Intellectual Disability: Parents Experiences with a Disabled Child

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Abstract

When a child has a disability, family problems increase. Demands for energy, time and financial resources add a heavy burden of stress. Emotionally, the greatest risk to which most mentally retarded children are exposed is the loss or lack of adequate relationship with an adult caregiver. This loss/Iack has profound implications (Bowlby, 1988).

Intellectually disabled children are particularly vulnerable to a range of negative attributions. The most powerful of these is likely to be the position of "social reject" to which, inevitably, they are subjected. Mentally retarded children are socially marginalized and rejected by almost all sections of the community.

So, keeping in view the problems associated with disability in the present study an effort has been made to understand the problem from the parent's perspective. Parents' attitudes are an important area of inquiry in search for improved services to families of mentally handicapped children and again, parental attitudes play a major role in the treatment and diagnosis of the mentally retarded child. The results of the study clearly reveals that there is a direct impact on family functioning, parents reactions in term of shock and along with other issues and challenges faced by family members.

Keywords: *Mental Retardation, Disability, Family*

INTRODUCTION:

Family unity is represented and characterized in the unity of the members who live together and share the basic burdens of life. The main goal of a family as a unit is to create a climate for the growth and maturity of the family members who do their best within the family and the existence of a disabled child in the family increase the anxiety and conflicts among spouses and spellings (Seligman & Darling, 2000). Mental retardation has existed in one form or another in all societies throughout time. The mentally retarded have been described in different terms, involving many diverse conceptualizations and varying characteristics, depending on societal and situational influences at the time.

Identifying the individuals' attitudes toward handicap -positive were or negative- is a base on which depend many handicap and handicapped-related decisions. The importance of identifying individuals' attitudes toward retardation / handicap lies in success of behaviour modification programs, preparing awareness and family therapy programs for handicapped children's parents , modification of individuals' attitudes toward handicap, awareness in order to adjust the concepts and attitudes regarding some types of handicap , and identifying the services and legislations that might be enacted by the society in favour of the various categories of handicap (Toa'imah & Al-Batsh, 1984).

Origin of the Problem

The most important figure in the child's immediate environment is a parent. Birth, for most families is a time for rejoicing, for pride, for gathering together loved ones and sharing with them in the celebration of a renewal of life. For other families birth may not be as joyful an occasion. On the contrary it may be a time for tears, despair, confusion and fear for those who become parents of children with mental retardation.

Those who become parents of children with mental retardation need to make huge emotional adjustments as they endeavour to come to term with the feeling brought by a sense of overwhelming disappointment and loss. They experience guilt and shame at having produced a child with special needs because it is not seen as perfect by the rest of society.

It may demand a totally new life of all involved, full of mysterious and unique problem. Parents have to develop a new routine, siblings have to learn to accept the new addiction to the family and often they may discovers feelings of loss which come as a result of parents being so involved with the baby. One of the primary stressors of life with a severely handicapped child is day to day care, feeding, dressing and toileting. Often the emotional and physical demands of that care leave the caregiver with no strength for other relationship or activities

In the search for meaning for their situation, some parents may resort to tradition beliefs and see their child as the consequence of a misled or misfortune of their own, or as a blessing in disguise from god, set to test their faith and fortitude. Families do not have the experience of caring for the mentally handicapped member and therefore need information and support to cope with the condition.

Studies reveal that like all other children, the mentally retarded child needs love, care and parental attention but it is possible only when the parents have positive attitude and proper insight regarding how to cope with the situation. The factors like poor living conditions, poor

nurturing, parental inattention, and faulty upbringing etc. may make the situation worst. The lack of insight, on the part of the family, how to cope with the situation, motivate the researcher to conduct this study. It is therefore, the intention of the researcher to explore the attitudes of parents towards their mentally retarded children as well as impact on family functioning.

International Status:

World Health Organization estimates that 10% of the world's population has some form of disability. Mental retardation (MR) is one form of disability and affects 1-3% of human population. Mental disorder is a particular state of functioning that begins in childhood and is characterized by decreased intelligence and adaptive skills and also is the most common developmental disorder.

Mental retardation is one of the most common disabilities occurring in childhood. Studies of the frequency of and risk factors for cognitive disorders in children have been almost entirely restricted to developed countries, where service records and registries provide a feasible means of case identification .Defining serious mental retardation in childhood as an intelligence quotient below 50 with deficits in adaptive behavior, prevalence is remarkably constant between 3 and 5 per 1,000 children, with relatively little variation over time, across socioeconomic conditions, or across populations. By contrast, defining mild mental retardation as an intelligence quotient in the range of 50-70 with deficits in adaptive behavior, prevalence in developed countries is highly variable, ranging across populations from as low as 2/1,000 to as high as 40/1,000. Epidemiologic and clinical studies of mental retardation in developed countries also show that severe retardation is much more commonly associated than is mild retardation with both known causes of retardation (including genetic, nutritional, infectious, toxic, traumatic, and other factors) and comorbid brain disorders (including cerebral palsy, seizures, vision impairments, and hearing impairments).

Pilot studies of severe mental retardation conducted in selected populations in Pakistan and India have reported extraordinarily high prevalence estimates in the range of 12-24 /1,000. Because some of the specific causes of and risk factors for mental retardation that are now uncommon in developed countries remain highly prevalent in less developed countries, and because child survival is beginning to improve in some countries (a situation which in developed countries appears to have resulted in increases in the prevalence of childhood

disability, the possibility of an elevated frequency of severe mental retardation in less developed countries is plausible and requires confirmation.

An estimated 10% of the world's population experiences some form of disability or impairment (WHO Action Plan 2006-2011). The number of people with disabilities is increasing due to population growth, ageing, emergence of chronic diseases and medical advances that preserve and prolong life, creating overwhelming demands for health and rehabilitation services (Srivastava and Khan 2008). In South-east Asia, the prevalence of disability ranges from 1.5 – 21.3% of the total population, depending on definition and severity of disability (Mont 2007). Despite the increase in prevalence of disability worldwide, due to various reasons, not much attention has been paid to its evaluation, management and prevention (WHO 2002).

The *United Nations* (UN) *Disability Statistic's Compendium* (DISTAT) noted that disability rates are not comparable across the world because of differences in survey design, definitions, concepts and methods, as the proportion of disabled people per national population varies between less than 1% in Peru and 21% in Austria (UN 1990). In 1981 UN/WHO studies estimated that on average 10% of all national populations were disabled. However in 1992, this estimate was modified to 4% for developing countries and 7% for industrialized countries (Metts 2000). The UN Development Program estimates a total global proportion of disabled people of 5% (Coleridge 1993), USAID at 10% and DFID at 4-7% (Yeo 2001). Depending on survey or census data different estimates are derived across the world with the United States census data estimating a disability prevalence rate of 20% in 2000 and a survey data estimating a 5% rate in China in 1987. (Mont 2007; Table 1) Differences are also seen across member states of the WHO South- East Asian Region (Table).

Table- No 1 Prevalence of disability in the different countries of the World

Censuses			Surveys		
Country	**Year**	**% of population with disability**	**Country**	**Year**	**% of population with disability**
United States	2000	19.4	New Zealand	1996	20.0
Canada	2001	18.5	Australia	2000	200
Brazil	2000	14.5	Uruguay	1992	16.0

United Kingdom	1991	12.2	Spain	1986	15.0
Poland	1988	10.0	Austria	1986	14.4
Ethiopia	1984	3.8	Zambia	2006	13.1
Uganda	2001	3.5	Sweden	1088	12.1
Mali	1987	2.7	Ecuador	2005	12.1
Mexico	2000	2.3	Netherlands	1986	11.6
Botswana	1991	2.2	Nicaragua	2003	10.3
Chile	1992	2.2	Germany	1992	8.4
India	2001	2.1	China	1987	5.0
Colombia	1993	1.8	Italy	1994	5.0
Bangladesh	1982	0.8	Egypt	1996	4.4
Kenya	1987	0.7			

National Status:

Different prevalence rates for disability are available in India. According to the Census 2001, there are 2.19 thousand people with disabilities in India who constitute 2.13 % of the total population (Census 2001). Out of the 21,906,769 people with disabilities, 12,605,635 are males and 9,301,134 females and this includes persons with visual, hearing, speech, locomotor and mental disabilities (Census 2001).

In contrast, the National Sample Survey Organization (NSSO) estimated that the number of persons with disabilities in India is 1.8% (49-90 million) of the Indian population (NSSO 2002), that 75% of persons with disabilities live in rural areas, 49% of the disabled population is literate and only 34% are employed (NSSO 2002). NSSO also includes the persons with visual, hearing, speech, locomotor and mental disabilities.

Patel et al. (2009) using NSSO 2002 data, observed that locomotors disabilities are the most prevalent type of disabilities affecting of all ages in India. Mental disabilities are the highest in the working age population, whereas visual and hearing disabilities are the highest in the aged. Further, onset of locomotor and speech disabilities mainly occur at early ages, whereas onset of visual and hearing disabilities are highly concentrated at later ages. Onset of mental

disabilities peaks at early ages and younger working age population. Severe disability is broadly concentrated at later ages (Patel et al. 2009).

In 2002, the NSSO estimated that the incidence rates for males were 77 and 75 per 100,000 respectively in rural and urban India as against 61 and 58 per 100.000 respectively among females during 2001-2002. (NSSO 2002) Urban/rural differences varied, ranging from 2 to 117 per 100,000 persons in rural India and from 11 to 132 per 100,000 persons in urban India. The incidence rate was highest in Andhra Pradesh and lowest in Assam (Figure 5) (NSSO 2002).

Table 2: Age and sex differentials in different types of disability in India

		Above 15			**Age**				
					15-59			**60 +**	
Types of disability	**Male**	**Female**	**No**	**Male**	**Female**	**No**	**Male**	**Female**	**No**
Mental	63.0	37.0	2872	62.2	37.8	7665	47.1	52.9	745
Visual	53.2	46.8	925	54.8	45.2	3748	41.9	58.1	6250
Hearing	55.6	44.4	2036	54.4	45.6	6153	50.3	49.7	4605
Speech	59.7	40.3	3809	62.1	37.9	5452	57.0	43.0	697
Locomotor	60.8	39.2	9082	66.6	33.4	24393	56.3	43.7	8314
Total	**60.0**	**40.0**	**18724**	**62.9**	**37.1**	**47410**	**50.2**	**49.8**	**20611**

Table: 3 Disabled Populations by Type of Disability India: 2011

Sr. No	Types of disability	Persons	Male	Female
1	In Seeing	5,032,463	2,638,516	2,393,947
2	In Hearing	5,071,007	2,677,544	2,393,463
3	In Speech	1,998,535	1,122,896	875,639
4	In Movement	5,436,604	3,370,374	2,066,230
5	Mental Retardation	1,505,624	870,708	634,916
6	Mental Illness	722,826	415,732	307,094
7	Multiple Disability	2,116,487	1,162,604	953,883

8	Any Other	4,927,011	2,727,828	2,199,183
	Total	**26,810,557**	**14,986,202**	**11,824,355**

Source: C-Series, Table C-20, Census of India 2011

RESEARCH DESIGN:

The researcher followed the phenomenological design for this study. The researcher used the applied cum exploratory research in the investigation. This design aims to understand and interpret the meaning that subjects give to their everyday lives. After conducting interviews, the researcher was in a position to understand participant's experience of family life or reaction to the realization that have a child with mental retardation, as expressed in their own words.

Qualitative as well as Quantitative approach was followed, the researcher opted a semi structured interview because the semi-structured interviews gives the researcher and participants much more flexibility and this also allow the researcher an opportunity to probe further on issues emerging during the interview, and the participant is able to give a fuller picture.

Universe:

Bless and Higson-Smith (2000) defines a population as the set of elements that the researcher focuses on and to which they obtained results should be generalized. The population in this study comprised of families who have children with mental retardation who also attend day care centers in the Vadodara district of Gujarat.

Objectives:

The objectives in of the study were as follows,

- To study the attitude and burden of care givers of children with intellectual disability enrolled in special schools.
- To study the educational, emotional and social adjustment problem of children with intellectual disability in their special schools, families and in their social environment.
- To assess the impact of mentally retardation on family functioning.
- To make recommendations based on the results of the study on the provision of services to families of person with mental with mental retardation.

Research Questions:

The researcher decided research question because it is more relevant in an exploratory study than a hypothesis. The research questions in this study were as follows:

- What is the attitude of parents towards intellectual disability?
- What are the educational, emotional and social adjustment problem of children with intellectual disability in their special schools, families and in their social environment
- What is the impact of intellectual disability on family functioning in the vadodara district of Gujarat?
- What kind of services may be useful for the parents of intellectual disabled children?

Sampling & Sample Size:

For the purpose of this study the researcher followed and used the probability sampling and a simple random sampling. In this case 60 individual parents (one per household) of children who have mental retardation were included in the sample. The 60 individual parents were interviewed using the semi- structured interview schedule at Vadodara district of Gujarat. They were selected by using a probability: simple random sampling and the sample was drawn from a list of all the registered special schools/ centre for mentally retarded children in the Vadodara District. The registered children have been attending the day care centers for the past three months before the interview.

Method of Data Collection:

In the present study the techniques of interviewing was formed the main basis, because it could provide the researcher with an opportunity to have the desired information elicited from the respondents, through interviews accorded by appointment, contacting them on their own terms and conditions.

Sources of the Data:

This study was based on both types of sources of data, primary and secondary.

MAJOR FINDINGS:

The findings in relation to impact of mental retardation on family functioning has been presented according to several themes have consequently been identified and they are presented as follows.

1. **In terms of explore the impact of mental retardation on family functioning it was found that:**

- Majority of the parents of mentally challenged Childs were found from middle class background and their attitude was positive towards their mentally retarded child.
- As the discloser of the diagnosis, most of the parents expressed their feeling such as depression and sorrow, feeling inferior etc.
- It was also found out from the study that financial support is very much needed in term of special arrangement for the parents to maintain their mentally retarded child.
- One of the important finding of this study is that parents spared most of their time with their mentally disable child. (mainly the mother of the child)
- It was found that the reaction of siblings towards their MR brother or sister were they feel worried and very sorry and sad for them.
- Most of the respondents in the study enjoyed support from their extended family members. Their own spouses and other children were also found to be very supportive by the respondents.
- One of the positive finding of the study is that according to the respondent in society or community no one can regarded their child as a social stigma.
- The siblings did not enjoy their childhood as they acted as carers for their brother or sister. They were required to rush home after school to assist their parents with the care of the sibling brother or sister who has mental retardation.

2. **In terms of the problems face by the Family member due to mentally retarded child it was found that:**

- The parents faced the problems like low social status, problems in social area lack of facilities, low financial status, Raising a child with a mentally retarded may be more expensive then raising a typical child. These expenses can arise from medical equipment and supplies, medical care giving expenses, private education tutoring, adaptive learning equipment or specialized transports.
- Tension and frustration are the common psychological problems suffer by the parents for their mentally retarded child's.

- The study concerned that parents of MR Childs face lot of emotional problem like stress, fear of taking care of their child after death, fear of losing them etc. They often struggle with guilt and sometimes they may feel that they are reason for their child to be victim of their selfishness.
- One of the main concerns of parents with mentally retarded children is about how their child will be taken care of when they die. They feel that no one else can take care of their child with same love and care that they have and they are scared about how their child will be able to manage to survive in the world.

3. **In relation to parents attitude towards mental retardation it was found that**:
    - Majority of parents were found to have a positive attitude towards their mentally retarded children. Although a small proportion of parents had a negative attitude, no parents were found to have a strongly negative attitude.
    - It has been observed in the present study that although most mothers and fathers displayed positive attitudes, more mothers than fathers had positive attitudes.
    - Another important finding of this study concerns the fact, that irrespective of the child's disability, parents loved and accepted their children.
    - Although parents expressed feelings of disappointment towards their mentally retarded children, they were not over-protective towards these children.
    - From the study it was fond many problems are not noticeable at birth but only develop or become noticeable, as the child grows older.
    - The findings of the study it was found that parents were not informed immediately after the birth of their children about the child’s disability. Professionals only did the formal discloser after the parents have communicated their suspicion and uncertainty about the child’s condition. Most of them moved from one traditional doctor to another trying to get an explanation of what might be the problem with the child but that did not bring any change.

CONCLUSION:

In conclusion, we can say that parents of mental retardation in Ajmer district of Rajasthan had positive attitudes towards their mentally retarded children and mental retardation has a great impact on family functioning. In concluding way we can say that

- The parents of children with mental retardation are not properly informed about the disability of their children by service provider.

- There are no service provided to the children with mental retardation and their families.
- Siblings automatically assume a caring role.
- The needs of many children with mental retardation have financial implications.
- There is no support received from the community.
- Parents enjoy support from their immediate and other relatives,
- Patents do not have skills to help them cope with the demands and challenges presented by the child.
- The discloser of the disability is not done soon after the birth of the child.

SUGGESTIONS AND RECOMMENDATIONS:

- Provision of adequate information and skills to parents of children with mental retardation to enhance copying.
- Awareness should be done in the community about mental retardation, its causes, treatment and how it can be prevented.
- Siblings should be well informed about the condition of their disabled brother or sister.
- Service providers should facilitate the establishment of community based care services.
- Families need assistance in dealing with problems in the larger society e.g. stigma and isolation
- Families need access to medical and psychological services and social worker and therapists can provide a practical assistance.
- The discloser of the handicap must be done soon after the birth of the child and follow up visits be made by the service provider
- Government should be make some plan & policies like bank credit, insurance to support the mentally challenged Childs.
- Awareness should be done in the community about mental retardation, its causes, treatment and how it can be prevented.
- They should gain suggestions from physician in time to time and also should inform behavioural changes of child to physician.
- Parents should create a good environment which may help the children to develop their mentality.
- Always try to follow suggestions of physicians and child specialists.

- Provisions of adequate information and skills to parents of children with mental retardation to enhance coping.
- Families must to be linked with available resources, for example the Department of Social Welfare for the application of social grants.
- Families need access to medical and psychological service and social workers and therapist can provide a practical assistance.

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