HEALTH SERVICES for MENTALLY RETARDED CHILDREN

a progress report 1956 -- 1960

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HEALTH SERVICES FOR MENTALLY
RETARDED CHILDREN

A PROGRESS REPORT

1956-1960

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Social Security Administration
Children's Bureau

1961

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The Children's Bureau concern for mentally retarded children stems initially from its responsibility under the Basic Act of 1912 to "investigate and report on all matters pertaining to the welfare of children and child life." In the first 6 years of its existence, three of the major studies produced by the Bureau dealt with mental retardation. This interest has continued.

The passage of the Social Security Act in 1935 and the assignment to the Bureau of the added responsibility of administering Federal grants for maternal and child health, crippled children and child welfare services, emphasized the principle that all of the people of the United States, through the Federal Government, share with the State and local governments responsibility for helping to provide community services that children need to have for a good start in life. The Social Security Act also afforded the Bureau an opportunity to help the States develop demonstrations and special programs in areas where there were gaps in services.

Health services to mentally retarded children has been one of these gaps. This report shows how the States have used the special maternal and child health grant-in-aid funds, consultation and existing resources in beginning to fill this gap. It does not include the program activities of the Division of Social Services in regard to mentally retarded children and their families.

Arthur J. Lesser, M.D.
Director
Division of Health Services
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Before 1940, mental retardation was not of great concern to this Nation. Most of the 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. Most States were fairly complacent about what they did for this group: chiefly, special classes for school-aged children in a few urban areas, and 75 State operated institutions for residential care of those who could not function in the community.

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. Almost 4 years were added to the expected life span of these babies.

As the population increased, so did the number of mentally retarded. Better care of all babies and medical advances resulted in the survival of more babies destined to be retarded. They began living longer, too. Mothers and fathers of retarded children began to band together to seek help for their children. Reports began to appear showing what some of the retarded children could achieve if help were provided.

By 1950, the 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 needs of retarded children was the Children's Bureau of the Department of Health, Education, and Welfare.

In 1954, the mentally retarded were one of the four groups of children cited by the Children's Bureau as being particularly disadvantaged and requiring special attention. To evaluate what could be done for this group, the Bureau through its health service grant-in-aid program assisted 4 States\(^1\) in 1955 in setting up special projects designed to demonstrate how clinical services might be developed for such children in the community. Special grants were made to these health departments.

Other constituent agencies of the Department of Health, Education, and Welfare were also becoming concerned with the problem of mental retardation. This general interest resulted in the development of an Intradepartmental Committee composed of representatives from the various agencies of the Department. This committee developed a balanced program for mentally retarded children and adults. Responsibility for specific services was assigned to various bureaus, branches, and divisions of major operating agencies.

\(^1\)Hawaii, District of Columbia, Washington and California.
The major assignment of the Children's Bureau was to stimulate the formation of services for children, particularly young children. The development of clinical services in the community appeared to be a major need. The National Association for Retarded Children, the then new national group speaking for the organized parents who had mentally retarded children, highlighted this need in the 1956 presentation to Congress.\(^2\)

Child guidance clinics at that time offered limited diagnostic services to mentally retarded children. Such services usually were only able to evaluate the problem presented and determine suitability for psychiatric treatment. In most instances, the treatment resources either were so limited that they were not available for the retarded person or were felt to be ineffective with them. Furthermore these clinics were serving chiefly school aged children. They usually did not get to see the mentally retarded children until they were in school and presenting adjustment problems.

The professional workers related to those crippled children's programs which dealt with cerebral palsey children were probably more familiar with most aspects of the problem of mental retardation than workers in other community services. However, the crippled children's program itself which is primarily a medical care program, did not appear to offer a framework on which to develop special services for the mentally retarded children who had no associated handicaps. In only one-fifth of the States did the crippled children's regulations specifically include the mentally retarded children in the category to be served. Almost half of the States specifically excluded mentally retarded children from eligibility for crippled children's services.

Maternal and child health activities in behalf of mentally retarded children and their families were extremely limited. Many local public health nurses were reporting suspected mentally retarded children in their case load, but for the most part they had few resources for making 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 level of development were being followed in well child conferences. While some further diagnostic appraisal was obtained for many of these children, no resources or services existed for future care or help once such a diagnosis had been made.

Testimony before the House Appropriations Committee in 1956 indicated that the principal needs for the mentally retarded children were to find them early, to make complete evaluation, to interpret the findings to their parents and to use the findings as a basis for ongoing help and care. By age groups, the greatest gap in services related to infants and preschool children. It appeared that lacking services could best be provided through the maternal and child health program.

On this basis and to achieve these goals, the Congress increased the annual maternal and child health appropriations for the fiscal year 1957 and earmarked $1 million specifically for special projects serving mentally retarded children.

\(^2\)Hearings for Departments of Labor and Health, Education, and Welfare Appropriations for 1957 before the subcommittee of the Committee on Appropriations, House of Representatives, Eighty-Fourth Congress, Second Session, (Statements of Members of Congress, Organizations and Interested Individuals), pp. 125-152.
children. Also the Appropriations Committee expressed the hope that a second million dollars of the increase to be distributed to the States on a regular formula basis be used to implement services for these children.

These beginnings of the Children's Bureau major program emphasis for mentally retarded children were also the first steps in a large scale public health attack on the problem.
During the first 3 years of its operation this program achieved many things.

52 States initiated special activities on behalf of mentally retarded children as a part of their public health activities.

46 States began providing clinical services to mentally retarded children and their families living at home.

50 specialized clinical teams began providing new kinds of help to mentally retarded children and their families.

Over 200 specialists from various disciplines were recruited and trained to provide service and leadership in these programs for the mentally retarded.

Over 25,000 public health nurses received some training and orientation in mental retardation and in assisting families in the home care of mentally retarded children.

14 medical schools began using the special clinical services to retarded children as the basis for training of medical students, residents and interns.

Some 4,500 medical students, residents and interns were trained in the newer concepts and approaches to the problem of mental retardation.

Over 1,200 nursing students received some preparation in working with the mentally retarded.

More than 25,000 retarded children were given complete evaluations and followup care.

Public health methods of screening were evolved to detect and prevent mental retardation due to phenylketonuria, an inborn error of metabolism.

26 States began utilizing these methods and set up programs to detect and treat phenylketonuria, and during 1960 more than 25 infants with phenylketonuria were detected and placed on a diet which will prevent mental retardation.
THE SPECIAL DEMONSTRATION PROJECTS

What they are

The core of the Children's Bureau Division of Health Services program for mentally retarded children has been the special demonstration projects. These projects have been set up and administered by State health departments with consultation from the Children's Bureau. The earmarked maternal and child health funds have primarily been used to assist States in developing these programs.

Approved project plans have one or more purposes:

1. Patient Care -- Projects designed to provide early detection, evaluation, and care needed by mentally retarded children, or to demonstrate new ways of providing this care.

2. Training of Professional Personnel -- Projects designed to train professional persons in better ways of dealing with retarded children and in more effective use of professional skills in their behalf.

3. Demonstration Studies -- Projects designed to reveal what is needed for an effective program, how such a program can best be set up and administered, what it will cost, how it can be evaluated, etc.

All of these demonstrations depend on developing a specialized clinical team. The majority of these projects are set up within a maternal and child health program. Their primary focus is early finding of children suspected of being retarded. Project services are geared chiefly to infants and preschool children. A pediatrician usually heads the treatment team, which includes a social worker, a clinical psychologist and a public health nursing consultant. Additional team members may be added from other specialists, or from different professional backgrounds.

By the end of fiscal year 1960, 32 States had developed special demonstrations with Federal funds. The growth of these programs can be seen from table I.

Table I

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>Number of States</th>
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<tbody>
<tr>
<td>1955</td>
<td>XX (2)</td>
</tr>
<tr>
<td>1956</td>
<td>XXXX (4)</td>
</tr>
<tr>
<td>1957</td>
<td>XXXXXXXXXXXXXXXXXX (25)</td>
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<tr>
<td>1958</td>
<td>XXXXXXXXXXXXXXXXXX XXXXX (27)</td>
</tr>
<tr>
<td>1959</td>
<td>XXXXXXXXXXXXXXXXXX XXXXX XXXXX (30)</td>
</tr>
<tr>
<td>1960</td>
<td>XXXXXXXXXXXXXXXXXX XXXXX XXXXX XXXXX (32)</td>
</tr>
</tbody>
</table>

3 The earmarked $1 million and an additional $400,000 in special project maternal and child health funds.
In addition to these projects which depend on Federal funds, the Bureau emphasis on mental retardation has resulted in 21 additional States developing demonstrations and service programs for retarded children as a part of their ongoing maternal and child health program. The States support these projects with maternal and child health funds, a part of which also includes Federal funds. The growth of these additional programs is shown in Table II.

Table II

Growth of Special Services in Regular MCH Programs

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>Number of States</th>
</tr>
</thead>
<tbody>
<tr>
<td>1958</td>
<td>XX (2)</td>
</tr>
<tr>
<td>1959</td>
<td>XXXXXXXXXX (14)</td>
</tr>
<tr>
<td>1960</td>
<td>XXXXXXXXXX (21)</td>
</tr>
</tbody>
</table>

Thus, by the beginning of 1961, only one out of 53 States did not have as a part of its approved health department plan some kind of special service for the mentally retarded.

The services that were provided

Services provided through this program can best be described by the amount and kind of patient care, professional training and demonstration studies that have flowed from it.

1. Patient care

By the end of 1960, 46 States were providing as a part of their demonstration some special direct clinical services to retarded children and their families. Based on reports from 38 States close to 12,000 mentally retarded children and their families were served by these programs during 1960. Seventy-five percent of the children were under 9 years of age. Over 50 percent had associated handicaps.

While these services would not have been available without this program and while the cost to the Federal Government was comparatively low, the total number of children served represents only a comparatively small proportion of the age group needing this help.

The emphasis in these programs has been on providing a demonstration of high quality service for a limited number. The actual numbers served, therefore, are not the main index of the success of these programs. They must be judged by how well they were able to show what makes up an evaluation of a retarded child, by what kind of help can be given to parents, and by how successful were they in finding abilities in these children which could be used as the basis for training and adjustment.
The real criteria on which these services will have to be judged will be the improved adjustment of the children and the families they serve and the extent to which they can stimulate good service in general to preschool retarded children.

2. Training of professional personnel

Almost all of the projects use their services for training of professional workers. Much of this training is on an informal, individual basis. It is accomplished by providing a setting where interested professionals can observe and can confer with a specialized team.

It is also achieved through contact with the variety of professionals in the community who have known the individual child being evaluated or treated. Physicians, social workers, public health nurses, teachers, etc., who have known the child are invited to participate in the staff conference and in the development of a program plan for the patient. In the course of this they are exposed to new concepts and ideas. Working with the team they are exposed to other viewpoints and approaches. Since in the average case at least 3 professionals outside of the clinical team are involved or concerned, we estimate that more than 25,000 professionals have had such exposure by these projects.

In order to obtain the kinds of services the projects feel these children need, they usually find it necessary to stimulate some inservice training programs for professionals and agencies with whom they need to work closely, and on whose services they are dependent in carrying out plans for the child. Public health nurses are an example of such a group. Through the stimulus of the projects, 9 out of every 10 public health nurses have received some inservice orientation and education in mental retardation during the past 3 years.

More formalized training is also being provided, especially through the 14 projects which have been set up at or in conjunction with medical schools. In these programs, the patient care is used for teaching medical students, interns, residents, and other personnel associated with medical schools. Formal course material is also prepared and presented in the regular curriculum. Last year, approximately 2,520 hours of staff time in these projects were used for training. Fifteen hundred second year residents and medical students, 200 nurses, and 300 teachers were trained. These projects also provide field work placement and supervision for approximately 30 social work students, and a few medical fellowships.

The Tulsa, Oklahoma, project provides special two-week training courses for clinical teams specializing in mental retardation and offers short, similar courses to public health nurses, social workers, nutritionists, physicians, psychologists, teachers, etc. Also, this program has offered special two and three day institutes for the clergy.

nursing educators, nutrition consultants and others. An institute on management of mentally retarded persons is planned for police officers.

3. Demonstration studies

Seven programs have been set up to study a particular phase of mental retardation or special ways of providing care. Some of the areas included in these projects were:

a. Study of the growth and development patterns of young retarded children (California).

b. Study of the services a metropolitan area needs for the mentally retarded and an assessment of how these services can be provided (Colorado).

c. Evaluation and study of the use of a traveling clinic to provide services to the mentally retarded over a large section (Idaho).

d. Study of record keeping and evaluation of patients in an ongoing program (Maryland).

e. Assessment of how to provide services in a rural area (Minnesota).

As the projects have developed, however, almost all have set up studies as a part of carrying out their major functions. Facets studied include dental problems of noninstitutionalized retarded children, problems of mental retardation in a population of Indian children living on reservations, waiting lists of children for admission to State institutions, the effect of the religious background of the family on their ability to accept the retarded child, the use of group approaches in family counseling, and attitudes of medical students towards the retarded.

There are tremendous potentialities for extended study and research being made available by the case material and experiences of these 44 programs.
The Children's Bureau Technical Committee on Clinical Programs grew out of the recommendations of a conference of maternal and child health directors and clinic directors held in Washington, D.C., in March of 1958.

Originally, the Committee consisted of 14 physicians, representing various regions of the country and fields such as pediatrics, psychiatry, maternal and child health, clinics, medical schools, and schools of public health. Subsequent additions brought in persons from all of the disciplines represented on the clinical team in the project. Technical assistance and staff help are supplied by the Children's Bureau, Division of Health Services.

Since 1958, the group has met annually. Seldom have deliberations been limited to the committee members. Free use has always been made of other experts invited to discuss particular areas. Requests for copies of the minutes of the annual meeting exceed 550.

In addition to providing guidance and advice to the Children's Bureau, the Association of Maternal and Child Health and Crippled Children's Directors, and other professional groups, this committee has:

1. Participated in the revision of the American Association on Mental Deficiency Manual on Terminology and Classification. Upon completion of this classification scheme, the Technical Committee stimulated its trial tests in the special community clinical programs and on the basis of this experience suggested further changes to AAMD. The classification has been adopted by 90 percent of the community clinical programs for mentally retarded persons. Thus in place of five previously used classification schemes, most programs are now using the same system. The collection and tabulation of comparable nationwide information on the medical classification and etiology of cases seen by the clinics are now possible.

2. Developed channels of communication among the projects. Clinical data and pictures of unusual cases have been given nationwide circulation through these channels. Brief case and progress reports as well as annual reports of special interest have been circulated. Several projects are publishing periodic newsletters for circulation. As a result, any one program can have access to the opinions and experience of 81 clinical teams throughout the country.

3. Stimulated the development of disciplinary working groups of professionals represented on the project team. For example, the public health nurses have set up an informal national committee. Several meetings have been held. The committee sponsored several working groups which are evolving principles and guides in regard to public health nursing activities in mental retardation. The clinical psychologists in the projects have also formed such a group. Through regional
meetings, these psychologists are not only clarifying problems of testing and assessment of retarded children, but are planning some cooperative research which would be a combined effort of several projects. The medical social workers have likewise organized a national group for a similar purpose which held its first meeting in Miami.

Each of these groups has a representative on the Technical Committee. This person will act as a liaison representative with their own disciplinary group and the Technical Committee.

4. Developed screening, detection and treatment services for phenylketonuria. This work has been the major achievement of the Technical Committee. Phenylketonuria is an inborn error of metabolism. The babies who have this condition are born normal. But early in life they begin to deteriorate because of an inherited defect in the enzyme which normally converts an essential amino acid contained in milk and food into a substance the body can use. If the condition is undetected and untreated, almost all of them become severely retarded.

While phenylketonuria (PKU) affects 1 in approximately 20,000 infants, it is one cause of mental retardation about which something can be done. The mental retardation can be prevented if the baby is placed on a special diet early enough.

How this condition of PKU is approached is important not only because the serious effects of the condition are amenable to treatment, but more important because of other similar inborn errors of metabolism which result in mental retardation. Some of the methods used in dealing with PKU may be applicable to other inborn errors of metabolism.

The methods of screening, detection and treating PKU which have been evolved are also examples of how known research findings can be applied and developed into an ongoing program.

In 1958, the Technical Committee had available to it some scattered research findings on PKU. Some screening tests were available, diets had been tested and the biochemical aspects of the condition had been clarified. What was needed was an effective method of screening, confirming diagnosis and managing diets on a large scale basis. Approached as a public health problem by the Committee, a series of suggestions based on public health methods were made by the Committee. Some of these approaches had worked with other conditions. Members of the Committee and the agencies they represented tested out these approaches and made some further refinements and suggestions.

A two-fold program was eventually outlined and recommended to the States:

- 10 -
a. Routine screening of well babies for PKU.

b. Screening of high risk groups, such as patients in institutions for the mentally retarded, special clinics for retarded children, special public school classes for retarded children, seizure and dermatology clinic populations, etc. It was estimated that such screening would show approximately 1 percent of these high risk groups had the condition. By tracing the families of these known cases, new babies born to them could be carefully screened. It was hoped that through such approaches a high proportion of new born siblings with PKU would be found early enough to prevent retardation.

As a result of these recommendations and the dissemination of the Committee's deliberations, more than half of the States have set up programs for PKU. These include statewide screening, laboratory facilities to confirm the diagnosis, and provisions for dietary management and followup. Seventeen States are routinely screening their well baby population. Seventeen States, including some of the above, are also screening and following up high risk groups. Almost all of the special clinical programs and the State institutions for the mentally retarded have set up routine screening programs for PKU. In addition, a great number of district and local health departments have set up PKU programs in areas where there is no statewide program.

Both local and State health departments are spending considerable time in helping private physicians carry out these programs with their private patients. Information, testing materials, laboratory facilities and dietary products have been made available to private physicians for work with their patients.

No complete survey has been made of the number of PKU infants who have been detected and placed on a diet as a result of this effort. However, it can safely be estimated that during 1960 at least 25 infants have been located and placed on a diet before damage or mental retardation took place. If these infants had remained undetected and untreated, probably most of them would have become so severely retarded that they would have required life long institutional care. Assuming that the median age at the time of death of these children after placement in an institution is between 35 and 40 years and that conservatively the average cost during those years to the State would be approximately $2,000 per year, these efforts can be said to involve a potential saving to the States of close to $2 million. To this saving must be added the value of the potential earnings and productivity of these infants.

Based on reports from selected State institutions. It is expected that within the next few decades, these median ages will continue to extend upward, and that cost of care will likewise increase.
MENTAL RETARDATION AND THE FUTURE

Within the next 10 years, the problem of mental retardation will undergo many changes. Some of these expected changes which will have to be taken into account in planning programs are:

An increase in the size of the problem

The number of individuals who are mentally retarded will increase. This growth will continue until more is learned about the prevention of the numerous conditions which can result in mental retardation. Without such success in identifying and removing or preventing some causal factors of mental retardation, the expected increase in the size of the problem is predicated on:

1. Anticipated general population growth

The expected growth in population will also increase the number of mentally retarded. At the present time, it is estimated that 3 percent of the population are retarded. Thus, in 1955 with a total population in the United States of 164,302,000, the number of mentally retarded individuals was estimated at approximately 5 million. The numbers in 1960 and projected for 1970 are shown in table III.

<table>
<thead>
<tr>
<th>Year</th>
<th>Population</th>
<th>Mentally Retarded Individuals (Millions)</th>
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</thead>
<tbody>
<tr>
<td>1960</td>
<td>179,323,000</td>
<td>5.4</td>
</tr>
<tr>
<td>1970</td>
<td>213,547,000</td>
<td>6.4</td>
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This would mean that by 1970, there would be six retarded individuals for every five who needed services in 1960.

2. Increased life span

Disease control, new drugs, and higher standards of living have steadily increased the life span of most Americans. While in 1900 a baby was expected to live for 50 years, the average baby born in 1960 can expect to live close to 70 years. Such lengthening of life expectancy considerably increases the number of the population at any given time.

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7. Interdepartmental Committee on Children and Youth: CHILDREN IN A CHANGING WORLD. Washington, D.C.: Interdepartmental Committee on Children and Youth, 1960. 84 pp. (Chart 16, p. 18)

Provided by the Maternal and Child Health Library, Georgetown University
While the mentally retarded as a group fall below the average life expectancy, the number of years the average retarded individual lives has been increasing proportionately with the overall average. Recent studies clearly document a diminishing death rate and an increased life span for the mentally retarded both in and out of institutions in the past decade.

This increase in life span adds materially to the number of mentally retarded persons, particularly in the upper age levels, and again increases the size of the total group.

The indications are that with the increased availability of health services, the life span of mentally retarded persons will continue to increase and move closer to the average life expectancy of the general population.

3. Increased infant survival rates

Improved and more extensive prenatal, obstetrical and pediatric care have brought about marked increases in the infant survival rate in the Nation over the past 20 years. Such efforts, along with increasing the chances of survival of all infants, has also increased the survival rates of infants who are premature or who have congenital handicaps or malformations. Since mental retardation is one of the major conditions associated with such handicaps in infants, improved care has to an extent also increased the number of the retarded for whom special services will be needed. No accurate estimate is available of the number of infants who now survive but who probably would have died in the past. An indication of the extent of such survival, however, can be seen in the changing characteristics of institutional populations and in the increased rates of first admissions of retarded infants to these institutions.

For example, a recent study compared rates of first admissions to State institutions for the years 1936 to 1938 with those from 1953 to 1955. This comparison showed that the admission rates for the ages 0 to 4 more than doubled, while there was a slight increase for ages 5 to 9, no change in admission rates for ages 10 to 14 and a decline in admission rates for all other age groups.

Such increased rates of survival of retarded infants will eventually have a marked effect on the size of the problem. A more immediate effect will be to increase the number of retarded infants who will require care. If this trend continues, and at present indications are that it will, plans will have to be made to serve 166 retarded infants by 1970 for every 100 now presenting some problem of mental retardation.


Drillien, Cevil Mary: The Incidence of Mental and Physical Handicaps in School-age Children of Very Low Birth Weight. PEDIATRICS, 1961, 27, 452-464 (March).

The retarded will be different as a group

Other aspects of the problem of mental retardation will also be changing in the next 10 years. Indications are that by 1970 the mentally retarded as a group will differ from what it is now. The age composition, the extent of associated handicaps, the assumed potentialities of subgroups, as well as presumed causal factors and resulting treatment approaches, all will undergo some changes.

1. Age composition

The increasing survival rate and the extended life span are already having marked effects on the individuals who are in the group, the problems needing help and consequently the programs and services needed. While there are marked variations in the age specific prevalence rates found in various studies\textsuperscript{11,12,13} of incidence, there is general agreement that the total group of mentally retarded contains comparatively few infants. The bulk of the group is made up of children in the 10-14 year age range, with a smaller number in the 15-19 age group and a still smaller number in the adult ages. Schematically, the studies of assumed prevalence of mental retardation by age groups can be consolidated into a graph somewhat like that in table IV.

Table IV
Approximate Prevalence of Mental Retardation by Age

<table>
<thead>
<tr>
<th>Rates Per 1,000 Population</th>
<th>1-4</th>
<th>5-9</th>
<th>10-14</th>
<th>15-19</th>
<th>20 and over</th>
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\textsuperscript{12}New York State Department of Mental Hygiene: A SPECIAL CENSUS OF SUSPECTED REFERRED MENTAL RETARDATION, ONODAGA COUNTY, NEW YORK. Syracuse, New York: New York State Department of Mental Hygiene. 69 pp.
\textsuperscript{13}Lemkau, Paul, Tietze, Christopher, and Cooper, Marla: Mental-Hygiene Problems in an Urban District. MENTAL HYGIENE, 1942, 26, 275-288 (January).
While we can expect some increase in the numbers in the 10 to 14 year old group by 1970, the proportionate increase in the birth to 4 and 20 and over groups will be much more marked. Very probably the bars at both ends of the above table will show a marked increase and thus tend to somewhat flatten out the curve.

This trend is already in evidence in the ages of mentally retarded individuals in State institutions. As a result, community program planning will have to pay more attention to services for persons on both ends of the curve.

2. Extent of associated handicaps

The increased survival rates of retarded infants will probably bring with it an increase in the number of retarded persons who have associated physical handicaps. Current reports to the Children's Bureau from clinical programs dealing with retarded children under 6 years of age indicate that even now in this group, 75 percent have associated physical disabilities.

Likewise, because the older individuals are now living longer, we can expect many of them to present the physical problems similar to the aged, senile group in our general population.

Both of these trends underline the need to plan for increased health and medical services. It is anticipated that such services will be a primary need, and that more consultation and assistance on medical management will be required by all programs serving the retarded.

3. Assumed potentialities

Our present means of assessing potentialities of social development, learning, work training and job placement of retarded persons are still crude. Classification in terms of gross achieved scores of intelligence has never served as an adequate gauge of potentiality nor as a good basis for grouping, planning or training. With these many changes in the composition of the group of mentally retarded individuals there will be an even greater need to develop criteria other than standardized intelligence tests to assess such potentials. More careful assessment of homogenous subgroups within the category of mental retardation in terms of levels of potentials may considerably change our present concept of which individuals can be helped. This should result in a more optimistic approach to the problem of mental retardation. Potentialities of some groups now labeled as "custodial" and "trainable" should become more evident. Again, all of this results in increased demand for services for individuals from categories to which services previously had not been extended because they were felt to be "hopeless."

4. Causal factors

The large segment of mentally retarded persons for whom no cause can be determined is gradually being decreased. Research findings
and better and more complete evaluative procedures are determining causes for cases of previously unknown etiology. Organic causes such as the inborn errors of metabolism are assuming much more important roles than previously suspected. These trends are bringing into prominence in the field of mental retardation certain professional groups such as the biochemist, geneticist, embryologist, etc., who had previously been comparatively uninvolved.

Problems will be more evident

Changing patterns in the American way of life will make many problems of mentally retarded persons more acute in the future. These changes will also highlight aspects of the problem of mental retardation which played a comparatively minor role before. As a result, some services will need to be expanded, new program emphasis will be needed, and a greater amount of flexibility which will allow adaptation to new needs will be required. Among the factors which will contribute to this changing emphasis are:

1. Families are growing larger

   The size of the typical American family has increased since World War II. The proportion of families with 2, 3 and 4 or more children has increased, as has the proportion of families with children under 18. In fewer instances therefore will a retarded child be an only child. Parents will have less time and fewer resources to devote to a retarded child. They will need more help in management and less of the family income and time can be devoted to the retarded child.

2. Changes in family living

   Large numbers of families are moving each year. Suburbs are growing nearly three times as fast as the total population of the United States. The large extended family of the past, which included grandparents, maiden aunts, etc., all living in the same household is disappearing. More and more of the burden of caring for the children is being placed on the mother.

   Families with retarded children who are involved in these changes will face greater challenges in attempting to manage their mentally retarded child at home. New neighbors do not easily accept a child who is different. The suburban father who can help only on weekends, the absence of the grandmother or other relatives make the problem of obtaining some relief for the mother more difficult. Many problems will be intensified and it will be more difficult for many families to manage their retarded children at home.

3. More mothers of young children are in the labor force

   Throughout the 1950 decade, there was an 83 percent increase in the number of mothers with children under 6 who were working. The
same factors which operate to induce a mother of a normal child to go to work, operate for the mother who has a retarded child. Many times these factors are even more forceful for the mother who has a retarded child. Substitute care for the retarded child however is more difficult to obtain. Frequently too, the retarded child is less able to understand the need for a parent substitute, and makes planning more difficult to carry out.

4. More children are going to school longer

The general level of education is rising in the Nation. As this trend continues, the mentally retarded whose disability shows itself in this area will be more marked. As educational standards and achievements continue to rise, a greater number of individuals who cannot keep up or achieve these levels will be discovered and will demand attention.

5. Machines replace unskilled labor

In the past, the majority of the mentally retarded children completing special classes for the educable in urban areas were able to find jobs on their own\textsuperscript{14,15}. There is some question whether this will continue to be so in the next 10 years without additional special help. Increased industrial specialization, automation and the intensified tempo of industrial production, pose new problems for even these higher functioning children. If fewer persons completing classes for the educable are able to find jobs in industry, the more will come to the attention of the community as problems.

Elevated educational standards in rural areas also are adding to the problem. Farming, which years ago provided a field of employment for many of the retarded, has become so highly specialized that persons who would have been employed in the past have a difficult time finding employment at all now.

6. New services create new demands

In the next 10 years, as new services demonstrate potentials and abilities in various groups of the retarded, extended or additional services will be needed. For example, the increased number of trainable children being offered school programs for the first time will create the problem of what to plan for them after this school experience. Previously most of these children led a sort of vegetative existence at home or in an institution. They are now being trained, stimulated and allowed to develop the potentialities, though limited, they have. On completion of training, neither they, their parents nor the community which invested in their training will be satisfied with


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vegetative existence for them. With little likelihood that this group can be absorbed in industrial life, new programs will need to be developed.

The interest professional workers are taking in special demonstrations, newer research findings, and training opportunities will support the demands for new services. Increased recognition of possible professional contributions, improved case findings, and diagnostic skills will make many professional workers anxious to follow up through new and extended services.

Programs not specifically set up to serve the mentally retarded will give more consideration to the condition as a secondary or associated handicap in children they now serve. Such existing services will need to be expanded so that they can treat the whole child.
PROGRAM GOALS

Overall Program Goals

In view of the anticipated increase in the size of the problem of mental retardation and the changing needs for service, it is important to recognize that sufficient specialized services developed specifically for the mentally retarded can never begin to meet the need. Furthermore, there is a serious question, even if it were possible to develop enough specialized services to meet the needs, whether this would be a desirable goal. Specialized services tend to set a group such as the mentally retarded apart from the community and frequently mean that some basic services which are available to all others are denied to the special group. Since the ultimate goal for the mentally retarded is to help them make as good an adjustment to the community as they possibly can, the framework of the services offered should of itself set the pattern for the basic goal -- making them as much like other people in the community as possible.

This means a segmentation of services. It means that like most people in our Nation, the mentally retarded would not obtain all services from one agency or source. They would use the physician for medical care, the help of the educator in training children, social agencies to help with family problems, etc.

Emphasis in the long-range program goal for the mentally retarded would therefore be on using the usual services and facilities for the rest of the population in meeting the needs of the mentally retarded. Specialized services which may be required should be seen as an extension of basic services. Better use can be made of available skills and services. More careful planning is needed so these services can be adapted to meet special needs of the retarded. Greater effort should be made to include in programs planned for normal groups some of the retarded who would be able to take part despite their limitations.

The coordination of these services on a State and local level requires much more attention. At present some States are working toward that end through special groups and coordinating bodies. These efforts need to be translated to the local level and the time and effort of the Children's Bureau and the project staffs could be used to assist in developing such coordinating machinery on a local level.

The availability of skilled professional workers to the field of mental retardation depends on the success of various professions in attracting trainees. Most of the professional skills which are needed in the field of mental retardation are in short supply. The prospects are that these shortages will continue for some time. It becomes most important therefore to continuously reevaluate the use which is being made of available personnel and to assess how they
might be employed more efficiently. It also becomes important to consider ways in which the status of individuals involved in mental retardation can be raised in the eyes of professionals so that this field becomes more attractive to qualified personnel.

In training personnel for work with the mentally retarded, the goal is not the development of super-specialists in mental retardation. The goal is rather in terms of attracting workers to this field who have broad professional training to work with children. Specialized training should aim to add to such a foundation, knowledge and techniques about dealing with these children who deviate from the normal.

At present there is an accumulation of research findings which have important implications in terms of programs and services for the mentally retarded. These findings have not as yet found their way into ongoing programs. There is a need to apply these. There is likewise a need to apply to the retarded, practices and principles which have been proven to be of value with other groups of children.

Basic research needs to be encouraged. A major need is in establishing the relationship of the symptom of mental retardation to a broader continuum of perinatal casualties, genetic factors and psychopathology, and searching out causes and prevention.

Health services to the mentally retarded

The components of maternal and child health programs, such as maternity care and child health services, need to be emphasized in community programs as an integral part of any special effort in mental retardation. These components will serve as the beginning of a program of prevention.

In addition, health services in the next 10 years need to explore, demonstrate and develop some of the following areas:

1. The use of the well child conference in early case finding and as a means of providing care and observation of growth and developmental rates in infants suspected of being mentally retarded.

2. Use of the resources of school health services in screening retarded children of school age for placement in special classes. Such information will be of much help to the teacher.

3. Development of standards and licensing practices for the growing number of nursery and day-care programs for very young mentally retarded children.

4. Development of relief programs for parents who have young severely retarded children.
5. Development of standards for privately operated residential schools and homes for the mentally retarded.

6. Development of health standards and medical services for State residential facilities for the retarded.

7. Exploration and clarification of the need for and the circumstances under which placement of very young mentally retarded infants is necessary and the development of some guides in this area.

In many of these activities, of course, other agencies such as welfare and education will also be involved.

Special demonstration projects

Because of the present state of our knowledge about mental retardation, there is a need to continue to develop special demonstration projects in the area of mental retardation. Through such separate, specialized services professional workers will have an opportunity to become familiar with and study various aspects of this problem. Special services provide an opportunity to concentrate skills, to test out concepts and to evolve efficient and effective methods of dealing with the problem. Such intensive specialized efforts to look at and deal with a particular problem will also provide the basis on which a decision can ultimately be made as to where these services belong in a total program for handicapped children, and which of the handicapping conditions can be grouped with the retarded for diagnosis and treatment.

Some of the immediate goals for these special demonstration projects within the next 10 years included:

1. Increased coverage
   a. Geographic -- Every State should have at least one project. There is a need to demonstrate various phases of service, study and training of professional workers and evolve some of the unique or peculiar ways in which these could best be carried out in a particular area with the pattern of service used by the area.
   b. Patients served -- There is a need to continue to extend these services to the retarded with a wide variety of associated handicaps in order to assess how groups such as the blind retarded and others can best be served.

2. Training of professional workers
   In order to carry out their objectives, projects will have to rely heavily on available community resources and on the services of individuals not involved with specialized programs. After demonstrating what to do and how to do it, the special projects will need to get this knowledge to other programs and professional workers:
a. by inservice training and orientation (private physicians, nurses, psychologists, welfare workers, teachers, etc.)

b. by helping to build into the professional training of these groups content material on mental retardation which will more adequately prepare them to work with these children and families.

3. Research

With complete evaluations and followup information available on mentally retarded children and their families and with almost 10,000 new cases being seen each year, these special projects have a tremendously valuable pool of material available for cooperative clinical research and for the answers to a variety of administrative questions. Personnel and staff time will need to be made available to make use of this volume of data.
APPENDIX A

PROGRAM PROGRESS NOTES

The First Year — A Beginning

When the specialist in health services for mentally retarded children joined the Children's Bureau staff, tentative approaches to the problem were considered with central and regional office personnel. With the earmarking of special MCH funds, the regional staff of the Bureau began to explore with maternal and child health directors in State health departments possibilities for special demonstrations.

Since most maternal and child health directors were not familiar with the problem of mental retardation, this exploration of interest frequently combined a process of familiarization with the problem, locating existing services already available in the State and assessing potential areas in which a demonstration might be set up. A typical approach used in several States involved joint tours with the specialist in services for mentally retarded children, the regional staff and the maternal and child health director in the State, of existing facilities, of meetings with various interested groups and agencies, etc.

This was a slow process, but during 1957, 27 States expressed an interest in this kind of exploration and assistance. Four regional conferences, involving 24 States and Territories were held to implement this. Health department personnel as well as representatives of other agencies in the region attended and discussed their programs and services. Newer concepts and current problems encountered in dealing with the retarded were discussed. The manner in which the maternal and child health program might contribute to existing services, how this might be done and where it might be started was considered.

As a followup of the regional conferences, six State health departments planning to set up special demonstration projects organized similar conferences on a State level. These were designed to familiarize State personnel and community groups with the problem of mental retardation and to develop a broader and firmer base of understanding for the special programs being planned.

As a result of this activity, a number of State health departments submitted plans for a special demonstration project. In the first 6 months, 11 projects in as many States were approved. In the second half of 1957, an additional 13 projects were approved, bringing the total to 24.
The initial projects

All of the initial projects called for the development of complete diagnostic and evaluation services. A basic clinical team -- consisting of a pediatric medical director, a psychologist, a social worker and a nursing consultant -- was used by most of these programs. The resources of the State health department, hospital facilities, and the consultant services of a wide variety of specialists were generously drawn upon. All diagnostic procedures which might contribute to an understanding of the child were used almost routinely in order to assess their value.

State plans for the initial projects clearly recognized that diagnosis and evaluation alone would be of little or no value to either the retarded child or his parents. It was assumed that most of the parents recognized that something was wrong with their child and that what they needed was not a label but help in understanding more fully the needs of their child and in planning for his maximum growth and development. The project planners also were fully aware that no one person and no one specialty had all of the answers. Mental retardation was viewed as a symptom with a variety of possible causes. The need for a team of workers to approach this problem was stressed in all of these projects.

The services flowing from the initial projects were all geared primarily to the preschool child. Emphasis was placed on those services required by retarded children who were too young or functioning too low to benefit from group approaches or activities. The mother in particular was recognized as a most important member of the helping team. She spent more time with the child at home than anyone else. Staff time was planned so that the bulk of the work would be with parents following the diagnosis. This would include guidance, counseling and training for the parents in how to work most effectively with their child at home. Demonstrations by professional staff showing how a child might be helped to become more proficient in activities of daily living such as eating and dressing were staged in the clinics while the parent observed. The generalized public health nurse was used extensively to further interpret to the parent the clinical findings and to help apply recommendations in particular home situations. Work with groups of children at the clinic was used as a means of providing some preliminary social experience for older children.

These project plans emphasized basic health services to these children on the assumption that if a child is in the best of physical health, he will be able to use the abilities he has more effectively.

Some demonstration studies were also included in these initial projects. Services to retarded children in rural areas, or in areas where specialized facilities are not readily available, were recognized as being of paramount importance. A few were purposely set up in relatively isolated rural counties in an attempt to find out how specialized staff sent to those areas might develop services for retarded children. These projects were clearly identified as special extensions of State health department services. More than half of the plans provided for the addition of personnel to the maternal and child
health programs on a State level as a means of translating the findings of a special project in a given area to the rest of the State.

One of the major problems in developing these projects was the scarcity of trained personnel who could be recruited to operate them. An assumption was made that qualified professional workers who were well trained to function independently within the area of their professional competency and who had some experience in working on a team basis could adapt their skills and knowledge sufficiently to function in these programs. These were the kinds of workers who were recruited.

The Second Year — One of Expansion

During 1958, six additional special projects were approved. Two demonstrations previously supported by earmarked special project funds were taken over by the States and supported with regular maternal and child health funds. This brought to 30 the number of States using special project funds to support the demonstrations and increased to 14 the number of States supporting them with regular maternal and child health funds. Budget allocations for these programs were slightly under $2 million.

Recruitment of staff in most of these programs was completed early in 1958. Filling the social work positions was the most difficult. Of 47 budgeted social work positions in these programs, 8 were unfilled.

During 1958, increasing emphasis was put on extension of the geographic area covered by some of the projects, the promotion of related community services and the continuation of training endeavors. Administrative processes were improved. Lists of children waiting to be served began to grow. During the year each program was able to accept for care about 120 new children. Requests for service were much greater than what the projects could provide. Only two out of every three children referred to the programs could be accepted.

An effort was made to add to the amount of pediatric and social work time in an effort to reduce backlogs of cases awaiting diagnosis. New needs such as services to blind retarded children were highlighted as a result of clinic activity. Potential new services were explored by a number of projects, such as coping with the dental problems of these children in Minnesota and the use of a home economist in Iowa. A total of some 5,000 children and their families were served by these projects during this year.

17Parsons, Mabel H.: A Home Economist in Service to Families With Mental Retardation. CHILDREN, 1960, 7, 184-189 (September-October).

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In addition to a large number of statewide conferences, special institutes and workshops for nurses, physicians and other health personnel, three national conferences were sponsored during this year.

The conferences were:

**Mental Retardation Conference of Maternal and Child Health Directors and Clinic Directors**

One hundred twenty-five persons participated, representing 50 States. One of the recommendations coming out of this conference was that a Technical Committee be organized. Such a committee was seen as:

1. assisting in the development of special clinical programs and in the coordination of their activities.

2. cooperating with the Advisory Committee of the American Association on Mental Deficiency in developing a new system of nomenclature and classification and coordinating the efforts of the clinics in testing this.

3. evaluating the possibility of a national register or file of cases seen by the special clinics, which in turn might serve as a basis for the pooling of data, subsequent research, etc.

4. developing a central file of unusual cases and gathering data relating to those cases as a basis for comparison and further research.

5. exploring interclinic communication by newsletters, the exchange of research information, abstracts of professional and technical papers, notices of conferences, etc.

6. developing the machinery for the exchange of a variety of administrative and program aids, such as record forms, statistical summaries, charts, visual aids, etc.

7. planning meetings and conferences of the clinic staffs.

**Institute on Nutrition and Diet in Relation to Mental Retardation**

Seventy professional persons representing 23 States attended. The institute provided an opportunity for the persons attending to exchange knowledge and experience which were used in planning and guiding nutrition services for the mentally retarded.

**Workshop for Public Health Nurses**

A selected group of 33 public health nursing consultants from special projects and maternal and child health divisions of State health departments attended. They discussed the organization and content of home training programs, the functions of the public health nurse as a member of the clinic team, administrative problems related to the implementation of services through local health agencies, and inservice education.
During this year, a special effort to stimulate the development of publications and program aids was made. The Mentally Retarded Child at Home, Newer Concepts of Mental Retardation in Medical Care Programs for Children, and various summaries of program development were issued. Three films on aspects of the projects and a directory of special clinics for the mentally retarded were started.

In the Nation as a whole, there was a growing awareness of the problem of mental retardation. The increasing number of local units of the National Association for Retarded Children, the rising interest of professional workers and the development of community programs and facilities underscored the size of the problem.

The trend in the States to organize interdepartmental committees to coordinate plans and services for the mentally retarded continued. Colorado, Connecticut, Delaware and New York already had set up such machinery. The special studies by the Denver and the Los Angeles community councils, which were supported with maternal and child health funds, provided some further suggestions on how this kind of coordination could be achieved on a local level.

The Third Year — a Time of Consolidation

Activities and services of maternal and child health programs in behalf of mentally retarded children and their families continued to expand. The special projects served 6,704 children and their families during this year. The children were being seen at an earlier age. Thirty and three-tenths percent of the children coming to the projects during this year were under 4 years of age, and 74.6 percent, under 9 years of age. In spite of the fact that close to 2,000 more children were served, applications for service continued to exceed the number of children which could be handled by the projects.

In order to cope with the mounting waiting lists, new ways of handling applications were tried. More selectivity and flexibility in using professional time, in establishing diagnoses, more efficient use of local resources, greater emphasis on training of local generalized personnel, and assignment of preliminary screening responsibility to local services were explored. All of these innovations provided a great variety of patterns of service which was most useful to new programs and gradually pinpointed some of the more efficient ways of using professional time and efforts.

Three biregional meetings of administrative and technical clinical staff of the demonstration projects were held.

1. Regions I and II -- An interdisciplinary "working" conference for 90 participants from 10 States (Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, Delaware, New Jersey, New York, Pennsylvania). Progress was made in identifying and sharpening the
focus of mental retardation activities, in strengthening relationships between the clinic centers and maternal and child health State and local programs and in exploring ways and means of extending services to larger numbers of children, particularly those living in rural areas.

2. Regions VI and VII -- Seventy persons from 12 States (Iowa, Kansas, Minnesota, Missouri, Nebraska, North Dakota, South Dakota, Arkansas, Louisiana, New Mexico, Oklahoma, and Texas) participated in this conference, which afforded an opportunity for an exchange of experiences and a discussion of problems encountered in development of special clinical services for the mentally retarded.


Training activities within the States were stepped up during this year. The Tulsa Training Center began to accept for training professional workers from States other than Oklahoma. Fifty-three trainees, including public health nurses, psychologists, social workers, nutritionists, teachers, and a vocational counselor received training at Tulsa during this year. A number of these persons in turn set up inservice training programs in their own States.

State conferences on mental retardation were held in Arizona, Florida, Arkansas, New Mexico, Michigan, Delaware, and Illinois. In addition, mental retardation was the subject of a special session in each of five Nemours conferences in Region IV (Alabama, Florida, Georgia, Mississippi, South Carolina, Tennessee).

Studies

Three significant studies were completed:

1. Louisiana made a statewide study of the caseload of mentally retarded children carried by public health nurses. Exclusive of the Parishes of New Orleans and Plaquemines, 1,118 cases were reported out of 41,189 families. Over 5,000 home visits were made to these retarded children by local nurses. The study pointed up the need for increased nursing services to preschool children and more complete evaluations of the children to be served.

2. Colorado also conducted a statewide survey of public health nursing services to mentally retarded children. The survey was carried out on a sampling basis which included 50 percent of the State's public health nurses as participants. Of the 1,541 mentally retarded children listed as known to public health nurses, only 429 were being carried in current caseloads. The largest number of those being carried were

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in the school-age group. The vast majority had been referred for public health nursing services for reasons other than mental retardation.

3. An analysis was made of the mentally retarded children accepted in the Iowa Crippled Children's Agency services. Of 3,616 crippled children seen at 34 field clinics in 1958, 172 had been referred for evaluation because of mental retardation or emotional problems and behavior problems. Of the 172 children, 61 were referred for mental retardation, 77 for behavior or emotional problems and 34 for both mental retardation and emotional problems. On the basis of these findings, the mental retardation project decided to use these field clinics for screening and following up of children who are referred as mentally retarded.

Typical of the newer studies undertaken this year was the one made by the Department of Pediatrics, University of Oklahoma Medical School. This involved a survey of the Oklahoma State institutions and special education classes for the retarded in order to find children who have phenylketonuria, and a follow-through with the families of the children in cooperation with the local health department. As a part of the project, the dietitians prepared listings of special diets, food mixtures and recipes for children with this condition.
# CHILDREN SERVED BY MENTAL RETARDATION PROGRAMS UNDER STATE HEALTH DEPARTMENTS SUMMARY OF STATE REPORTS, 1958, 1959, 1960

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Source of data: CB-251-H
## Children Served by Mental Retardation Programs

Under State Health Departments Age Distribution of New Cases, 1958, 1959, 1960

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<td></td>
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\(^1\)Excludes cases for which age was not stated.

Source of data: CB-251-H
APPENDIX C

PUBLICATIONS AND PROGRAM AIDS

As a part of this program, a number of Children's Bureau publications have been produced. Among the more important of those on sale by the Superintendent of Documents, U.S. Government Printing Office, Washington 25, D. C., are:


In addition, a number of publications prepared and distributed by the Bureau have stemmed from this program:

1. Selected Reading Suggestions for Parents of Mentally Retarded Children. 8 pp.


4. Two charts on mental retardation: Where Are the Mentally Retarded? What Are the Potentialities of the Mentally Retarded?


6. The Clinical Team Looks at Phenylketonuria. 30 pp.


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Three motion picture films have been developed as a part of this program.

1. "The Public Health Nurse and the Retarded Child" produced by the Oklahoma State Department of Health;

2. "Beyond the Shadows" produced by Western Cine Productions; and

3. "Pioneering Dental Health for Retarded Children" produced by Bay State Film Productions for the Joseph Samuels Dental Clinic of the Rhode Island Hospital.

"The Public Health Nurse and the Retarded Child" has been used in 40 States. At the 1959 annual meeting of the University Film Producers Association at Purdue University, it was selected as third best out of 1,000 films.

"Beyond the Shadows" was selected for the finals in the International Film Festival.

A fourth film on which production has been completed and which will soon be released by the Oklahoma Health Department is entitled "The Role of the Physician in Mental Retardation", and features the private physician.
APPENDIX D

ADDITIONAL REFERENCES


U.S. Children's Bureau
Technical Committee on Special Clinic Programs for Mentally Retarded Children (Minutes of Meetings, 1958, 1959, 1960, 1961)
Annual Reports
Project Progress Reports


White House Conference on Children and Youth -- 1960
"Children in a Changing World" -- (A book of charts)
"Focus on Children and Youth" -- (Report of National Organizations)
"The States Report on Children and Youth"

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