

Parents of Intellectually Disabled Children: A Study of Their Needs and Expectations

Amrita Sahay¹, Jai Prakash², Abdul Khaique³, Priti Kumar⁴

¹Dr. Amrita Sahay, Clinical Psychologist, National Institute for the Mentally Handicapped, New Delhi

²Jai Prakash, Psychologist, Vocational Rehabilitation Centre for Handicapped, Ludhiana, Punjab

³Dr Abdul Khaique, Reader, Psychology Department, Ranchi University, Ranchi

⁴Priti Kumar, Special Educator, New Delhi

ABSTRACT: Needs has been defined as the basic requirement expressed by an individual for survival. The needs expressed by families of children with intellectual disabilities are different from person to person and family to family. The present study examined a total of 45 parents of children with intellectual disabilities; children were under treatment at National Institute for the Mentally Handicapped, Regional Centre New Delhi. The Family Needs Survey Scale (Bailey and Simeonsson, 1988) was used to find out the needs of the parents of intellectual disabilities. Finding suggested that parents referred to strong needs about information of current and future service available in society and the community (88.7%) which is followed by basic expenses (82.7%), teaching strategies and therapy (80%), day care services (77.8%). Parents showed less expected needs towards the professional influences (Minister, 4.4%). This study helps to understand the implementation of Government Policies and services model in the community to provide financial support to family with intellectual disabilities.

KEYWORDS: Intellectual Disability and Needs of Parents

I. INTRODUCTION

Intellectual disability is not a single, isolated disorder. The American Association of Intellectual and Developmental Disability (AAIDD) provide a tri-dimensional definition of intellectual disability, which is currently the most widely accepted. Intellectual disability, which originates before the age of 18, is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior (AAIDD, 2007). As defined by the American Academy of Child & Adolescent Psychiatry (AACAP,1999), adaptive behavior covers a range of everyday social and practical skills in communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. This categorization sub-classifies intellectual disability according to the intensity and nature of needed supports. In addition, it emphasizes the need for detailed assessment in all relevant domains, including psychological and emotional functioning (AACAP, 1999). In recent years, the American Association on Mental Retardation (AAIDD, 2007) have adopted the new terminology and replaced the term “mental retardation” with intellectual disability. “Mental retardation” is still used, however, in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000). In a rough estimate, about 2% of the Indian population constitutes persons with mental retardation (Shalini, 1982). In India prevalence of mental retardation varies from 0.22- 32.7 per thousand populations. ID children are more and more dependent on their family caregivers and particularly on parents. Therefore, they required more support and help for various needs as per their requirement. Needs has been defined as the basic requirement expressed by an individual for survival. Basic needs are food, shelter and clothes. However, for survival in society needs expressed by an individual or families are social support, informative needs, financial needs, childcare needs, and professional support and community services. Informative needs are about intellectually disabled children’s condition, about handling their behavior, about how to teach such children, how to play or talk with them and their development (Bailey and Simeonsson, 1988). Supportive needs include support required by other family members and support of doctors, dentist, babysitters and day care centre. A financial need is about paying for basic expenses, paying for special equipment, paying for the therapy / daycare centre, paying for a baby sitter, etc. Family functioning is about discussing problems or reaching solutions, supporting each other, deciding on household tasks, etc.

Needs express by families of children with intellectual disabilities vary from person to person and from family to family. Rao (2008) also admitted the various on needs of the parents of mentally challenged children. Some of them need supportive services, some of them need money, some of them require information, etc. Mentally challenged children in families show negative and positive impact on family and family’s demand for some specific needs. Singh et al., (2008) found a negative impact (25.26%) which included difficulties in meeting extra demands for physical care of the child, experiencing health-related problems, making career

adjustments, experiencing loss of support from the spouses, etc. Further, they found that parents' were having a maximum negative impact on the domains like 'physical care and financial areas'. It means that the parents' are having problems in the allocation of funds in the care and training of their retarded children as well as in other necessary domestic requirements. Becoming a parent of a mentally challenged child is not a choice of parents but it is forced upon them. Therefore, the birth of a mentally challenged child is a shock for them and they undergo hostile stage like shock, denial and anger before accepting the child. Therefore, they need special needs and extra requirement for child and family for the complete development of the child. The most pertinent areas where parents need to have support and guidance are relieving them from a stressful situation, ensuring family stability, managing child's maladaptive behavior, placement options and future planning for their mentally handicapped child. Some other important needs expressed by families of mentally challenged individual are: information about the condition of the child, management of child's condition, seeking for the available services for present life and future of child with special needs, educational and vocational rehabilitation, marriage of the child, emotional needs expressed by the child and the parents themselves, societal acceptance of the child, government benefits and legislation, relief of burden (financial and respite) etc. The needs of the families having a mentally challenged child are very complex and call for developing support programs for these families. Bailey et al., (1992) concluded in their study that the factor structure for fathers was significantly different from that obtained for mothers. Mothers expressed significantly more needs than did fathers, mother expressed needs primarily in family and social support, explaining to other and childcare. They mainly expressed financial needs. Bailey and Simeonsson (1988) suggested group of needs expressed by families for program planning in early intervention.

The present study was undertaken to explicitly study the family needs in the perspective of parents of children with intellectual disabilities. It was designed to explore several needs expressed by family members of children with intellectual disabilities. More specifically, it had the following objectives:

To identify the needs of parents of children with intellectual disabilities.

To compare the fathers and mothers of children with intellectual disabilities on their needs.

To examine the parent's needs in respect of gender of children with intellectual disabilities, family income, parent's occupation/ education and severity level of intellectual disabilities.

II. METHODOLOGY

This study applied mixed methods (quantitative and qualitative methods) combined in one study, In adopting a qualitative research approach, we sought an identification of the elements of care that parent considered most important rather than setting a priori expectations. The use of mixed methods (quantitative and qualitative methods combined in one study), commonly employed in social science research, has gained increasing acceptance in health research. This is, in part, due to a growing recognition of the complex nature of many health interventions and evaluations (Moffatt, White, Mackintosh, and Howell, 2006; Pope and Mays, 2000) In addition to providing insights into parents' perspectives, the data from the study were intended to inform further quantitative examination of the important attributes of service models (Fitzpatrick et al., 2007) and semi structured interviews techniques to examine parents' needs following diagnosis of children/adults with intellectual disabilities.

III. SAMPLE

The sample of the present study consisted of 45 parents of children with intellectual disabilities who were enrolled in Ankur Diagnostic and Intervention Centre (NIMH RC New Delhi). The study included only enrolled children with intellectual disabilities below 70 Intellectual Quotient. In selecting the sample, variability was sought with regard to objective of the study. Children with additional disabilities were excluded such as learning disabilities, cerebral palsy, physically handicapped, hearing handicapped, visual impairment and epilepsy.

IV. TOOLS

The following tools were used in the present study:

Socio-demographic Data Sheet: It was developed by the researcher to collect the specific socio-demographic and clinical variables such as age, gender, education, locality, occupation, income and level of intellectually disability.

The Family Needs Survey Scale: It was developed by Bailey and Simeonsson, (1988) and designed to identify family needs for the purpose of program planning in early intervention. It is a rating scale and consists of 35 items and these items divided in seven domains. Each item consists of statements about a specific need and parent or other caregivers respond in these ways: definitely do not need help score 1, not sure score 2 and definitely need help, Score 3

DOMAINS	Theme
Family and social support	Includes supporting each other in the family, discussing problems, reaching solution, ideas of childcare tasks, support of friends
Informational needs	About child's condition and disability, handling child's behaviour, how to talk to the child and how to play with children, future services for the child
Financial needs	Need of basic expenses, money for special equipments, money for therapy and counseling, paying for a babysitter and toys
Explaining to others	Need to explain to in-laws, relatives and neighbors
Child care	Need of child care as a baby sitter, school and church/ daycare
Professional support	Sometime family needs professional support like minister, counselor, therapist and special teacher
Community services	Need of doctors, therapists and need to talk to the parents of other handicapped children

V. PROCEDURE

We conducted individual in-person interviews by using a semi-structured interview Schedule and The Family Needs Survey Scale. The parents were asked about their view of several needs like informative and financial needs, community services; professional, family/ social support and childcare and explain to others. The participants were encouraged to think about the strengths and gaps in the existing needs to assist them in formulating their ideas. They were encouraged to support their responses with examples from their personal experiences.

Data collection was conducted over a period of 4 months, and the same interviewer conducted all interviews. The parents were encouraged to share their perspectives according to their level of comfort and to focus on issues of importance to them based on their experiences in caring for their intellectually disabled children. They were also encouraged to support their responses with examples from their personal experiences.

VI. STATISTICAL ANALYSIS

Descriptive data analyses were performed to describe sample characteristics, the prevalence of support needs and level of met need by using the statistical package for social sciences (SPSS 17.0) -window version.

VII. RESULTS

In the present study out of the total sample (n=54) 9 subjects were excluded as 5 were with average intelligence and 4 were excluded due to the incomplete information. Forty-five parents of children with intellectual disabilities were included in this study. Demographic information was collected from the participants for the better understanding their needs and external factors that might influence their views. This information was collected to provide more detailed contextual information that can assist with data interpretation in qualitative research. The small sample size and nature of qualitative research precluded a statistical analysis of factors that predict parents view on various needs. The key socio-demographic and clinical characteristics of the children and parents are detailed in Table-1.

Table-1: Socio-demographic characteristics of the sample

Demographic Variables	N		Percent	
	Age of the child			
Below 6 Years	5			11.1%
Above 6 Years	40			88.9%
Level of Intellectual Disabilities	Boys		Girls	
	N	Percent	N	Percent
Mild	16	35.5%	7	15.6%
Moderate	5	11.2%	5	11.2%
Severe	7	15.5%	3	6.6%
Profound	1	2.2%	1	2.2%
Total	29	64.4%	16	35.6%
Education	Father		Mother	
	N	Percent	N	Percent
Less than SSE	9	20%	14	31.1%
10th	11	24.4%	11	24.4%
Inter	12	26.7%	8	17.8%
Graduate & Post Graduate	9	20%	8	17.8%

Professional	4	8.9%	4	8.9%
Occupation	Father		Mother	
	N	Percent	N	Percent
Professional	8	17.4%	3	6.6%
Clerk, Self employment	13	28.9%	4	8.8%
Skilled and Semi Skilled	4	8.9%	7	15.5%
Unskilled	14	31.1%	12	26.6%
Unemployment	6	13.3%	19	42.2%
Family Income**	N		Percent	
Below Rs.6500	34		75.6%	
Rs.6501-10000	5		11.1%	
Above 10001	6		13.3%	
Developmental Milestones	N		Percent	
Normal	3		6.7%	
Delayed	42		93.3%	
Types of Schooling	N		Percent	
Regular School	9		20%	
Special School	36		80%	

**According to Assistance to Disabled Person for Purchase/Fitting of Aids and Appliances (ADIP Scheme) norm of Govt. of India.

A look at Table 1 reveals the following points:

- The majority (88.9%) of children with intellectual disabilities were above 06 years of age.
- The percentage of boys (64.4%) was more than that of girls (35.6%) on the overall level of intellectual disability. However, in four levels of intellectual disability, that is, mild, moderate. Severe and profound, the majority of boys (35.5%) and girls (15.6%) were found to have a mild level of intellectual disability. Although both boys and girls had the same level of moderate (11.2%) and profound (2.2%) intellectual disabilities, they differed with regard to severe level of Intellectual Disability. Here more boys (15.5%) than girls (6.6%) were found to be found the victim.
- In education level both fathers and mothers of children with intellectual disabilities differed. Fathers seemed to have a slightly better education than mothers.
- The unemployed ratio favored mothers (42.2%) as compared to fathers (13.3%) . However, majority of both fathers (31.1%) and mothers (26. 6%) were unskilled workers. Most of the fathers (28.9%) were found to be clerk or self-employed whereas mothers (15.5%) were skilled and semi- skilled workers.
- The family incomes of most of the children with intellectual disabilities (75.6%) were below RS 6500/ per month.
- They were also found to have delayed developmental milestone (93.3%).
- Eighty percent of them were studying in special schools as against 20% in regular schools.

Table-2 Arithmetical mean and percentage of responses of all parents (N= 45)

Domain/Item	M	Yes N %	Not sure N %	No N %
Family and Social Support				
1. Someone in my family to talk to	1.84	15 33.3%	8 17.8%	22 48.9%
2. More friends to talk to	1.87	15 33.3%	9 20%	21 46.7%
3. More time for myself	1.84	13 28.9%	12 26.7%	20 44.4%
4. Spouse	1.73	4 8.9%	25 55.6%	16 35.6
5. Discussing problems/reaching solutions	2.29	23 51%	12 26.7	10 22.3%
6. Supporting each other	2.21	19 42.1%	12 26.7%	14 31.1%
7. Household and child care tasks	2.16	22	8	15

		48.9%	17.8%	33.3%
8. Recreational activities	1.96	15 33.3%	13 28.9%	17 37.8%
Informational Needs	M	Yes N %	Not sure N %	No N %
1. Child's condition or disability	2.49	30 66.7%	7 15.6%	8 17.8%
2. Handling child's behaviour	2.31	26 57.8%	7 15.6%	12 26.7%
3. How to teach child	2.69	36 80%	4 8.9%	5 11.1%
4. How to play or talk with the child	2.36	27 60%	7 15.6%	11 24.4%
5. Future services	2.80	39 86.7%	3 6.7%	3 6.7%
6. Current services	2.80	39 86.7%	3 6.7%	3 6.7%
7. How children grow and develop	2.36	27 60%	7 15.6%	11 24.4%
Financial Needs	M	Yes N %	Not sure N %	No N %
1. Basic expenses	2.73	37 82.7%	4 8.9%	4 8.9%
2. Special equipment	2.60	33 73.3%	6 13.3%	6 13.3%
3. Therapy , day care services	2.67	35 77.8%	5 11.1%	5 11.1%
4. Job counselling	2.67	34 75.6%	7 15.9%	4 8.9%
5. Baby-sitting /respite care	1.93	19 42.2%	4 8.9%	22 48.9%
6. Toys	2.09	20 44.4%	9 20%	16 35.6%
Explaining to Others	M	Yes N %	Not sure N %	No N %
1. My parents or in-laws	1.78	12 26.7%	11 24.4%	22 45.7%
2. Sibling	1.84	14 31.1%	10 22.2%	21 46.7%
3. Friends/neighbours/strangers	2.07	20 44.4%	8 17.8%	17 37.8%
4. Other children	2.00	19 42.2%	7 15.6%	19 42.2%
5. Reading material about other families	1.91	13 28.9%	15 33.3%	17 37.8%
Child care	M	Yes N %	Not sure N %	No N %
1. Baby –sitter/ respite care	1.47	6 13.3%	9 20%	30 66.7%
2. Day care or preschool	2.38	28 62.2%	6 13.3%	11 24.4%
3. Church/synagogue care	1.80	14	8	23

		31.1%	17.8%	51.1%
Professional Support	M	Yes N %	Not sure N %	No N %
1. Minister	1.82	2 4.4%	33 73.3%	10 22.2%
2. Counselor	2.33	27 60%	6 13.3%	12 26.7%
3. Time to talk to my child's teacher or therapist	2.33	25 55.6%	10 22.2%	10 22.2%
Community Services	M	Yes N %	Not sure N %	No N %
1. Other parents of handicapped children	2.09	21 46.7%	7 15.6%	17 37.8%
2. Doctor	2.49	20 66.7%	7 15.6%	8 17.8%
3. Dentist	1.64	10 22.2%	9 20%	26 57.8%

Arithmetical means and percentile values of the collected data were worked out to determine the needs expressed by parents having children with intellectual disabilities. The Family Needs Survey Scale used in the present study focused on seven (7) domains and 35 needs.

Table-2 shows the frequency and percentage of responses relating to each of the domains and needs identified. The top percentage level was observed in the domain of information (86.7%) and financial needs (82.7%). The average percentage level was observed in the domain of community services (66%) and professional support (60%) and low percentage level was observed in the domain of family and social support, explaining to another and childcare with the score of 48.9% to 44.4% except the need day care or preschool under the childcare domain.

At least 51% of parents expressed the need for discussing the problem and reaching its solutions. The need for information about services their child might receive in the future and services that are presently available was expressed by 86.7% of parents. The need for information about how to teach the child and the child's condition or disabilities was expressed 80% and 66.7% of parents respectively. The need for information about child's future growth and development, methods to play or talk with child and management of child's behavior was expressed by 60% and 57.8% of parents. The need for financial assistance for basic expenses, special equipment, therapy and job counseling was expressed by 80%,73.3%,77.8% and 75.6% of parents respectively.62.2% of parents expressed the needs about the child daycare or preschool facilities. The needs for professional support or guidance such as counselor and doctor were expressed by 66.7% and 60% of parents respectively.

VIII. DISCUSSION

This study was designed to examine the needs of parents under seven domains such as family, social and professional support, information and financial needs, childcare, community services and explaining to others. The result of this study indicated that most of the parents expressed the need for information and financial support, the average percentage of parents expressed the needs of childcare, community services and professional support and very less percentage of parents expressed the need of family and social support and explaining to others. The result can be explained by the fact that parents needs information about the child's condition or disability, handling child behavior. Thus other need of children with intellectual disabilities and their parents are ignored especially about the explaining other and family and social support, because most of parents didn't want to disclose the information about child and didn't needs family and social support due to the nuclear family and culture of society.

Parents favored a strong need for information about future and current service available in society and the community, a need for ongoing, up-to-date information throughout the continuum of care, particularly in the technology development. A large number of parents expressed the need for information on various educational and teaching methods of the child such as home tutoring and additional support through the educational system. With regard to the nature of expressed needs, the pattern reported by families in this study is highly consistent with that found in previous researches (Baily et al., 1992; Bailey and Simeonsson, 1998, Barnhart et al., 1994; Cooper and Allred, 1992; Garshelis and Mc Connell, 1993: Sexton et al., 1992). For example, the domain of information needs has consistently shown to be higher than other areas of need. Further on the item level needs

related specially to the child's disability (e.g. reading material about families of other children with disabilities opportunities to meet other families, more time to talk with the child's teacher or therapist) were generally rated higher than more general family needs (e.g. Doctor, counselor, job counseling). Two systematize problems appeared to affect the process of receiving appropriate support for some families in the early stages of diagnosis: (a) knowledge of and access to the various services/resources that were available and (b) the lack of coordination within clinics and between various clinic providers and agencies. With time, parents seemed to learn how to navigate the system and were generally very satisfied with the ongoing services that were provided. It is unclear from the literature whether this information is not provided because clinicians are unaware that parents desire such information, are uncomfortable discussing prognostic information, or simply do not have evidence-based prognostic indicators. While parents generally felt that the providers they encountered were highly knowledgeable about intellectual disabilities, they also commented that they would like to receive professional guidance in seeking information beyond that offered by clinic providers.

Many parents expressed the desire to know the child's condition or disabilities, how to play or talk with the child and their potential to develop spoken communication. Essentially, parents wanted the best available evidence supporting intervention outcomes for management of the child's behavior. Walker and colleagues (1989) found that 91% of parents of children with chronic health conditions expressed needs for information about their child's condition, treatment and long-term implications of the child's health condition. Forty-seven percent of families of children with a diagnosis of autism, pervasive developmental disorder or mental retardation had needs for information. Research involving families of children with disabilities or special health care needs has identified several types of family needs. Families of children with physical disabilities most often expressed needs for information about services (59%) and their child's condition (43%) (Sloper & Turner 1992). 21–32% of the parents had needs for support, community services, family functioning and explaining their child's condition to others (Ellis et al. 2002). The high percentage of parents who expressed needs for information about current services, community resources and supports is consistent with previous findings for families of children with disabilities (Sloper & Turner 1992; Ellis et al. 2002), including mothers of children with CP (Nitta et al. 2005). Our findings may partly reflect a parental attitude that it is impossible to have too much information. Comments from parents when completing these items indicated that many felt they were very well informed but that it is 'always good to know more'.

Some of the families identified a variety of other desirable supports from the publicly funded care system, including financial support for equipments and travel, and contact with other parents who had experienced the process of intellectual disabilities of child because 75.5% parents belong to low socioeconomic status. At face value, the low percentage of parents who expressed needs of family and social supports and explaining their child's condition is encouraging. Others have cautioned that parents of children with disabilities are more focused on needs related to their children's development than needs for the whole family (Graves & Hayes 1996; Perrin et al. 2000).

In our research, parents were more concerned with receiving guidance on how to access the various information about the child's condition or disabilities and its management, as well as they also need information about the financial facilities provided by central and state Governments. Our findings also differed from studies emanating from the United States, where the physicians or medical homes play a role in managing the child with hearing loss (Gravel and McCaughey, 2004). There was little discussion of physician's involvement for screened children and little involvement beyond the initial referral phase for those families whose children were identified through traditional referral routes. This may simply reflect a difference in how services are organized in the two countries, with education and therapy responsible for the management of the child with intellectual disabilities separately from a primary health care (Bailely et al 1992).

However, the findings of the study are based on a varied sample of parents of children who differed in severity of intellectual disabilities. In addition, the needs of families who reside outside major regional centers require further examination. Further research should evaluate whether some of the problems encountered by families, particularly with respect to the lack of coordinated services, have been resolved and also should focus on how to implement and aware the parents to avail the services and financial benefits provided by the Government of India and awareness about the service model and financial schemes may reduce or even prevent intellectual disabilities.

The findings of our research can be used in optimizing models of services and implementation of Government policies for children with intellectual disabilities and families, ensuring that parents' perspectives are taken into account throughout the continuum of care. Because effective communication is known to be associated with optimal health outcomes, understanding what, when, and how information should be delivered to parents becomes vital to ensuring the delivery of appropriate care. Such knowledge can help tailor programs and services to achieve more effective communication and patient decision making and perhaps ultimately improved outcomes for children with intellectual disabilities and their families.

This study provides an awareness of parents' needs from their perspectives and their description of current strengths and gaps in the system. From a policy perspective, an understanding of how parents value the components of service delivery can provide insights into the most valued services for families.

In summary, this study contributes to the growing evidence base to know the parents' awareness level about the services and financial support and needs of parent in specific areas. Our study adds to the understanding of parents' perceptions of their needs of family and social support, information and financial needs etc. By virtue of its intensive and long-term nature, service provision for children with intellectual disabilities involves a social contract with families that must be recognized and given priority. Parents want more information about current and future services and financial support provided by society. The findings support the need for information about the child condition or disabilities, management of the child's behavior and overall development of the child. Further understanding of parents' needs may improve the appropriate implementation of Government policies and services model in community and provision financial support to family who belongs to low socio economic status.

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