A Study on

The socio-economic and cultural challenges faced by the caregivers of children with Autism Spectrum Disorder and Cerebral Palsy in Guwahati, Assam.

A dissertation submitted to the Department of Social Work for the partial fulfilment of the requirement for the award of the degree of Master of Social Work

Submitted to:

Department of Social Work

MSSV, Guwahati Unit

Submitted by:

Purbashree Devi

MSW 4th Semester

Roll No: MSW-09/23

Registration No: MSSV- 0023-008-001449

Session: 2023-25

Guided by:

Dr. Deepshikha Carpenter

HOD(i/c) & Assistant Professor

Department of Social Work

Mahapurusha Srimanta Sankaradeva Viswavidyalaya

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মহাপুৰুষ শ্ৰীমন্ত শঙ্কৰদেৱ বিশ্ববিদ্যালয়
MAHAPURUSHA SRIMANTA SANKARADEVA VISWAVIDYALAYA
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GUWAHATI CONSTITUENT UNIT
Sankari Sanskriti Kendra, Rupnagar, Bhangagarh, Guwahati-781032, Assam

Department of Social Work

CERTIFICATE

I have the pleasure to certify that **Miss Purbashree Devi** , MSW 4th Semester student bearing Roll No: **MSW-09/23** with Registration No: **MSSV-0023-008-001449** of **2023**, MSSV has successfully completed the dissertation entitled **"A study on the socio-economic challenges faced by the caregivers of children with Autism Spectrum Disorder and Cerebral Palsy in Guwahati, Assam"**. She has made a successful completion of this research by her own.

I wish her bright future.

09/06/25
Dr. Deepshikha Carpenter)
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Department of Social Work

CERTIFICATE FROM SUPERVISOR

This is to certify that **Miss Purbashree Devi,** student of MSW 4th Semester bearing Roll No: **MSW-09/23** with Registration No: **MSSV-0023-008-001449 of 2023**, MSSV, Guwahati Unit has successfully carried out her dissertation entitled **"A study on the socio-economic challenges faced by the caregivers of children with Autism Spectrum Disorder and Cerebral Palsy in Guwahati, Assam"**, as a researcher under my supervision and guidance for the partial fulfilment of the requirement for the award of the degree of **MASTER OF SOCIAL WORK (MSW).**

The work reported in this research has not been submitted elsewhere and the facts presented here are true to the best of my knowledge.

I wish her all the very best for her future endeavour.

(Dr. Deepshikha Carpenter)
HOD (i/c)
Department of Social Work
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Place: MSSV, Guwahati unit
Date: 09/06/25

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DECLARATION OF ORIGINALITY

I, Purbashree Devi, student of 4th semester, Department of Social Work (Roll No. MSW 09/23 and Registration No. MSSV-0023-008-001449), Guwahati Unit, Mahapurusha Srimanta Sankaradeva Viswavidyalaya (MSSV), Nagaon do hereby declare that this dissertation, entitled **" A study on the socio-economic challenges faced by the caregivers of children with Autism Spectrum Disorder and Cerebral Palsy in Guwahati, Assam "** is an original work of mine and is the result of my own intellectual efforts, under the guidance of Dr. Deepshikha Carpenter, Head of the Department (i/c), Department of Social Work, MSSV, Guwahati Unit.

I affirm that this research study has not been previously submitted for academic credit or publication, nor has it been copied or plagiarized in whole or in part from any other source.

I confirm that all data collected for the research study has been obtained through ethical means, and that all participants involved in the study were informed about the purpose and nature of the research, and gave their informed consent to participate.

Purbashree Devi

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This research is dedicated to the caregivers who continue to carry immense responsibility with strength and love, and to the children who inspire us to create a more inclusive and compassionate world.

ABBREVIATION

ASD	Autism Spectrum Disorder
CP	Cerebral Palsy
RPwD	Rights of Person with Disability
WHO	World Health Organization
NIMH	National Institute of Mental Health
CDC	Centres for Disease Control and Prevention
NGO	Non-Profit Organization
CRC:	Composite Regional Centre
GMCH	Guwahati Medical College and Hospital
LLU	Leisure Learning Unit
AAC	Augmentative and Alternative Communication

ABSTRACT

The daily challenges faced by parents of children in Guwahati, Assam, with conditions such as Cerebral Palsy (CP) and Autism Spectrum Disorder (ASD) are investigated in this study. Through interviews with 20 caregivers including parents, teachers, and institutional caretakers, the research uncovers the physical, emotional, and financial difficulties they encounter. Key challenges include a lack of training, limited access to therapy resources, societal stigma, and deeply rooted gender inequalities that place most caregiving responsibilities on women. Though less often, fathers suffer uncertainty about their ability because of cultural assumptions. Caregivers reported feeling overwhelmed by round-the-clock care, financial stress from medical expenses, and isolation due to societal misunderstandings about disabilities. Many described their children being labelled as "cursed" or "naughty," leading to exclusion from community activities. The COVID-19 pandemic worsened these issues, disrupting therapy sessions and leaving families without support.

The study emphasizes the need for urgent action. Suggestions include practical training programs for caregivers, affordable therapy services, and community workshops to reduce stigma. Policy changes are critical to easing caregivers' burdens. Additionally, gender-sensitive initiatives could encourage shared caregiving roles and support male caregivers. By addressing these systemic gaps, Assam can build a more inclusive environment where caregivers feel empowered and children with disabilities receive equitable opportunities. This research calls for collaborative efforts from governments, NGOs, and communities to transform caregiving into_a supported and dignified responsibility.

Keywords: Autism Spectrum Disorder, Cerebral Palsy, Caregivers, Challenges, Gender roles, Therapy,

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CHAPTER I

INTRODUCTION

1.1 INTRODUCTION

Disability as a long-term impairment that could be physical, mental, intellectual, or sensory that makes it difficult for a person to participate in society. World Health Organization (WHO) emphasizes that disability is not just a medical condition but a complex interaction between an individual's health condition and environmental and social barriers that may hinder full and effective participation in society. It highlights that disabilities can be physical, sensory, cognitive, or mental, and they can be temporary, permanent, progressive, or static.

World Health Organization (WHO) 2001, defines disability as "the result of interactions between health conditions and environmental and personal factors." It reflects the interaction between individuals with a health condition such as cerebral palsy, autism, spinal cord injury, etc and personal and environmental factors such as negative attitudes, inaccessible transportation, public buildings, and limited social support.

The RPwD Act 2016, defines "person with disability" as "A person with long-term physical, mental, intellectual, or sensory impairment, which, in interaction with barriers, hinders their full and effective participation in society equally with others."

Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects how a person communicates, interacts with others, and experiences the world around them. Because the symptoms and severity can differ greatly from person to person, it is referred to as a "spectrum."

According to World Health Organization (WHO)2022, "Autism spectrum disorders (ASD) are a group of diverse conditions related to the development of the brain. They are characterized by some degree of difficulty with social interaction and communication. Other characteristics are atypical patterns of activities and behaviours, such as difficulty with transition from one activity to another, a focus on details, and unusual reactions to sensations.

National Institute of Mental Health (NIMH) "Autism spectrum disorder (ASD) is a developmental disorder that affects communication and behaviour. Although ASD can be diagnosed at any age, it is described as a 'developmental disorder' because symptoms generally appear in the first two years of life."

Characteristics of ASD

- Difficulty with social communication and interaction: Individuals may struggle with making eye contact, understanding social cues, or building relationships.
- Repetitive behaviours and restricted interests: This can include repetitive movements (like hand-flapping), strict routines, or intense focus on specific topics or objects.
- Sensory sensitivities: Many individuals with ASD are highly sensitive to sounds, lights, textures, or smells, which can lead to discomfort or distress.

Causes of ASD

- <u>Genetic factors:</u>
  - ASD often runs in families.
  - Certain gene mutations are associated with autism.
  - Linked to genetic conditions like Fragile X syndrome or Rett syndrome.

- <u>Environmental factors:</u>
  - Advanced parental age (especially paternal).
  - Maternal infections during pregnancy.
  - Exposure to air pollution or certain chemicals.
  - Complications during birth, such as oxygen deprivation.
- <u>Brain development:</u>
  - Differences in brain structure and connectivity.
  - Early brain overgrowth in some children with ASD.

Cerebral Palsy (CP)

Cerebral palsy is a neurological disorder that impacts a person's movement, muscle tone, and posture.

According to **Centres for Disease Control and Prevention (CDC)** "Cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain balance and posture. It is the most common motor disability in childhood."

Characteristics of CP

- Movement and coordination difficulties: Children with Cerebral Palsy often struggle with controlling their movements, which may appear uncoordinated and clumsy.
- Muscle stiffness or floppiness: Some children have very tight muscles, while others may have low muscle tone, making their limbs seem floppy.
- Poor balance and posture: Individual may face difficulty maintaining upright posture or walking steadily is common.
- Delayed motor development: Milestones of children such as crawling, sitting, or walking may be delayed or achieved with difficulty.
- Involuntary movements: Some children may experience sudden, uncontrolled movements or shaking without their will.
- Speech and swallowing problems: An individual's muscle control issues can affect the ability to speak clearly or swallow safely.
- Intellectual or learning challenges (in some cases): While many children with CP have normal intelligence, some may experience cognitive delays.

Causes of CP

- Prenatal (before birth) causes:
  - Lack of oxygen to the brain (hypoxia) during foetal development
  - Infections during pregnancy such as rubella, cytomegalovirus, toxoplasmosis.
  - Abnormal development of brain due to genetic or unknown factors

    - Exposure to toxins or harmful substances during pregnancy
- Perinatal (during birth) causes:
    - Birth complications like prolonged labour or breech delivery
    - Low birth weight or premature birth
    - Lack of oxygen during delivery
- Postnatal (after birth) causes:
    - Severe jaundice in newborns
    - Brain infections
    - Head injury due to accidents or abuse in early infancy
    - Stroke or bleeding in the brain

Giving birth to a child with a disability brings unique challenges to the family, but it also fosters resilience, strengthens family bonds, and encourages at least one member, typically the parents. Caring for a child with a disability requires immense strength, patience, and unwavering dedication. But in the reality the caregivers often faced many problems in their daily life. These problems hinder in providing proper care and love for their child. It may have an impact on the standard of care given to kids with disabilities. When caregivers experience stress, exhaustion, or financial difficulties, they may struggle to meet the child's physical, emotional, and developmental needs.

Caring for a child is a profound journey filled with joys, hopes, and dreams. However, when a child is diagnosed with Autism Spectrum Disorder (ASD) or Cerebral Palsy (CP), this journey often becomes more complex and demanding. Caregivers such as parents or close family members find themselves navigating a world filled with uncertainties, emotional struggles, and practical challenges that can affect every aspect of their lives. Their roles extend far beyond typical parenting; they become advocates, therapists, and tireless supporters, all while managing their own emotional and physical well-being.

Despite their crucial role, the experiences and challenges faced by these caregivers often remain hidden, overshadowed by the focus on the child's condition itself. Understanding these challenges is essential and not only to acknowledge their sacrifices and resilience but also to inform policies, support systems, and interventions that can make their journey more manageable. This research aims to give voice to these caregivers, exploring the multifaceted challenges they encounter daily, from emotional stress and social isolation to financial strain and accessing appropriate services.

This research aims to investigate and assess the main challenges experienced by parents and caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral palsy (CP). By listening deeply to the lived experiences of caregivers of children with ASD and CP, this study seeks to shed light on their realities and highlight the need for comprehensive support that empowers them to care for their children while also caring for themselves. This study looks at the available literature to understand which caregivers struggle the most in providing essential care for their child with a disability. It also evaluates their overall/ and holistic condition.

1.2 OPERATIONAL DEFINITION

- **Child:** The researcher uses the "child" terminology to define who are under 10 years old.
- **Disability:** Disability is a condition that makes daily activities harder due to physical, mental, or sensory challenges. It can be present from birth or result from illness, injury, or aging. Some disabilities are visible, while others are not. When provided with proper support and inclusion, individuals with disabilities can lead rich, fulfilling lives. This research focuses on the Autism Spectrum Disorder and Cerebral palsy as disability.
- **Autism Spectrum Disorder (ASD):** Autism Spectrum Disorder (ASD) is a developmental condition that affects how a person communicates, interacts with others. They might also be sensitive to sounds, lights, or touch. Since it is a spectrum, each person with autism is different some may need a lot of support, while others can manage daily life more independently.

- **Cerebral Palsy:** Cerebral Palsy (CP) is a condition that affects movement, balance, and muscle control. It occurs when a baby's brain does not develop properly, during, or after birth. People with CP may have trouble walking, using their hands, or speaking clearly, and their muscles might be too stiff or too weak.
- **Caregivers:** Caregivers are people who help others who assist others with daily tasks like eating, dressing, and taking medicine. Caregivers can be family, friends, or paid helpers who provide care, support, and love to make life easier and more comfortable for those in need. The researcher refers primary caregivers such as mother, father and family members and secondary caregivers such as teachers, special caretakers of any NGO etc.
- **Socio-economic challenges:** Socio-economic challenges are problems people face because of their money and social situation. These problems include not having enough money, being unemployed, not having enough education, or not being able to get healthcare. These challenges can make life harder.

1.3 STATEMENT OF THE PROBLEM

Caring for a child with a disability presents unique and multifaceted challenges that significantly impact the physical, emotional, social, and financial well-being of caregivers. Despite the growing recognition of the critical role caregivers play in the lives of children with disabilities, there remains a limited understanding of the specific challenges they face, particularly in Guwahati area.

Existing research has highlighted issues such as emotional stress, financial strain, social isolation, and lack of access to support services. However, many studies have focused on broader caregiver populations or specific disabilities, leaving gaps in understanding the diverse and intersectional challenges faced by caregivers across different contexts. Furthermore, there is insufficient exploration of how these challenges evolve over time, how they vary based on the type and severity of the child's disability, and how caregivers cope with these demands.

This study focuses on the problems for which the children cannot get all the required services and care.

1.4 SIGNIFICANCE OF THE STUDY

The research on the socio-economic challenges faced by the caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP) carries profound significance for various reasons. It helps to better understand the struggles these caregivers face, such as dealing with cultural beliefs, money problems, and lack of resources. The findings can be used to create better support systems, improve policies, and design programs that make life easier for both caregivers and their children. It also raises awareness about the needs of these families, encouraging communities and governments to act.

By focusing on the Guwahati region, this research aims to bridge gaps in understanding the systemic, cultural, and socioeconomic challenges faced by caregivers of children with disabilities. The findings will guide the design of context-specific strategies to alleviate caregiver burden and improve holistic outcomes for families navigating disability-related care.

1.5 OBJECTIVES OF THE STUDY

- To identify the various types of challenges faced by the caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP).
- To understand the caregivers' need for advocacy and awareness.
- To explore the role of gender in caregiving responsibilities.
- To identify the coping strategies used by the caregivers to overcome their problems.
- To identify the impact of COVID-19 pandemic on the quality of care given by the caregiver to their children.

1.6 RESEARCH QUESTIONS

- What are the various types of challenges faced by the caregivers of children with disability?
- What is the role of gender in caregiving responsibilities?
- Are the caregivers aware of the existing government policies or schemes for the children with disability.
- What are the coping strategies used by the caregivers to solve their problems?
- What is the impact of COVID-19 pandemic on the quality of care given by the caregiver to their children?

CHAPTER II

REVIEW OF LITERATURE

WORLD'S PERSPECTIVE

- **Murphy et al. (2006)** conducted study on "*The Health of Caregivers for Children with Disabilities: Caregiver Perspectives*" they explored the health-related challenges faced by caregivers of children with disabilities in the United States. The study emphasized the physical, emotional, and psychological consequences of long-term informal caregiving. Using a mixed-method approach, the researchers conducted questionnaires and focus groups with 40 caregivers from urban, suburban, and rural areas of Utah to assess their perspectives on their own health and well-being. The study identified five key themes: stress of caregiving, negative impact on caregiver health, sharing the burden, worry about the future, and caregiver coping strategies. Notably, 41% of caregivers reported a decline in their health over the past year, attributing to limited time, loss of control, and decreased psychosocial energy. The findings suggested that caregiving leads to significant stress and health deterioration, reinforcing the need for targeted interventions to support caregivers. They highlighted the importance of improving services and developing strategies to sustain caregivers. Addressing their health needs through supportive policies and interventions could ultimately enhance both caregivers' well-being and the overall care provided to children with disabilities.

- **Sen and Yurtsever (2007)** conducted a descriptive study on "*Struggles of caregivers*" examined the difficulties faced by families raising children with disabilities in Turkey. The study involved families from one public and two private rehabilitation centers, using questionnaires for data collection. Findings revealed that most families, particularly mothers, experienced emotional distress, including sadness and social isolation. Parents reported disruptions in their social lives, work, and family relationships, along with financial hardships. The study highlighted a lack of knowledge among families regarding their child's disability, contributing to increased stress. Sen and Yurtsever emphasize the important role healthcare professionals, especially nurses, play in supporting these families through education and emotional guidance. The study called for comprehensive support systems to address both emotional and financial challenges faced by caregivers. Although limited by its geographic focus, the research offers valuable insights into the lived experiences of families caring for disabled children and underscores the need for family-centered care practices.

- **Brown & Rodger (2009)** in their study *"Children with disabilities: Problems faced by foster parents"* explored the challenges faced by licensed foster parents caring for children with disabilities in a major Canadian city. Using a qualitative approach, they collected 85 unique responses to the question, "What are the problems you encounter fostering a child with a disability?" Foster parents grouped these responses, and subsequent statistical analyses identified seven key concepts. These included difficulties in accessing specialized professional services, high financial costs, emotional and behavioral challenges, and lack of adequate support from child welfare agencies. The study highlighted the complex needs of children with disabilities in foster care and the corresponding demands placed on foster families. They emphasized the necessity for increased resources, better service coordination, and more comprehensive support systems for foster parents. Despite the study's specific geographic focus, its findings offer valuable insights into the universal challenges of fostering children with disabilities and inform policy and practice improvements.

- **Resch et al. (2010)** in the article "*Giving Parents a Voice: A Qualitative Study of the Challenges Experienced by Parents of Children with Disabilities*" explored the challenges faced by parents of children with disabilities, emphasizing the need for better environmental support systems.

Through focus groups with 40 parent caregivers, the study identifies four key barriers to positive parental well-being: (a) limited access to information and services, (b) financial constraints, (c) inclusion in schools and communities, and (d) the absence of adequate family support. The research highlighted the disconnect between caregiver needs and the availability of services, resources, and community support. Many parents struggled to find the information necessary to access appropriate interventions, which exacerbates stress and financial burdens. Additionally, issues related to school and community inclusion create further isolation, while inadequate family support leaves many parents feeling overwhelmed. The study called for further research and policy interventions that focus on strengthening environmental support structures for parents.

- **Pousada et al. (2013)** done a study on the *"Impact of Caring for a Child with Cerebral Palsy on the Quality of Life of Parents: A Systematic Review of the Literature"* and analyzed 46 eligible studies, the review highlighted the significant emotional and psychological burden experienced by caregivers, including high levels of stress, depression, and diminished quality of life compared to parents of neurotypical children. Key factors influencing caregiver distress include the child's behavioral and cognitive issues, low self-efficacy among caregivers, and insufficient social support. The authors emphasized the importance of comprehensive family-centered interventions aimed at strengthening parental coping resources, enhancing caregiver competence, and addressing the multifaceted demands of long-term caregiving. The findings served as a foundation for improving support systems and designing targeted programs that benefit both children with CP and their families.

- **Faw & Leustek (2015)** in his article *"Sharing the load: An exploratory analysis of the challenges experienced by parent caregivers of children with disabilities"* examined challenges discussed by parent caregivers of children with disabilities within their informal networks through 40 conversational analyses, identifying seven key themes: isolation, strained relationships, stigma, parenting complexities, logistical difficulties, socialization barriers, and transitioning to adulthood. The authors emphasized informal networks' role in mitigating caregiving uncertainties, advocating for their recognition alongside policy reforms. While the focused on real-world dialogues enhances ecological validity, limitations include a small, potentially homogenous sample and insufficient demographic context, restricting generalizability. The exploratory design underscored the need for follow-up studies to examine causal relationships and intersectional factors influencing caregiving experiences. Despite these constraints, the research highlighted the multifaceted stressors faced by families, offering insights for healthcare providers and policymakers to strengthen community-based support systems.

- **Gona et al (2016)** conducted a study on *"Challenges and coping strategies of parents of children with autism on the Kenyan coast."* This qualitative study explored the experiences of parents raising children with autism on the Kenyan coast, focusing on the challenges faced and coping strategies employed. Data was collected through 37 interviews and eight focus group discussions involving parents and professionals, analyzed using NVivo. Findings revealed widespread challenges including stigma, lack of treatment options, and financial strain, and consistency across religious and cultural lines. Parents used both problem-focused strategies, such as diet management and respect, and emotion-focused strategies, including spiritual healing and prayer. The study highlights the psychological and practical burden on caregivers and emphasizes the importance of culturally appropriate, community-based rehabilitation services. The insights provided underscore the need for tailored support mechanisms that address both the physical needs of the child and the mental well-being of the caregiver in resource-limited settings.

- **Taderera & Hall (2017)** in the article *"Challenges Faced by Parents of Children with Learning Disabilities in Opuwo, Namibia"* examined the difficulties parents face in raising children with learning disabilities in Opuwo, Namibia. The study highlighted the importance of knowledge, resources, and access to support services, which are often lacking in developing countries. Through in-depth interviews with eight parents, the researchers explored the various obstacles parents encounter in addressing their children's learning and developmental needs. Many participants had only a vague understanding of learning disabilities and were unaware of existing services, programs, and policies designed to support their children. Stereotypes and prejudices within families and the broader community further complicated the challenges. Additionally, most children with learning disabilities were raised by single, unemployed parents who struggled financially due to a lack of support from the other parents. These financial difficulties further limited access to necessary resources and services. The authors concluded that financial instability and a lack of knowledge about learning disabilities are significant barriers for parents. The study underscored the need for better policy education and grassroots-level intervention to enhance awareness and provide necessary support systems for parents and children facing learning disabilities in Namibia.

- **Pretorius & Steadman (2017)** in their article *"Barriers and Facilitators to Caring for a Child with Cerebral Palsy in Rural Communities of the Western Cape, South Africa"* investigated the experiences of 15 caregivers of children with cerebral palsy (CP) in rural areas of the Western Cape, South Africa. Key barriers included limited access to disability-friendly services, financial constraints, and insufficient public awareness about disabilities.

Despite some improvements in service provision, caregivers continue to face challenges in accessing support such as respite care, special education, and reliable transportation. On the other hand, social support and governmental financial assistance were noted as crucial facilitators that eased the caregiving burden. The study emphasized the need for more inclusive and accessible services tailored to the realities of rural communities. It highlighted the importance of policy and program development aimed at enhancing the quality of life for both children with CP and their families through sustained and targeted interventions.

- **Bahry et al. (2019)** conducted a study on *"Challenges Faced by Malaysian Parents in Caregiving of a Child with Disabilities"* and examined the financial and psychological burdens faced by Malaysian parents in caregiving for a child with disabilities. The study highlighted how raising a child with special needs significantly increases costs and stress levels, making it necessary for parents to work harder to afford treatments and other caregiving necessities. The research also explored how these challenges vary based on the nature of the child's disability. The study discussed the difficulty parents face in balancing work, caregiving responsibilities, and stress management. The findings indicated that financial strain is one of the primary challenges, as parents must cover medical expenses, therapy, and special education costs. Additionally, the psychological toll of caregiving led to increased stress levels, further complicating parents' ability to maintain work-life balance. They provided valuable insights into the struggles of Malaysian parents caring for children with disabilities. The study contributed to the development of a conceptual model that outlines these challenges, offering a foundation for future research and policy recommendations. Addressing these concerns through supportive policies and interventions could significantly improve the well-being of both caregivers and children.

- **Liao & Li (2020)** in their article on *"Economic burdens on parents of children with autism"* analyzed 33 studies across 10 countries to assess the economic impact on parents of children with autism. The review found that parents, particularly mothers, faced significant financial burdens and adverse employment consequences. Studies reviewed included quantitative, qualitative, and mixed methods, highlighting global consistency in economic challenges. The authors emphasized the need for improved medical resource allocation and policy support to alleviate financial stress on families affected by autism.

- **Zahaika et al. (2021)** conducted a cross-sectional study on *"Challenges facing family caregivers of children with disabilities during COVID-19 pandemic in Palestine*" examined the challenges faced by 130 family caregivers of children with disabilities in Palestine during the COVID-19 pandemic. Using the Burden Scale for Family Caregivers-Short Version ,they found a high caregiver burden, with a mean score of 20.17. Physical exhaustion (88.5%), financial strain (75.4%), and reduced access to health and rehabilitation services were the most common challenges. The study revealed strong correlations between caregiver burden and factors such as disability type and the child's self-care limitations. While the focus on maternal caregivers (76.9%) and the Palestine-specific context may limit generalizability, the research highlights how the pandemic worsened pre-existing systemic gaps. The authors emphasizedd the need for family-centered policies and inclusive support systems, particularly during public health crises. Their findings underline the importance of addressing caregivers' multidimensional needs through culturally responsive and targeted interventions to improve caregiver well-being.
- **Lamba et al. (2022)** conducted a study on *"Exploring challenges and support structures of mothers with children with Autism Spectrum Disorder*

in the United Arab Emirates" and explored the lived experiences of 17 expatriate mothers of children with ASD in the UAE. Using in-depth interviews, the study identified key challenges such as delays in diagnosis, difficulty accessing services, cultural stigma, and lack of inclusive education. Despite these barriers, mothers relied heavily on informal support networks and personal resilience. The findings revealed the urgent need for culturally sensitive intervention policies and structured support systems in the UAE. This study contributed to the sparse literature on parenting children with ASD in Gulf countries, underscoring systemic and emotional gaps in care.

- **Singwane & Sandhleni (2023)** explore the challenges and livelihoods of caregivers of children with disabilities in South Africa in their article *on "The Livelihoods and Challenges Faced by Caregivers of Children with Disabilities in South Africa"*. This qualitative study investigated the financial, social, and psychosocial burdens that caregivers face due to the lack of adequate support services from both governmental and non-governmental organizations. The study purposefully selected nine female caregivers of children aged 1 to 17 in Mbombela and conducted semi-structured interviews to gather data. Thematic analysis of the data revealed several key issues, including the inaccessibility of services, financial constraints exacerbated by absentee fathers, and the stigma caregivers experience. The research also examined coping mechanisms caregivers use to navigate these difficulties. A central theme was the struggle caregivers face in educating their children due to limited support structures. The study highlighted the urgent need for strategic interventions to alleviate the burden on caregivers and enhance their ability to provide for their children. They provided valuable insights into the hardships faced by caregivers in South Africa and emphasize the necessity of targeted policies and support systems to improve their quality of life. Addressing these challenges would contribute to better outcomes for both caregivers and children with disabilities.

- **Mwinbam, M. M et al (2023)** have done a study on *"Family caregivers' experience of care with a child with cerebral palsy: The lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana."* and explored the lived experiences and challenges of caregivers of children with cerebral palsy (CP) in northern Ghana, a resource-limited setting. Using phenomenological principles and inductive content analysis, data was gathered from 13 caregivers through in-depth interviews at Tamale Teaching Hospital. Findings revealed multifaceted challenges, including sociocultural stigma, discrimination, economic hardship, physical caregiving burdens, and limited access to health information and education. Many caregivers experienced job loss and financial strain due to caregiving responsibilities. The study highlighted a pressing need for social support systems and policy reforms aimed at alleviating caregiver burdens and improving the quality of life for children with CP. These findings underscored the importance of culturally appropriate interventions that support both caregivers and children in similar low-resource environments.

- **Sakwape et al. (2023)** conducted a qualitative study on "*Exploring role strain and experiences of caregivers of children living with disabilities exploring the role strain experienced by caregivers of children living with disabilities.*" By using a descriptive and contextual design, the researchers purposively selected 11 participants from caregivers receiving community support services. Data was gathered through semi-structured interviews and analyzed using content analysis. The study identified four major themes: caregiving negatively impacts caregivers' health, imposes financial strain, disrupts other social roles, and requires coping strategies to manage stress. The findings highlighted the significant physical, emotional, and economic burdens caregivers face. The study emphasized the need for targeted interventions and support systems to alleviate role strain and improve caregiver's well-being. While the small sample size limits generalizability, the study provided important insights into the challenges experienced by caregivers in similar socio-economic contexts, contributing to the broader understanding of caregiving for children with disabilities in developing regions.

INDIAN PERSPECTIVE

- **Divan, G., et al (2012)** conducted a study on *"Challenges, coping strategies, and unmet needs of families with a child with Autism Spectrum Disorder in Goa, India."* and this qualitative study explored the lived experiences of families raising children with Autism Spectrum Disorder (ASD) in Goa, India. Through 20 in-depth interviews and nine focus group discussions with families and key community stakeholders, the researchers identified multiple challenges, including emotional strain, discrimination, and a lack of professional awareness. Families reported initial social isolation followed by eventual reintegration supported by social networks and health providers. The findings highlighted the multidimensional impact of ASD affecting not only personal lives but also community engagement. The study emphasized the unmet needs in professional services, awareness, and systemic support, underlining the urgent need for informed policies and integrated care frameworks to assist families managing ASD in low-resource settings.
- **Isa et al. (2014***)* in the article on *"Health and quality of life among the caregivers of children with disabilities: A review of literature."* examined the impact of caregiving for children with disabilities on the health and quality of life of caregivers. The authors conducted a search across multiple electronic databases, resulting in the review of 31 peer-reviewed articles

published between 2009 and 2014. Most of the studies were quantitative in design. The findings highlighted the considerable variation in how caregivers adapt to the demands and stressors of caregiving, which in turn affects their health and well-being. Key factors influencing caregivers' health and quality of life include sociodemographic characteristics and child disability-related factors. The review also discussed mediators and moderators such as coping strategies, social support, parental stress, self-esteem, and self-efficacy, which play a significant role in caregiving experience. The authors emphasized the importance of understanding these factors to gain a deeper understanding of the complex nature of stress processes and the adaptations caregivers make to manage their children's disabilities. The review underscored the need for support systems that address these factors to improve the health and quality of life of caregivers.

- **Ganjiwale et al. (2016)** conducted a cross-sectional study on *"Quality of Life and Coping Strategies Among Caregivers of Children with Disabilities in Gujarat"* assessed the Quality of Life (QOL)and coping strategies of caregivers of children with physical and mental disabilities in Anand, Gujarat. Using the WHO-QOL and BREF COPE scales, the study found that caregivers performed best in the social relationship domain, while the environment domain scored the lowest. The predominant coping mechanism was active emotional coping. The study highlighted the significant differences in QOL based on the type of disability, suggesting the need for rehabilitation programs that provide psychological support to caregivers.

- **Murthy (2016)** in his *article "Caregiving and caregivers: Challenges and opportunities in India"* explored the emotional and practical aspects of caregiving for individuals with mental illness in India. With limited alternative care facilities, family members are the primary caregivers, a situation complicated by shifting social dynamics such as urbanization and the rise of nuclear families. These changes place an increasing burden on caregivers, which can range from stressful to fulfilling. The article discussed the emotional dimensions of caregiving and underscored the importance of using caregiving situations as opportunities to prevent mental health disorders, promote mental well-being, and reduce the stigma surrounding mental illness. Murthy also highlighted a significant gap in research, noting that while much of the focus has been on the burden on caregivers, less attention has been given to caregiving across different communities and demographic groups. The author called for the development of support systems and training programs to assist caregivers, ultimately aiming to reduce stress and enhance the positive aspects of caregiving. The article advocated for a more holistic approach to caregiving that benefits both caregivers and those they care for.

- **Adithyan & Jacob (2017)** conducted a study on *"the positive and negative impacts on caregivers of children with intellectual disabilities in*". and they used a mixed-methods approach, combining quantitative and qualitative techniques to analyze caregivers' experiences. The findings revealed significant challenges, including emotional stress, financial strain, and social isolation, which negatively impact caregivers' well-being. However, the study also identified positive aspects, such as personal resilience, strengthened family relationships, and a sense of fulfillment derived from caregiving. These hopeful signs highlighted the complex and multifaceted nature of caregiving experiences. The authors emphasized that empowering caregivers is crucial for the successful inclusion of children with intellectual disabilities in society. The study suggested various strategies to achieve this goal, including the establishment of support networks, educational programs, and policy initiatives that address caregivers' needs. This research provided valuable insights into the lived experiences of caregivers in India, underscoring the need for comprehensive support systems. By acknowledging both the hardships and rewards of caregiving, the study offered practical recommendations for improving caregivers' quality of life, ultimately fostering a more inclusive and supportive environment for children with intellectual disabilities.

- **Thathapudi et al. (2019)** conducted a study on *"Success and challenges in recruiting and retaining caregivers for children with disabilities in India"* and examined the challenges and strategies in recruiting and retaining caregivers for children with disabilities in India. The study focused on Sarah's Covenant Homes (SCH), an organization that provides group-home services to 135 children in Andhra Pradesh and Telangana. Given the mandate of the Juvenile Justice Act of 2015, which emphasized family-based care, the study highlighted the critical role of caregivers in ensuring quality support for children with disabilities. Using personnel file reviews and interviews with staff members who have been with the organization for at least five years, the study identified key factors contributing to caregiver retention. These included referral buses, transparent compensation, paid leave, and workplace safety. The findings suggested that financial and workplace incentives play a significant role in improving caregiver stability and job satisfaction. The study provided valuable insights into recruitment and retention strategies for caregivers in the disability care sector. It underscored the importance of structured policies that prioritize caregiver well-being, ensuring continuity of care for vulnerable children. By addressing both challenges and best practices, the study serves as a reference for policymakers and organizations working to improve caregiver retention in similar settings.

- **Geetha et al (2019)** conducted a study on *"Autism in India: A case–control study to understand the association between socio-economic and environmental risk factors."* and investigated the relationship between autism spectrum disorder (ASD) and various socio-economic, environmental, and prenatal factors in Coimbatore, India. Data from 55 children with ASD and 55 typically developing peers revealed that paternal age over 40, family history of autism, poor maternal nutrition, fetal hypoxia, and NICU stay significantly increased ASD risk. The findings emphasized the influence of prenatal and environmental exposures on ASD development, suggesting that prevention efforts should target these modifiable factors during early fetal development.

- **Francis (2020)** presented a comprehensive study on "*Understanding autism in Goa, India: A holistic exploration of psychosocial experiences, community engagement, and institutional support*" of autism spectrum disorder (ASD) in Goa, India, combining case studies and literature review to analyze psychosocial challenges, cultural perceptions, and institutional responses. The article examined the role of community and governmental support, highlighted advancements in service provision while noting ongoing issues such as professional shortages and limited access. The research underscored the necessity for integrated community involvement and policy-backed support systems to create inclusive environments.

- **Muthukaruppan et al. (2020)** conducted a study on "*Impact of a family-centered early intervention program in South India on caregivers of children with developmental delays*" and examined the effects of a family-centered early intervention program on caregiver strain and family empowerment in South India. An open design was used, tracking changes from baseline to two years after participation in the program. The study involved 308 caregivers, with 91% being women, who were responsible for children with developmental delays, including cerebral palsy. The intervention focused on training and educating caregivers.

- **Gokhale (2021)** conducted a study on *"Service Gaps and Challenges Faced by Caregivers of Children with Disabilities in India"* and reviewed literature on caregivers' needs in India, emphasizing the gaps in medical and social sector services. The study identified a lack of information about conditions, prognosis, and management among caregivers. Key challenges included difficulties in accessing medical care, rehabilitation services, and educational guidance. Economic hardships compounded these issues, worsened by poor coordination between healthcare and social services. The study underscored the necessity for integrated and comprehensive support systems. This study highlightsed the urgent need for policies that enhance caregiver support through structured rehabilitation programs and improved access to information and services.

- **Mitra et al. (2021)** conducted a qualitative study on *"A qualitative lens on the sources of stress and coping pattern of caregivers of children with autism spectrum disorder"* to examined the stress and coping mechanisms of caregivers, particularly mothers, of children with ASD in India. The study revealed that caregivers experience significant stress, especially during the early years of the child's life. However, over time, caregivers develop coping strategies to manage stress. The study highlighted the importance of a humanistic and empathetic approach in supporting caregivers. It also pointed to societal factors that contributed to stress and the need for interventions that are sensitive to the cultural context.

- **Tathgur, & Kang (2021)** in their article *"Challenges of the caregivers in managing a child with autism spectrum disorder—A qualitative analysis. Indian Journal of Psychological Medicine"* explored the multifaceted challenges caregivers face in raising children with autism spectrum disorder

(ASD). Findings highlighted the significant physical, psychological, financial, and social burdens caregivers endure. Participants reported stress, anxiety, and restricted daily activities, often exacerbated by societal stigma, limited healthcare access, and high out-of-pocket expenses. The study underscored the urgent need for improved support systems, professional guidance, and policy reforms tailored to caregiver needs. The authors advocated for comprehensive health services, increased awareness, and education among professionals to enhance the management and well-being of both caregivers and children with ASD. These findings contributed to meaningful insights into caregiver experiences and offer valuable recommendations for systemic improvements.

- **Viswanathan et al (2022)** conducted a study on *"Lived experiences of siblings of individuals with autism spectrum disorder in India: An interpretative phenomenological analysis."* and explores the lived experiences of 14 siblings (aged 15–36) of individuals with autism spectrum disorder (ASD) in India using interpretative phenomenological analysis (IPA). Participants were recruited from hospitals, schools, and private institutes, and interviewed with a semi-structured schedule. Thematic analysis revealed a range of experiences from basic challenges in understanding ASD to complex concerns such as future caregiving roles, personal identity, emotional needs, and the importance of support systems. Despite their struggles, many siblings prioritized the needs of their autistic sibling over their own, often downplaying personal difficulties. Some participants reported positive aspects of their sibling relationship, although these were less common. The study underscored the need for targeted support services that address both the emotional and practical challenges faced by siblings of individuals with ASD, particularly in the Indian socio-cultural context.

- **Raju et al (2023)** in their article *"Quality of life in parents of children with Autism spectrum disorder: Emphasizing challenges in the Indian context."* explored the quality of life (QOL) among Indian parents of children with autism spectrum disorder (ASD), using a self-reported socio-demographic questionnaire. A comparative analysis was conducted between parents of children with ASD and those of typically developing children (N = 60). Results revealed a significant disparity in QOL, with ASD caregivers reporting lower well-being. Additionally, certain socio-demographic factors showed a positive correlation with QOL. The study underscored the pressing need for supportive interventions aimed at enhancing family functioning, accessible services, and equipping caregivers with effective coping mechanisms tailored to the Indian context.

- **Twinkal & Jadhav (2024)** in the article *"Stress and Quality of Life Among Caregivers of Children with Intellectual Disabilities in Rajasthan"* explored the relationship between stress and quality of life among caregivers. The study collected quantitative data from 50 caregivers through surveys and qualitative data from 10 participants via in-person interviews. The Beach Centre Family Quality of Life Scale and the Parental Stress Scale were used to measure stress and quality of life. Findings revealed that caregiving challenges, financial constraints, self-guilt, social stigma, and lack of support were key stressors. The research highlighted the need for targeted social work interventions to mitigate caregiver stress and enhance well-being. Addressing financial, emotional, and societal challenges can improve caregiver support and mental health outcomes. These findings offered valuable insights for policymakers and social workers in designing effective support strategies, ultimately benefiting children with intellectual disabilities and their families.

- **Vaghela, M., & Bodla, S. K. (2024)** conducted a study on *"Challenges faced by parents of intellectually disabled children in rural and urban areas."* and explored the distinct challenges faced by parents of children with intellectual disabilities in rural and urban settings. In rural areas, parents often struggle with limited access to healthcare and educational resources, which delays early diagnosis and intervention. The scarcity of specialized professionals and support networks contributes to parental isolation and a lack of awareness. Additionally, societal stigma against intellectual disabilities is more pronounced in rural communities, further marginalizing families. Conversely, urban parents typically have easier access to healthcare and educational services but are often burdened by financial constraints. The high cost of specialized care and therapies leads to disparities in the quality of services available. Moreover, the fast-paced urban lifestyle can exacerbate stress, leaving parents with little time for self-care or quality family interactions. Both rural and urban families faced challenges related to inclusive education, with limited access to mainstream schools and inadequate support for inclusion. These barriers hindered the social and academic development of children, restricting their ability to integrate into society. Overall, the study highlighted the need for improved access to resources and support networks for parents and children with intellectual disabilities across both rural and urban environments.
- **Majumdar et al. (2025)** conducted a study on *"Awareness of Disability Rights, Certification, and Welfare Schemes Among Caregivers of Children with Disabilities in India"* a hospital-based cross-sectional survey to assess caregivers' awareness of disability rights, certification, benefits, and welfare schemes. The study included caregivers of children aged 3 to 18 years with locomotor disabilities and autism spectrum disorder, recruited from a Physical Medicine and Rehabilitation outpatient department. They used a pre-structured proforma, the researchers collected demographic data and responses to 25 questions regarding disability-related rights and government

support programs. The findings revealed a significant lack of awareness among caregivers, leading to the underutilization of rehabilitation and welfare services. Many caregivers were unaware of disability certification and available benefits, limiting access to essential resources. The study highlighted the urgent need for increased awareness initiatives among healthcare professionals at district and community levels. By improving knowledge of disability rights and available support systems, accessibility to rehabilitation services can be enhanced. The authors emphasized that educating caregivers can lead to better utilization of services, ultimately benefiting children with disabilities. This research underscored the importance of policy-driven interventions to bridge the information gap and ensure that caregivers receive adequate support in managing their children's needs.

- **Hasan & Dubey (2025)** done a study on *"Addressing psychological challenges of caregivers and children living with cerebral palsy."* explored the psychological challenges experienced by children with cerebral palsy (CP) and their caregivers, emphasized the mental health implications of this lifelong motor disorder. The authors reviewed existing literature to highlight how physical limitations, pain, sleep issues, communication difficulties, and reduced mobility contribute to cognitive, emotional, and behavioral problems in children with CP. These included anxiety, depression, ADHD, autism, sensory processing issues, and learning disabilities. Social difficulties, particularly bullying in school settings, further exacerbate mental health issues. The study underscored the necessity of targeted psychological interventions that support emotional well-being, improve coping strategies, and foster inclusion for children with CP and their caregivers. The article advocated for more comprehensive mental health services in both clinical and educational environments, contributing valuable insights to the field of developmental and clinical psychology.

NORTH-EAST INDIA

- **Sarmah et al (2017)** done a study on the *"Impact of stress, coping, social support, and resilience of families having children with autism"* and this study investigated the psychological impact on families of children with autism (CWA) in Northeast India, a region with limited specialized care. Using structured tools like the Parental Stress Scale and Family Resilience Assessment Scale, researchers assessed stress levels, coping strategies, social support, and family resilience among caregivers. Findings revealed high parental stress, particularly due to time constraints that affected professional life. Despite limited resources, families displayed adaptive coping strategies and resilience, often turning to spirituality for support. Responses regarding social support from extended networks such as family, friends, and neighbors were mixed. While the study highlighted the strength of familial coping,' it is limited by its single-center sample and potential bias from social desirability and participant fatigue. Nonetheless, it provided valuable insights into caregiver challenges and underlined the urgent need for improved services and policy attention toward autism care in this underserved region.

- **Naheed et al. (2020)** conducted a study on *"Burden of major depressive disorder and quality of life among mothers of children with autism spectrum disorder in urban Bangladesh"* and investigated the burden of depression and quality of life (QoL) among mothers of children with ASD in urban Bangladesh. The study found a high prevalence of major depressive disorder (MDD) in 45% of mothers, particularly among those with limited childcare support, low satisfaction with healthcare services, and negative social attitudes toward their children. MDD was negatively associated with QoL, while a higher family income and improvements in the child's school attendance were positively correlated with better QoL. The authors emphasized integrating mental health support for mothers to improve both their mental health and their overall quality of life.

- **Thapaliya (2025)** in his study *"Challenges and supporting strategies of Nepali parents of children with autism spectrum conditions"* explored the lived experiences of Nepali parents raising children with autism spectrum disorder (ASD) using a qualitative phenomenological approach. Semi-structured interviews with five parents revealed two key themes: the multifaceted challenges of caregiving and the strategies employed to manage them. Parents faced significant social stigma, psychological stress, financial constraints, and limited access to support services. Despite these challenges, they utilized coping mechanisms such as family and professional support, adaptive parenting, and personal acceptance. The study emphasized the urgent need for government-led support systems, financial aid, and awareness programs to assist families and promote inclusive education in Nepal.
- **Nath (2017)** conducted a study on *"Socio-economic situation of persons with disability in Cachar district of Assam."* and explored the socio-economic conditions of persons with disabilities (PWDs) in Cachar district, Assam, using an exploratory design. Based on data from 50 conveniently selected respondents, the study examined key socio-personal and economic indicators such as education, income, occupation, marital status, caste, and type of disability. The findings revealed that most participants face significant challenges in achieving economic sustainability and quality of life. The paper highlighted gaps in access to education and livelihood opportunities and reflects on respondents' perceptions of their current situations. It emphasizesd the urgent need for inclusive development and targeted interventions to enhance the living standards of PWDs in rural and semi-urban Indian contexts.

- **Das & Nath (2024)** conducted a study on *"Quality of life of children with cerebral palsy: Evidence from Assam, India."* and this study evaluated the quality of life (QOL) among 140 children with cerebral palsy (CP) in Assam, India, using the CP-QOL questionnaire. The average QOL score was low with significant variation based on age, schooling, maternal education, and social support. The study emphasized the need for targeted interventions, caregiver education, and inclusive policies to enhance QOL for children with CP. Reliability testing and robust statistical diagnostics strengthen the findings.

- **Goswami (2024)** in his article *"Gendered nature of caregiving across the lifespan: A study on 'disabled households"* and investigated the gendered dynamics of caregiving in households with women with locomotor impairments in an urban district of Assam, India. Drawing on interviews with 18 women aged 18–57 and using intersectionality as a framework, the study revealed that caregiving responsibilities, though shifting from parents to siblings over time, remain largely gendered. The analysis highlighted how disability experiences were shaped by multiple intersecting factors such as impairment severity, class, and location. It emphasized the persistent and often invisible gendered burden of care within familial settings, particularly in contexts where formal support systems were weak. The findings underscored the need for inclusive, gender-sensitive policies addressing the layered realities of disabled women in the global South.

- **Sahu et al (2017).** done a study on *"Impact of stress, coping, social support, and resilience of families having children with autism"* and this study explored the psychological and social dynamics of families raising children with autism in Northeast India. Using structured scales, it assessed parental stress, coping strategies, social support, and family resilience. Findings showed high parental stress, especially due to time constraints and professional impact, yet many families demonstrated effective coping and resilience. Social support responses varied, with religious coping being prominent. Despite being limited to one centre and facing issues like social desirability bias, the study sheds critical light on caregiver challenges in a resource-scarce region. It emphasized the need for focused policies on rehabilitation and long-term care for CWA and their families in Northeast India.

CHAPTER III

METHODOLOGY

In the previous chapter the researcher done a literature review, organized them thematically. In this chapter the researcher focuses on the methodology which refers a step-by-step plan to solve a research problem and get reliable results. It includes how data is collected and analysed, and it's designed to fit the goals of the study.

For this research, the researcher uses a descriptive approach under qualitative research. This means the researcher examines the topic in depth, focusing on understanding ideas and experiences rather than just numbers.

3.1 Theoretical framework

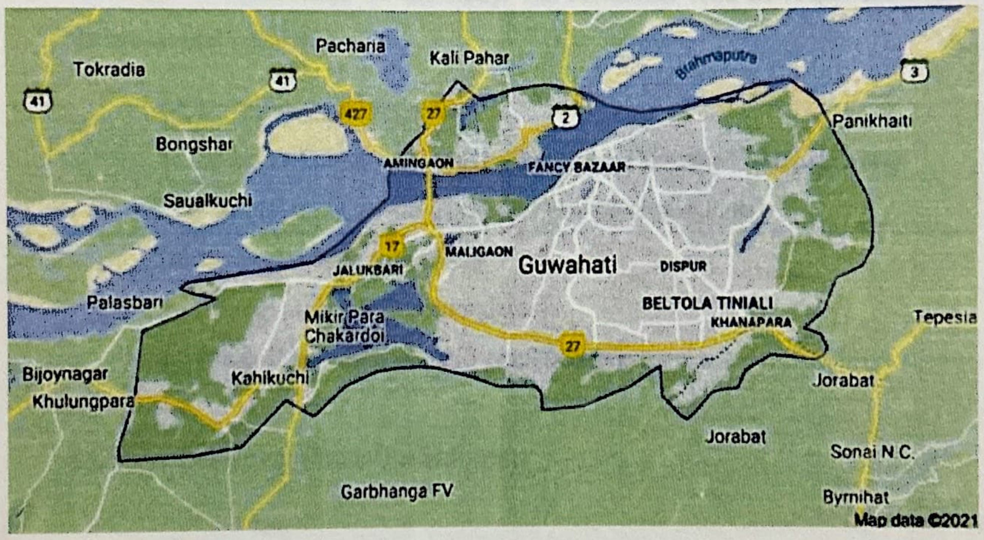
The Stress-Coping Theory by Lazarus and Folkman (1984) provides a valuable framework for understanding the socio-economic challenges faced by caregivers of children with disabilities. Caregivers often experience chronic stress due to financial burdens, limited employment opportunities, high medical expenses, and emotional exhaustion. According to this theory, stress arises when individuals perceive that their demands exceed their available resources. Caregivers employ different coping strategies to manage these challenges. Problem-focused coping involves seeking financial assistance, accessing government or community support, and advocating for better healthcare and educational services. On the other hand, emotion-focused coping includes strategies like seeking social support, practicing self-care, or relying on religious and cultural beliefs to maintain emotional resilience. However, when caregivers lack sufficient financial resources, social networks, or institutional support, they may experience burnout, anxiety, and even depression. By applying this theory, researchers can explore the effectiveness of different coping mechanisms and identify interventions that can help caregivers better manage their socio-economic challenges.

3.2 Research Design:

The researcher uses descriptive research design to gain a better understanding on the core cultural and socioeconomic challenges faced by the caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP). This research design aims to assess the overall quality of life of caregivers of children with disabilities by exploring the various physical, emotional, social, and economic factors that influence their daily lives and well-being.

3.3 Universe of the Study:

The study focuses on caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP) in Guwahati, Assam.



<u>FIG:</u> Map of Guwahati

<u>Photo Source:</u> Google map

https://maps.app.goo.gl/XLau9wUHm128XU36A?g_st=i&utm_campaign=ac-im

3.4 SAMPLING PROCEDURE

A sample is a small part of a group used to study the whole group. The researcher uses purposive sampling as the sampling technique for her study on the cultural and socioeconomic challenges faced by caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP). This technique involves intentionally selecting participants who are directly experiencing the phenomenon under investigation, ensuring that the sample is highly relevant and capable of providing rich, in-depth insights.

3.5 Sample Size:

Sample size refers to the number of respondents which are selected by the researcher to collect data for the study. The researcher took 20 respondents to gather crucial information.

3.5.1 Primary caregivers

- Parents of child with Autism Spectrum Disorder (7 respondents)
- Parents of child with Cerebral Palsy (7 respondents)

3.5.2 Secondary caregivers

- Special teachers (3 respondents)
- Professional caretakers (3 respondents)

3.6 Data Collection (Tools/Techniques):

3.6.1 **Interviews:** The researcher conducts to explore the experiences, perceptions, and insights of participants regarding the cultural and socioeconomic challenges faced by caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP) by using semi-structured interview schedule.

3.6.2 **Observation:** The researcher observes how the caregivers face difficulties while looking after the children with disability during home visits, school visits, rehabilitation centre.

3.7 Ethical Consideration and Consent:

3.7.1 **Informed Consent:** Participants receive comprehensive details about the study's goals, methods, possible risks, and benefits. Their voluntary involvement is confirmed through written informed consent, ensuring they fully understand and agree to participate.

3.7.2 **Confidentiality:** The researcher uphold strict confidentiality measures to ensure the privacy and rights of all participants are fully protected throughout the study

3.8 Limitations:

3.8.1 **Sample Size:** The study may involve a relatively small sample size (20 respondents) due to the qualitative nature of the research, which limits the generalizability of the findings to a broader population.

3.8.2 **Dynamic Nature of Challenges**: The cultural and socio-economic challenges faced by caregivers are often dynamic and context dependent. The study may not fully capture how these challenges evolve over time or in different circumstances.

3.8.3 **Geographical limitation:** The data is collected from the parents/ caregivers from Guwahati area only.

3.9 Exclusion and inclusion Criteria:

3.9.1 Inclusion Criteria:

- This research focuses exclusively on analysing the socio-economic challenges faced by caregivers of children with disabilities aged 0-10 years.
- Caregivers of only child with autism spectrum disorder (ASD), Cerebral Palsy (CP) are focused on this study.

3.9.2 Exclusion Criteria:

- This study does not cover the caregivers of adults with disability or the child above 10 years old.
- This study does not cover the other disabilities as it is difficult for the researcher to cover all the disabilities in this study.

CHATPTER IV

DATA ANALYSIS AND INTERPRETATION

This chapter presents the analysis and interpretation of data gathered from interviews with caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP). A thematic analysis approach was adopted to explore and interpret the qualitative data. To assist with data organization, coding, and retrieval, the researcher utilized QDA Miner version 3.0.5. This software played a key role in managing the large volume of textual data and in identifying significant themes and patterns within the participants' responses. The analysis was structured around the main research questions, which examined the challenges caregivers face, the influence of gender roles, the need for advocacy, coping mechanisms, and the impact of the COVID-19 pandemic. Employing QDA Miner helped ensure a systematic and transparent process, contributing to the credibility and depth of the findings. The identified themes are discussed in detail in the subsequent sections.

TRANSCRIPTIONS

- **PARENTS OF CHILDREN WITH Autism Spectrum Disorder AND Cerebral Palsy**

RESPONDENT -

The respondent, Mrs. Das, is a 34-year-old mother residing in Guwahati, Assam. She holds a graduate degree in Arts and is currently a homemaker. She lives with her husband, who works in a private firm, and their two children. Her younger child has been diagnosed with autism spectrum disorder (ASD). Her family consists of four members—herself, her husband, and their two children. the child is generally calm at home but tends to become anxious and distressed in unfamiliar or noisy environments. He is affectionate toward close family members but faces difficulties in expressing emotions and communicating his needs. She reported that she is the primary caregiver. Her husband helps when he is available, particularly by accompanying the child to therapy sessions. The elder sibling also contributes in small ways, such as helping to calm the child during meltdowns or playing with him. The respondent shared that caregiving involves many daily challenges, including feeding, toilet training, communication difficulties, and managing behavioural episodes. She also mentioned the stress caused by the child's irregular sleep patterns and the lack of societal understanding. Initially, she found the situation overwhelming and confusing. However, with time, she has learned more about autism and adapted to the child's needs. Despite this, the emotional and physical demands of caregiving continue to be significant. She expressed a need for more information on behavioural therapy techniques and special education strategies to help manage her child's development more effectively. The respondent mentioned that she lacks clear knowledge about government schemes and legal rights for children with disabilities. She also feels unsure about long-term care planning and future educational opportunities for her child. She feels that awareness in her community is very limited. People often misunderstand the child's behaviour, and there is a general lack of empathy and information among neighbours and even extended family members. She has reached out to a few NGOs and therapy centres in Guwahati such as CRC near GMCH for guidance and support. Mothers are usually expected to take full responsibility for caregiving, regardless of whether they work or stay at home. The respondent copes through small moments of self-care, emotional support from her husband, and connecting with other mothers in similar situations. She shared that the lockdown was especially hard. Therapy sessions were discontinued, and the disruption in routine caused the child's behaviour to more restlessness. She had to manage everything alone during that period without external help. The respondent noted that access to therapy became very difficult during the pandemic. Online sessions were offered by some centres, but they were not always effective due to the child's inability to engage through a screen. She suggested that regular support groups, financial assistance, better awareness in schools, and training programs for parents could make a significant difference. She expressed that although the journey has been very challenging, it has also taught her patience and unconditional love. She hopes that society becomes more inclusive and understanding toward children with special needs and their families. Her suggestions include increasing public awareness, improving access to affordable therapies, and providing formal training to caregivers. She also recommends more involvement from local government bodies to support such families financially.

RESPONDENT 2

The respondent is a 38-year-old single father living in Guwahati, Assam. He holds a diploma in mechanical engineering and works as a technician. He lives with his only son, who has been diagnosed with autism. There are two members in his household—himself and his son. Mr. Sharma shared that his son is mostly attached to him and feels secure in his presence. However, the child often has difficulties in social interaction, struggles with communication, and sometimes shows aggressive behaviour when he is overwhelmed or overstimulated. As a single parent, he takes full responsibility for caregiving. Occasionally, his sister or mother helps when he is at work or in urgent need of support, but day-to-day caregiving is solely handled by him. The respondent shared that managing his job and caregiving simultaneously is a major challenge. He also struggles with his child's unpredictable behaviour, difficulty in communication, and lack of proper sleep. Additionally, societal judgment and lack of understanding make it harder for him to access basic services. He said that the challenges have become more manageable in some ways because he has learned how to respond to his son's needs better. However, the physical and emotional strain has increased with time, especially without a partner's support. Mr. Sharma believes he needs more knowledge about alternative communication methods, behaviour management strategies, and vocational options for children with ASD as they grow older. Yes, he feels uncertain about his child's future especially related to long-term care, legal rights, and government support schemes. He also mentioned needing guidance on how to handle teenage behavioural changes in children with autism. He feels there is very limited support or awareness in the community. He often faces insensitive comments and misconceptions about autism, which makes him feel isolated. He has approached a couple of local therapy centres and NGOs. While some have been helpful, he mentioned that most services are expensive or difficult to access due to timing and lack of staff. According to him, caregiving is often seen as a woman's role, and as a father, he faces extra judgment. People often express surprise or doubt about his ability to care for his child properly, which adds emotional stress. He finds strength in his son's small achievements and progress. He also copes through reading, occasional exercise, and the support of a few close friends. Talking to other parents of children with autism also helps. The lockdown made things very difficult. His son's routine was completely disrupted, leading to behavioural issues. With no school or therapy, Mr. Sharma had to manage everything alone while balancing work from home. Yes, therapy sessions were stopped during the lockdown. Although some therapists offered online sessions, his son could not concentrate during video calls, making them largely ineffective. He suggests the establishment of government-supported daycare or learning centres for children with special needs. He shared that being a single father is emotionally and physically challenging, but he is proud of how far he and his son have come. He hopes more people become accepting and that systems become more inclusive. His suggestions include better financial support for single parents of children with disabilities, inclusive education, more training for teachers, and the creation of father-focused support groups to address their unique challenges.

RESPONDENT 3

The respondent, Mrs. Barman, is a 36-year-old mother residing in Guwahati, Assam. She completed her higher secondary education and is a homemaker. She lives in a joint family that includes her husband, in-laws, brother-in-law's family, and her two children. Her younger son, aged 6, has been diagnosed with autism. There are nine members in the household, including Mrs. Barman, her husband, their two children, her in-laws, and her brother-in-law's family. Her son usually avoids eye contact. He is close to her and shows affection in limited ways. With others in the family, he is mostly quiet and prefers to stay in his comfort zone. She mentioned that although she is the primary caregiver, her in-laws, especially her mother-in-law, provide occasional help such as watching the child when she is busy with household chores. However, there is still a lack of deep understanding of autism among family members, which sometimes causes misunderstanding and family dispute. Her biggest challenges include managing her child's unpredictable behaviour while also attending to the needs of other family members. The joint family setup adds pressure, as not everyone is supportive or patient with her child's condition. Balancing caregiving with household expectations is emotionally draining. Initially, the family was in denial about the diagnosis. Over time, some members have started to accept it, but understanding remains limited. She feels more isolated within the family despite being surrounded by people. Mrs. Barman expressed a need for information in simple language about behaviour management, speech therapy exercises that can be done at home, and how to teach daily living skills. She admitted she is not well-informed about government schemes or support networks for children with autism. She also lacks guidance on how to manage sensory issues or deal with public behaviour challenges. She believes awareness is very low. Neighbours and extended family often label the child as "naughty" or "spoiled," which causes emotional pain and isolation. She visited a therapy centre on a few occasions, but managing travel and therapy appointments with the responsibilities of a joint household is difficult. She has not received much external support yet. She feels the burden of caregiving automatically falls on the mother. In a joint family, the expectations from daughters-in-law are high, and she is expected to manage both household responsibilities and caregiving without much acknowledgment or relief. She finds peace in spiritual practices and in the rare quiet moments when her child is calm. Speaking with other mothers at therapy sessions gives her comfort and reassurance. During the lockdown, the child's routine was severely disrupted. Therapy sessions stopped. Additionally, with all family members at home, she had more responsibilities and less personal time, which made the situation very stressful. All therapy was paused, and she did not know how to conduct activities at home. No one in the family could assist her, and she felt completely overwhelmed. She suggests that there should be more awareness programs in local communities, mobile therapy services, and training workshops for family members. She also emphasized the need for home-based guidance and emotional support for mothers. She shared that living in a joint family has its pros and cons while there is occasional help, there is also judgment and lack of understanding. She hopes that society and families become more empathetic toward mothers of special children. Her suggestions include awareness drives in local neighbourhoods, basic autism training for family members, and stronger community-based support systems for home-bound caregivers.

RESPONDENT 4

The respondent, Mrs. Begum, is a 30-year-old mother living in a low-income neighbourhood in Guwahati, Assam. She has studied up to class 8 and works as a part-time domestic helper. Her husband works as a daily wage labourer. They have two children, and the younger one, aged 5, has been diagnosed with autism. Her family consists of four members herself, her husband, and their two children. She described her son as loving but difficult to handle. He cannot speak properly, often throws tantrums, and does not respond when called. He clings to her most of the time and is easily frightened by noise or strangers. She is the sole caregiver. Her husband goes out for work early and returns late. He helps, when possible, but most of the time, she manages alone, even while working in multiple households to earn money. Mrs. Begum faces several daily challenges such as managing the child's behaviour, feeding, ensuring safety, and attending to household chores. The child requires constant attention, and she cannot leave him alone, making it hard to go to work or attend social functions. Initially, she did not understand what was wrong. Over time, after visiting a government hospital, she learned about autism. While her understanding has improved, the financial burden and emotional stress have increased. She needs basic information in her local language about how to teach her son to speak, behave, and do small tasks independently. She is unaware of any rights, government support, or free services. She does not know where to go for help beyond the local health centre. Most neighbours believe her child is "mad" or "cursed." People make comments and ask her to keep him indoors to avoid shame. She once went to a government hospital, where a doctor mentioned autism. But she was not given further guidance. She has not been able to approach any NGOs due to lack of information and fear of being turned away. She believes women, especially mothers, are expected to bear everything. Nobody asks the father what he's doing for the child. In poor families, caregiving is not even seen as work it's just expected from the mother. She finds strength in her child's small progress. When he tries to make eye contact or smile, it gives her hope. She loves to sing so whenever she is stress, she sings. The lockdown made things worse. Her husband lost work, and her child became more aggressive due to being stuck indoors all the time. They could not afford medicine or therapy, and she had to stop working temporarily. Any access they had stopped completely. She does not have a smartphone for online therapy and did not know how to ask for help. She suggested that free therapy services should be made available in local health centres. Social workers or community health workers should visit homes to educate mothers. Financial help, even small, would make a big difference. She said that being poor and having a special child is a double burden. People do not understand, and there is no one to guide them. She feels invisible most of the time but wants to do her best for her child. Her suggestions include free therapy and education at government centres, training for poor mothers in local languages, monthly financial assistance, and neighbourhood awareness programs to reduce stigma and isolation.

RESPONDENT 5

Mrs. Das is a 36-year-old working mother residing in Bhangagarh, Guwahati. She holds a bachelor's degree in commerce and works assistant in a private college. Her family consists of four members that are her husband, who is employed in a government office, and their two children. Her younger son, aged 6, has been diagnosed with Autism Spectrum Disorder (ASD). The child is deeply attached to his mother but struggles to communicate with others. He often experiences meltdowns, especially when there is a change in routine or in unfamiliar social situations. Rina's husband contributes to caregiving in the evenings, while their 10-year-old daughter tries to engage her brother in simple activities. However, most caregiving responsibilities fall on her. One of the main challenges she faces is balancing her job with her son's care. Managing therapy sessions and addressing his emotional needs after a long workday is particularly exhausting for her.at first the experience was emotionally overwhelming and confusing for her. Over time, she has gained more knowledge and learned to cope better, although the mental and physical fatigue continues. She feels the need for more information on behavioural therapy, available speech therapy services in Guwahati, and nutritional guidance for children with ASD. She believes she lacks adequate understanding of managing sensory processing issues and preparing her child for integration into a school environment. According to her, awareness in the community is very limited. Many people still perceive her child's behaviour as mischief or poor discipline. she reached out to a local NGO that provided initial guidance, conducted an assessment, and connected her with a special educator. She feels societal expectations place the burden of caregiving on mothers. Fathers are rarely expected to alter their routines, which adds pressure on women. She copes by talking to other mothers in similar situations and practicing yoga to manage her stress. The pandemic lockdown made caregiving more difficult. Therapy sessions stopped, her son became more stubborn, and she had to manage working from home while handling his increased emotional needs. Therapy became irregular and was conducted online, which she felt was not effective for her son. She suggests the establishment of more affordable and accessible therapy centres, the creation of support groups, and the availability of flexible working conditions for mothers. She described the journey as one that demands immense patience and strength. She cherishes every small improvement as a significant milestone. She recommends increasing public awareness through community programs, hiring more trained professionals in government hospitals, and offering financial aid to support therapy for children with ASD.

RESPONDENT 6

Mrs. Sharma is a 43 year-old middle-class mother living in Guwahati, Assam. She holds a bachelor's degree in arts and previously worked as a schoolteacher but left her job to become a full-time caregiver to her 7-year-old son, who has been diagnosed with Autism Spectrum Disorder (ASD). Her husband is employed in a private sector. The family includes her husband, her son, and herself. Her child is affectionate but struggles with verbal communication. He often shows signs of hyperactivity, has difficulty concentrating, and becomes frustrated when he cannot express himself. He clings to her and is uncomfortable around strangers or unfamiliar environments. Her husband supports financially and helps with some caregiving during weekends. However, she is the primary caregiver and manages daily tasks such as therapy sessions, feeding, and handling behavioural issues. Besides managing her son's behaviour and emotional needs, one of the hardest parts for her is dealing with judgment and lack of understanding from neighbours, extended family, and even some school staff. She feels isolated and often blamed for her child's condition or behaviour. She hoped for community support but soon realized that stigma runs deep. Over time, she has grown emotionally stronger, but the constant need to defend and explain her son's behaviour has been mentally exhausting. She wants more awareness programs for the public, as well as guidance on behaviour management and inclusive education opportunities. She feels she lacks knowledge about her legal rights as a caregiver, how to advocate for inclusive education, and how to access government support schemes. She strongly believes that stigma is still prevalent. People often make hurtful remarks or suggest that poor parenting is the cause of the child's behaviour. she approached an NGO in Guwahati for guidance, where she received basic training and was connected to a therapy centre. However, she feels there is still a lack of emotional support for parents. She feels that as a mother, she is constantly judged if her child has a tantrum in public, people blame her directly. Fathers are not held to the same standard. Writing a personal journal helps her cope. The lockdown was extremely difficult. Her son's routine was disrupted, therapy stopped, and his behaviour worsened. She had to manage alone without any external help. Therapy was halted during the lockdown, and even afterward, it took time to resume full services. She tried online sessions, but they were not effective for her child. She believes schools and public spaces should be more inclusive, and support systems for caregivers including counselling should be made available. She shares that while the journey has been filled with challenges, it has also taught her patience, resilience, and unconditional love. She urges others to look beyond the label and see the child as an individual. She suggests regular community workshops, mandatory training for school staff on special needs education, and government-backed awareness campaigns to reduce stigma.

RESPONDENT 7

The respondent is a 34-year-old mother residing in Guwahati, Assam. She holds a graduate degree and lives in a joint family consisting of five members herself, her husband, their two children, and her mother-in-law. There are five members in the family. The child, who has been diagnosed with a developmental condition, often experiences meltdowns and has difficulty communicating. While he occasionally expresses affection in subtle ways, his behaviour is largely shaped by frustration and sensory overload, which impacts his interactions with others. The primary responsibility of caregiving falls on the mother. Her husband contributes, when possible, though his long working hours limit his involvement. The mother-in-law assists occasionally but is not deeply involved in daily care. The mother reports emotional exhaustion, difficulty managing the child's unpredictable behaviour, and a lack of personal time. Managing therapy sessions, household duties, and caregiving simultaneously is physically and mentally taxing. Initially, the family faced confusion and denial. Over time, while some coping mechanisms have developed, the challenges have intensified as the child grows, and his needs become more complex. She feels a need for clear, accessible information on managing behavioural issues, therapy options, and rights or schemes available for children with disabilities. Particularly regarding government support services, she feels she a lack of knowledge. She believes that support and awareness remain limited. While a few schools and therapists are beginning to recognize developmental disabilities, widespread stigma persists. Community understanding is superficial, and many families still hide their child's diagnosis for fear of judgment. She has reached out to a local non-governmental organization offering fortnightly support meetings, which she found informative but under-resourced. Then she went to a private therapy centre, where waiting lists and fees were prohibitive. lastly, she went to a government health service, which were accessible but lacked specialized therapists. Traditional gender roles place the burden of care squarely on mothers. Fathers are often unable to reprioritize work commitments. Extended family may criticize the mother's competence, reinforcing the notion that caregiving is "women's work." She cites several coping strategies such as she gets a brief "time-out" break when her mother-in-law steps in. She shares experiences with other mothers in an online peer group. She also goes to occasional outings with friends to recharge while she has stress. The lockdown exacerbated challenges such as all in-person therapy sessions where face to face or physical therapy were stopped. The child's routine was disrupted, leading to more frequent outburst and breakdowns. When home-based learning placed its burdens on her because she had to take on more responsibilities. The child struggled with online formats due to attention and sensory issues. She feels certain changes in access to services like therapy as many therapists shifted to teletherapy, but her child faced problems such as because of poor internet connectivity sometimes caused session dropouts. The child struggled with online formats due to attention and sensory issues. She suggests regular community awareness workshops to reduce stigma she also wants centralized helpline for information on government schemes and services. She emphasizes the emotional isolation caregivers face and the small victories like the child's first clear sentence that keep her resilient. She urges policymakers to remember that caregivers need emotional support.

RESPONDENT 8

Mrs. Mahanta is a 46-year-old mother. Her educational qualification is Higher Secondary passed now is a homemaker and full-time caregiver to her 8-year-old son who has been diagnosed with cerebral palsy (CP). she lives with her husband, who is a small business owner, and her mother-in-law at Bhangagarh, Guwahati. There are four members in her family she herself, her husband, her son, and her mother-in-law. Her son is a calm and loving child, though he often cries when he's in pain or uncomfortable. He is closest to her, as she understands his needs best. Her husband tries to help with physical tasks like lifting or taking him to appointments when he is not working. Her mother-in-law assists with small chores, but most caregiving responsibilities fall on her. Managing his physical needs, feeding, bathing, and transporting him is physically exhausting. They do not have access to nearby therapy centres and carrying him has taken a toll on her health. Earlier, she was hopeful that treatment would lead to quick improvement, but over time, she has realized it's a long process. Now, her energy levels are lower, and the emotional burden feels heavier. She wants more clarity on home-based physiotherapy techniques, disability rights, and government schemes available for children with Cerebral Palsy. She thinks she has lack of knowledge on especially regarding long-term care planning, assistive devices, and inclusive education options in Guwahati. She said that there is very little awareness in the society. Most people do not understand what CP is and often stare or ask inappropriate questions. She visited a centre in Ganeshguri for therapy advice, but they could not continue due to travel difficulties. In society, mothers are expected to give up everything for caregiving. Fathers are rarely judged if they're less involved, but mothers are. Spiritual practices and her husband's support also keeps her going. In the lockdown they were completely cut off from therapy and had no way to consult doctors. His muscles became stiffer, and they felt helpless. Therapy was stopped completely for several months. they tried to do some exercises at home, but without professional guidance, it was not very effective. Home visits by professionals, and a helpline for caregivers would make a huge difference and will be beneficial for the parents. She shared that caring for a child with CP is a full-time responsibility. It's lonely at times, but she has accepted this life with love. She suggests that local authorities should create more disability-friendly infrastructure and involve mothers in home-based exercises.

RESPONDENT 9

Mrs. Deka is a 40-year-old woman from Guwahati, Assam. She has a postgraduate degree in History and previously worked as a schoolteacher. However, she had to leave her job to care for her 5-year-old son who was diagnosed with cerebral palsy. There are seven members in her joint family, including her husband, children, and in-laws. Her child is gentle but highly dependent on her for all activities. He struggles with mobility and requires assistance with feeding, dressing, and movement. He enjoys being around family members but becomes anxious if separated from his mother. While her in-laws offer occasional help, such as feeding or watching the child for short periods, most of the caregiving responsibilities fall on her. Her husband assists when he is at home but is often at work. The greatest challenge she faces is managing therapy and medical appointments, which are both physically and financially draining. Having to leave her job has increased the financial burden on the family, and therapy sessions are expensive and frequent. In the beginning, the family was hopeful that therapy would bring quick improvement. But over time, the emotional and financial toll has increased, especially with ongoing therapy costs and assistive device needs. Mrs. Deka needs information on home-based exercises that could reduce dependence on paid sessions, and guidance on government schemes for children with disabilities. She feels uncertain about long-term care planning, financial aid opportunities, and inclusive education options. She believes awareness is still lacking. Even within the extended family, people do not fully understand the condition, which sometimes results in unrealistic expectations or insensitive comments. She has consulted a local NGO, which helped guide her to a physiotherapy center, but continuous expenses are still a major concern. She believes women are expected to make all the sacrifices. Despite living in a joint family, she is solely responsible for the child's care, while her husband's professional role is prioritized. She finds comfort in small gardening work. Listening to music also helps her cope emotionally. Therapy centers were closed in the pandemic, and home care became more difficult. The child regressed in mobility and flexibility during the lockdown period. Access was cut off temporarily, and she had to manage exercises at home without proper guidance. She suggests free or subsidized therapy services, awareness programs for joint families, and better inclusion in mainstream schools. She shares that despite living in a large household, caregiving can still feel lonely. It's a full-time role with little understanding or support from others. She believes that caregiving to a child with disability is very hard and all mothers and other caregivers should be strong. The government should also provide financial support to the economically weaker caregivers.

RESPONDENT 10

Mrs. Das, aged 37, lives in Guwahati with her joint family consisting of her husband, son, parents-in-law, and brother-in-law's family. She is a graduate in Commerce and used to work in a private office but had to resign to provide full-time care for her 8-year-old son with cerebral palsy. There are nine members living together in her joint family household. Her son is emotionally expressive and shows affection to family members. However, his mobility limitations and speech difficulties mean he often becomes frustrated or restless. While the family is generally supportive, day-to-day caregiving such as feeding, assisting with walking, and managing therapy is handled entirely by her. Managing time, household chores, and her son's intensive care needs is exhausting. The main problem she faces is that she cannot go anywhere leaving her son home. The financial burden of therapy is overwhelming, and she often must skip sessions due to cost, and this is affecting her son's progress. In the first stage the family helped more, but over time, most responsibilities shifted to her. Expenses increased as the child grew older and needed more professional support, equipment, and transport. She needs financial planning guidance, lists of free or subsidized services, and home-based therapy plans she can implement herself. She does not fully understand government disability benefits, rehabilitation grants, or how to enroll her son in a special school. Even family members sometimes view her son's condition as a "burden" or something to "hide." Society still stigmatizes children with CP. She tried reaching out to a few organizations, but they were either too far or had waiting lists. Currently her son is going to Shishu Sarothi and is a student of LLU. She says that as a mother, she is expected to give up everything, and if she complains, she is labeled as being selfish or weak. She finds relief in seeing even small progress in her child's health and movement. Occasionally talking to her mother also helps. It worsened the situation significantly in the lockdown. Therapy was irregular and her son lost some of the motor skills he had gained. The household financial situation also deteriorated. Therapy stopped during lockdown, and resuming it afterward was financially difficult. They still must skip sessions due to cost. She strongly recommends free community-based therapy programs, home visits by professionals, and financial schemes that meet therapy costs. She says she has learned to be patient but feels emotionally and financially drained. Living in a joint family does not always mean shared responsibility. She suggests government tie-ups with private therapy centers, better caregiver health insurance, and community awareness programs on cerebral palsy.

RESPONDENT 11

Mrs. Borah is a 34-year-old mother living in Guwahati, Assam. She has a bachelor's degree in education and worked as a part-time tutor before leaving her job to care for her 7-year-old daughter, who has cerebral palsy. Her daughter currently attends Sishu Sarothi for therapy and special education. She lives with her husband and her daughter in a nuclear family setup. There are three members in her family herself, her husband, and their daughter. Her daughter is cheerful and affectionate but has limited speech and mobility. She enjoys going to Sishu Sarothi and responds well to structured routines. At home, she is dependent on her for almost all daily activities. Her husband is supportive but works full-time, so most of the caregiving, including transport to therapy and home-based care, is handled by her. Transporting her daughter to and from Sishu Sarothi, maintaining therapy schedules, managing home responsibilities, and handling financial costs related to her child's care are her primary challenges. The physical strain of caregiving and lack of rest also affects her health. At first, she was overwhelmed and unsure about how to proceed. Over time, enrolling her daughter in Sishu Sarothi gave her hope and structure. However, the ongoing effort and emotional fatigue have continued. She wants more knowledge on home-based physiotherapy, assistive devices, and long-term planning for inclusive education and vocational training. She feels she lacks understanding of disability laws, educational rights for children with special needs, and how to secure financial assistance or government benefits. She feels that awareness is slowly growing, especially due to centers like Sishu Sarothi, but society still lacks sensitivity and often judges children based on their disabilities. Sishu Sarothi has been a major support system for her. The therapies and structured education there have helped her daughter improve, and the staff has also guided her as a parent. She believes that mothers are automatically expected to give up their careers and personal time. While her husband is supportive, all major responsibilities fall on her as the mother. The positive environment at Sishu Sarothi and seeing her daughter make small improvements give her strength. She also finds emotional support through interaction with her parents and friends. The lockdown was very difficult, and therapy sessions had to be done online, which was not as effective. She had to manage everything on her own, which was mentally and physically draining. in-person therapy was stopped during the lockdown. Though Sishu Sarothi tried to continue sessions online, the lack of professional hands-on support impacted progress. She suggests providing transport support for special needs children, and increased financial assistance for therapy, She shares that caring for a child with CP is a full-time job, but it's also a journey filled with emotional growth. She's thankful for organizations like Sishu Sarothi but believes more such centers are needed across Assam. Her suggestions include more therapy centers with government support, public campaigns to reduce stigma, and training programs for parents on managing special needs at home.

RESPONDENT 12

Mrs. Kalita is a 32-year-old single mother living in Guwahati, Assam. She completed her higher secondary education and was a homemaker before her husband's untimely death two years ago. After his death, her in-laws abandoned her and her child. She now lives with her own parents and her 6-year-old son, who has cerebral palsy. Her parents and younger brother are her sole support system. There are five members living together she herself, her son, her parents, and her brother. Her son is emotionally very attached to her and her parents. He requires constant attention, has limited mobility, and depends entirely on others for daily tasks. He gets anxious if She is not around but responds positively to her parents and uncle. Her parents are actively involved in caregiving. Her mother helps with feeding and bathing, while her father accompanies her to therapy sessions when needed. Her brother plays a major role in financial support and often helps manage appointments and transportation. Being a single parent, she finds it emotionally and physically draining to care for her child without a partner. Although her family supports her, she struggles with feelings of insecurity and dependence. Financial costs for therapy, special equipment, and medication are also constant stressors, though covered by her brother. At first, she had some support from her in-laws, but after her husband's death, things became much harder. Emotional pressure and loneliness increased, though her parents stepped in to help. As her son grows older, managing his needs has become more complex. She wants more knowledge about low-cost home therapies, emotional behavior management, and long-term support planning for single mothers of children with disabilities. She lacks understanding of legal rights for single mothers, financial schemes for disabled children. She often feels judged as a single mother. People assume the child's condition is the result of her personal failures or karma, which is painful and unfair. She reached out to a center that provides therapy. Her brother bears the cost, but accessing services is not always easy due to limited availability and transport challenges. She believes that as a mother and widow, she is judged more harshly. Expectations are placed solely on her to sacrifice, while fathers in similar positions might be seen as brave for "trying." Her parents' emotional support and her brother's financial help are her lifelines. She also finds peace through spiritual practices and drawing strength from her son's small progress. Therapy sessions stopped completely during the lockdown, and her child's progress slowed. She had to rely on her father to help with basic exercises at home, but the disruption had lasting effects. Access was severely affected. They had to shift to occasional online sessions, which were not very effective due to lack of interaction and hands-on guidance. She suggests that single caregivers should get special government support both financial and emotional. Counseling, free therapy access, and legal aid should be available for women in her situation. She says that while life has become difficult, she is proud of how her family came together to support her. She urges society to be kinder to single mothers raising children with disabilities. She recommends the government establish dedicated schemes for single mothers of disabled children, ensure accessible therapy in every area, and start awareness campaigns to reduce stigma in families and communities.

RESPONDENT 13

Mrs. Nath is a 38-year-old mother from Guwahati. She has a master's degree in Assamese literature and was working as a librarian before her son's diagnosis. Her 9-

year-old son has cerebral palsy, with limited speech and mobility. She lives in a nuclear family with her husband and son. Her son is emotionally sensitive and becomes easily overwhelmed in new environments. He prefers a predictable routine and shows distress if his daily schedule is disrupted. Her husband helps during evenings and weekends, but most caregiving tasks feeding, bathing, therapy visits, and communication with school staff are handled by her. Her biggest struggle is emotional isolation. Friends have drifted away, neighbors avoid inviting them to events, and she feels excluded socially. She also struggles with finding a school that will accept her child and provide inclusive education. She received some emotional support from friends and extended family. But over time, as caregiving demands increased, her social connections disappeared. She now feels invisible outside her caregiving role. She wants to learn how to prepare her child for school. She feels lost when it comes to legal rights regarding school admissions for children with disabilities and how to advocate for inclusive education. She feels people are unaware and often afraid of what they do not understand. Her child is often avoided, even by other children. She tried to seek support from a local NGO, but they had limited resources. She's now part of an online support group for parents, which helps emotionally. She believes society always expects the mother to sacrifice everything and is judged harshly if she shows signs of stress or seeks personal time. Reading, journaling, and connecting online with other mothers help her cope. The lockdown cut off therapy and made her son more anxious. She had to manage all care alone without any external help. And services stopped, and online sessions were not effective for her child. She Build more inclusive schools, train teachers, and offer mental health support for caregivers will be better. She wishes people would treat her son with dignity and not pity. She wants to see a future where he can learn and participate in society like any other child. She makes inclusive education compulsory, training school staff.

RESPONDENT 14

Mrs. Bhuyan is a 41-year-old mother living in Guwahati. She completed her education up to Class 12 and is a full-time homemaker. Her 10-year-old daughter has spastic cerebral palsy. She lives with her husband, daughter, and mother-in-law. Four members herself, her husband, daughter, and mother-in-law. Her daughter is friendly and loves music. Though her speech is limited, she responds with laughter, hand movements, and eye contact. She is calm and cooperative during therapy sessions. Her husband helps financially and drives them to therapy. Her mother-in-law offers moral support but is old and unable to help physically. She handles all physical caregiving tasks. Lifting her daughter, especially during bathing and dressing, is becoming more difficult as her daughter grows. The lack of accessible transport and wheelchairs makes every outing a challenge. Earlier, the physical burden was manageable, but now it's taking a toll on her back and arms. Her daughter also needs more frequent therapy, which increases travel. She wants to learn more about ways to improve her daughter's independence in small tasks. She does not know how to apply disability cards and support services through government channels. In her area, awareness is very limited. People are not rude, but they simply do not know how to help or what to say. She gets therapy support from a local center and recently learned about a special school in Rehabari from a neighbour. She believes that women naturally end up doing most of the care work, and society takes it for granted. Her daughter's smile and improvements in small milestones keep her going. She says she's thankful for what she has. She missed several months of therapy and could not find any transport. She used videos sent by the therapist to continue exercises at home. Services were completely shut during lockdown. After reopening, they had to wait for weeks to get an appointment. She suggests that therapy centers offer transportation support and caregivers be trained in basic physiotherapy techniques. says that with community support, things can improve. She believes in remaining hopeful and wants to learn more so she can help other mothers too. Provide affordable assistive devices, increase access to therapy in rural areas, and offer financial subsidies for middle- and lower-income families.

- **TEACHERS AS CAREGIVERS**

RESPONDENT 15

The respondent holds a degree diploma in Inclusive education and her teaching designation is special educator. She is experienced with children with disabilities for four years teaching learners with Autism and CP. She was drawn to this field after helping her younger cousin with developmental delays, which sparked a deep interest in inclusive teaching. She uses assistive technology where possible, breaks tasks into small manageable steps, and communicates with speech and occupational therapists. The workload sometimes affects her work-life balance, and she occasionally feels emotionally overwhelmed. However, she finds the work rewarding. Behavioural issues, communication barriers, and lack of proper support staff make the job difficult. She also struggles with large class sizes. She believes that initial teacher education did not fully prepare her for real-world scenarios. Most training is theoretical and lacks practical classroom applications. She sees improvement, especially through awareness campaigns, but some stigma and misinformation still exist among parents and even teachers. She notes that caregiving roles often fall to women, and male colleagues are less likely to be assigned special needs learners. She engages in mindfulness practices, attends peer support groups, and occasionally seeks professional counselling to manage emotional stress. The pandemic made it difficult to maintain consistency. Online learning was not effective for most of her students due to sensory and attention challenges. Parents also struggled to implement strategies at home. She recommends more practical training, availability of learning assistants, regular workshops, and a stronger support system within the school for inclusive education.

RESPONDENT 16

The respondent has six years of teaching experience and works at an inclusive elementary school. Her interest in special education developed through personal family experience. She holds a bachelor's degree in education with a specialization in special needs. Her class includes students with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP). She adapts materials by using visuals, technological tools, and social groups to support learning She explained that challenges differ depending on the disability:

autism often involves difficulties with communication and behaviour, whereas cerebral palsy mainly relates to physical accessibility issues. She has undergone training but emphasized the need for more up-to-date resources and continuous professional development. She has noticed increased awareness among school staff but feels that understanding and support are still limited in the wider community. she has participated in local advocacy efforts and supports initiatives such as workshops, peer education, and parent training programs. She believes that gender should not influence caregiving or teaching responsibilities and that duties should be shared equally. She copes with stress through relying on peer support networks. During the pandemic, she adapted by using virtual tools and provided coaching to parents to continue supporting their children's learning at home. She recommends increased co-planning time, more technological resources, and greater recognition for the work of special educators.

RESPONDENT 17

The respondent holds a degree in education and her teaching designation is special educator. She has 4 years of experience. She is dealing with two children with autism spectrum disorder and one child with cerebral palsy. She was introduced to inclusive education when her school started integrating learners with disabilities. Although hesitant at first, she developed a passion for it after seeing how much progress was possible with the right support. She focuses on physical support like helping with mobility and fine motor tasks, adapts classroom routines, and communicates regularly with physiotherapists. She also creates visual materials and modifies lesson plans for accessibility The demands of the role have left her with little time or energy for her family. She often feels emotionally depleted and struggles with guilt for not being present at home. Teaching consumes most of her mental space, even after school hours. She experiences burnout due to constant multitasking and emotional demands. The school lacks basic assistive equipment, such as proper seating and communication tools. She is frustrated that many parents do not reinforce learning or therapy at home, making classroom progress inconsistent. Additionally, her salary does not reflect the emotional and physical effort her role requires, which demotivates her. She feels underprepared. While she received basic training, most of her learning has been informal. She often has to research techniques herself or reach out to NGOs for guidance. She feels that although inclusion is talked about, many colleagues and community members still treat learners with disabilities as an afterthought. She believes her role was assigned largely because she is seen as "patient" and "motherly," not necessarily because of her skills, which she finds limiting and unfair. Her main coping method is emotional detachment—she tries not to carry every challenge home. Occasionally, she attends church support groups to find relief. During lockdowns, learners with CP regressed significantly due to lack of physical therapy. Remote learning was ineffective due to both technological limitations and low parental involvement. She advocates for better salaries, teaching assistants in inclusive classrooms, and mobile support units that can follow up with learners at home.

- CARETAKERS

RESPONDENT 18

She has worked as a general caretaker in a rural rehabilitation center for about two years. She assists children with feeding, dressing, and basic hygiene. She is responsible for three children with Autism and one child with Cerebral Palsy. She often does not know how to respond to certain behaviors. One autistic child bites and screams, especially when routines change. She lacks strategies to manage meltdowns. There are no therapy materials or safety equipment. The facility does not provide gloves or even proper seating for children with mobility issues. She believes most staff and community members think these children are just "mentally ill" or "possessed." She had never heard of Autism before working here. She thinks caretakers should be trained before working and should be paid fairly. More awareness is needed so people stop blaming the child or the parents. She feels women are expected to handle emotional outbursts and cleaning duties more than men. She prays and talks to her mother for emotional support. There is no counseling or help offered at work. She lost her job during the lockdown and was called back months later. She feels children's behaviours worsened after the break. The workload has increased but the pay has not. She also worries more about her health after the pandemic. She recommends training sessions, higher pay, and more support staff. She also wants breaks during the day.

RESPONDENT 19

He has been working as a caretaker in a state-run facility for five years. His duties include lifting, feeding, and monitoring children during activities. He assists with four children that are two with CP and two with Autism. He finds physical work exhausting, especially lifting older children. One child with ASD has bitten him several times. He also struggles to calm aggressive outbursts. Wheelchairs are broken or too old. Staff-to-child ratio is poor. There's no proper training or crisis intervention support. He thinks administrators treat children as a burden, and families do not know much about their children's conditions. He believes caregivers need mental health support and training on handling aggressive behavior. Safety gear like bite sleeves and more beds are needed. He feels male caregivers are expected to do heavy lifting but not emotional care. Women are often made to clean or soothe the children. He drinks tea, listens to music, and tries to rest. There is no counseling at work. He worked without protective equipment during COVID. He was afraid to bring the virus home. Children seem more sensitive and difficult to calm. There are fewer staff, and pressure has increased. He suggests hazard pay, better equipment, training, and hiring more workers.

RESPONDENT 20

She recently joined a private daycare and was assigned to work with special needs children without any prior experience or briefing. She looks after two children with Autism and one with mild Cerebral Palsy. She often does not understand why a child is crying or suddenly aggressive. She has been bitten more than once and feels unprepared to handle such behavior. There are no therapists on-site. No guidelines or materials are provided. She must improvise daily. She feels the school is more concerned about appearances than actual support. Most staff do not even know what CP or ASD really mean. She believes more workshops are needed. She also wants emotional support, as the job is mentally draining. She sees that women are expected to do the nurturing and emotional labor while men are kept away from challenging children. She talks to her sibling about the bad days but does not have any formal support system. She started working after the pandemic but says the children seem easily agitated and unresponsive at times. Protocols like masks and distancing were not followed consistently. She feels the children's learning regressed during lockdown. She suggests caregiver training, better salaries, and clear behavioral guidelines from professionals.

ANALYSIS

4.1 Challenges of Caregivers

This theme captures the multifaceted struggles faced by caregivers of children with ASD and CP, including physical, emotional, logistical, and societal barriers.

4.1.1 Daily Care Burden

Caregivers are responsible for round-the-clock tasks such as feeding, toileting, therapy management, and behavioural regulation. These demands are exhausting and often leave little time for personal rest or work. The continuous demands of caregiving can result in burnout, physical exhaustion, and mental health challenges. Mrs. Begum (Respondent 4) stated that managing the child's behaviour, feeding, ensuring safety, and attending to household chores. The child requires constant attention, and she cannot leave him alone, making it hard to go to work or attend social functions.

4.1.2 Social Isolation and Stigma

Due to widespread misconceptions about disabilities, caregivers often encounter social stigma, blame, and exclusion. This includes insensitive remarks, labelling the child as "naughty," or attributing the condition to parental failure. Stigma isolates caregivers, reduces social support, and exacerbates emotional distress. Mrs. Barman (Respondent 3) tells that extended family often misunderstand the child's behaviour, leading to disputes and isolation.

4.1.3 Informational Gaps

Caregivers lack access to clear, practical information about therapies, government schemes, legal rights, or long-term care planning. This gap leaves caregivers unprepared to advocate for their child's needs or access critical resources. Mrs. Das (Respondent 1) says that she lacks knowledge about government schemes and legal rights for children with disabilities and feels unsure about long-term care planning.

4.1.4 Balancing Other Work

The researcher got to know that juggling caregiving with employment or household duties creates immense stress, especially for working mothers or single parents. Financial pressures and role overload force caregivers to sacrifice career opportunities or personal well-being. Mr. Sharma (Respondent 2) says that managing his job and caregiving simultaneously is a major challenge.

4.1.5 Financial Constraints

It is seen that high therapy costs, loss of income due to quitting jobs, and lack of government aid create severe economic strain. Financial barriers limit access to essential services and worsen quality of life for families. Mrs. Kalita (Respondent 12*)* tells that financial costs for therapy and medication are constant stressors which are covered by her brother. This problem is found in most of the cases by the researcher. About all the parents going through financial crisis.

4.1.6 Physical Health

Caregivers experience physical strain from lifting, transporting, or assisting children with mobility challenges. Ongoing physical fatigue can negatively affect caregivers' health, reducing their capacity to effectively care for their child. Some of the parents are facing health related problems and Mrs. Mahanta (Respondent 8) says that carrying her son has taken a toll on her health. Managing his physical needs is exhausting.

4.1.7 Logistical Barriers

Limited access to therapy centres, schools, or trained professionals due to geographic or systemic limitations. Barriers delay interventions and reduce opportunities for the child's development. Mrs. Barman (Respondent 3) shares that managing travel and therapy appointments with joint household responsibilities is difficult.

4.1.8 Emotional Strain

Caregivers endure psychological stress from isolation, societal judgment, and the relentless nature of caregiving. Emotional strain can result in anxiety, depression, and a sense of helplessness. Mrs. Nath (Respondent 13) tells that her biggest struggle is emotional isolation. Friends have drifted away.

4.1.9 Transport Barriers

Many parents are facing difficulty commuting to therapy or medical appointments due to poor infrastructure, lack of accessible vehicles, or financial constraints. Transport challenges disrupt therapy consistency and limit access to critical services. One of the respondents (Mrs. Bhuyan) says that "The lack of accessible transport and wheelchairs makes every outing a challenge."

4.2. Need for Awareness and Advocacy

This theme highlights systemic and societal gaps in understanding disabilities, necessitating campaigns, policy reforms, and community education.

4.2.1 Lack of Community Awareness

This code refers the widespread ignorance about ASD/CP leads to stigma, exclusion, and harmful stereotypes e.g., labelling children as "cursed". These kinds of misunderstanding perpetuate discrimination and denies family's social support. Mrs. Begum (Respondent 4) shares that neighbours believe her child is 'mad' or "cursed." People make comments and ask her to keep him indoors to avoid shame.

4.2.2 Need for Public Sensitization

This theme talks about the advocacy for inclusive education, awareness campaigns, and training for teachers/community members because there is lack of public sensitization. It is believed that sensitization fosters empathy, reduces stigma, and creates inclusive environments. Many respondents emphasise the need of public sensitization. Mrs. Sharma (Respondent 6) says that Schools and public spaces should be more inclusive and support systems for caregivers are needed.

4.2.3 Lack of Policy Awareness

Caregivers are unaware of legal rights, disability laws, or government schemes e.g., financial aid, therapy subsidies. Policy gaps leave families unsupported and unable to secure their child's future. Mrs. Das (Respondent 10) says related to this theme that She does not fully understand government disability benefits, rehabilitation grants, or how to enrol her son in a special school. This issue is seen in all the cases.

4.3 Role of Gender in Caregiving

This theme highlights the societal norms disproportionately assign caregiving to women, while fathers face unique challenges and judgment.

4.3.1 Gendered Expectations

It is mostly found that mothers are expected to prioritize caregiving over careers or personal needs, even in joint families. Gender roles perpetuate inequality and overburden women. Mrs. Barman (Respondent 3) shares that in a joint family, expectations from daughters-in-law are high and she is expected to manage both household responsibilities and caregiving without much acknowledgment or relief. she is expected to manage everything.

4.3.2 Barriers Faced by Male Caregivers

The researcher code this while she interviewed one single father with his son with ASD. Only one respondent among all is under this code. Fathers who take on caregiving roles face scepticism or criticism, as caregiving is seen as a "woman's role." Stereotypes discourage male involvement and isolate single fathers. Mr. Sharma (Respondent 2) shares that as a father, he faces extra judgment, people doubt his ability to care for his child.

4.3.3 Gendered Judgement

This theme highlighted that mothers are scrutinized more harshly for their child's behaviour, while fathers receive leniency or praise for minimal involvement. Unequal scrutiny reinforces Mrs. Sharma (Respondent 6) says that if her child has a tantrum in public, people blame her directly... fathers are not held to the same standard.

4.4 Coping Strategies

This theme focuses that caregivers adopt emotional, social, and practical strategies to manage stress and sustain resilience.

4.4.1 Emotional Coping

The respondents use some emotional practices like spirituality, journaling, or hobbies help them to cope with stress and maintain mental health. Emotional outlets prevent burnout and foster resilience of caregivers Mrs. Begum (Respondent 4) shares She finds strength in her child's small progress child's small progress. When he tries to make eye contact or smile, it gives her hope. She loves to sing so whenever she is stress, she sings this helps her to relieve stress.

4.4.2 Family Support

Family support such as assistance from spouses, siblings, or extended family alleviates caregiving burdens. Shared responsibilities reduce isolation and improve well-being of the caregivers. Mrs. Kalita is a respondent who shares that her parents and brother are her sole support system, and her brother bears therapy costs. (Respondent 12):

4.4.3 Peer Support

Building connections with fellow caregivers offers emotional support, shared practical insights, and a sense of solidarity. Peer support is also the most common strategy adopted by most of the parents. Peer networks combat isolation and empower caregivers with shared knowledge. Mrs. Das (Respondent 1) states that connecting with other mothers in similar situations gives her comfort.

4.5 Impact of COVID-19

This theme highlights that the pandemic intensified existing challenges by disrupting routines, halting therapies, and increasing isolation. In this period almost every caregiver faced many challenges and issues which increased burden and stress among the parents.

4.5.1 Therapy Disruptions

Lockdowns halted in-person therapies, and online alternatives were ineffective for children with sensory or attention challenges. Disrupted therapies delayed developmental progress and increased caregiver workload. For example, Mrs. Sharma (Respondent 6) says that therapy was halted during lockdown and online sessions were not effective for her child.

4.5.2 Increased Care Burden

Caregivers managed heightened behavioural issues, household duties, and work-from-home responsibilities alone. The pandemic exacerbated physical and emotional exhaustion of the parents. Mrs. Barman (Respondent 3) tells that During lockdown, she had more responsibilities and less personal time, and she felt overwhelmed.

4.5.3 Gaps in Digital Access

In this code the researcher focuses on the gaps in digital access such as lack of smartphones, internet, or digital literacy which prevented access to online therapies or support. Marginalized families were further excluded from digital classes for their children. Because of many reasons many parents are not able to access to those digital resources as Mrs. Begum (Respondent 4) shares that She does not have a smartphone for online therapy, and she does not know how to ask for help.

TEACHERS

4.6 Challenges faced by the teachers

Teachers (caregivers) dealing with children with ASD and CP often experience intense emotional fatigue and physical exhaustion because of many reasons. The ongoing demands of caregiving, both inside and outside the classroom, leave them with little time or energy for personal life.

4.6.1 Emotional overwhelm

Caregivers feel mentally exhausted due to emotional demands. The burden is intensified by challenging behaviours, inadequate support systems, and lack of recognition, leading to feelings of helplessness, sadness, frustration, and burnout. Caregivers often serve as the primary emotional anchors for children with complex needs, managing tantrums, aggression, and communication barriers. However, without proper training or mental health support, these sustained emotional demands result in a buildup of stress. Respondent 15 said that sometimes she feels emotionally overwhelmed. Especially when a child keeps crying and she does not know what to do. This quote reveals a moment of vulnerability and self-doubt, a common experience among caregivers in under-resourced settings.

4.6.2 Lack of Systemic Support

Systemic gaps include insufficient classroom resources such as assistive tools, inadequate staffing as lack of learning assistants, and inconsistent parental collaboration. These challenges hinder effective caregiving. Respondent 15 shares that lack of proper support staff make the job difficult and she struggles with large class sizes. Respondent 17 also says that the school lacks basic assistive equipment and many parents do not reinforce learning or therapy at home, making classroom progress inconsistent.

4.6.3 Inadequate Training

Caregivers feel unprepared due to theory-heavy initial education. Real-world skills such as managing meltdowns, adapting lessons are often self-taught or learned through informal channels. Respondent16 shares that most training is theoretical and lacks practical classroom applications. Along with that Respondent 17 shares that she feels underprepared and most of her learning has been informal.

4.7 Need for Advocacy and Awareness

4.7.1 Stigma and Misinformation

Societal stigma and myths about disabilities persist, even among educators and parents. Misconceptions such as viewing ASD/CP as a “burden”, undermine inclusion efforts. Respondent 15 shares that some stigma and misinformation still exist among parents and even teachers. Respondent 17 also tells many colleagues and community members still treat learners with disabilities as an afterthought.

4.7.2 Institutional Advocacy

Caregivers demand systemic reforms, including better resources for example assistive tools, staffing such as teaching assistants, and policy changes for example salary equity. Respondent 15 says that recommends more practical training, availability of learning assistants, regular workshops, and stronger school support systems. Respondent 17 also states advocates for better salaries, teaching assistants, and mobile support units for home follow-ups.

4.7.3 Parental Engagement

Collaboration with parents is critical but often lacking. Caregivers’ express frustration when parents fail to reinforce therapies or strategies at home. Respondent 17 also states that they are frustrated that many parents do not reinforce learning or therapy at home.

4.8 Gendered Caregiving Responsibilities

4.8.1 Gendered Stereotypes

Caregiving is perceived as a "feminine" role, with women assumed to be inherently "patient" or "nurturing." This limits opportunities for male caregivers and reinforces gender bias. To this context Respondent 15 says that caregiving roles often fall to women, and male colleagues are less likely to be assigned special needs learners. And Respondent 17 says that her role was assigned largely because she is seen as 'patient' and 'motherly,' not because of her skills.

4.8.2 Unequal Workload

Women disproportionately shoulder caregiving tasks, both in schools and households, perpetuating systemic inequality. Respondent 17 says that male colleagues are less likely to be assigned special needs learners.

4.9 Coping Strategies

This theme highlights the coping strategies practiced by the caregivers while there were stressed.

4.9.1 Peer and Professional Support

Caregivers rely on mindfulness, peer networks, and counselling to manage stress. These strategies provide emotional relief and practical advice. Respondent 15 tells that engages in mindfulness practices, attends peer support groups, and occasionally seeks professional counselling.

4.9.2 Emotional Detachment

To preserve mental health, some caregivers consciously separate work stress from personal life, though this can lead to feelings of disconnection. Respondent 17 shares that her main coping method is emotional detachment, she tries not to carry every challenge home.

CHAPTER V

DISCUSSION AND FINDINGS

This chapter presents the major findings derived from in-depth interviews with parents, caregivers, and special educators of children diagnosed with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP). The narratives highlight personal struggles, systemic barriers, and lived realities of those navigating life as caregivers within varying socio-economic, cultural, and family structures.

- **Caregiving is a Full-Time, Overwhelming Responsibility**

A recurring theme throughout the interviews was the demanding and relentless nature of caregiving. Most respondents reported that caregiving had become a full-time role, regardless of whether they were employed, unemployed, or had previously held a career. For caregivers of children with Cerebral Palsy (CP), the physical effort involved in lifting, bathing, and transporting a non-ambulatory child was particularly taxing. Mothers of children with Autism Spectrum Disorder (ASD) reported persistent emotional exhaustion due to the need to constantly monitor the child's behaviour, manage meltdowns, and maintain a highly structured daily routine. The burden was compounded by sleep disturbances, safety concerns, and the emotional toll of watching a child struggle with basic developmental tasks. Many caregivers mentioned that their own physical and mental health had deteriorated over time. These findings underscore the need to recognize caregiving as labour-intensive work requiring support and resources.

- **The Gendered Nature of Caregiving: Mothers as Primary Caregivers**

Gendered expectations played a significant role in shaping caregiving dynamics. In nearly every household, mothers were identified as the principal caregivers. Regardless of whether they were part of a nuclear or joint family, working or stay-at-home, the caregiving responsibilities that are ranging from therapy appointments to managing meltdowns which fell almost entirely on them. Fathers, while often supportive financially or during weekends, were rarely expected to modify their professional routines. Several mothers reported resigning from their jobs to become full-time caregivers. One mother shared that even in a house full of people, it is she who must manage everything such as his therapy, feeding, bathing. If she complains, she was told that she is being selfish. This recurring pattern highlights the entrenched gender roles that place the burden of care disproportionately on women, reinforcing the perception that caregiving is inherently a mother's duty.

- **Communication and Behavioural Challenges are Central Struggles**

Caregivers of children with both ASD and CP identified communication challenges as a primary source of stress. Many children were either non-verbal or had significant speech delays, which resulted in frequent behavioural outbursts due to frustration or sensory overload. Caregivers described their children as easily triggered by loud noises, unfamiliar environments, or changes in routine which are leading to meltdowns that were difficult to manage in public and private settings. Parents expressed a lack of knowledge and training in behavioural intervention strategies. Without access to tools such as augmentative and alternative communication (AAC) or consistent behavioural therapy, many caregivers felt helpless and emotionally overwhelmed. The lack of guidance on handling these issues at home left parents feeling unsupported and unprepared, further contributing to caregiver burnout.

- **Social Stigma and Misunderstanding Intensify Emotional Strain**

Caregivers across socioeconomic and educational backgrounds reported that stigma, both subtle and overt, was a persistent feature of their social environments. Children with developmental disabilities were frequently perceived as "naughty," "spoiled," "possessed," or even "cursed," reflecting deeply ingrained cultural misconceptions. Such views often resulted in social exclusion for both the child and the caregiver. Mothers shared that neighbours and even extended family members were unsympathetic or judgmental, sometimes avoiding the family entirely or offering unsolicited and harmful advice. Public meltdowns were met with stares, ridicule, or criticism, further exacerbating caregivers' feelings of shame and isolation. This emotional burden, combined with physical exhaustion, often led to depression, self-blame, and withdrawal from social life. These findings affirm the importance of community awareness and stigma reduction as part of any disability-inclusive policy framework.

- **Lack of Access to Services and Information**

A striking finding was the widespread lack of awareness among caregivers regarding government schemes, disability rights, and available support services. While a few respondents had approached local NGOs or therapy centres, many did not know how to apply for benefits, obtain disability certificates, or access inclusive education options. This knowledge gap was particularly acute among caregivers from lower educational or income backgrounds. Access to services was also impeded by infrastructural and financial barriers. Private therapy centres were often prohibitively expensive, and government centres, while more affordable, were either understaffed or lacked trained professionals. In rural and low-income urban areas, transportation to therapy facilities posed a significant challenge. These systemic gaps not only limit access to early intervention and rehabilitation but also deepen inequalities among families based on socioeconomic status.

- **COVID-19 Lockdown Exacerbated Existing Challenges**

The COVID-19 pandemic seriously disrupted the daily routines of families caring for children with disabilities. Almost all caregivers shared that therapy sessions either stopped completely or shifted online. However, online therapy did not work well for most children, especially those with attention, sensory, or communication challenges. For some families, it was not even an option because they did not have smartphones, internet access, or knew how to use digital tools. This sudden break in regular care caused many children to lose progress they had made particularly in areas like movement, speech, and managing emotions. At the same time, caregivers had to handle more household responsibilities without any outside help. Financial pressure also increased, as many families faced job losses and could not afford therapy or support services. These experiences highlight just how vulnerable these families are during emergencies and why there needs to be better planning and support for children with disabilities in times of crisis.

- **Coping Strategies are Rooted in Resilience and Peer Support**

Even with all the difficulties they faced, many caregivers found their own ways to stay emotionally strong. To manage stress, some caregivers found relief through spiritual practices, yoga, music, gardening, or journaling. What kept many of them going were the small moments of progress in their children like a smile, a new word, or a calm day. These small wins gave them hope and a reason to keep pushing forward. Talking to other parents in similar situations also made a big difference. Whether it was chatting informally at therapy centres or joining online support groups, connecting with others helped them feel less alone. These support groups served as safe environments where caregivers could exchange advice, share their feelings, and find understanding. Some caregivers even described these peer groups as "lifesaving," showing just how powerful and important community support can be especially when formal help is limited or unavailable.

- **Caregivers Express a Strong Need for Structured Support**

Caregivers consistently emphasized the urgent need for well-structured, easily accessible, and affordable support systems. They proposed several key measures, including:

a. Providing financial aid to help cover expenses related to therapy, mobility aids, transportation, and specialized education.

b. Offering home-based services such as physiotherapy, behaviour support, and speech therapy conducted by trained professionals.

c. Establishing centralized government helplines or one-stop service centres to provide clear information on legal rights, available programs, and referral services.

d. Launching community-wide awareness efforts through schools, healthcare facilities, and local organizations to foster acceptance and reduce the stigma surrounding disability.

e. Enforcing inclusive education policies that require teacher training and ensure that learning environments are accessible and accommodating for children with disabilities.

TEACHERS

- **Professional Motivations and Entry into Special Education**

All educators were driven by personal experiences, such as supporting family members with developmental delays or witnessing student progress during school integration. These experiences transformed initial hesitations into a commitment to inclusive education. The educators highlighted that witnessing tangible progress in students with disabilities strengthened their commitment to the field, emphasizing how lived experiences have shaped their career choices.

- **Teaching Strategies and Classroom Challenges**

Educators employ adaptive techniques like task simplification, assistive technology, visual aids, and collaboration with therapists to support learners. However, systemic barriers such as inadequate assistive tools such as adaptive seating, communication devices, inconsistent parental involvement in reinforcing strategies at home, and large class sizes. These challenges are exacerbated by resource shortages, leaving teachers to improvise solutions independently.

- **Systemic and Emotional Strain**

The role requires considerable emotional effort because of behavioural challenges, difficulties in communication, and the need to multitask in classrooms with limited staff. Teachers report burnout, guilt over work-life imbalance, and frustration with low salaries that do not reflect their workload. Infrastructure gaps, such as the absence of sensory-friendly spaces or mobility aids, further strain their ability to deliver effective instruction.

- **Gaps in Teacher Training and Professional Development**

Initial teacher education was criticized for being overly theoretical, lacking hands-on preparation for real-world scenarios like managing behavioural issues or adapting lessons. Educators compensate through self-directed learning, peer networks, and NGO collaborations. Current professional development programs fail to address emerging needs, such as trauma-informed practices or technology integration for diverse learners.

- **Sociocultural Attitudes and Gender Dynamics**

Persistent stigma and misinformation about disabilities exist among parents and colleagues, with some viewing challenges as behavioural rather than neurodevelopmental. Gender biases are evident, as female educators are disproportionately assigned caregiving roles, while male colleagues rarely handle high-needs students. This reinforces stereotypes and limits opportunities for equitable role distribution.

- **Impact of the COVID-19 Pandemic**

Remote learning disproportionately affected students with disabilities, leading to skill regression, particularly in those requiring physical therapy (e.g., cerebral palsy). Online platforms were inaccessible for learners with sensory or attention challenges, and low parental engagement hindered home-based interventions. The pandemic underscored the need for flexible, hybrid support systems.

- **Coping Mechanisms and Recommendations**

Educators rely on mindfulness practices, peer support groups, and professional counselling to manage stress. They advocate for systemic changes, including better salaries, teaching assistants in inclusive classrooms, practical training modules, and mobile support teams for home follow-ups. Additionally, they emphasize the need for awareness campaigns to combat stigma and workshops to empower parents and colleagues in fostering inclusion.

CARETAKERS (Professional Caregivers)

- **Lack of Training and Resources**

All three caregivers said they started their jobs without proper training. For example, Respondent 18 did not even know what Autism was before starting, and Respondent 20 was given the job of caring for special needs children without any instructions or support. They had to come up with their own ways to handle things because they did not have basic therapy tools, safety gear like gloves or bite sleeves, or working equipment such as wheelchairs or special seats. The facilities cared more about how things looked than helping the children. As a result, caregivers had to deal with difficult behaviours like biting or emotional outbursts without proper training or help from therapists.

- **Physical and Emotional Strain**

Caregivers experienced both physical and emotional stress from their work. They got tired from lifting children who could not move on their own (like Respondent 19) and sometimes got hurt by aggressive behaviours, such as biting. Emotionally, they felt worn out because they did not get support from their workplaces, and they had to deal with negative attitudes from society for example, some people called the children "possessed." Caregivers often felt guilty when they could not control difficult behaviours. Since there were no mental health services or counselling, they coped by praying or talking to family members.

- **Pandemic-Related Challenges**

COVID-19 made things even harder for caregivers. During lockdowns, some lost their jobs (like Respondent 18), and many children's behaviour got worse because their routines were disrupted and they missed out on therapy. Caregivers had to keep working without masks or safety gear and feared getting sick. Safety rules, like wearing masks or keeping distance, were not followed consistently, which made it harder to give proper care. After the pandemic, there were fewer staff members, more work, and children were more restless and difficult to calm.

- 5. Societal Stigma and Misunderstanding

Many people, including staff, families, and communities, had wrong ideas about disabilities. Children with Autism or Cerebral Palsy were often seen as "mentally ill," badly behaved, or even "possessed." Families often did not understand the child's condition, and some staff especially in government-run centres like Respondent 19 did not take their needs seriously. In private facilities like Respondent 20, appearances were more important than real support. These misunderstandings made it harder to give proper care and kept negative stereotypes alive.

CHAPTER VI

CONCLUSION AND SUGGESTIONS

CONCLUSION

This research highlights on the multifaceted socio-economic and cultural challenges faced by caregivers of children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP) in Guwahati, Assam. By conducting detailed interviews with a diverse group of 20 caregivers comprising parents, teachers, and institutional support staff, the study brought forth the emotional, financial, and social challenges that significantly affect the quality of care provided. The findings reveal that caregivers, particularly mothers, often bear the full weight of responsibility, receiving minimal assistance from their families or support systems. Key issues included a lack of awareness about existing welfare schemes, limited access to affordable therapies, emotional burnout, and deep-rooted gender roles that influence caregiving dynamics. The COVID-19 pandemic worsened these hardships, disrupting therapy and isolating families from much-needed support services. Despite these adversities, many caregivers demonstrated strong resilience, turning to spiritual beliefs, informal peer networks, and personal coping strategies. However, systemic limitations such as inadequate infrastructure, scarce professional support, and social stigma continue to hinder their efforts. Caregiving fathers, though few, often faced additional scrutiny due to societal perceptions.

This study shows that there is an urgent need to provide all-round support to caregivers. It calls for increased public awareness, practical training programs, financial aid, inclusive policies, and gender-sensitive interventions. Creating community-based support systems and ensuring access to quality services can significantly reduce the burden on caregivers. By addressing these critical gaps, society can move toward greater inclusion, where caregivers feel supported and children with disabilities are given equitable opportunities to thrive.

This chapter highlights the suggestions which the researcher wants to give by overviewing the findings of this study. there are systemic barriers such as financial strain, societal stigma, lack of training, and gender disparities that exacerbate caregiver burdens. This chapter transitions into actionable recommendations to address these issues, emphasizing community awareness, equitable policy reforms, and accessible support systems. The chapter underscores the needs and suggestions such as:

- In the very first this study recommends that there should be establishment of free, accessible workshops and certification courses for caregivers such for parents, teachers, and institutional staff, to equip them with practical skills in managing behavioural challenges, using assistive tools, and implementing home-based therapies. This type of training should focus on real-world scenarios, such as handling meltdowns in children with ASD or safe lifting techniques for children with CP, to address the widespread lack of preparedness reported by participants.

- This study recommends the implementation financial support schemes. It would be helpful if the government provided financial support, like monthly disability payments, low-cost therapy, and insurance for assistive devices. This kind of help could ease the financial stress on families, especially those who have had to give up work or reduce their income to care for a loved one full-time.

- It also suggests the launch of community awareness campaigns in the local areas. By organizing grassroots initiatives to combat stigma and misinformation about disabilities. Collaborate with local leaders, schools, and media to educate communities about ASD and CP, emphasizing acceptance and inclusion to reduce isolation faced by caregivers and children.

- This research also suggests promoting gender-equitable caregiving policies. Advocate for policies that challenge traditional gender roles, such as paid paternal leave for caregiving and workplace flexibility for fathers. There should be encouragement for male participation in caregiving through public campaigns to reduce stigma around men in nurturing roles.

- Improve support systems after the pandemic is also a suggestion of this study. There should be a set up a mix of online and in-person therapy options to keep care going during emergencies. Caregivers need training on how to use digital tools, along with access to affordable internet and devices. This will help them stay connected, even during future emergencies like the COVID-19 pandemic.

- This study suggests making education more inclusive because teachers require to be trained in how to support students with disabilities, and make sure schools have accessible features like ramps and sensory-friendly classrooms. Schools should also work with therapists to develop personalized learning plans for children with ASD or CP.

- Expanding access to local support networks is another suggestion of this study. There should be establishment of community hubs that provide essential services such as counselling, peer support groups, and respite care for caregivers of individuals with disabilities. These centres should also function as resource hubs offering guidance on government welfare schemes, legal entitlements, and affordable therapeutic options.

- Another recommendation is to make services easier to access in both rural and urban areas. Deploy mobile therapy units to underserved rural regions and enhance urban healthcare facilities with disability-inclusive infrastructure. Ensure accessible and affordable transportation options, including subsidized travel and wheelchair-accessible vehicles, to enable regular attendance at therapy and medical appointments.

- This study also suggests improving how policies are put into action and regularly checking to make sure they are being followed properly. For that the government should create dedicated committees to ensure the effective execution of disability welfare policies, such as the Rights of Persons with Disabilities Act. These committees should incorporate regular needs assessments of caregivers through surveys and feedback loops and actively involve them in shaping responsive and inclusive policies.

- Fostering multi-stakeholder collaboration is another suggestion of this study. Promoting partnerships among NGOs, healthcare professionals, and local authorities can help to build integrated and community-based care systems. Because of that NGOs can train community health workers to offer in-home support and guidance, easing the burden on centralized urban services and extending reach to marginalized populations.

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APPENDIX

Informed Consent

I, Purbashree Devi, a student of the Department of Social Work, Mahapurusha Srimanta Sankaradeva Viswavidyalaya (MSSV), Guwahati unit, am conducting academic research titled *"The Socio-Economic and Cultural Challenges Faced by the Caregivers of Children with Autism Spectrum Disorder (ASD) and Cerebral Palsy (CP)"* under the guidance of Dr. Deepshikha Carpenter, HOD(i/c). Your participation is voluntary, and you may withdraw or skip questions at any time. All responses will remain strictly confidential, no personal details will be shared, and data will be used for academic use only. By proceeding, you consent to your anonymized insights contributing to this study. For queries, contact me at purbashree93@gmail.com. Thank you for your valuable contribution.

Purbashree
Devi
Roll no. MSW-09/23
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Semi- Structured Interview Schedule

(for parents)

Q1: Can you tell me a little about yourself and your family?

- Name.
- Age:
- Educational Qualification:
- Place of residence:

Q2:_How many members are there in your family?

Q3: How the child's behaviour towards them?

Q4: How the other family members take caregiving responsibility?

Q5: What are the challenges you face on daily basis in caring your child?

Q6: How have these challenges changed out time since the child was first diagnosed?

Q7: What type of information do you feel you need to effectively care for your child?

Q8: Are there any specific issues on which you think you have lack of knowing?

Q9: Do You feel there is enough support and awareness about children with ASD and CP in your community?

Q10: Do you have any experiences in seeking help from any organization?

Q11: How does gender affect the support of children?

Q12: What helps you to cope with the stress or challenges of caregiving?

Q13: How did the lockdown of covid19 pandemic affect your ability to care for the child?

Q14: Were there any changes in access to services like therapy?

Q15: What do you think could be done to better support caregivers like you?

Q16: Is there anything else would you like to share about your experience?

Q17: What are the suggestions you want to provide?

(For Teachers)

1. Educational qualification:
2. Teaching designation:
3. Years of teaching experience:
4. Experience with children with disabilities:
5. Current number of students with Autism or CP in your class:
6. How did you become interested in working with children with disabilities?
7. What type of services are you providing to the children with autism spectrum disorder and children with cerebral palsy?
8. How does this role of special educator affect your personal life?
9. What are the most common challenges you face while teaching children with Autism or Cerebral Palsy?
10. Do you receive adequate training to handle these challenges?
11. Do you feel there is sufficient awareness in your school or community about Autism and CP?
12. Do you think gender plays a role in assigning responsibilities when it comes to teaching children with special needs?
13. What strategies or methods help you manage stress or emotional challenges in your role?
14. How did the COVID-19 pandemic affect your ability to teach children with Autism or CP?
15. What changes would you recommend to better support teachers of children with Autism and CP?

(For Institutional Caretakers)

1. What is your role and how long have you worked with children with Autism or Cerebral Palsy?
2. How many children with Autism and/or CP are currently under your care?
3. What are the most common challenges you face when caring for children with Autism and CP?
4. How do resource limitations affect your caregiving work?
5. Do you feel there is enough awareness about Autism and CP in your organization or community?
6. What kind of advocacy or support do you think is most needed for caregivers and children?
7. In your experience, does gender influence how caregiving responsibilities are assigned or perceived?
8. Are female caregivers expected to take on more caregiving duties than male caregivers?
9. What strategies or methods do you use to cope with stress and emotional strain?
10. How did the COVID-19 pandemic affect your ability to care for children with Autism and CP?
11. How has your experience as a caregiver changed since the pandemic?
12. What changes would you recommend to better support caregivers in your role?