THE CHILD WITH MONGOLISM IN THE HOME

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I

MPlicit in the diagnosis of mongolism is a pessimism and finality which only recently has been challenged.\textsuperscript{1-7} The pediatrician's relationship to the infant with mongolism has often been brief—a diagnostic \textit{fait accompli}, coupled with the recommendation for immediate removal from the family. Widespread concern with all the needs of retarded children has made this attitude untenable.\textsuperscript{3-5} Systematic observation of the growth and development of the retarded child in his family setting is new,\textsuperscript{6,7} yet the pediatrician is now called upon to take the initiative in interpreting the child's abilities, as well as his limitations, and supporting the parents as they move from shock to adjustment.\textsuperscript{8-13}

Wolf and Lourie\textsuperscript{14} emphasized the need for determining the impact of the mentally retarded child on the family unit. What are the values and hazards of keeping the retarded child at home in terms of: 1) the intellectual and personality development of the child; 2) the parents—their needs and their relationships with each other, their families, the neighborhood and the community; 3) the involvement of normal children in the family; and 4) the availability of community resources.

Children with mongolism and their families were chosen for observation because among the more retarded children, they stand out as a clearly defined group.\textsuperscript{15-19} The physical stigmata lead to early diagnosis, and the intellectual handicaps usually preclude education beyond a mental age of 5 or 6 years. Mongolism is a common problem; Kramer\textsuperscript{20} estimates that at least 9,000 infants with mongolism are born each year in the United States.

HISTORICAL

The relatively recent concern of physicians, educators, social workers and others with children who are mentally deficient\textsuperscript{21,22} is in contrast to the long period described by Lemkau\textsuperscript{23} when the major professional interest was on the part of "the faithful institutional psychiatrists" who carried the burden of care. The role of the parents of retarded children is dramatic: individually and through organized groups they have focused attention on retarded children. National interest has been aroused, and money has been appropriated by the Congress so that as stated by Lesser,\textsuperscript{24} "clinical programs for the mentally retarded (have emerged) as a major activity in maternal and child health."

At a round table conference in October, 1957, Watson\textsuperscript{25} reviewed the traditional approach to the counseling of parents of retarded children. In the case of those with mongolism, Brennemann had held unequivocally that institutionalization was to be immediate. And Aldrich, who championed babies as people, urged that the baby with mongolism be removed from the family at birth and suggested that the physician take the lead in precipitating an immediate crisis, in order to prevent more serious later difficulty.

Other considerations aside, immediate institutionalization is usually not feasible. Most public institutions have long waiting lists, and many have no provisions for children under 5 years of age. Private custodial homes exist to fill the gap, but the charges average $100 to $200 monthly and the care is too often minimal, even for physical needs. The financial burden of
purchasing care for the infant with mongolism can be more upsetting to the parents and siblings than the presence of the infant in the home.

Kirman suggests that the separation of the infant with mongolism from the family at birth is damaging to the parents' mental health. The anxiety of the parents is sufficient, without "adding rejection and stirring up guilt." Jolly believes that rather than discussing concern that the mother will become attached to the baby, it is better to recognize that the mother has been attached to the baby since long before its birth. He recommends that the mother take the baby home so that she can see for herself that the child is not normal and may be in need of special facilities.

The young retarded child in an institution suffers the blighting effects long recognized for the normal child. There is a high rate of mortality among infants with mongolism within the first few months of admission to institutions. Walker refers to the emotional reaction of the defective as reflected by Wetzel grid curves which show weight shifts of such degree as would be considered abnormal in noninstitutionalized individuals. Comparisons of institutionalized infants with mongolism with those seen at a clinic revealed significantly higher mental ages and social ages in the clinic group. McNeil also observed that the infants with mongolism raised at home were superior in all aspects of growth measured. After years of working with and for retarded children, Yannet concludes "It is my impression that the mongoloid child profits significantly from an environment which includes the advantages of a mother-child relationship during the first few years of life."

OBSERVATIONS
Facilities and Material

"Services for the Retarded Child" opened in the spring of 1955 as a facility of the Bureau of Maternal and Child Health in the District of Columbia Department of Public Health. (It was one of the four original special project grants from the U.S. Children's Bureau.) Staff includes two full-time social workers; and a pediatrician, a clinical psychologist, a consultant psychiatrist and a child development specialist, on a part-time basis. The diagnostic and rehabilitative resources of the Crippled Children's Services in the Bureau of Maternal and Child Health are utilized extensively.

Several features of the program deserve mention: Services are provided without charge; continuing service to the family after diagnosis provides, as needed, social casework, psychotherapy, home training and referral to other community agencies; children with obvious physical handicaps are served elsewhere, but emphasis on early recognition has resulted in serving more seriously retarded children.

The director is a pediatrician, and it is this physician who interprets to the parents after the evaluation has been completed. Both parents are encouraged to come for the interpretation, for which an uninterrupted hour is set. Presentation of findings is woven into answers to questions the parents ask, rather than being given in didactic fashion. Staff recommendations are discussed with the parents in the light of what would seem to be the most appropriate and feasible plan for this child, in this family, at this particular stage of development.

A feature of the program has been the follow-up service, which lends support to the parents by assuring them of the continuing interest in their problem and which offers re-evaluation at critical points, such as the time when chronologically the child is of school age.

Of 250 retarded children of all types, 43 had mongolism. They ranged in age from infancy to 14 years, and were referred largely by physicians, school personnel and other parents. The reason for referral was usually "mongolism" per se, although a few were for school planning, specific behavior disturbance, etc. Families represented fairly evenly: unskilled laborers, skilled laborers, or white collar workers and professionals. The majority of couples were in the age range of 30 to 35; three mothers were under 20 and eight were over 40. Race distribution was 26 white and 17 Negro; it is of interest that two children had oriental grandfathers. Sex distribution was males 25 and females 18.
Medical Problems

The medical problems of the retarded child\textsuperscript{34} have very practical bearing on the impact of the child on the family (as well as the extent to which the physician will be involved). The variability of the physical stigmata of mongolism has been noted by Levinson.\textsuperscript{35}

Despite the “antibiotic age,” the death rate during the first few years is high: 11\% in this series. The five with mongolism who died gained poorly from the beginning and were more asthenic than many of the robust babies in the series. Four died between 11 months and 2 years of age; two of these babies had congenital cardiac defects described pre-mortem. The only post-mortem examination was of a 3-year-old (whose normal female twin survives); this showed pneumonia and congestive heart failure. The medical problems are summarized in Table I.

Apart from the developmental slowness which would have caused the parents to seek advice and counsel from the physician, more acute disorders befell the child with mongolism, and there were many other congenital defects (excluding the stigmata of mongolism) which involved the families in referrals for various specialized diagnostic and treatment services. The number of illnesses and visits to the physician will be more than usual and necessarily make more demands on the mother, as well as the physician.

Two children received combined pituitary-thyroid therapy, as suggested by Benda,\textsuperscript{36} from birth and continuing in one case for 5 years. Several had shorter courses of thyroid supplementation, although chemical examinations of the blood, when performed, had revealed no chemical evidence of deficiency. A few with mongolism had been included in glutamic-acid studies of 5 years ago. When seen at Services for the Retarded Child, the treated individuals seemed neither taller, healthier, nor more advanced than the untreated children with mongolism.

Psychologic Capacities

Detailed analysis of developmental data has been made by others\textsuperscript{31,38} and is beyond the scope of this presentation, but certain factors are important in understanding the type of child being considered. Not one child fell in the “idiot” range (I.Q. below 20). Conversely, early hopes based on motor achievement and social responsiveness lead to disappointments as language skills and abstract thinking lag; several parents had been erroneously reassured that their child presented “a touch of mongolism” or was “a high grade mongol.”

### TABLE I

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
<th>Comment</th>
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<tbody>
<tr>
<td>Acute illnesses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average* number</td>
<td>24</td>
<td>Respiratory infections predominate, usually subsiding at age 5-6.</td>
</tr>
<tr>
<td>More than average number</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>Congenital defects (other than physical stigmata of mongolism)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiac</td>
<td>7</td>
<td>Includes corrected patent ductus arteriosus.</td>
</tr>
<tr>
<td>Eye</td>
<td>24</td>
<td>Refractive errors and/or strabismus.</td>
</tr>
<tr>
<td>Neurologic</td>
<td>4</td>
<td>Convulsive disorder, cerebral vascular accident, “organic brain syndrome.”</td>
</tr>
<tr>
<td>Other</td>
<td>19</td>
<td>Poly- and syndactyly, undescended testes, absent uvula, dental anomalies and mild orthopedic problems.</td>
</tr>
</tbody>
</table>

* The average child was found by Geppert\textsuperscript{22} to have 100 illnesses by the age of 10 years, and for these and routine well baby care and immunizations makes a minimum of 30 visits to the doctor.
The mean ages for attaining early developmental milestones were:

- Sitting: 1 year
- Walking: 2 years
- Words: 2½ years
- Toilet training: 3½ years

There is considerable range for the individual child, but at the times when anxious parents ask for long-range prognoses, it is helpful to speak with some measure of confidence about short-term goals.

All children showed higher social ability than would be expected from the associated mental age, confirming earlier observations of Benda and Pototsky. The mean Social Quotient was in the range 50-69 (so-called "moron"), significantly above the mean Intelligence Quotient which was somewhat below 50 (the "trainable" or "imbecile" range). The labels "mongolian idiot" or "mongolian imbecile" are not accurate intellectual or social descriptions of the child with mongolism living at home.

**Personality Development**

Nine referrals to us of children with mongolism were specifically about disturbed behavior.

**Situational Problems:** Six were reacting unfavorably to parental attitudes which were amenable to change through interpretation of the developmental level and/or casework approach to the parents' problems. As examples:

a) N.A. Ned is a 13-year-old boy with mongolism who hit his mother angrily Christmas morning. She was very upset and feared this as the proverbial "turning mean." Inquiry revealed that the scene had occurred in the bathroom where the mother had gone to give Ned his bath. Discussion with Mrs. A. helped her to see that Ned was well able to supervise his own personal hygiene and to accept him as an adolescent with need for privacy. There were no further outbursts.

b) B.B. Billy was referred from a child guidance clinic as a negativistic, controlling and hyperactive 5-year-old with mongolism. Treatment was directed at both child and parents: Billy was seen in brief play sessions where he experienced achievement at his level of ability and was allowed to express his hostile feelings; the mother was helped through casework to set and maintain behavioral standards. Serious sleep problems abated as Mrs. B. became more confident in her handling. Fortunately, the parents were able to obtain excellent school placement in a trainable class, where Billy progresses in learning controls and socializing with his peers.

c) F.B. Flora is a 4-year-old, whose mother complained that she is stubborn and gets into everything. There is a 5½-year-old sister and Mrs. B. has long thought of the girls as a matched pair, dressing them alike and buying identical playthings and expecting similar performance. The parents were told that Flora was able to achieve at a much less mature level than they had been demanding and the mother was encouraged to lessen competition between the girls.

**Long-term Problems:** Three children with mongolism presented the effects of long-term mishandling by parents who were unable to change:

a) T.U.A. Tom is an overfed, belligerent, and stubborn 10-year-old who has failed in a succession of special schools. His parents deny that he presents any problems at home, but will go through the motions of seeking help for the behavior problems "outside the home." The parents have not come to grips with their own feelings, each goes his own way, refusing to discuss it with the other. Tom gets lost somewhere in the middle, receiving no support from them. Residential schooling would seem to be this boy's only hope for acceptance and direction, but the parents, in denying the problems, also deny him this opportunity.

b) J.X.A. Jim was expelled from special class at 14 because of "uncontrolled aggressivity which makes him a hazard to smaller children." The parents and a grandmother, who cares for him while the mother works, are unable to be consistent in setting limits. He is overprotected, and yet his failures cannot be accepted without loss of approval. Faced with continual frustration and failure, Jim tries to be the bully; psychologic testing shows deep-seated fears and anxieties. The mother, successful in business and other endeavors, has been unable to accept counseling and continues to use verbosity in covering the distressing picture of her son.
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Early Reaction to Diagnosis of Mongolism

Diagnosis was made at birth 27 times, no abnormality was recorded on the hospital records 14 times, and 2 infants were suspected of "endocrine disorder." In 13 cases, diagnosis was either not made or the parents were not informed of it until the child was 4 months old, or later; 2 were not diagnosed until age 4 years. Parental reaction to the diagnosis is indicated in Table II. Examples of "Catastrophic Reactions" follow:

a) H.B. Harry's mother was not allowed to see the infant, who was consigned by the pediatrician directly to the state institution. However, no bed was available and while other arrangements were being worked out, the grandmother agreed to keep the baby in her home. By 3 months the grandparents were amazed to witness the social responsiveness and motor progress of this purportedly "hopeless idiot." Interfamily relationships deteriorated as the grandparents assumed the role of defending Harry from his parents. Almost 3 years later, the grandmother still has him: she is just beginning to have the social contacts which once filled her free time, as she allows a maid to care for Harry. The parents have done nothing further about institutionalization, rarely see Harry, and never discuss him with the grandparents. The mother is deeply disturbed about her moral responsibility toward the child. On one occasion when she wanted to discuss this with the pediatrician, he replied that institutionalization had been his recommendation and he did not want to hear about Harry again.

b) C.A. Carl was diagnosed as mongolism at birth, and the father so informed. Because of the mother's "nervousness" and general malaise following cesarean section, they agreed not to tell her right away. At 1 month, Carl was rushed to the hospital with bronchopneumonia and cardiac failure. At this time the physician told the mother of the basic diagnosis. He advised her of his interest in her and the baby and assured her that there was no need for basic decisions at this time . . . "take him home and love him." Mrs. A. became increasingly upset. She refused the support offered by the physician and her husband and turned to her own mother in a very dependent way. Active social casework with the mother was

<table>
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<tr>
<th>Age of Child When Parents Told Diagnosis</th>
<th>Initial Reaction to Diagnosis</th>
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<tbody>
<tr>
<td></td>
<td>Acceptance</td>
</tr>
<tr>
<td>Birth to 4 months</td>
<td>19</td>
</tr>
<tr>
<td>4 months to 4 years</td>
<td>10</td>
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</table>

"Acceptance" is used here to indicate only that the parents admitted to having heard the physician say that the child would be slow or was "mongoloid." To some, this is a meaningless term—for example, the mother who naively related it in some way to the obstetrical resident who was Chinese! Other parents "hear" the physician's diagnosis but do not allow themselves to react, i.e., they "accept" superficially, but emotionally withdraw from the problem.

"Denial" is another frequent protective response of parents. Several parents had gone from doctor to doctor, hoping to find someone who would concur in their denial of the problem.

The "catastrophic reactions" illustrate the extremes of immediate reaction to the diagnosis of mongolism (see text).
disappointing except for mobilizing her to obtain needed physical care for her other child. Carl died suddenly at 11 months. In this case the “bad” was interred with his bones, and after a proper funeral Mrs. A. was able to resume her role as wife and mother.

The physician can precipitate a series of events which disrupt family living; on the other hand, his valiant efforts to maintain the mental health of the family are doomed if the parent’s own adjustment is immature or marginal.

Two pediatricians became emotionally involved to the extent that they withheld the diagnosis, hoping that the parents themselves would notice the peculiarities of the baby. The result was total misunderstanding and the parents were never able to forgive the physician: in both cases the parents were upset because the diagnosis was common knowledge in their circles of professional acquaintance before they themselves were aware just what was amiss.

Later Reactions of Parents

Sooner or later, as parents adjust to the fact that their child is handicapped, they ask “why,” and guilt issues are raised.

Self-reckonishment: Several mothers blamed themselves for causing the child to be mongoloid. Where the misapprehension concerns hereditary factors, it is helpful to review the family history (which is usually noncontributory as regards others with mongolism or retarded individuals) and mention the normal siblings, if any. A few mothers wondered if worries about finances and other family problems could have caused the condition; here also reassurance can be offered. In several instances the reasons for the mother’s self-reckonishment were more disturbing (attempted abortion) or not understood (“Why has God punished me?”); however, a general statement about inability of medical science to pinpoint the exact cause of mongolism helps allay anxiety.

Interpretation with both parents present is helpful in bringing out into the discussion the secret worries earlier confided in the social worker; two mothers groundlessly felt their husbands were angry with them for having borne children with mongolism.

Projection of Guilt: Two mothers who were very accepting of the mongoloid child and his handicaps said, without rancor, that their husbands had been sickly in infancy or slow in early development. Joint interpretation is again helpful, and mention of “common misunderstandings” about causes of retardation is made purposefully to dispel nagging misgivings and re-enforce parental accord.

Projection of blame was one more cudgel to use against “the other side of the family” in several families where tensions and parental friction antedated the birth of a child with mongolism.

Two obstetricians were the unknowing recipients of blame, although the parents in both cases basically knew better. No attempt was made to break down these defenses, which were important to them at the time.

I.B. Mrs. B. believes the delivery was mishandled. She is a very immature woman who has threatened to run away with her mongoloid baby, leaving the other children and her husband, who seems to be more realistic and wanting to help his wife. The mother had taken the baby to at least one other diagnostic center and refused to accept the diagnosis. At “Services for the Retarded Child” she was offered continuing casework in an effort to help with her deep-seated problems and avoid complete disruption of normal family life.

F. A. Mr. A. denies that Francisco is his child, maintaining over the years that the doctor, seeing that he was “a poor immigrant,” changed babies in the newborn nursery. There are serious marital problems as well as cultural, financial, and health considerations which contribute to Mr. A.’s inability to change his attitudes. Through the efforts of the staff, Francisco was granted full tuition scholarship at a private day school for retarded children, but the father sabotaged the plan by refusing to arrange for his transportation part way, even though he himself is a cab driver. In lieu of school, the child development worker helped the mother in structuring home activities. Mrs. A. is a warm, experienced mother, who accepts
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the disappointments without heroics and has not needed casework.

**Impact on the Family Unit (Table III)**

**"Well-adjusted" Families:** More than two-thirds of the families have been able to integrate the child with mongolism into family living, and their way of life is not adversely changed because of the presence of such a child in the home. Of these 31 families, 17 have “no other problems” and are able to accept the child with his handicap. They are grieved, but anxious to help the child in achieving his maximum potential. These parents are glad for the opportunity of child health conference in its broadest sense. “Anticipatory guidance” is particularly rewarding and can avert the pitfalls of overprotection or disciplinary laxness.

R.B. Ruth’s mother wondered about the resentment her other children felt as she allowed the 4-year-old with mongolism to play in dresser drawers. She admitted that this was foreign to her way of housekeeping and that none of the others were allowed this activity. Mrs. B. was reassured that it was not only “all right” to set the same limits for Ruth, but desirable for preventing further irritations to family harmony.

Fourteen other families are presenting a “solid front,” but there are problems which may be disruptive. In six families serious financial and personal problems existed before the advent of the retarded child and are not significantly changed by it; eight families needed much guidance and support to assure a firm basis for continuing good adjustments.

a) M.B. Mike is a friendly 2-year-old with mongolism who presents no medical problems and whose development is steadily progressing, albeit at a retarded level. The father refuses to admit that Mike is different in any way, ascribing each of the many typical mongoloid stigmata to relatives. He stoutly maintains this “front,” adding that this is the most precious of his children and he will spare no expense in making him normal. Yet, he complains that no one will tell him anything and no one appreciates what it is like “to be hit in the face with a child like Mike.”

b) J.Q.B. Jane’s parents neatly solved the problem of dealing with her retardation. Since she is functioning at about 50% of normal, and is quite petite for a 4-year-old, they have resolved to “make her 2,” changing the year of birth as needed to suit her mental age.

c) B.B. Billy was mentioned previously as illustrating the way effective handling and community resources can combine to restore acceptable behavior. Billy’s mother has done a very fine job. Now, she is pregnant and is understandably anxious. There are other retarded children in her own family, as well as another mongoloid; she herself is now 40. We believe that her own inner resources coupled with her husband’s support will carry her through this crisis which involves the whole family.

**"Disrupted" Families:** For certain parents (5) with serious financial or social problems, the child with mongolism was “the straw that broke the camel’s back.”

a) D.A. David’s father became an alcoholic after the birth of his mongoloid child. That he was already a disturbed, insecure, and unsuccessful individual was overlooked as he received pity because of little David’s handicap.

b) O.B. Mrs. B. was observed to be highly agitated, presumably because of the mongoloid baby. Further investigation revealed longstanding marital difficulty and friction in the handling of the normal children.

Three mothers were unable to recover emotional stability following the birth of a child with mongolism. All three were basically immature women who turned to their mothers in very dependent fashion, ignoring the support offered by the husbands.

**TABLE III**

<table>
<thead>
<tr>
<th>Group</th>
<th>Total</th>
<th>No Other Problems</th>
<th>Other Family Problems</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Financial or Social</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Psychologic</td>
</tr>
<tr>
<td>Well-adjusted</td>
<td>31</td>
<td>17</td>
<td>6</td>
</tr>
<tr>
<td>Disturbed family</td>
<td>12</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

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There were four families whose way of life was absolutely disrupted because of the mongoloid child:

a) M.Y.A. At the time Marie was first seen, the mother was completely withdrawn. Mrs. A. blamed herself for “Marie’s condition,” citing her own webbed toes as hereditary pathology, and was sure that her husband hated her for it. With brief casework, the mother’s recovery was dramatic, and she was able to accept the handicaps, make plans for schooling and benefit from parents’ groups. She told the social worker that she wanted to feel “the way a mother should, whether or not the child is different.”

b) J.B. Jack is now 14 and his widowed mother is unable to face separation from him. His community has no school, sheltered workshop, or social opportunities. Mrs. B. complains about the responsibilities, wishes that she were “free” to go out and get a little job, and enumerates the years of special care she has given Jack. Unable to afford private residential school, she refuses the well-rounded program of the public institution with the excuse that others need it more.

c) and d) H.B. and L.B. The grandmothers of these two mongoloid boys are certainly leading different lives than they would have had circumstances not involved them in the care of their retarded kin.

Role of the Father

The attitudes of the father in 12 families bear mention as they differed from those of the mother. Six fathers persisted in denying that the child had any special problems or that the wife needed support. Their wives expressed in many ways the desire to discuss their feelings not only with the husband but also in a casework situation; the husbands’ hostility and negative approach precluded help.

Three fathers were able to accept the child and his problems much more realistically than their wives, who rebuffed the husbands’ support and understanding because of their own immaturity or deep-seated personal problem.

In three other families, marital problems of many years duration blocked the father from assuming any role which would help either the child with mongolism, the other children, or the wife.

Parents’ Role in Own Family

Six mothers of children with mongolism reverted to immature dependency on their own mothers following the diagnosis, and in each instance the mothers themselves caused more family disturbance than the baby. The fathers and maternal grandmothers stood by to offer support until the mother could be helped to accept the diagnosis and see the need to move forward from sorrow and self-pity to consider the next steps for the child and his family.

Two mothers refused to discuss the child’s problems with their own mothers. One “could” not, and the other had a clear mandate from her mother not to allow the mongoloid boy to associate with retarded children.

In two other families, the mothers have been criticized for the behavioral differences of the child with mongolism. In the case of Billy B., whose social functioning is optimal for mental age, the mother was crushed when a close relative castigated her for the way she had handled him and urged institutionalization as his only salvation. (The fact that this relative had not been able to cope with her own child with mongolism during a similar period of development lessened the blow.)

Effect on Siblings of a Child with Mongolism in the Home (Table IV)

Histories were taken from parents and often supplemented by observations of the siblings at home.

“WELL-ADJUSTED” SIBLINGS: Three-fourths

### TABLE IV

<table>
<thead>
<tr>
<th>Group</th>
<th>Total Families</th>
<th>Other Family Problems</th>
<th>Disturbed by Mongolism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well-adjusted siblings</td>
<td>33</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Disturbed siblings</td>
<td>10</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

*WELL-ADJUSTED SIBLINGS: Three-fourths*
of the siblings were happy, well-adjusted children and young adults. In five families, the children apparently had no problems, but the parents' attitude toward the child with mongolism was unhealthy (denial, overprotection, unconstructive anxiety), and could be the basis for trouble.

Children from three families showed that the siblings could make a good adjustment despite upset home life or undesirable parental effect.

a) W.A. Wayne had required almost continual nursing during his early years and the family fortunes had been a succession of serious problems unrelated to mongolism. The mother always had a rather hopeless air and was depressed about everything. Yet she was able to carry through with a severely constricted standard of living, to set up a nursery group in her home to help Wayne obtain social opportunities, and to give of herself to the teen-age sisters who were described as "poised and delightful girls."

b) J.X.A. and J.B. Both these mongoloid boys have mothers who are anxious and ineffectual in handling them. Their teen-age siblings have been able to take mother and brother in their stride, and are infinitely more secure and competent than their mothers.

"DISTURBED" SIBLINGS: Four families had children with behavior or school problems which were felt to be due to general family problems, unrelated to the presence of a retarded child. In these families all children had unmet needs due to marital discord, or other personal problems.

a) O.A. Olive is an 8-year-old who presents no problems at home. Two siblings are bed-wetters. There is serious parental friction over the management of all children. The father was discharged from the service because of neuropsychiatric disturbance, but has been able to adjust sufficiently to hold a job.

b) I.A. Two of this boy’s siblings are failing in school. Mrs. A. describes one of them as "the kind of child who makes you want to kill her," obese, and "exactly like" the mother’s sister who was given college education at the exclusion of Mrs. A. and is now in a psychiatric hospital. Mr. A. is belligerent and aggressive; he did not complete professional education.

In six families, the behavioral difficulty presented by the sibling was probably caused by the retarded child’s presence in the home. Problems presented by three children seemed related to the extra demands on the mother’s time; one child wanted to be babied, another was demanding and cranky, and the third withheld urine and feces in a controlling, hostile way. These symptoms disappeared when the mothers were helped to reapportion their time and attention to the siblings. In one family, the siblings felt unfairness because of the disciplinary laxness where the child with mongolism was concerned; again, counseling prevented more serious problems. Two girls, not yet teen-age, resented the child with mongolism because each was made responsible for the child until the parents returned from work. In each instance the mothers were encouraged to help the daughter accept this responsibility as her needed contribution to the family and to excuse the girl from some other chore.

It can be concluded that the normal siblings can adjust to the child with mongolism in the home with minimal adverse effects. When parents understand the needs of all the children, and are realistic in their thinking about the retarded child, fewer negative reactions occur in the siblings. Several teen-age siblings expressed interest in teaching careers and possibly in special education to help other retarded children.

Relations with Neighbors and Community

The child with mongolism, his siblings and his parents were accepted in the neighborhood more often than not. Neighborhood relationships were disturbed in only 10 families either because of unacceptable behavior of the child with mongolism or because of withdrawal of the parent from contacts because of the “shame” of having a retarded child.

a) The child presented problems in the neighborhood when the parents were ineffective in setting limits for behavior or unable to face the need for training outside the home (usually meaning institutionalization).
J.B. is now 14 and a neighborhood problem, since he plays on a level of the 4-year-olds, but gets blamed, rightly or wrongly, for any mishaps that occur. There is no school or workshop available to him in the community. It was felt that institutionalization was needed to further Jack’s development. He had long dominated the family scene and, in recognition of this, casework was begun with the mother in an effort to help her see that the optimal time for separation was at hand.

b) Inability to “face” neighbors was reported several times. When occasioned by groundless worries about heredity or family “taints,” the mother was able to gain understanding through genuine acceptance by the professional staff and discussion of the issues. One immature, highly agitated mother reported that a neighbor taunts her with questions about her “idiot child,” and another feels that her friends look at the mongoloid child “and don’t know what to say.” Here again, helping the mother with her own problems was necessary before she could help the child in the neighborhood.

Some parents of children with mongolism became leaders in community efforts to make more opportunities available to all retarded children.

The Child with Mongolism in the Community

Several with mongolism, under age 7 (the “legal school age”), attend regular preschool nursery groups. Happily, because of small stature, they fit into younger groups that are commensurate with their developmental immaturity.

Of 22 children with mongolism 7 years of age or older, only 8 attend special classes for the “trainable,” 5 in public schools and 3 privately. The other 14 are at home, with no training opportunity available at the time of evaluation or subsequently. During the past 3 years, new resources have become available to retarded children in the Washington metropolitan area; the several school districts have opened classes for trainable children and schools for the handicapped have extended their programs to include the mentally handicapped, and private schools have been organized by parents and parent groups to serve those “left out.”

There is a sheltered workshop for vocational habilitation of retarded persons who are 16 years or older; this does not yet meet the need of any children discussed here. Several churches have arranged special “Sunday school” type programs for retarded children. There is one “teen club,” and special units of Camp Fire Girls, Boy Scouts, etc. are in the planning stage.

Institutionalization was recommended for seven children with mongolism for the following reasons:

a) for five pre-adolescents the state training school for mental defectives offers well-rounded programs of training and social experience not available in the community or not attainable because of parental attitudes.

b) for two children (I.Q. range 20-29) where care at home involves the mother at expense of normal intrafamily relationships.

It behooves the pediatrician to be aware of the opportunities for the more retarded or “trainable” children in his community and to know what facilities exist in the institutions of his state.

DISCUSSION

The pediatrician who diagnoses mongolism or who is called upon to interpret this diagnosis to parents cannot count on any one recommendation to apply to all infants and families. Similarly, one interpretation to the parents will not suffice to answer all their questions. No major decisions should be forced on parents who are upset and confused. Hopefully, the pediatrician can refrain from stressing only the negative connotations of mongolism and point out the positive aspects. Presenting such facts that the child will indeed walk and talk and be toilet trained helps make the immediate future comprehensible, and a word about the friendly, emotionally rewarding dependence of the child with mongolism allays possibly ungrounded worries.

Through his regular professional contact
with the patient and his family during infancy and early childhood, the pediatrician can acquire understanding of some of the important variables which will influence his attitude: 1) the mental health of the family; 2) financial and social conditions; and 3) the maturity and competence of the parents and their ability not only to accept the prolonged dependence of the patient, but also to allow independence in self-care as he is able. Judicious temporizing is not only acceptable, but is probably the best way to serve the infant with mongolism and his family. The pediatrician can reassure the family that watchful waiting has value, and support them as they acquire understanding of their child's limitations and what this means to the family.

The values and hazards of keeping the affected child in the home change as the child grows. During infancy there are values in having him at home. Here, the infant can receive optimal care and emotional warmth. The parents and siblings can see that the unfortunate child is, after all, a human: physically, not too unattractive and socially, responsive. The main problem is medical, the infant with mongolism requiring somewhat more than average medical care. During early childhood, the same values in home living obtain for the affected child. The practical considerations continue, in that the child with mongolism still requires more of the mother's time. All such children are dependent on their mothers for a longer period of time. Socially, these children are more competent than their mental ages would indicate.

At school age, the child with mongolism can achieve independence in usual activities of daily childhood living. If the family has overprotected him, independence may be delayed. Neighborhood considerations enter if he is to have opportunities for socialization.

As these children approach adolescence, they can continue to live happily at home, but outside factors become increasingly important. The child now needs, for his own mental and emotional growth, stimulation from adults experienced in meeting the needs of the retarded. He needs to know success, not always failure or frustration. The parents need respite from overprolonged dependency, and the siblings and neighborhood may need relief. Although more community resources are being opened to these older individuals, the institution will continue to offer the most realistic plan for training and living for many and placement should be encouraged or the older ones can come to dominate the family for no constructive purpose.

There have been few helps available to professionals or to mothers for the home training of the retarded child.\(^1\)\(^2\) Our child development specialist recently prepared a manual\(^3\) for the Children's Bureau, which should help parents, public health nurses, physicians and others. For professional workers, the Symposium on Mongolism\(^4\) has additional observations, and these have been recorded as part of a general book for lay reading.\(^5\) Also helpful for parents is a brief orientation booklet, such as prepared by Centerwall.\(^6\)

Parents can be directed to the local units of parent groups organized for meeting the needs of retarded children or referred to one of the national organizations, such as the National Association for Retarded Children\(^7\) which has a newsletter and various publications of interest. Knowing the quality and quantity of interest in the problems of mental retardation can give support to parents in adjusting to the particular problem they face.

**SUMMARY**

The records of 43 children with mongolism living at home are reviewed to determine what the presence of such a child means to the parents and the normal siblings.

Long-range decisions are usually not needed for the infant with mongolism, and the pediatrician can best serve the child and his family by assuring them that it is "all right" to have the child at home. In this series only two families were disrupted during the neonatal period of the affected infant.
The child with mongolism will require somewhat more than average medical care, and his parents will need more than average support and continuous counseling.

Of 43 families, 31 adjusted to the affected child without adverse effect on their way of living. The families with problems were found to need specific help and were referred to social workers or family agencies.

In 33 families the normal siblings adjusted to the abnormal one with minimal adverse effects; several teen-age siblings were more realistic than their parents in accepting the assets and limitations of the handicapped child.

As the child with mongolism approaches adolescence, he may be deprived of optimal training and personal guidance if he continues to live at home and in a community where no provisions are made for him; and without an adequate plan, he may come to dominate family living. In communities where special classes, social groups and sheltered workshops exist, the pediatrician can continue judicious temporizing.

Through his continuing contacts with the affected child and his family, the pediatrician can support the parents in their decisions, at the same time pointing out the values and hazards of keeping the child at home at various stages of development. Frank, yet kindly, discussions with the parents help them clarify their own feelings about the place of such a child in the home. Such consideration is well justified when it helps the parents through the initial shock, allows for adjustment to the child with mongolism as a handicapped child. It also enables them to choose the way to obtain optimal benefits either for the child or for the rest of the family.

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**THE CHILD WITH MONGOLISM IN THE HOME**
Martha Taylor Schipper

*Pediatrics* 1959;24;132

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