planned for the transfer of the club to a regular groupwork agency.

The club centered around Pete, an extremely bright, 10-year-old boy suffering from muscular dystrophy. A previous group formed around him had not worked out well because of lack of interest on the part of its members. The new group, formed at the termination of the first, seemed to bring pleasure to all its members during its first year.

In the second year, however, certain problems arose. The members were physically far more active than they had been earlier. Also, they had become surfeited with the kind of activities they had previously engaged in and even Pete was bored. There was a marked increase in physical horseplay—dangerous for Pete. At one meeting one of the boys started to wrestle with him. It was obvious to the worker that if such incidents were to continue, the experience would reinforce the boy's feelings of inadequacy. Moreover, one of the boys had indicated his impatience by suggesting, at three different meetings, programs which were utterly beyond Pete's capabilities.

Eventually the worker decided to alter procedures in order to enable Pete to have a satisfying experience and to permit the total group to continue to function as a club. While he had been allowing the group to determine its own program insofar as possible, he now attempted to develop program primarily on the basis of Pete's leisure-time interests. For the next 6 months the worker conceived the ideas for the
majority of programs, allowing the group members to have a say only in minor ways. Fortunately, they enjoyed the activities the leader devised and Pete was able to participate completely in the social interplay. Among these activities were discussions on adventures in science, simple experiments, and the construction of telegraph and radio equipment.

While recognizing the benefits of this approach for Pete, the worker noted that some of the needs of other members were being slighted. Although the boys attended the meetings regularly with apparent satisfaction, some of them were not being helped in a way in which they might have been in a less controlled group. For example, two of the boys had many problems around authority with which the worker, in the position of a controlling figure, was unable to help them as much as he might have otherwise.

At the end of the group’s second year, the worker came to the conclusion that the normal boys had gained as much as they could from the protective group experience the department offered, and that Pete was also ready for experience with a regular groupwork agency. The boy had been anxious to go away to camp for the summer, had not used withdrawal as a defense in his second years’ experience with the group, and had exhibited a strong drive for new experiences.

The worker, therefore, made plans to transfer the club to a nearby neighborhood house where another professional worker was assigned as group leader. Even in this new setting the members still have to control themselves in the original group because of Pete’s condition. However, their affiliation with the house gives them an opportunity, while continuing in the club, to join other groups in which they may be under less restraint and in which their need for self-expression can be more directly met.

Sooner or later groups must break up. The leader attempts to make this separation by talking with the handicapped child and the rest of the club, at least several months in advance, about termination of his work with them and by dealing with the feelings which arise; by attempting to transfer members, as individuals, or as a group, to a neighborhood center; and by followup contacts with the handicapped child after termination.

**Implications of the Experience**

Definitive information on methods of rehabilitating physically handicapped children is badly needed. The material just presented clarifies some of the factors that must be taken into account in making a groupwork contribution to the rehabilitative process. However, the knowledge it imparts is necessarily partial and, in some respects, subject to revision on the basis of further experience. The groupworkers in our department of neighborhood clubs have learned a great deal in their practice, but many of their findings must be stated tentatively.

We can, however, make a few definite statements on the basis of this work, all of which point up the importance of planning individually for each child. We have found that:

A group experience with normal children is desirable for many handicapped children. Not all such group experiences, however, are helpful to them. One does not necessarily reduce the problems that a handicapped child has in relating to his normal peers by simply exposing him to peer relationships in a group under the guidance of an interested adult. While one child can be helped by such a procedure, another may be placed under too much stress.

If groupworkers focusing on rehabilitation wish to increase the likelihood of a handicapped child’s being helped by a group experience with normal children, they must carefully plan the child’s introduction or reintroduction into the social life of his associates. Wherever possible, they must try to bring the handicapped child into the kind of a club in which the structure and activities of the group are related to his emotional and physical needs. They must provide him with a leader who is trained to understand the feelings of handicapped children and their parents in regard to social relationships and who has some awareness of the possible effects of relationships with handicapped children upon the feelings of their healthy peers.

These principles, while presenting great difficulties for any large-scale program, point the direction for helping handicapped children to find physical and emotional security in group experience with their normal peers.
COORDINATING HEALTH SERVICES FOR HANDICAPPED CHILDREN

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ALMOST ANY community with a strong interest in fostering rehabilitation of handicapped children eventually faces the problem of coordination of services.

The problem, in fact, actually reflects the vitality of the community's interest, for it exists only where concern for the handicapped has resulted in the provision of a number of services by a variety of agencies. Communities with little interest and consequently few, if any, services have nothing to coordinate.

Handicapped children fall into many diagnostic categories. They include: children with orthopedic, neuromuscular, and neurological problems; children with rheumatic fever or heart disease or both; children with congenital malformations or birth injuries of all types; children with convulsive disorder; children with cleft palate and cleft lip; children with hearing impairment; children with visual defect; children with malocclusion; children with speech defect; children who are mentally retarded; and children who are emotionally disturbed. An increasing number of State or community programs for handicapped children are including children having any type of chronic illness, including, among others, diabetes, nephrosis, asthma, and celiac disease.

With so many diagnostic categories included in the definition, the total number of handicapped children is bound to be large. Accurate data on the number in this country are not available, but conservative estimates put the total at 5,615,000. The largest groups are composed of children with speech defects, orthopedic conditions, mental retardation, rheumatic fever and heart disease, and hearing impairment.

The types of services needed by handicapped children in any of these categories are also many and varied. They include: (1) early case finding; (2) referral and counseling; (3) evaluation, diagnosis, treatment, and rehabilitation on a team basis with consideration of health, social, psychological, educational, vocational, and recreational aspects; (4) provision of opportunity to continue either in regular school classes, special classes or special schools, or with home teachers, according to the child's condition; (5) provision of vocational testing, guidance, training, and job placement for teen-aged handicapped youth; (6) provision of recreational opportunities, including day programs and camping; (7) provision of foster-home placement for those who need it; (8) provision of home-care help for home-bound children; (9) provision of special housing for some handicapped children and their families; (10) special transportation facilities to enable some children and young people to attend school, recreational programs, treatment services, or work; (11) residential or custodial care for severely disabled children who show no evidence of response to the rehabilitation process over a period of years.

A well-rounded program for the handicapped will also be concerned with the kinds of health and educational programs that can prevent further handicapping conditions from developing either in normal children or in children already handicapped.

Obviously all of these services must be of high caliber if the broad rehabilitation of handicapped children is to be achieved. Moreover, they are as
applicable to children in any one of the diagnostic categories as to those in any other. However, few, if any, of the handicapped children of any diagnostic category will need all of the services listed. Some children will need only a few services; others will need many.

**Why Coordination?**

The association between chronic illness and medical indigency is well known. It means that most low-income families and many middle-income families with handicapped children need assistance at some point in the various stages of their rehabilitation. Therefore, the community must be prepared to carry the financial responsibility from both official and voluntary sources for a large share of the services for the handicapped. While services to handicapped children have a strong fund-raising appeal, nevertheless sufficient funds never seem to be available to do a complete job in all aspects of service for all those needing service.

Care of handicapped children is expensive, particularly where services are developed on a team basis, as is currently recommended. For example, in a service for children with cerebral palsy, an effective team contains these essential members: pediatrician; orthopedist; physiatrist; social worker; public-health nurse; physical, occupational, and speech therapists; psychologist; teacher; and vocational counselor. To their services may be added those of an ophthalmologist, neurologist, psychiatrist, and hearing specialists. In a service for children with hearing impairment, a fully staffed team includes: pediatrician; otologist; social worker; public-health nurse; speech therapist; psychologist; teacher; vocational counselor; audiologist; and audiometric technician.

Obviously, for the community to employ a complete team for handicapped children of each type would involve considerable expense as well as duplication, for both teams require some of the same types of personnel. This aggravates a serious problem posed by a scarcity of trained personnel. A recent report of the Health Resources Advisory Committee indicates a shortage of trained personnel exists in practically all of the professions necessary for the rehabilitation of the handicapped. Therefore, from the viewpoint both of conserving funds and reaching as many as possible of the children who need help with the personnel available, joint planning and coordination of services are necessary.

Where there is no joint planning and coordination among the services for handicapped children, continuity of care is not always provided, not all children receive all of the services they need at the time most appropriate for them, and multiple diagnostic work-ups are often performed which are both distressing to the patient and wasteful of professional time.

**Methods of Coordination**

Agreement on the need for joint planning and coordination of services immediately brings up the question: "What are some possible methods by which coordination can be accomplished?" This can be approached at two levels—community organization and the direct provision of care to the individual child and his family.

Let us look first at the community. For my first two years as director of a crippled children's program in a large metropolis, I spent a considerable amount of time with my staff in looking at the services available, determining unmet needs, and attempting to plan new services to meet those needs. While we managed to secure a great deal of information, we had little or no success in developing new services. This was highly discouraging. However, as we went around to look at the services that were available, we became acquainted with a number of staff members of the four other official agencies and about 25 to 30 voluntary agencies serving handicapped children. We found that the representatives of most of these agencies had the same types of problems and had recognized many of the same needs that we were beginning to recognize. We also found that each one of us had been trying individually to develop services, with hardly any tangible success. As a result, a meeting of all agencies serving handicapped children was called to see what the group could accomplish together. It turned out to be the first of continuing regular monthly meetings.

At the first meeting, the conferees selected priority items from a long list of unmet needs. Then they went to work through subcommittees, drawing up statements of the need and recommendations for a community plan.

Through this joint planning, the agencies achieved the following accomplishments:

1. A jointly financed study of transportation of the handicapped, which took 6 months. This resulted in the revamping and improvement of the entire method of transporting handicapped children to school.

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2. The development of a plan for services for handicapped children of school age, which was the basis of recommendations to the mayor made by a special advisory group appointed by him for the purpose. As a result of these recommendations, services were expanded to enable many more handicapped children to attend school and to receive more complete service at school when they did so.

3. A statement of housing needs of families with handicapped children. This resulted in some priority being given these families in assignment of apartments in new low-cost housing projects.

4. A recommendation that a foster-home program for handicapped children be developed. While the child-placement agencies in the community did not completely follow this recommendation, they did take an increased interest in finding foster-family homes for handicapped children so that more such children were placed in them from hospitals and convalescent homes.

5. A recommendation that the official crippled children's agency pay for outpatient care of handicapped children. Some initial success in this direction has been followed by increased attention to the problem.

6. The development of a plan for a home-care program for the homebound. Implementation of this plan has been impeded by lack of a source of financing.

7. An agreement by the agencies to review together the annual budget request of the official crippled children's agency and to select items in it they wished to support. As a result, representatives appeared at budget hearings to speak in behalf of the request and did a great deal of "behind the scenes" work to get the budget adopted. This support was largely responsible for whatever success was achieved in the development of new services in the official budget.

This particular method of coordination—consisting of monthly meetings of all community agencies concerned with handicapped children, their agreement on the most important unmet needs, their working out of a joint plan, and their pulling together to promote its adoption—was carried out entirely informally. When agencies were asked if they would like to have some official recognition for their joint work, they turned it down on the theory that the informality of their efforts gave them more freedom of operation.

Committees and Commissions

A formal extension of this method, which has met with considerable success, is the establishment of a statewide or community crippled children's commission for handicapped children. Such a commission usually has advisory functions only and is composed of professional and lay persons interested in developing, promoting, and coordinating services for all types of handicapped children.

Another method for coordinating efforts for handicapped children is the establishment of a joint legislative committee on handicapped children, appointed by the Governor and composed of selected legislators, professional personnel, and lay leaders. In New York State a joint legislative committee on cerebral palsy, established at the instigation of United Cerebral Palsy, has accomplished a number of objectives, including appropriations for: a study of the number and needs of children with cerebral palsy; the training of all kinds of professional personnel; grants to institutions giving out-patient care to cerebral-palsied children; expansion of in-patient service in one State institution. The committee annually reviews the service data, caseloads, budgets, and budget requests of the four State departments of government concerned with cerebral palsy—health, education, welfare, and mental hygiene—and makes recommendations to them.

This council has been in existence 10 years. Because of its success, a movement is on foot now, initiated and spearheaded by the United Cerebral Palsy itself, to broaden the council's concern to include all types of handicapped children.

Still another method of coordinated planning is the use of advisory committees for agencies working with the handicapped. For example, in New York City whenever the official crippled children's program is considering the development of an entirely new service, an official advisory committee is formed, composed of clinical experts, representatives of pertinent voluntary agencies and, at times, lay leaders. Facts about the needs are presented, and a recommended plan for community action is usually developed. In this way, the voluntary agencies are brought into the planning early, duplication of services is avoided, and some coordination of agency services is achieved. The reverse also takes place. In New York many of the voluntary agencies have formed professional advisory committees, of which clinical experts and representatives of the official programs are members.

Such close working relationship means that the
official programs are assisted in assuming responsibility for many of the basic routine services while the voluntary agencies, with their greater flexibility, can use more of their funds to try out new ideas and initiate pilot programs. Thus, the community can make progress more quickly in taking care of unmet needs, can reach more children and their families in need of help, and can use the funds available for handicapped children in a sounder way than would otherwise be possible.

Such a close working relationship cannot develop overnight. In New York it came about only as workers in the field came to know each other and to develop mutual trust and respect. It required fostering a feeling of sharing a common goal to displace a feeling of competitiveness.

**Direct Services**

Now, let us look at what can be done to provide coordinated care to the individual child and his family. During the current century, and especially in the last two decades, interest in specific diseases has resulted in the establishment of so many voluntary organizations on a diagnostic categorical basis that in many communities today services to the handicapped are provided through numerous separate agencies. It is not uncommon to find in one community separate agencies for patients with cerebral palsy, muscular dystrophy, multiple sclerosis, cardiac problems, convulsive disorder, mental retardation, arthritis, and hearing impairment.

The provision of these services for the various kinds of handicapping conditions separately can have a number of undesirable effects. For example, in the care of cerebral-palsied children, it may mean that a cerebral-palsied child suspected of having a hearing impairment will either receive an inadequate hearing evaluation in the cerebral-palsy service or be referred to another agency for hearing service. Or if the same child has convulsions, he may not achieve full control of his seizures through the special cerebral-palsy service and may have to be referred to another agency serving children with convulsive disorders. This would again be true if he had a visual defect or a cleft palate.

Thus, diagnostic fragmentation of services presents the possibility of incomplete evaluations in some instances and of repetition of parts of services in others, and frequently makes it necessary for the child and his family to go from place to place to achieve complete service. For these reasons, as well as to prevent wastage of community funds and of the time and energies of available personnel, it seems sounder to provide such services through a general multidiagnostic, treatment, and rehabilitation agency interested in all types of handicapped children, located in one place and staffed with all the kinds of personnel necessary to meet all the needs of all handicapped children. This approach means that the individual child and his family receive better care, more children are helped, the professional personnel are used more efficiently, and the cost to the community per child is reduced.

**The Team Approach**

Another coordinating device can be found in the "team approach," a term which has been widely used for years, but not as widely translated into practice. What can the team approach mean for the individual child and his family? It might mean eventually the difference between an independent and productive young adult on the one hand, and a long-term public-assistance recipient on the other. In other words, in one case, the presence of a vocational counselor as an integral part of a team for handicapped children may mean the application of vocational testing, guidance, training, and placement to the teen-ager at the time when he is most ready for it. In another case, a child who is participating in the rehabilitation process may reach a plateau in his climb toward normality, either because of physical or psychological impediments. The inclusion of a skilled psychologist on the team may make it possible to ascertain the inhibiting factors.

The chances for the child’s attaining his maximum potential for rehabilitation will be greatly enhanced if the full team is used for the initial evaluation and for frequent periodic reappraisals. When the team is thus used one member must be designated as responsible for the continuing care of the individual child and his family, to follow the child’s progress, and to pull together the team members’ various efforts. Without this type of coordination, the team’s activities may also be merely fragmented services.

Also important in coordinating services for the individual child and his family is the provision of continuity between care given at a central point, as in an inpatient or outpatient service of a hospital or school, and care at home.

It is not uncommon for a child who has made significant progress on an inpatient service, to regress after returning home. Simple oversights are often behind such regression. The child may have been
provided with a wheelchair which is too wide for the doorways at home. He may have been taught to care for his toilet needs through techniques applicable only in the hospital’s toilet facilities and not in those at his home. In order to facilitate proper care at home, the community’s public health nursing service can be of great assistance in reporting home conditions to hospital personnel, in preparing the home and family to receive the child, and in helping the family to adopt some of the rehabilitation techniques at home.

Each professional worker has numerous opportunities for promoting coordination of health services. These opportunities occur each time he sees a child who is known to other professional workers, as well as when he participates in complex community planning efforts. It is important to bring to the child the particular service he needs at the time most appropriate for him in relation to his individual growth and development. Unless services are coordinated, obstacles may obstruct this essential factor of proper timing and so prevent the best possible job from being done for him. The goal of coordination of services for handicapped children is the maximum rehabilitation of as many children as possible, using the available professional personnel to their fullest, with the least possible cost to the community.

**The Import**

With the increased aging of our population, health personnel of all types will in the future be more and more concerned with the care and rehabilitation of adults with chronic illness. Some lessons may be drawn from experience in working with children with chronic disease, so services for chronically ill may not have to go through many of the trial-and-error methods which the children’s services have had to do. This not only applies to the problem of coordination of services for adults in the community. It also raises the question of coordination of services for children with chronic illness with the newer services being developed for adults with chronic illness. Anticipating this may help us avoid the complication of the problem by approaching it too late.


HELPING PARENTS OF HANDICAPPED CHILDREN

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FEW, IF ANY, parents know instinctively how best to help a handicapped child, and how best to handle the intense feelings of disappointment, guilt and resentment which pour over them when they realize that their child may never walk or talk, or learn, or love as other children do. Learning to live with their handicapped child, and with their feelings about him, imposes upon parents the necessity for tremendous spiritual growth and intellectual understanding. This does not come over-night. Finding out what the child needs and how to give it to him is a slow learning process. Parents need wise and patient guidance if the lesson is to become an integrated part of their thinking and being.

Handicapped children belong to emotionally healthy and mature parents and to neurotic and insecure parents. Most often they belong to average parents who are able to withstand a moderate amount of stress and strain, but who may develop serious problems of adjustment if the stress becomes very great. In other words, the typical parent of a handicapped child is, like most of us, a person who can take just so much and no more. This parent is subject to great emotional strain, which may affect his ability to plan appropriately for his child and himself unless relief in the form of counseling and other professional services is available.

Severely handicapped children do not, like normal children, “just grow.” The growth of a normal child is governed by an inner law of development. The child will “just grow” as a physical being and as a personality—if granted a reasonably favorable physical and emotional environment.

But the inner law of development which governs the growth of a child who was born with cerebral palsy, for example, has lost its reliability. Who, then, knows how it will operate? Certainly not the child’s poor parents—at least, not at first. They are apt to be average—not exceptionally bright, not exceptionally slow. They are familiar with the way their average children grow, and they are doing fairly well by them. But what now? Their little girl is 18 months old and she does not even crawl, or say “mama,” or feed herself cookies. The doctors say she will probably always be handicapped, but hasten to add that there is much that can be done to help her.

It is that word “much” that does it. Remember, the little girl’s parents are the kind of people whose tolerance for stress is just average. They can take so much but no more. And here comes much more—hours of exercises, speech stimulation, assistance in feeding and dressing, plus days and weeks of discouragement and frustration when there seems to be

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no tangible reward for such a great investment of effort. The goal? Well perhaps the little girl may, at some far distant day, reach that goal her brothers and sisters achieved without even trying—functional independence.

On whom will the final responsibility for achieving this goal rest? Not on the child alone; only partially on doctors, nurses, social workers, and therapists. It will rest chiefly, in the long run, on the child's parents. They are the ones who must face the major responsibility for stimulating artificially the physical and emotional development of a child whose natural potentialities for development have been disastrously tampered with. No wonder that a handicapped child's parents often say, in one way or another: "This is too much to ask of me."

**Parents as People**

There are many ways in which parents of handicapped children say "This is too much." Social workers and nurses have heard them all again and again.

When a parent of a handicapped child says, in effect: "But I have my own life to lead," he means that the burden of his handicapped child is becoming too heavy and that he is asking, however indirectly, for help. This reaction to stress is sometimes labeled "parental rejection." On the surface that is what it seems, but the professional person who looks further may find that it is a fairly wholesome response to an almost intolerable pressure.

Twentieth-century American parents who read a great deal about child care in the periodicals are likely to come to the conclusion that our society regards them as less important than their children. Our child-centered culture expects parents to make great sacrifices in order to provide their children with "security"—that "elusive" goal of modern living. So saturated are most of us with the concept of the almightiness of the child, that we recoil when we hear a parent protest: "But I have my own life to live!" When we hear the parent of a handicapped child say this, we recoil further. "How selfish and self-centered can a parent be?" we ask.

A professional person should not be dismayed when a parent of a handicapped child protests: "But I have my own life to live!" After all, he speaks the truth. He is right, and he needs to be told he is right. He cannot be a good parent if he does not have some of the satisfactions and rewards which he needs as an individual in his own right. He cannot give up his whole life for his handicapped child and expect to be a well-adjusted, self-respecting, contributing member of society.

Professional persons must accept the task of lightening the load for such parents and giving them a chance to be free—free of guilt, remorse, and resentment and free of a 24-hour-a-day schedule of child care and therapy. We can say, in effect: "You do have your own life to lead, and you should be free to lead it. We will help you by sharing the physical burden, by giving you knowledge of why and how this happened so you won't feel so badly about it, and by finding adequate financial assistance for you so that the cost of medical care will not leave you bankrupt."

This approach involves the professional person in a threefold responsibility:

1. **Sharing the physical burden** may mean helping the parents secure admission for the child to a treatment facility, a hospital school, a special camp, or a day center. In some instances, it may even mean helping the parents to make a decision in favor of permanent institutionalization and acquainting them with appropriate facilities for long-term care. In either event, the professional person must share with the parents a sound knowledge of the resources available for handicapped children and must pave the way toward referral.

2. **Supplying the "know-why" and "know-how"** involves the professional person in individual or group counseling with the parents, usually over an extended period of time. In some cases, this may require the combined efforts of a professional team, including doctors, psychologists, social workers, and parent-education specialists. It also requires the professional person to participate in public-information campaigns.

3. **Securing adequate financial assistance for the care and treatment of a handicapped child** means that the professional person will probably have to refer the parents to the services equipped or responsible for meeting their needs. This may be a clinic for crippled children, run under public, semipublic or voluntary auspices, where medical care can be secured free or at low cost; or a local welfare department, service club, or voluntary social agency which can help out with the expense of braces, wheelchairs, prostheses, or other appliances.

Such services can go far toward restoring to a parent his own life to lead as he sees fit. They do not take from a parent any of the rights or responsi-
bilities which are inherent in his parenthood. They merely give him a little more time, a little more assurance, a little more security, which he can share with his family and his community. Everyone benefits, particularly the handicapped child.

Unsure Parents

Some parents have another way of saying that they need help. They say, “I do not have the patience to work with a handicapped child. I cannot give my little boy what he needs. I am too nervous.”

A professional person who looks behind this statement may find that the child’s parents are young and unsure of themselves, and that grandma, experienced and very sure of herself, has taken over: she compulsively follows every order the doctor gives; having hours to devote to the child, she decides he might as well live with her and benefit from her determination and devotion; she exercises limbs, she fortifies diets, she stimulates speech; she does everything.

In such a situation, the young parents feel more helpless than ever and decide that they can never be as adequate as they must be to meet the child’s needs. They have had so little chance to get to know their own child that he is a stranger to them. They find it increasingly difficult to find a place in their lives for him. Eventually, he is deprived of normal family experiences, his parents feel guilty about their rejection and withdrawal, and grandma continues to overprotect him because of her own need to control and dominate. For this little boy personal relationships are badly snarled. He gets his therapy daily and his vitamins every morning. But he does not know who he is or where he belongs, and his disposition is deplorable.

This illustration does not mean that grandparents are not useful and necessary to the family of a handicapped child. It means, however, that there are grave dangers for the handicapped child inherent in any situation which takes ongoing responsibility away from the natural parents.

A similar situation sometimes develops when a handicapped child is placed in foster care by official authorities because his own parents are neglecting his physical care. Like grandma, the foster parents may be determined to do everything just right. But foster homes often fade fast, since the care of handicapped children is more demanding than many foster parents ever dream. So these children all too often lose their foster parents. Who then takes their place? Who has been growing up to the ongoing responsibility of meeting their emotional needs? Not the parents—they have no permanent responsibility, and know it.

The truth is, no one has grown up with the problem. The child’s own home is lost; the foster home is lost; the child, unfortunately, is probably lost, too. Too late we may recognize the hard, cold fact that half a home of his own is better for the child than no home at all, and that ineffective parents are better than none. The professional person’s task is not to find new parents for handicapped children—except in rare instances, substitute parents just don’t work out on a long-term basis—but whenever possible to help natural parents with their load so that they will be better able to carry it.

Moral support is what insecure parents need and the offer of concrete services together with recognition that they have a hard row to hoe. Once granted respect by the community and relief from the burden of ignorance and debts under which some of them stagger, these parents often show a remarkable ability to handle responsibility which might once have been taken away from them.

Denial of Reality

There is a third way in which parents of handicapped children tell us that they are beginning to crack under the strain of their responsibility. With what appears to be unrealistic optimism they say, “Billy is doing just fine. We are pleased with his progress.”

Denial of reality as a reaction to stress is found among the parents of severely handicapped children, and especially among those whose physically handicapped children are also mentally retarded. During such a child’s infancy, his parents may have gradually learned to accept the fact that he is crippled. But this seems to be as far as they can go. As the child advances in chronological age but fails to advance mentally, the parents cannot accept the additional stress of a second disability, and, although they have been told repeatedly that their child is mentally retarded, they say, “We are convinced that our little boy is a bright child. It is only his physical handicap that holds him back.”

It is true that the parents of the handicapped must have help. But it must never be given in a patronizing “I know better—now you listen to me” way. In the final analysis, the parents know their child better than the professional person does and they’ll probably tell the truth about him if given a chance, for a defense usually crumbles in time before
a truly sympathetic listener. They'll need to be absolutely sure they are not in disrepute for past shortcomings, or that an honest confession will not be used to cut off their access to services. The professional person who understands that “he is doing just fine” is merely a defensive verbal barricade against deeply feared reality and not the expression of an unshakable conviction, will be better able to help.

Of course, there are parents whose denial of reality becomes so extreme that only intensive psychotherapy can help them. The professional person has to find out how severe this reaction is before he can judge whether or not it can be handled successfully without psychiatric help. Nurses and social workers know that they are not competent to treat severely aberrant reactions in the parents they seek to help. But recognition of their limitations should not block them from doing what they can to ease anxiety in deeply disturbed parents. They need never be afraid to listen sympathetically to persons in distress. This may not help, but it will never hurt. Afterwards they will want to consult with a competent psychiatrist about the next step to take.

The Hopeless

Not so different from the unrealistic optimists are the unduly pessimistic parents who say, “It’s a lost cause.” They are afraid to be hopeful lest their hopes be dashed. Fearing that they cannot sustain the emotional stress of another disappointment, they say, “We expect nothing. If progress occurs in our child, we’ll regard it as a miracle.”

These parents react to stress with a defeated attitude; they are afraid to keep trying. A professional person should remember that when the parents of a handicapped child sound a note of defeat they are probably trying to defend themselves against an overpowering fear. He should let them know that he knows how hard it is to be cheerful in the face of cruel disappointment. But he must turn the focus to the hopeful facts—the child’s strengths, his potential for improvement. He should offer services and let the parents know that a treatment center, a hospital school, a speech correctionist, or whatever is needed will share the burden of their fears and help them make appropriate plans for their child’s habilitation. In such cases, nothing succeeds like success. When such parents learn about their child’s potentialities and about the services available and see the child improving under appropriate treatment, the truth frees them of their fear of failure. But always the professional person must remember never to deviate from the truth, never to hold out unjustified hope.

Projection and Withdrawal

There is a fifth way in which parents tell professional persons that they need help. They say: “It was all the doctor’s fault. He was careless when the baby was born,” or “He should have known I was RH negative. The baby should have been transfused at birth,” or “It runs in my husband’s family.”

Some of these parents are factually right. Some are very wrong. But whatever the facts, they are reacting to stress by projecting blame for the cause of their predicament upon someone else. This relieves them of a sense of full responsibility for their own actions and attitudes, and so stands in the way of their planning a sound program for their child. Such parents need the kind of counseling which can help them express their feelings and free themselves of any sense of guilt they might have in regard to the child’s retardation.

There is yet another way in which parents of handicapped children tell professional persons that they need help. They simply do not say a word. They withdraw into their shells and do not talk about their child. They seem ashamed and sometimes even try to hide their imperfect child from the world to avoid embarrassment. Such parents are saying, in their silent way, that they cannot carry the weight of their shame about their inability to produce a normal child. They see their offspring as a product of their own imperfections. The child is a constant reminder of their inadequacy. Lest this inadequacy be paraded before the world, the parents keep themselves and their child from society and the child grows up without normal social experiences.

In its extreme forms, this type of withdrawal indicates deep-seated mental illness. In milder forms, the warm support of a professional person can do much to encourage such parents to make normal social contacts for themselves and their child. “Ego-supportive treatment” is the term social caseworkers use to describe the process which seems to be most helpful in relieving the anxieties of those who tend to withdraw. The parents are warmly approved for any positive steps they make toward regaining
contact with society. They gain confidence in their own worth from the knowledge that their doctors, nurses, and social workers like them, esteem them, and care about them as individuals. With more self-assurance, they begin to appreciate the worth of their child, however handicapped he may be. Having learned to relate in a new way to a person whose friendship offers them longed-for security, they find confidence to face the world.

Guilt Reactions

Some parents indicate when the strain of their burden is becoming too great by showing feelings of guilt in regard to the child's handicap. "I blame only myself," they say. "It is not the child's fault."

Some of these parents know why they feel guilty. They tell about not having secured proper medical care for a sick baby, or having allowed the child to go swimming during the polio season, or not having followed diet instructions during pregnancy, or having taken the child to a chiropractor instead of to a physician. Others are pervaded through their whole being with a sense of guilt, the source of which they cannot name. The guilty feeling, then, may stem from deeply buried fears of religious or sexual error, the child's handicap being regarded as a punishment from God for the parents' sins.

To care for a crippled child under a heavy burden of guilt is a heavy task. The guilt-laden parent needs immediate help. He needs counseling, education, services—everything that will help him regard the handicapping condition not as a punishment but as an accident. When his energies are no longer totally invested in inner conflict but free to make plans and find care for the child, then the whole family, including the handicapped child, stand to gain immeasurably.

Parental Attitudes

These are a few of the ways in which families of handicapped children give warning that they are faltering under their burden and ask for help. Let us hope that the ears of doctors, nurses, and social workers will be tuned to hear the true meaning of what is being said, and that their professional services will be broad enough and flexible enough to meet the needs. For if the families of handicapped children can be salvaged the children can probably be salvaged, too. But if the parents are lost, the cause is lost.
PARENTS OF CHILDREN WITH CONGENITAL AMPUTATION

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"IT DOESN'T SEEM to bother Tommy that he was born without a hand. He never mentions it."

As the social worker for the Child Amputee Prosthetics Project at the University of California, Los Angeles, it bothered me when I heard a mother make this statement. Social workers know that a child is concerned about being different from other children even though he may not express his feelings about this. At this point we have learned that the replacement of an arm or hand by a “good functioning” artificial one is not the sole answer to a child’s problem and that his ability to use the prosthesis will be largely conditioned by his parents’ attitudes.

In 1955 a grant to the university from the Federal Children’s Bureau assured the continuance and expansion of an interdisciplinary approach to prosthetics planning with child amputees and their families. Physicians, prosthetists, engineers, occupational and physical therapists, a psychologist, and a social worker came together as a team to learn what constituted a successful prosthetics experience—a well-made artificial limb (in this instance an arm), acceptable and useful to the patient.

The members of the disciplines within the project have sought to obtain information that would: (1) identify the various factors influencing prosthetics planning; (2) indicate methods of overcoming or modifying conditions that interfered with prosthesis acceptance; and (3) suggest the kind of program that could test results and be useful to other organizations working in the same or a similar field. This plan was in keeping with Dr. Bechtol’s suggestion that studies should be initiated to learn more about the full import of the loss of a limb to a patient and to his family. Preschool-age children with upper extremity amputations and children with upper extremity malformations were given preference for inclusion in the study because little was known about their problems and the methods of dealing with them. The caseload at present includes approximately 130 children from the State of California.

Established on an outpatient basis, the project requires at least one parent to accompany each child and encourages other family members to participate in all phases of the program. Hospitalization is arranged for a patient when a surgical procedure is necessary. Families who live near the project come from their own homes. Those who live too far away to go and come in a day are housed in a nearby motel, with some of the cost borne by the project if the branch of the State crippled children’s service in the family’s home community corroborates the need for such assistance.

We have attempted to make the program a family-oriented approach to prosthetics planning, on the theory that the more closely the family unit can be maintained and used as a support for the child the less likely is his difference to dominate his personality and so become detrimental to his development.

Because 80 percent of the children who came to the project had been born with their amputation, we found we were working with parents who questioned their adequacy to produce a complete child, and with
children who could not find a satisfactory answer to the question, "What happened?" We suspected that such parents could not accept a substitute mechanical arm for their child if they continued to hope they would wake up from a nightmare to find that he had two perfectly normal hands. Because children tend to adopt the attitudes of their parents we could learn from the parents the child's degree of readiness to accept an artificial arm and be trained in its use.

The project provides time in each case for parent and child orientation and for professional evaluation before a final decision is reached on whether or not to prescribe a prosthesis. Parents and patient are introduced to the project facilities, procedures, and personnel by the administrator. For some parents this is the first time they have seen or even heard about the split-hook type of terminal device. Its appearance offends those who have need for a lifelike hand and sends some of them scurrying for reasons why their child has no need for a prosthesis. Others who may feel the same immediate repugnance to the prosthesis are more realistic about their child's needs.

Following the introduction to the project, the pediatrician examines the patient and obtains the family's medical history. While revealing family history bothers some parents it seems to give most of them a feeling of having something important to contribute to the project as well as to receive from it.

The day after the pediatric examination the social worker interviews the parents and the psychologist tests the child. The occupational therapist also interviews the parents, explaining the nature of the training program at the project and pointing out the importance of follow-up through a therapist in their home community. The parents are told that regular visits to the project will be scheduled 3 or 4 times a year for checking the fit and mechanical operation of the prosthesis and introducing new activities to help the child achieve greater use of the device.

Later, at a staff conference, the question of prescribing a prosthesis is considered in the light of the findings of the team members. Physical therapy or surgical procedures may be recommended prior to prosthetic fitting. The psychosocial factors are considered and therapeutic measures appropriate to the family's needs recommended.

Our experience indicates that readiness for a prosthetics program begins when parents sense they are making a contribution to knowledge through relating family history and participating in social-work and psychological interviews, and when they reveal a capacity to envisage the future through acceptance of responsibility for providing continuity of training.

The Social Worker's Role

Social work in the Child Amputee Project is similar to social work in any medical setting, the casework relationship being the medium for study, diagnosis, and social-work treatment. Through interviews in which facts as well as feelings and attitudes are elicited, the social worker gains understanding of the meaning of illness or disability to the patient and his family and of the patient-family relationships. On the basis of a social diagnosis a plan is made for meeting the social and emotional needs of the patient, his family, and others important to them, in relation to the child's disability, so that the patient might achieve maximum use of the prosthesis prescribed.

Specifically the social worker in the Child Amputee Prosthetics Project:

1. Evaluates the family's readiness to accept the prosthetics program; helps with problems which may interfere with the successful use of a prosthesis; and assists the parents in obtaining help in meeting other needs of the child or of themselves.

2. Functions as a member of the prosthetics team, contributing such information as is appropriate to a better understanding of the patient and his family and helping the family members to understand their relationship to the project and to the various members of the team.

3. Acts on behalf of the family as liaison with other social agencies, public and private, in helping the family gain the greatest benefit from the prosthetics program through the use of other appropriate resources.

The social worker's research goal has been identification of important psychosocial factors indicating a family's readiness for a prosthetics program. Since social-work literature has little to offer in developing a study of parents of amputees, it was necessary to begin an exploratory basis. Before setting up a specific research project, recordings of social-work interviews with a selected number of parents of 20 child amputees were reviewed. These interviews had been carried on in an unstructured manner to allow parents to express concerns about themselves, the project, the child, and the prosthetics device. On the basis of the findings of this review a pilot study was developed. This was limited to
new requests for admission to the hospital and involved the parents of 25 congenital amputees.

It was our impression that a family's general life pattern, experiences at the time of the birth of the patient, quality of relationships both in and outside the family group, the nature of communication among the family members, and the parents' capacity to involve themselves in a social-work interview had a direct bearing on the patient's readiness to proceed with a treatment program. In order to test this hypothesis we sought to identify in our analysis the parents' attitudes toward their child and his amputation, their reasons for coming for treatment, and their ability to accept help for the child and themselves.

Study Results

Following are some of the preliminary findings based on interviews with the parents of the 25 children with congenital amputation.

Parents apply to the prosthetics project for a variety of reasons and with varying degrees of understanding of prosthetics and of themselves. They can be classified into three groups:

1. Parents who have sufficiently coped with the traumatic experience of having given birth to a child with an anomaly to be able to discuss the disability realistically; who realize and accept the child's need for both independence and dependence; and who have so freed themselves from self-blame that they can communicate understanding to the child and be helpful to him with his own problems of being different from other children.

2. Parents who are bewildered by the problems that are created by a child who is different; who continue to be troubled by a feeling of having caused the anomaly; who express concern about the reactions of strangers, friends, and relatives to the amputation and to a prosthesis; but who have the strength to look at their reactions and concerns and to make use of help.

3. Parents who have attempted to absorb the child in their own needs and conflicts; or who have isolated the child through avoidance of communication or insistence upon complete self-sufficiency; or who have withdrawn from close association with the family by illnesses or flights into activity; and who in defense deny the need for help.

The birth of a child with a congenital amputation does not necessarily cause the family to adopt a new pattern of behavior, but more often provides the critical incident that reveals the ways the members of the family handle stress individually and as a group. The stress is sudden and brought about by an event which is irrevocable and loaded with notions of misdeeds and punishment. "What did I do wrong?" is an almost universal question of mothers of congenitally deformed children.

Sound planning for a prosthesis must include recognition of the responses of the child's parents to his amputation for they tend to repeat similar responses in varying degrees when they see their child wearing a prosthesis.

The children of the parents described in the following three groups all have a short below-elbow type of amputation.

Parents in Group 1

Parents in this group have been able to handle their feelings and are not inclined to dwell in their discussion on their possible responsibility for the malformation, on possible concealment of the amputated side, or on a resolve to act differently toward this child because they "did not give him a hand." These parents ask for help with specific problems they recognize in the child and in themselves. They may, for instance, express worry about the effects on the patient's brother or sister of focusing so much attention on the patient. They are not so absorbed in their own needs that they cannot see the needs of others.

A mother in this group spoke of her immediate feeling of self-pity after her child Ricky was born. As she lay in her bed in the maternity ward she observed patients and visitors looking in at her as they passed down the corridor and was certain they were saying, "That is the mother of the baby without a hand." Later when she was permitted to walk around she discovered she was looking into each room as she went by. She thereupon realized what harm she could do to herself and her family by expecting people to point fingers at her. She spoke of the closeness she felt toward her husband before Ricky's birth, but added that from the moment he told her about the absence of a hand in the child their shared sorrow brought them still closer together and became a source of strength.

Ricky is not a compliant child, but a boy with energy and curiosity. His mother has learned when and how to loosen or tighten the reins and to distinguish those of his troubles which arise from being different and those which are typical of any little boy of 4. She told the social worker about incidents that had happened and how they were met. She also discussed the problems that Ricky might meet as his world expands. She knows her child is different because he has only one hand, but she has learned there are ways of keeping him from being overwhelmed by this difference.
Parents in Group 2

A majority of parents in the study were classified in the second group. These parents most often talked about problems which revealed inability to be consistent in discipline, overconcern about appearance, discomfort with the curiosity of outsiders, and difficulty in understanding their own feelings. Fitting and training were delayed for the children of some of these parents until the parents received help with their feelings and attitudes, so that they in turn could be more helpful to their children. So it was with Tommy, mentioned in the beginning of this article.

As Tommy's mother expanded on why she believed his lack of a hand did not seem to bother him, it became apparent that he was not the only uncommunicative member of the family. His mother and father had talked very little with each other about their feelings of being parents of a child born with an amputation. The mother expressed concern about the father, sensing his distress about Tommy's anomaly, but had not talked to him about it. On two occasions when she had seen Tommy crying after people had made remarks about his stump, she did not speak to him about these incidents and he never mentioned them to her.

The mother brought Tommy to the project when he was 10 because she thought he should learn to use a prosthesis at this age in preparation for the day when he would need to be employed. Tommy would not talk about his amputation or the need for a prosthesis.

Following a recommendation that prescription for a prosthesis be delayed, casework with the mother was instituted. The focus was on helping her to communicate feelings to the social worker and to find ways of establishing communication with her son. At the same time Tommy had an opportunity to observe other patients being trained in the use of a prosthesis. After a few months Tommy requested an artificial arm and talked with his mother about some of the reasons for his desire. During the period when he was being trained in the use of his prosthesis, his mother and the social worker discussed ways of preparing his school for his appearance with it. Through this experience the mother found additional ways of communicating to her son her understanding of some of his difficulties.

Prostheses were recommended for the children of some parents in Group 2 with the understanding that the parents would receive casework help while their child received training. This was true of 4-year-old Sally.

Interviews prior to prescription with each of Sally's parents had revealed they had difficulty in setting limits for her and were preoccupied with her appearance. Although the mother could not talk about the child's birth, the father had graphically described his reactions: "I had to keep telling myself, 'she is my child and I have to make it somehow or another.' " He also described how the mother cried when she came home with the baby and had looked in a closet at the dresses of Sally's older sister, remarking that Sally could never wear puffed sleeves, because everyone would see she had no hand.

During the training period, interviews with the father and mother revealed that their reactions to the prosthesis presented difficulties not too different from those experienced with the amputation itself. Frequently the mother asked if Sally should wear her prosthesis to this or that place, reflecting her concern about appearance. Although the parents said that their two daughters were handled in similar ways, they indicated that they felt guilty when Sally had to be punished, a fact which the child exploited.

The occupational therapist and social worker worked out a plan together to allow the mother to be present during the latter part of each training period only. The therapist was firm in her training approach with Sally. This plan worked effectively with Sally and although exclusion from the training room aroused the mother's anxiety, it helped her focus more quickly on her problem.

The mother continues to be concerned about appearance but has become less anxious about permitting Sally to make good use of the training program and about disciplining her. This latter gain has also helped the older sister's behavior.

The parents in the second group seem to believe they should not give vent to their feelings because they have been told so many times they should be grateful that the disability is no greater than it is. A mother of a 15-year-old boy expressed her reaction to the social worker. "For the first time since he was born, I feel I can let go and talk about me."

The families in this group have one important characteristic—at least one parent has the capacity to look at his reactions and make use of help.

Parents in Group 3

The parents of the third group pose problems in relation to themselves, the patient, and the project. Most of them have come to the project because they had been told they should do this to benefit their child. The need to assuage their guilt is so great they accept the referral.

The personality difficulties of many of these parents are so deep seated as to interfere with the effectiveness of working with the child. Some have so absorbed the child he cannot function independently of the parent. Some ward off professional help through a consistent depreciation of the services. Some interrupt or completely cancel their association with the project on the basis of their own ill health or other excuses.

These parents have so internalized their problem they cannot tolerate a program that is designed to deal realistically with the amputation. Those who have remained in the project have taxed the energies and skills of all the personnel.

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Danny's mother explained in the initial review with the social worker that she experienced no shock when the doctor told her Danny had no hand. She told of seeing this condition in a vision before he was born and said that she knew then that she would "be his other arm." She carried out her resolve to such an extent that at the age of 7 Danny did not share in any of the household tasks expected of his four older brothers and sisters and had been allowed to sleep with her almost every night since infancy. She described her anger when anyone brought up the subject of Danny's arm.

At 7 Danny acted like a 3-year-old. Psychological testing revealed that he was emotionally but not mentally retarded.

The team's decision to prescribe a prosthesis for Danny was made with full knowledge that its proper use might be impeded by the severe emotional problems in parents and child, and that these would have to be analyzed in an effort to find ways of dealing with them.

Attempts to involve the mother in casework interviews each time Danny came to the project for training bore little fruit until she expressed some concern about her son's continued desire to sleep with her. The social worker used this bit of anxiety to stimulate in her a desire to understand more about her child. When Danny showed signs of failing in school, the mother's anxieties became so acute that she was willing to accept a psychiatric referral. This was a full year after the prescription of the prosthesis. Until then Danny had made little use of the prosthesis although he and his mother had kept all their appointments at the project. Some progress is now evident, but the problem within the mother is of such long duration and Danny's emotional development so retarded that good prosthetic use cannot be achieved until the emotional disturbances have been ameliorated.

In dealing with parents in Group 3, the prosthetics project is faced with a major therapeutic problem. Recognition by a professional person that a patient needs psychiatric care does not mean the patient can accept this. Thus a few parents have refused to continue with the program and have terminated their contact during the orientation-evaluation period.

When this happens the project explains the fact to the State crippled children's service worker in the family's home community who may initiate there whatever services may be available, and whatever devices may be possible in helping the family move toward an acceptance of professional help. Our project is too new for us to be able to tell how many and how soon such parents may return to us for help. Some may reject any further contact with the agency that referred them to such a disturbing experience.

The children of some of these parents have had other physical conditions requiring treatment. One parent is receiving casework services in a cleft-palate program. In some cases the child's behavior at school has prompted the school to initiate help.

Discussion

Conceivably the parents in Group 2 would become more like those in Group 1 after, or if, they have been able to achieve greater understanding of the cause of their reactions to their child's anomaly. Some parents of Group 3 may be able to effect some change within themselves, but the process of doing this will undoubtedly require a long time and in most cases the changes will be small.

The social worker's determination of the families' readiness to enter the prosthetics project helps the occupational therapist to plan programs differentially to meet the needs of individual children. Parents who have been freed from involvement with their own problems can be expected to grasp the intent of a training program and follow through with it at home. Parents who are still struggling with the question of whether the child should wear the prosthesis outside the home or at all are not able to turn their attention to the function of a prosthesis.

Evaluation of the potential of the patient and parents for prosthesis acceptance becomes critical when viewed in the light of the limited community resources for this type of care and the costs of such care. It is unwise to expend $200 to $500 for a prosthesis when the family is not ready to accept the need for it. An initial failure with a prosthesis may make it even more difficult, if not impossible, for parents and child to achieve motivation toward prosthesis acceptance at a later date.

The Child Amputee Prosthetics Project is evaluating the methods that determine readiness and the factors within the patient and family that may contraindicate an immediate prosthetics program for the patient. This is but one of the many facets of the program and of the social worker's part in it. Few projects as extensive and intensive as this one are available throughout the country. However, if our findings on readiness are valid, projects of a more limited nature, supplemented by existing services within communities, may be able to use them in providing sound prosthetics programs.

Further research is necessary to find ways of helping many child amputees and their parents to a successful acceptance of prosthesis.

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THE FAMILY APPROACH TO FEEDING 
CHRONICALLY ILL CHILDREN

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It has often been observed that tasks are more interesting, and even easier, when several are done at one time. Perhaps this is one reason why the family approach to feeding chronically ill children is so gratifying, involving as it does at least three simultaneous challenges: the feeding needs of childhood; the demands of family feeding; and the special feeding requirements imposed by the chronic disorder. The way these simultaneous challenges are met may spare the child needless damage from the disease, and equally important, may salvage the benefits that sound feeding practices can bring to him and to his whole family.

There are innumerable chronic diseases which beset childhood. They are of infinite variety and may involve any or all systems of the body. Some involve the digestive tract or food utilization. Some, such as those accompanied by fevers or requiring surgery, create increased food needs. Some other conditions have little to do with food per se, but can so preoccupy a family that proper feeding gets overlooked, as may immunizations and other forms of general child care. One pediatrician, for example, was struck with this when called to attend a group of blind preschool children. He said that after the initial shock of being confronted by so many small blind children, the next impact was the realization that the majority of them presented severe nutritional problems. He felt that the parents had been so overwhelmed with the visual problems that they had neglected the usual concerns about childhood feeding.

Common Denominators

Although chronic conditions are numerous and varied, there are common denominators which enable us to get our professional bearings and help children and their families. These are the growth and development tasks of childhood; for, sick or well, children struggle along in an attempt to accomplish these indispensable tasks. They enter into a family approach to the feeding of a child with chronic illness by raising several questions:

1. At this particular child’s age, what are the usual nutritional demands of growth and development? What does food and the feeding process need to offer him for his physical growth? for his physical, social, and emotional development?

2. Does the chronic condition from which the child suffers increase, or otherwise alter normal needs: Does it pose obstacles in meeting them? nausea? pain? fatigue? loss of appetite from drugs? or does it raise other impediments?

3. How can the growth and development needs be reconciled with the demands of the illness?

4. How can the resultant dietary plan for the child be brought into harmony with sound feeding practices for the whole family, so that insofar as possible it can strengthen and unite the entire family rather
than weaken family feeding and family unity as it does when the focus is on one member of the group and includes only dietary treatment.

These basic considerations are worth considering even in a short-term illness. They become imperative in long-term disability. The differences in planning for a short illness and planning for a long period of disability are like the differences in planning for a short storm and planning for a poor climate. Long-term stresses of climate or of chronic disorders cannot be met with makeshift temporary approaches that might suffice for a short emergency. Situations of lasting stress require the best provisions our minds can contrive. In respect to feeding, this means that in chronic disability, the closer the feeding practices can come to meeting the needs of childhood, and of families, the sounder those practices are likely to be.

In feeding children, we usually get our bearings by thinking of “ages and stages.” For example, from the physical standpoint we recognize clear distinctions between the infant, the preschool child, the elementary-school child, and the adolescent.

In infancy we see a characteristically rapid growth, very early advanced motor controls of lips, mouth, and throat, and gradual establishment of motor mastery in other parts of the body. Then in the preschool period we see almost constant motor activity, and slower, but still-continuing growth.

In the little school child we see continued strenuous physical activity, and an increase in stockiness of build, though a lessened linear growth. The child now faces the onslaughts of the common communicable diseases and the physical demands of preparing for the growth spurts of adolescence.

In regard to adolescents we must be aware of additional growth needs and of possible problems of obesity and acne. In addition, persons who fully contemplate nutritional needs will always bear in mind the thought that the nutritional needs of adolescent girls must be regarded as “pre-prenatal.”

While all these developments are going on physically, mental development is being influenced too, especially in infancy and early childhood, for feeding is a learning experience. The mouth is a sensory organ of prime importance. A physician acquaints himself with his patient through the classical approaches of inspection, palpation, auscultation, and percussion. The child acquaints himself with his environment in the same way, but he uses his mouth to inspect, to palpate (that is, to feel), auscultate (listen), and to percuss (rap and bite), and to get the general knowledge of the world about him.

Feeding needs to be conducted in a way that lets these tasks be accomplished. The child needs opportunity to chew goodness from meat, even if that means that for a few weeks he does not want to swallow what remains after he has extracted the flavor. He needs opportunity to learn to make new uses of his newly acquired eye-hand-mouth techniques, using them now not only to locate things and to put them in his mouth, but also to retrieve strange-feeling or strange-tasting items with his fingers, and to eye them studiously. He also needs a chance to learn to cope with slippery foods, and to become acquainted with the pleasures and annoyances of variations in sweetness, sourness, and intensity of flavors.

Emotional considerations are of paramount importance in family feeding. Children grow physically according to general patterns, passing through the same stages in the same order, but not necessarily at the same rate. Social and emotional growth behave similarly, having general patterns but high degrees of individualization. These emotional “ages and stages” are closely related to feeding needs.

**Feeding Needs**

_The infant’s task_ is to work toward security and to acquire a sense of trust. Through satisfaction of hunger demands, he gets a feeling of the world as a dependable place, and in the course of the feeding process he and the feeder delight each other and launch what is for him the first of a lifetime of interpersonal relationships.

Infant feeding works best when it is close to another human being. Bottle propping is to be deplored, not only because of the hazards of aspiration pneumonia, but because the baby needs to feast not only on the bottle’s contents but also on human companionship—especially the mother’s. Erich Fromm speaks of the difference between a woman who can give her children milk and one who can give them “milk and honey.” The “honey” part requires the closeness of human companionship, which is the beginning of the child’s closeness with the family.

_The preschool child_ strives for mastery of his body and himself and for some degree of independence. He works almost incessantly during his waking hours—climbing, running, pulling, tugging, shoving, and investigating. Just as these large muscle pursuits of autonomy require calories and good food-stuffs, they also require imagination, independence,
and initiative in feeding. Since children are highly imitative, adult and peer examples are important. Children are quick to follow good (or bad) examples at the family table. This is true not just of etiquette, but of eating patterns.

Readiness and ritual need to be considered, too. Young children have a readiness to experiment which they may not have later, yet at the same time they show a love of ritual which parents can utilize to reinforce good feeding practices and to strengthen family ties. The children can be fed at least part of the time with the family. At this age feeding practices for normal children can be brought so close to family feeding that the child's nutritional needs can be regarded as the core of a family-meal plan, which with slight variations can be made interesting and palatable for the entire family. Child feeding can thus serve as the beginning of lasting improvements in total family diet. Well-planned meals for a child at this crucial period can establish good dietary patterns for the family, and for the child for his whole lifetime.

*The adolescent* usually tries to loosen old ties with childhood and home, and in so doing clings tightly to his own age group and turns to young adult figures that he can admire and copy. Young people in this age group need to be able to conform as much as possible and to be, within reasonable limits, in charge of their own dietary regimes. They are almost constitutionally obliged to break rules laid down by parents and other authority figures so that this becomes an extraordinarily dangerous period for such groups as the rigidly dieted diabetic.

**Family Approaches**

In dealing with chronic illness, we must think of the special dietary requirements for the particular chronically ill child at his particular age, and then consider to what extent those requirements can be derived from family care that would be suitable for the whole family. Additions, deletions, and modifications may then have to be made for the child—or perhaps for the rest of the family—but the part of the food which they can all share needs to be clearly established, for that becomes the foundation on which salutary influences can be built.

During his school years a child has a great need for a sense of accomplishment. He is at an age when it is normal to try to keep up with other children, and a sense of failure in this may be reflected in eating problems—overeating for consolation, or loss of appetite out of sheer discouragement. In addition, of course, physical inadequacies stemming from poor nutrition may actually be factors predisposing to real personal failures.

Anything we do to increase a valid sense of personal worth in a child may help him to move on to further maturity. This has important implications for our dealings with a child whose activities or diet must be curtailed because of chronic disease. It makes a great difference to a child whether treatment makes him feel cherished or chastised.

One family may deal with dietary prescriptions in such a way that their child recognizes the dietary modifications as a form of cherishing and care on his behalf, enforced because his family love him deeply. Another family may administer the very same prescription in such a manner that their child feels punished and deprived.

These contrasts are often seen in orthopedic clinics where efforts are made to hold weight down. Some families and some health personnel present diet restrictions in a way that make children feel ashamed and unhappy. They may even alienate children from the clinic. Such unfortunate approaches can be a frequent cause of clinic absenteeism. Appointments may be broken because of embarrassment at weight gain and dread of scoldings, humiliations, or derision.

Punitive pressures in diet restriction are resented, but so are loose generalizations. Some orthopedic clinics have found it important in obesity not to just tell children to "be careful" with their diet but to get right down to work with them and their families in a specific approach to the whole subject of the child's and family's diet.

Chronic illness prescriptions for adolescents need to be as unembarrassing as possible. When adult guidance and supervision in regard to them are necessary they might better come from someone outside the home, someone the adolescent does not need to defy, but may even wish to emulate. An adolescent may be able to derive "peer help" from others of his own age group who happen to be on similar restrictions.

**Feeding and Sociability**

Feeding and sociability go together, but dangers ensue when food is used as a substitute for comforting companionship. If there are deficits in the social aspects of living, food may be used to make up the difference. For example, in infancy there is
noticeable dawdling over feeding by children who are put down too promptly at the end of the feeding instead of having a little postprandial cuddling and sociability. In contrast, the preschool child’s sociability needs may be such that he climbs down from the table and runs away to join his friends without finishing his meal.

School children and adolescents may eat for comfort and companionship if sociability needs are not met elsewhere. Some families tend to use the house chiefly as a dressing, sleeping, and feeding center, rather than as a center for being together. In such establishments children of a certain temperament may prolong and extend their feeding time—and food intake—in an effort to eke out and prolong the available companionship.

If feeding sociability has to be curtailed for a chronically ill child it is necessary to consider, along with other dietary planning, how some other tightly knit form of family sociability might be encouraged which would include him. For example, the family might gather around the sick child for such activities as playing games, designing Christmas cards, planning a vacation trip, or another shared occupation and thus achieve the “togetherness” normally found at the dinner table.

Family feeding even in health seems to work best when related closely to the cultural patterns of the family and their congenial associates. For example, in certain groups cottage cheese and sour cream are greatly enjoyed items, whereas in other groups they are almost offensive. The closer the chronic-disease diet—or any childhood diet for that matter—can fit into the enjoyed cultural practices of the family, the more likely that diet is to become a lasting pattern of eating and not just a therapeutic gymnastic carried on during a health crisis.

Closeness to cultural patterns seems to help, too, in making it possible for the child to snuggle up against the supports of family ritual, an experience pleasing to most children, and particularly salutary to those whose illness and its prescriptions tend to keep them from being completely integrated into the family group.

Chronic illness strains the family purse, which is seldom very full anyway in families with young children. Food is usually one of the first items on which a family tries to curtail expenses, as other big expenses—rent or housing costs, and medical care—are often difficult or impossible to alter. Many families show more courage than competence in these efforts. There are few ways in which families can accomplish more good in the feeding of a child with chronic illness than through the help of a nutritionist collaborating with a social worker or budget counselor.

In Summary

In childhood there are innumerable varieties of chronic conditions requiring dietary care. Sometimes all that is needed is a simple increase in the wholesome fare suitable for any child. Other conditions demand all manner of dietary modifications, restrictions, or special inclusions. But whatever the chronic disease and whatever its special prescription, there are also other considerations to be met. These include the needs of normal growth and development involving the child in relation to his whole family.

Widening the angle of dietary vision to include the whole family is the basic and most logical way to feed a child. This not only helps the chronically ill child but may benefit the entire family.

THE DENTAL PROBLEMS
OF HANDICAPPED CHILDREN

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IT IS SAID we face the world with our face. Facial malformations and bad teeth, suffered by many handicapped persons because of poor oral habits and care, are a potent factor in personality maladjustment and withdrawal from normal social contacts. Employment agencies which try to place the handicapped in useful jobs are conscious of the fact that, while some crippling conditions are overlooked by employers, facial deformities are a tremendous handicap for the employee to overcome in his adjustment with other employees. Judges of juvenile courts have noted that young persons who cannot find social acceptance because of physical deformity of the face often turn to juvenile delinquency.¹

Dental treatment for the handicapped child in many communities is an almost totally unsolved problem, and dental health programs for handicapped children are alarmingly backward.² While numerous social agencies, public and voluntary, provide training facilities for the handicapped, very few, except in some large cities, concern themselves with or allot funds for a complete dental program to maintain and restore the teeth and the tissues of the mouth.

The little that is done is usually on a limited volunteer basis by dentists, their local societies, some service clubs, and locally administered trust funds for welfare work. Dental programs sponsored by social agencies too often provide nothing more than emergency relief of pain by indiscriminate extraction of teeth.

Examinations of various groups of handicapped children throughout the country have disclosed the fact that they suffer from a great variety of untreated dental disturbances: incoordination of facial and masticating muscles; food impactions around and between the teeth; congenital defects of the teeth and tissues; spontaneous bruxism (grinding of the teeth); mouth breathing; alterations in the gingival blood supply; excessive caries; malocclusion; gingival changes due to drugs; abnormal tongue pressure effects; nutritional defects which affect the gums and teeth; inflammatory changes due to chronic abscesses; broken teeth, poorly calcified and discolored teeth; drifting of the teeth; crowding and other position abnormalities; cheek or lip biting; and many other defects. These have been aggravated by lack of understanding of the meaning of dental hygiene, lack of a routine program of teeth cleaning, absence of functional stimulus of the gum tissues.

The presence of these conditions in the handicapped child depends entirely upon the amount of routine care given the child. Studies have indicated that when the handicapped child is given proper dental care the percentages of abnormalities, and their DMF index (decayed, missing, filled teeth index) are similar to those for normal average children.³ ⁴ ⁵ ⁶

These studies show that when average dental attention is not available to children with cerebral palsy, a large percentage of them become dental cripples by the time they reach their teens, losing as much as 20 percent of all their permanent teeth by the age of 12. That means that if the same rate of loss continues through their teens, the mouth is endentulous by the time the individual is twenty-one. In these children the muscles of mastication—of the throat and tongue—are abnormal and bruxism or teeth grinding is frequently present; moreover, such children are prone to falls. Therefore, many of them cannot wear or tolerate removable appliances or dentures. One study found
Evident of bruxism in 80 percent of the cerebral-palsied children studied. The bruxism causes ordinary fillings to break out easily and prevents construction of many types of dental restorations.

A high percentage of caries in anterior teeth is found in handicapped children, with many teeth showing hypoplasia, or defects in formation. Nearly all of these defects are accompanied by some degree of inflammation of the gum tissues which eventually leads to puffy bleeding gums and loosening of the teeth. Thick hypertrophic gum tissues are characteristically found in epileptic children who take dilantin regularly as an anticonvulsant. Broken and chipped anterior teeth are common among children who fall frequently because of epilepsy, cerebral palsy, or the effort to learn to use braces or crutches.

**Oral Hygiene**

Lack of good oral hygiene undoubtedly contributes to the high incidence of dental caries in many handicapped children, especially those with cerebral palsy. But this lack of oral hygiene cannot be laid simply to neglect. Even those who are able to dress and feed themselves are not able to acquire real skill in daily hygiene procedures until they have undergone a considerable amount of training. Ordinary tooth brushing techniques are often impossible for them to master without the use of special brushes or specially constructed handles on the brushes. Mechanical tooth brushes are of value where arm motions are limited. Parents may try to do a good job of teeth cleaning for these children, but they also need special training.

Food intake may fulfill all requirements for proteins, carbohydrates, fats, minerals, vitamins, with normal caloric content, but if the food is soft, semi-liquid, and sticky, food particles pack around the teeth, and it becomes cariogenic. This type of food is fed to many cerebral-palsied children because it is easiest for parent and child to manage. Training clinics for these children should give more attention to helping children learn how to use specially constructed utensils and to master techniques of mastication so that they can attain a more fibrous, self-cleansing, dentally acceptable diet.

Children with neuromuscular difficulties are especially handicapped in their ability to masticate food for they have facial and masticatory muscles which do not respond normally. Often the resulting movements are involuntary and jerky. There may be semirigidity, or, on the other hand, a slackness in muscle tone. Since the shape of the dental ridge that holds the teeth is influenced to some extent by muscle use and function during the growth period, chewing methods, associated habits such as finger sucking and mouth breathing, tonicity of lips, size and activity of tongue, all exert a molding influence. As a result, variation in the dentofacial pattern is in direct ratio to the degree of physical handicap or deformity.

Many children with neuromuscular handicaps cannot chew because excessive extractions have resulted in drift of the remaining teeth. Open bite, or inability to articulate any anterior teeth, is common among such children. Their teeth may also be pushed out of position because of tongue habits, an extra large tongue, or overactivity of the tongue. If these conditions are not corrected insofar as possible during childhood and the teenage period, the mouth becomes “socially unacceptable” in adulthood.

Effective dental care primarily depends upon two things: (1) prevention of the development of dental caries, occlusal deformities, and oral diseases; (2) prompt early correction of defects, with adequate restorations or treatment as indicated. Preventive measures and training procedures can be effective if carried out in a continuous process by skilled individuals. However, trained personnel to form a team of dentists and dental auxiliary personnel such as hygienists are in short supply, and few are willing or able to carry out on a purely altruistic basis the continuous kind of program needed for each child. Social agencies should be made aware of the value of expending funds for adequate dental facilities and treatment.

**Costs and Shortages**

In comparison with many forms of medical treatment complete dental treatment is not expensive, though it often seems expensive when estimates are based on a single restoration rather than on total care. The Bureau of Dentistry, New York City Department of Health, has reported that, with administration included, it cost about $500,000 to give complete dental rehabilitation services to 2,662 children last year, or approximately $190 per child.

Clinical facilities for this type of dental care are almost completely lacking in small communities and small community hospitals. This is in part due to the shortage of dentists in general. A report published in 1959 by the Public Health Service, U.S. Department of Health, Education, and Welfare, shows a continuing decline in the ratio of dentists to
population, and warns that unless efforts are made immediately to correct it there will be only 50 dentists per 100,000 persons in 1975 compared with 57 in 1958 and 62 in 1940. A group of consultants to the Surgeon General has recommended a billion-dollar program to expand and extend medical and dental schools. They included in their recommendations the formation of 22 new dental schools.

In addition to an increase in the number of dentists, efforts are needed for increasing the ability of dentists to deal with handicapped children. Some moves are already being made in this direction, though more are needed. For example, the Office of Vocational Rehabilitation, U.S. Department of Health, Education, and Welfare, during the past 2 years has been sponsoring institutes for graduate dentists at various universities in the care of handicapped children and adults and persons with chronic disease. The New York University College of Dentistry is now offering two new graduate fellowships in dental care for the chronically ill and handicapped, with a master of science degree for a year's study.

An important part of building adequate care for handicapped children is developing a program for the child who cannot because of his physical defects give the dental-chair cooperation needed and also for the child with behavior difficulties due to neurological involvement or mental deficiency. In many of these cases the only way restorative or minor surgical work can be done is under a general anesthesia in a hospital or similar facility. Such time-consuming restorative work under these conditions requires special equipment and a special team of workers. The usual hospital operating room is not entirely suitable because it lacks dental units and the instruments needed in this kind of work, and because the necessity of room sterility requires certain procedures hampering dental work.

The homebound child also presents special difficulties. While the child might be transported to a hospital in an ambulance or through some other arrangement, this is not usually economically practical. Portable equipment which can be set up in the home is now under construction by several of the dental equipment firms. This type of equipment has been already demonstrated at several of the recent dental conventions and has met with surprising interest. When produced, it will solve a dental problem both for dentists who wish to use it in homes and for small community hospitals. Many such hospitals are financially unable to purchase a full permanent room of dental equipment which will be used only for the occasional patient and remain idle for several hours or days at a time.

There are estimated to be 750,000 cerebrally or neurologically damaged children and adults in the United States, one-third of whom are under 21. If we add to these the thousands who are blind or have multiple sclerosis, muscular dystrophy, epilepsy, or rheumatic fever, or are slightly deficient mentally, and those afflicted with any of the many other handicapping conditions, the total is staggering, running into the millions.

The majority of these children can be trained to have a productive life by being taught to use what they have. Any complete rehabilitation program must include consideration of dental welfare. For a child to have to live with his handicaps is enough of an emotional stress without having the additional burden of preventable and correctable disfiguring dental destruction, crooked teeth, pain and chronic debilitating infection from infected teeth.

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6 ———: The dental problem of the spastic or the athetoid child. American Journal of Orthodontics, February 1951.
Mothers, fathers, and siblings are all a part of a family-oriented approach in . . .

A NURSERY SCHOOL FOR CEREBRAL PALSYED CHILDREN

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THOSE WHO have worked with the handicapped know what a heavy emotional impact the birth and rearing of a handicapped child has upon a family. This impact is especially strong when the child has cerebral palsy, a condition which is frequently accompanied by visual, oral, and mental as well as motor handicaps.

Families with such children are often confused in their understanding of their child’s condition and in their own feelings about the child. They are under pressures of anxiety, hostility, and feelings of guilt; are often drained financially by their efforts to secure the necessary medical care, therapy, education, and other special services; and drained physically by the enormous amounts of attention required by the child.

While special schools and classes are available in many places to the handicapped child of school age, for younger children, whose parents are often panic-stricken by their problems, help is meager and fragmentary.

In California, the United Cerebral Palsy Association of San Mateo County has developed a program designed to meet the needs of the young cerebral palsied child and to relieve his parents of some of the intolerable pressures upon them. The whole family—father, mother, cerebral palsied child, and his sisters and brothers—has been drawn into the efforts of a cooperative nursery school for very young cerebral palsied children.

The parents of the children who attend the nursery are required to participate in the school’s program and attend parent education classes. Closely correlated with this educational and therapeutic program for the children are psychological services which provide sustained individual psychotherapy and group psychotherapy for the mothers. This combination of all services and the close working association of parents and staff gives the program its potential by involving the parents more deeply than can be done through the provision of occasional consultation or participation on a volunteer basis. The general feeling in this school is that the parents are proprietors and auxiliary staff.

The Beginnings

Five years ago, after consideration of the needs of the families with cerebral palsied children in the community, the association secured a psychiatric social worker as a first step toward meeting these needs. This worker, called a family counselor, found that her service was eagerly received by a number of families, but that others—especially those whose handicapped children were very young—first needed practical help in securing immediate treatment for their children and developing greater understanding of their children’s potentials. While the local public school could, and often did, take children as young as 3 years of age into its nursery kindergarten, the school had to reject some such children as not sufficiently mature physically and emotionally for a public school program. Even 3 years
It is rather late for beginning much of the therapy cerebral palsied children need. If no service is offered before then the parents have to struggle alone to help the child in his early crucial years.

For some time cooperative or parent-participation nursery schools for normal children had been popular throughout California, and the association decided that such a program could be adapted to the needs of the cerebral palsied. In such a program very young children could receive therapy and social experiences in a relaxed setting. In participating in the program the parents could obtain a fuller understanding of the therapy, while some of their own needs could be met through the educational program of the nursery school and the individual and group psychotherapy offered by the family counselor.

The association considered some possible drawbacks to this program. These generally were expressed as: participating in the program would further concentrate the parent's attention upon the handicapped child who was already receiving more attention than the other children in the family; the presence and emotional attitudes of the parents might interfere with therapy; the parents could not be of much help in a treatment regime requiring a great deal of training and skill. Recognizing these possible drawbacks, the association nevertheless decided that some of them could be overcome or eliminated and that others would be negligible as compared with the values received.

Therefore, in 1956 the San Mateo Cerebral Palsy Nursery School was established, under the joint sponsorship of the United Cerebral Palsy Association of San Mateo County and the College of San Mateo. Fees paid by the parents were included in the financial support. The college was chiefly concerned with the parent education aspects and paid most of the teacher's salary for the first 3 years. The college then withdrew from the program and the association assumed the full support. The program has continued for 4 years and is still in operation.

The Program

At first cerebral palsied children from 18 months to 5 years of age were accepted, with physical and mental handicaps ranging from mild to extremely severe. Later, mothers were encouraged to bring even younger children so that they could receive help with feeding and other problems and the therapists could begin some of the treatment the children needed for their early development.

The nursery school usually has from 10 to 14 handicapped children enrolled. Most of them come to school three mornings a week, from 9 a.m. to 11:30 a.m., though a few of the younger children come only once a week. Mothers are required to participate one morning a week. They bring their children to school from homes scattered all over the county, sometimes forming car pools to do so.

The school staff consists of a nursery school director or teacher, an orthopedist as medical consultant, a physical therapist, an occupational therapist, and a speech therapist. These staff members have available to them constantly through weekly staff meetings and informal conferences the consultation of the psychiatric social worker and on occasion, necessary, of a psychiatrist. Psychological testing is readily available from a number of sources. The psychiatric social worker also works with members of the larger community in efforts to establish needed resources.

The nursery school program is patterned very closely on the programs of most nursery schools, especially parent-participation schools. Regular nursery school activities and procedures are followed as far as possible with special emphasis upon the encouragement of self-help and on activities which fit in with the therapies needed by the individual child. Each child receives individual therapy sessions regularly each week with the therapists appropriate for his particular handicaps.

Each mother (in one family the father) has participated in the school program one morning a week. This means that each morning one third of the mothers are participating. The duties of the mothers are similar to those of mothers in other cooperative nursery schools in supervising and guiding the children's activities. In addition, they help feed, dress, and toilet the children, many of whom are very handicapped. Frequently the mothers help the therapists or observe the therapy to better understand the purposes and techniques. They occasionally make written observations on their own or other children.

The mothers also attend a parent education class. These evening sessions, conducted by the nursery school teacher, concentrate on child behavior and development in general as well as on subjects related to cerebral palsy, and on the nursery school program, its philosophies, therapies, and plans. Mothers discuss their problems concerning their normal as well as their handicapped children. Speakers and films are often used to focus discussion. Mothers are encouraged to ask "why", to feel free to disagree, and to take part in improvement of service, and generally
are treated as important collaborators. During the first 3 years this class was held one evening a week. Following the withdrawal of the college's support, the association continued this class on a monthly basis. However, parents and staff agree that once a month is not sufficient to meet the parents' needs.

The fathers usually meet once a month for similar discussions. Fathers also occasionally observe the morning nursery school sessions. Some help with building equipment and repairs. Occasionally the school is conducted on a Saturday so that as many of the fathers as possible can observe the activities and therapy.

The physical, occupational, and speech therapists work with the children under the direction of the nursery school medical consultant, an orthopedist. A monthly clinic is held so that the progress of the children can be evaluated periodically and parents' questions answered. In the morning sessions, the therapists enlist the assistance of the mothers, instructing them in how to work with the children to achieve self-help in feeding, dressing, and toileting. They also teach the mothers some therapy techniques that can be applied at home and that can help them to understand better the purposes of the formal therapy sessions.

Normal Siblings

Some misconceptions held by parents were revealed early in this program. The mothers of handicapped children, particularly those who have no other children, frequently attribute all their child's problems and modes of behavior to the cerebral palsy, even behavior common among normal children. These misconceptions were corrected when normal children were also included in the program. Siblings of the handicapped children are now included if they are of nursery school age. Mothers can observe normal child behavior and, by comparing it with the behavior of the handicapped, can see more easily which behavior pattern in their child can be attributed largely to the handicap and which to the normal emotional and physical reactions of a child.

Admitting these normal siblings to the nursery school also has other values. The normal children stimulate the handicapped children to greater achievement and, by giving them an opportunity to associate with other than handicapped children, help them to receive a less warped view of the world. They also make it possible for a mother of both a normal and a handicapped child to bring them both with her to the nursery school and so to solve the problem of being away from the normal child on her day at the nursery.

At first a few people objected to the inclusion of normal siblings in the program, contending that the normal children might tend to copy the handicapped children and thus become retarded in their own development. We have found a tendency to copy occurring only when the child first comes to the nursery school and then in only a minor way. If the handicapped child has been receiving a great deal of attention at home to the neglect of the normal child, the latter tends to become more dependent and to copy the handicapped child in some ways. However, as the normal child gains more attention and the parents receive a more objective and realistic view of the needs of both the handicapped child and his siblings within the family, this tendency disappears.

As the program progressed, it was obvious to both staff and parents that, valuable as it was, it had some limitations. These stemmed from the fact that the program was not providing for the expression of the deeper feelings of guilt, resentment, and frustration which so often interfere with parent-child relationships. Therefore the psychiatric social worker described the values of group psychotherapy to the mothers in one of their discussion sessions with the teacher. They expressed interest in this type of help, and all of the mothers voluntarily decided to participate in a 1-hour group therapy session once a week, with the psychiatric social worker as leader.

Nearly all of the mothers have participated in these sessions, which are held while the children are involved in nursery school activities. In them they discuss freely their deeper feelings and problems, and receive help and support both from each other and from the professional worker. Shortly after these sessions were underway, the professional worker, the nursery school staff, the medical consultant, and the parents themselves began to observe considerable improvement in the parents' attitudes toward their children. More parents were motivated to seek individual help from the psychiatric social worker.

Observable Results

One of the first results observed in the program was the almost immediate lessening of some of the mothers' tension. Many mothers remarked that they felt frighteningly alone with their problem until they entered the nursery school program, but that after
they began participating in the program and became friends with the parents of other handicapped children, the sharing of their common problem made them feel less isolated. Mothers have also made it clear that, as in all cooperative nursery schools, the knowledge and experience they gain from supervising and observing a number of small children is of value to them as they work with their own children and that it also helps them feel more confident in continuing the self-help activities and therapy at home.

The nursery school's medical consultant has observed that the parents who have been in the program for about 2 years have come to a greater acceptance of medical evaluation and a more realistic view of their child's handicap and potential than other parents with similar problems. He has stated that the nursery school parents seem to have less resentment, misunderstanding, and destructive attitudes than other parents of handicapped children he has known. Similarly, teachers in the public school who by now have received some of the children once in the nursery school have said that their parents seem to have a more objective view of themselves and their children than parents in similar circumstances whose children have not attended the nursery school.

The nursery school staff as a whole has observed much growth on the part of both parents and children. The children have developed socially, emotionally, and physically. Moreover, they have probably suffered less emotional trauma from the various types of therapy they have undergone than they might have if their parents had not been so obviously involved in the nursery school program.

The staff has found that the presence and emotional attitudes of parents have not handicapped the therapists' work, although, of course, some individual problems have occurred. When parental attitudes have been disturbing, the parents have had an opportunity to work out the emotions behind them in the group psychotherapy or with the the psychiatric social worker or nursery school teacher. The therapists and nursery school teacher have been able to gear each mother's participation to her understanding and ability, and to help each parent appreciate the fact that some things are beyond her capacity.

Although some persons had feared that the mother's concentration on the handicapped child in the nursery school would cause her to neglect the other children in the family, this did not seem to happen. When mothers were able to relax more in relation to their handicapped child because of the diminishing of their sense of guilt, of their resentment, and of other tensions, they could devote more thought and attention to themselves and their other children. The parent education classes and group psychotherapy sessions helped them to understand the normal children and their problems as well as the handicapped and so to see their role as mothers in the entire family in better perspective. Many of them achieved a good balance between attention to the handicapped child and consideration of their other children, their husbands, and themselves. Family life has thus been strengthened.

As Parents See It

Over the years no parent who has remained in the community has withdrawn from the program, except those whose children have been taken into the public school's special classes. The parents have all carried out their required participation willingly, and many of them have helped with additional projects.

After the program had been in operation for 2 years the staff sent a questionnaire to the 14 mothers to be answered anonymously. These were all returned promptly.

The questionnaire results indicated that the mothers spent an average of 8 hours a week each in the program—in transporting their children to the school, helping in the school activities, and attending the parent education and group psychotherapy sessions. To the question of whether this amount of time was compensated for by the values received, 12 of the 14 mothers replied that they felt it did.

In their returns the mothers indicated that the most useful results of their participation in all facets of the program were: (1) a clearer understanding of the child's handicap; (2) a perspective on the child in relationship to other children and to his own potential. Twelve mothers recommended the continuation of a parent participation program as against a shift to a program for children only.

The returns also showed that in the beginning the mothers had been uneasy about working with children who were severely handicapped physically or mentally. Thirteen of the 14 mothers said that they had been disturbed at the prospect of working with severely physically handicapped children; 11 were disturbed about working with the mentally handicapped. Eleven of the 14 mothers said that after a period of participation with these children they were no longer disturbed at all by working
with physically or mentally handicapped children.

One mother wrote of her participation in the nursery school:

"I think it has helped my husband and me to become much more relaxed with our handicapped child. We couldn't have loved her any more than we already did, but we began to understand her so much better in her needs and wants. It also helped me in not babying her so much and waiting hand and foot on her. It has helped me to understand that she must do things for herself that she is capable of doing but take her a long time to do. Also it has helped her to become used to my not being with her all the time. She used to cry when she first started nursery school, but after a while she felt secure when I left her for the two and a half hours to shop and she had to stay there without me."

In regard to the family counseling and group psychotherapy the returns indicated that on the whole the mothers felt that it had helped them to understand themselves and their relationship to their children and to learn to handle themselves and their family situations more constructively; that it had relieved their anxiety about their child and increased their acceptance of his limitations and realization of his abilities.

The mothers reported that the group psychotherapy had helped them to recognize that others have similar feelings and family problems; to discuss their problems freely and receive help in regard to them; to formulate thoughts and feelings that they were only partly aware of previously; to assert in an accepting environment more of their own feelings and attitudes about their child, negative and positive; and to exchange pertinent experiences with other parents.

The others were asked, "If you were involved in setting up a nursery school for handicapped children would you recommend to such a group that the program include: individual family counseling? group psychotherapy?" Thirteen of the mothers answered "yes" in regard to individual counseling (one did not answer); and 14 answered "yes" to group therapy.

A Family Approach

What experience in the program can mean to a family may be illustrated with the A family in which the cerebral palsied child, a boy of 4, had been diagnosed as both mentally retarded and emotionally disturbed. The mother came to the nursery school in a very questioning mood, inclined to disbelieve that her child was badly handicapped. She herself was a seriously withdrawn individual, unable to express herself, and very antisocial. After a long emotional struggle in which the other mothers and the psychotherapist participated, she came to realize the severity of her child's mental retardation.

Through the total family approach, which included staff talks with the father and his participation in fathers' meetings, as well as the mother's participation in the school activities and the psychotherapeutic sessions, she and her husband came to accept a fairly accurate appraisal of their child. The mother gained in her emotional stability and became more outgoing. She learned to cope with the very difficult behavior of a younger, normal child, who was included in the nursery school, and along with her husband was able to take appropriate steps for long-term care of their handicapped child after accepting the facts and their feelings about them.

Staff, parents, and interested observers of this program have come to believe that the key to helping such families as the A's has been the combination of services given to them and the awareness of the whole family's needs in all phases of the program. They also believe that this type of program would be applicable in work with children with other types of handicaps.
TODAY there are approximately 35,000 children and young people under 21 years of age in this country who are blind. Although the incidence of blindness in infancy has been sharply reduced since the relationship of retrolental fibroplasia to an oversupply of oxygen in the care of premature babies was demonstrated in 1953 and 1954, the children who suffered this condition are still with us, as are children whose blindness comes from congenital or other causes. Many of these children are growing and developing well, and are already engaged in educational programs or are about to enter school. There are, however, some children who have been blind since infancy, who are presenting grave problems to their parents and to professional persons interested in providing them with appropriate educational and social services.

The blind children who are presenting these difficulties may be said to be “multiply handicapped”; but their additional handicaps are of an intangible behavioral nature rather than an obvious physical disability such as a hearing loss or a crippling condition. When seen in physicians’ offices, diagnostic centers, child guidance clinics, and speech centers they are variously described as being “autistic,” “mentally deficient,” “psychotic,” “aphasic,” “emotionally disturbed” and/or “brain damaged.” Many of them have been denied admission to or have been dismissed from educational programs as being too immature, not fitting into the school, uneducable, unable to talk, or in need of more individual attention.

The meager professional literature about this type of child describes an easily recognized picture of a child often frail in appearance, lacking in muscle tone, and seemingly a victim of overprotection, understimulation, and overexpectation. The one characteristic common to all such children is their developmental retardation. In the preschool years the child may be slow in responding to the efforts of his parents to teach him self-help skills such as feeding, dressing, and toileting. Often a parent will report that he is sure the child comprehends but seems almost to be teasing the adult by not wanting to cooperate.

Another frequently observed characteristic is the child’s lack of language for purposes of communication. Some nonverbal children are reported as having talked at one time, perhaps in the early preschool period, and as then having gradually stopped. Others may verbalize readily or repeat in an echolalic fashion much of what they hear: abrupt phrases, television commercials, and the like. Some children speak only in the third person, never using the pronoun “I.” Others do not make any attempt to communicate verbally.

This lack of communication seems to supplement the autistic or withdrawing qualities often observed. A child may appear to be indifferent to persons in his environment by simply remaining passive and initiating little activity. On the other hand, he may slowly comply with the suggestion of an adult but exhibit no change or affect. A child may show little or no preference among adults; for example, he may take the hand of a stranger as readily as that of his parent, giving little impression of discrimination between persons.

This pose of unawareness or indifference to people is most pronounced when children with similar problems are brought together in a group situation. They may be alert to the presence of each other
and at times disturbed even to the point of being jealous of attention, yet they do not necessarily communicate with one another.

In gross mobility, the child often seems extremely awkward, with apparently aimless movements of arms and legs. In contrast, finer motor coordination or dexterity may be well developed. Some children may exhibit a tenseness suggestive of a spastic condition; many of the blind have been at some time or another described as “slightly palsied.” Toe walking is sometimes seen as well as a toeing outward and a stiff almost stamping tread.

Many of these children exhibit behavior patterns such as head banging, rocking, face slapping, and biting. An unusual rote memory has been noted often as well as a high capacity for recall as measured by psychological instruments. These rhythmic patterns plus the ability to recall tend to enhance the child’s enjoyment of music, a characteristic often capitalized upon by the adults in their lives.

These children confront the professional worker with three major questions:

1. How may this blind child’s potentialities be adequately appraised or evaluated?
2. What may be contributing factors to the child’s present development and is it possible to modify his retardation?
3. What kinds of services—educational, social, and psychological—are necessary to help him develop to his optimum potential?

**Appraisal**

Most of the children presenting problems in addition to their blindness come to the attention of the professional worker as they approach school age. Though the child might have seemed to be retarded in development earlier in his preschool years, there was always the possibility that given enough time to grow and develop he would “catch up” with his peers by the time he should be entering school.

Many schools require a psychological examination of the child before or shortly after his enrollment, particularly if he has a physical handicap. In some instances the test score will determine the child’s acceptance in the program. In others, it may be used only as one of the tools of measuring his development. Authorities in child development often regard children who are blind as presenting a difficult challenge as far as appropriate evaluation is concerned especially in the preschool years. Not only are the instruments of measurement considered inadequate, but the children themselves are apt to be deceptive in appearance and their performance to

believe their true potential. Yet an evaluation should be helpful to those who will be planning for and working with the child.

Much variation has been observed in the appraisal process. Some children are evaluated on the basis of one appointment with the psychologist, plus as much supplementary information as may be secured. On the other hand, sometimes the child who presents problems may be seen in a residential setting from 2 to 10 days with a parent also present. Some authorities maintain that the child who is “difficult to evaluate” should be studied for a 6-month period, preferably on an inpatient basis, before any attempt at appraisal is made.

The examiner responsible for evaluating the blind child may feel inadequate if he is unfamiliar with some of the characteristic behavior and skills of a person functioning without sight, such as his use of auditory cues or methods of orientation in a new environment. Bauman has discussed some ways of working with the adult blind client which may be suggestive also for the person working with children.

A complete history of the child’s physical and emotional development during his first 5 years of life should be available to contribute to the evaluating process. If the child is entering an educational program, any report of early group experience, such as nursery school or kindergarten attendance, should add to the educator’s understanding of the child’s development. He will want to know, too, if the child has ever been hospitalized for any length of time, particularly in infancy when first relationships with people are generally formed. Moreover, such knowledge may be helpful in understanding the parents’ feelings toward their baby.

Of special significance in planning for the child will be the ocular report indicating the cause of blindness, congenital or otherwise, and the length of time the child has had a visual loss. When interpreting the report one will note especially the age of the child at the onset of blindness and the amount of his visual acuity if there is light perception or more residual vision. Such information may help to explain why some of the child’s concepts in certain areas may be weak.

According to studies of the development of children who are blind, behavior which in children with vision would seem to be symptomatic of mental deficiency, brain injury, or severe emotional disturbance must in a blind child be looked at not in relation to the development and functioning of the
sighted individual, but in relation to its purposefulness or meaning to a person who is growing and functioning with little or no sight.3

For example, the examiner may be cognizant of the factors in the early life of the blind child which might have contributed to his passivity or autistic behavior, such as isolation in an incubator, the early attitudes of his parent toward his blindness, and evidences of emotional deprivation. Or the examiner may note the motor activity of the child. Perhaps the child's stiff gait results from lack of early motor experiences. Perhaps his toeing outward and the slight stamp in his step may be part of his effort to get auditory cues for orientation purposes as he walks. The excellent memory of many blind children can be of real advantage to their functioning as blind persons and should not be regarded as a negative factor indicative of bizarre development.

The examiner will realize that some children refer to themselves in the third person because that is what they have always heard. He will also want to know how much life experience the child has had that could contribute to his development of a positive concept of self.4

As has already been indicated, the psychological instruments themselves are limited. At present the Interim Hayes Binet Tests for the Blind (1942 Revision) is the only standardized instrument for children who are blind.5 Most psychologists agree that this test is not reliable for children under 6 and do not advise it for those over 12.

For the very young blind child the Maxfield-Buchholz Social Maturity Scale may be used. As the name implies, it is a measure of social maturity only. In using it the examiner is dependent upon the responses of the parent to questions concerning activities indicative of the child's development. The limitations of such a scale are obvious, as it is natural for parents to be anxious about their child's performance in relation to other children.

Blind children may also be examined with selected parts of certain standardized tests for sighted children, such as the Cattell Infancy Scale, the Wechsler Intelligence Scale for Children, and the Merrill-Palmer Scale. Again, many examiners will use selected portions of these instruments, depending upon the individual being evaluated.

Most blind children are able to cooperate with the psychologist during the tests, but those who present the most baffling problems sometimes do not respond in the normal test situation. Most evaluations, therefore, are the composite result of the observations and thinking of the psychologist, pediatrician, ophthalmologist, and social worker who know the child, supplemented by information furnished by the parents. Even with all this help, some children are singularly hard to evaluate for there is always the question as to whether one is dealing with true mental retardation or with a developmental retardation resulting from a multiplicity of factors, not the least of which is the traditional way of thinking about blindness.

Factors in Retardation

Many questions must be raised when a blind child exhibits signs of retardation. Does his retardation have a true biogenic basis? Is he slow to respond because he has been deprived, unwittingly, of learning experiences? Has his development been conditioned by the emotional climate in which he has been living? Has the sensory deficit, his blindness, contributed from infancy to the retardation by preventing him from using in the same way as a sighted person the neurological pathways ordinarily stimulated by vision.

For many years in the past blindness in a child was considered to be invariably accompanied by mental deficiency or with at least some degree of mental incapacity. Early literature indicates that the only care or attention given to blind persons was in institutions for the “mentally defective and the blind.” Only in the last few decades have services been offered to blind persons on the basis of a consideration of their well-being. The realization by more than a few persons that the very young child who has severe visual loss may have excellent potentials is even more recent. Even within the last decade parents of blind babies have frequently been told, “Your child is blind and perhaps the best thing to do is to put him away, forget about him, and have another baby.”

Because more than 50 percent of the blind children born within the last two decades have a visual loss as a result of retrolental fibroplasia, a condition they acquired as premature babies, it has been easy to think of all blind children in terms of this diagnostic entity and, conversely, to think that the child who has retrolental fibroplasia exhibits characteristics common to all blind children. In consequence the adjective “retrolental” has for many people certain false connotations.

Studies by Hayes5 have indicated no marked difference in the development of the child blind from
retrolental fibroplasia and the development of children blind from other causes. Though oxygen has been found to be a significant factor in causing blindness in the premature eye, the studies of Krause and Patz have seemed to indicate that only the eye was damaged. No evidence was found of neurological injury. However, prematurity does have its hazards and the same child may be a victim of some of its complications as well as of blindness.

Information pertaining to the cerebral activity of children blind from infancy is meager. Gibbs found the electroencephalogram pattern in blind children to be similar to that of brain-injured children. However, it should be noted that 33½ percent of the sampling used in his study was drawn from a school for mental defectives. One should also bear in mind the fact that neurologists are apt to see blind persons only when they are institutionalized or are patients who have come to their attention because of questions in regard to their neurological functioning.

Though some neurologists report a spiked pattern characteristic of impairment, there are also reports of blind children with bizarre behavior for whom the electroencephalograms show no significant abnormalities. Parmelee found that the electroencephalograms on six children, blind from retrolental fibroplasia, were “not diagnostically significant, though two were suggestively abnormal.” A more extensive comparative study of blind children in an institution for the mentally retarded and in a residential school reveals “no neurological impairment due to factors responsible for retrolental fibroplasia.”

General Observations

A study of numerous case records of blind children, including health reports, developmental histories, and material descriptive of the environment in which the children have been growing has led to the following observations:

1. These children represent a variety of social and ethnic backgrounds. Many children come from homes of “average” or “above average” socioeconomic status.
2. When informed of the diagnosis of blindness parents have nearly always been told that the child has a poor prognosis not only regarding the possibilities of vision but also in terms of anticipated development.
3. In many instances the diagnosis of blindness was made after the child was some months old. The parents presumably delayed taking their child to the doctor in the hope that their fears of a visual loss were unwarranted, or that the child would be able to see as in growing older he overcame the handicap of his prematurity.
4. Mothers frequently express more difficulty than fathers in their feelings toward the child and his blindness; fathers often express a sense of inadequacy in knowing how to function with the child.
5. The child who is blind seems to be more emotionally vulnerable than other children and therefore to suffer more keenly when parents tend to be compulsive in their treatment or unable to give their warmth to the child. Parents may not be able to unbend toward the child because of their own feelings toward blindness.
6. There has generally been a multiple-discipline approach to the child’s problems. In many instances children have attended one or more school programs and have been known to several social and health agencies.

Few blind children in the total population have such gross abnormalities as to need custodial care. However, the symptomatic behavior of the children under discussion is not always irreversible and should not be regarded as a basis for institutionalization. Parents can be so overwhelmed with grief and fear that they can offer little in the way of the one-to-one relationship needed by the very young child.

Some blind children have resembled in appearance and behavior the emotionally deprived babies studied by René Spitz. Moreover, they have responded effectively to management and treatment based on an understanding of their functioning in relation to their sensory deficit. As Norris has reported, the parents’ initial attitudes toward the child and the existence and use of the appropriate community resources available to meet his needs will determine in large measure the “opportunities for learning” which the child will enjoy as well as his subsequent development.

Appropriate Services

Perhaps the first steps in enabling a blind child to enjoy and benefit from an educational program must be directed toward helping his parents, for it is in the home in early life where the child normally develops trust, confidence, and belief in himself as a person. Accordingly, programs for blind children emphasize social casework service for the parents in an effort to give them a better understanding of blindness, of their own feelings toward their blind child, and of his developmental needs in relation to his visual loss. A second major focus of a program for blind children may be on helping the child himself to a better understanding of himself as a person. In some instances the child may need psychotherapy or “play therapy,” carried out by a
skilled technician familiar with the effects of blindness. However, the expense and in some areas the inaccessibility of such skilled help may make such treatment prohibitive for many families.

For the younger child a carefully selected nursery school may be recommended where the child can learn about himself as he is learning to respond to teaching techniques. Many blind children who exhibit bizarre behavior have never experienced the kind of close, warm, or continuing and satisfying relationship with adults provided in many nursery schools.

Many persons who have worked with children with atypical behavior say that attention should be given to helping to build in the child a realization of personal worth rather than upon treating a particular symptom of emotional deprivation such as a lack of speech. However, speech therapy, per se, may be needed by some blind children who have articulatory problems or hearing defects.

Some of these blind children with behavior problems may have above average potentialities. Their keen sensitivity may be behind the severity of their reactions to the circumstances in which they have been growing. Such children may respond to learning experiences directed at broadening their knowledge of people, of the community, and of the world in which they are living without the great aid of sight.

Other children may be slower learners who require and respond to a slow approach with repetition and patience. But whether slow or bright the child needs some group experience and some individual help. The teacher, perhaps, must be part therapist—to know when to bring the child to a new experience—and part artist—to know how to provide this experience for him.

Many children upon reaching school age need an educational program provided on a residential basis, preferably in a location where the administrators may have available expert medical, social, and psychological services. Such a program allows the child to experience a change from the environment which may have been accentuating his problems, provides consistency of treatment, and permits opportunity for observation of his behavior by skilled professional persons on a continuum.

Every effort should be made to see that none of these blind children is overlooked, and that each receives the kind of individual attention that will permit and enable him to grow and develop to the maximum of his potentiality.

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THE INFLUENCE OF HANDICAPPING CONDITIONS ON CHILD DEVELOPMENT

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WHAT DOES IT DO to a child never to have had the opportunity to chase a butterfly? Or never to have been able to read "The Three Little Pigs" or "Cinderella", but only to have heard the stories? What happens to a child's nervous system—made to receive, assimilate, and interpret a full range of sound frequencies—when it can only get a limited range of damped frequencies to work with because the child can hear only parts of sounds? What does it do to a child if he gets a low return on his efforts to communicate with others because of a speech defect?

Does the constant bombardment of a brain by muscle-sense perceptions from the incessant movements of a hyperactive child lead to the development of protective patterns of nonresponse? And does such nonresponse spread and account for inattention to sensory perceptions from ears and eyes so that the youngster is unable to concentrate on anything? Can a retarded child's central nervous system, which has multiple functions, only a few of which may be operating defectively, adjust to the imbalance caused by the blocking of one or another integrative channel?

In other words, what difference to the child's total personality does an imbalance in "input" from the senses really make? What difference can a deficit of a few billion input impulses from one direction or another make in the total integration of a few billion functioning cells in the central nervous system?

The writer of this article certainly cannot answer all these questions, and it is doubtful whether anyone can do so at this moment of scientific history. But they are questions appropriate to a discussion of the possible influence of handicapping conditions on the child.

Attitudes toward handicapping conditions are changing under the impact of new scientific findings. We used to approach handicapped children mainly with sympathy, trying to imagine what life must be like for them. Sometimes, we tore our hearts out to give them more of something, including compassion, in order to make them feel less different and less deprived, and often, too, to make ourselves feel less guilty in our inability to relieve their defects appreciably. This often led to oversolicitous, protective care which prevented the child from receiving the stimuli he needed.

The quality of sympathy and compassion is needed no less now than it was in the past. But there is new information to deal with, and there are new concepts to be applied in thinking about the effect of handicaps. Attitudes of sympathy need to be supplemented with interpretations from the scientific field that may make our compassion more effective in helping the handicapped person to achieve a more complete range of experience.

According to the stimulus-response theory of personality formation, the individual can be nothing except what his experience, in interaction with his physical inheritance, has made him. One who has
never seen can have no conception of what “seeing” in the literal sense is. Unless there is a stimulus, there can be no response to be elaborated and integrated into thoughts, word pictures, symbols, and all the other things that the human brain can produce.

The stimulus-response theory needs a great deal of elaboration to fit the actual facts. Such elaboration, however, is not needed for the main point to be made here: the importance of providing a handicapped child with as much as possible of the variety of stimuli to which a normal child is subjected.

It is important to remember that because of the great variety of inherited traits and capacities, human variation is very great. The effect of a stimulus is not the same on every organism unless the organism itself is identical with every other in a series. This does not happen anywhere in biology and certainly not in human beings.

**Deprivation of Stimulus**

Until fairly recently psychology and physiology tended to run along side by side without coming together at any point. Physiology prided itself on dealing with demonstrable changes, the pull of a muscle, an action current, or a chemical change. Psychology tended to be concerned with thoughts and feelings, phenomena which, in general, tended to be extremely hard to measure. The amalgamation of these two streams of information into a unified science has been very hard to accomplish. The problem of getting the two together, known in philosophy as “the mind-body problem,” has provoked various analogies over the years. Some persons have talked of the parallelism of things happening in the body with things happening in the mind and vice versa. Others have spoken of the two “aspects” of interpreting the same action, the “aspect” of thought and feeling and that of the physiological concomitant of thought and feeling; and again, vice versa.

Psychology has been beset by having to speak very often in terms of analogy. Mental deficiency has been called a handicap like an amputation. Poor pronunciation has been called a handicap like a limp. Inability to interpret sounds has been regarded as similar to the inability to hear sounds at all.

Some progress has been made in finding the relationship of psychological symptoms to physiological facts, so that there are areas now where the psychologist does not have to use analogy, where he can say, “I am not talking about something that is similar to a physiological phenomenon but of something that is the same and has the same scientific validity.” The advances that have made this possible have come mainly from experiments on deprivation of stimulation—deliberate experiments with animals, and, with humans, observation of the effects of deprivation that has already occurred.

For example, it has been known for a long time that people with severe strabismus end up with an eye which cannot see even though it started out as a structurally sound eye. This is called amblyopia exanopsia, and it is prevented—while awaiting time for a corrective operation—by deliberately interfering with the vision of each eye alternately so that both eyes must be used part of the time. The explanation for the loss of vision in the unused eye appears to be that the brain neglects the stimulus it furnishes, since two images are confusing; and the result is that the neglected eye eventually becomes unable to send out stimuli at all.

Animal experimentation shows that if the eye is not allowed to receive light at all, that is, does not have the opportunity to receive its normal stimulus, it will eventually be unable to receive a stimulus adequately, and the animal will not have useful vision. Some research workers have found that this is related to the fact that light falling on the retina is necessary to stimulate the formation of certain chemical substances essential for vision.1 Once this sort of blindness is induced, it does not recover easily; indeed, if the animal is not exposed to light during a certain “critical” period, it will always be blind. The capacity to see appears to be lost unless it is used.

Years ago it was found that if babies admitted to pediatric hospitals because of acute infectious diseases were not sent home immediately upon recovery, they developed marasmus, a condition characterized by loss of muscle tone, low-grade fever, low hemoglobin, usually marked loss of weight, chronic diarrhea and, finally, a great under-responsiveness and lethargy. Lest you have forgotten that this existed, look at the awful pictures of such children Chapin published in 1908.2 The cure for this condition was to send the baby home to be stimulated by the attention and activities normal in most families but lacking in hospital wards visited only by doctors and nurses. In these infants apparently the whole child was responding to lack of stimulation in the same way the eye reacted to a deprivation of light—by becoming useless, by dying.3

The slow process by which this idea found its
way into hospital administration is now history. The result can now be seen in bright, stimulating pediatric wards populated not only by patients, nurses, and doctors but also by play therapists, occupational therapists and, more and more, by the children's own parents. One objective of these changes is to prevent children from dying from understimulation.

**Unbalanced Stimulation**

A great deal of research carried on in recent years has been concerned with more subtle effects of understimulation than the massive marasmus described by Chapin. Bowlby collected most of these studies made before 1951 in his book, "Maternal Care and Mental Health." He maintains that children deprived of proper parental care in infancy and early childhood show an irreversible trait of "affectionlessness," an inability to establish an affectionate relationship with others. There is much less scientific certainty about such subtle deficits than there is about the overwhelming deprivations of the old pediatric hospital or the kind of orphanage Dickens might have described. Nevertheless Bowlby's work tends to confirm the theory that deprivation of stimulation if continued long enough means loss of function. This theory is of tremendous importance in understanding the effects of handicaps on children.

Every handicapped child is a child deprived of certain experiences. The range of the deprivation goes from that experienced by a bed-fast, blind, and deaf idiot—about the maximum deprivation compatible with life—to that experienced by a child with a slight limp deprived only perhaps of being able to win a foot race. The problem for the person who wishes to preserve as much as possible the normal development of the personality of the handicapped child is to see to it that the deprivations, and understimulation he suffers are minimal. Thus the maximal restoration and preservation of function becomes the first priority for attention in almost all cases.

The brain is put together so that it can integrate and make meaningful the information brought in through the senses, including muscle and position senses. In a normal person this information is pouring into the brain all the time a person is awake. Some of the information gets into consciousness and is recognized as a particular feeling or sensation. Other items in the stream of inflowing information need not come to consciousness at all to be effective in influencing behavior. For example, the balancing and muscle sense items that make walking possible come in and lead to adjustments of position quite automatically without reaching consciousness.

Normally, this inflow of sensory input is in a certain balance, each sense with the other. We do not know today exactly what this balance is nor can we make quantitative measurements of how much sight and how much hearing and how much taste and smell or balance and position sense enter the normal inflow, but we do know that the normal brain is equipped to handle it and make it meaningful. Suppose now that this balanced inflow is interfered with by decreased sight or hearing. This represents a loss of stimulation, a deprivation of experience to the individual concerned. That part of his brain used to "integrate" the material from these senses would also be understimulated. If the insufficiency of stimulation at this internal level were severe enough and came during a "critical" period of his development, there might well result a failure to develop the function of integration, which adds meaning to experience, just as the unused eye fails to develop its function of seeing. Fortunately the brain appears to act for many purposes as though its functional connections were very widespread. Probably because of this, the integration function appears not to suffer too much from the deprivation of input from a single sense.

On the basis of this theory, the first concern in preventing disordered personality development in handicapped children is the maximal restoration of sensory input. It is necessary to preserve as far as possible the balance of input of sensory data to the brain since the brain is adjusted to such sensory balance. Detailed research to test the theory remains, for the most part, yet to be done.

The balance of input can be disturbed by lack of vision or deafness, but it can also be disturbed by an overabundance of one or another kind of sensation. Such overabundance of input in vision is uncommon. But one of the troubles of hard of hearing persons who use hearing aids appears to be an overabundance of noise which the brain finds it difficult to separate into what is meaningful and what is meaningless. Another type of overstimulation occurs in cerebral palsy, with or without spontaneous, unpredictable movements.

In this condition the musculature is likely to be more tense than normal and a pitching struggle for balance continually goes on. The proprioceptors in the muscles are constantly bombarded by impulses due to the tension, the random movements, the struggle to adjust the muscle to maintain balance.
What a stream of proprioceptive input must come from all this poorly coordinated movement and how different it must be from the proprioceptive inflow in the normal person! How much it must overbalance sight and vision as compared with the normal! Is it any wonder that the effort to interpret this inflow puts the familiar expression of intense concentration on the faces of little children with cerebral palsy who are being taught to walk? Is it any wonder that with such abnormal input the personality might also be disturbed?

Obviously we can think about any sort of motor disability in this way. The differences are more in a quantitative than in a qualitative direction.

No impulse can originate from an amputated limb, yet the "balance of input" seems to demand them so strongly that many amputees find the central nervous system produces them itself. They suffer from pain or fatigue in the limb that is gone so definitely that medicine invented the term "phantom limb" to describe the sensations. Similarly one can imagine that the jolt of a limping gait adds more impulses for nervous system integration than a smooth pattern of walking. The subtleties of the differences made by these varied patterns of stimulus-input balance is, again, largely a matter for future research.

The Effect of Time

Many observers have noted that the stage of development at which a handicap appears makes a great deal of difference in the effect on handicapped person. The usual conclusion is that the earlier in life the disability appears the less likely it is to disturb personality functioning.

The phantom limb previously discussed disappears after a few months. The nervous system seems to be able, after a while, to adapt to the loss of incoming stimuli from that area of the body. Put into the usual scientific language, the statement is that the "body image," the concept one has of how he looks and is, has become adapted to the loss of the limb. It is likely that in a nonhearing or nonseeing child whose defect was present at birth or soon after, the "body image" never included the lost sense, and adjustment to the loss was never required. When deprivation of a sense comes later, adjustment of "body image" is necessary; making the adjustment then appears to induce more severe personality disorder in the deprived person.

Very early or congenital loss of hearing may be an exception to this general conclusion, quite possibly because the absence of the input of hearing signals to the brain during the critical period for language formation leaves a damaged capacity for learning communication skills. Incidentally, it may well be that the lesser efficiency of communication by "finger talk" as compared with even an impaired auditory signal may be due to the fact that the manual dexterity necessary for sign language is not within the capacity of the child until after the age at which communication capacity may have passed the optimum point of its critical period for development. Such speculation demonstrates how complex these problems are.

Another type of handicap must be considered. This is present in some children who do not show any physical incoordination nor even any easily observable sensory loss. Examples are the motor hyperactivity of some brain-damaged children and the many sorts of thinking and learning difficulties, such as inability to handle abstract symbols and ideas, some types of reading disability, or mathematical disability of children who do not, through the usual tests, show evidence of organic damage. Included in this group, probably, are those children Drs. Hardy and Pauls have been concerned about, who can hear sounds but are unable to attach meaning to them. The group also includes a category very difficult to fit into any theory; those mental defectives whose condition defies any more exact diagnosis.

As far as can presently be judged, the children with these various symptoms are suffering from a block of the integrative processes within the brain.

There is a tremendous amount of research to be done in this area, laboratory research on brain structure and function as well as clinical examination which will more clearly identify the defects being dealt with. Research in the last decade or two has demonstrated that there are many more cases of mild or minimal brain damage among the nondescriptor group of cases frequently labeled "behavior problems" and "mental defectives" than had previously been suspected. In these cases the conditions may be interpretable as coming from insufficient, excessive, or unbalanced input of signals impinging upon the remaining normally functioning brain.

A case of this sort of handicap, showing the kinds of problems unbalanced functioning present in everyday life, has recently come to my attention. This concerns a child who is known to have suffered brain damage at some time early in life, perhaps during intra-uterine existence. There is some general
retardation but reading ability is almost up to age-grade level. This preadolescent youngster is out of step with her age mates; those who read at her level are not interested in the simple games and doll play that interest her. She fits in no place socially and is lonesome and, to some extent, isolated by this peculiar imbalance of abilities.

This article began with some words about compassion, pointing out that, for many conditions, compassion may now be reinforced with better knowledge and more complete theory. Perhaps it is wise to point out also that, in practice, treatment and management are often based on compassion and sympathy long before knowledge and theory have caught up with the problem. The protection of children from the unstimulating atmosphere of the old-time institution came through a reform movement to provide care for homeless children in foster homes a long time before even Chapin's significant work was published.

Compassion certainly dictates that, for handicapped children, the maximal use of normal channels of input should be made, though acceptance of this idea is not yet universal in regard to all types of handicaps. There have been sharp differences of opinion on the issue of whether hearing aids should replace sign language for children with severe hearing loss. However, there is almost no difference of opinion about the wisdom of following this policy in regard to children with visual handicaps. The same is true of children with crippling conditions.

Knowledge and informed theory can keep compassion working at maximal efficiency.

1 Hayden, H.: Histological factors in behavior changes. Address delivered at the opening ceremonies of the Psychiatric Institute, University of Maryland School of Medicine, Baltimore, November 18, 1952.
GROUP EDUCATION FOR PARENTS OF THE HANDICAPPED

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Throughout the country there is a growing interest in group programs for parents of handicapped children, an interest which is not surprising since group programs for parents of well children have become part of many American communities. This interest is being picked up by the increasing number of parents' organizations that have been formed around disabilities to acquaint the public with the nature of the handicap, to raise funds for research, and to push for more and better services for their children. Quite naturally the major attention of these organizations has from their inception been concentrated on the children.

But individual parents have been reaching out for more—a kind of knowledge and help that they have hardly defined for themselves. Their desire for help has been revealed in informal discussions around the edges of business meetings, sometimes even taking the center of the stage and interfering with the main purpose of the meeting.

Thus many agencies serving the handicapped have come to see the need for two different types of parents' programs—one with focus on community action to improve services for all children having the specific handicap with which they were concerned, and the other with focus on helping the parents in their daily living with their children. Where separate programs could not be set up, parents' meetings have been more effective when the two goals have been identified and handled separately.

Agencies providing services for handicapped children have often held informational meetings for parents in the form of lectures by the professional staff, describing the disability and the therapeutic, educational, and other services available. While these meetings have been useful, the persons programming them have often felt that more should be offered, through casework services or another kind of group program or both, to meet the needs of the parents as they themselves see them.

However, in attempting to develop more meaningful group programs, agencies have often been limited by the lack of group leaders. Even well-trained social workers and psychologists often feel unprepared to conduct group programs of this nature. Therefore, professional persons of various types have been turning to the Child Study Association of America for preparation for this work.

Parent Group Education

Within the past 10 years the association has given training in parent group education to selected social workers, psychologists, educators from various settings, and public health and hospital nurses. This training has concentrated on the use of group discussion geared to the needs of the parents in the group and developed from their expressed concerns in a flexible procedure, rather than to a predetermined curriculum.

In parent group education the goal of the leader is to help group members explore all aspects of the situation in which they find themselves with their children, to gain greater knowledge and understanding of their children's physical and emotional de-
velopment, of their own roles as parents, and of the complexity of parent-child relations. They do this through the exchange of ideas and experiences within the group interplay, looking at both facts and feelings—theirs and their children's. Sharing their reactions with others under skillful leadership seems to free the parents to move on to new attitudes and new behavior, or to have greater confidence in what they are already doing.

The goals and techniques of group education are different from those of group therapy. The group education leader does not focus on the pathology of the members, or probe into the unconscious. Although he must take into account the unconscious factors that influence behavior, he deliberately directs group thinking toward aspects of ego functioning, in order to develop ego strengths.

Some Questions

In the early programs of training leaders for parent group education, the focus was on parents of normal children. As the interest mounted in establishing programs for parents of the handicapped the association was asked to set up a special training program for social workers who would be working with families of children with disabilities.

Implied in this request were a number of important issues:

- Is the method of group education developed for parents of normal children applicable to groups of parents of children with such different problems?
- How similar and how different are the concerns of parents of chronically ill or disabled children from those of parents of well children who present merely the normal range of developmental problems as they grow up?
- Can group education be expected to ease the extraordinary burdens on parents of the handicapped and help them to handle their lives and those of all their children, including the nonhandicapped, with greater ease and satisfaction for all?
- Do adaptations in techniques have to be made in working with parents of the handicapped to achieve the basic goals of group education for all parents, and, if so, what is their nature?

The association had already recognized that these questions needed further exploration in practice as well as in theory. It had, therefore, set up experimental groups, under the sponsorship of various health and rehabilitation agencies, for parents of children with muscular dystrophy, cerebral palsy, mental retardation, and two congenital blood diseases. The groups were conducted by association staff members who had familiarized themselves with the nature of these specific disabilities and the special problems they presented for parents as well as children. A social worker from the cooperating agency usually participated as a resource person. The association also had had experience in adapting the basic approaches of parent group education in programs to train public health and maternity nurses to lead groups of expectant parents.

Encouraged by these experiences, the association, with a foundation grant, set up a demonstration program to train social workers in parent group education for parents of handicapped children. The hope was that the experience of the social workers in conducting parent discussion groups in their own agencies would throw more light on the foregoing questions. The association also looked to the project to explore some questions regarding the recruitment and readiness of parents for this type of experience, and the effect on the groups, of their makeup, in relation to degree of homogeneity in the parents' backgrounds, and in the prognosis and severity of their children's conditions.

A New Project

The project was initiated with a selected group of social workers from the staffs of hospital social service departments and health and rehabilitation agencies in New York City, and from the New York City Health Department. These agencies were interested in developing group educational services for parents and had experienced social workers who were familiar with the disability of the children with whose parents they would be working.

The program included 15 weekly sessions devoted to a review of the principles of child growth and development and the many distortions created by various disabilities; discussion of the parental concerns common to all parents as they are colored by the nature, prognosis, and special meaning to parents of their children's handicaps; and presentation of the principles, goals, and techniques of parent group education as applied to the needs of parents of handicapped children. These sessions, conducted by guest experts from the fields of medicine and rehabilitation, psychiatry, psychology, education, sociology, and cultural anthropology have been supplemented by seminars led by association staff members who also supervised the participants as they conducted parent groups in their own agencies, in health and rehabilitation organizations or in special clinics, recreation...
and workshop centers, hospitals, and public schools. Each parent group was concerned with a specific disability—orthopedic handicaps, cerebral palsy, mental retardation, or cleft palate—except for two groups of parents whose children's disabilities were not all the same.

**What Emerges?**

What takes place in such groups? Since the subject matter is not preplanned but is developed from the interests of the members, there can be no general answer. Parent group education, like casework, focuses on the parents and their concerns, meeting them "where they are." So the discussion may start at almost any point.

Often the early meetings of a series are taken up with practical problems of routine care as compounded by the child's disability. Parents of young children who are mentally retarded or cerebral palsied or both bring up their struggles with the whole range of developmental tasks they are trying to help their children to learn—feeding, toileting, dressing and undressing, climbing stairs. Parents of severely orthopedically handicapped teenagers may talk about the constant chore of getting their young people to school, a recreation center, or just outside the house.

Everyday problems continue to appear in many forms throughout the series of meetings, and in these discussions the parents gain a great deal from the experiences of others. Even though the degree to which their children are disabled may vary enormously, the ingenious procedures some parents have worked out often open up new ideas relevant to many different situations, which the parents often adapt to the needs of their own children. Sometimes a parent has tried a new way of bathing a severely crippled child, for example, or a different approach to getting a cerebral-palsied child to feed himself, or a rearrangement of the furniture to provide greater play space.

While the parents discuss these ideas, they are constantly working on one of the baffling aspects of their problems, that of evaluating their child's particular timetable of growth and development. For many handicapped children, there is no set guide. Each parent has to find out what stage his child has reached, in relation not to age, but to the limitations imposed by his disability as well as to his capacities.

With the leader's encouragement, parents are often able to bring out the basic questions that lie behind these practical discussions, revealing a few central themes variously expressed. The common question, "How much can my child really do?" may be a front for many others: What is the true extent of his disability? What does this mean for me? How much should I do for him and how can I best help him learn to do things for himself? What is my real role as a parent, what kind of a parent do I want to be, and can I really carry out what I think I should do? Will he be able to take care of himself later on? What does the future really hold? Will I ever be free of this endless burden?

Whatever the parents begin to talk about may uncork a flood of feelings. Sometimes these feelings burst through in first or second meetings, sometimes they are held back until late in the series, when the parents feel more at ease. Parents often reveal in groups what they say they find it more difficult to reveal in one-to-one talks with doctors, psychologists, and social workers—especially their confusion about what they have been told regarding their child's disability. Often they say that they have not been told enough and that they have not been met with sympathy and understanding. The frequency of these comments even though the medical, nursing, and social service personnel are known to have been competent, thoughtful, and friendly suggests the extent of these parents' need for support and perhaps also their difficulty in absorbing the reality of what they face.

Many parents gradually come to see the extent of this need as well as the unreality of their expectations. They discuss what may be pushing them to continue to "shop around"—the wish for a magic cure or a new diagnosis since the reality seems so unbearable. Yet at the same time they recognize that they must reach out for all the services available to the child and press for more if needed.

Other feelings emerge in different ways from group to group. There seems to be a strong, deep undercurrent of anger, frustration, and guilt that needs to find an outlet and breaks through whenever it can. Within the supportive atmosphere of the group, parents begin to talk about their anger and frustration, sometimes directed at the child himself but more often at medical services, random happenings or just fate. When they recognize that these reactions are shared by others and are accepted as natural by the leader and the group, they come to feel less guilty about them and are better able to look at them more realistically.

A similar process occurs when parents bring out their feelings of deep disappointment in their child,
of having a constant, endless burden and, sometimes, of being drained of all individuality. They say again and again that they feel personally responsible for the disability, although rarely is there any justification for their self-reproach.

These complex feelings appear to be almost universal in our culture. They seem to flow from a basic part of our emotional lives, from our expectations and dreams, our hopes and fears regarding our children. The degree and expressions of such feelings, however, vary considerably, according to the parents' individual temperaments, the nature and severity of the child's disability, its causes and prognosis, and the special significance it may have for the parents.

Yet whatever these feelings may be, looking at them honestly with others who share them to some degree at least, seems to open the way for parents to accept themselves a little better and to be able to test the feelings against reality. This testing in turn seems to free them to gain a better understanding of all their family members' needs and of their own inner resources.

Some people, of course, are so caught up in their emotions that they cannot make use of group educational experiences of this kind. Therefore, some of the agencies in this project opened the groups only to parents who seemed to their social service personnel likely to profit from the experience. Others invited all parents on a general list of patient contacts to attend. Still others invited any parent in the general public who had a child with the particular disability. Whatever the method of group recruitment, the leaders were alert for parents who either showed no movement during the series or seemed disturbed by the discussions in ways the group could not be expected to resolve, and referred them to casework or psychiatric treatment services. However, some parents who presented a discouraging picture, during earlier sessions, eventually showed surprising shifts of attitude, often first moving out of their own preoccupations to help other parents in the group and then applying a new approach to their own problems.

**Comparisons**

How different are these group sessions from sessions with parents of well children? The association's staff believes that there is a basic similarity in the nature of the experiences for all parents, but that there is a marked difference in the intensity of the feelings expressed and in the quality and degree of parental concerns.

The range of questions that come from parents of children with handicaps are actually very similar to those raised in groups of parents of normal children. For example, parents of well children are also concerned about how much their children can do, how they can best help them to develop their capacities without pushing them too hard, on the one hand, or not giving them enough stimulation and encouragement, on the other. They too, often voice the disappointments they feel as they compare their children with the dream children they had looked forward to.

The difference lies in the reality behind the words, in all the complicating factors connected with the disability that so often leave parents of the handicapped child struggling to find their way alone day by day in dealing with their child and in coping with their own emotional reactions. The burdens of these parents are infinitely greater and the reality is much more threatening, both now and for the future. The practical choices open to them in such matters as schooling, family mobility, and social life for the children and for themselves are far more limited. The satisfactions of parenthood for them are less apparent, though they can find satisfactions if they can move past their difficulties to recognize them. For them the experience of parenthood is a constant problem, in which the concerns of other parents are greatly magnified.

And so the feelings, when they come, pour out in these meetings with greater intensity. This is true not only with parents who have recently been confronted with the problem of having a handicapped child, but also with parents who have lived with the problem for some years. In the case of the latter, one can only speculate as to why the intensity of feeling has continued. Perhaps these parents have never fully faced the shock of knowing their child is handicapped and so have not thoroughly lived through the crisis that comes with this knowledge. Perhaps, because of the constant demands on them, their lives seem to be one crisis after another. Perhaps they have never before had the chance to express what they feel.

**Leadership Problems**

Parents' feelings are an important part of any group educational experience, but the intensity of feelings of parents of disabled children present some leadership problems which are not unique to these groups but appear in exaggerated form. Once the dam of pent-up feelings gives way, it is often hard to stop the flow. How long should the leader allow
the talk to continue in this vein? How much do the parents have to “get off their chests” before they can begin to look at the meaning of these feelings and learn to handle them better? When is it wise to help them out of the morass of emotions, so that they will not get stuck and only feed each other’s self-pity? How can one do this without cutting them off before their feelings are fully relieved?

The answers to these questions depend on the leader’s sensitivity to the reactions of the individuals in the group and on his judgment of the impact on them of the group interplay. He also makes use of his social casework knowledge of how and when to further the client’s movement toward new insight.

Some group leaders with a background of social casework became uneasy when the parents spilled over their strong and often hostile feelings. Although they were prepared to handle such outpourings in a casework interview, they were afraid they might not be able to handle them in a group. As they gained more experience and worked on the problem with their child study consultants, they found that these outpourings, like any other material presented by the parents, could be discussed within the group and used to good advantage, even though difficult moments might occur. They discovered too that the situation is often eased by the spontaneous, self-regulating dynamics of the group; that the members themselves pull away when the impact of the discussion is too heavy and often support and reassure a parent who may be revealing too much. They found too that the leader can step in when necessary, to put the parent’s revelation into a more impersonal framework, by universalizing it with a sympathetic comment or directing the discussion into some other, more general, area.

These parent groups have exhibited considerable variation in mood. In some, the mood apparently stems from the chance combination of personalities, but, in others it seems to be related to the nature and severity of the children’s disability. For example, the meetings of a group of parents of severely cerebral-palsied and mentally retarded young adults were noticeably depressed in tone. These parents had lived with their children’s problem for 20 years or more and saw no hope of improvement.

The leader of a group like this faces the danger of becoming caught up in similar feelings. He can, however, guard against this and try to help the parents talk not only about their heartaches and problems but also about what they have accomplished for their sons and daughters and for themselves.

Helping parents examine their successes as well as their failures is basic in all parent group education. In groups where the parents face especially tragic situations the attitudes reflected in the group tone are often fixed and hard to shift. The group works slowly as though in low gear. Yet a skillful leader who makes full use of group support and sympathetically encourages the parents to look at different facets of their experiences, can help the parents achieve another perspective and, sometimes, a little break in mood. Such groups, however, might be encouraged to meet for more sessions, and their members should perhaps be offered periodic casework contacts.

Mixed Groups

Other variations in group movement are found in groups composed of parents of children with different disabilities or children who have a similar disability but a wide range of impairment. The basis for these parents coming together is that they share the common experience of having a handicapped child, but differences in the nature or degree of the child’s handicap may set each family off in a separate category. Even in groups built around a common label, such as mental retardation or orthopedic handicaps, parents often become preoccupied with the fact that their child is much more (or less) disabled than the children of the other group members. Whether they are deeply envious of the other parents or relieved at their own favorable situation, their awareness of the differences makes it hard for them to see and share their common problems and so to learn from one another. These groups too work at a slower pace and require unusually sensitive leadership.

Experience so far suggests that parent groups function more effectively if they focus on children whose disabilities are fairly similar and who are within a defined age range. However, in groups of parents of the handicapped, the age range of the children can be wider than in groups of parents of well children, who follow a developmental timetable much more closely. More experimentation is needed before one can begin to assess adequately the advantages and disadvantages of homogeneity and of problems in these parent groups.

Leadership Techniques

All parent groups require a flexible and creative use of group leadership techniques to meet the needs
of the particular parents in the group. The charge of parent group education under any circumstances is to use these skills to further the parents' total understanding of their children, of themselves as parents, of parent-child relations, and of the interplay between the family members. With parents of handicapped children there is the added factor of the handicap and its effect on all the family, as well as on the disabled child. But the approach to these parents involves the same goals and techniques as to other parent groups, consciously applied to their special needs.

Social workers are especially well equipped for leadership of these parent groups as they bring to the task a rich background of knowledge and experience with individuals and families and a keen understanding of the dynamics of behavior. Those who have participated in the training projects have also brought a thorough knowledge of the specific disabilities involved and their implications for children, though they have not always seen the children clearly against the background of normal child development. Sometimes out of eagerness to see that the children are helped to develop as far as possible, they have overlooked their emotional needs as children. Some have found it difficult to maintain a balance of empathy and have tended to identify either with the parents or with the children.

At first some of the social workers were preoccupied with and somewhat fearful of the group approach. As a result, at times they failed to recognize the way in which they were already carrying out the objectives of the program in basing their leadership on social work concepts, adapted to the group and directed along broadly educational lines. In time, however, they came to realize this and their leadership skills developed with a new spurt.

Several social workers have reported that the program has sharpened their casework skills by sensitizing them to listening more thoughtfully for the deeper concerns of parents of the handicapped. They have also said that they now recognize more clearly that these parents are able, within a guided group experience, to develop strengths which they can consciously use to help their handicapped children.

COMMUNICATIVE DISORDERS IN CHILDREN

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COMMUNICATION is a process defined somewhat differently by the disciplines of engineering, sociology, physics, public speaking psychology, and others. No single definition is likely to suit all of these fields; essentially, communication is a process of transferring meanings from one person to another.¹

In this article the term "communicative disorders," as used by speech pathologists and audiologists, refers to impairments in speech, hearing, or language.

How soon can a communicative disorder be recognized in a child? How soon shall something be done? What should be done? Who shall do it? A discussion of these questions requires an understanding of the normal development of communication.

Speech

Communication begins when the baby signals his arrival into the world. For a period of 3 or 4 weeks his crying, at first, is simply a reflex action and, to our ears, is undifferentiated. His parents cannot always tell whether it means he has hunger pangs or pants problems, but by the end of 3 months both baby and mother agree that certain kinds of cries are to have different meanings. By this time, he has developed a rudimentary monitoring system whereby both auditory and kinesthetic stimuli constitute feedback clues which are used to modify his vocalizations to express different meanings. At this stage too, the baby begins to repeat consonants and vowels in a random fashion, without any linguistic purpose. Most speech authorities refer to this as the beginning of the babbling stage. When the baby is about 6 months of age, this vocal play increases and inflectional patterns appear. Around the ninth month, he begins to repeat sounds in a more differentiated, less random, way. Repeated syllables become meaningful, such as "mama" and "bye-bye," etc. His vocal pattern reflects the fact that through listening he has been learning to mimic and echo what he hears. At 12 months his one word may stand for a whole sentence to the listener who understands the context.

Then the baby's rate of linguistic growth begins to spurt. The jargon he uses, although it is largely unintelligible, does not seem to be as random nor as meaningless as his early babbling. The mythical average child then begins to talk at one year, only if the definition of the word talk is not too rigorous.

Hearing

Hearing is necessary to this early speech development for if the child cannot hear he does not learn to mimic sounds and inflectional patterns, even though he may make a variety of sounds. If he cannot hear in the fullest sense of the word he does not learn that sounds are symbols. He is delayed in forming the concepts and verbalizations which mark a language system. His delay in language learning continues to
be a serious handicap throughout his life if his hearing impairment is severe.

The newborn’s response to sound is a blink, or a startled reflex, or a movement of his body. Between 3 and 4 months, he may respond to loud sharp noises with a gross body reflex. At about this age, he tries to locate a gentle sound by turning his head toward it. By 6 months, he responds to the quiet sounds to which he has become conditioned. Between his first and second year, if he has normal hearing, he responds to his own name and may comply with a command or a direction. By the age of 2 years, he locates and identifies familiar sounds, and responds to commands. At this age the child’s hearing can be tested with a pure tone audiometer in a clinical situation by using some of the more sophisticated methods of maintaining rapport. Research is still being conducted on the infant’s response to sounds. The Johns Hopkins University has just finished a new color film which demonstrates a method of testing the infant’s response to sounds. [See page 126.]

As the child develops, he is more and more able to respond to specific sounds and to reproduce those sounds. He copies the language which he hears about him both in its grammatical structure and in its phonetic aspects. He learns to monitor his own speech, gradually learning to make it conform to the speech he hears.

The hearing function, of course, includes more than an acuity for loudness. It includes the function of comprehension. The development of language depends upon a complex cortical activity, including the integration of stimuli received from all senses. Other sensory impairment, as well as a hearing impairment, such as the deprivation of visual, tactile, and olfactory stimuli, may affect language development adversely. These senses are important to the development of concepts.

Language

Normal language development begins when the child learns to modify his crying to get desirable responses from his environment. This crude symbol system is quite efficient considering the infant’s limited needs and his limited environment. As a child becomes more independent—creeping, standing, and walking—he has to make a wider range of responses toward his environment and also he seeks more discriminate responses from others. His language-symbol system must grow rapidly in both verbal and nonverbal aspects to keep pace with his social achievements.

Parents respond to the child’s different noises in an increasingly precise way. These reactions help the child to become conscious that a language system exists. His vocal play is repeated by his parents and he soon learns to expect a pleasurable reaction from talking or other communicative actions. He becomes conditioned to specific auditory stimuli so that these stimuli become meaningful. Later these signals become generalized in their meaning and the child begins to build his language without having to be taught every single word. At 9 to 12 months the average child comprehends a great deal of what he hears. He relates symbols to objects, responds to commands, and understands questions. His own words do not have a sentence structure as yet, but by 3 years he uses language very well.

However, until cortical levels are fully developed physically, true conversational speech should not be expected. The child who has not developed normally in other respects should not be expected to be ready for speech at an early age.

This brief look at the development of communication applies to the mythical average child. Although individual variation is great, the sequence of development is fairly uniform. If the child cannot achieve a further level of development, his communication problem requires a thorough diagnostic evaluation in order to determine the etiology, prognosis, and treatment.

Disorders

Communicative disorders can be considered under the main divisions of impairments of speech, hearing, and language. Speech impairments include defects in articulation, voice production, or fluency of speaking, such as stuttering. By far the most common defects are articulation errors in which sounds are omitted, or distorted, or substitutions are made. In the normal maturation of articulation, those sounds which are made with two lips and which are easily visible such as b, p, m, and w develop early and are least likely to be incorrectly used. Some of the back tongue sounds, for instance, the k, g, and h, may be heard first. The tongue-tip sounds such as t, d, and n develop later, and those which require fine motor coordination to produce friction noises such as the s, z, and th develop still later.

The blending of consonants such as the bl of blue, the fr of free, and the st of stay call for even more intricate muscle adjustments and therefore children may be able to sound the consonants correctly without...
being able to put them into blends. A child who has just a few sound errors, who substitutes one sound for another, omits a few sounds, or distorts some of them, generally makes these errors on the sounds which are latest in normal development. Connected speech is characterized by the blending of the sounds at the end of one word with the sounds at the beginning of the next word, thus making a phrase sound like one long complicated word. A child may have difficulty in understanding such a message, let alone reproducing its parts.

Although the child of 1 to 2 years is not expected to be clearly intelligible to everyone, a 3-year-old should be fairly intelligible and the 4- to 5-year-old should have good intelligibility. Children who have such serious articulation problems as to be very unintelligible are frequently categorized as having delayed speech. Such children are very likely to be delayed in language development too. Furthermore, they may be delayed in many other aspects of growth and development. Therefore, a careful evaluation of the child's growth and behavior is important in making a decision about the nature and severity of the communicative disorder.

The search for causes is particularly important in making a differential diagnosis of communication problems. For instance, if the child has a hearing loss of a conductive type, the prognosis and treatment are different than when the child has an impairment of the sensory neural type. In the latter case, the auditory stimulus may have been distorted when presented to the cortical level, not just diminished. Of course a hearing impairment at the cortical level in which the meaning is not comprehended at all is still a different problem. If the cause of a communication problem is a cleft palate, different services are needed than if the cause is brain damage which resulted in muscle incoordination, or in cortical dysfunction without motor involvement. Such causes as mental retardation, or emotional disturbance, or the influence of adverse environmental factors result in different kinds of communication problems which require different kinds of treatment.

**Needs**

What are some of the needs of the child with a communicative disorder? Specific needs for each child will become evident as he is studied, but there are, however, some basic needs which can guide professional personnel in applying their knowledge of their own field to that of communicative disorders.

First, the most pressing need for the child with such a problem is for the problem to be identified and evaluated properly. It is not enough for a speech therapist to state that a speech problem exists, or for some other professional person to guess that the child will "grow out of it." For example, take one of the speech defects which is spoken of as a *simple lisp*. If this defect is treated as a problem in faulty learning, certain habit breaking and habit forming techniques might be recommended as therapeutic. But if the child who lisps has a mother or father who also lisps, then certainly the defect must be evaluated differently. Perhaps the child lisps only under emotional strain during which time other behavioral patterns also regress toward an infantile pattern. If a child has a severe malocclusion along with tongue thrusting habits, the lisp must be evaluated in a different category than *simple*. Clearly, the child with a lisp needs the benefit of services from disciplines which deal with both physical conditions and behavioral relationships.

Early identification of a child with a potential communication problem is not always possible, but there are some indicators. For example, a child who has a cleft palate will invariably need speech help. Children with sensory or motor dysfunctions at birth are very likely to need help even though not all physical conditions affect the speech and hearing mechanism directly. Other examples of children whose communication problems need to be evaluated carefully are those who appear to be mentally retarded, or emotionally disturbed, or whose environment may be lacking in the kinds of conditions which stimulate speech.

Other indicators that a child might eventually develop a speech problem may not be definite signs but nevertheless deserve attention. For instance, if the infant exhibits difficulty in nursing, the motor and sensory development of the oral mechanism may be at fault. Speech development depends upon the proper development of other activities too, such as biting, chewing, bubbling, and sipping. All of these activities occur within the first year. Failure of a child to respond to noises and voices may suggest a hearing impairment either in receiving sounds or in reacting to sound stimuli. If a child's vocalizations do not develop through the stage of playful babbling to a stage of inflectional changes, this too may suggest a hearing problem. If he cannot imitate sounds, does not comprehend, or cannot produce meaningful sounds, he is not going to have a speech impairment: he already has one. The first need then is that the communicative disorder should be identi-
fied and evaluated early so that the family can provide the appropriate services and training at the time when the child is ready.

**Stimulation and Motivation**

The second need of the child with a communication problem is to be stimulated. If he has a loss of auditory acuity, he may need a hearing aid. Visual stimulation can help him get the meanings of what others are trying to convey. If he has a loss of visual abilities, he needs special attention, for vision helps to develop the language system of symbols. He needs kinesthetic stimulation so that his oral structure becomes sensitive to the positions of the sounds produced. Any sensory impairment can affect the development of language concepts. Therefore, the child needs additional clues to reinforce those that he does receive.

He will need the stimulation that comes from parental responses to his noises. This encourages the development of an awareness that sounds can become symbols. The child needs to have his parents engage in vocal play with him: not to have them engage in baby talk, but rather to encourage him to make whatever noises he can make. It seems like a fairly simple thing for a parent to talk with his child, and it is, providing the child talks back. But even when the child does not verbalize, it is important for his parents to continue to talk to him. Speech stimulation can be enjoyable if it is made interesting with rhymes, jingles, songs, and word games.

The child's third need is to be provided with motivation. The strongest source of motivation is success.

As a first step in assuring success, parents should accept, reinforce, and reward speech attempts. On the other hand, they should not be so "accepting" that the child continues to use distortions which he could overcome. Since the child must feel that he is succeeding in communication, it is important to reduce goals to a realistic level. Phonetic precision is not a necessity. Speech which is too difficult for the child should not be expected. This kind of stimulation may lead to frustration and withdrawal: it does not promote learning. Acceptance of some phonetic deviation is necessary in order to give the child the kind of permissive environment in which he can learn. This creation of a feeling of belonging and security is an important first step in any therapy program.

The second step to success in learning is to help the child develop an awareness of differences. He should be taught the meanings of different sounds, but training in meanings should not be limited to acoustic differences. The differences in size, shape, texture, and color are important learning steps, especially to a child with a language difficulty.

The third step to success in learning is to help the child in using whatever speech he has. Situations should be set up to stimulate the child to use whatever speech he can in meaningful communicative attempts, not just in practices and drills. Such opportunities for him to succeed must recur regularly.

A fourth step to success is to try to reduce psychological barriers to the child's development which stem from frustration, bewilderment, anger, and hostility.

All of these steps can be met to some extent by the child's parents, and all of them are the proper concern of many different professional workers.

Parents, of course, need encouragement and counseling. They need information about their child's physical and emotional status, and his potentialities for overcoming his problem. They need someone to talk to who will take time to sort out their unreasonable fears from their reasonable anxieties. They need instruction which emphasizes the significance of other aspects of growth and development to the process of communication.

Children with voice disorders and stuttering have different specific needs from those who have articulation problems, but the principles discussed are equally significant to all communicative disorders.

The child with a hearing impairment especially needs stimulation by auditory, visual, and kinesthetic means. If the impairment could be removed, such a child would be free to learn. The responsibility, then, to overcome this impairment seems crucial. Above all, the child's difficulty must be discovered early in his life. Otologists believe that from 50 percent to 80 percent of impairments are of the kind which can be reversed or modified by early medical treatment. If medical care does not eliminate the hearing problem, the child may need a hearing aid. He will need instruction in recognizing speech visually by watching lip and other facial movements. He will need special instruction, if he has a severe hearing loss, to learn to monitor his own speech by kinesthetic and other clues.

Fulfilling the needs of a child with a language problem is difficult if the problem stems from a
specific impairment in the language centers of the brain. The child with such a problem needs a special training program; those planned for the mentally retarded, the emotionally disturbed, or the deaf are not adequate. A careful differential diagnosis must be made to avoid providing the child with inappropriate learning experiences. If, in addition to the specific language impairment, the child has other handicaps, then the program planned for him will have to be a compromise based upon an evaluation of his assets and potentialities.

In summary, I should like to reiterate the importance of early identification of the child with a communicative disorder and early evaluation of his problem. I should also like to stress the importance of stimulation aimed at overcoming sensory deprivation, and at improving the environmental factors which influence speech development; and of motivating the child toward success through the adoption of an accepting attitude toward him, helping him to develop an awareness of differences, encouraging him to say what he can in meaningful situations, and reducing psychological barriers to growth as far as possible.

ADOPTION OPPORTUNITIES
FOR THE HANDICAPPED

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DOES the social work principle, “Every child has a right to a home and a family that loves and wants him for himself,” include the severely physically handicapped or mentally defective child?

Present attitudes in our culture toward such children (referred to hereafter as “special” children) are much more positive than they were even a few decades ago. In the distant past children with severe defects were hidden, ridiculed, and tortured. Romans and Greeks destroyed them without feeling guilty or remorseful. Even in countries where there were more humane attitudes, such children often aroused feelings of hostility or fear. Unfortunately, remnants of these negative feelings toward the severely handicapped are still present in most of us. It took some actual experiences to help me overcome my own feelings about placing such “special” children for adoption. Until child welfare workers can be helped to recognize and overcome their negative feelings about severely handicapped children and can believe firmly that every child is entitled to a home, they will not go far in attaining this goal.

A “special” child has the same basic needs as every other child. First of all, it is important to remember that he is a human being with needs, feelings and lovable and unlovable characteristics. Second, it is necessary to view the abnormal conditions realistically, not through pity or hopelessness, but with sympathy and compassion. Next, every possible resource should be called upon to help the child become as presentable and as near normal as possible. Only as child welfare workers have the knowledge and the courage to discuss the problem of homeless, handicapped children clearly, will the general public develop enough of a knowledge of it to lead to the uncovering of many potential resources for their care. Unfortunately, however, when a diligent search needs to be made for adoptive parents who have that “plus quality” required for accepting a handicapped child and helping him develop to his maximum capacity, some workers do not really believe that there are people who have the capacity to welcome and cope with these “special” children. Yet experience has shown that a hopeful resource for adoptive parents for such children lies in carefully selected foster parents who in their efforts to help the child overcome his handicaps might learn to love him and want him as their own.

Several experiences have convinced me that adoptions should not be ruled out for severely handicapped children.

Jimmy
First, there was Jimmy, born after an extremely difficult delivery. Soon after his birth, Jimmy’s mother, who was considered to be mentally retarded, was told that her child had suffered brain damage.
and could not be placed for adoption as she and her parents had requested. Jimmy was placed in an oxygen tent and remained in the hospital for 5 months, until he was taken to a nursing home where he stayed, receiving custodial care only until he was 2½ years old. Then he was brought to our public child welfare agency's attention by one of his relatives, who was concerned about him. When the child welfare worker first saw him she was shocked and heartsick. The child was pale, listless, and completely unresponsive. He made a queer babbling sound, but could not talk. He evidently had not had any solid food, as he did not know how to chew. His gait was staggered and he ran into objects. Later it was discovered that he could not see farther than a foot. His head was unusually large; there was a squint in one of his eyes; his teeth were small, stubby, and separated; and he was pigeon breasted. He commanded attention by beating his head on the floor or by having temper tantrums.

The child welfare worker arranged for Jimmy to have a complete physical and psychological examination. Testing indicated an IQ of 36, with a diagnosis of obvious mental and physical retardation. Adoption certainly did not seem feasible at this point.

Jimmy was placed in a carefully selected foster home where he could experience love, as well as good physical care. The foster parents were a farm couple who were happy and secure and who had an unusual capacity for loving a child. They were frankly told about his problems and were asked to observe this extremely neglected child closely and to give him every chance to develop.

After only 3 days of tender loving care, this sad, apathetic child began to respond to his foster parents. He rewarded them with his first smile and began taking some interest in his surroundings. The foster parents received their first clue to his potentials when they noticed that he observed what was going on around him and imitated readily. He soon learned to say "mamma" and looked to the foster mother to supply his needs.

Gradually the foster parents' initial feeling of pity began to change to love and pride in his progress. They had many discouragements during the first few months, but they never even considered giving him up. Neighbors made disparaging remarks. Their family physician frankly told them the child was not normal and advised them to return him to the welfare office before they became too attached to him. When the doctor's attitude became known, the child welfare worker persuaded him and the foster family to refer the child to a well-known pediatrician.

This pediatrician deserves much credit for Jimmy's eventual progress. He was hopeful from the first and gave generously of his time, talking with and encouraging the foster parents. He has said that, if Jimmy had remained in the nursing home another 6 months, he would probably have died of marasmus.

Convinced that Jimmy had possibilities, the child welfare worker supported the foster parents in all their efforts, helped them evaluate his progress, and gave them many helpful suggestions for handling specific problems.

After an eye specialist fitted him with glasses, Jimmy immediately learned to walk better, to explore, and to act more normally. This provided further indication of his potenialities. Later he underwent a double hernia operation, a tonsillectomy, and an adenoidectomy. All of these corrections helped to improve Jimmy's general health and disposition, and further strengthened the child welfare unit's conviction that probably he would become adoptable.

Six months after Jimmy's placement in their home, the foster parents petitioned for legal custody. From then on there was no question—Jimmy had found a permanent home. He was tested by the pediatrician and a school psychologist. This time his IQ was in the low normal range. Both examiners predicted he would be able to attend regular school.

Jimmy was legally adopted by his foster parents just 2 years after he had been placed in their home. Fortunately, he had been originally placed in a boarding home which might later be approved as an adoptive home, so that replacement for adoption was unnecessary. This, no doubt, would have caused regression.

Jimmy is now a happy, secure child. He runs and plays like a normal child and is well behaved. He still has a slight speech impediment, but has a good vocabulary and is very inquisitive. He has a retentive memory, likes books, and has learned to write his name. He was 7 years old in March and is now attending school. The only reason he did not attend kindergarten or nursery school was that there were no such facilities in his community. His foster parents have also adopted a little girl, and the two children are very congenial.

Manny

Manny is another child that once seemed to be unadoptable. He was born with a congenital heart condition. He underwent open-heart surgery for
banning the pulmonary artery and has since been in and out of the hospital several times. The doctor, who admitted him the last time in February 1961, said that he probably would not live very long.

Manny had been removed from his own home under court action because of neglect. He was weak, listless, and wheezed when he breathed. Placed in a good foster home after discharge from the hospital, he, too, responded to the patient, loving care of his foster parents. After 3 months in the foster home, he was walking and talking quite well, was toilet trained, and seemed happy and secure. His physical condition has improved to such an extent that now there are no restrictions on his activities. As in Jimmy’s case, Manny’s foster parents have fallen in love with him and have already petitioned to adopt him.

**Mack**

Another entirely different type of handicapped child is Mack who was born without legs. Otherwise he was a healthy, attractive baby. His parents were so horrified by his handicap that they refused to take him home from the hospital. He was placed in a boarding home with a foster mother who had previously been told about his condition, who was not shocked when she saw him, and who had the capacity to love him for himself. Arrangements were also made, through the State Crippled Children’s Service, to take him to the Amputee Center in Grand Rapids, Mich., where after two visits he was fitted with a prosthesis.

Mack’s first prosthesis was a plastic bucket which fit his hips and was fastened to a dolly so that he could move about with the aid of crutches. His sturdy body, strong arms, and a strong spine were assets in using this walker, which he loved because it enabled him to go places.

Mack is now 3 years old. At the age of 2 he was fitted with artificial legs, and he quickly learned to walk.

Mack is a happy child and has such an outgoing personality that he readily sells himself. He learned to talk early, could feed himself before he was 2, and was partially toilet trained. His desire to be independent was an asset in motivating him to use the artificial legs he will always need.

Fortunately there were foster parents who would accept Mack and who helped develop a better understanding of handicaps in their entire community. Some of their neighbors changed from attitudes of horror and ridicule to over-solicitousness. Others, as soon as they were exposed to the foster parents’ and worker’s enthusiasm and optimism, accepted him wholeheartedly. The State Crippled Children’s Service, the Missouri Society for Crippled Children, the county court, and the child welfare services of the Division of Welfare, State Department of Public Health and Welfare, contributed both money and service to meet Mack’s needs.

On one of our trips to the Amputee Center with Mack, the child welfare worker and I learned that two of the most severely handicapped, but apparently happy, children we saw there had been adopted. One of them had been born not only without legs, but also with a severe mouth deformity. When he was born, his lower jaw, lips, and tongue were fused together. They had to be separated by surgery before he could swallow, chew, or talk.

This child, now 8 years old, is able to walk and run well on his artificial legs without the use of crutches. His mouth is still deformed, but he can talk audibly and eat solid foods. Never have I seen a happier child or prouder adoptive parents. They told us that he had done more for them than they could ever do for him and that they had no regrets for the many hours spent in taking him to clinics and in teaching him to use his prosthesis, nor for the money they have spent on him and will need to continue to spend to help him develop to his maximum capacity.

This convinced us that somewhere there were parents for Mack, too. The next step was to obtain accurate diagnoses of both his mental and physical potentialities. Then efforts were made to find a permanent home for him.

When he was 2 years and 4 months old, Mack was placed for adoption with a couple who when they had applied for a child had not thought of a handicapped child but who, the worker sensed, had that “plus” quality needed by parents of the handicapped. She arranged for them to meet Mack and he readily sold himself to them.

Mack’s adoptive parents realize the responsibility they are assuming in accepting this permanently handicapped boy as their own, but they have no qualms about it. Aged 35 and 31, they have a son of their own aged 12. They live in a small town of 1,500 people, where Mack has already endeared himself to their friends and neighbors.

**Attaining the Goal**

Unfortunately there is still much disregard for
the value and rights of every individual, regardless of his condition. Who can predict which child may make the greatest contribution to society and which one is "worthy" of being helped? One of the doctors at the Amputee Center was a double amputee—as was the man who made the prosthesis. What a loss to society if they had been cast aside or neglected because of their handicaps!

Not long ago a 13-year-old boy who was born without legs was presented the St. John Ambulance Life Saving Award for saving a friend from drowning. A 10-year-old North Dakota boy, born without hands or feet, was named the 1960 National Easter Seal Child. This boy, with the use of artificial legs and hands, plays baseball, shoots marbles, is a Cub Scout, and receives better than average grades in school. Many severely handicapped children, if given a chance, can become self-supporting, responsible citizens. This "chance" involves receiving not only correction of their defects insofar as possible, but also the tender loving care and security of a home of their own.

In order to attain what should be our goal, a home for every child who is free for adoption, further attention needs to be focused on effective ways of achieving this goal. Briefly, in planning for a child with a severe handicap or an undiagnosed serious illness—it is well to select foster parents who might adopt, but it is important to let them understand clearly from the first that adoption may or may not be possible.

Potential adoptive parents should be involved in helping the child to become adoptable. They may grow to love him during his period of helplessness and dependency. The younger a child is placed, the more readily will he be acceptable and responsive. The child should always be honestly presented, but not oversold. Foster parents should not be made to feel they are expected to adopt the child. Neither should they be made to feel guilty if they have done all they can and the child does not respond, or it is found that their home does not meet his needs. If the child sells himself to the foster parents, if the worker is convinced of the high quality of love and care given him, and if the foster parents ask to adopt him, their wish to do so should be given serious consideration.

The "Child Welfare League of America Standards for Adoption Service," states:

Consideration should be given to supplementing the income of families that have the essential qualifications to meet the needs of children for whom there are insufficient homes, but whose income is too low to assume the full cost of care of a child. In this way children who might otherwise never be placed for adoption might be given the emotional security of legal adoption at no greater cost to the community than for long-time boarding home or institution care. A new group of applicants might be reached who do not apply because of limited income. Some boarding home parents to whom a child has become attached might be able to adopt him if financial support were continued.

In following these standards, goals must always be realistic. All community treatment resources available must be put to use in meeting the "special" child's needs. In planning for these "special" children, the child welfare worker should not only possess professional skill, but an abundance of courage, imagination, faith, and initiative. Backed by these qualities, efforts expended for "special" children can succeed.

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THE NEW THRESHOLD
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ACCENT ON PREVENTION THROUGH IMPROVED SERVICE

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On October 24, 1963, almost exactly a year after he received the report of the President's Panel on Mental Retardation, President Kennedy signed a bill which lays the groundwork for a broad attack on the problem of mental retardation along four major fronts underscored in the Panel's recommendations: preventive service, care and treatment, research, and community planning. As already reported in CHILDREN (see November-December 1963, page 243), the statute amends the Social Security Act to authorize:

* Increasing from $25 to $50 million, over a 7-year period, the ceiling on grants to the States for maternal and child health services, beginning in 1964 with an increase of $5 million a year.
* Similarly increasing the ceiling for grants to the States for crippled children's services to a maximum of $50 million in 1970.
* A new 5-year program of grants up to 75 percent of cost, to public health agencies for prenatal, delivery, and postnatal care for mothers and their infants regarded as facing special health hazards and unlikely otherwise to receive such care. The total authorization for this program is $110 million, in steps of $5 million in fiscal 1964, $15 million in 1965, and $30 million each year from 1966 through 1968.
* A new program, up to $8 million a year, of grants, contracts, or cooperative arrangements for research relating to maternal and child health services and crippled children's services.
* A onetime appropriation of $2.2 million for grants to the States, up to 75 percent of the cost, for planning comprehensive programs of prevention, treatment, and amelioration of mental retardation.

Under delegation from the Secretary of Health, Education, and Welfare, the Children's Bureau will administer the grants for maternal and child health services and crippled children's services, as it has in the past, and also the grants for special maternity and infant care projects and for research. The planning grants are to be administered by the Public Health Service.

Behind the broad scope of these provisions was the realization, spelled out clearly in the Panel's report, that the accent in any program to reduce and alleviate the increasingly vast problem of mental retardation in this country must be on prevention—prevention of the physical conditions in mothers and infants that lead to mental retardation and prevention of the social and emotional conditions that block
the development of whatever potential retarded children have. Both types of prevention, generally known as primary and secondary, come from two directions—applying what we know, and finding out what we do not know.

**Primary Prevention**

The goal of primary prevention is to give the child a healthy start in life. Important channels for reaching this goal are the maternal and child health services provided by the States and localities with the help of Federal funds made available under the Social Security Act. These services, which the new amendments open to expansion, have implications for maternal and child health far beyond the prevention of mental retardation. Focused largely on the provision of prenatal and postnatal care, well child supervision, immunization against communicable disease, school health examinations, dental services, and clinical services for mentally retarded children, they have undoubtedly played a major role in the reduction of infant and maternal mortality over the years and in the prevention and alleviation of disease and disability in infancy and childhood. They have not, however, generally kept pace with increases in the child population, with advances in medical knowledge in some respects, and with increases in the costs of professional service. Hence the need for expansion in all their aspects.

Basic to reducing the incidence of retardation associated with childbearing is the expansion of maternity services. As is pointed out in the report of the President's Panel on Mental Retardation, the prevalence of mental retardation is higher in population groups having inadequate maternity care. The rate of premature births is highest among these groups, and the incidence of mental retardation is substantially higher among premature infants than among full-term infants. It is not difficult to guess who the groups of women are who receive inadequate maternity care. They are, in simple terms, the poor.

According to an AFL-CIO study of 1958 incomes, there were more than 41 million people in the United States, or 24 percent of the population, in families with incomes under $3,000 a year. However, if poverty is defined by the lower criterion of having an income of not more than $2,500 for a family of four, and proportionately higher for larger families, then 19 percent of the population, or 32 million people, are poor. Where these families are might be surmised by a look at recent infant mortality rates, another indication of inadequate maternal and infant care.

In 1960, nine of the 10 largest cities in this country had infant mortality rates exceeding the national rate of 26 per 1,000 live births. In 7 of these 10 cities, there were increases in infant mortality rates between 1950 and 1960, ranging from 5.6 percent to 26.4 percent. In nonmetropolitan counties—those with centers of population smaller than 50,000—the infant mortality rate in 1960 was also higher than the national rate.

These data point to a concentration of problems of maternal and child health in the larger cities and in the rural counties. This has always been true of the rural areas; what is new is the growing seriousness of the situation in the cities.

In recent years, there has been an increasing concentration of low-income families in the major cities where they constitute a larger proportion of the population than they do nationally. Such changes result in heavy demands on public health services. For example, in Baltimore registration at prenatal clinics rose 133 percent in the decade between 1950 and 1960, and in well-baby clinics, 59 percent. Other cities are having similar experiences. For example, in the District of Columbia, it has been found that only 40 percent of the births to women residents are attended by physicians as private patients. In New York City, only 60 percent of the city's residents giving birth are private patients. Thirty percent of all infants in the city receive their health supervision at the health department's well-baby clinics; in one district, the proportion is over 80 percent. In Dallas, a recent study revealed that 36 percent of the maternity patients make partial or no payment.

In seeking medical care, these low-income families are straining the resources of the communities in which they live. For the most part, they receive outpatient and hospital care in the tax-supported hospitals as voluntary hospitals increasingly require payment by or in behalf of each patient admitted. The result has been a great overcrowding of many city tax-supported hospitals, leading, along with understaffing, to conditions which are incompatible with a decent quality of care.

To accommodate such large numbers, some hospitals discharge maternity patients 24 to 72 hours after delivery. In Chicago the Cook County Hospital delivered almost 20,000 patients in 1962, and as a result of overcrowding is in danger of losing its accreditation. Yet the Cook County Hospital is required by law to accept all eligible patients.
Michael Reese Hospital, the only voluntary hospital in Chicago which takes large numbers of indigent maternity patients, periodically closes intake in its prenatal and other clinics because of the excessive caseload. The Cook County Hospital cannot do this, and consequently clinic patients often have to wait all day to be seen, and sometimes have to return the next day. Demands on well-baby clinics are similarly high, yet in Chicago the number of well-baby clinics operated by the health department was cut down from 98 in 1945 to 49 in 1960. A 26-percent decrease also took place in well-baby clinics sponsored by the Infant Welfare Society, a voluntary organization.

Dr. John D. Thompson, professor and chairman, department of obstetrics and gynecology at Emory University School of Medicine, Atlanta (Ga.), in an unpublished report has aptly described the situation in many city hospitals:

On the obstetrical services of these large charity hospitals, the massiveness of the prenatal clinics is unbelievable. It is simply not possible to give adequate prenatal care under these circumstances of too many patients and too few doctors, nurses, and social workers, and inadequate facilities. Each patient is seen by a doctor for only a very few minutes. The doctor does not get to know the patient and the patient does not get to know the doctor. Many important aspects of prenatal care have to be omitted. In a recent study in our hospital (Grady Memorial), it was found that 23 percent of all patients delivered came to the hospital first when they were in labor, having had no prenatal care. Only 11 percent of all delivered patients came for prenatal care in the first trimester of their pregnancy. This is in marked contrast to the experience in private practice. Ninety to 95 percent of the patients delivered by private obstetricians had had prenatal care beginning in the first trimester. I point to our hospital only as an example of a situation I know to exist in almost all of the large charity hospitals in this country.

In support of Dr. Thompson's statement are figures which show that in Dallas, approximately one-third of low-income obstetrical patients had received no prenatal care; at the Los Angeles County Hospital in 1958 the proportion was 20 percent; at the D.C. General Hospital in Washington, D.C., 45 percent.

Studies of why women have failed to receive prenatal care cite a number of deterring factors important among which are: transportation difficulties and expense caused by the centralization of clinics; unrealistic financial and residential eligibility requirements for clinic care; and dissatisfaction with the long waiting hours and impersonal attitudes encountered in the clinics.

The relationship between the lack of prenatal care and prematurity has been well-established.

In Philadelphia in 1961, in a district where only 1 percent of the maternity patients had had poor or no prenatal care, the prematurity rate was 7.9 percent. In another district where 36 percent of the women had had poor or no prenatal care, the prematurity rate was 15.7 percent.

A study done in New York City in 1957 found that among 70,952 women with adequate prenatal care, the prematurity rate was 7.8 percent. Among 8,083 women with no prenatal care, the prematurity rate was 20.3 percent.

In Chicago in 1961, the prematurity rate in the highest income census tracts was 7.5 percent; in the lowest, it was 14 percent. Comparable figures in New York are 6.2 percent and 16.5 percent.

Because prematurity, as defined by birth weight, occurs more frequently among nonwhite groups, the possibility of a relationship of this increased frequency to genetic or racial factors is sometimes expressed. Studies of rates of prematurity among Negro private patients do not bear this out. The study of Negro maternity patients in a prepaid group practice medical care plan in New York (Health Insurance Plan) shows that 8.5 percent had premature infants. While higher than the white rate of 5.5, it is close to the national average and far below the rates quoted here of women giving birth in unfavorable circumstances.

Roads to Improvement

The recent amendments to the Social Security Act related to maternal and child health services hold out great promise for attacking these problems more effectively. They may make it possible for State and local health departments to:

- Increase the number of prenatal and postnatal clinics.
- Bring such clinics close to the population served.
- Establish special clinics for some patients with complications of pregnancy (where more time by obstetricians, nurses, social workers, nutritionists, and others can be provided).
- Pay for hospital care not only for the delivery but also during the prenatal period as needed.
- Relieve overcrowding in tax-supported hospitals by paying for care of indigent patients in voluntary hospitals.
- Pay for hospital care of premature infants and other infants needing special attention.
First, we must seek out the causes of mental illness and of mental retardation and eradicate them. Here, more than in any other area, "an ounce of prevention is worth more than a pound of cure." For prevention is far more desirable for all concerned. . . .

Second, we must strengthen the underlying resources of knowledge and, above all, of skilled manpower which are necessary to mount and sustain our attack on mental disability for many years to come. . . .

Third, we must strengthen and improve the programs and facilities serving the mentally ill and the mentally retarded. The emphasis should be upon timely and intensive diagnosis, treatment, training, and rehabilitation. . . .

. . . For too long the shabby treatment of the many millions of the mentally disabled in custodial institutions and many millions more now in communities needing help has been justified on grounds of inadequate funds, further studies, and future promises. We can procrastinate no more. . . .

JOHN F. KENNEDY, in his message to Congress on mental illness and mental retardation, February 5, 1963.

• Provide medical consultation services for patients with complicated conditions.

Under the special projects provision of the amendments, the use of project grants rather than the formulae apportionment system used in the other programs means that aid can be channeled on request to places of greatest need. Large cities as well as rural areas may be included.

The expansion of the maternal and child health program may also make it possible for explorations to be made in methods of providing comprehensive health care, as recommended by the report of the President's Panel on Mental Retardation. The report, for example, recommended that the Children's Bureau support some demonstration programs in the provision of long-range child health supervision among poorly motivated families. This would have pertinence for children who become retarded because of the lack of stimulation in their environment. One way of providing continuity in care suggested by the Panel was the establishment of maternal and child health centers in which the professional staff would divide their time between the centers and the hospitals.

Additional explorations might also be made into ways of making the most effective use of hospital and clinic staff in face of the serious shortages of professional personnel.

Most important perhaps will be the ability a stepped up program will give the States to keep pace in their ongoing maternal and child health services with increases in the population and advances in medical knowledge. The result will be earlier detection of conditions in mothers and children which lead to mental retardation as well as earlier case finding of retarded children themselves.

Secondary Prevention

A major part of these stepped up maternal and child health services is envisioned as being an expansion of diagnostic and treatment services for mentally retarded children. Today 77 special clinics operating as a part of maternal and child health programs are providing diagnostic evaluations of mentally retarded children, interpretations to their families, and followup help with child care and management. Such services are important tools in secondary prevention, for through the parents they help the child to make the most of his capacities. In 1962 these 77 clinics served 20,000 children, most of them of preschool age, in 46 States. But this has not been enough. Waiting lists at all these clinics are long, and for many families with retarded children the nearest clinic is too far away to help. Even before passage of the amendments, 24 States had asked for additional Federal funds to expand existing clinics so that they might extend their services to more families.

This goal will soon become possible. It will also become possible to develop new clinics so that eventually every State will have a network of clinical programs. Another goal is to help established clinic programs extend the types of services they offer to include genetic counseling and chromosome analysis for couples who are worried about the possibilities of having a defective child.

Other goals are to expand the professional training programs carried on in such clinics to pediatricians, clinical psychologists, and other professional
personnel, and to train auxiliary workers, such as recreational and occupational therapists, day-care teachers, and institutional workers in ways of working more effectively with the retarded.

Demonstrations may also be made through these clinics of ways in which intensive pediatric care begun early in life can prevent the development of secondary handicaps in retarded children.

Children who carry the double burden of physical and mental handicaps have been the least likely to get the services they need. State crippled children's programs have not been able to keep pace with the rise in demand for their services—due largely to the rise in child population—nor with the rising costs of medical and hospital services. Hospital costs, which comprise 40 percent of the cost of crippled children's services, rose from an average daily cost per patient of $16.77 in 1951 to $34.98 in 1961, and are continuing to increase at the rate of almost 7 percent a year. Nevertheless, during 1962 State crippled children's agencies, with $25 million in Federal funds and $54 million in State and local funds, provided medical care and other corrective services to 384,500 children with such conditions as congenital heart disease, cerebral palsy, rheumatic heart disease, hearing impairment, epilepsy, and orthopedic problems.

In some States the proportion of children served in these programs who had mental as well as physical handicaps was as high as 17 percent. In many States, however, the crippled children's agencies, faced with waiting lists and limited funds, pass over severely retarded children in making selections of who is to be served. Sixteen States make no attempt to provide crippled children's services to children in institutions for the retarded, and 24 other States provide only very limited services to such children.

A major goal in the expansion of crippled children's services, as authorized under the new amendments, is to help the States extend their crippled children's services to retarded children both in and outside of institutions. Another goal is the establishment of clinical centers for children with multiple handicaps, including retardation. Only a few States now have such clinics. Their obvious advantage is that they make it possible for the child to be evaluated as a whole, with the interrelationships of his physical and mental handicaps taken into account in his management and treatment. Another advantage is the reduction of strain both on parents and child when they no longer have to travel from clinic to clinic to secure the kind of care the child needs.

Correcting a mentally retarded child's physical handicaps is an important aspect of secondary prevention, for when a physical burden is lifted or lightened the emotional burden which aggravates retardation is also alleviated.

Any child who has a handicap of any kind ought to get the professional attention and care he needs. Unfortunately, some crippled children's agencies have been able to offer service only in regard to a few specific handicapping conditions. Therefore, the priority goal in looking toward the expansion of these services is to bring about a broadening of the term “crippling” so that services may be provided to children handicapped by any form of disability or long-term illness, including mental retardation. Other goals are the development of inpatient and outpatient facilities for adolescents and an increase in demonstration and specialized training projects.

Research

New scientific knowledge about the causes of mental retardation—the foundation of preventive efforts—must come from basic research into the biological and psychological processes of human growth and development. Such research is now being carried on in many parts of the country, much of it under the auspices of the National Institutes of Health. But unless there is also research into the application of knowledge through services, preventive efforts may prove ineffective.

Until passage of the recent amendments to the Social Security Act, the Children's Bureau had no specific authority to make grants for research related to maternal and child health services and crippled children's services. It did, however, support a few studies, such as the trials of the Guthrie blood-drop test for detecting phenylketonuria, an inborn error of metabolism responsible for serious retardation in untreated children. (See Children, September-October 1963, page 201.) However, under the new research authorization for making grants to public and other nonprofit agencies and universities, other questions important to the evaluation and improvement of services can be sought in a systematic fashion. Among those specifically concerned with services to retarded children are:

- What methods of assessing a mentally retarded child's potential for progress can be developed which would not require a full diagnostic team and could be applicable in the physician's office?
- What are the costs and comparative effectiveness

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of providing clinical services to mentally retarded children through various settings—hospitals, local health departments, traveling clinics, and so forth?

- What is the availability of services for blind retarded children, and what kinds of services do they require?

Other researchable questions important to the improvement of maternal and child health services and crippled children's services are:

- How can school health services be improved, especially in relation to followup on recommendations for medical care?
- What are the problems which low-income families experience in obtaining medical care?
- What experimental approaches can be developed to assist physicians in the provision of medical care?
- What are the indices for determining the quality of hospital care for mothers and newborn infants?
- How many children with operable congenital heart conditions are not receiving care, and why?

**A Rounded Approach**

Rounding out this broadened program of services to mother and children, with its heavy accent on prevention of both mental and physical disabilities, is the authorization for project grants to the States for planning action to combat mental retardation. The major goals of this provision are to engender interest and support for services within States and communities and to foster the development and coordination of the mental retardation aspects of programs of education, rehabilitation, welfare, employment, health, recreation, and legal protection of the mentally retarded.

The importance of coordinated planning was strongly stressed in the report of the President's Panel on Mental Retardation, which specifically recommended that such grants be authorized. Behind the recommendation was the finding that resources for the mentally retarded vary widely from State to State and among cities and counties within the States. Stimulation of community interest and coordinated action would be necessary, the report indicated, for filling those gaps.

Mankind is a long way from the millennium of eliminating the tragic problem of mental retardation. In the new amendments to the Social Security Act, however, vast opportunities have been opened for preventing its occurrence in many families and for alleviating the suffering it causes in many others.

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