

## **Parents of children with Intellectual Disability: Anxiety and Challenges**

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### **ABSTRACT**

**INTRODUCTION:** To a parent, every child is special in his or her own way. Family, especially parents are responsible for providing basic needs support such as food, shelter, education, and care at all times especially during times of crisis. Every parent wants his or her child to be physically and developmentally perfect. However, the possibility of having a retarded child is very traumatic. Parents of a child with intellectual disability have additional responsibilities and roles to take care of their differently able child. Family members go through a significant amount of stress and anguish in the process of raising a special child. The purpose of this study is to explore the psychological, social, and economic challenges that parents experience while dealing with their children with intellectual disability and manner in which they address or deal with it.

**METHODOLOGY:** The study was conducted in the Child Guidance Centre in Delhi. In-depth Interviews were conducted with the parents of children with Intellectual Disability followed by two focus groups discussions (FGDs). Data analysis was done using content analysis.

**RESULT:** The study discovered psychological, social, and economic challenges parents experience while living with their children with intellectual disability. Parents had feeling of sadness, inner pain and bitterness due to the disturbing behaviour of the child. Social challenges include inadequate social services for their children, stigma, burden of caring task, lack of public awareness and social support. The economic challenges are poverty, extra expenses associated with the child's disability etc. The support system of these parents can be enhanced by organizing self-help groups, which can serve as vehicles for communication. Support groups can also diminish the feeling of isolation experienced by some families.

**CONCLUSIONS:** Caregivers of special children experience various psychological, social, and economic challenges. Professional assistance, public awareness, social support by the government, private sector, and non-governmental organizations (NGOs) play important role in addressing these challenges.

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### **I. INTRODUCTION**

Parents play an important role in child development. For a parent, every child is special in his or her own way. Children look to parents for basic needs support such as food, shelter, education, and care at all times. They spend nearly all of the time with their family, especially in the early years. Children develop confidence, socialization skills, morals, values and views on life through interaction with parents.

Every parent wants his or her child to be physically and developmentally perfect. However, the possibility of having a retarded child is very traumatic. The child has special needs in addition to the regular needs of all children, and parents find themselves overwhelmed by various medical, caregiving and educational responsibilities. Whether the special needs of the child are minimal or complex, the parents are inevitably affected. Support from family, friends, the community or paid caregivers is critical to maintaining balance in the home. Parents of intellectually disabled children commonly experience a gamut of emotions over the years. Furthermore, our culture has not established satisfactory rituals or practices for dealing with intellectual disability. The prevailing approach has traditionally been to abandon the mentally retarded as "hopeless" and to exclude them from the realm. This situation has been supported in literature which suggests that parents find acceptance of mentally retarded child difficult which has been regarded as "internalization of death wishes". The report has also suggested that it's not person's disability, but political, social attitudinal, architectural and environmental barriers that child encounters. (Strasbourg Symposium of the International League of Societies for the Mentally Handicapped (1967).

Parents often struggle with guilt. They may feel as they somehow caused the child to be disabled, whether from genetics, alcohol use, stress, or other logical or illogical reasons. This guilt harms the emotional health of parents. Some parents struggle with "why" and experience a spiritual crisis or blame their partner.

Many parents have aspirations for the child from the time of the birth and can experience severe disappointment seeing delayed development of the child.

Parents of a child with intellectual disability have additional responsibilities and roles to take care of their differently able child. Family members go through a significant amount of stress and anguish in the process of raising a special child. Lack of understanding of the causes of retardation has further contributed to social ostracism and to a general tendency to deal with mental retardation through denial.

Raising a child with intellectual disability is a daunting and exhausting task. There are many appointments to keep. Finding and funding the needed **support services** can easily overwhelm families. Family members cope with the daily stress of seeing their child struggle. It is natural to feel grief, resentment, disappointment, and frustration. Sometimes these feelings can lead to feelings of guilt, hopelessness, and depression. It should come as no surprise that these families need their own supportive services- community supports, respite and emergency care services, family therapy and support groups etc. Other than these supports, services require for intellectual disabled are- Specialized medical and health care services, early intervention care, individualized family services plan, individualized education programme, legal services, availability of orthotic and prosthetic appliances, vocational training etc.

The purpose of this study is to explore the **psychological, social, and economic** challenges that parents experience while dealing with their children with intellectual disability and manner in which they address or deal with it.

## II. METHODOLOGY

The study was conducted in 2012-13 at the Child Guidance Centre in Delhi. Parents and children with intellectual disability (ID) come regularly at the centre for assessments and counseling. Twenty eight parents of children with ID were selected randomly; (details are given in table-1) In-depth Interviews were conducted with them followed by two focus groups discussions (FGDs). Data analysis was done using content analysis.

Table- 1

S. No.	IQ level of the child	No. of Parents (both father and mother)
1.	Borderline IQ (70 to 85 )	4
1.	Mild IQ level (50 to 70)	8
2.	Moderate IQ level (35 to 49)	10
3.	Severe IQ level (20 to 34)	6
	TOTAL	28

According to DSM V (The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition)

## III. RESULTS

### Psychological Challenges

Most parents revealed disturbing thoughts about living with a child with intellectual disability. They expressed being stressed by the explicit behaviour of the child that caused problems not only for them but also to people nearby such as neighbours. Behaviour of the children with ID being aggressive, destructive, restless or hyperactive, making noise, and they lack of proper eating skills.

Worrying about the future life of the child was another form of disturbing thought that parents experienced due to the inability of the child to accomplish personal and social needs such as self-care and education. They showed these concerns when the child could not do certain developmental tasks expected at specific ages such as feeding, toileting, bathing, and dressing.

Parents were also disturbed by the complexity of caring responsibilities that demanded a lot of work and being available most of time to meet the daily needs of the child. The issues about how to handle the child and ensure security if the parent died.

Varying degrees of emotional distress were experienced which included having feelings of sadness and inner pain or bitterness. Parents experienced these negative emotions due to disturbing behaviour of the child, extra care-giving responsibilities, family and social problems caused by the child, and people's perception about families having a child with intellectual disability.

Parents described living with special child as a disturbing and yet unavoidable situation. They had to accept it since they had no other alternative. They viewed their caring duty for the child as very difficult and distressing.

The inability of the child to express needs was another source of psychological and emotional distress. This caused parents, unable to understand the child especially when he/she had problems. Sometimes when the child went out, he/she was mistreated by other people and returned home crying. When he/she was asked by the parent to explain what happened he/she couldn't explain.

## IV. SOCIAL CHALLENGES

Caring for a child with intellectual disability is found to be associated with many social challenges. Social services, stigma and caring responsibilities are the areas which poses major concerns for parents. Other important issues include lack of public awareness, social support, and social life.

Inadequate social services for children with mental disorders is the most challenging issue for parents. They had concerns about education for the child and to a lesser degree medical care. The most distressing aspect was inability of the child to acquire education due to an inadequate number of schools. Parents spent a lot of time looking for schools that could accommodate the child.

Living with the child with intellectual disability was found to be associated with stigma. The child was mistreated by people in various ways. Sometimes he/she was labelled and made fun of at school, considered to be useless and even rejected by the parent because of the disability.

Parents were sometimes held responsible for the child's behaviour. They were thought to be spoiling the child by not being strict enough when the child behaves strangely.

The burden of caring for the mentally ill child was found to be mainly borne by the mother. Mothers complained about the role that fathers played in everyday care of the child. They expressed that some fathers were only supporting the child financially and others did not care at all.

Ignorance about mental disorders is perceived by caregivers to be common. Some children with ID and their parents suffered stigma and mistreatment out of ignorance. In spite of great technological advances with respect to mental retardation during recent years, a surprising number of professionals in the medical and behavioral sciences have little knowledge about the condition. Misdiagnosis and dispensation of misinformation are still common. Some parents are still assured that their child will "outgrow" the difficulty, and others are confronted with the "hopelessness" of their child's condition and are urged to proceed with immediate institutionalization. Parents in this study expressed their concern about not receiving the needed support from neighbours and people in the society. Some people ignore the child in a critical condition like having seizures.

The social life of parents was found to be disrupted by the presence of a child with ID in the family. Sometimes parents avoided going with the child to social gatherings because of the child's disturbing behaviour. Parents also experienced conflicts in the neighborhood and sometimes were accused when the child destroys somebody's property. This creates tension and results lack of peace. It was noted that mentally ill children were vulnerable and suffered mistreatment from people by being beaten, pushed, and burned. The child who could not speak seemed to be more vulnerable since he/she could not mention a person who was responsible for the cruel action when parents wanted to know.

These children were also reported to be at risk of being physically and sexually abused such as being burned or raped as explained by some mothers of children with intellectual disability.

The parent of a child with this developmental disabilities may have to deal with complex issues related to education. Parents often have to advocate for their child to receive a quality educational experience that will enrich her. This often requires close parental contact with the school system. The parent must monitor the child's interactions with others to ensure she is not being bullied. Transportation to and from school may require a specialized bus or van, and children with severe disabilities may need to be schooled at home.

A serious defect in one's child may be interpreted as a defect in one's self, particularly when a parent identifies closely with his child. Our society tends to foster the concept that children are extensions of parents and reflect on their parents.

## **V. ECONOMIC CHALLENGES**

Three major themes emerged that explained how living with a child with ID interfered with economic activities of the families. These were: existing poverty, interference with various income generating activities, and extra expenditure due to the illness.

Raising a child with a mental challenge may be more expensive than raising a typical child. These expenses arise from medical equipment and supplies, medical care, caregiving expenses, private education, tutoring, adaptive learning equipment or specialized transportation. The care of the child may last a lifetime instead of 18 years. Parents may have to set aside money in a trust fund for the child's care when they pass away. Poverty was revealed by parents as being responsible for their inability to meet certain important needs of the child. Home makers who did not have any means of earning income and depended solely on their partners; those who did not have partners expected to get help from other people, especially relatives. They (including fathers) could not manage buying medicines for their children when they did not receive them at the hospital. They also could not afford bus fare to attend the clinic with their children on the day of their appointment.

Daily life and activities of parents in this study were very much affected by the presence a special child. Much time was spent looking after the child and as a result they were not able to do other important activities. Income generation in the family was affected and this further escalated family poverty as explained by a mother of a child

## **VI. CONCLUSIONS**

Caregivers of special children experience various psychological, social, and economic challenges. Professional assistance, public awareness, social support by the government, private sector, and non-governmental organizations (NGOs) play important role in addressing these challenges.

Understanding how to manage the negative consequences of caregiving is critical to developing and implementing realistic, appropriate response strategies. There is no doubt that psychological evaluation and intervention programs should be considered as vital adjuncts to the management of ID; particularly among inaccessible segments of the population. The present findings have practical implications for assessing the health needs of caregivers who are taking responsibilities of a child with intellectual disability. In India where there are limited resources and it is high time that we should realize that we may not develop holistic health of the children if the caregivers are overburdened. So treatment providers should also shift their focus to the mental health of care givers too along with that of individuals with ID.

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