

# Mother's involvement and caring towards disabled children-A study in Guwahati city, Assam

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**Abstract:** This study examines how the mothers of disabled children involve and care for their children with their day-to-day lives. The perception towards the disabled children by the mother is a complex range of feelings, viz. love, joy, sadness, and loss. When a child is first diagnosed with symptoms of being disabled, their goals and dreams for the future have been lost. Strong support systems from the other members of family can result in more constructive attitudes and coping mechanisms, whereas a lack of support can exacerbate stress and feelings of inadequacy. This paper hence aims to investigate the involvement and the caring pattern of mothers with their disabled children in Guwahati City. The investigator has taken 30 mothers as samples in different categories of disabled children for the study on the basis of the purposive sampling technique. The questionnaire for the mothers has been used as the tool of the study. The findings highlight the profound roles of mothers in involvement and caring for their disabled children with multifaceted challenges.

**Key Words:** Disability, Care-giving, Involvement, Autistic, Down syndrome, Intellectual disability, Anxiety disorders, Depression, Impaired mobility

## INTRODUCTION

A "disability" is a physical or mental impairment that restricts a person's capacity to carry out everyday duties including walking, talking, seeing, hearing, and other activities. People of all ages and backgrounds may be impacted by disabilities, which can result from a number of causes. Physical impairments are conditions that impact the structure or function of the body, including:-----Impaired mobility (e.g., muscular dystrophy, spinal cord injury)limitations of the senses (such as blindness or deafness) ,Chronic conditions (such as diabetes and arthritis).Mental health disabilities are illnesses that impact a person's mental health, including:----Mental diseases (such as anxiety disorders and depression) Neuro developmental disorders, such as -attention deficit hyperactivity disorder and autism spectrum disorder. Conditions that impact a person's cognitive, motor, or social development are known

as developmental disabilities. These conditions include:--Intellectual disability, Palsy in the brain ,Down syndrome .Conditions that impair a person's capacity to notice their surroundings include sensory impairments like ----.Visual problems, such as low vision or blindness ,Deafness and hard of hearing, Disorders of auditory processing.

To meet the physical, emotional, and developmental needs of a child, mothers of disabled children provides direct and hands-on assistance on daily basis such as in feeding, bathing, dressing, and assisting with mobility, in managing medical needs (medication, therapy, doctor visits) ,in providing emotional comfort and psychological support as well as .maintaining routines and ensuring safety. Care giving is also essential for the child's survival and quality of life, especially for the children with disabilities who require specialized care. The involvement of mothers towards their disabled children is a matter of concern. Their engagement is not only confined with the attending school meetings, therapy sessions, or medical consultations but also supporting the child's education by helping with homework. They also encourage their child's rights in social or institutional settings. They also encourage the child's participation in social and recreational activities.

## Place of disabilities in society

There are many different viewpoints and experiences on the complicated and multidimensional topic of disabilities' place in society. People with disabilities have frequently been excluded from society, ostracized, and marginalized throughout history. As a result, there is a lack of comprehension, acceptance, and inclusivity. People with disabilities continue to be viewed negatively by many, who see them as "broken" or "less capable." These viewpoints have the potential to sustain exclusion and prejudice. People with impairments may find it challenging to

fully participate in society due to societal constraints, physical obstacles, communication obstacles, information obstacles, attitude barriers like stigma, ignorance, and negative stereotypes.

#### Need of the study---

For a mother, every child is a child without thinking anything. Mothers use a variety of coping mechanisms to manage the difficulties of raising a disabled child. This may entail going to therapy, participating in support groups, and emphasizing self-care. Like all other children, disabled children have the same human rights, such as the right to life, dignity, and access to social services, healthcare, and education. All human beings, regardless of their abilities or impairments, have intrinsic worth and should be treated with dignity, empathy, and understanding. With proper care and support by the parents specially by the mothers, children with disabilities can grow and develop in the same ways as other child even though they might need extra help and accommodations, empathy and compassion. In schools, communities, and society at large, now-days, it has been fostered inclusion and equality by offering assistance and accommodations to children with disabilities. Giving disadvantaged children the chance to socialize, form friendships, and participate in activities they can enjoy, help them to avoid social isolation. Providing care for children with disabilities fosters more understanding, acceptance, and inclusivity, which benefits society as a whole.

The emotional and psychological bonds that mothers have with their disabled child inspire them to support and care for them. Even in the face of difficulties, mothers have a strong sense of duty to look after their disabled children. Mothers of disabled always feel stress, anxiety along with the depression. They always feel worrying about their future. Due to lack of socio-economic support, mothers always feel of guilt, stigma. Mothers might find a sense of fulfilment and purpose in their lives by providing care for a disabled child. They may feel more fulfilled and satisfied when they are providing healthcare, special education for a disabled child though they are taking multiple roles for upbringing their disabled child. Sometimes, it is seen that their disabled children make their mothers as stronger character and independent character who are negotiating, managing and approaching their

daily lifestyles. Hence, it is necessary to study the types of involvement and caring of mothers towards their disabled children.

#### Statement of the problem-----

For above the reasons, the investigator has stated the problem "Mother's involvement and caring towards disabled children-A study in Guwahati city, Assam."

#### Objectives of the study---

1. To investigate the involvement of mothers to their disabled children in Guwahati
2. To find out the caring pattern undertaken by the mothers towards disabled children.

#### Hypothesis of the study

Since the study is exploratory in nature, there is no need to frame the hypothesis for the study.

#### Methodology of the study

Descriptive study method will be used to analysis the study.

#### Population and sample of the study

The populations for the study are the mothers of the disabled children Autistic (8nos.), Down syndrome (5nos.), Intellectual disability (10nos.), Anxiety disorders (2 nos.), Depression (2 nos.), Impaired mobility (3 nos.) who are living in Guwahati city. Intellectual disability

The investigator has taken all the 30 nos. mothers from 6 nos. groups of disability as the sample for the study on the basis of saturated sampling technique to achieve the objectives.

#### Tools of the study

The investigator will take interview for the mothers whose children are found in disabled category.

#### Delimitations of the study—

1. The study is delimited to the involvements and care of mothers of six categories (Autistic, Down syndrome, Intellectual disability i.e. slow learner, Anxiety, Depression and Intellectual disability) disabled children.
2. The study is delimited to Guwahati city, of Assam.

#### ANALYSIS OF THE OBJECTIVES

Table 1 General information about the disabled children

Particulars	Options	Age of the child in years	Disability identified at the age of	No. of mothers
Disability type	Autism	3-6yrs	4yrs	2
	Anxiety	11-15yrs	14yrs	8
	Depression	12-16yrs	13yrs	2
	Down syndrome	1-2 yrs	2yrs	5
	Impaired Mobility	2-7 yrs	5 yrs	3
	Slow Learner	4-9 yrs	5yrs	10

Objective no .1: To investigate the involvement of mothers to their disabled children in Guwahati  
 To fulfill the objective, the investigator has taken the responses of the disabled children’s mothers regarding their involvement which is shown in the following table-----

Types of disabilities	Patterns of involvement of mothers	Responses of mothers	
		Yes	No
Autism	Emotional support	100	0
	Medical management	95	05
	Educational Support	70	30
	Advocacy	67	33
	Ensures sibling support	45	55
Anxiety	Adjusting with Behavioural strategy	81	19
	Emotional support	93	07
	Creating coping mechanism(as role model)	72	28
	Creates balanced lifestyles	86	14
	Social support	62	28
	Education support	91	09
	Careful about the needs	87	13
	Preparation of routine	48	52
Depression	Caring for child’s needs	91	9
	Patterns of interaction	63	37
	Monitoring & Understanding the behaviour	95	05
	Creating healthy lifestyle habits	91	09
	Aware of their mental health	94	06
	Sharing	90	10
Down syndrome	Emotional support	100	0
	Education	94	06
	Collaboration with Professional bodies	97	03
	Helps in social etiquette	92	08
	Seeks social network	27	73
	Fostering relationship among family members	90	10
Impaired Mobility	Emotional support & Bonding	100	0
	Guides in routine work & social skills	100	0
	Using adaptive technologies related to mobility	42	58
	Involves for providing, self care ,	100	0
	Education care	39	61

Slow Learner	Active involvement in education	94	06
	Gives positive reinforcement	93	07
	Attends regular parents' meeting	97	03
	Manages stress	74	26
	Analysis their behavior	85	15

With respect to the involvement of mothers, it is summarized as-----

All the mothers opined that their child's need for emotional support is wearing them out; they are good at getting services for child; they spend more of time in arranging and providing social activities for their child; and they are good at providing for child's social activities. In Autistic type disabled children, 100% mothers are involved emotionally, 95% and 70% mothers are involved in medical and education support whereas 67% are involved in advocacy for networking whereas and 45% mothers involve her other children for caring their disabled sibling. With the Anxiety type disabled children, 81% and 93% mothers are involved in their child's behavior and emotion. They help the child develop coping strategies, such as deep breathing, mindfulness, or cognitive reframing, to manage anxious thought. They provide reassurance, comfort, and a safe space for the child to express their feelings without fear of judgment. 72% mothers act as a role model in front of their children. Mothers teach problem-solving skills, allowing the child to take manageable risks, and promoting self-efficacy to build resilience. They manage their own stress and anxiety to serve as a positive role model, ensuring they can effectively support their child without burnout. 86% mothers are involved in balancing the lifestyles of their anxious children. 62% and 91% mothers are fully involved for helping their anxious children to get social support as well as education. They try to facilitate healthy social interactions, encouraging friendships, and helping the child develop confidence in social settings. The mothers communicate with teachers

Objective no.2: To find out the caring pattern undertaken by the mothers towards disabled children

With respect to the care of mothers towards the disabled children it is found that

Caring Pattern	Responses	
	Yes	No
Emotional Support and Bonding	89	11
Physical Care and Assistance	77	23
Educational and Cognitive Support	78	22
Socialization and Inclusion Efforts	55	45
Psychological and Behavioral Guidance	63	37
Advocacy and Networking	59	41
Financial and Resource Management	47	53

and school counselors to ensure that their children can get academic supportive environment. 87% mothers are very careful about the various needs of their children whereas 48% mothers are involved with the preparation of the daily routine work of their anxious children. They try to establish a predictable routine to create a sense of stability and security, which can help reduce anxiety. The mothers of Depressed children are very much involved in different patterns of involvement. 91% mothers take care in everything whereas only 63% mothers interact with the children who are in depression mood. On the other hand, above 90% mothers are involved in monitoring, understanding, creating healthy habits lifestyles. They are also aware about the mental status of their depressed children. 100% mothers are involved emotionally with their Down Syndrome children. Above 90% mothers of this category are involved in providing education, talking with various professional bodies about the problem of their children, helping to develop social etiquette and fostering relationship with other members of the family. Only 27% mothers involve with the social etiquette of their down syndrome children whereas 100% Mothers are involved in emotion, routine work, providing social work, self-care whereas 39% mothers are in providing education and only 42% mothers help the disabled children to use adaptive technology. The above 100% mothers of (Slow Learns) whereas Above 90%) are also involved in providing education, regular parent meeting, of street children whereas 74% mothers do not know how to manage the stress and 85% mothers are concerned in analysis of their children's behavior.

It is found that the caring patterns of disabled children by their mothers vary based on the child's specific needs, the family's socio-economic conditions, cultural factors, and available support systems. 89 % mothers play a crucial role in providing emotional reassurance, love, and acceptance to their children with their emotional support and bonding. Depending on the type of disability, 77 % mothers assist with daily activities such as feeding, bathing, dressing, and mobility. 78% mothers engage in home-based learning activities or seek special education services to enhance their child's intellectual development. They also collaborate with teachers and therapists to adapt learning methods for their child. 55 % mothers encourage their disabled children for social interactions by facilitating play dates, enrolling children in group activities, and advocating for inclusive education. They work to build awareness and acceptance of their child's condition within the community. 63 % mothers help their disabled children to develop coping mechanisms, self-regulation skills, and self-esteem. They use structured routines, positive reinforcement, and patience to support their child's emotional well-being. 59% mothers become active for disability rights, seeking better healthcare, education, and social inclusion policies. They join support groups or community organizations to share experiences and gain knowledge for the upliftment of their disabled children. Only 47 % mothers handle financial planning for medical expenses, special equipment, and therapy sessions.

#### CONCLUSION

Mothers' attitudes about their impaired children are complex and impacted by a variety of situations. Despite various types of challenges faced by mothers with the journey like emotional stress, exhaustion, and burnout due to continuous care giving, lack of social support, financial strain in medical and therapy costs etc. mothers manage to adjust, support, and acknowledge the individuality and skills of their children. As time passes, many mothers adjust and discover fresh ways to honor their child's accomplishments, encouraging resilience and happiness. Mothers of disabled children play a vital role in their child's physical, emotional, and social development. While the mothers' involvement and care giving journey with their disabled children are demanding, their

unconditional love and dedication significantly enhance the child's quality of life. More societal support, policies, and awareness can ease their burden and help create an inclusive environment for children with disabilities. Mothers' care giving ensures the disabled child's to meet their basic needs, while involvement enriches their growth and development.

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