

1968

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PARENTAL ATTITUDES
IN INSTITUTIONALIZING CHILDREN
AFFLICTED WITH DOWN'S SYNDROME

By

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A THESIS

Presented to the Faculty of
The College of Medicine in the University of Nebraska
In Partial Fulfillment of Requirements
For the Degree of Doctor of Medicine

Under the Supervision of Robert B. Kugel, M.D.

Omaha, Nebraska

February 1, 1968

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Introduction

In the early 1900's a means for testing intelligence was devised by Binet, and since that time much interest has been generated in studying mental retardation. Among the areas studied have been those dealing with institutionalization of a mentally retarded child, and the effect this has on the child and the child's family.

In the early 1940's and prior to that time, it was felt that the mechanism causing mental retardation was hereditary. This theory led families who had the misfortune of having one of their members as being mentally retarded to have severe guilt feelings. Thus most of the mentally retarded children born during this time were either institutionalized at an early age or isolated from society by the family, which in turn limited much of the child's normal family life and activities.

These policies have slowly undergone changes in the past 20 years, and now it appears that the best results for both the mentally retarded child and the child's family are obtained by rearing the child at home. This has been brought about in part by determining numerous etiologies causing mental retardation other than hereditary factors, and in

part by being socially acceptable to rear a mentally retarded child at home.

This then leads one to ponder over the fact that numerous mentally retarded children are still being institutionalized even today. There are probably numerous reasons why parents consider institutionalizing their child, but who and/or what are the main factors which influence parents to institutionalize their child? I propose that since physicians play a primary role in diagnosing and informing the parents as to the prognosis of their child, they also play a primary role in influencing parents either to institutionalize their child or rear their child at home.

Materials and Methods

In order to determine factors in institutionalizing mentally retarded children, a selected population of mentally retarded children was needed. Children afflicted with the Down's Syndrome residing at Beatrice State Home for the Mentally Retarded were selected. There are approximately 2700 patients at this state hospital, of which 321 are mongoloids.

Charts of all the mongoloid children under the age of 21 years were reviewed for the address of parents, age of child, date of admission to the State Home, and any medical problems the child might have had. Questionnaires were then sent to the parents of these children covering the following items: age and occupation of the parents, number and age of siblings, size and ownership of home, religion, community

activity of the parents, parents' education, age of child when diagnosis of mongolism was made, and the main reason(s) for institutionalization of the child. There were 143 mongoloid patients under the age of 21. However, 13 sets of parents either had no address listed or had moved and had left no forwarding address. One set of twins was included in the study; hence, there was a total of 129 possible responses. Eighty-eight (68.2%) of the responses were obtained.

Discussion of Results

The results showed the average age of the mongoloids at the present time to be 12 years with a range of 6 months to 21 years. The average age at the time of institutionalization was 4.9 years with a range of 10 days to 15.33 years.

TABLE I

Age and Sex Distribution

<u>Age</u>	<u>Boys</u>	<u>Girls</u>	<u>Total</u>
1-7	11	6	17
7-14	23	10	33
14-21	<u>20</u>	<u>18</u>	<u>38</u>
Total	54	34	88

It was felt that there may have been differences such as socioeconomic status, size of family, etc., between the groups of responses that may also have influenced the parents in the decision to institutionalize their child. Thus as many of the variables as possible were included in the questionnaire and analyzed to see if there were differences other than the basic reason given for institutionalization of the child. The questionnaire results were divided into four groups according to the basic reason given for institutionalization which include: 1) Only physician's advice, 2) Physician's advice plus another reason, 3) Single reason other than

physician's advice, 4) Multiple reasons other than physician's advice. (Table II)

Socioeconomic status has often been stated as having great influence on the parents' decision to institutionalize their child. In determining the socioeconomic status, a percentile ranking was given to each family based on occupation, income and education of the parents. The possible scores ranged from 1 to 100 with an average of 50 for the United States. The scores in this study ranged from 20 to 91 and the average for the entire group was 60. The average for the North Central region of the United States, which includes Nebraska, has been found to be 58. There was a difference of only three percentile points between the four groups from the Beatrice State Home, and two percentile points between the average of the groups and the average for the North Central region of the United States; hence, one may conclude that socioeconomic status played little or no part in influencing parent's decision to institutionalize their child. (Table II)

Religion was also evaluated as to whether the parents were Catholic or Protestant. There was no statistically significant difference between the four groups. (Table II) However, data listing the proportion of the population in each religious group in the state of Nebraska was not available; hence, no conclusions can be reached between the group studied and the general population in regards to religion.

Size of town was evaluated to determine if there was any difference between rural and urban regions. The two

TABLE II

Questionnaire Responses

	No. of Responses	Socioeconomic Percentile	Religion	Size of Town
Only Physicians Advice	37	61	Catholic....15(43%)	5,000 or less...15(42%)
			Protestant..20(57%)	5,000 - 30,000.. 7(19%)
				Over 30,000.....14(39%)
Physicians Advice Plus Another Reason	31	60	Catholic....14(45%)	5,000 or less...11(35%)
			Protestant..17(55%)	5,000 - 30,000.. 7(23%)
				Over 30,000.....13(42%)
Single Reason Other Than Physicians Advice	15	58	Catholic.... 8(54%)	5,000 or less... 5(33%)
			Protestant.. 7(46%)	5,000 - 30,000.. 5(33%)
				Over 30,000..... 5(33%)
Multiple Reasons Other Than Physicians Advice	5	61	Catholic.... 0(0%)	5,000 or less... 1(20%)
			Protestant.. 5(100%)	5,000 - 30,000.. 2(40%)
				Over 30,000..... 2(40%)
Total	88	60	Catholic....37(43%)	5,000 or less...32(37%)
			Protestant..49(57%)	5,000 - 30,000..21(24%)
				Over 30,000.....34(39%)

smaller groups varied significantly from the average for the four groups, but this difference is felt not to be genuine due to the small numbers in the groups. However, the average of the four groups varied significantly from the population in general in the state of Nebraska. Thirty-seven percent of the responses were obtained from the population group of 5,000 or less where as 53% of the state's general population are located in this group. Conversely 24% and 39% of the responses were obtained from the 5,000 to 30,000 and over 30,000 population groups, respectively, where as 17% and 30% of the state's general population were located in these groups. This then leads one to believe that more families living in smaller towns or rural areas tend to rear mongoloid children at home.

Other possible differences evaluated include age of parents, age and number of siblings in the family, age of child when diagnosis of mongolism was made, and age of child when institutionalized. There was no significant difference between the four groups listed on Table II in regards to the above factors.

The rest of the discussion will be an evaluation of the reasons listed for institutionalization of the mongoloid child. The reasons will be discussed separately as listed on Table III.

Advised by Physician: It is appalling that 68 sets of parents were advised by a physician to institutionalize their child, and in 37 cases this was the only reason given for

TABLE III

Reasons for Institutionalizing Child

	Number	% of Parents Giving This Reason
Advised by Physician	68 (37**)	77 %
Inadequate School Facilities	20 (4**)	23 %
Financial Burden	4	4.5%
Child's Health Required It	8 (2**)	9 %
Siblings Could Not Adjust to Child	3	3.3%
Best for Child	9	10.2%
Disruptive Behavior of Child at Home	5 (1**)	5.7%
Other Reasons *	16 (8**)	18 %

** Only reasons given by parents:

1. Necessary on account of loss of mother
2. Unable to care for child
3. Pastor and psychiatrist advised it
4. Committed by court hearing
5. Father was a minister and mother's health was poor
6. Mother's health so she couldn't care for child
7. Not fair to other children
8. Impossible to watch and keep safe

* Other reasons

1. Neighbors complained
2. Mother paraplegic
3. Case worker advised it
4. Minister and relatives advised it
5. Mongoloid twins - couldn't care for them
6. Minister advised it
7. Mother was pregnant with another child
8. Wife was exhausted

institutionalization. Centerwall and Centerwall¹ compared the IQ and SQ of mongoloid children reared in foster homes since the neonatal period of life to those reared at home until $2\frac{1}{2}$ years of age. They showed that both the IQ and SQ of the mongoloid children at age seven were statistically higher in those reared at home in comparison to those raised in foster homes.

Since this is the case, why are physicians still recommending institutionalization of mentally retarded children, especially mongoloids? Perhaps the physician feels that a mongoloid child will be detrimental to a "normal" family situation and should be removed as soon as possible. This concept may express good intentions but is often unfavorable. Pitt⁷ found that only 2 of 34 families interviewed in his study felt that rearing a mongoloid child at home had caused family difficulties. Even more important is that 25 of 34 families considered the mongoloid child to be beneficial to the family environment, and seven families felt it had made no significant difference. Pitt also points out that several mothers had severe guilt reactions following institutionalization of their child.

According to Quaytman⁸ only 10-20% of mongoloids live in institutions. This in itself tends to support the concept that a mongoloid child is not detrimental to the family environment in most cases. If they were disruptive to the family situation, a higher percent of these children would undoubtedly be institutionalized in attempts to get the family environment back to "normal."

Possibly the role of the physician should be changed to that of counseling parents of mongoloid children. Yannet⁹, Hormuth³ and Quaytman⁸ have expressed that in too many cases the physician does not take time to explain the advantages, disadvantages and prognosis of a mongoloid child. They also express the concept that a physician should supply the parents with the accurate information, and then allow the parents to make the decision regarding institutionalization.

Inadequate School Facilities: Twenty sets of parents felt there were inadequate school facilities for their child. This is definitely a problem in some areas of Nebraska. There are only three places at the present time which have state supported schooling for the mentally retarded. These three places are: Beatrice, which has no age limit or minimum IQ requirements; Cozad, which has IQ requirement of 30-60 and age limit of 8 to 16 years; and Lincoln, which has IQ requirement of less than 80 and age requirement of over 16 years. There are numerous private and semi-private facilities available throughout the state. Hastings, Omaha, Axtell, Grand Island, Norfolk, Fremont, North Platte, Broken Bow, Columbus, Nebraska City, Valentine, Dixon, Plattsmouth and Beatrice all have some private or semi-private facilities available for education of mentally retarded children.

Four sets of parents listed inadequate school facilities as their only reason for institutionalizing their child.

In two cases parents lived in towns which have educational facilities for the mentally retarded. The other two cases lived approximately 50 miles from the nearest educational facility for the mentally retarded. In all the above cases the child was five years of age or older at the time of institutionalization.

In 12 of the remaining 16 cases, the parents lived in a town that offered educational facilities. In the remaining four cases, the parents lived a considerable distance from an educational facility for the mentally retarded. The ages of these children ranged from age 5 to 15 at the time of institutionalization, and the majority of cases were 8 to 10 years of age at the time of institutionalization. Thus in all of the cases where the parents indicated there was a lack of educational facilities for their child, the child was older at the time of institutionalization than the average age of institutionalization for the entire group studied, which was 4.9 years. The majority of the cases had only private or semi-private educational facilities available; and hence, it is not known whether the parents had any knowledge of the facilities or whether they were financially able to send their child to one of these. In any case this would tend to support the idea of a need for more state facilities for education of the mentally retarded child, and possibly a greater knowledge of present existing private and semi-private facilities.

Financial Burden: Four sets of parents felt they could not afford to keep the child at home. In one case the father was deceased, and the mother was working full-time. In the second case the husband's occupation was a craftsman and the mother worked part-time. They had two children living at home and were buying a two-bedroom home. According to salaries listed in the World Almanac of 1965², a craftsman would be expected to earn \$6,013 per year where as the average salary in 1965 was \$5,431 per year. In the third case the husband's occupation was also a craftsman, but the mother did not work. They had six children living at home and were renting a three-bedroom home. In the fourth case the husband was a clerical worker, and the mother did not work. They had two children living at home and owned a three-bedroom home. The average salary of clerical workers in 1965 was \$5,483, in comparison to the average salary of \$5,431.

It must be realized that in some cases the mongoloid child may be ill more often which would require frequent medical attention and be a financial burden. However, none of the parents indicated this as a reason. Therefore, only the case where the father was deceased, and possibly in the case where six children were living at home could one conclude that the mongoloid child would actually be a financial burden to the family and could not be properly cared for at home.

Child's Health Required It: A total of eight sets of parents stated that the child's health required hospital-

ization. Of these, two gave this as the only reason for institutionalization. In reviewing the records, it was noted that one of their two children had a ventricular septal defect, and the other had numerous upper respiratory infections. Neither child required continuous hospitalization. In the other six cases it was also noted that none of the children required continual hospitalization. However, in one case the mother was paraplegic and felt she could not properly care for the child. In another case there were twin mongoloids, and the mother stated she "became exhausted" in an attempt to care for the children who apparently were sick quite frequently. It should be realized that even though some patients do not require continuous hospitalization, they are ill frequently enough to require intermittent hospitalization, and therefore, this could be a financial burden on the average or even above average income family. However, in no cases where the parents felt the child's health required hospitalization was there any definite indication that the child's health actually caused a financial burden on the family.

Siblings Could Not Adjust to Child: Three sets of parents felt that the siblings could not adjust to the mongoloid child. However, in none of these cases was this the only reason given for institutionalizing the child. It is quite conceivable that there could be cases in which siblings would be ashamed of a mongoloid child, causing a family hardship. There are probably some cases where some of the siblings were only one or two years older

and/or younger than the mongoloid child, and felt cheated or left out by the parents due to the extra amount of time and care that might be necessary for the mongoloid child. All three of the families had other children (one with 2, one with 3, one with 4) ranging in age from 3 years to 12 years. Proper counseling of the parents and siblings in these cases would be necessary. However, satisfactory results may not always be obtained.

Best for Child: In nine cases the parents felt that it would be best for the child to have him institutionalized. In seven out of nine of these cases, physicians advised institutionalization of the child. Thus, the physician may have played a primary role in making the decision and advising the parents that it would be best for the child if he were institutionalized. In the other two cases the parents felt that there was also a lack of educational facilities for their child.

Disruptive Behavior of Child at Home: This reason was listed as the cause for institutionalization in five cases. It was the only reason given for institutionalization of the child in one case. It is quite conceivable that a small percent of mentally retarded children just like a small percent of "normal" intelligence children could not be handled at home due to behavior problems.

Other Reasons: The other reasons for institutionalization are listed separately on Table III and are self explanatory.

Conclusion

In conclusion, one must observe that 68 out of 88 (76.1%) sets of parents stated that a physician had advised institutionalization of their child. These figures compare with those reported by Kugel⁴ and associates in a survey done by them in Iowa. They found that 43 of 77 (55.8%) families were greatly influenced by a physician in seeking admission of their child to an institution.

Therefore, one must conclude that physicians do indeed influence parents in their decision to institutionalize their child. This influence may be misleading to the parents, and therefore, in the future, the primary role of the physician should be that of counseling the parents and explaining the prognosis of their child. The role of the physician along with providing adequate state supported school facilities for the mentally retarded could reduce the rate of institutionalization of the mentally retarded child and make them a productive part of society in the future.

Summary

In summary I believe that physicians played a primary role in influencing the parents' decision to institutionalize their mentally retarded child. In order to determine factors influencing parents in their decision, questionnaires were sent to 129 parents of mongoloid children institutionalized at Beatrice State Home for the Mentally Retarded. Eighty-eight responses were obtained.

The results showed that 68 of the 88 cases were advised by a physician to institutionalize their child. Twenty cases felt there were inadequate school facilities for their child without institutionalization. Nine thought it was best for the child to be institutionalized. Eight felt the child's health required it. A total of 36 other reasons were given by the parents for institutionalizing their child.

Therefore, it is quite apparent that by far the most common response given by parents as the reason for institutionalizing their child was that a physician had advised it.

REFERENCES

1. Centerwall, S. A., and Centerwall, W. R.: A Study of Children with Mongolism Reared in the Home Compared to Those Reared Away from Home, Ped 25:678-85
2. Hansen, Harry: The World Almanac 1965 and Book of Facts, New York: New York World Telegram, 1965
3. Hormuth, R. P.: Home Problems and Family Care of the Mongoloid Child, Quart Rev Pediat 8:274, 1953
4. Kugel, et al: An Analysis of Reasons for Institutionalizing Children with Mongolism, J of Peds 64:68
5. Kugel, R. B.: New and Old Frontiers in Mental Retardation, Med Times 91:936-40, Oct. 1963
6. Kugel, R. B., and Parsons, Mabel H.: Children of Deprivation, Washington, D. C.: U. S. Government Printing Office, 1967
7. Pitt, D.: Mongolism - The Modern Management, M J Australia 47:971, 1960
8. Quaytman, W.: The Psychological Capacities of Mongoloid Children in a Community Clinic, Quart Rev Pediat 8:255, 1953
9. Yannet, H.: Pediatric Management of Mongoloid Children, Quart Rev Pediat 8:131, 1953
10. _____ Nebraska Blue Book, Lincoln, Nebraska: Joe Christensen, Inc., 1964