



ISSUES & CHALLENGES FACED BY PARENTS OF INTELLECTUALLY DISABLED CHILDREN: A STUDY OF GUJARAT STATE

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Abstract:

Intellectual disabilities present unique challenges for parents, and these challenges can be even more pronounced in rural and urban areas. In rural areas, parents encounter limited access to specialized healthcare and educational resources. The lack of trained professionals and facilities for early intervention and assessment can delay the identification and diagnosis of intellectual disabilities. This delay often hampers the child's potential for early intervention and appropriate educational support, leading to long-term setbacks in their development. Furthermore, the scarcity of awareness programs and support networks in rural areas leaves parents feeling isolated, with limited access to guidance and support from other families facing similar challenges. The stigma associated with intellectual disabilities can also be more prevalent in rural communities, further isolating families and inhibiting the acceptance and inclusion of their children. On the other hand, parents in urban areas face a different set of challenges. While they may have relatively easier access to healthcare and educational resources, they often struggle with financial constraints. Specialized services and therapies can be costly, and not all families can afford them, leading to a disparity in the quality and level of care received by intellectually disabled children. Urban areas also tend to have a faster-paced lifestyle, which can add additional stress and strain on parents. Juggling work, caregiving responsibilities, and attending therapy sessions can be overwhelming for parents, leaving them with limited time for self-care or spending quality time with their child. The pressure to meet societal expectations and norms can further exacerbate these challenges. In both rural and urban areas, parents face challenges related to the lack of inclusive educational opportunities for their intellectually disabled children. Limited access to mainstream schools and inadequate inclusion support within existing educational systems can hinder the child's social and academic growth. This can ultimately limit their potential for independence and integration into society.

Keywords: Challenges, Parents, Rural, Urban, Intellectual Disable Children.

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INTRODUCTION:

Intellectual disability is characterized by deficits in various cognitive processes, including logical reasoning, planning, problem-solving, abstract thinking, judgment, academic learning, and the ability to learn from experiences. These deficits typically become noticeable during infancy. Additionally, individuals with intellectual disabilities may struggle with adaptive functioning in areas such as social interaction, independent living, and communication skills.

In many cases, children with intellectual disabilities may also have additional conditions such as autism spectrum disorders, seizures, or cerebral palsy. Differentiating between autism and intellectual impairment can often be challenging, as many children have both. However, autism is typically characterized by social and communication impairments, such as difficulties with conversation and forming friendships. Repetitive or restricted interests and behaviors, like repetitive hand flapping, are also commonly observed in autism.

Causes of Intellectual Disability:

The causes of intellectual disability may be as follows.

Prior to Conception: A healthy, typical baby's birth is significantly influenced by the mother's age. There are certain populations who are at higher risk for chromosomal anomalies, premature births, and miscarriages. For pregnancy and the growth of the fetus, factors such as large families, addictions, nutrition, and the mother's health are crucial.

During delivery: Premature, post-maturity, multiple pregnancies, abnormal presentations, convulsions, prolapsed chord, delivery location, etc. are some of the high risk variables during delivery.

From birth up to 18 years of Age: Infants with evident congenital abnormalities, infections, seizures, nutritional deficits, cognitive delays, etc., as well as those who wail after a delayed delivery.

Psycho-social Causes: Mental retardation may also result from these. Parental psychic health has an impact on both the delivery and development of the child. The social circumstances of the parents have a big impact on the new born child. It is very challenging to raise a baby if there is no help from family or society.

Role of Family:

The family plays a crucial role in shaping an individual's identity and fostering their growth in most countries worldwide. It serves as the primary and most enduring unit of society. Even as individuals with intellectual disabilities progress through their lives, family members often provide invaluable support and assistance, making a significant impact on their well-being and development. Engaging in conversations with both individuals with intellectual disabilities and their family members can provide valuable insights into the various perspectives, perceptions, and societal reactions surrounding intellectual disability across different settings. By involving family members in these discussions, one can gain a more comprehensive understanding of the concept. Additionally, it can be beneficial for family members to be aware of the available resources and support needed to ensure a high quality of life for individuals with disabilities. This knowledge can empower families to access the necessary assistance and services for their loved ones' well-being.

There is a common saying that when one family member becomes seriously ill, it affects the entire family's well-being. This chapter specifically explores the impact of cerebral

impairment on families. In such households, parents and siblings often assume crucial roles as primary caregivers, taking on significant responsibilities to support and care for their loved one with cerebral impairment. Regardless of the specific type of impairment, the role of the family is of utmost importance in supporting individuals with intellectual disabilities. While doctors, psychologists, nurses, therapists, special educators, and other community professionals play essential roles in managing intellectual disabilities, the family's involvement is crucial.

Research indicates that parents of children with disabilities experience higher levels of stress compared to those with typically developing children, and their overall emotional well-being may also be impacted. Recognizing and addressing the emotional needs of parents and family members is important for their own well-being and for providing optimal care for individuals with intellectual disabilities. Parents of children with intellectual disabilities may experience a range of emotions, including depression, anxiety, feelings of hopelessness, guilt, and a sense of failure. It is common for parents to report feeling less confident in their parenting skills and a potential impact on their overall marital happiness. These emotions can be attributed to the unique challenges and added responsibilities that come with caring for a child with special needs. It is important for parents to seek support from professionals, support groups, and their community to address these feelings and ensure their own emotional well-being.

Challenges in the Family:

When a child has a mental disability, it poses three challenges for the household. The first obstacle involves addressing the practical aspects. The family needs to understand the origins of the mental disability, its prognosis, any potential complications, the daily routines and schedules, and the reasons behind therapy. The second challenge is to adapt the child's everyday life to accommodate the disability both in the present and in the future. This requires the family to make adjustments and modifications to the child's activities, taking into account the restrictions imposed by the treatment and the disability itself. The second challenge revolves around the mental aspects of the disability. Mental illness can present behavioral challenges that require attention. In order to allow the family to fulfil their other important responsibilities, it becomes necessary to integrate rehabilitation routines, hospital visits, and special educational programs into the family's activities. It's important to acknowledge that the child's abilities to perform certain tasks may change over time, and the family should remain observant and provide assistance when needed. This flexibility and support are vital to ensure the well-being and progress of the child with a mental disability.

Institutes Working in the Field of Disability:

Under MSJE, there are seven National Institutes dedicated to the study of disabilities. These institutions work on developing human resources in the area of impairments, offering assistance to those who need rehabilitation, and conducting research and development. 80 classes lasting a year or longer are offered by these National Institutes, including their regional centres and combined regional centers.

The seven National Institutes are:-

1. National Institute for the Visually Handicapped (NIVH), Dehradun
2. National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai.
3. Swami Vivekanand National Institute for the Rehabilitation, Training and Research (SVNIRTAR), Cuttack.
4. National Institute for the Hearing Handicapped (NIHH), Mumbai.
5. National Institute for the Mentally Handicapped (NIMH), Secunderabad.
6. National Institute for the Orthopaedically Handicapped (NIOH), Kolkata
7. Pt. Deendayal Upadhyaya Institute for the Physically Handicapped (PDUIPH), New Delhi. H5

RESEARCH DESIGN:

This research study utilizes a descriptive research design comprising both qualitative and quantitative methods. The study focuses on parents of children with intellectual disabilities residing in both rural and urban areas of Vadodara district in Gujarat state. The target population for the study includes parents of disabled children. A total of 66 parents from rural and urban areas of Vadodara district were selected using the snowball sampling method.

To collect data for the study, both primary and secondary methods were employed. Primary data collection involved directly gathering information from the parents of children with intellectual disabilities through interviews, surveys, or observations. Secondary data, on the other hand, refers to information obtained from existing sources such as books, articles, or official records.

For the analysis and interpretation of the collected data, a simple percentage method was utilized. This involves calculating the proportion or percentage of responses or occurrences related to specific variables or themes. By using this method, the researchers were able to summarize and understand the data in a straightforward manner.

Data Analysis & Interpretation.

RESULT & DISCUSSION:

The major description of the result is presented below.

Table: 1 Information related to awareness about Child's problem

No=66

Awareness about Child's problem	Rural		Urban	
	Frequency	Percentage (%)	Frequency	Percentage (%)
Slightly Aware	18	27.2	11	16.7
Moderately Aware	07	10.6	15	22.7

Extremely Aware	05	7.6	10	15.2
Total	30	45.4	36	54.6

It's crucial to be conscious of a child's problems. Parents can properly care for their intellectual disabled children if they are adequately informed about the issue. Children with intellectual disabilities must endure more suffering if they are unaware.

From the above table it can be seen that in Rural areas 27.2% (n=18) parents are slightly aware about their child's problems, 10.6% (n=7) parents are moderately aware about their child's problem and 7.6 (n=5) parents are extremely aware about child's problem.

From Urban areas 16.7% (n=11) parents are slightly aware about their child's problem, 22.7% (n=15) parents are moderately aware about their child's problem and 15.2% (n=10) parents are extremely aware about their child's problem.

MF: It can be concluded that majority of parents are slightly aware about their child's problem in Rural community (27.2%) and moderately aware in Urban (22.7%) areas.

Table: 2 Information related to Cooperation and Understanding from Family

No=66

Cooperation and Understanding from Family	Rural		Urban	
	Frequency	Percentage (%)	Frequency	Percentage (%)
Rarely	02	3.0	05	7.6
Sometime	06	9.1	06	9.1
Always	22	33.3	25	37.9
Total	30	45.4	36	54.9

Cooperative and supportive family will result the faster growth and development of intellectually disabled children. Looking in to this the researcher analyzed that from the above table and figure that in Rural area 3.0% (n=2) parents said they are getting rare cooperation and understanding from family, 9.1% (n=6) parents said they are sometime getting cooperation and understanding from family and 33.3% (n=22) parents said they are always getting cooperation and understanding from family.

In Urban area 7.6% (n=5) parents said they are getting rare cooperation and understanding from family, 9.1% (n=6) parents said they are sometime getting cooperation and understanding from family and 37.9% (n=25) parents said they are always getting cooperation and understanding from family.

MF: Therefore, it can be concluded that majority of parents are always getting cooperation and understanding from the family in both Rural (33.3%) and Urban (37.9%) areas.

Table: 3 Information related to Parent's Regular participation in Social Activities

No=66

Parent's Regular participation in Social Activities	Rural		Urban	
	Frequency	Percentage (%)	Frequency	Percentage (%)
Yes	17	25.7	33	50.0
No	13	19.7	03	4.6
Total	30	45.4	36	54.6

Regular participation in social activities will give mental and physical refreshment to the parents of intellectually disabled children. Looking in to this it can be analyzed that in Rural areas 25.7% (n=17) parents said that they are regularly participating in social activities, 19.7% (n=13) parents said that they are not participating social activities.

When we are talking about Urban areas it can be said that 50% (n=33) parents said that they are regularly participating in social activities, 4.6% (n=3) parents said that they are not participating social activities.

MF: Thus, it can be concluded that majority of parents are regularly participating in social activities in both rural (25.7%) and urban (50.0%) Community.

Table: 4 Information related behavior of society for intellectually disabled children

No=66

Behavior of society for intellectually disabled children	Rural		Urban	
	Frequency	Percentage (%)	Frequency	Percentage (%)
Good	08	12.1	07	10.6
Cooperative	12	18.2	22	33.3
Medium	03	4.5	04	6.1
Ignoring	07	10.6	03	4.6
Total	30	45.4	36	54.6

Society where we are living is next family for each and every human being. They are always there in all ups and down of any family. From the above table and figure it can be analyzed that in Rural Community 12.1% (n=8) parents said the members of the society are behaving properly with their family followed by 18.2% (n=12) parents said that the members of the society are cooperative followed by 4.5% (n=3) parents said that the members of the society are normal in behavior that means they do not mind if they have intellectual disable child

followed by 10.6% (n=7) parents said that the members of the society are ignoring them. While in Urban Community 10.6% (n=7) parents said the members of the society are behaving properly with their family followed by 33.3% (n=22) parents said that the members of the society are cooperative followed by 6.1% (n=4) parents said that the members of the society are normal in behavior that means they do not mind if they have intellectual disabled child followed by 4.6% (n=3) parents said that the members of the society are ignoring them.

MF: Hence, it can be concluded that majority of parents from rural (18.2%) and urban (33.3%) Community said that the members of the society are cooperative towards their intellectually disabled child.

Table: 5 Information related to Parents of intellectually disabled children are getting any help from the society

No=66

Parents of intellectually disabled children are getting any help from the society	Rural		Urban	
	Frequency	Percentage (%)	Frequency	Percentage (%)
Never	2	3.0	03	4.6
Rarely	07	10.6	06	9.1
Sometime	05	7.6	06	9.1
Always	16	24.2	21	31.8
Total	30	45.4	36	54.6

Many people from the society are helping the family of intellectually disabled children as the expenses of intellectually disabled children are more as compare to normal children. So many families are not capable to bear with the expenses of intellectually disabled children. Hence the researched has identified that that in Rural areas 3.0% (n=2) parents are never getting any help from the society followed by 10.6% (n=7) parents are rarely getting help from the society followed by 7.6% (n=5) parents are sometime getting help from the society followed by 24.2% (n=16) parents are always getting help from the society.

From Urban areas, 4.6% (n=3) parents are never getting any help from the society followed by 9.1% (n=6) parents are rarely getting help from the society followed by 9.1% (n=6) parents are sometime getting help from the society followed by 31.8% (n=21) parents are always getting help from the society.

MF: Hence, it can be concluded that majority of parents from both rural (24.2%) and urban (31.8%) areas are always getting help from the society.

Table: 6 Information related to Income of family per month

No=66

Income of family per month	Rural		Urban	
	Frequency	Percentage (%)	Frequency	Percentage (%)
1,000 TO 10,000	00	0	00	0
11,000 TO 20,000	04	6.1	02	3.0
21,000 TO 30,000	07	10.6	05	7.6
31,000 TO 40,000	07	10.6	09	13.6
41,000 TO 50,000	09	13.6	15	22.8
More than 50,000	03	4.5	05	7.6
Total	30	45.4	36	54.6

According to the aforementioned table and graph, 6.1% (n=4) of parents in rural areas reported that their family's monthly income is between Rs. 11000 and 20000, 10.6% (n=7) of parents reported that their family's monthly income is between Rs. 21000 and 30000, 10.6% (n=7) of parents reported that their family's monthly income is between Rs. 31000 and 40000, 13.6% (n=9) of parents reported that their family's monthly income is between Rs. 41000.

In urban settings 3.0% (n=2) of parents reported that their family's monthly income is between Rs. 11000 and 20000, 7.6% (n=5) of parents reported that it is between Rs. 21000 and 30000, 13.6% (n=9) of parents reported that it is between Rs. 31000 and 40000, 22.8% (n=15) of parents reported that it is between Rs. 41000 and 50000, and 7.6% (n=5) of parents reported that it is above Rs. 50000.

MF: Therefore, it can be concluded that majority families are earning 41000 to 50000 Rs. per month in both rural (13.6%) and urban (22.8%) areas.

Table: 7 Information related to monthly expenses of intellectually disabled children

No=66

Monthly expenses of intellectually disabled children	Rural		Urban	
	Frequency	Percentage (%)	Frequency	Percentage (%)
1,000 TO 10,000	02	3.0	00	0
11,000 TO 20,000	09	13.6	11	16.7
21,000 TO 30,000	13	19.7	09	13.6
31,000 TO 40,000	04	6.1	07	10.6
41,000 TO 50,000	02	3.0	04	6.1

More than 50,000	0	0	05	7.6
Total	30	45.4	36	54.6

Information related to monthly expenses of intellectually disabled child shows that in Rural areas 3.0% (n=2) parents said that monthly expenses of their intellectual disable child are 1000 to 10000 Rs. per month followed by 13.6% (n=9) parents said that monthly expenses of their intellectual disable child are 11000 to 20000 Rs. per month followed by 19.7% (n=13) parents said that monthly expenses of their intellectual disable child are 21000 to 30000 Rs. per month followed by 6.1% (n=4) parents said that monthly expenses of their intellectual disable child are 21000 to 30000 Rs. per month followed by 3.0% (n=2) parents said that monthly expenses of their intellectual disable child are 21000 to 30000 Rs. per month.

In Urban areas 16.7% (n=11) parents said that monthly expenses of their intellectual disable child are 11000 to 20000 Rs. per month followed by 13.6% (n=9) parents said that monthly expenses of their intellectual disable child are 21000 to 30000 Rs. per month followed by 10.6% (n=7) parents said that monthly expenses of their intellectual disable child are 21000 to 30000 Rs. per month followed by 6.1% (n=4) parents said that monthly expenses of their intellectual disable child are 21000 to 30000 Rs. per month followed by 7.6% (n=5) parents said that monthly expenses of their intellectual disable child are more than 50000 Rs. per month.

MF: Thus, it can be concluded that majority of parents of rural (19.7%) areas said that the monthly expense behind their intellectual child is 21000 to 30000 Rs. per month and in urban (16.7%) areas the monthly expense behind their intellectual child is 11000 to 20000 Rs. per month

Table: 8 Information related to getting any help from government

No=66

Getting any help from government	Rural		Urban	
	Frequency	Percentage (%)	Frequency	Percentage (%)
Yes	21	31.8	20	30.3
No	09	13.6	16	24.3
Total	30	45.4	36	54.6

In rural areas, 31.8% (n=21) of parents reported getting government assistance, while 13.6% (n=9) of parents said they received no help from the government, according to the aforementioned chart.

In a city, 30.3% of parents (n = 20) said they received government aid, while 24.3% (n = 16) said they didn't.

MF: Thus, it can be concluded that majority of parents are getting help from government both in rural (31.8%) and urban (30.3%) community.

Table: 9 showing how much do you want your child to be educated

No=66

HOW MUCH DO YOU WANT YOUR CHILD TO BE EDUCATED	Rural		Urban	
	Frequency	Percentage(%)	Frequency	Percentage(%)
Till the child wish	08	12.1	09	13.6
S.S.C	02	3.0	05	7.6
Read and write	19	28.8	19	28.8
Other	01	1.5	03	4.6
Total	30	45.4	36	54.6

Every child is special for their parents. They want to make them successful and for their success parents will do whatever is needed. So here in this table and chart it can be identified that Rural areas 12.1% (n=8) parents said that they want to fulfill the wishes of their child in education, 3.0% (n=2) parents said that they want to educate their child till S.S.C, 28.8% (n=19) parents want to educate their child till he/she can read and write, 1.5% (n=1) parents are thinking some other things about their child's education.

In Urban areas 13.6% (n=9) parents said that they want to fulfill the wishes of their child in education, 7.6% (n=5) parents said that they want to educate their child till S.S.C, 28.8% (n=19) parents wants to educate their child till he/she can read and write, 4.6% (n=3) parents are thinking some other things about their child's education.

MF: Hence, it can be concluded that majority of parents want to educate their child till he/she can read and write.

Table: 10 showing what you think about your child's future

No=66

WHAT YOU THINK ABOUT YOUR CHILD'S FUTURE	Rural		Urban	
	Frequency	Percentage(%)	Frequency	Percentage(%)
He/She Will be an example for Society	19	28.2	28	43.0
He/She is Burden on us	08	12.1	03	4.6
Worried about future	03	4.5	05	7.6
Total	30	44.8	36	55.2

Information related to child's future shows that in Rural areas 28.2% (n=19) parents said that they want to set an example in the society by making future of their intellectually disabled child, 12.1% (n=8) parents said that their intellectually disabled child is burden on them, 4.5% (n=3) parents said that they are worried about the future of their intellectually disabled child.

In Urban areas 43.0% (n=28) parents said that they want to set an example in the society by making future of their intellectually disabled child, 4.6% (n=3) parents said that their intellectually disabled child is burden on them, 7.6% (n=5) parents said that they are worried about the future of their intellectually disabled child.

MF: Therefore, it can be concluded that majority of parents wants to send an example in the society by growing and building future of their intellectually disabled child.

Major Findings:

From the above study the major findings are as follow.

1. In rural communities, around 27.2% of parents have some level of awareness regarding their child's issues, while in urban areas, this awareness increases to about 22.7% of parents.
2. In both Rural (33.3%) and Urban (37.9%) areas, most parents experience cooperation and understanding from their family members.
3. In both rural (25.7%) and urban (50.0%) communities, a significant number of parents actively engage in social activities on a regular basis.
4. According to the majority of parents from both rural (18.2%) and urban (33.3%) communities, they perceive that the society members show cooperation towards their child with intellectual disabilities.
5. The majority of parents in both rural (24.2%) and urban (31.8%) areas consistently receive assistance from the community.
6. In both rural (13.6%) and urban (22.8%) areas, the majority of families have a monthly income ranging from 41000 to 50000 Rs.
7. The majority of parents in rural areas (19.7%) reported that they spend between 21000 to 30000 Rs. per month on their intellectually disabled child, while in urban areas (16.7%), the majority of parents spend between 11000 to 20000 Rs. per month on their intellectually disabled child.
8. In both rural (31.8%) and urban (30.3%) communities, the majority of parents receive assistance from the government.
9. The majority of parents aspire to provide education for their child until they are capable of reading and writing.
10. The majority of parents aim to set an inspiring example in society by nurturing and shaping the future of their intellectually disabled child.

Suggestions and Recommendation

For parents of intellectually disabled children, who have a monthly expense ranging from 21000 to 30000 Rs. in rural areas and 11000 to 20000 Rs. in urban areas, it may be helpful to explore financial assistance programs or support groups specifically designed for families with special needs children. These resources can help alleviate some of the financial burden and provide guidance on managing expenses effectively.

Since the majority of parents in both rural and urban areas are receiving government assistance, it would be beneficial to stay informed about available government programs, grants, or initiatives that cater to the needs of intellectually disabled children. Regularly checking official websites or contacting local government agencies can provide valuable information about financial aid, educational support, and other resources.

To fulfill the desire of parents who want to educate their child until they can read and write, it is important to explore inclusive education options available in their respective communities. Engaging with special education schools, inclusive classrooms, or seeking support from educational professionals can help create a suitable learning environment for the child's intellectual development.

For parents who aspire to set an example in society by nurturing their intellectually disabled child and building their future, it is essential to prioritize early intervention programs, therapies, and specialized services. Collaborating with local disability organizations, support groups, or seeking guidance from professionals can ensure access to comprehensive resources and opportunities for the child's overall growth and development.

Conclusion:

Supporting individuals with intellectual disabilities is a significant challenge for parents, family members, and society as a whole. It is crucial for everyone in the community to collaborate in order to foster the development and well-being of these children. Parents should seek education and information about intellectual disabilities, while the government needs to implement new programs and initiatives to assist them. Additionally, organizations and special schools should prioritize hiring trained teachers who can provide the best support for individuals with intellectual disabilities. Parents can explore various methods and techniques to effectively train and support their intellectually disabled children. There are numerous resources available, including specialized books, online courses, and support groups that can provide valuable insights and guidance. By being open to different approaches, parents can tailor their training methods to suit their child's unique needs and abilities. It's all about finding the most suitable strategies that can help their children thrive and reach their full potential.

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