



December 1986

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### Recommended Citation

Rabinowitz, Jonathan (1986) "Assessing the Needs of Mothers with Mentally Retarded Offspring: An Empirical Approach," *The Journal of Sociology & Social Welfare*: Vol. 13 : Iss. 4 , Article 8.

Available at: <https://scholarworks.wmich.edu/jssw/vol13/iss4/8>

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ASSESSING THE NEEDS OF  
MOTHERS WITH MENTALLY  
RETARDED OFFSPRING  
an empirical approach

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Abstract

This exploratory study assesses the needs of mothers with retarded offspring living at home. Previous studies have focused on meeting those parental needs which would benefit their retarded offspring. This study does not limit parental needs to those needs, which if met would benefit the retarded child, and defines parents as an independent group with special needs.

Introduction

Services for mentally retarded people continue to develop. An outgrowth of concern for retarded children is the development of services for parents with mentally retarded children, i.e. parents' advocacy and therapy groups.

However, a concerted effort to plan comprehensive services for parents with mentally retarded offspring has not gained adequate attention among practitioners and administrators. Interest in parents' feelings and attitudes has arisen inasmuch as they are of crucial importance in planning for (the child's) effective treatment and rehabilitation." (Thurston, 1959) Most recently, interest is

being focused on parents attitudes towards normalization, "as parental attitudes can not only influence children's behavior, but can, in fact, undermine the acquisition of behavior skills...." (Ferrara, 1979) However, little attention is given to the needs of parents of retarded children other than those needs which are believed to influence the children.

This study attempts to assess needs of a sample of mothers with retarded offspring who live at home, via their responses to a structured interview schedule which was developed for this study. This study focuses on the need to develop more adequate services for parents of retarded children.

### Review of the Literature

The literature identifies parental concerns and reactions to their retarded child, recommends services to address these concerns and reactions and cites services that parents of retarded children use and find beneficial. A portion of the studies are based on empirical work, however most are based upon clinical observations.

### Parental Reactions

The discovery that a child is retarded is a painfully scarring event for parents. It is suggested that parents of mentally retarded children react with loss of self-esteem, shame, ambivalence, depression, self-sacrifice, defensiveness, disillusionment, vulnerability, inequity, insignificance, past orientation and loss of immortality. (Roos, 1979) Others have added to this list of parental reactions guilt, anger and death wish. (Olshansky, 1966) Some believe that these scars never heal and that they persist with these feelings, living in a state called "chronic sorrow." According to this, these parents have "little to look forward to; they

will always be burdened by the child's unrelenting demands and unaltered dependency. The woes, the trials, the moments of despair will continue until either their own death or the child's death." (Olshansky, 1962)

Others have proposed that parents can ultimately accept the child's condition, a response they have termed "constructive adaptive." (Zaider, 1982) A continuum suggested of parental reactions range from 1) "mature acknowledgement of actuality" in which "the child is accepted as he is" 2) "disguise of reality" in which "the handicap is seen clearly but is ascribed to some circumstances, the correction of which would restore the child to normality" and 3) "complete inability to face reality in any form" leading to "uncompromising denial" in which the parents believe that "there is absolutely nothing wrong with the child." (Kanner, 1953)

Both extremes, the constructive adaptive and chronic sorrow are believed to be the end result of a series of emotional stages through which the parents traverse. Gearheart and Litton (1975) propose the following chain of parental reactions: 1) awareness of retardation, 2) denial, 3) recognition, 4) search for a cause, 5) search for a cure and 6) acceptance. Leland and Smith (1974) have similarly proposed three phases of parental reaction: 1) "initial grief reaction", 2) "transitional stage of adjustment" and 3) beginning acceptance of the situation by parents.

Rather than a series of phases in an adaptive or maladaptive process, parental reactions are also seen as a series of responses to crisis involved in parenting retarded children. These crisis are: 1) Novelty shock: this occurs when parents first learn that the child is not normal and are faced with the discrepancy between their expectations of having a normal healthy child and their retar-

ded infant. 2) Value crisis this reflects the parents' conflict regarding "the meaning the child represents." A value crisis tends to extend for a considerable length of time, "but once resolved they are not likely to again become a major source of conflict." 3) Reality Crisis which are parental reactions to daily management problems due to the presence of a retarded child in the home and accompanying factors such as social pressure ( Zaider, 1982).

### Parental Concerns

The reality crisis described above manifests itself in parental concerns. These areas of parental concern in order of prevalence are education, family living and physical care. Parents concern for the former is that better training programs be developed for their children. (Wolfensberger, 1970) The retarded child interferes with family life by: 1) weakening integration 2) creating additional expenses and 3) limiting family activities. (Gearheart, 1975) Families have tended to sacrifice gratifying needs of other family members over those of the retarded child. (Koch, 1971) Additionally, the retarded child living at home places serious restrictions on the mobility of the family. (Boggs, 1970)

Parents are concerned about such aspects of physical care as the possibility that the child will be the victim of physical harassment finding suitable living conditions for the child and planning for the future (Skelton, 1972). An example of this is the well being of the child after parents' death, (Roos, 1977) which is more prevalent among parents of the adult mentally retarded. (Goodman, 1978) Additional concerns are leaving the child unaccompanied, for example, riding public transportation. (Roos,1977)

A concern particularly of parents with

adolescent and adult retarded offspring are the dangers posed by the child's sexuality. (Goodman, 1971) Parents are also concerned with finding suitable recreation and companionship for their retarded offspring. (Skelton, 1972)

### Community Services

On the basis of the aforementioned parental concerns, the literature recommends services that would benefit parents of retarded children. Improving educational services is recommended to address the primary concern of parents, which is training and education. Clinics providing family counseling are recommended to help families with familial problems related to having a retarded child in the family, (Skelton, 1972) as well as for training parents in child management, for example, behavior modification techniques. (Olshansky 1966)

Concerns for physical care of retarded children are being addressed through short-term holiday care, thus enabling the parents to have a vacation and freedom from worrying about the child's physical care and hostels providing permanent accommodations to mentally retarded adults. "Families" comprised of retarded persons is recommended to provide retarded adults with recreation and companionship. (Skelton, 1972) Other services recommended also based on concerns of parents are babysitting and adequate education past age 16. (Olshansky, 1966)

The aforementioned services are recommendations of professionals and based on clinical observations. The empirical studies of service utilization by parents reveals that home visits by nurses, the activities of parents' associations, and nursery schools are the most widely utilized and are felt by the parents to be the most beneficial services. (Ehlers.

1966)

Previous studies assessing parents' needs in order to recommend services have either addressed parental needs through services beneficial to the child or have prescribed services based on an understanding of parental needs gained through observations of reactions and concerns of parents. In this study an attempt was made to ascertain from mothers themselves their concerns, reactions and the services they use, as well as services they feel would be beneficial.

This study attempts to identify mothers' perceptions of: concrete unmet needs, services missing and several dimensions of specific life areas (social, marital and communal). Information was also obtained from the case record of each child, which included information about: family composition, child's age, mental and physical functioning. Attempts were made to identify significant relationships between variables by crosstabulating the information obtained from mothers with data from case records.

### Instrument

As the approach taken in this study to assess the needs of parents with retarded children was not found elsewhere, an exploratory study using a small sample of mothers of of mentally retarded adults and children living in Tiberias, Israel was first embarked upon. The instrument used for this initial study was a Hebrew version of the Thurston Sentence Completion Form which includes 45 incomplete sentences divided into seven attitudinal and reactional areas. (Thurston, 1959) The item selection and instrument design of the final instrument is based on the results of the exploratory study and the reviewed literature. An interview was conducted with a planner from AKIM, the national organization

for retarded persons. He knew of no other such efforts in Israel. The final instrument was designed primarily by members of the Research Department of the Israeli Ministry of Labor and Social Affairs and the author of this paper.

The questionnaire is comprised of two parts, the first part consists of information obtained from the child's case record which includes: I.Q., type of test and test date, family composition, birth order, age, parents ages, country of origin, occupation, and number of occupants in the parents' home. The second part is an interview schedule administered to the mothers, which took between 25 and 50 minutes. The questions asked in the interview are about the child, parents, siblings, and extended family.

The questions the mothers are asked about the retarded child included the following areas: level of functioning (bodily, motor and sensory), use of medications, institutional affiliation (sheltered workshop, day care center or special education), satisfaction-discomfiture in institution and social network. Mothers are asked about their social life, religious life, marital relationship, care-taking patterns of child, help-seeking patterns (use of friends, neighbors, professionals, agencies and relations), service utilization, assessment of effectiveness of institutions, agencies, and specific human service professionals. They are also asked to identify unanswered needs and services, special family problems and their attitudes towards the place of the retarded persons in the community.

### Participants

The final instrument was administered as a structured interview schedule to 69 out of a total population of 79 mothers with retarded



offspring in Tiberias, Israel, who live at home and range in age from 6 to 26. The mean age of the retarded children is 11.8 years and the median is 10 years. Forty-six percent of the children are female and fifty-four percent male. The 10 not interviewed either moved from Tiberias during the study period or relocated in Tiberias and left no forwarding address.

The children of study participants attend the local day-care program the "maon", the sheltered workshop the "mass", or special education tracks within the public school system. These children range in I.Q. between 28 and 76. Because of the large number of missing I.Q. scores, and variety of tests used and variability of testing dates, central tendency data was not representative. Retarded persons are divided by law into two groups those with an I.Q. of less than 70 who are serviced by the Welfare Office and its institutions and those with an I.Q. of greater than 70 who are serviced by the Department of Education. Some idea of the I.Q. spread can be gained by the fact that 34% of the children participate in Welfare Office run institutions (indicating an I.Q. less than 70). The remaining 66% of the sample attend special education classes, which reflects an I.Q. that exceeds 69.

Most of the mothers interviewed reside in upper Tiberias in densely populated public housing projects. This area is a target of Israel's urban renewal program, "Project Renewal." Upper Tiberias, which houses over 1/3 of the city's population, is plagued with crowded living conditions for large families, juvenile delinquency, crime and poverty. In 1978, the total population of the city was 27,500 of which 36% were members of large families (families with 8 children or more) (Berman, 1979). The average age of the mothers in this study was 34. The oldest mother was

59 and the youngest mother was 21. Less than 10% of the women in this study are natives of Israel. Almost 80% are immigrants from North African countries.

### Findings

The most frequently reported unmet concrete needs were: help for the child with school work (20%), household furnishings (17%), food and clothing (12%), and financial assistance (10%). Other unmet needs were: automobile (9%), home enlargement (4%), household aid (4%), transportation reimbursement (3%), transportation arrangements (3%), babysitting for the retarded child (2%), and after school program for the retarded child (1%).

A majority of respondents (67%) felt that there were services missing. Of these parents 35% could not identify the services missing. The parents who could identify missing services listed the following: 22% felt clubs or meeting places and playgrounds for retarded children were missing, 8% felt schools for retarded children were missing, 5% cited a need for tutors for the retarded child to aid them with school work and 3% felt that volunteers to work with retarded children were missing.

When asked, most of the mothers (67%) said that they would like to go out more frequently for entertainment. The following were the responses of these mothers asked what would facilitate their home going out more frequently: baby sitter (47%), money (34%), home arrangements for the retarded child (5%), car (5%), household help (2%) and caretaker for other sick family members (5%).

Almost 70% of the respondents wanted to vacation more frequently. Almost forty five percent wished to do so with their retarded child and the remainder without the child.

When asked what would facilitate taking a vacation, the following were identified: babysitter (49%), money (43%), car (6%) and caretaker for other ill family members (3%).

Mothers were asked about their satisfaction with their neighborhoods. Slightly less than one quarter expressed a desire to relocate. Almost half of those favoring relocation related this wish to their retarded offspring. These included moving to a "more accepting area", an area "with more developed programs for retarded children" and concerns that the child is harassed where they currently live.

When asked about their interest in participating in meetings with other parents, slightly more than half responded favorably, about one third were not interested and the remainder were uncertain. Most of these mothers (63%) had never met with other parents. Those that had participated in a parents' meeting, were split six to four with the majority having enjoyed those meetings. Forty percent of all the mothers, when asked "if meetings were important" said "Yes" and an equal amount said "no" and the remainder were undecided.

Agendas suggested for parents meetings by the mothers were: suggestions and discussions on each child (53%), entertainment and to "forget about their troubles" (13%), learn methods of helping the child (10%), professional guidance (10%), comfort and consolation (7%), gain an "intellectual understanding of the problem" (3%) and to gain an ability to discuss topics related to mental retardation (3%).

More than one third of the mothers rated their marital relationships as very tense, almost fifteen percent slightly tense and just over one half as good and less than ten per-

cent as pretty good. Only slightly more than one quarter speak very frequently with their husband about the retarded child. One quarter do not speak at all with their husbands about the retarded child, 32% speak little and 17% speak frequently. If something unpleasant occurs relating to the retarded child, less than half of the mothers speak with their husbands and almost one third speak with no one. Slightly over ten percent speak with older offspring. Less than five percent speak with professionals, siblings, parents and friends or neighbors.

In an attempt to identify significant relationships between variables, a needs index was compiled and several cross tabulations were done. The needs index is obtained by counting the needs identified by any given mother. For example, a mother who expressed a need for a babysitter and household goods, rated a 2 on the index. The index ranged from 0 to 3. The relationships studied were between the needs index and mother's marital status, use of services, mother's burden, child's satisfactions-discomfiture in school or training program, child's age, sex of child and amount of visiting in the home by friends, mother's religious observance (based on response to self reporting scale widely used in Israel). It was thought that each of these variables might have some relationship to the amount of needs identified by a given mother. For example, the age of the child it was thought might impact on the amount of needs of the child's mother. Of these cross tabulations, child's age (see Table 1), home religious observance (see Table 2) and the amount of visiting in the home by friends (see Table 3), approached significance.

### Discussion

This study identifies needs of mothers with retarded offspring through their respon-

ses to an interview schedule. Assessing only maternal needs and not parental needs was done in this study because of the technical difficulties involved in locating and interviewing both parents. This approach has precedent in the literature as for example Ehler's (1966) study. This study hypothesized that mothers represent the extreme needs of parents. This is supported by the following.

70% of the mothers claim to have little or no help from their husbands. 50% of the mothers said they do all the shopping. Twenty three percent said their husbands do the shopping and 27% said shopping responsibilities are shared by parents and children. The mother-daughter dyad clean 85% of the homes and the fathers clean less than 3% of the homes. Of the 37% of the children who wake in the middle of night and require assistance, 72% are assisted by their mothers, 11% by their fathers and in 15% of the households this responsibility is shared.

No ongoing parents' groups exist in Tiberias. Parents' meetings are arranged on occasion through the childrens' institutions. A small number of couples reported that they had been involved in post-natal groups for parents of retarded children at Rambam Hospital in Haifa. At the time of this study, Akim, the National Organization for Retarded Persons, was in the process of opening a center for activities in Tiberias.

The services available for parents with retarded children in Tiberias are limited. The welfare office sponsors a day-care program and a sheltered workshop and provides concrete services to the families with retarded offspring centering on the retarded child. The office lacks the resources to address the emotional needs of the families and parents of the retarded. The special education system is not designed to provide services for parents

or families with the exception of an occasional parent/teacher meeting.

Future studies should apply a comparative perspective by including in the sample a group of parents of nonretarded children, in order to better discern those needs exclusive to parenting a retarded child. Fathers should also be included in future studies. To improve the generalizability of the findings and discern cultural factors, attempts should be made to include non-Israeli mothers of retarded and nonretarded children. Within Israel itself it would be informative to compare among the diverse cultural groups in that country. This was not possible in this study as 80% of the mothers were immigrants from North Africa. Attempts to control for socioeconomic status and I.Q. were unsuccessful as accurate information about the former was not available, and regarding the latter, many I.Q. scores are missing from case records and of the available scores, many of them were old and from several different test editions.

Consideration in future studies should be given as to the extent to which the needs of these parents are similar to the needs of other groups of parents of handicapped children. Results of such a study may suggest a possibility of amalgamation of groups of parents with children having various handicaps in order to provide more extensive parental services to all groups involved, particularly in small towns like Tiberias. Little is known about service needs of the entire family. The literature identifies debilitating effects a retarded child has on the family, however there is little consideration of family-geared services, which is an area for future study.

#### Implications for Practice

The results of this study suggest that the parents of retarded children in this popula-

tion live in isolation. Possible evidence of this is that no mother refused to be interviewed and the mothers in many cases spoke at great lengths with the interviewers. This finding suggests that what Ehlers found to be the most appreciated service, visiting nurses, may be a very worthwhile service filling a real need in Tiberias. As funding is a constraint AKIN (the National Association for the Retarded Persons) might be a source of volunteers to make home visits.

The concrete service needs identified in this study also give a flavor of isolation, in particular the perceived need of parents for increased socialization and entertainment. The obstacles to fulfilling this are money and babysitting. In an effort to meet this need, theatre tickets could be obtained, possibly on a philanthropic basis, and volunteer babysitters found or funding found to subsidize babysitters equipped to handle retarded children. Regarding the need for more vacations, services are already available in some areas (not in Tiberias) for example, holiday care for retarded children facilitates parental excursions without the retarded child. However, for those who identified a need for family vacations with the child but needed funds, no such funds are available.

Other services suggested in this study were aids to help the children with school work and parents' groups. From the perspective of this study, the former would be more important in lessening the mother's burden. The data regarding interest in parents' groups is encouraging in regard to the possible formation of such groups, although it must be remembered that there have never been ongoing parents' groups in Tiberias, hence the mothers' responses reflect sporadic parent meetings held at the various institutions and not an ongoing group experience.

Many of the interviews were conducted by this writer and the remainder by interviewers trained by him. A problem frequently encountered was that the participants in the study seemed to maintain erroneous "messianic" hopes about changes that this study might bring about. We attempted to give this group of mothers no reason to anticipate rapid change and in fact, we made great efforts not to instill false hopes in this very desperate, indigent and lonely group of mothers. Any damage caused by this study is greatly regretted.

This exploratory study is a preliminary attempt at assessing the needs of mothers with retarded children as a population with needs independent of those of their children. This study is based on a belief that parents with retarded children are a group with many needs which go unmet, and that mothers represent the extreme needs of the family. This study differs from previous studies which viewed providing services to the parents as a means of helping the retarded child. Parents' needs in previous studies are either masked by the numerous needs of their children or receive attention to the extent that they are viewed as a means of helping the children. It is likely that any help given to the parents with retarded children will aid their children, however, this study argues that the former need not be a criteria for providing services to parents with retarded children.



## Chi Square

Cross tabulations of amount of mother's needs and several variables (less needs 0-2, more needs 2-3)

### Table 1

Age of child x needs index

|                | less needs | more needs |                              |
|----------------|------------|------------|------------------------------|
| child over 12  | 86%        | 14%        | x <sup>2</sup> =2.22<br>df=1 |
| child under 12 | 70%        | 30%        | p 7.1                        |

### Table 2

Mothers level of religious observance x needs index

|                | less needs | more needs |                              |
|----------------|------------|------------|------------------------------|
| less religious | 70%        | 30%        | x <sup>2</sup> =1.35<br>df=1 |
| more religious | 82%        | 18%        | p 7.2                        |

### Table 3

Frequency of friends visiting in home x needs index

|                                   | less needs | more needs |                              |
|-----------------------------------|------------|------------|------------------------------|
| friends visit frequently          | 63.6%      | 36.4%      | x <sup>2</sup> =3.46<br>df=1 |
| friends visit sometimes or rarely | 82%        | 18%        | p 7.2                        |

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## Notes

When this study was conducted the author was a Community Organization Social Worker for Project Renewal in Israel. I acknowledge the efforts of: Dr. Solomon Egelstein, Division Head, State of Israel Ministry of Labor and Social Affairs Research Division and his staffers, Dr. Menachem Gottesman, Yehudit Sali, primary author of research instrument, for instruction and guidance, Pedro Lindenfeld and Leah Zakut, for technical assistance. I thank Dr. Zev Harel, who reviewed an earlier copy of the paper and Stephen Oliven who aided in carrying out the field research.

A copy of the interview schedule can be obtained by contacting the author of this paper. The primary author of this instrument was Yehudit Sali.