

# Psycho Social Problems of Parents of Special Children

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## **Introduction:**

Child is the most important word to be seen in the society for the future generation and development if they are excluded from the holistic care and development we can imagine what is our country 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 paralyzed so that they cannot empower themselves to live a life of their own.

Children with Special Healthcare Needs (CSHCN) are defined by the Maternal and Child Health Bureau as: "Those who have one or more chronic physical, developmental, behavioral, or emotional conditions and who. Also require health and related services of a type or amount beyond that required by children generally.

Stephen Hawking said; "People with disabilities are vulnerable because of the many barriers we face: attitudinal, physical, and financial. Addressing these barriers is within our reach and we have a moral duty to do so..... But most important, addressing these barriers will unlock the potential of so many people with so much to contribute to the world. Governments everywhere can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education, and employment—and never get the chance to shine."

Intellectual disability (ID), once called mental retardation, is characterized by below-average intelligence or mental ability and a lack of skills necessary for day-to-day living. People with intellectual disabilities can and do learn new skills, but they learn them more slowly. There are varying degrees of intellectual disability, from mild to profound

## **Importance:**

Children are the blessing from God. Parents are the backbone and foundation value giver for children. For special children also these points are equally needed as for any other child. Family is the place where a child learns values, morals and behavioral traits. Parents are also to be seen as important as the children of the special needs. There was a case in Bangalore few months back in which a mother killed her special child by throwing from the fourth floor of the building. Mother was a teacher. The point here to be seen is not what the society wants to tell about the incident but to take your heart and mind to the problem of ignoring the parents of the special children. Parents need education, encouragement and

awareness regarding what they are for their children. It's not easy to develop a child, so imagine how difficult it would be to develop a special child.

### **Special Children in India:**

Children with Disabilities According to UN Enable, around 10% 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% of street youth are disabled. Some countries where IMR rates are high, mortality rates for children with disabilities is as high as 80%. Some suspect that children with disabilities are being purposely weeded out. 90% 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 (Child Right Information Network) over 150 million children worldwide have a disability. 50% of children with a hearing impairment and 60% 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% 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 comes under the purview of the Ministry of Social Justice & 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% of the 0-19 population has a disability. 35.29% of all people living with disabilities are children. Other estimates say that India has 12 million children living with disabilities. Only 1% 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% of children with disabilities will not survive past age forty.

Census 2001 has revealed that over 21 million people in India as suffering from one or the other kind of disability. This is equivalent to 2.1% 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 is more in rural and urban areas. Such proportion of the disabled by sex in rural and urban areas. Such proportion has been reported between 57-58 percent for males and 42-43 percent females. The disability rate (number of disabled per 100,000 populations) for the country as 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% 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 (1.8million), 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.

As per Census 2011, in India, out of the 121 Cr population, about 2.68 Cr persons are 'disabled' which is 2.21% of the total population. In an era where 'inclusive development' is being emphasized as the right path towards sustainable development, focused initiatives for the welfare of disabled persons are essential. This emphasizes the need for strengthening disability statistics in the Country.

There are ample reasons for developing a sound national disability statistic. Information on their sociodemographic 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. 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 endeavor to reach the furthest behind first. The implementation and monitoring of these international commitments demand sound database of disabled persons.

### 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 behaviors.** 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 behaviors, 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% of the population. Of those affected, 85% 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
- Behavior 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:

Anytime something interferes with normal brain development, intellectual disability can result. 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 fetal 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.
- **None of the above**: 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 fetal 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 behaviors. A child is considered intellectually disabled if he or she has deficits in both IQ *and* adaptive behaviors. 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.

### Psycho Social Problems of Parents:

Parents are till today not considered as important part in a special child's life. Parents till today are suffering many emotional, psychological and social problems which are not seen by any one of us. Society "a large group of people who live together in an organized way, making decisions about how to do things and sharing the work that needs to be done. All the people in a country, or in several similar countries, can be referred to as a society (Definition by Cambridge Dictionary). We as so called society has to come up to include these parents also as holistically growth and development is only possible if parents are considered and accepted.



Some problems seen by the secondary data study are:

**Denial**

**Anger**

**Relationship problems in the Family**

**Fear**

**Guilt**

**Confusion**

**Rejection**

These problems are interconnected and interrelated. As till today no body dealt with these problems so these social people are not seen in any of the social gathering because of all these problems that they faced since the birth of their child or after they diagnosed that their child is special. When we say special it means these people who are the care givers of these special ones should be also considered important and special by our country but we have always labeled them with sinners, cursed people and many other worse names.

### Causes:

The main causes of these problems are **lack of social involvement, lack of education** regarding a special child, **lack of awareness** of the various rights programmers for their child, **social stigma, lack of motivation, lack of encouragement** and last but not the least **lack of knowledge regarding the development aspects of the special child**.

### Solutions:

- Assistance by other parents.
- Communication between the family and society.
- Rely on positive sources.
- Developing platforms to seek information
- Teach them not to be intimidated
- Motivational programs to be conducted.
- Various education programs to be conducted.
- Teaching parents the various skills for the development of their child.

### Conclusion:

Parents are the one to be first helped with to make a special child able and independent. As a part of my research what I would like to suggest the organizations 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 as a human as it teaches us moral values, behavior traits and holistic development to shape us as a good individual .Parents are the main pillar of that home that manifests these values on the special children . Its my plea to all the organization and people who work for the upliftment of the special children to see parents also as they see children. Holistic development is possible only when holistic care is given.

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