families of mongoloid children
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ELIZABETH R. KRAMM
Health Research Specialist
Division of Research

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Foreword

We, as a nation, have only recently begun to face the problems of our mentally handicapped citizens. But we have begun, and steps are being taken which will eventually mean the salvage of thousands of lives which are now being wasted in a sort of living death.

In establishing his Panel on Mental Retardation, in October 1961, President Kennedy said: “The manner in which our nation cares for its citizens and conserves its manpower resources is more than an index to its concern for the less fortunate. It is a key to its future. Both wisdom and humanity dictate a deep interest in the physically handicapped, the mentally ill, and the mentally retarded. . . . We as a nation have for too long postponed an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected.”

A year later, in October 1962, the Panel made its report to the President on the needs of the mentally retarded. This report shows that the retarded child needs schooling, recreation, vocational training, and all the other services which we give routinely to the normal child. And in addition, he has special needs growing out of his special handicap. Among these is the need for greater public awareness of the problems which face these children and their families.

The Children's Bureau is publishing this study of 50 families who had a mongoloid child living in the home, in order to help people generally to understand what the problems are, to see what it means to be responsible for bringing up such a child with little community support. Here is an authentic story of actual parents, varying widely in their education and social situations, who tell in their own words what it meant to them to learn that they had a child with this lifelong handicap, what they did or failed to do about the child, and what their ultimate adjustment has been.

The material presented here is immediate and real. It brings home to all of us a deeper appreciation of the burdens some citizens are now bearing alone, and will inspire many of us to help as we learn more about effective ways of meeting the multiple problems of mongoloid children.

KATHERINE B. OETTINGER
Chief, Children's Bureau.

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THE PROBLEM

Background

One out of every six or seven hundred children born in the United States suffers from a congenital defect known as mongolism or Down's syndrome. Thus six or seven thousand such babies are born in this country every year. In varying degrees these infants are physically and mentally damaged. According to the best available estimates, the condition accounts for about five or six percent of all mentally retarded persons in the nation and for about ten percent of all institutionalized retarded persons. The same handicapping disorder is found at all social and economic levels and in all parts of the world.

Mongoloid children usually show certain physical peculiarities at birth. They are often flabby, and lack the muscle tone of normal babies. The slanted eyes frequently noted in these babies are in part due to a skull defect and in part to an over-development of the skin fold at the inner corner of the eyes. This "slanting" accompanied by a characteristic flattening of the bridge of the nose gives an appearance similar to that of northeastern Asians. Langdon Down, the British physician who first clearly described these children about a century ago, was responsible for coining the term "mongolism"; the condition, however, can be recognized in a Chinese or Japanese child almost as easily as in a European. Usually the head of such children is smaller than normal and is flattened at the back. The ears may be oddly shaped, the arms and legs shorter than usual, the hands stubby and the little finger curved inward at the tip. The tongue may protrude, and relaxed joints and ligaments lead to an unusual degree of joint movement. These defects may be accompanied by abnormalities of almost any part of the body but most commonly of the chest, heart, and eyes. There are variations in the number of physical abnormal-
ities and in the intellectual level of the children; if certain physical signs are inconspicuous at birth, early diagnosis without laboratory confirmation may be difficult.

Mongoloid children mature at a much slower rate than normal children. In general they reach in their first ten years the stage of development which other children reach by the age of three or four. Activities such as walking and talking are almost always delayed; tooth development may be delayed and abnormal. Sexual growth is frequently arrested and sexual drives are limited. Among the girls menses may be delayed and irregular; there are few mongoloid women known to have borne a child.

When the capacity for mental growth comes to an end, sometime following puberty, mongoloid persons are still retarded at varying levels. Their capacity to develop socially is at a higher level than their capacity for mental growth.

Children with mongolism have extreme susceptibility to infectious diseases. The use of antibiotics, however, has increased the average life expectancy to about thirty years; some mongoloid persons may live many years longer.

The search for the underlying cause of this disorder is still a perplexing problem. Maternal age is accepted as one factor associated with mongolism. While the chances of having a mongoloid baby increase considerably among mothers over thirty-five, many younger mothers may also have a mongoloid child.

Investigators recently found that the body cells of mongoloid persons have chromosomal deviations not found in most normal persons. One type of deviation is the formation of an extra chromosome resulting from a process called non-disjunction. It is believed that non-disjunction occurs more frequently in the pregnancies of older women. Another far less common type of deviation is translocation, or displacement of a part of one chromosome to another. Occasionally healthy normal parents are transmitters of the translocation.

Most mongoloid births are due to non-disjunction which is apparently nonhereditary. While the risk of having more than one mongoloid child in a family is reasonably remote, it is greater in cases where the translocated chromosome is present in the parents. With a view toward preventing mongoloid births due to a hereditary trait, retardation centers are beginning to recommend a chromosomal analysis of mothers who have had a mongoloid child.

There is no cure for mongolism, but children with this condition can be helped by training and good care. Although rehabilitation for them has lagged pitifully, advances have been made during the period since 1950. In that year the National Association for Retarded Children (a voluntary agency representing the interests of all retarded children) was organized, and the public schools be-
gan making appreciable increases in the number of classes open to trainable children. For the first time large numbers of mongoloid children were being enrolled in special classes throughout the country. Sheltered workshops began offering mongoloid persons some opportunity to contribute to their self-support. At present a few such persons are employed in regular industry.

While it is believed that most mongoloid children will eventually need some type of continuing custodial care, there is a strong argument against indiscriminate early admission to an institution. Institutional living, at best, is known to have an ill effect on the development of infants and young children. And mongoloid children, particularly, fail to develop to the level they are capable of when deprived of the individual attention and affection that only a family can give. Before deciding what ought to be done about the child, more information is needed about the effect he has on his family.

The study

It is commonly believed that the presence of any mentally subnormal child in the home is likely to destroy its normal atmosphere and to injure other children in the family by making it impossible for them to have natural healthy relations with their parents, their friends and neighbors. For this reason, many people believe that these defective children should be institutionalized as soon as possible. But this is largely guesswork. Not enough is known about how family members actually react to a defective child, and how they feel about him.

In order to obtain such information, plans were made for an intensive study of fifty families which had a mongoloid child living in the home. The families, all of whom lived in the same metropolitan county, were found with the help of a child clinic, a county school system, and a parent organization for retarded children.

All parents were interviewed in their home by one person. The mongoloid child and most of his brothers and sisters were present during some part of the visit. While the number of home visits and the length of each varied from family to family, the total time spent in each home averaged eight hours.

Couples were interviewed together and separately. They were asked for facts about their age, education, occupation, the number of other children in the family, the mother's pregnancy experience, and so on. Using an indirect method of inquiry, questions that were more difficult to answer were also asked—about the parents' reaction to learning that they had a mongoloid child, changes in their family life and in their activities, their plans for the child's future care, their feelings about him and about themselves, and the child's relationship
with his brothers and sisters and with children and parents in the neighborhood. Often these questions could not be readily answered and contradictory replies were given.

The parents talked freely and thoughtfully, even though emotion was frequently expressed by tears, angry gestures, long silences, or by the nervous fluency of their speech. They seemed glad, however, of the opportunity to talk over with someone who represented a helping person, situations that had occupied a major place in their lives for many years.

These conversations were written down sometimes during but usually shortly after each home visit. Later the composite data from all of the families were classified, tabulated, and analyzed.

**Characteristics**

Even though all but seven of these families owned their own homes, they differed greatly in their economic and social situation. Twenty fathers and twelve mothers had had some education or specialized training after completing high school; at the other extreme, four fathers and two mothers had not completed the eighth grade. (The average number of school years completed by these parents, however, was higher than the average for all persons over twenty-one who lived in the same county.) Sixteen fathers were in professional, administrative, or executive work, and eighteen were either semi-skilled or unskilled laborers in repetitive work; the others held positions in clerical and skilled work. Of the hundred parents, eighty-eight were born in the United States and seventy-seven of them in the same State in which they were then living. All but one of the fifty mongoloid children were born in the United States. Three families were Negro, the others Caucasian. Fifty-six of the parents were Roman Catholic; thirty-nine, Protestant; and five, Jewish. They ranged between twenty-five and seventy years of age. At the time the mongoloid baby was born, twenty-two mothers were between thirty-five and forty-five years of age; twenty, were between twenty-five and thirty-five years, and the others were not yet twenty-five.

The families included 122 other children still living at the time of the study (Appendix, Table 1). Most of these children lived at home. Two-thirds of them were under twenty years of age, and twenty-eight were younger than the mongoloid child. Of the thirty-seven who had completed high school at the time of the study, fourteen were in college or had had two or more years of college training.

Of the fifty mongoloid children, thirty were boys and twenty, girls. Forty of them were between six and sixteen years of age, five were between three and six, and five between sixteen and thirty-two.
Their social age (measured by the Vineland Social Maturity Scale*) ranged, however, from one to nine years. The variation in the social maturity of these children can be seen in the group of eleven who were all ten years of age and who ranged in social competence between the age of a two- and an eight-year-old child.

The average normal child walks at about fifteen months and has daytime control of the bladder at about twenty-four months. The mongoloid children in the study group walked, on the average, at thirty months and had daytime bladder control at four years. The normal child begins to say words at around twelve months. Of these children eight, ranging from four to eleven years, had no speech at all; twenty-one, ranging from four to twenty-two years, spoke in phrases of three words or less; the other twenty-one, ranging from nine to thirty-two years, spoke in sentences of four or more words and related their day-to-day experiences to members of their family and to friends; six in the latter group used phrases and conversed with relative ease and clarity.

The most significant findings of this study—the highlights—are presented in the following pages, and are illustrated with direct quotations from the parents, and sometimes from their children. While generalizations are drawn from the statistics and tables, they give only a diagram of the facts; the dynamics—the heart and full reality—is in the voices of the parents.

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*The scale, devised by Edgar A. Doll, is a composite measure of social competence, in self-help, self-direction, locomotion, occupation, communication, and social relations. Items on a scale in each of these areas are arranged in order of increasing difficulty and represent progressive maturation.
LEARNING THE CHILD IS MONGOLOID

Almost all parents in this study, even those who had suspected for months or years that something was wrong, suffered a deep emotional shock when they were told that their child was mongoloid. The reactions of many were immediate and violent; for others prolonged, quiet and agonizing. At the time of the interview most of these parents recalled the emotional trauma in the beginning and the length of time it took to have a comeback from the immediate reaction of hysteria, weeping, vomiting, diarrhea, numbness, and the wish to die. Five had thought of taking their own lives and that of the baby; eight others said that the death of the child would have brought release to them. Some parents referred to this period as lasting a few days, a week or six months; but many said it had lasted two years, five years, or had been a slow and gradual process, lasting many years.

Most parents said or implied that the doctor's interpretation of mongolism and of its implications had made it either much harder or much easier for them to bear; few felt that the way in which they had been told the facts was of no consequence to them.

The doctor who first diagnoses the child's condition is faced with a difficult decision. How soon, how, and how much should he tell the parents? The answers vary over a wide range. The limited therapeutic outlook of the child and the awe which still accompanies a mental malfunction as against a physical one, makes telling parents a particularly delicate situation. At one extreme is the doctor who, unable to face the parent's grief, says nothing at all. At the other extreme is the doctor who, seeing a mentally impaired baby, feels the parent should be told the worst, and at once.

How soon they learned

By inspection alone, mongolism can be accurately diagnosed at birth in about 85 percent of the cases. Of these fifty families, twenty-three were told at the time of birth that their child was normal. In eight cases the doctor said nothing, one way or the other. Later, ten
of these thirty-one doctors admitted that at the time they had known that the child was mongoloid but either felt it was “best for the parents to find out for themselves” or “could not bring himself to tell the mother.” Of the nineteen doctors who warned the family that something was wrong, seven told one or both parents within a week following the birth that the baby was mongoloid; one other family was told that the child was retarded—not mongoloid; the other ten doctors gave only the barest hints: “There is something wrong, but I do not know what.” “He won’t be like others.” “His outlook in life is dim.” “He has a heart defect.” Within six months another thirteen families learned about the child, and by the end of the first year, another ten; nineteen families did not learn the truth until he was more than a year old; in ten of these, the children were between three and eight years of age. Altogether, in thirty families the parents saw for themselves that “something was wrong” before they were told by their doctors. They worried because: “He wouldn’t suckle.” “We had to force feed her.” “His eyes didn’t focus.” “She didn’t sit up or walk as soon as my others.” But they attributed the slowness to the baby’s prematurity, to his bad heart, or to pneumonia, or whooping cough.

Eventually the parents learned the truth. In the days, months, or years following the baby’s birth, they turned to the clinics and child specialists for a diagnosis. By the time this study was made all parents in the study group had been told the facts.

How they learned

The parents were asked how they felt about the way in which they first learned the child was mongoloid and whether they thought they had been told in the best possible way.

Twenty-two of the hundred parents were satisfied with the treatment they had received. Six of these felt that their doctor had been kind in not telling them too suddenly. One mother, who had not learned that her child was mongoloid until he was more than two years old, said:

Oh, I’m so glad the doctor didn’t tell me earlier. It was considerate of him. I was so wrapped up in the child that I would not have been able to take it.

Her husband added:

Yes, after all the doctors know when is the best time to tell a parent and how well the mother can take it. That’s their business. In time, the mother will recognize for herself that the child is not developing rightly.

Eleven parents felt that although the doctor had been blunt, and even harsh, they had wanted the truth and had gotten it; two of these
parents were glad that they had not “shopped around.” One mother said:

The doctor used psychology on us by painting the worst possible picture. He said Jimmie would not walk or talk; he gave us no hope at all. We were so pleased when the child did show progress. The doctor told us to save our money and not go to other doctors because the child would not change. He told us to have another baby right away. We had three more after Jimmie.

The other five satisfied parents felt that the doctor had been neither kind nor harsh; he simply explained what mongolism was.

Eleven parents were unable to say whether they liked the way they had been told or not. A father said:

The doctors are too professional; they lack tact. But what can they say? What position can they take if they have no solution?

Among this same group of parents a mother said:

Doctors have feelings too, and I suppose it was hard for him to tell us. I had waited so long for our baby. I was so happy, that first year. On the other hand, if I’d known sooner I would have been better able to cope with neighborhood gossip.

But sixty-seven parents—two-thirds of the group—were definitely dissatisfied; they felt that the doctor’s way of handling their orientation to the problem had deepened the “shock of discovery” and had prolonged the period of comeback. Twenty-one of these complained that the doctor had not told them enough, or had not told them soon enough. One father said:

We know the doctor couldn’t prevent the child from being mongoloid but he could have taken at least five minutes to explain.

His wife added:

I later asked a friend what mongolism meant. She looked the word up in the dictionary, then told me Beth was just like a mongrel dog. I felt so terrible I cried.

A mother, whose first-born baby was mongoloid, said:

Our family doctor . . . told us the child wasn’t normal but he wouldn’t say what was wrong. We had to pump him. Finally when my husband asked him if there was something wrong with the child’s brain the doctor said yes, but he wouldn’t tell us what was wrong until after returning from his vacation three weeks later. During those three weeks we concluded ourselves that the baby was mongoloid. I feel the doctor’s attitude was bad. He didn’t even give the normal support any doctor would give to a new mother. He said the baby would probably die in a year anyway. He lost complete interest in him.
Another father said:

Mongolism was diagnosed a few days after Ben's birth but we were not told until two years later. Our family doctor said he "just needed time." When Ben was so ill with pneumonia, we called in a pediatrician. Ben was two then. After we found out, we contacted all previous doctors who had ever attended him. We learned then that several doctors had examined him soon after birth. Each doctor said he thought we knew—that we had been told by some other doctor. I felt like two cents when I found out he was retarded. I used to stand him up against the wall when he was one and a half years old. I couldn't understand why he'd sag over to the side. Now I don't force him.

His wife added:

We felt we should have been told immediately. Maybe we'd have placed him earlier. Now we like him and it's harder.

Another father said:

I would like to have known sooner. After all, I was paying $5 per monthly visit to the doctor, and I feel I was entitled to know something as important as this.

Forty-six parents complained because they had been told too harshly and "without understanding of the human element." In eighteen instances little or no explanation was given except that the baby was referred to as a "mongolian idiot," "half-child" and as "better dead."

One mother said:

The obstetrician called in a specialist after Ruth was born. The specialist was cold, blunt and brisk. He said, "You have a mongoloid. She is going to be a complete idiot. If she lives only one week, you will be fortunate. She won't eat, or sleep. She'll run you ragged!" I said to him, "I don't believe you! How can you judge a baby within the first few hours after birth!"

Another mother said:

The doctor was blunt. He didn't seem to want to talk. All he said was, "It is my personal observation that the child is mongoloid." My head swam. I fell backwards, gasping.

Her husband added:

I swore at the doctor when he gave the diagnosis. I told him that a gruff policeman, who didn't have nearly as much education as he had, would prepare a parent for bad news.

Another father said:

When Paul was five the doctor told us that he was physically well but was mongoloid. He said "This child can be helped but life is too swift to bother with him. I'll call in a social worker; she
will fill in an application for you to place him." We feel the
doctor had no right to say that life is too swift to be bothered
helping the handicapped child.

Another mother said:

The very next day after his birth they told me that he was a
mongoloid and that there was nothing to do except to put him
in an institution. On the eighth day two other doctors, one in
the afternoon and one in the evening, examined David and con-
firmed the diagnosis. The one in the afternoon said, "He's going
to be retarded all his life and there's nothing you can do about it."
The one in the evening said, "He has all the symptoms of mon-
golism and there is nothing left for you to do but put him in an
institution." The other doctor gave me no encouragement what-
soever. It was the blunt curtness of his response to my questions
that hurt. When I would ask questions like, "When will he sit
up?" he would reply shortly, "I don't know if he'll ever sit up!"
It was that sort of thing that got me. When I took David in for
his first six-week check-up, the pediatrician never told me how he
was progressing or expressed interest. He merely undressed him,
looked at him, said he'd always be sickly and susceptible to pneu-
monia. So what was I supposed to do, hang David on a tree
because he was susceptible to pneumonia! I simply dreaded the
six-week check-ups.

Eighty-four of the one hundred parents expressed a clear opin-
ion about the way in which they had been handled. Of those who
commented favorably, one-third were grateful for the doctor's soft
evasive treatment, two-thirds for his blunt harsh treatment. Of those
who disapproved, one-third complained about his evasive soft treat-
ment, two-thirds about the blunt harsh treatment.

It is clear that many of these parents could have been oriented
in a better way. They could have been given more facts, and told
in a more humane manner. But it is also clear that the personality
of the individual parents had a great deal to do with how well they
reacted to the diagnosis. Apparently two-thirds of these people felt
that they had been handled harshly. But the proportions that were
satisfied and that complained, are the same in the evasive soft treat-
ment and in the harsh.

About the same number of fathers and mothers were dissatisfied
with their initial orientation to the problem. In the ten homes
where the first-born child was the mongoloid all but two of the twenty
parents were extremely dissatisfied: fathers in large families (four or
more children) reacted better than fathers in small families; among
mothers, a proportionate number tended to be dissatisfied in both
large and small families; Catholics reacted better than non-Catholics;
and those with the least education (less than high school) better than
those with more education. This latter difference may have been culturally conditioned since in the group studied, those with the least education included a disproportionate number of foreign-born or first generation Americans. A father with a Polish background said: “Whatever happens, you take it. That’s the way I was brought up. I’ve always had to face things.” A Scot said: “Our people have always been accustomed to a certain amount of pushing around.”

What they learned

Leaving aside the question of how parents learned, one can ask: What did they learn? After the doctors had discussed the subject with them to the best of their ability, how much did these parents understand about what had happened?

Immediately after hearing that their child was mongoloid, most of these parents went through a period of turmoil in which they alternately refused to believe it, blamed the doctor, and blamed themselves. They asked why mongolism happened to them and searched for both a cause of the condition and a purpose for the existence of such a child. The mother of an eleven-year-old mongoloid said:

My husband didn’t want to believe the baby was mongoloid at first. He couldn’t accept it. He had never known anything like this to happen in his family. He kept wondering ‘Why?’ He kept searching back, looking for a cause and asking, “Why? Why? Why?” I think that’s foolish, and told him so. Finally I had a talk with him and told him that it was just something that happened.

Eventually the parents became less emotional in their responses and were satisfied in their own minds that they understood the situation. Awareness that their child would “never be well” had grown with each added year of his life; twenty-nine said in substance: “If I had known then what I know now.” But when asked at the time of the study what they thought had caused the child’s condition, about half of them gave replies that were contradictory or showed misinformation. Only thirty of the one-hundred parents said either that they had no idea or that “nobody really knows.” The majority thought the baby had been injured by something that had happened to the mother before or during her pregnancy, such as illness (measles or a severe cold), a bad shock (one mother had witnessed a suicide), nervous strain, hard work, a run-down condition, the change of life. Seven of these later said they really believed it was caused by something the doctor or hospital attendant had done (a forceps baby, or cortisone treatment for jaundice). Six felt it was caused by “bad seed” on the mother’s side; two, by “bad seed” on the father’s side; and three others by the father’s ill health (war fatigue, goiter).
Twelve parents in addition to giving a physiologic cause for the child's defect also said or implied that the child must have been sent by God—either as a punishment or as a test of their faith. The mother of a ten-year-old mongoloid, and of five older normal children, said:

Before Russell was born I told the priest I didn't want this baby. He told me that wasn't right—that the child would bring me a blessing—for me to wait and see. Then Russell was born. I don't know, maybe he has brought a blessing. The priest says God only gives to a very patient person a child like this. Maybe so. But I often feel I am being punished. My husband tells me God doesn't punish in such a way. I am trying to believe him.

The father of a seven-year-old mongoloid said:

I have never felt it was anything we did that made Alice this way.

His wife added:

The doctor said it wasn't our fault. I know God didn't make her this way but He permitted it to be; it was the only way I could have been brought to God; I used to swear and drink. . . . By God's permission I expect some day Alice will be healed—I really do.

Another mother of a four-year-old mongoloid said:

I feel horrible, just horrible. . . . Why did I have something like this? I'm good.

Of fifteen parents who in the beginning denied that their child could be mongoloid, six were still denying that anything very much out of the ordinary had happened. Four expected the child would eventually "catch up" with his age group. Another said that all the child needed was speech therapy, and still another appeared completely unaware of the nature of the handicap. One father of a ten-year-old mongoloid girl said:

With the progress Martha's making, we feel she isn't severely retarded and may outgrow the condition. I really feel she'll be all right. . . . We moved out here in order to put her in school. It was a big sacrifice in comparison to how little she's learning. I think we should be looking for a private school.

His wife said:

It was hard to take when she didn't pass the I.Q. test. It was an unfair test.
All homes in this study experienced increased commotion and tension during the first six to ten years following the birth of the mongoloid baby. This period roughly corresponds to the first four years of growth and development of the normal child. Parents of the mongoloid child commented that he was either “so sick,” or “so restless,” or “so listless—didn’t eat, sleep, walk, or talk,” or “had so many odd habits,” or was “constantly running away.” Over half the mothers said that worse even than the initial shock was the amount of physical care required by the child during his early life. But eventually he required less care. The mother of a fourteen-year-old mongoloid son said:

It was rough with three babies. Perhaps if Fred had been the last instead of the first, it would not have been so difficult. I look back and wonder how I got through the first five or six years after he was born. I was always waiting on him; I could never sit down to a meal and enjoy it. The constant vomiting and the messes I had to clean up. Then with the toilet training—Oh dear Lord—if I had only known that I should wait until he had more understanding.

The mother of a sixteen-year-old mongoloid girl said:

She never cried for food; she was never hungry; she would just lie there; I had to force feed her; it was a constant battle. Sometimes I had wished she could die. Then at the age of seven, she saw a dish of peas on the table, picked up a spoon and started to feed herself.

The mother of an eight-year-old mongoloid son said:

His temper tantrums the first four or five years were nerve-wracking; he would yell and yell and bang his head against the wall;
he would pitch everything within his reach. He's quieted down now.

Traits, behavior, and discipline

Whatever personality traits and behavior were attributed to the mongoloid child, most of the parents said, "We had to learn to live with him." In fourteen families the child's incessant demand for attention when friends or visitors came to the home, was given as his most annoying trait; in twelve other families, it was the child's stubborn or contrary nature; in eleven families, his temper tantrums when not given his way; and in others, his pesky, rough, or aggressive behavior, or his moody, shy, or nervous disposition. Only twenty-five parents said, "We took him in stride right from the start."

But in time the child grew older, stronger, and more able to care for himself. Earlier traits dropped away, and even though replaced by other peculiarities more in keeping with his age, the parents had become accustomed to the child and were more able to accept him as he was. Family members in forty-one homes described the child as being affectionate, friendly, sociable, good-natured, happy, and sweet. Some spoke of his wit, humor and shrewdness, others mentioned his sensitivity and sympathy, and still others, his neatness. Twelve of the mongoloid children were praised for their good memory, and for their ability to observe and imitate.

At the time of this study, thirty-one mothers said their mongoloid child was "extremely well behaved," "easy to manage," or "such a good child" that he required very little disciplining. They remarked that just raising their voice or giving the child a light tap seemed to bring about the required results. In these families the use of discipline in the management of all of the children in the home was consistent but individualized to meet the needs of each child. Greater emphasis and persistence had been required to train the mongoloid child in contrast to the normal child during his early years. As a rule a routine for training him had been established and carried out in a relaxed repetitious manner. One of these mothers said:

Within his limitations we are treating Jack like a normal little boy and discipline him. When he misbehaves, we make him sit quietly in his chair for a while; we explain why he is having to sit in his chair. We'll always expect more of his normal brother.

Another mother said:

I had to handle each of my children differently—talk to some, demand of others. I must admit I had to have more patience with Frank than with the others. Toilet training was quite an ordeal. He wasn't trained until he was seven. To me he doesn't
behave too abnormally. He's just like all boys—runs, plays. I don’t like to be harsh or holler at him. Children copy a lot and I don't want him to get into bad habits. Of course, sometimes I'm more impatient than at other times—or than I should be. I always try to reason with him—to impress on him what he should or should not do.

Eleven families reported that the mongoloid child's behavior was “good only some of the time” and eight others that it was extremely poor or “unmanageable most of the time.” Some of these families were especially lenient with the retarded child and some especially severe. In contrast to families that were satisfied with the child’s behavior, parents in these homes were inconsistent in their method of handling the child and made a greater distinction between him and his normal brothers and sisters. One mother said:

Rose is sometimes so good and sometimes so bad. She runs around in the stores touching everything and calling attention to herself. She throws stones at the children. Her father wants to protect her. He carries her around, wants to do everything for her. He never says no to her. He’s strict with the boys but he lets Rosie get away with everything. Sometimes the younger boy teases her. Once he called her “Nosy-Rosy.” My husband got very angry and said, "Don't let me ever hear you say that again!” I told him if he took that stand the boys would get to hate Rose.

As interpreted by many of the parents, the term “to discipline” implied punishment for misbehavior instead of control of behavior. One such mother said:

We have to keep a constant watch on Russell. Every chance he gets he'll run out of the yard and down the street. He has no sense of danger. It wasn’t so bad before he was five, but then he learned to negotiate the fence. If he is let loose for one minute he’ll just keep going. We're afraid of the street crossings and the railroad tracks. Or even if he is upstairs, I have to check to see what he is doing. He just seems to wait till my back is turned and off he goes. All doors have a latch and chain on them above his reach. At night we tie these with string so that if he awakens first he can't slip out of the house. But he has learned that he can stand on a chair and cut the string with the butcher knife. He has done this several times as early as seven in the morning.

We have bedrooms to spare but we keep Russell in the same room with us. When I want to sleep on a Sunday morning, I’ll take a huge safety pin and pin his pajamas in which he is sleeping to the mattress, so I’ll know he’ll be home when I awaken. We get so provoked, we thrash him at the end of each day. That quiets him down for the evening.
Russell's father said:

We never had to discipline our other children. If the boys fought we separated them before the brawling became too serious. We could talk and reason with the others but with Russell it's different. He likes to be Mr. Big. We don't seem to reach him. We have to bang him—but not so it will injure him.

"Explaining" the child

The crisis-meeting resources of the parents were put to their hardest test when they had to explain for the first time to their families, neighbors and friends that the child was mongoloid or was retarded. Many couples found it hard to tell the members of their own family; many more found it even harder to tell neighbors and friends. One mother said that she had never talked to anyone—not even to her mother, because she wanted to hide it. A father said:

It took a while before my wife and I could talk freely to one another and to our in-laws. Then, a school nurse visited us; she told us about schooling for Tess; we felt so much better. After that we could talk to anyone.

Another mother said:

For about four or five months after Ruby was born I couldn't talk to my neighbors about her. They just thought it was a heart condition. A neighbor friend had a baby like mine four months later. That helped me. Now I can talk to anyone. Her child can't talk like mine. I feel so sorry for her.

At the time of this study thirty-three couples said they had discussed the retarded child's welfare frequently between themselves and in front of their older children. In eight of these families, no formal explanation was made to the normal children. A daughter said, "I just grew up knowing." In the other twenty-five families the parents explained the term "mongolism" to their children individually as they grew old enough to understand. One father said that the medical program on television offered just the occasion for explaining the condition to his eight-year-old normal daughter.

But in seventeen families the parents "explained" only that the child was "born different" or "born retarded": the use of the term "mongoloid" was avoided. Parents in nine homes felt that by "typing" the child he would be harmed or that the other children would be harmed. One of these mothers explained that although she had told her other children to be more patient with their brother because it would take him longer to understand, she had not told them that he was mongoloid. She said:
I don't think it's good to type a child. I want him to have as much chance as possible. . . . My oldest girl knows now that he is mongoloid and I think maybe the boys do. I haven't told Carol and she hasn't said anything. The way the others learned was that one day Bert kept crying and crying. I let him cry longer than I would generally let a child cry because I felt it was good for him to cry; it would help him. They asked me why I didn't stop his crying and I explained to them.

Another mother whose normal older son was sixteen said:

Phil doesn't ask questions. He doesn't think in a category. I haven't told him Jacqueline is mongoloid. I think it's best not to. I have saved different clippings. When he's older, I'll have him read these clippings so that he can draw his own conclusions.

One or the other or both parents in the eight other families still felt too emotional to talk even between themselves about the child.

Although the great majority of parents talked freely with neighbors and friends, only thirty said they had never found it hard. One father who took his son on weekend trips said:

I tell the fellows outright, "He's retarded; that's why he can't talk."
That way they understand and there's no problem.

Twenty-seven still found it hard to talk to any but very close neighbors and sixteen others still avoided neighborhood contacts. Several remarked that when they took their child on walks, the neighbors seemed so obviously uncomfortable in the child's presence that they felt uncertain whether or not to explain. A few parents said that they never took their child on walks or let him play with neighborhood children because they feared that they themselves would start to compare him with the others.

Grandparents

There were no grandparents in about a third of the families. Among those that were in contact with grandparents, one-half found them sympathetic, helpful and easy to talk to; the others avoided discussion because of the grandparents' unrealistic, critical or sorrowful attitude. Eight grandparents insisted that the child was normal, "just spoiled" or "just slow"; four blamed the child's condition on the son- or daughter-in-law's background. Twelve grandparents took the fact that they had a defective grandchild very hard and made the parents even more unhappy than they already were. One grandfather said that he felt tortured every time he saw the child. A father said:

The initial impact was terrible. It was the end for my mother. She could not accept Kenny's handicap. Her constant brooding
upset my wife terribly; finally we had to move. My mother died of heartache; she had a coronary three years after Kenny's birth.

Another father said:

My mother waited hand and foot on Robin and criticized my wife for not giving in to her when she had temper tantrums. My mother didn’t want us to have another child; when we did she ignored her. Finally I told her that she had to treat both girls alike, that when she gave something to Robin she would have to give something to Roxie too.

His wife added:

Once when Robin threw a temper tantrum, and I was at my wits end, I had to forcefully take Robin out of her grandmother’s arms and tell her that Robin probably acted the way she did because she was so sick and tired of always having her parents and grandmother hovering over her. I put Robin outdoors with the other children; inside of fifteen minutes she was smiling happily. My mother-in-law said she would never visit us again. Since then she has; relationships have improved. My own parents are plain-spoken, matter-of-fact people; they helped us realize that we must expect obedience of Robin just as we would of any normal child and not spoil her.

Brothers and sisters

Just as most of the children were docile and affectionate, so most of the normal brothers and sisters were sympathetic and helpful. Only a few were not. In general, the parents who experienced the most intense feelings of guilt, denial, pity for themselves and for the child found him difficult to control and their other normal children antagonistic. In families where couples had made a satisfactory adjustment and were mutually dependent on one another for support and happiness, both the mongoloid child and his normal brothers and sisters contributed to the value of the home. But the expected levels of performance were different. The parents had indicated by their actions and attitude and by how they had “explained” the child to the normal children what his role was to be in the family. He was the one child who was not expected to grow up: who was disciplined, praised, teased, humored, coddled, was expected to have no will of his own, but around whom family members, especially the parents, rotated.

In twenty-one families the parents said that all their children loved the mongoloid child, petted him and took pride in the things he was able to do. His learning to say a new word could become a topic of family discussion. Most of these parents did not expect
their other children to take care of the retarded child. In eighteen families the parents mentioned times when one child or another had been irritated or embarrassed in front of friends. One family said that all their children disliked the handicapped child. In ten families either the normal children were too young to have an attitude one way or the other, or the mongoloid was an only child. One mother of a fourteen-year-old boy said:

Keith thrives on love. Our family does everything together. When we drove to [an institution] once to look it over, the children all said with tears in their eyes that they wanted Keith home with them. Sam, my son-in-law, said that Keith would always have a home with him and Mary. Of course, we would never consider having our children assume the care of Keith. But wasn’t it fine of Sam to offer?

Another mother said:

When the children were younger my husband and I never left Hugh to be cared for by them. On trips we always took him along. Stephen, my husband, wouldn’t go unless Hugh went. He said that Hugh was our responsibility, not that of our children. One woman I know said that Hugh should be put in a home because it would affect Eileen’s chances to be married. Stephen said that if that was the way we’d have to have a son-in-law—by living a lie—it would be better not having one. . . . Eileen used to get upset when Hugh made noises. It embarrassed her when she had friends over. But she got over it. The boys didn’t seem to pay attention.

The predominant type of interaction between the mongoloid child and his brothers and sisters was paternal. And it remained relatively constant over the years. Even though younger brothers and sisters were frequently his playmates, they also assumed the role of protector and teacher. The type of interaction between him and the other children, however, was influenced by the retarded child’s ordinal position in the family, his age in relation to the age of his brother or sister, by the size of the family, and by the mutual interdependence of all family members. One mother of a five-year-old boy and of two older normal children said:

I have very responsible children. Both are better with the baby than either my husband or myself. I feel I don’t give full time to the other two. I try, but often feel too drained. They accept this. Everything about their little brother is all right with them. He can climb all over them, mess up their school work, do anything. They don’t mind.

Mandy’s not like other teenagers. She’s very serious, very deep. She possesses very rare gifts. She lives for her little brother.
They bring out the best in each other. He follows her around like a shadow. She can do things for him I could never do—I don’t have the gift. Then too, she can be more objective. She says she’s learning from her little brother. Since she shows such interest in him, I think she should go into special education (work with handicapped children).

A father whose eight-year-old mongoloid son was the oldest child, said:

At first I was afraid of the effect John might have on my younger children, but not now. Dick is very sensitive to other children’s affections and problems; he is only five but already he is protective of John and bawls other children out if they touch him. Then again, he’ll say to his playmates, “Come on, let’s get away from Johnnie.” I can’t blame him. Sometimes John sweeps down with one stroke of the arm, something the children have made.

A mother in a family of five said:

The boys are all very good to him. Al and Stan have always played with him more. They showed him how to play basketball, how to box and to wrestle. Sometimes when Larry gets balky they have to force him. Walter is stricter with him than the others are; also he teases him more. Myrtle, my youngest, sits with him a lot—more than the others do—and shows him how to write. The children are all very considerate.

Just as rivalry and jealousy between brothers and sisters can exist in almost any family, so in some of these families jealousy between the normal child and the mongoloid child sometimes existed. One twelve-year-old mongoloid girl complained that her four-year-old normal sister “got more kissin’.” In contrast, the mother of a normal son, aged eight, and of a six-year-old mongoloid girl said:

He adores his little sister and is very affectionate. But sometimes I worry. The other day when the children were playing together, I overheard Bob say to his sister, “Why are you so small? Why don’t you grow? Well, never mind. I guess I’ll have to love you anyway. I wish I were you.” I used to hold and rock Simone for hours at a time—when she was so ill. Bob often saw me weeping over her.

Although in life age a few of the mongoloid young people in this study were adults, they were regarded as children. One sister of a thirty-two year old mongoloid brother coaxed, “Come, honey, eat your dinner like a good boy.” The younger brother of a sixteen-year-old mongoloid sister inquired, “Have you been a good girl today?” Still other children referred to their mongoloid brother or sister as “Little Jack” or “Little Jane” irrespective of age. If the retarded
child was the first born, his brothers and sisters grew up past him and
looked back on him as the last born and as the “baby” of the family.
One twelve-year-old brother of an older mongoloid boy said:

Ross sure keeps his drawers neater than mine—and you’d better not
muss them! He’s a good kid; we like him.

The younger sister of a twenty-year-old said:

Chuck is good natured and lovable; he sort of wins you over; he
gets such a cute teasing look in his eyes. Sometimes when we want
him, he’ll hide around a corner just to tease, or he’ll turn the radio
off when we leave the room—he knows we don’t like that. He
loves my brother’s new baby and makes over her, but when we
say we’re going to bring her home, he says, “Paul’s baby.” He’s
the big shot here, and he knows it.

Neighbors

There were no culturally determined patterns of acceptance of
the mongoloid child in the various neighborhoods. Parents, individu-
ally, had to take the lead in establishing the kinds of relationship and
interaction desired between their family and neighborhood families
and between neighborhood children and the mongoloid child. Some
couples remarked that in areas where the school system had special
classes for retarded children, neighbors were better informed and
more accepting of the child.

Most parents worried, at least for a time, about how the child
would be accepted by others. Twenty-eight of the fifty families had
remained in the neighborhood where they were living when the child
was born. In many cases this was because they knew the child was
accepted there. Even though they wanted to live in a smaller house or
a larger house or in a better house or neighborhood, they remained
where they were. They said that if they moved to a new neighbor-
hood, among strangers, the child might be ridiculed, the family
isolated, and the normal children have a hard time making friends.

Most of the families that had moved into a new neighborhood
had investigated it carefully. Unless the overall attitude toward re-
tarded children was kind or tolerant, no move was made. The twenty-
two families that did move were faced with the problem of “explain-
ing” the child. In a few cases, neighbors visited the home and bluntly
asked what was wrong with the child. Young neighborhood children
were especially curious as to why the retarded child looked “different”
or did not go to school. Parents in most of these twenty-two families
had felt obliged to visit their neighbors and “to explain” the child.

But irrespective of whether these families lived in “new” or
“old” neighborhoods, thirty-five spoke warmly about the friendliness
and goodwill their neighbors had shown. Twenty-three mentioned, particularly, the kindness of neighborhood children, and that many had been instructed by their own parents to never tease the retarded child. One mother said:

At first the children noticed that Gerald was different; they stood around and watched him. I didn’t let on to Gerald that I noticed. I let him alone. He had his own little way of getting around the children; before too long he was playing with them. They know he’s slower than they are and they make allowances. When they play basketball, they always see to it that he has his turn. That’s nice. Sometimes when they play competitively, I’ll hear them say to him, “How about you swinging on the swing for awhile and then playing with us later?” So Gerald goes over to the swings. He’s happy and they’re happy. I don’t mind when children act that way. They have never said, “You can’t play with us.”

Another said:

Emma hit one of the new boys in the neighborhood with a rock. I was so frightened. I took him inside immediately and cleaned the cut with alcohol. We offered to take him to the doctor and to pay the bill.

Later, when I saw his mother coming here, I thought, “Oh, oh. This is it.” But she was so nice. She said that the neighbors had told her about Emma and that she wanted to come down just to meet me. . . . When Emma was so sick last year the neighbors sent sympathy cards. Some mothers cried when she went to the hospital, and took up a collection to help with the hospital bill.

A father said:

Tom is a quiet, polite little boy. He is well liked by his family and the neighbors. We’ve run into very nice people here. The neighbors all take an interest in Tom and often drive him down the hill to school. They’ll stop and talk to him and if they see him where he shouldn’t be they’ll either send him home or phone and tell us where he is.

The majority of parents reported that in spite of the goodwill of neighbors, their retarded child was snubbed, teased or made fun of at some time or other during his life. In some instances he was rejected by other children because he was either too large physically, or too young mentally. Also, some nationality groups were not as accepting as others. In still other instances, the attitude of the parents themselves may have influenced, to some extent, the friendliness of neighbors, their acceptance of the child and his interaction with other children. One mother said:
It wouldn’t be so hard on parents if there were more understanding people. I don’t feel that Hilda’s a burden or hindrance until someone mimicks her. Then I blow my top. One little girl up the street has the idea Hilda’s insane. She’ll say to the other children, "Don’t bother with Hilda, she’s crazy."

Another mother said:

Some neighbors are understanding but not my people [her own nationality]. They told me that they didn’t like Maria and that we should put her away; Maria realizes she is different. If she sees other children, when we go on walks, she’ll say, "Run, mommy, run." They have sometimes laughed at her. It makes me so nervous. We avoid neighborhood children and people who don’t like her.

Another said:

My husband has never quite understood his feelings about Esther. He wants to protect her from all eyes. The other day my daughter took Esther for a walk. They stopped in a neighbor’s yard to swing. Jan and the neighbor boy got into an argument; he was angry and to retaliate said, motioning to Esther, "And you can take that thing off the swing and go home."

Later, when Jan told her father and me what happened, Al wanted to go at once to the boy’s parents and say something that would hurt them. I said, "No, we cannot do that; we must not think that way."

A father said:

The neighbors have asked us to keep Rick home; he’s such an active boy. They’re afraid he might break something or do something he shouldn’t while they’re not watching. The mother of a boy down the street forgets that her kid plays in our yard, and also broke some of our raspberry vines while trying to get the berries; we never said anything even though taking the berries involved morals. They think my wife is careless. She tries to watch Rick and tells his brother and sister to stay with him, but they don’t like to play with him all the time.

The older mongoloid children had ceased to be the playmates of the children in the neighborhood. After the age of sixteen, they no longer were eligible for school training in the area where this study was made. Many of their older brothers and sisters had already left the family home. These children were thrown back on aging parents for the companionship, stimulation and motivation which was theirs for such a few years. The mother of a sixteen-year-old said:

Lucy is such a lonely child. The children she once played with have moved away; the younger ones won’t let her play with them;
they laugh at her as children will. I know she feels deeply hurt. No matter what parents say about their retarded child playing with other children they just don't—or not for very long.

Fears about sexual maturity

As the mongoloid child grew older, many of the parents became uneasy about what sexual maturity would bring. Few of them had been told that sexual underdevelopment is common in these children, and that heterosexual interest is rarely present. Based on their own observations, the parents of older children said that they need not have worried. Generally, careful training, supervision and emphasis on acceptable behavior were sufficient.

But the parents of the younger children worried. The mother of a ten-year-old girl dreaded the time when her daughter would start menstruating. She said that she was afraid her daughter would “not have the sense to take care of herself.” However, the mother of a thirteen-year-old girl said:

Kate watched her sister use pads and wanted to do the same. I hardly know when she's having her period.

The mother of another young girl, whose physician had died a few days after their last visit to him, said:

I haven't slept a wink. I feel so badly. The doctor who had always been so kind to Emma said, “Place her in an institution right away; she will become pregnant.” That was the first time he ever talked that way to us. He didn’t say she “may” or “might” become pregnant, he said she “will.”

Now we're in a turmoil. Did he know something about Emma we don’t know? I want to talk to someone, but I feel too terrible, too hurt, and too embarrassed.

The mother of a fifteen-year-old boy said:

Up until a year ago, his genitals were like a baby’s. When he developed he started playing with himself. I was quite annoyed and had to watch him closely for awhile. Then I bought different kind of clothing for him. Since then there's been no difficulty. I heard someone say that these children become sex perverts. I don’t think that’s true.

A mother who had been faced with the same problem said:

Whenever I saw my boy rub himself, I whacked his hand. Now I
never see him do that. He's as innocent as a newborn babe.

Meeting needs

Attempts on the part of the organized local parent group to provide training, “socialization,” and recreational programs for their retarded children were at best sporadic and inadequate to meet the need. There were no well-organized day-care centers available to help mothers in the techniques of handling their “pre-school” mongoloid children; nor were there sheltered workshops in the area for meeting the needs of the older mongoloid children and adults.

The public and parochial schools offered the only substantial programs for training and educating school-age mongoloid children living in the area. Most of these special classes had become available only during the four-year period preceding the time this study was made. At that time, twenty-seven of the mongoloid children were enrolled in special classes for trainable children. Eight, who could have been in school, were still too restless or had not yet been toilet trained (a requirement for enrollment); the others were either too young (under six years) or too old (over sixteen years). A few families were highly critical of the school administration and said that there was limited knowledge of the “real” needs of the children. Some complained that there was too much emphasis on academic learning and others, that there was too little. In a few instances the parents’ criticism seemed justified, but in as many others, unjustified. One family felt that their ten-year-old mongoloid girl was being held back by slower pupils. The mother said:

I don’t resent that Martha’s in a “trainable” class, but I do expect the schools to give her the chance to be in a more advanced group and not hold her back just because she’s mongoloid. She’s not getting proper motivation. When I ask her what she has learned in class, she’ll say, “Just the same old thing.” She’s bored. So much stress is placed on health and happiness and not enough on academic subjects. She should be pushed a bit in areas of writing and reading just as she was pushed to learn to tie her shoe laces. When a child’s training determines whether she’ll get something out of life later on, then parents have a right to complain about what is being taught.

But seventeen families could not say enough in praise of the schools and of the teachers. Their child’s enrollment gave most of these parents a “terrific mental lift” and a feeling that something was being done. They felt that the child was “getting his chance in life.” They said:

He’s so happy in school. It makes me happy to see him so happy.
She has something to look forward to. She has an interest in life.

He has companionship without ridicule.

He's making such progress. He's not nearly as retarded as we had thought.

She's being taught fundamentals and how to behave.

He's learning to talk.

Eight mothers particularly mentioned their own relief at not having the child "always underfoot."

"Schooling" for the child also helped some of the parents to understand his capabilities and limitations better. One mother of a sixteen-year-old girl who was no longer eligible for training in school said:

Kate has had her chance. I no longer have the anxiety I once had, or the desire to force her. As a younger mother I felt she should have her share in the community; I saw response in the child; I felt something should be done; yet there was no help. Then with going to school there was hope. Her teachers say that Kate is capable of more, that more could be done for her. But I feel this is the end for Kate.

Feelings of hopelessness and despair were expressed by many of the parents of the children born too soon to benefit by special education or other training programs. One mother of an eighteen-year-old boy said:

Mothers who have mongoloid children today don't know how fortunate they are as compared to when I had Joe. If only he could have had help when he was younger or have had a chance to socialize and be in competition with those his own mental age, or even if I could have had the kind of help I needed so that I could have been of more help to him! Once I followed for three blocks a mother who had a child who looked like mine. All I wanted to know was if she had similar problems—if her child acted like mine.

Some parents were so engulfed by their despair that they were unaware of any advancement that had been made on behalf of mongoloid and other retarded children. A father said:

There's nothing left but to institutionalize. You'd think the State would do more—provide more. I give to all the charities, but these children get none of it. They are forgotten. Nobody cares. What is the answer?
THE FUTURE

The question of custodial care of the child evoked the parents' strongest feelings of anxiety, doubt, and anger. Forty-four of the fifty families had been advised to institutionalize the child at the time they learned that he was mongoloid. Thirty-one were urged to place him at once; thirteen others, to consider placement if things did not work out at home, and three were told that because the child would soon die, placement would not be necessary; three couples could not remember what had been said.

In most cases the advice to place the child at once had increased the parents' feeling of desperation and shock. To them, it indicated that the doctor considered the situation so hopeless that he wanted to be immediately relieved of further responsibility for the child. One mother of a sixteen-year-old mongoloid child and of two normal children, still became excited whenever she thought about that period. She said:

It was the way in which I was advised to place him! How dare they say such things to me in that manner. What do they know about such things? This child needs me. I love him. I'm his mother. How dare they speak to me like that. How dare they. When a child is handicapped, parents never forget that child—they are always with him.

Later, social workers and educators gave parents the same advice. Little consideration was given to the effect of institutional living on the very young child, the limited training facilities in public institutions, or even to the existing bed shortage in them. (Ninety-eight percent of all mentally subnormal persons who have been institutionalized are in public institutions.)

Most of the parents in the study group wanted to keep the child at home, at least during his early years. And they wanted him home for essentially three reasons: they felt they could give him better care and more individual attention and love than an institution; they felt he contributed to the happiness of the home and to "character-building" of the other children; and, to a lesser extent, they felt he was
their responsibility. A father said:

We feel the child needs us and can benefit by being at home. I couldn't live with myself otherwise. Just because a ship is lost at sea one doesn't abandon it. Maybe we are selfish. We want to make Cliff happy. That is the main thing.

A mother said:

I have wonderful children. I think that just their being around Mike has made them take notice and think. If anything, the family bond was tightened because of his presence. He has given more than he has taken. We would miss him.

When the parents were asked what they thought an institution could do for a retarded child, only fifteen of the one hundred mentioned special benefits; some of these thought he might receive better training and supervised recreation; others, that he would have round-the-clock supervision, good medical care, and the companionship of "his own kind." Fifty parents said that an institution had no advantage except to give shelter to the child after the parents were dead. Twenty-two others stated flatly that the institution could do nothing at all for the retarded child. Thirteen had no opinion; they had never thought about an institution in connection with their child.

But regardless of what the parents thought the institution could or could not do for the retarded child, twenty-three families had filed their first application for placement. In thirteen of these families, neither parent had ever visited an institution for retarded children. This was also the case in nineteen of the twenty-seven families that had not filed an application. Among those who had applied were ten families in which the parents could not agree about placement. Only two of these twenty parents had ever gone to see the place where their child might be sent.

On the waiting list

In the area in which these parents lived, placing a subnormal child in a public institution was done in two steps. The parents first filed a preliminary application. If the child was accepted for admission, his name was put on a waiting list. When a suitable vacancy occurred, that is, when there was room for a child of that age, sex, and type of handicap, the parents of the child next in line on the waiting list were notified and asked to file a second and final application. The average length of time between the first and second application was five years at the time of this study. At this point, the parents could either place the child or request that his name be kept on a list for future placement.

Three families had filed their first application less than a year
prior to the time of this study; twelve had applied from one to five years prior, but eight others had been on a waiting list for over five years. Two of these families had been notified of a vacancy and had just filed their second application; it was now a matter of only a month or two before the child would be placed. In three other families, the parents said that they would place the child as soon as possible.

What kinds of situations finally precipitated the decision to file an application? Among the five families desiring early placement, the mongoloid was either the oldest or next to the oldest child in the family. The decision to place him had been made shortly after the diagnosis was made. But it was strengthened during the waiting period by the child's unpredictable behavior, the stress of rearing other children, and in some instances, by the family's rejection of the child. In several families the parents were satisfied that placement would be a good thing for everybody. One mother in a family that had applied for admission to two institutions, said:

We'll place Jimmie in whichever institution has an opening first. We prefer the smaller one. I don't feel I can give the proper care to the other children because Jimmie requires so much time. He is getting harder to manage physically. When he get mad, he's really mad. He could kill someone, he's so strong. It worries me that he might hurt the neighborhood children as well as my own. He doesn't realize he's hurting the children. We don't have a normal everyday life. I always have to keep an eye on him. He has no fear of anything. He might be taken advantage of by others as he grows older. We don't feel the other children should be burdened with him. My husband feels the same way. We feel the institution will teach him so much more than I'll ever be able to. Maybe under a regimented life, he could be taught to be self-supporting.

In others, the parents felt torn, and seemed to be acting under a compulsion. One mother said:

I wonder if I'm really doing right by placing Dorothy. Especially now that she's in school and doing so nicely. I feel quite guilty. I'm going to miss her. She's always so happy to see me when she comes home from school . . . All my relatives feel she should be placed. My mother said, "You'll just have to put her away." My sister doesn't ask to have her visit them. She only asks John. I feel by placing Dorothy we will avoid embarrassment for John when he dates—also loss of family friends who might stay away on account of her.

The father added:

We feel the institution will give Dorothy security and that the
longer she's home, the harder it will be for her to become accli-
mated. It's better for her to be with her own kind. I was favor-
ably impressed with what I saw at [the institution]. My only
criticism is the crowded conditions and the lack of personnel.

In ten families the problem of custodial care was one of dis-
agreement between parents. The conflict was often intense. One
parent wanted immediate placement and the other did not. Among
these twenty parents were some that denied the handicap, and some
that may have used it as cover for a more basic problem in the home.
In one family the mother had just signed the first application form
after refusing to do so for ten years. Her husband said:

He should have been put in an institution immediately. He
could have been trained and helped. Now it is hopeless. His
mother prayed that he would be made well—believed in miracles.
I told her to put him away. But I'm glad she didn't listen. I'm
glad. Now she knows a miracle won't cure him. Now she sees
what he has done to her and to the other children. My daughter
should be thinking of marriage. What chance does she have?
Her life is being ruined. She doesn't invite young men home be-
cause he screams and hollers and might even pull his pants down in
front of a young man visiting her. Now she knows what it has
done to the children. I'm tired when I come home. I work hard.
I deal with the public. I'm known as "the man with the smile."
When I come home, I want quietness. We don't live like other
married people. We don't go out together. I don't know how
she stands it—every day—and every day.

The wife, who had been crying softly during this, said:

He has had too much wine tonight.

In another family, the father had been told of the child's condition
shortly after her birth; the mother learned a few years later by a
chance remark made by a relative. Even after several years had passed,
she held it against her husband that he had not told her. She said:

Everybody knew the child was mongoloid—everybody, except me.
That's a bitter story. I'll never forgive Carl for that... If
you're asking me, he couldn't face up to having a child of his at
[the institution].... The children are crazy about Lucy, but
they rarely bring their friends home. It's not that they don't love
her, it's that we rarely have a quiet evening. She's into everything.
One evening every member of the family had an engagement. I
phoned to a neighbor and asked her to look after Lucy for just an
hour. My oldest son heard me and said, I'll stay home and take
care of her." He wouldn't go to his practice. That did it. When
my children started telling their mother that she couldn't leave
Lucy for one hour, it was time to put a stop to it. Carl wouldn't
hear of placing her. Now, you'd think it was his idea. The big
lump! A couple in back of us have a retarded son; their life revolves around him. Carl began watching the family closely. One day he said he'd seen enough. Lucy had to go—but not to spare me—only to give the other children a normal life.

Parents in eight families said that they would not place the child until they had to, that he would probably have to go eventually but that they wanted to keep him with them as long as they could. Some of these parents had applied for placement when the child was very young and before he started to respond. One young mother said:

We applied for placement when Matt was four months old because we were so emotionally upset. Just before Matt started walking he would continually make horrible snorting noises and look up with a vacant stare till we thought we would go out of our minds. I'd given anything then to have dropped him out of the third story window. I was so embarrassed in front of my friends. It was at that time that we felt he really was worse than he was and that we could do nothing with him. Then I started thinking less about myself and more about him. He's made such progress. He's been on the waiting list for four years. If I suddenly got notice that he was accepted—well, I don't know what I'd do. I don't think he is ready for placement yet. He's made too much progress with us. We're so pleased, we want to keep him. Later if it seems that he is unmanageable, we may. It is of prime importance to us to keep Matt contented and happy and to make the most of what he has. The nursery at [the institution] is so pathetic.

But the greater number of parents made the decision to apply when they began to think about their own health, their advancing age and eventual death. One mother said:

We made application for placement three years ago when Alan's health began to fail. We want to protect Ronnie without burdening his brothers. A friend took Alan aside one day and said he could probably help us to hasten the placement, but we did nothing about it.

Another said:

We want to see what we can do for Bob—if we can manage. All the relatives say keep him—don't let him be taken away. We have all learned to love him. We'll keep him as long as we can. We applied for care to give Bob security only because we hate the thought of his being left out if we die.

Families not on the waiting list

Parents who had not applied for custodial care prior to the time of this study were also young, middle-aged and aged. In vary-
ing degrees, the same kinds of situations that were present among families that had applied were also present among the twenty-seven that had not. How then were the two groups different? Or was it just a matter of time before all of the families would apply? According to data from several State institutions, only a small proportion of mongoloid persons placed on a waiting list are actually institutionalized.

Among the twenty-seven families who had not applied, four said they were considering it, but that it was difficult to take the first step. One mother said:

We've been thinking about it; we keep putting it off. He's such a good child; he's so well liked by his family and friends; if he were mean it might be easier. At first my mother thought [the institution] was best, but, now that Ben's in school and doing so well at home, she's changed her mind. My sister-in-law who was very much against the institution later conceded—after her friend who has a retarded child died—that it might be best for Ben.

Her husband added:

We've heard nothing bad about [the institution]. They say the meals are good and that some children can have a dog. The doctor told us no one can make us keep him there if later we changed our minds.

Parents in ten families could not say what they expected to do, or just what the ultimate solution was. They were satisfied that for the time being the child was progressing well. Some wanted to wait and see how the child developed. Most of the parents in this group thought of the institution as a place for “hopeless” children. One father said:

I can't see [the institution]. I've talked to many people who live around that area. They say the children are placed and cared for in large groups. We feel individual attention is best for Robin. I can see a place like [the institution] for children who can't talk, walk or learn, but there's love in Robin; she responds; she's no real problem.

Another mother said:

Various people have suggested that we put him in an institution. I think such a place would be good if I felt hopeless, but I don't feel hopeless. We keep thinking that if we wait we may find that he can take care of himself through special training in one of the workshops being started. Of course it might be harder on him to be put away later after being home all these years. Still, some people I know waited before putting their son in an institution.
and he's getting along fine. We want to wait and see. We're still hoping.

Two families expected the child to die before anything would have to be done about him. But parents in eleven families expected to care for the child at home for the remainder of their lives. Eight in this group were laying aside money for the child's care in later life. Five families assumed that the normal brothers and sisters would take over his direct care after their death. A few were more determined than others that their child should never be placed in an institution. One father said:

I feel a child should definitely remain at home even if worse off than Martha—if it's any half way decent home. Only if a child lives in the slums should he be placed. We feel we can do much more for Martha at home through individualized attention. She has made so much progress. Why should we deny her love and attention on the basis that something might happen to us? If all things continue as they have been, I'll have plenty for her and us to live on comfortably for the rest of our lives in another twenty years or so. By that time we expect her to be able to care for herself and do housework so that she will not be a burden to the one with whom she lives.

His wife added:

Parents who place their child are trying to take the easy way out. Our families on both sides feel that Martha should remain home.

The other families realized that this was a problem they would have to think through soon. The mother of an eleven-year-old said:

The only thing that worries his father and me is what will happen to Alex if anything happens to us. This is more recent thinking because the mister and I are getting along. His dad has always thought of his future. I'm sure that is the reason why, just as soon as we knew about Alex, he took out a twenty-year policy for him. We've never tried to put him away. We want to keep him home. He's not a bad child. I'm strong. I don't mind doing for him. Still, we can't expect his brothers and sisters to take care of him.

The father of a sixteen-year-old said:

The exact means of providing for Spike has not yet been solved. But if one has the money laid aside there is no problem. I do not feel as cold toward institutions now as I did formerly. If I felt unable to provide for him I wouldn't object. We might have considered a private institution if one had been closer to home or if I had been financially able. But as long as we are spared we will care for him. We feel Spike profits from the association with his sisters and brother. But whatever we do, my wife and I
will be in agreement. I feel the mother's opinion is the deter-
mining factor to make for a happy environment.

The mother of a thirty-two-year-old mongoloid son, and of
two older normal daughters, said:

Ten years ago when I broke my leg, Malcolm was so cooperative
and helpful. He prepared trays of food for me, did dishes, was
so helpful. I thought then I was being repaid for all the years of
effort devoted to him. But just in the past three years he has
become uncooperative and stubborn. He says, "I too tired. I too
tired." Maybe he is aging.

He used to sit in with his family and friends. Now he retires.
When he was ten years old he would swim in the river and play
with normal children his own age. They accepted him. Today
those boys are grown. When he was growing up, he played ball
with the boys in the park. The young children now, who don't
know about him, won't let him play ball with them. They take
his money and tease him. He chases them. When he was a baby,
his sisters made over him. Later they didn't pay much attention
to him because of age differences. Sometimes they felt self-
conscious. Both girls married fine men. When they dated, the
young men would stare the first time they came over, would say
"Hi, Malcolm" the second time, and shake hands the next.

Earlier, I thought he would grow up to be a comfort to me. Now,
we have to coax him so long it's hardly worth while. I hope
we'll outlive him or all go together. I wish he could be placed
in a happy individualized atmosphere, near home, before I die.

The father said:

We'd never dump him on our other children or suggest they care
for him. If they suggested it, that would be different, but they
have their own life to live and we keep out of it. The thing now
is to find a place for Malcolm. And if there's money, that's pos-
sible. But we'd miss him if he were gone.

The mother said:

I would like to wake up in the morning and find that a miracle
drug had been discovered and that Malcolm was well. Perhaps he
would have been a famous doctor and would have come home
week-ends to visit us with his wife and children. Maybe he
wouldn't have married, but would have just lived with us.

The father said:

You can't tell. Maybe if Malcolm had been normal he wouldn't
have been a doctor. He may still have brought us sorrow. You can't tell. If he had married, his wife may not have liked us.

Patterns

Parents who were keeping their child at home said that they were doing this because it was good for the child, or good for the family, or the right thing to do. Parents who were placing their child in an institution also said that they did this because it was good for the child, or good for the family, or the right thing to do. Those who were keeping him tended to stress his welfare whereas those who were placing him, the family's welfare.

When the families who had applied for placement were compared with those who had not (Appendix, Table II), it was found that the first group included a greater number of families who said that they were not able to give enough attention to their other children (12 out of the 17 who reported this), that the emotional bond between the parents was strained (7 out of the 10 reporting), that their normal social activities were disrupted (15 out of the 28 reporting), and that their other children were socially embarrassed (8 out of the 13 reporting). It also included a greater number of families who said that the child's behavior was poor or unmanageable (11 out of the 19 reporting), that the child was aware of his limitations and unhappy (10 out of the 16 reporting), and that he had little or no contact with neighborhood children (16 out of the 27 reporting this). The chance of the mongoloid child being placed on the waiting list was greater if he was the first born (7 out of 11) but decreased steadily as he was the second, third, or still later born (5 out of 9, 5 out of 13, and 6 out of 17, respectively). Also, as the child's social quotient (measure of social competence) rose, his chances of being placed on a list decreased (5 out of 9 with an SQ of 15 through 29, 13 out of 26 with an SQ of 30 through 49, and 5 out of 15 with an SQ of 50 through 84).

The number of other children in the family, and the occupation and education of the father tended to have little influence on the family's decision to apply for placement.
THE EFFECT ON THE PARENTS

What effect did all this have on the parents themselves, on their marriage, their plans for a family, their activities, and their personal attitudes?

Marital closeness

The fifty mothers were asked whether the mongoloid child had had any effect on the relation between them and their husband. Twenty-one said that, if anything, the child had drawn them closer together. Nineteen did not feel that the child had made any difference; eleven of these added that they and their husbands had always been close. Many, in both groups, said that their marriage had been strained for a while, in the beginning, but that this had passed. Statements of this kind were especially frequent in families where the mongoloid was the first-born child. The mother of a four-year-old said:

Our marriage was affected only during the first year after Matt was born. It was mainly my fault. I couldn’t stand the thought of another baby. I was thinking only of myself and Matt. Once I stopped thinking “Why me? Why not some one else?” and started thinking “How can I help him?” things started working out. That was a year of acceptance and maturing for me. I never want to go through that again.

The father of a seven-year-old said:

We decided to face this thing together and be happy. For awhile after Leo was born, we would both look at each other and burst into tears. Then I told my wife that this would never do, that we would destroy our marriage. I encouraged her to talk over everything with me, regardless of what it was. . . . It’s surprising how well one can live with a great personal tragedy—how one can live even a better life than before.
Ten women felt that the child had separated them and their husband, to some extent. Four of these families had talked about divorce. The mother of a seven-year-old said:

Beth makes me so jittery—always follows me around—constantly giggles—always pooping in her pants—I know she can’t help it—poor little thing. I get so jittery, I start to yell and everything is horrible. Some say having a kid like mine makes a couple closer. It didn’t. We’ve even talked about a divorce. But then we always did fight.

Religious affiliation may have been a factor in holding together the marriages of some of these couples (fifty-six percent of the study group of parents were Catholic). But in the one home that had started divorce proceedings at the time this study was being made, the mother said that if anything, she tried to make the marriage work because of the retarded child.

Family planning

The mothers were also asked whether having a mongoloid child had made them avoid having other children later. Nine families had kept from having any more children after they learned that their baby was mongoloid.

One mother said:

We’re too tense to even think about having more children. My greatest fear now is having a baby.

Another mother, whose first child had died during infancy, said:

I wouldn’t want another now, not because I’m afraid but because we want to give Ruby every advantage. If we had others we would naturally have to divide our attention. We don’t feel it would be fair to Ruby. I guess after losing the first, we were happy to take Ruby as she was. She’s better than nothing.

Eleven families delayed having another child but eventually did. One mother with a son older and a daughter younger than the mongoloid girl said:

I feel that three children are all that I can handle. If I am to bring Susan up right it is best not to have more. I only wanted two children, really. After Susan’s birth my husband said, “No more children.” Then he went into the service. One of the Navy doctors helped to change his mind about having more children. We planned Sophie. She turned out to be all that we ever wanted—all that I ever dreamed of—a perfect little girl that I could dress in pretty frilly things. Now we have our two children—and also our baby. When our other two are gone we will
still have Susan. She is not a stranger to us and is not going to be treated as such. She was never a burden. We got used to her right away.

Thirty families said the mongoloid child had no effect on the number of children wanted. Ten of these families had another child within the next two years; two would have liked another child but "nothing happened." In twelve families, the mother was either over forty or in her late thirties at the time the child was born and already had considered her family complete. Six younger mothers also said they had all the children they had planned for.

Activities

Twenty-two families said that their social activities had not been affected by having the child in the home; twelve said that theirs had been severely restricted; and sixteen that theirs had been restricted to some extent. Fourteen families felt that some old friends were less cordial than formerly.

The activities of some couples were rechanneled as a result of having a mongoloid child. In sixteen families one or both parents became active in organizations for retarded children. Some mothers did volunteer work in nursery classes or a hospital clinic or drove a school bus. Three fathers were active politically in trying to get better institutions and better legislation for retarded children. In a few cases the parents devoted themselves to this work to the exclusion of other activities. A mother said:

"It's not that old friends are not kind and sympathetic, it's simply that we no longer have time for former friends and activities. Our work in the parent group takes all of our time. Our closest friends now are among these families. I hope it will continue that way. It's more than that it's helpful knowing other parents with retarded children—it's that the need is so great."

Personal attitudes

Most of these parents had come to terms with their problem and seemed to move on as even a keel as their neighbors. But not all. When asked what they would wish for if they were given a wish, about forty percent of the answers were for things that concerned the family as a whole, and not the child specifically, things that any parents might wish for, such as good health, a new home, financial security. Thirty-six wishes were for the child; twenty-four, that he might be normal; six that his future might be secure; and six, that there might be better training facilities for him. Sixteen parents wished for relief
for themselves—for leisure, freedom, and so on. One father said, 
“Quietness!” and this was echoed in the answers of four others. One 
said:

I would take my dog and go on a long hunting trip away from 
people—where there was absolute quietness.

Eight others could not think of anything to wish for. They said:
“I have a home;” “I have my health;” “I am content.”

The parents were also asked what effect the whole experience 
had had on them, whether they had learned anything from it. Ten 
parents had found the experience wholly bad. One mother of a 
four-year-old said:

The four years haven’t changed a thing. Every day I feel worse. 
I don’t know how I’ll stand it.

The father of a ten-year-old said:

This kind of child brings only worry and sacrifice. If it’s just 
work and physical care that’s involved, you can take it—you know 
it will come out all right in the end—but not this—if you have 
your faculties you have everything—but when you don’t have 
them. . . .

The mother of a fifteen-year-old said:

What use is it to have children when you have this kind? What 
good are they? They change your life and personality. You 
become flat. They take everything from you and give nothing in 
return. They tie you down and there is no one to help you. It 
takes a lot out of you. You become a machine. Everything has 
to be done in a routine order to train them. It’s not just doing 
the same thing over and over. It’s that there’s so little progress 
to show for the effort.

The mother of a twenty-two year old said:

I have some allergies I didn’t have before. He just about ruined 
my life. Just when he should be taking me around I have to take 
him. I just wonder how much longer it will last.

Fourteen parents said that they had learned nothing from the ex-
perience beyond the fact that “there are these kind of children” and 
did not feel that they had been changed in any way. One said, “I 
have always been patient” and another, “I can always wait.”

But the great majority—seventy-six percent of the parents— 
said that they had benefited from the experience. They had learned 
to “do for others.” Some felt they had become better parents and 
were more able to understand all children—not just retarded chil-
dren. One father said that he now had “a greater feeling how
grateful parents should be for their children and how they should try to bring them up right."

Most of these parents felt that they had learned to be patient, sympathetic, tolerant; seven mentioned specifically their increased humility. They had a greater appreciation of spiritual values and of "things taken for granted." Some had become more deeply religious. Forty-one spoke of religion as "the greatest help in a time like this." One father commented that he had "learned there is a God. I learned to pray." A mother said:

Before I had Gerald I always thought of neighbors as just people next door you said hello to. One doesn't know what life is, just to go along taking everything for granted. It made me look at things differently. I have a better view of humanity. People mean more to me now because when they're nice to Gerald, they're even more than a neighbor—they're a friend.

Another mother said:

The first three or four years I prayed and looked for a miracle. Finally I realized this couldn't be. At around the same time Effie started to improve, she had fewer temper tantrums, she started to walk, to listen and to respond. Then she started to school. . . . We feel our lives have been enriched—not materially—but in other ways. We were feeling smug before this happened. Life was going along so smoothly. It has made us more thoughtful, more patient. We feel our other children will be better out in society for having had a sister like Effie.

The father added:

It has been a humbling experience. It took a few pins out from under me. Nothing like this had ever happened in my life. I had always gone along pretty easily and comfortably. I always did what I wanted to do. I'm learning to take less for granted. I think a lot more of others. I have deeper sympathy for all people and for people with handicaps. I'm more considerate.

Some of the assertions that the experience had changed the parents' values seemed to be based on the human need to find a purpose in misery. The mother of five children, the youngest a six-year-old mongoloid girl, said:

If my other children were to die young I would mourn for them because they had not realized their potential. I would mourn for Darleen too. I would miss her. At the same time, it would be a release for me, knowing she was cared for. . . . Ed and I have both discovered a vast untapped store of strength we never dreamed we had. I mean spiritual strength. Ed has become more tolerant of people. He has mellowed. He is not at all bitter. As for myself, before Darleen came my life was pointless. Now I have
a feeling of being an essential part of life. One learns most through pain.

The father added:

Our family is a better, more cooperative family because of Darleen. She has brought a blessing to this home, to me, to our other children, to our friends, and to our children's friends. You believe, don't you, that every sorrow and every tragedy is created to serve a purpose? There must be a set of balances. I've thought a lot on this since Darleen's birth. There simply must be a good purpose to outweigh the bad. It was bad that Darleen is like this, so there must be some good, somewhere, to outweigh the bad.

But many of the assertions rested on a simple, earthly, pleasure in the child. The father of a fifteen-year-old mongoloid boy and of three normal children, said:

We never felt having Spike was a cross. A normal child could turn out being a criminal. And as far as expense goes, Spike hasn't required as much as the others. I see no difference between physical and mental handicap. One gives a home to a dog, why not to one's own? Why differentiate? We enjoy doing for him. A lot depends on one's philosophy of life. Maybe parents with a retarded child will be better able to work out their salvation. God gives these children to parents who can best take care of them. If one believes in a heaven or hell—well, then, we know these children have a one-way trip to heaven. They are innocent.

The mother of a seven-year-old mongoloid boy, her only child, said:

Just at first it was hard taking Tony out. Not that I was ashamed—I guess I was just mad at society for not knowing that these things can happen. Now I don't mind the staring. At first I felt bitter—but not for long. Tony has added more to this home than he has taken from it. Life without children would be empty. I would like to have Tony normal, but since that can't be, I want more children and normal ones.
IMPLICATIONS

The capacity of families in the study group to adjust and adapt themselves to the needs of the mongoloid child was outstanding. It was the more remarkable because of the lack of professional guidance for the parents and the scarcity of community facilities for helping the children. But the acuteness of the need urged these parents into developing whatever physical, moral, or spiritual strength they possessed; with or without help, they had to come to terms with an irrevocable condition. They could not change the child; therefore, they had to develop techniques for handling him. In the presence of self perpetuating public attitudes of depreciation toward mental malfunction, the parents had to take the lead in establishing the kind of relationships and interaction desired between their other children, relatives, neighbors, and the retarded child.

The child’s presence in the home did not break up a marriage that was strong prior to his birth; if anything, family bonds were strengthened. The brothers and sisters of the mongoloid child tended to reflect their parents’ attitude. Most of them took an affectionate, protective interest in the child. This attitude was affected somewhat by age differences. Those closest in age to the retarded child were sometimes “neglected” or demanding children. The attitude of most neighbors was sympathetic and kind. But this was frequently because the parents themselves “had explained” the child to them.

Most of the parents had gone through periods of agony. First they were faced with the horror of something they could not understand; next, they were haunted by the unreasonable but terrible question: “What have I done?” While they were resolving these things for themselves they were still afraid of what their families and neighbors would think. Still later they asked, “How will my child be accepted by others?” “How can I help him?” Training for the child in the public schools gave them their first feeling of hope. Something was being done. But this kind of help came only after six to ten years had elapsed. And most of these parents needed help or professional support shortly after the child’s birth.

All of the parents showed a basic human need to see the child
grow, and to feel that they had done all within their power to help him. Not until they felt convinced within themselves that it was necessary for the child's future security could they even consider the idea of placing him.

Most of these parents loved the child and were worried about his happiness, not their own. This is a very significant thing. It shows that love does not depend on pride—that one can love a child, for his own sake, without thinking about the glory he may reflect on his family in the future, or on any other profit he may bring. It also shows that these children are human beings, as precious and with as much claim on our sympathy and understanding as any child.

These families were all carrying a very heavy burden. For some of them, it was too heavy, and they were breaking down under it. It was easier for those who felt that their relatives backed them and that their neighbors were sympathetic. But it was still a very heavy burden. There are many things that a community might do to help these families.

**Information programs**

A public information program is needed to modify current attitudes toward all forms of mental deficiency and to relieve the pressures created by loss of social status for families who have a subnormal child. The general public and all who work with such families should be informed about the specific kinds of support that are needed to meet the problems of a particular child and a particular situation. The general public also needs to be informed about how mentally subnormal adults can be integrated into the community without hurting the social structure. Such an educational program should be directed to groups at various community levels.

It is important for the public and for parents to recognize that a subnormal child can be born into a family regardless of the family's social situation. Practically all parents in the study group mentioned that prior to the birth of their own child they had not heard of mongolism or had dismissed it as something that only occurred among disreputable people. This attitude is changing but is still sufficiently prevalent to warrant serious attention.

Physicians, and all other professional persons working directly with retarded children and their families should be made more aware of the fact that a diagnosis of subnormality can create a crisis situation for some families. Their treatment of families who are learning for the first time that they have a subnormal child can set the stage for a whole series of negative or positive chain reactions. All professional workers who are likely to come in contact with such families need to be more aware of the difficulty most people have in under-
standing problems connected with subnormality when they have had no personal experience to guide them.

**Initial counseling**

The initial counseling situation is crucial for parents; they should be treated professionally but with sympathetic regard for the particular kind of problem with which they are faced. Parents come to physicians with different cultural and educational backgrounds; some may need to have the medical diagnosis explained in detail; others need only be given the implications of the diagnosis in simple, practical terms of how best to care for and manage the child. All should be given accurate information, however, and full frank answers to their questions. The information should include an accurate explanation of the multiple factors related to mongolism.

The focus should be on the total child—not on just one aspect of the child. A realistic picture of his developmental prognosis is essential. Parents should be told what they might or might not be able to expect of him in general and in specific day-to-day terms. His assets should be given as well as his limitations. But dire predictions of calamity because of his handicap are not justified. Many families adjust and adapt themselves to the child's special needs.

It should be made clear that children with mongolism vary from one another in their mental and social capacity and that they have in common with their brothers and sisters many family characteristics. Use of the term “mongolian idiot” should be eliminated. As well as being an inaccurate description of the mental capacity of most mongoloid persons, the term also bears a harmful connotation of stigma. The current movement to use the term “Down’s syndrome” when referring to this condition should be encouraged.

It is important that parents understand early that mongolism is a condition that will not be outgrown; but that the child can be helped by training, good care and love. It is also important that they understand that the child is not essentially a “sick child” but a child with a specific kind of handicap, who should be handled in ways which will best promote his individual growth and development. Only as parents understand these two important facts will they be able to set realistic goals for the child and save themselves and him needless frustration.

Parents should be given the opportunity to “talk through” their numerous fears about the cause of mongolism. Lack of understanding leads to hopes of cure on the part of some parents, and to building up deep resentments and distrust of all professional personnel on the part of others.

Denial of the handicap and feelings of guilt, if allowed to
persist, lead some parents to the use of inadequate, harmful methods of managing the child. Mongoloid children, characteristically thought of as friendly and manageable, can and do become frustrated and unmanageable. The consequences for the whole family are disorganization and needless upsets.

Guidance in supervision

The mother of the newborn mongoloid baby should be given the kind of pediatric support peculiar to the particular problems involved in his care and management. In the absence of available literature on the newborn mongoloid, it becomes even more essential for these mothers to be given some idea of what to expect. For example, the pediatrician should give "anticipatory guidance" to mothers on the feeding problems of mongoloids, their frequent colds, their listlessness, and on numerous other small deviations found in these infants which are not as likely to be found in normal infants.

The mother whose first born child is mongoloid should be given even more support than other mothers because she has had no previous experience in the care of normal newborn infants. When feasible, young mothers should be given special "genetic counseling."

Parents should also be given support, encouragement, and guidance on the general care and management of the child during his first six or ten years of life. Frequently many changes must be made in family organization in order to adjust to the child's prolonged infancy. In the absence of outside support and guidance, all parents have some difficulty in adjusting to the child, and some parents have a great deal of difficulty.

Most mothers in the group studied expressed a need for instruction not only with regard to the child's slowness in learning developmental skills such as feeding, walking, talking, toilet training, but also in recognizing his readiness to learn these simple activities. The public health nurse, in both rural and urban areas, can perform a useful function in helping mothers to train and guide their mongoloid child at home. The social worker can also perform a useful function by helping parents to understand better their family situation and their feelings about their mongoloid child.

Continuing guidance, or therapeutic discussions, if needed, should be made available to parents. The rearing of a mongoloid child, as with any child, is not static. New situations constantly arise and may throw some parents into new lows of despair and indecision.

Services

In addition to guidance for parents, systematic follow-up services should be available to the child and his progress evaluated and
reviewed with the parents from time to time.

Mothers should have some respite away from the constant care of the child. Even one day, or one afternoon, a week away from him would do a great deal toward relieving nervous tension or enabling the mother to take care of the numerous other chores connected with homemaking. Homemaker services should be made available to mothers who do not have recourse to additional help from family members. Parents themselves should organize to baby-sit for one another whenever possible.

A supervised day-care center to which mothers could bring the young mongoloid child once or twice a week would offer mothers an opportunity to observe their child in a group and to pick up techniques in training and handling him. Also, the child's exposure to an early social experience with children of his own mental age would help to prepare him for a later school experience in a larger group.

Mongoloid children would profit from a longer course of training in public school programs. Because of their slow development, they are usually not ready to enter a training class before the age of eight or nine years. Yet at the age of sixteen or eighteen, they are no longer eligible for training or education in most schools throughout the country.

Care should be taken by the schools to place these children individually in classes appropriate to their level of development. Some school systems tend to place all mongoloid children in classes of the lowest functioning group, on the basis of a low opinion of their potentialities rather than on the basis of the capacity of the individual child.

Facilities for the recreation, training, and employment of older mongoloid children and adults, as well as of other retarded persons, should be developed in the community and accepted as part of its normal structure. In this regard the effective training and employment of mongoloid persons in sheltered workshops should be further explored. Most parents of older children in the study group spoke of the child's loneliness, lack of motivation, and of their own inability to give him the needed stimulation.

Institutionalization

Only after parents have had time to assimilate the implications of the medical diagnosis should institutional placement be presented as a means of helping them assess the child's needs in terms of the total family situation. The assessment should take into consideration the personality patterns of the parents, their age, how well they are able to adjust and adapt to the child's special needs, the child's effect on his brothers and sisters and on the general atmosphere of the home, the
attitude of neighbors, the availability of school and other community facilities for helping the parents and the child, and the type of institution available, its cost, and its location.

In most instances the physician should not advise placement. He (or the child welfare worker) should, however, help parents in coming to an independent decision through self-assessment. Community resources should be known in order to give direction to parents seeking to familiarize themselves with what a private or State institution can offer the child in contrast to what parents can offer him in terms of individual care, love, companionship with normal children, and the kinds of stimulation most conducive to his mental and social development. In cases where parents feel unable to keep the child at home while he is young, placement in a foster home should be considered as an alternative.

Parents who decide to care for the child at home during his early years should be given assurance that the institution will accept him at a later age if placement is warranted. Institutional policies should be extended to give this insurance, especially now that the modern trend points away from early placement of the mongoloid. Similarly, the parents should appoint someone to assume legal responsibility for the child in the event that their death occurs before that of the child.

Many parents in the study group perceived the institution as a place for bad, hopeless, or destructive children, whereas they saw their own child as loving, responsive, or "not that much trouble." Particularly for the mongoloid child, a cottage type of home near the community in which the parents live and where he could be given more individualized care and attention would be a solution to the anxiety felt by most aging parents of the older mongoloid.

Research

Further investigations should be made on the social behavior of families and their adjustment to having one of their members mentally retarded. Such studies could yield an important body of knowledge on the continuing care and treatment of retarded children and their families, as well as a body of knowledge in the specialized area of child growth and development.

More centers for diagnostic work-up, counseling, treatment, and management for individuals who are mentally retarded should be established throughout the country. These centers should be used not only to develop techniques for the evaluation of patients but also to accumulate data and to develop research on the causes and prevention of retardation. The clinics should provide opportunities for the instruction of students of medicine, nursing, social work, psychology,
special education, and of all other professional workers carrying responsibility for the mentally retarded.

Continuing research on the unique characteristics of mothers who produce mongoloid babies should go on. Efforts should be directed at learning what factors operate in the mongoloid child that prevent him from maturing in a normal way. Programs should continue to investigate the causes and mechanism of chromosomal abnormalities in mongoloid children, and the possibility of similar abnormalities in members of their immediate family and in other persons with congenital defects and mental subnormality. The effect of the various therapies—drug, speech, and play—on the functioning of the mongoloid should be further investigated. Science progresses by small steps and many investigations and experiments are needed to reach a final goal.
Appendix

Table I

THE ORDER OF BIRTH OF THE MONGOLOID CHILD IN HIS FAMILY by the number of live-born children in each family in the study group

<table>
<thead>
<tr>
<th>Order of birth of mongolid</th>
<th>Number of live born children in family</th>
<th>Number of mongoloids</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>1 5 4 1</td>
<td>11</td>
</tr>
<tr>
<td>Second</td>
<td>4 5</td>
<td>9</td>
</tr>
<tr>
<td>Third</td>
<td>10 3</td>
<td>13</td>
</tr>
<tr>
<td>Fourth</td>
<td>7 2</td>
<td>9</td>
</tr>
<tr>
<td>Fifth</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Sixth</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Seventh</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Eighth</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>All families</td>
<td>1 9 19 11 6 2</td>
<td>50</td>
</tr>
<tr>
<td>All children</td>
<td>1 18 57 44 30 12</td>
<td>16</td>
</tr>
</tbody>
</table>

*Of a total of 178 live-born children, 6 died prior to the time this study was made.
Table II

NUMBER OF FAMILIES ON THE WAITING LIST by selected characteristics of the mongoloid child and his parents, and by the reported effect the child had on his family

<table>
<thead>
<tr>
<th>characteristics</th>
<th>all families</th>
<th>on waiting list</th>
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</thead>
<tbody>
<tr>
<td>Total</td>
<td>50</td>
<td>23</td>
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*Social Quotient of Mongoloid

<table>
<thead>
<tr>
<th>Social Quotient of Mongoloid</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>15-29</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>30-49</td>
<td>26</td>
<td>13</td>
</tr>
<tr>
<td>50-84</td>
<td>15</td>
<td>5</td>
</tr>
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</table>

Life Age of Mongoloid

<table>
<thead>
<tr>
<th>Life Age of Mongoloid</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3-4</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>5-9</td>
<td>17</td>
<td>6</td>
</tr>
<tr>
<td>10-14</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>15-32</td>
<td>9</td>
<td>5</td>
</tr>
</tbody>
</table>

Order of Live Birth of Mongoloid

<table>
<thead>
<tr>
<th>Order of Live Birth of Mongoloid</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>11</td>
<td>7</td>
</tr>
<tr>
<td>Second</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Third</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>Fourth or over</td>
<td>17</td>
<td>6</td>
</tr>
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</table>

Number of Children in Family

<table>
<thead>
<tr>
<th>Number of Children in Family</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Two or fewer</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Three</td>
<td>19</td>
<td>8</td>
</tr>
<tr>
<td>Four or more</td>
<td>21</td>
<td>10</td>
</tr>
</tbody>
</table>

*The social quotient (SQ) equals 100 times the social age divided by the life age of the child.
<table>
<thead>
<tr>
<th>Age of Mother at Time of Home Visit</th>
</tr>
</thead>
<tbody>
<tr>
<td>25–34</td>
</tr>
<tr>
<td>35–49</td>
</tr>
<tr>
<td>50–70</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Occupation of Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional and semi-professional</td>
</tr>
<tr>
<td>Clerical and highly skilled</td>
</tr>
<tr>
<td>Repetitive semi-skilled and unskilled work</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education of Father</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than high school</td>
</tr>
<tr>
<td>Completed high school</td>
</tr>
<tr>
<td>Some college or completed college</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Effect Mongoloid Had on Taxing Mother’s Strength</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some</td>
</tr>
<tr>
<td>Considerable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Effect Mongoloid Had on Disrupting Harmony of Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
</tr>
<tr>
<td>Some or considerable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Effect Mongoloid Had on Restricting Parents’ Social Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
</tr>
<tr>
<td>Some or considerable</td>
</tr>
<tr>
<td>characteristics</td>
</tr>
<tr>
<td>--------------------------------------------------------</td>
</tr>
<tr>
<td>Extent to Which Parents Neglected Normal Children</td>
</tr>
<tr>
<td>Not at all</td>
</tr>
<tr>
<td>Some or considerable</td>
</tr>
<tr>
<td>No brothers or sisters</td>
</tr>
<tr>
<td>Interaction Between Mongoloid and Neighborhood Children</td>
</tr>
<tr>
<td>Play well together</td>
</tr>
<tr>
<td>Little or no contact</td>
</tr>
<tr>
<td>Mongoloid's Awareness of His Handicap</td>
</tr>
<tr>
<td>Little or no awareness</td>
</tr>
<tr>
<td>Child aware and unhappy</td>
</tr>
<tr>
<td>Effect Mongoloid Had on Attitude of Normal Children</td>
</tr>
<tr>
<td>No negative effect</td>
</tr>
<tr>
<td>No negative effect yet</td>
</tr>
<tr>
<td>Normal siblings self-conscious or annoyed</td>
</tr>
<tr>
<td>No brothers or sisters</td>
</tr>
<tr>
<td>Behavior of Mongoloid in Home</td>
</tr>
<tr>
<td>Very good or good most of time</td>
</tr>
<tr>
<td>Poor or unmanageable</td>
</tr>
</tbody>
</table>
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