

# Challenges Faced by the Parents of Special Children

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**Abstract:** Family is the important social institution devoted to the growth of the child and parents are the important agents of socialization. This paper examines the challenges faced by the parents of special children. Special children are those who are affected by intellectual disability which is manifested by limitations in intellectual functioning and adaptive behaviours. Intellectual disability affects about 2-3 percent of the general population. Intellectual disability is caused by genetic conditions, problems during pregnancy, problems during childbirth or illness or injury. However, certain causes of intellectual disability are preventable. Intellectual disability may be diagnosed through interviews with the parents, observation of the child, and testing of intelligence and adaptive behaviours. Remedies include learning everything one can about intellectual disabilities, encouraging the child's independence, getting the child involved in group activities, staying involved and getting to know other parents of intellectually disabled children. In India, children with disabilities mainly come under the purview of the Ministry of Social Justice and Empowerment. Disability in India is still functioning in the realm of social welfare instead of a rights perspective. Census 2001 has revealed that over 21 million people in India are suffering from one or the other kind of disability. This is equivalent to 2.1 percent of the population. Among the five types of disabilities, disability in seeing is highest at 48.5 percent followed by disability in movement (27.9%), mental retardation (10.3%), in speech (7.5%), and in hearing (5.8%).

**Key words:** Special children, Intellectual disability, Mental retardation, Intelligence quotient (IQ), Down syndrome.

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## Introduction

Family is the most beautiful social unit that comprises the total and holistic growth of the child. Parents are called as the first teachers for a child as they are the moral and value developers in the child's life. The first lessons which a child receives at his or her house constructs the future and the person that child would be in future.

Child is the most important word to be seen in the society for the future generation and development. If children are excluded from the holistic care and development we can imagine what our country is heading to. The word special only tells the significance of the topic as they are special so they need special consideration for everything. They should be taken care but not made paralysed so that they cannot empower themselves to live a life of their own.

Intellectual disability (ID), also known as general learning disability, and mental retardation (MR), is a generalized neurodevelopment disorder characterized by significantly impaired intellectual and adaptive functioning. It is defined by an IQ score under 70 in addition to deficits in two or more adaptive behaviours that affect every day, general living.

Once focused almost entirely on cognition, the definition now includes both a component relating to mental functioning and one relating to individual's functional skills in their environments. As a result of this focus on the person's abilities in practice, a person with an unusually low IQ may not be considered to have intellectual disability.

Intellectual disability is subdivided into syndrome intellectual disability, in which intellectual deficits associated with other medical and behavioural signs and symptoms are present, and non-syndrome intellectual disability, in which intellectual deficits appear without other abnormalities. Down syndrome and fragile X syndrome are examples of syndrome intellectual disabilities.

Intellectual disability affects about 2-3 percent of the general population. Seventy five to ninety percent of the affected people have mild intellectual disability. Non-syndrome or idiopathic cases account for 30-50 percent of cases. About a quarter of cases are caused by a genetic disorder, and about 5 percent of cases are inherited from a

person's parents. Cases of unknown causes affect about 95 million people as of 2013.

## Special Child

Someone with intellectual disability has limitations in two areas. These areas are:

- Intellectual functioning. Also known as IQ, this refers to a person's ability to learn, reason, make decisions and solve problems.
- Adaptive behaviours. These are skills necessary for day-to-day life, such as being able to communicate effectively, interact with others, and take care of oneself.

IQ (intelligence quotient) is measured by an IQ test. The average IQ is 100, with the majority of people scoring between 85 and 115. A person is considered intellectually disabled if he or she has an IQ of less than 70 to 75.

To measure a child's adaptive behaviours, a specialist will observe the child's skills and compare them to other children of the same age. Things that may be observed include how well the child can feed or dress himself or herself; how well the child is able to communicate with and understand others; and how the child interacts with family, friends, and other children of the same age.

Intellectual disability is thought to affect about 1 percent of the population. Of those affected, 85 percent have mild intellectual disability. This means they are just a little slower than average to learn new information or skills. With the right support, most will be able to live independently as adults.

## Signs of Special Children

There are many different signs of intellectual disability in children. Signs may appear during infancy, or they may not be noticeable until a child reaches school age. It often depends on the severity of the disability. Some of the most common signs of intellectual disability are:

- Rolling over, sitting up, crawling, or walking late
- Talking late or having trouble with talking

- Slow to master things like potty training, dressing, and feeding himself or herself
- Difficulty remembering things
- Inability to connect actions with consequences
- Behaviour problems such as explosive tantrums
- Difficulty with problem-solving or logical thinking

In children with severe or profound intellectual disability, there may be other health problems as well. These problems may include seizures, mood disorders (anxiety, autism, etc.), motor skills impairment, vision problems or hearing problems.

## Causes

Intellectual disability can result anytime when something interferes with normal brain development. However, a specific cause for intellectual disability can only be pinpointed about a third of the time.

The most common causes of intellectual disability are:

**Genetic conditions:** These include things like Down syndrome and fragile X syndrome.

**Problems during pregnancy:** Things that can interfere with foetal brain development include alcohol or drug use, malnutrition, certain infections, or preeclampsia.

**Problems during childbirth:** Intellectual disability may result if a baby is deprived of oxygen during childbirth or born extremely premature.

**Illness or injury:** Infections like meningitis, whooping cough, or the measles can lead to intellectual disability. Severe head injury, near-drowning, extreme malnutrition, infections in the brain, exposure to toxic substances such as lead, and severe neglect or abuse can also cause it.

**Unknown causes:** In two-thirds of all children who have intellectual disability, the cause is unknown.

## Prevention

Certain causes of intellectual disability are preventable. The most common of these is foetal alcohol syndrome. Pregnant women shouldn't drink alcohol. Getting proper prenatal care, taking a prenatal vitamin, and

getting vaccinated against certain infectious diseases can also lower the risk that your child will be born with intellectual disabilities. In families with a history of genetic disorders, genetic testing may be recommended before conception.

Certain tests, such as ultrasound and amniocentesis, can also be performed during pregnancy to look for problems associated with intellectual disability. Although these tests may identify problems before birth, they cannot correct them.

### **Diagnosis**

Intellectual disability may be suspected for many different reasons. If a baby has physical abnormalities that suggest a genetic or metabolic disorder, a variety of tests may be done to confirm the diagnosis. These include blood tests, urine tests, imaging tests to look for structural problems in the brain, or electroencephalogram (EEG) to look for evidence of seizures.

In children with developmental delays, the doctor will perform tests to rule out other problems, including hearing problems and certain neurological disorders. If no other cause can be found for the delays, the child will be referred for formal testing.

Three things factor into the diagnosis of intellectual disability: interviews with the parents, observation of the child, and testing of intelligence and adaptive behaviours. A child is considered intellectually disabled if he or she has deficits in both IQ and adaptive behaviours. If only one or the other is present, the child is not considered intellectually disabled.

After a diagnosis of intellectual disability is made, a team of professionals will assess the child's particular strengths and weaknesses. This helps them determine how much and what kind of support the child will need to succeed at home, in school and in the community.

### **Remedies**

Steps to help your intellectually disabled child include:

- Learn everything you can about intellectual disabilities. The more you know the better advocate you can be for your child.

- Encourage your child's independence. Let your child try new things and encourage your child to do things by himself or herself. Provide guidance when it's needed and give positive feedback when your child does something well or masters something new.
- Get your child involved in group activities. Taking an art class or participating in Scouts will help your child build social skills.
- Stay involved. By keeping in touch with your child's teachers, you'll be able to follow his or her progress and reinforce what your child is learning at school through practice at home.
- Get to know other parents of intellectually disabled children. They can be a great source of advice and emotional support

### **Special Children in India**

Children with disabilities according to UN enable, around 10 percent of the world's populations, 650 million people, live with disabilities. Women and girls with disabilities are particularly at a risk of abuse. According to a UNICEF survey, 30 percent of street youth are disabled. Some countries where IMR rates are high, mortality rates for children with disabilities is as high as 80 percent. Some suspect that children with disabilities are being purposely weeded out. 90 percent of children with disabilities worldwide do not attend school. Conflict areas find that for every one child that is killed, three are injured and permanently disabled. Children with disabilities are at a 1.7 times greater risk of being subjected to some form of violence.

According to CRIN over 150 million children worldwide have a disability. 50 percent of children with a hearing impairment and 60 percent of those with an intellectual impairment are sexually abused. There are many medical professionals who kill children with disabilities and right them of as mercy killings. 90 percent of the children with disabilities will not survive pass twenty years of age. Children with disabilities face discrimination not only in services but also in the justice system as they are often not considered credible witnesses.

In India children with disabilities mainly come under the purview of the Ministry of Social Justice and Empowerment. Some

of the issues are dealt with by the health ministry. But no single ministry has been assigned the protection of these children, which leads to varying data about occurrence of disability amongst children. In India 1.67 percent of the 0-19 population has a disability. 35.29 percent of all people living with disabilities are children. Other estimates say that India has 12 million children living with disabilities. Only 1 percent of children with disabilities have access to school and one third of most disabilities are preventable. Under-nutrition is a severe problem with children who suffer from cerebral palsy. In India 80 percent of children with disabilities will not survive past age forty.

Disability in India is still functioning in the realm of social welfare instead of a rights perspective. Teachers are not trained and schools don't have the infrastructure to deal with children with disabilities. Neither are paediatric wards of hospitals equipped to deal with them. There is not enough data on the number of children living with disabilities to allow the government to provide the necessary services. Mental health disorders account for one sixth of all health disorders yet India spends 0.83 percent of its health budget on mental health.

Census 2001 has revealed that over 21 million people in India are suffering from one or the other kind of disability. This is equivalent to 2.1 percent of the population. Among the total disabled in the country, 12.6 million are males and 9.3 million are females. Although the number of disabled are more in rural than urban areas such proportion has been reported between 57-58 percent for males and 42-43 percent for females. The disability rate (number of disabled per 100,000 populations) for the country as a whole works out to 2130. This is 2,369 in the case of males and 1,874 in the case of females.

Among the five types of disabilities on which data has been collected, disability in seeing at 48.5 percent emerges as the top category. Others in sequence are: in movement (27.9%), mental (10.3%), in speech (7.5%), and in hearing (5.8%). The disabled by sex follow a similar pattern except for that the proportion of disabled females is higher in the category in seeing and in hearing.

Across the country, the highest number of disabled has been reported from the state of Uttar Pradesh (3.6 million). Significant

numbers of disabled have also been reported from the state like Bihar (1.9 million), West Bengal (1.8 million), Tamil Nadu and Maharashtra (1.6 million each). Tamil Nadu is the only state, which has a higher number of disabled females than males. Among the states, Arunachal Pradesh has the highest proportion of disabled males (66.6%) and lowest proportion of female disabled.

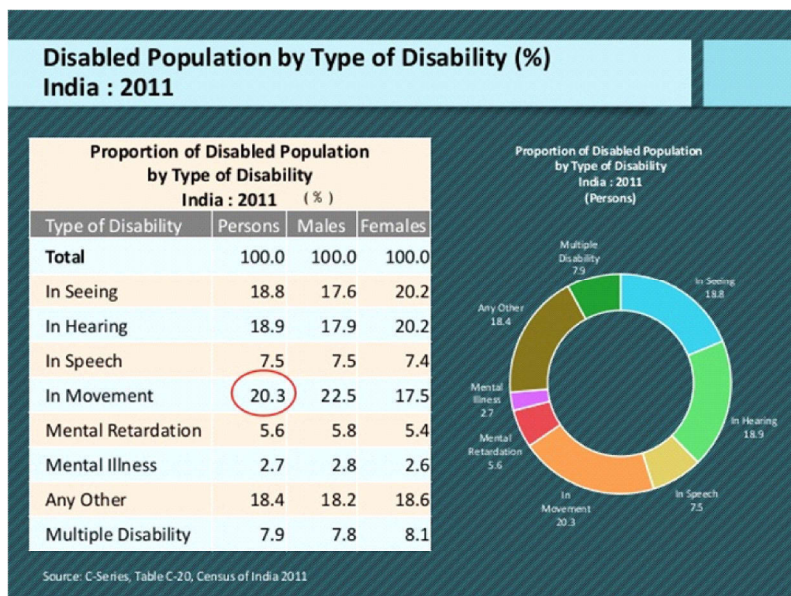
**Table 1: Number of Disabled Population and the Type of Disability**

	Population	Percentage
Total population	1,028,610,328	100.0
Total disabled population	21,906,769	2.1
Disability rate (per lakh population)	2,130	—
Type of Disability		
(a) In seeing	10,634,881	1.0
(b) In speech	1,640,868	0.2
(c) In hearing	1,261,722	0.1
(d) In movement	6,105,477	0.6
(e) Mental	2,263,821	0.2

Source: Census of India 2001.

As per Census 2011, in India, out of the 121 crore population, about 2.68 crore persons are 'disabled' which is 2.21 percent of the total population. In an era where 'inclusive development' is being emphasised as the right path towards sustainable development, focussed initiatives for the welfare of disabled persons are essential. This emphasises the need for strengthening disability statistics in the country.

There are ample reasons for developing a sound national disability statistics. Information on their socio-demographic profile is essential for welfare of disabled persons. Information about their functional status is important to identify needs since two individuals with the same impairment may face different types of difficulties in undertaking certain activities, and so have different needs that require different kinds of interventions. Functional status data is essential for determining the broader social needs of persons with disabilities, such as provision of assistive technology for use in employment or education or broader policy and laws.



Population disability data is essential for monitoring the quality and outcomes of policies for persons with disabilities. In particular, these data help to identify policy outcomes that maximize the participation of persons with disabilities in all areas of social life from transportation and communication, to participation in community life. Finally, with complete and reliable disability statistics, state agencies will have the tools for assessing the cost-effectiveness of policies for persons with disabilities, which in turn can provide the evidence to persuade governments of their ultimate benefit for all citizens.

The National Policy for Persons with Disabilities (2006) recognizes that persons with disabilities are valuable human resource for the country and seeks to create an environment that provides equal opportunities, protection of their rights and full participation in society. To facilitate the national objective, there is a need for collection, compilation and analysis of data on disability.

A number of international commitments and guidelines came into effect in the recent past targeting the welfare of the disabled persons. India is a signatory to the 'Declaration on the Full Participation

and Equality of People with Disabilities in the Asia Pacific Region' (2000). India has ratified the 'UN Convention on the rights of Persons with Disabilities' (2008). India is also a signatory to the 'Biwako Millennium Framework (2002) for action towards an inclusive, barrier free and rights based society. The 'Biwako Plus Five (2007): further efforts towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific' added the emphasis.

The Incheon Strategy to "Make the Right Deal" for Persons with Disabilities in Asia and the Pacific (2012) provides the Asian and Pacific region and the world with the first set of regionally agreed disability inclusive development goals. The Incheon strategy will enable to track progress towards improving the quality of life, and the fulfilment of the rights, of the region's persons with disability.

The Sustainable Development Goals (2015) pledges for 'leaving no one behind'. Recognizing that the dignity of the human being is fundamental, the SDGs wish to see the Goals and targets met for all nations and peoples and for all segments of society and to endeavour to reach the furthest behind first. The implementation and monitoring of these international commitments demand sound database of disabled persons.

### Challenges Faced by Parents

Children are low in every sense so they don't under go with social, family and psychological problems in the early age but the parents face various challenges to bring these children and also become solitary beings because of these children.

The below figure shows that family of an Intellectually Disable child always are in search of the meaning about what's wrong with their child because our country don't have proper guidance and education for these parents so they are seeking continuous cure acceptance and fighting against the stigma caused by the society for the child.

The figure also tells about the two questions that every parent of the intellectually disable children have their child's future and the life of their children after their deaths.

In our country's context also it's the same scenario. Parents are in trouble more than that they have fear of life of their children after them?

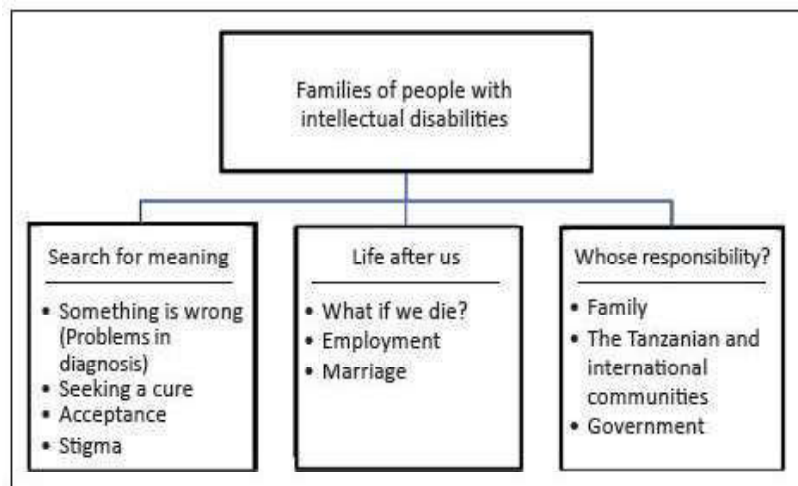


FIGURE 1: Results: Three themes of Dar es Salaam family experiences with intellectual disabilities.

### Problems Faced By the Parents

The problems faced by the parents have been seen in six different areas:

- Educational
- Psychological
- Emotional
- Social
- Family related issues
- Financial

### Educational

Education is the main tool for the development of any nation if we talk about the SDGs then we are much aware about this factor as how importance this factor is in the sense of development and construction of the nation. Lack of education regarding the intellectual

disability they are having zero knowledge about the different rights and policies in the country for their children. They do not know how to develop their children so that they can be made self dependent and self stable.

### Psychological

Parents are depressed as India till today thinks that MR children or special children are curse of God to the families. India has grown just infra-structural, growth sometimes we feel when we see these parents suffering from self pity, loneliness, self blame and frustration as being only left or excluded because they are the parents of a special child.

Lack of motivation has made the children bad from worse as these parents are now tired of taking care and helping these children in their way of development. They are anxious regarding the future of their children and the present.

### Emotional

Every person in the whole universe wants to be associated and connected to people or community as human beings are called social animals. These parents are denied from these social and emotional attachments which have caused denial, fear, guilt and anger in these parents.

### Social

Isolated from the social functions and social gathering sometimes because of the social and community pressure and sometimes because of the fear of the society these children suffer.

### Family

Parents are even seen like outsiders in the family where they live in. Husband wife relationship is disturbed because the wife gave birth to a special child. Family isolation is worse than the society because we see them every single second of our life time.

### Financial

Parents bring up children also for the future assistance for their life. For these parents, this ray of hope finishes as they diagnosis

that the child is special so the trauma of financial assistance to this child life long will always toil in their hearts and minds.

### **Suggestions for these Challenges to be sorted**

- Including parents also in the developmental procedure of their children by the NGOs or Organisations who provide care and assistance to their children.
- Educating parents about the various development needs of their children so that they can also help the children in the developmental phase in which results can be better and earlier.
- Providing knowledge to the parents regarding the various govt. policies and rights of their children.
- Motivating parents by various motivational talks and recreational spaces.
- Encouraging parents for what they are doing, what they did that can be helpful for them for the future developments of the child.
- Intervention programmes to be conducted by the Govt. organisations and NGOs for the construction and developments of the parents which would lead to the holistic development of the children directly.

### **Conclusion**

The impact of empowering the parents will eventually open immense possibilities and make a special child able and independent. As a conceptual study I found that this is the most important part that usually we as social workers exclude the special children's parents. After acquiring the knowledge from the secondary and primary data; what I would like to conclude and suggest the organisations and the practitioners to come up with modules and training materials to train the parents of special children so that they can love their child and admire the wonders what their child can do in the society. Home is called as the first place of education for a human, as it teaches us moral values, behaviour traits and holistic development to shape us as a good individual. The pursuit of making a special child capable needs to begin at home with parents; who can restore dignity and acceptance in child and making him or her inevitable for the society.

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