

**A Qualitative Study on Mental Health and Caregiving practices of Parents of Children  
with Special Needs**

By

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A thesis submitted to Brac Institute of Educational Development in partial fulfillment of the  
requirements for the degree of Master of Science in Early Childhood Development

Brac Institute of Educational Development

Brac University

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## **Declaration**

It is hereby declared that

1. The thesis submitted is my original work while completing my degree at Brac University.
2. The thesis does not contain material previously published or written by a third party, except where this is appropriately cited through full and accurate referencing.
3. The thesis does not contain material that has been accepted or submitted, for any other degree or diploma at a university or other institution.
4. I have acknowledged all main sources of help.

**Student's Full Name & Signature:**

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## **Approval**

The thesis/project titled “**A Qualitative Study on Mental Health and Caregiving practices of Parents of Children with Special Needs**” submitted by Md. Taifur Islam (Student ID- 22355015) Summer, 2024 has been accepted as satisfactory in partial fulfillment of the requirement for the degree of Master of Science in Early Childhood Development in May 2024.

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## **Ethics Statement**

Title of Thesis Topic: **A Qualitative Study on Mental Health and Caregiving practices of Parents of Children with Special Needs**

Student name: Md. Taifur Islam

1. Source of population: Mothers of children aged not more than 07 months
2. Does the study involve (yes, or no)
  - a) Physical risk to the subjects- no
  - b) Social risk- no
  - c) Psychological risk to subjects- no
  - d) discomfort to subjects- no
  - e) Invasion of privacy- no
3. Will subjects be informed about (yes or no)
  - a) Nature and purpose of the study- yes
  - b) Procedures to be followed- yes
  - c) Physical risk- yes
  - d) Sensitive questions- yes
  - e) Benefits to be derived- yes
  - f) Right to refuse to participate or to withdraw from the study- yes
  - g) Confidential handling of data- yes
  - h) Compensation and/or treatment where there are risks or privacy is involved- yes
4. Will Signed verbal consent be required (yes or no)
  - a) from study participants- yes
  - b) Will precautions be taken to protect the anonymity of subjects- yes
5. Check documents being submitted herewith to the Committee:
  - a) Proposal- yes
  - b) Consent Form- yes
  - c) Questionnaire or interview schedule- yes

### **Ethical Review Committee:**

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## **Abstract**

To explore the mental health issues and caregiving practices of parents of children with special needs, a qualitative study was conducted. 8 in-depth interviews (IDIs) and one focus group discussion (FGD) with both parents of 3-8 years children who were selected purposively in Dhaka city. The content analysis method was followed to analyze the data. The findings show that maintaining a secure attachment with children, prioritizing their interests, and spending quality time and following daily routine with them are the most common practices among the parents. Mothers were more involved in caregiving practices than fathers. Parents mentioned common mental health issues like frustration, anxiety, and stress. Some parents also experienced social anxiety, panic attacks, and obsessive compulsive disorder. The study also revealed that parents faced challenges in child rearing practices, such as lack of family and social support, managing children's behavior, lack of institutional care and knowledge about child rearing. Most parents coped by accepting the situation, practicing self-care, and seeking help from mental health professionals. The study suggested a holistic approach, including parental care, family support, social services, institutional care, and government, NGO, and other organizations, to meet these challenges and provide healthy living for both the child and caregiver.

**Key words:** Parents of children with special needs, Caregiving practices, Mental Health, Challenges and Coping

## **Dedication**

*This thesis work is dedicated to my beloved family.*

## **Acknowledgment**

First and foremost, I want to express my sincere gratitude to Allah, the Almighty, for giving me the chance to further enhance my education. I want to sincerely thank Brac Institute of Educational Development for giving me the chance to pursue a post-graduate degree in Early Childhood Development. I am grateful to *Dr. Erum Mariam*, Executive Director of the Brac Institute of Educational Development, for choosing me for this Master's program and believing in my abilities. My supervisor, *Sakila Yesmin*, Senior Lecturer & Research lead, BRAC Institute of Educational Development, BRAC University, has been a tremendous inspiration to me throughout not only this thesis but also the entire Master's program, and I am very grateful for all that she has done. I have learned a lot of things that I didn't have any idea before. She guided me in such a way that I felt motivated to work on the completion of the thesis. Her feedback always inspires me to recognize my abilities and constantly better myself. I truly thank the BRAC IED faculties for their direction, feedback, and cooperation.

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## **List of Acronyms**

ADHD: Attention Deficit and Hyperactivity Disorder

ADD: Attention Deficit Disorder

CSNs: Children with Special Needs

WHO: World Health Organization

## **Chapter: 1: Introduction and Background**

### **Introduction**

Bangladesh is one of the world's most densely populated countries, home to almost 160 million people. According to the National Taskforce on Disability-friendly Disaster Management Affairs, there were 15, 93,070 officially registered disabled persons in Bangladesh as of 2018. 10% of the total population in Bangladesh, or about 16 million individuals, are thought to be disabled. Every year, a large number of newborns in the country are born with special needs as a result of various adverse factors such as low educational attainment, malnourishment, and insufficient maternity healthcare. Among the many children in Bangladesh who need special care are those with autism spectrum disorder, cerebral palsy, Down syndrome, deaf-blindness, intellectual disability, hearing impairment, physical impairment, speech impairment, visual impairment, and multiple impairments. Indeed, we are witnessing a generation that has a high level of sensitivity to early development, particularly when it comes to newborns who have special needs. This hypersensitivity stands in stark contrast to the challenges parents often have in trying to help the children develop adaptive social behaviour, which includes, among other things, making enough progress in education.

Parents have a significant influence on an individual's development, particularly from the early years and till adulthood. A young person's development of a well-rounded and emotionally stable personality requires strict guidance and effective parental care. Especially when moving from a large family to a nuclear family and then back to a single-parent home. To effectively manage and rectify any undesirable behavioral traits that their child may exhibit, parents work to recognize their child's individuality and address any deviations with compassion and knowledge. In order to successfully regulate their child's level of engagement and obedience, parents employ

a variety of parenting strategies, including the deliberate management of both nurturing and punishment. Parents have different parenting styles, and the level of rigor and demands they place on their children will determine how responsive and assertive they are.

Despite the challenges of parenthood, raising children with special needs has resulted in more complex duties for parents (Jambekar et al., 2018). Managing a variety of evolving standards that are unique to each child's needs is a common challenge for parents of special needs children (Isa et al., 2016). When parents find out their children have special needs, they could feel conflicted about it (Sen & Yurtsever, 2007). Having children with certain illnesses, such as autism, Attention Deficit Hyperactivity Disorder (ADHD), and other disorders, probably made parents' psychological difficulties worsen. Compared to parenting children who are usually developing, parenting children with special needs can lead to problems with family functioning, parental distress, and inconsistent parenting styles (Masulani-mwale et al., 2018). When a child has special needs, parents can encounter emotional and social difficulties.. They often experienced a wide range of negative feelings, including stress, worry, and melancholy, as a result of increased concern for their own and their children's futures, which may have an impact on their wellbeing (Parameswari & Eljo, 2009). Furthermore, they were far more likely to suffer from psychological distress than parents of neurotypical children. According to Drapéau et al. (2012), psychological distress is a state of emotional suffering marked by signs of anxiety and despair. It has been demonstrated that children who have high levels of internalizing and externalizing concerns experience a considerable amount of stress (Ricci et al., 2017). Given that parents bear the lion's share of the growing everyday care load for young children, they may be more susceptible to extreme stress and, in some cases, depression (Kobayashi et al., 2012). Therefore, determining the extent of the psychological distress that parents of children with special needs endured was

crucial to the development of practical remedies, therapies, and methods to support and help these parents. Previous research indicate that parents of special needs children experience numerous difficulties on a regular basis. However, compared to parents of generally developing children, parents of special needs children encounter more physical, social, and emotional issues (Sen & Yurtsever, 2007). In addition, they are more likely to encounter an elevated susceptibility to psychological distress and encounter a range of mental health issues, including anxiety (Wolf et al., 2026), depression (Kucuk et al., 2018), marital discord (Hartley et al., 2017), and sleep disturbances (Neece et al., 2017). Parents who have children with special needs may experience several sorts of mental health issues, but anxiety and depression are the most prevalent (Gerstein et al 2009). The levels of anxiety and depression in parents of special needs children were markedly greater compared to parents of generally developing children, as indicated by a study conducted by Gerstein et al in 2009. On the other hand, Blekeley et al. (2012) found that there was constant and significant concurrence between parents and children in the assessment of anxiety and depression. Research has indicated that parents of children with autism spectrum disorder tend to have a higher prevalence of mental health issues compared to parents of children with other types of disability, such as intellectual disabilities (Baker et al., 2011). Previous research has examined several anticipated factors that influence the mental well-being of parents with special needs children, including economic and social standing (Emerson et al., 2013), joblessness (Ellis et al., 2002), stress related to parenting (Estes et al., 2013), behavioral issues in children (Davis et al., 2008), and social assistance (Ekas et al., 2010). Typically, parents of children with special needs must consistently pursue additional specialized care, medical devices, and educational programs, which are more likely to result in increased financial strain (Emerson et al., 2015). Meanwhile, it is necessary for one of the parents to consistently fulfill the

role of primary caregiver for the special needs children, which can lead to a general decrease in the family's capacity to engage in employment and result in a reduction of the family's income (Venneilich et al., 2016). Consequently, parents of children with special needs consistently face hardship due to their inferior economic and social standing or unemployment in comparison to their peers (Gerstein et al 2009), which worsens mental health issues (Venneilich et al 2016). Furthermore, parents face significant challenges in dealing with the profound behavioral and emotional difficulties exhibited by special needs children, as well as the immense pressure associated with raising such children (Totshika et al., 2014). In comparison to typically developing children, special needs children are more prone to displaying externalized behaviors, such as challenges in communication, impaired social connections, and oppositional defiant disorder (Fauth et al., 2017). The spectrum of severe behavioral issues consistently intensifies parental stress and precipitates parents into a cycle of poor mental well-being. The occurrence of regulation difficulties in children, such as sleep problems, is linked to a decline in the mental well-being of parents (Mörelus et al 2014). The co-occurrence of children's behavioral problems with parenting stress consistently predicts parental mental health. In addition, other research has indicated that social support has a crucial role in diminishing parenting stress and enhancing their capacity to manage mental health issues (Ekas et al., 2010). Unfortunately, parents of children with special needs are frequently marginalized by society and receive less attention. However, it has been shown time and time again that parents who view raising special needs children positively usually report higher levels of social support (Ekas et al., 2010). The mental health problems that parents of special needs children have are made worse by these risk factors.

## **Statement of the Problem**

The global prevalence of children with children with special needs is on the rise. In recent decades, scientists from several disciplines have increasingly focused on the challenges faced by parents raising children with special needs children and the psychological and social effects this has on them. These topics have gained prominence in public health debates and conversations worldwide. Parents of children with special needs often face greater social, psychological, physical, and economical challenges than parents of children without such difficulties (Krenawi et al., 2011). The primary causes contributing to the burden include social stigma and the absence of both informal and institutional support structures to address the difficulties associated with child-rearing in developing nations such as Bangladesh (Tigere & Makhubele, 2019). These events frequently have a detrimental impact on their mental health, psychological well-being, and family life (Verma & Kishore, 2009). The responsibility of caring for children can lead to various manifestations and intensities of depression, anxiety, and elevated levels of stress, sadness, concerns, grief, and resentment (Uskan and Gundogar, 2010).

There are a minimum of two causes that can account for the documented elevated occurrence of mental illness in parents of children with special needs. Initially, parents may modify their social and family routines to suit their children, as the task of caring for a child with special needs is a substantial obligation that amplifies the intricacy and extent of the parent's role (Boyd 2002).

Approximately 25% of parents with children who have impairments indicated that their social life is impacted by their caregiving responsibilities. Furthermore, 30.8% of parents reported a complete loss of contact with friends, relatives, and even their extended family (Heiman et al., 2002). Parents with children with special needs reported lower levels of relationship satisfaction compared to parents of children without special needs, as found in a study by Santamaria et al. in



2012. Based on the Australian Bureau of Statistics (2009), 21.2% of primary caregivers of children aged 0-14 with disabilities reported having a difficult relationship, while 23.3% of primary caregivers reported not having enough time alone together. Furthermore, it is widely recognized that providing care for a child with special needs can lead to financial strain on the entire family as a result of heightened expenditures and reduced income (Zeng et al., 2017). Childhood disabilities typically presents as a long-term condition that can substantially raise the financial burden on families. For instance, according to Zeng et al (2017), 35.3% of parents saw a notable rise in their living expenses upon assuming the role of primary caregiver. Conversely, considering that parents of children with special needs must allocate time to care for their children, a significant number of them modify their work schedules to accommodate their parental duties (Barnett et al., 1995). Approximately 45.5% of employed parents with special needs children experienced a decline in their engagement in the workforce after taking on their caregiving responsibilities, while 37.3% of them reported a fall in their household income. In general, parents may undergo feelings of sorrow, seclusion, and significant strain, resulting in mental health conditions such as sadness and anxiety (Singer et al 2006).

Current research suggests that barriers exist that hinder parents of children with special needs from obtaining mental health care. Participating in caring duties presents difficulties in scheduling appointments (Gilson et al., 2018). Parents of children with special needs may prioritize their children's well-being over their own and may be reluctant to seek help for their own health concerns (Schulz et al., 1999). Moreover, there is convincing evidence suggesting that the support available for parents of children with special needs is inadequate, along with the challenges they may face. Research indicates that over 19.1% of primary caregivers were dissatisfied with the support resources meant to help them with their caregiving duties. The

percentage of parents with children with impairments requesting more help increased from 40.5% in 2012 to 57.4% in 2018, suggesting unmet needs within this group. The Convention on the Rights of Persons with Disabilities defines disability as long-term physical, mental, intellectual, or sensory problems that hinder individuals from participating in society. More over one billion individuals globally have disabilities, and the percentage of individuals with intellectual disability is nearly twice as high in developing nations. In Bangladesh, the prevalence of impairments ranges from 1.4% to 9% of the population. Parenting children with intellectual disabilities negatively affects quality of life, mental health, satisfaction with life, and marital relationships. Studies indicate that parenting children with exceptional needs impacts parents' mental health and their coping mechanisms for handling these difficulties. (Gray, D.E. 1993).

### **Purpose of the Study**

The purpose of the study was to explore the mental health issues and caregiving practices among the parents of children with special needs.

### **Specific Objectives**

- To understand the caregiving practices of the parents of CSNs
- To understand the mental health issues of the parents who have CSNs
- To understand how mental health issues impact on child-rearing practices
- To know the coping strategies of the parents to deal with their mental health issues

### **Significance and Justification of the Study**

The prevalence of intellectual disability in children is widespread and is on the rise due to the global increase in child survival rates. Based on the survey, 1.7% of children in Bangladesh have

one of the twelve disabilities specified in the Persons with Disability Rights and Protection Act 2013. Additionally, 3.6% of children experience functional challenges in at least one of the following areas: vision, hearing, mobility, fine motor skills, communication, learning, play, or behavior control. Previous studies have shown that parents, especially mothers, of individuals with autism spectrum disorders (ASDs) are more likely to face mental health challenges like parenting stress, depression, suicidal thoughts, anxiety, and other emotional disturbances, including stigma (Al-Farsi et al., 2016; Montes and Cianca, 2014; Patra and Patro, 2019). The consequences of this negative psychosocial environment could be very serious. There have been reports indicating a high probability of parents committing filicide, specifically targeting children with special needs, and then promptly committing suicide themselves. 55% of filicide victims were children with Autism Spectrum Disorder (ASD), with parental depression being the most often recognized risk factor (Coorg and Tournay, 2013). Singer conducted a meta-analysis of 18 comparative studies in 2006, revealing that 29% of mothers with children facing developmental challenges, such as Autism Spectrum Disorder (ASD), were reported to be suffering from depression. Over 90% of suicide instances are linked to psychiatric issues, with depression being the main determinant (Mamun and Griffiths, 2019, 2020; Mamun et al., 2020). Previous research has found a high occurrence of suicidal behaviors and suicide among individuals with Autism Spectrum Disorder (ASD). However, there has been no previous study that specifically investigated the tendency for mothers of children with ASD to exhibit suicidal thoughts or actions (Gilson et al., 2018; Storch et al., 2013). Moreover, there is a growing trend of ASD prevalence rates worldwide. Taking this increase into account, it is expected that a significant number of mothers with ASD children (MwASDC) will experience psychiatric comorbidities, such as depression and suicidality, compared to mothers with typically developing children

(MwTDC) (Gyawali, and Patra, 2019; Manohar et al., 2020). However, there is a lack of empirical evidence on this matter, which is the main focus of the present study. The findings demonstrated that mothers of children with autism experienced higher levels of parenting stress. There was a notable disparity in gender and a noteworthy correlation between children's social interaction and behavior with autism, as well as parenting stress. Greater emphasis should be placed on addressing the needs of parents, particularly women. Efforts should be made to establish social support systems and use various coping mechanisms to effectively address the evolving needs of individuals and alleviate the stress experienced by parents raising a child with Autism. The study results will offer valuable insights to the parents with special needs, mental health professionals, ECD workers, policy makers etc. in Bangladesh, potentially aiding in the reduction of parenting stress experienced by moms of children with autism. The social, cultural, and religious aspects of parenting and the dynamics of the husband-wife relationship in Bangladesh differ from other contexts. In Bangladesh, parents are not considered as distinct individuals, but rather as integral members of the entire family unit. Typically, the choice to care for and raise the newborn is affected by other family members. Due to its high value placed on social and familial connections, the country considers them to be of utmost importance (Habib et al., 2018). Nevertheless, there is a scarcity of knowledge regarding the psychological and relational aspects of raising a child with an intellectual handicap in the specific context of a developing nation such as Bangladesh. The objective of this study is to address the lack of information in this area. As a result, the study looked at how having a child with an intellectual disability affects marital happiness and parents' mental health. This study compared parents whose children had intellectual disabilities to those whose children did not, looking specifically at the rates of depression and marital satisfaction. Additionally, the study looked at the parental

cohorts in Bangladesh to see what variables were associated with marital happiness and sadness. The present study aims to offer insights into the diverse parenting strategies implemented by parents with their children. This will provide information to other parents, researchers, service providers, and policy makers to aid them in their decision-making process and changing the strategies.

### **Research Question**

- What are the caregiving practices of the parents of children with special needs?
- What are the mental health issues faced by the parents during child rearing?
- What are the consequences of mental health problems in Parents' personal, professional and social life?
- What are the coping strategies that are followed by the parent to deal with their mental health issues?

### **Operational Definition**

A special needs child is a youth who has been determined to require special attention and specific necessities that other children do not. The state may declare this status for the purpose of offering benefits and assistance for the child's well-being and growth. Special needs can also be a legal designation, particularly in the adoption and foster care community, wherein the child and caregivers receive support to help them both lead productive lives. (Kagan, 2023)

#### **1. Mental Health abnormalities consist of:**

a. Elevated mental state frequently recognized for its population of intellectually brilliant children, who possess not only above-average intellectual abilities but also demonstrate notable levels of creativity and responsibility towards their tasks. (Gede Wira Bayu1 et al. 2019)

c. Cognitively impaired Individuals with below-average intellectual capacity, sometimes known as poor mental ability or IQ, can be categorized into two groups: slow learners, referring to children with an IQ ranging from 70 to 90. Children with an IQ below 70 are typically recognized as children with special needs. c. Learning disabilities learning challenges pertain to the attainment of academic achievements by students. Children with specific learning difficulties are those who possess average intellectual potential but exhibit below-average academic performance in specific academic domains. (Gede Wira Bayu1 et al. 2019)

**2. Physical abnormalities include:** a. Physical deformity (Tunadaksa) b. Visual impairment (Blindness) c. auditory impairment (Deafness) d. Speech impairments (Gede Wira Bayu1 et al. 2019)

**3. Emotional Disorders** Emotional disturbance is a psychological condition that is identifiable by observable behavioural manifestations. The taxonomy of emotional disorders include several indicators of disrupted emotional functioning. a) Behavioural disorder, b) Attention deficit disorder (ADD), c) Hyperactive children (ADHD). (Gede Wira Bayu1 et al. 2019).

### **Caregiving practices**

Caregiving Practices encompass the various approaches that parents employ to nurture their children, with the aim of fostering either positive or negative outcomes in society. Helping and consoling someone else is known as caregiving. Grocery shopping; assistance with dressing, eating, and toileting; or offering emotional support to someone else as they work through a physical, emotional, or health issue are just a few of the many tasks that can be included. In care giving, children are looked after and well at all phases of their lives and in all situations.

Youngsters are looked after both at home and in institutions. Caregiving methods are dynamic and change with the communities. (Jane Waithira Mbugua, 2011)

### **Mental Health Issues of the Parents**

Comprehending human behavior relies heavily on mental health. The state of our mental health has a significant impact on various dimensions of our lives, including our physical well-being, social interactions, and behavioral patterns.

Various organizations and researchers have provided different definitions of mental health, as outlined below: An individual is considered to be in a state of mental health when they are self-aware, able to cope with everyday stresses, have positive work outcomes, and are able to make positive contributions to their community (WHO, 2011).

According to Legg (2020), mental health encompasses our cognitive, behavioral, and emotional well-being. It revolves around our cognition, emotions, and actions. The phrase mental health is occasionally employed to denote the absence of a mental disease.

The U.S. Surgeon General (2000) defines mental health as the effective execution of mental processes, leading to productive endeavors, satisfying interpersonal connections, and the capacity to adjust to change and handle challenges.

Anxiety, depression, stress, discomfort, and other related conditions are significant aspects of mental well-being. This study will specifically focus on investigating the mental health concerns experienced by parents of children with exceptional needs.

## **Chapter: 2: Literature Review**

The mental health, coping mechanisms, and caregiving behaviors of parents with children with special needs are the main topics covered in this section. Many effects on central nervous systems (CNSs) are covered in the literature, which is organized into two main categories: global and Bangladeshi context.

### **Global Context**

Autism continues to be a complex illness for children and their families, both worldwide and specifically in Bangladesh. So far, a significant portion of the research on Autism has been carried out with a focus on individual countries and the global scale. A comprehensive review has been conducted on many pertinent sources such as articles, books, and research studies, focusing on autism.

Reviewing the pertinent literature connected to empirical research is an essential first step. Literature reviews provide a comprehensive understanding of the current knowledge in a specific field. Additionally, it aids in identifying the deficiencies in research. Regarding the goal of this study, the following discussion encompasses the research and pertinent evidence concerning the mental well-being of parents with autistic children in connection to their education, income, and employment status.

#### **i) Parents' Behavior in daily life**

In 2006, D. E. Gray did a research titled "Coping over Time: The Parents of Children with Autism". The study presents the findings of a long-term investigation on how parents manage the challenges of autism for around ten years. Parents who are raising a child with autism encounter significant challenges in managing problematic behaviors, facilitating their child's



communication, teaching fundamental life skills, ensuring their child's safety, and preparing their child for adulthood (Dyches et al., 2004).

The challenging symptoms, such as outbursts, self-harming behaviors, and other socially unacceptable actions linked to the disease, provide a significant challenge to manage. As a result, parents of children with autism often face angry or insensitive reactions from the public, primarily due to the inappropriate behavior exhibited by their children. The response from the general public towards such families is frequently characterized by stereotypical and unfavorable attitudes (Gray 1993).

Caregivers of autistic children may regard their children as having a more challenging temperament compared to typical children, leading them to employ more stringent management measures. Therefore, the way caregivers perceive their children's qualities can impact their interactions with them (Kesari et al 1997).

Research indicates that parenting has a significant impact on the externalization of children's behavior. Donna Hancock Hoskins (2014) examines the impact of parental behavior on the behavioral and emotional outcomes of children in her review. The author states that much focus has been given to the systems that determine parenting, which in turn affects the results of teenagers.

## **ii) Parent's Mental Health Condition**

The presence of significant risk factors might potentially trigger acute or chronic stress and trauma in parents of autistic children, which can subsequently result in dysfunctional parenting. The factors contributing to the challenges of diagnosing a child's disorder include: a) the uncertainty in determining the diagnosis; b) the seriousness and length of the child's disorder; c)

a significantly low intelligence quotient; d) deviation from societal norms, unusual patterns of speech and behavior; and e) persistent disruptive or disordered behaviors (Kourkoutas, et al 2012).

Parents of children with autism require social support to manage the stress and adjustment associated with raising a children with developmental difficulties (Meral et al., 2012). Parents of children with special needs are commonly believed to encounter adverse psychological consequences, such as an increased likelihood of depression, social seclusion, and marital conflict. Some parents may also undergo phases of incredulity, profound sorrow, and depression, as well as self-reproach and culpability, while others may suffer powerlessness, emotions of insufficiency, wrath, astonishment, and guilt (Gupta and Singhal 2005). Parental anxiety can be attributed to specific stresses such as anxieties about the long-term nature of their child's illness, societal disapproval of autistic behaviors, and lack of acceptance from other family members, and insufficient social support from fellow parents (Prince 2007).

The mental well-being of parents can be significantly impacted particularly when the disability is Autism Spectrum Disorder (ASD), which encompasses a broad spectrum of behaviors, particularly those related to social interactions (Nourin, 2009). Diverse research have indicated that various attributes of autistic disorders in children have distinct effects on the levels of stress experienced by their parents. The research also demonstrated a correlation between elevated levels of parental stress and the more severe symptoms seen by children with autism (Gupta & Singhal, 2005).

Several studies have also discovered that parents of children with autism have reported experiencing high levels of frustration and pessimism. These parents exhibit specific characteristics such as anxiety, schizoid traits, tension, aloofness, hypersensitivity, and rigidity.

These traits individually and collectively indicate the magnitude of stress experienced by these parents (Firat et al., 2002). In a study conducted by Tarabek (2011), it was found that parents with autistic children experience unique marital hardship and conflict.

Furthermore, a study conducted by Al-Dujaili and Al-Mossawy (2017) demonstrated that caregivers of autistic children reported having a significant degree of psychosocial load. These findings indicate a notable disparity between the psychosocial responsibilities of caregivers and certain demographic factors, such as gender and monthly income. Multiple studies have also indicated that having an autistic child in the household might lead to a substantial psychological load among other family members (Feinberg et al., 2014; Van Steijn et al., 2014).

Additionally, it is well-established that mothers take on the main role of child care (Firat et al., 2002). Researchers Foody et al. (2015) found that caregivers of neurotypical children have lower levels of anxiety than caregivers of children with Autism Spectrum Disorder (ASD). Another study indicated that compared to caregivers of typically developing children, those caring for autistic children were more likely to report depressed symptoms (Lajiness-O'Neill & Menard, 2008). Caregivers of children with Autism Spectrum Disorder (ASD) endure more psychological distress than parents of typically developing children, according to research by Yirmiya and Shaked (2016). The mental health of moms was the focus of a study by Shu et al. (2000).

In a similar vein, Fairthorne et al. (2015) conducted a study on Autism Spectrum Disorder (ASD) in which they gathered a total of 60 papers. The study findings revealed that moms of autistic children reported experiencing inferior mental well-being compared to mothers of children with Down syndrome and intellectual disabilities. Several studies have also suggested that moms of children with autism experience diminished mental well-being, reduced self-esteem, and

decreased life satisfaction. Additionally, they are more likely to encounter elevated levels of stress and despair.

The references cited are Hsiao (2016) and Kim et al. (2016). Ang and Loh (2019) did a study in Singapore that examined the relationship between mental health and coping strategies among parents of children with autism spectrum condition. This study included a sample of 97 fathers and 106 women who have autistic children. The study findings revealed that moms reported experiencing elevated levels of stress compared to their counterparts.

According to research by Gardiner and Iarocci (2012), there is a connection between children's symptoms of Autism and the general health of the children and their families. Similarly, research by Hastings and Taunt (2002) found that parents whose children have autism are more likely to suffer from severe mental health disorders than parents whose children do not have autism.

Parents whose children have Autism Spectrum Disorder (ASD) report worse rates of mental health than parents whose children have other types of disability, according to research by Gupta (2007).

Based on a study, when a child is initially diagnosed with a severe disability, the majority of parents experience a sequence of emotional responses including shock, denial, guilt, anger, and despair before eventually adapting to the situation (Peterson, 1987). Parents may exhibit profound despair in response to certain situations (Farbe, 1959; Bristol, Gallagher & Schopler, 1988). Many individuals undergo a form of mourning process, as if their child had passed away (Farber, 1986), and they may desire to communicate their experience with others.

Another study discovered that in households with a disabled child, men typically do not provide more support to mothers by increasing their presence, assisting with household chores, or taking

care of the children (Gallagher & Bristol, 1988). The father may seek employment in a secondary occupation to assist in covering the supplementary costs, resulting in a significant reduction of his presence in the household. A mother who deems this behavior suitable and affectionate approves of it. Another mother may perceive the father's behavior as a strategy to evade the problem and shirk accountability, which could lead to significant dissatisfaction in that particular scenario. This study will elucidate the allocation of tasks that a mother and father undertake in caring for a children with special needs.

The perception of families with autistic children varies throughout societies, leading to the influence of society-specific views about autism on these families. Due to societal prejudice, both the autistic children and their family face significant discrimination, as the family is unjustly associated with the condition. Many families choose to avoid seeking professional diagnosis for their children due to the apprehension of discrimination and the negative associations attached to disability. By declining to undergo diagnosis, families might evade the acquisition of disability identities (Ecker, 2010).

### **iii) Pattern of Caregiving Practices**

The origins of parenting style can be dated back to the year 1800. Approximately 75 years ago, research began examining how variations in overall parenting methods could impact child development, rather than solely focusing on specific behaviors like breast versus bottle feeding or physical discipline versus time out. These scholars have attempted to determine the child development association with overall cross-situational variance in parenting method, also known as parenting style or dimensions.

In a 2019 qualitative study conducted by Gede Wira Bayu and Nyoman Kusmariyatni, it was found that the appropriate parenting approach for children with special needs involves several key factors. Firstly, parents should strive to be role models for their children. Secondly, they should avoid providing education that is beyond their means. Thirdly, discipline should remain a priority in guiding the children. Fourthly, parents should emphasize the importance of religion and instill good moral values in their children from an early age. Fifthly, communication should be open and enjoyable, but with certain limitations. Lastly, parents should refrain from engaging in negative actions towards their children.

The study examines the longitudinal associations between children's social wariness/inhibition and parents' perceptions regarding the most effective methods of socializing their children (1999). The findings suggested that there were minimal disparities between the parenting styles exhibited by mothers and fathers when their children were 2 and 4 years old. The results confirm the hypothesis that the dispositional traits of early children can predict the conduct of their mothers and fathers in the future.

Suzuki et al. (2016) conducted a longitudinal study to investigate the relationship between children's behaviour and the parenting methods used by their caregivers. The researcher observed an association between children's problematic behaviour at 7.5 years of age and the following manifestation of excessively reactive parenting in their caregivers at nine years of age. Consequently, this resulted in a rise in the children's troublesome conduct and a decline in their positive social behaviour by the time they reached nine years old.

In a study conducted by Benito Leon-del-Barco and colleagues (2019), the researchers examined the correlation between parental psychological control and the occurrence of emotional and behavioural disorders in Spanish adolescents. This study investigates the importance of perceived psychological control, which parents perceive as a type of negative control, in the development of emotional and behavioural disorders in children and adolescents.

Hani Hanafi and Abdel Aziz Mousa Thabet conducted a study in 2017 to investigate the relationship between the parenting strategies utilised by Palestinian parents and the prevalence of mental health problems in pre-school children. The study found that Palestinian parents frequently utilised both authoritarian and flexible parenting strategies. Preschool children displayed a notable incidence of mental health disorders.

A study conducted by Johari Talib et. al. (2011) examined the impact of parenting style on children's development. The findings suggest that both mothers' and fathers' authoritative parenting methods have a good impact on children's behavior and academic performance, regardless of gender. Conversely, the lenient and authoritarian styles have detrimental impacts on children's conduct and academic performance.

The aforementioned research demonstrate that parenting styles can have either a favorable or unfavorable impact on the level of emotional intelligence and the occurrence of behavioral disorders related to emotions. Additionally, they can also affect life satisfaction and self-perception. Parenting style, parental warmth, and engaging in different roles contribute to the advancement, maturation, and enhanced performance within society.

## **Bangladesh Context**

### **i) Parents' Behavior in daily life**

Uddin and Ashrafun (2023) conducted a separate investigation which found that parents who are responsible for a children with autism encounter feelings of melancholy, exasperation, and seclusion. Parents of children with autism often face significant difficulties, which are further exacerbated by the negative attitudes, avoidance, and derogatory comments they encounter from their own relatives and neighbors.

A study conducted by Haq and Murshida (2022) found that parental attitudes towards child raising and development differ based on the intellectual and physical talents of their children. The greater the extent of a child's impairment, the more unfavorable the attitude towards that youngster would be. Parents are unaware of their impaired child's unfavorable attitude.

Acquiring awareness of such mindset would be advantageous for them to alter their conduct. In order for the child with a disability to get significant psychological, emotional, and social assistance, it is imperative that a change in attitude occurs among the parents.

Many parents of children with intellectual disabilities suffer from moderate depression, according to research by Akter (2022). On the contrary, most parents whose children do not have intellectual disabilities nevertheless go through a minor psychological adjustment. In Bangladesh, parents who have children with intellectual disabilities are more likely to report high levels of marital satisfaction and higher rates of depression compared to parents without intellectual disabilities.

### **ii) Parent's Mental Health Condition**



In their study, Akter and Khatun (2020) discovered a statistically significant disparity between the gender of children and the level of parenting stress. Mothers of female children with autism experienced higher levels of parenting stress. The correlation between interaction and behavior in individuals with autism and parenting stress is statistically significant. This implies that moms who had children with limited social contact and behavioral issues experienced higher levels of stress related to parenting. The findings indicate that parents of children experiencing developmental difficulties and children with mental health issues had higher levels of stress. The results of the other study were in line with the experience of stress related to parenting. Furthermore, a notable disparity was observed in the scores of mothers with children experiencing chronic medical difficulties and moms with children facing psychiatric diseases in terms of dysfunctional contact between parent and child.

In their study, Kayesh and Imrul (2021) discovered notable disparities in anxiety, despair, and stress levels between parents of autistic children and parents of non-autistic children. The findings indicated a notable disparity between fathers and mothers of children with autism in terms of anxiety, sadness, and stress levels. Furthermore, the study revealed that parents who hold postgraduate degrees exhibit superior mental well-being compared to both graduate and undergraduate parents. Similarly, parents who have completed their education at the graduate level also display higher levels of mental health compared to parents who have only completed their education at the undergraduate level. The study also revealed that parents belonging to the high-income group had reduced levels of stress compared to parents from the middle and low-income groups when faced with stressors. Likewise, parents belonging to the medium income group had lower levels of stress compared to parents from the low-income group.

In their study, Begum et al. (2020) classified coping mechanisms into eight groups: facing the problem directly avoiding it, seeking social support, self-controlling, accepting responsibility, solving problems systematically, escaping, and positively reevaluating the situation. Out of all the parents surveyed, the following groups chose the following responses: "at least try," "not overanalyzing," "get professional help," "separate own feelings," "conduct self-evaluation," "apply more effort," "hand over," "fantasies for turn the," "wish for over the," and "change daily lifestyle," in that order. Furthermore, a notable correlation was shown between the educational background of parents and the adoption of the technique known as "accepting responsibilities."

### **iii) Patern of Caregiving Practices**

Samiullah Sarwar (2016) found that authoritarian parenting results in children developing rebellious tendencies and adopting problematic conduct. This is attributed to the excessive use of power by parents over their children.

The research conducted by Rashid Zaman et. al (2017) investigated the impact of parenting style on the behaviour of children. The study discovered that children's behaviour is impacted by their parents' parenting style, which is influenced by factors such as the external environment, support, affection, and accessible possibilities.

### **Chapter: 3: Research Methodology**

**i. Study Design** The study was employed a qualitative approach to gain insight into the shared and divergent practices, beliefs, and ideologies of the parents. The qualitative approach was chosen because the topic was yet understudied in our country's context. So there was required flexibility to explore questions with the participants. A qualitative research method was used for studying participants' experiences from their own viewpoints to address the study objectives. Furthermore, it was aimed to explore the emotional impact and interpretation of those experiences on individuals. Employing the adaptable and open-ended data collection procedures linked with qualitative research was ideal for this type of investigation. (Merriam & Tisdell, 2015).

**ii. Study Sample** For the IDIs the study participants were selected based on the following inclusion criteria: i. both groups (father and mother will be equally selected) were from similar socioeconomic (i.e. middle-income) ii. All participants were from urban areas of Dhaka city, iii. Parents had children aged 3-8 years.

**iii. Study Setting** Study participants were taken from the city of Dhaka.

**iv. Sample Size:** 8 participants were selected for the IDI and a group of 8 members for the FGD was selected for this qualitative research.

**v. Sampling method** The study was identified a certain cohort of individuals or units for analysis. It was employed purposive sampling as it possessed a distinct understanding of the precise traits or attributes that need to investigate. This method was allowed to select a sample that accurately represented these characteristics and concentrate on particular areas of interest, enabling to obtain comprehensive data on these themes.

**vi. Data Collection Procedure and Tool:** The study was employed qualitative methods, specifically 8 In-depth Interviews (IDI) and one Focus Group Discussion (FGD), to get insights about parenting practices. Firstly, the IDI and FGD guideline were developed by the researcher himself. And then the draft guidelines were reviewed by the experts to obtain their feedback. After incorporating feedback, the revised guidelines were piloted in the field. Before data collection the oral and written consent were taken from the participants. Both IDIs and FGD were conducted in person in the convenient places. The length of each IDI and FGD were 60-90 minutes. Data were recorded using mobile recorder with the permission of the participants.

#### **vii. Data Management and Data Analysis Plan**

Qualitative research required good data management. Before data collection, the researcher designed a data organization plan. Throughout the project, the data from the qualitative research was being analyzed. The analysis was started at the beginning of the data collection. Qualitative data was then analyzed following the content analysis technique. The following steps of the content analysis are given below

#### **Transcribe and Organize the Data**

Researcher captured data from in-depth interviews and FGDs using handwritten notes, audio recordings and transcriptions, and first-person observation and reporting. Researchers verified data and analyze notes, transcripts, and other materials. All notes were photocopied and data read for legibility. Compiling data according to data collecting methods were one way to organize data. In-depth interviews and FGDs captured in several data categories.

#### **Read and Review the Data**

After sorting the data, the researcher reviewed it to make sure they didn't miss any pre-set questions and to identify any important issues. Researcher read for hours and highlighted data that answers research queries.

### **Themes and Issues**

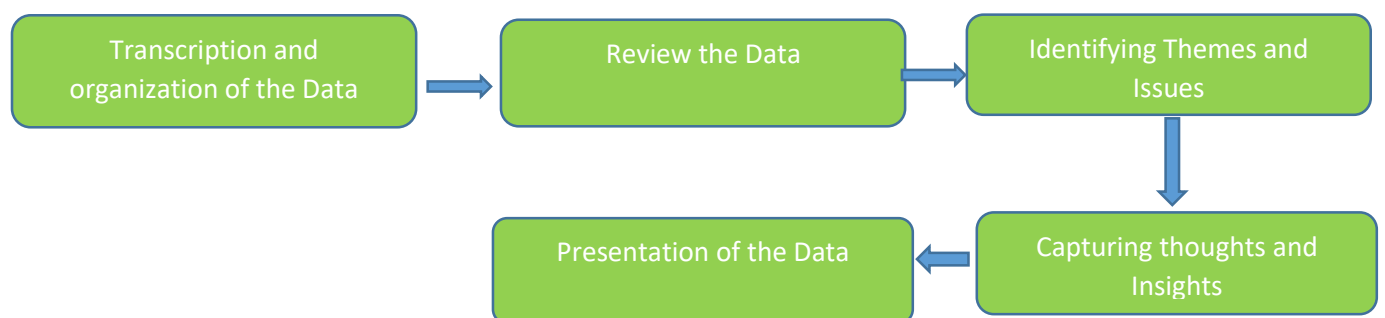
Reviewing was identified theme and subthemes. Ideas and insights was written under subjects. Father and mother data and IDI and FGD data was triangulated.

### **Capturing Thoughts and Insights**

The moderator and researcher remained impartial during the FGD, avoiding personal opinions. However, by examining and identifying trends and difficulties, researchers added their views and portray the data meaningfully.

### **Presenting Qualitative Data**

Incorporating quotes directly from the FGD and IDI, this section was displayed the gathered data under topics and subthemes.



**Figure 1: Flow chart of data analysis**

## **ix. Ethical Considerations**

Ethical standards were upheld throughout the research process. Ethical approval from BRAC University was obtained by the researcher before the research could be conducted. In order to conduct the IDI and FGD, consent from the participants was taken. Participants were assured that their personal information was used exclusively for research purposes and was not given to anyone else when they provided their oral consent. The study included individuals who voluntarily agreed to take part. In addition, they were provided with all the necessary details about the research, including the study's background, goal, objectives, rationale for approaching them, and researcher's biography, if necessary. Those who were willing to participate, they were invited in the interview. For this aim, a code number was utilized instead of the actual names or pseudonyms of the participants. As a psychologist, the researcher offered psychosocial support and referrals to individual participants who experienced mental health issues or concerns.

## **x. Limitations of the Study**

The study had few limitations and they are given below:

- The study's time constraint was its primary limitation.
- The focus was solely on urban areas.
- One constraint is the type of the participants. This was not taken into account parents from diverse socioeconomic backgrounds.

## **Chapter: 4: Results & Discussion**

### **Results**

The purpose of the study was to explore the mental health and caregiving practices of parents of children with special needs. The qualitative approach was conducted including 8 IDIs and one FGD and the participants were selected purposively from the Dhaka city. The content analysis method was followed to analyze the data where the findings were divided into some major themes and sub-themes.

### **Findings**

The descriptions of the findings are given below:

#### **Theme 1: Caregiving Practices of Parents of CSNs**

From the responses (both IDI and FGD) of the participants, it was evident that providing care for children with special needs entails engaging in various activities and employing specialized approaches tailored to the child's specific condition. Although intricate, the family has fully embraced a collection of routines that are now an integral part of their everyday lives.

Recognizing the significance of addressing the needs, ensuring safety and security, prioritizing the child's interests, and ensuring excellent health, food, and nutrition are all equally vital aspects of caring for a child with special needs. This understanding helps caregivers to better comprehend the intricacies of their task. The practices had many similarities as well as differences. These differ according to the child and according to the special needs of the child.

But in the case of most of the parents, among the issues that came up are:

### ***Sub-theme 1: Following the daily routine for the child***

Majority of the parents (in both FGD and IDI) stated that, routines were essential for managing children with special needs. Implementing these regular practices in the care of a child with special needs revealed the family's dedication to upholding optimal well-being. Routines were crucial for three distinct reasons: firstly, they served as the primary focal point for the family; secondly, they were deeply ingrained in the environment and culture of the families; and thirdly, they facilitated interaction between the children and the dynamics of the family. According to some parents, they acquired caring skills by regularly practicing daily routines and following the guidance and suggestions of healthcare specialists. Nevertheless, the caregiver is directly accountable for implementing them on a daily basis. The majority of parents stated that feeding was one of the activities that demanded a significant amount of time and expertise. Due to its potential for specialization, it was refined through experience. Feeding posed considerable difficulties for a child with a disability and its caregiver. Nevertheless, it evolved into a crucial daily task that influenced the family's eating schedule and customs. However, it was observed that while caregivers implemented regular schedules, taking care of children with a disability sometimes necessitates modifications, which might result in more intricate routines.

Attempting to establish a consistent daily routine for the child, encompassing the period from getting up in the morning to going to bed at night. Establishing a structured schedule for the child that included designated hours for sleeping, feeding, playing, socializing, and listening to music. A mother expressed her consistent efforts to establish a schedule for her child throughout their early years,

*“My child has developed the ability to recognize the appropriate times for feeding and sleeping. Occasionally, adhering to a regular schedule becomes unattainable while he is unwell. However,*



*adhering to a schedule can greatly facilitate various tasks. Allowing him to brush his teeth, permitting him to complete his responsibilities to some extent, and allowing him to wear his preferred attire. I always focus on what he wants” (IDI # 1, 15.04.2024)*

During sleep, they played music, showed pictures of their favorite books. It became normal for them to live their day in the same way.

*Another Mother said, “I always tried to follow a fixed routine for my child. But it is not possible for me to follow accordingly. Because sometimes my child became shows rigidity, sometimes I am involved in lots of family engagement. But when it is possible to follow the routine, life become easier” (IDI # 2, 17.04.2024)*

### ***Sub-theme 2: Responding to Children's Needs***

Most of the parents (from both IDI and FGD) said that they might not be able to raise their special needs children the same way as other children. But after birth there was such a bonding that as parents they knew what their child needed at the right time. Some of their children couldn't speak at all, but wanted to communicate a lot by pointing, or yelling, they could understand them too. However, some parents found to suffer from deterioration in their mental health, saying they struggled to understand their child's needs. Most of the participants said they developed a set of rules on how to raise the child based on the child's needs. They said that they had to try different ways so that the children listen to them. Many were like controlling the children. They said some children are very stubborn and that made the fathers very angry. Some mothers also shared about children's fear of their fathers.

*One mother said, “I try hard to understand and respond to my child's needs. I can't throw away my own child. You know he is my own child, I can't do it. But many times the child's father does*

*not even remember that the child is not like others. Sometimes he lost his temper. And then it becomes difficult to handle the child” (IDI# 4, 18.04.2024)*

*A father said, “I try to understand my child's needs. However, due to lack of communication, it is not possible to understand and respond properly to the child. Maybe I don't understand the way his mother does.” (IDI # 5, 22.04.2024)*

### ***Sub-theme 3: Spending Quality time***

Majority of the parents (from FGD and IDIs) believed that play time was the best moment for them. Because it facilitated the child's engagement with familiar things. Nevertheless, the manner in which they engaged in play differs from that of other children. However, parents assumed that every children enjoyed this game. Children enjoyed sports, mischief, and fun. Their children experienced the highest level of happiness when engaged in play. Despite occasional obstinacy, play provided children with the most valuable lessons.

*A mother expressed, “I loved the moment when I am playing with my child that I momentarily overlooks his particular disability. He derives pleasure from playing. I greatly enjoy it. Therefore, I advise the child's father to engage in physical activities and accompany the youngster on walks for as much time as he can spare.” (IDI # 1, 15.04.2024)*

Majority of the parents (both IDI and FGD) said that taking the child outside like to the roof of the house or for a walk during afternoon that gave the child so pleasure and they also seemed to be relaxed also. Some said that they had parks next to them where they tried to take them for a ride. At that time they saw other children and they felt very happy to see other children. Most of the parents practiced taking their children for outings. According to them, staying at home all day at one time was not good for them and also not very healthy for the children. Most of the

participants tried to at least take the child for a walk somewhere far away around the house so that the child's mind is good. They thought that children liked going outside. In the nearby parks, other children also came and play. Their children felt good when they saw other children. But some were upset because they couldn't go and play with them, they insist.

Some Parents said that it was important to take colors with them and draw pictures like other children in spite of understanding nothing, couldn't draw. They dint understand the shapes. But their children also did the things like picking up paint, putting paint on their hands and enjoying it very much.

A mother said, *“We have kept a place in the house where our child can play with colors together with his brothers and sisters. He likes it very much.” (FGD, 15.05.2023)*

#### ***Sub-theme 4: Keeping the environment comfortable***

Most of the parents think that a good environment is needed at home for the child to grow up. No child grows properly without a good environment. And most of the parents think that it is very important to be aware of the environment of the house in the case of children with special needs. Some parents are very concerned about the living room environment of their children. Some parents said that they try to keep the room very comfortable, noiseless for the child.

One mother said, *“All of his favorite things are kept in the room. Many of his favorite colors are kept in the room. He feels very calm when he sees them.” (IDI # 2, 17.04.2024)*

On the other hand, few parents said that it was not always possible to keep a separate room and the environment comfortable for them. Because there were many things happened in the house and also when the relatives came to visit it was not always possible for them to maintain.

A father said, *“We are middle class family. We have to ensure all the expenditure by our monthly income. It was sometimes luxury for us to ensure all the things for the children as per their need especially a separate room for the child.”* (IDI # 6, 22.04.2024)

#### ***Sub-them 5: Keep Bonding between siblings***

Relationships have been observed to be stronger in families with more siblings. Some parents said that there was less pressure when there were siblings at home. Fostering became much easier when the attachment was formed between siblings. Because brothers and sisters became their friends. Parents mentioned that when brothers and sisters become friends together, there is a peace of mind.

A mother said, *“I have to do a lot of housework besides taking care of the baby all day long. My baby has a wonderful bonding with my elder son. I made this and taught it to my older son. Now, it seems that the pressure on me is somewhat reduced when they spend time together.”* (IDI # 1, 15.04.2024)

Few parents also said that all the siblings were not supportive always. It depended on if the siblings understood the situation or not.

A mother said, *“My younger child sometimes is not understanding. He felt that i gave more time to my special need child. But I hope as soon as he will understand him, he will be more supportive.”* (IDI# 4, 18.04.2024)

#### **Sub theme 6: Good Health, Food and nutrition**

Most parents said they tried to be aware of their child's health. They thought their health risks were more than others. And if their health deteriorates, their pressure increased, so they tried to pay special attention to the health of the child.

A mother said, *“My child has difficulty breathing. I became more restless when his breathing was difficult. So I always try to keep eyes on his health.” (IDI # 3, 18.04.2024)*

All participants said that they tried to give their children the food that is eaten in the family. But they cannot be fed all the food. A certain diet should be followed. Many times it was not possible to follow the child's diet due to their other work pressure.

A father said, *“We try as much as we can but we are not capable always. When the child become ill, we go through lots of struggles.” (FGD, 15.05.2023)*

### ***Sub-theme 7: Safety and security***

Most of the parents said that it was very important to ensure the safety and security of the child. More than others, they feel that they needed to be more aware of maintaining the safety and security of their children. They were mostly dependent on others so they have to be more careful about safety and security. They should always be careful so that they do not fall victim to any accident.

A Mother said, *“You know, my child is more vulnerable than the other normal child. Because she cannot take care of himself. She is more dependent on me and my family. So we always have to be more careful about her safety and security.” (IDI # 2, 17.04.2024)*

On the other hand, A Father said, *“It was not always possible to keep eyes on my child. Sometimes he fall with accident, sometimes he does something that is dangerous and he has no idea about this.” (IDI # 5, 22.04.2024)*

### ***Sub-theme 8: Prioritizing Child Interest***

Every parent felt that the child's needs or wants were not always given priority. According to them, their children were often unable to do the things they were supposed to be able to do according to their age or some are too fickle to override their wishes. So in most cases parents themselves took decisions which would be better for the child. Some parents said that they tried to understand their child's interest first. Because understanding their interests, favorite activities, they could treat them accordingly. Then they were also calm and happy and easy to manage.

A mother said, *"I know what my child wants, what is her interest. I always try my best to give the priority of his interest and ask her."* (FGD, 15.05.2023)

Another Mother said, *"As my child was fully dependent on me, I have to be more alert about to know his interest. It is not always possible to give the priority and sometimes I need to insist for his betterment."* (FGD, 15.05.2023)

### ***Sub-theme 9: Attachment with Child***

Most of the parents described their relationship with their children very well. They had a lot of love and affection towards the child. They felt that even though their children had special needs, they dint feel any different from the way parents relate to other normal children. Because their children also tried to explain in different ways that their parents were very important to them. Parents thought it might be because of the constant attachment with the children.

A mother talking about her relationship with her child said, *"I have 1 more child. My 2nd child has special needs. But I have never felt different in terms of attachment with any child since their birth. Rather, I always have to be more careful about his care"* (IDI # 2, 17.04.2024)

A father said, *“When we conceived, we had many dreams. Ever since the birth of a child, love has never been lacking. The older I got, the more I realized that my child was having a problem. But the relationship has never diminished to some extent. Rather, I think no one will understand my child as I do”* (IDI # 5, 22.04.2024)

### ***Sub-theme 10: Ensuring Family Involvement***

All parents agreed that raising children with special needs couldn't be done with a single effort. If there was an understanding among everyone in the family, if everyone understood that everyone's small contribution would make raising the child much easier, then the work will go a long way. Everyone had a mixed reaction when it comes to family involvement. Some said family involvement was much needed while others said family involvement was not received always. Everyone divided the work from their place and gave time to the child.

A mother said, *“Caregiving is not only for the mother or the parents. It is more about involving family for the child rearing. When you get the proper support from your family, it will be smooth but when not, it will feel like hell for you.”* (IDI # 3, 18.04.2024)

### **Theme 2: Mental Health of the Parents of CSNs**

From both IDIs and FGD, it was seen that special need in children might result in an emotional and social burden to the parents. Since they were far more concerned about their own and their children's futures, which could affect their health, they frequently felt a wide range of unpleasant emotions, including stress, anxiety, and sadness. Furthermore, compared to parents of typical children, they were much more likely to experience psychological discomfort. A psychological discomfort was defined as an emotional state marked by symptoms of worry and despair. The high stress level was shown to be influenced by the high levels of internalizing and externalizing

worries in youngsters. Being the primary caregivers for these children, the parents may be more susceptible to severe stress and, in certain cases, depression. To help and support the parents in these situations, it was therefore imperative to assess the degree of psychological suffering among parents of special needs children.

Talking to parents it seemed that every parent was very vulnerable mentally. A separate trouble surrounds them. It was very difficult for them to be mentally well. While discussing with parents, many types of mental health issues came up:

### ***Sub-theme 1: Frustration***

Every parent talked about depression in their life. Every parent said that they lived in a kind of emotional panic from child birth onwards when their child was diagnosed as having special needs. Different views of society, relatives, and various comments have made their lives more difficult. Most parents said depression was always with them. All the disappointments of life revolve around children.

*A mother said, "When people say it's the curse of God. It is very difficult then. It seems that I am very sinful in the world. My child is the result of my sin. Not a day goes by that I don't cry at night. Depression is my life partner." (IDI # 3, 18.04.2024)*

Most parents say they couldn't sleep like before. Sleep problems increased a lot. Sleep was not the same as before. Going to sleep at night is very late, wakes up repeatedly. The next days were not good because of lack of sleep.

*A mother said, "I can't sleep like before. I don't remember when I slept well. One day I can't close my eyelids properly. Not sleeping has become very normal now." (IDI # 2, 17.04.2024)*



From the discussion of every parent, it was understood that it has a lot of impact on their personal and professional life. Personal life changed more than before it has become very difficult to stay focused in professional life.

Every mother said that suicidal thoughts were very prominent in the beginning. Because most people blamed them.

One mother said, she felt like such a failure and said,

*“It seems that there is no hope in life. I always felt like dying.” (IDI # 1, 15.04.2024)*

### ***Sub-theme 2: Anxiety***

Most of the Parents talked about anxiety about various things in their lives. Parents have been shown to report different symptoms of anxiety. They said they were more restless than ever, had trouble breathing, and some said their body temperature was higher than ever. There was always some sort of restlessness at work, with pressure rising and various problems mentioned.

A father said, *“Physically I was very healthy. But after coming to the situation, I have increased so much instability that I think I will die of a heart attack at any time. (FGD, 15.05.2023)*

It has become difficult to maintain concentration as before. It is not possible to concentrate on anything like before.

A mother said, *“I was not like that before. I also have normal life. But my life became abnormal after the birth of the child. I can't to read a book or watch a program for on TV for a certain time as before. I felt always restless” (IDI # 1, 15.04.2024)*

### ***Sub-theme 3: Feeling of Uncertainty***

Parents talked about the uncertainty of their lives. They were very worried about the future of the child. They were very worried about how they will raise their children, and they would not be able to have ten children. They mentioned uncertainty about their future. All the parents were uncertain about the future. It seemed like there was no hope in their life. Uncertainty was more prominent in the mother rather than father.

*A mother said, "I don't know what will happen to my child in the future. Now I am taking care of him by bearing everything as mother says. But what happens when I'm not there?" (FGD, 15.05.2023)*

*A father said, "There are not so many opportunities in the country like abroad. The opportunity to teach the child, no one says that our child has the right to grow up. It becomes difficult to cope with society at times." (IDI # 3, 18.04.2024)*

### ***Sub-theme 4: Social anxiety***

Every parent said that after their child's diagnosis, when everyone around them knew that their child had special needs, they gradually reduced social interaction. A kind of fear and panic worked. They didn't go to social events. Socially, relationships with those who were friends before are also decreasing.

*A mother said, "The way I used to go to social events I don't go now because there will be a lot of gossip. Many people will remind me again and again that it is a curse, so I don't go and I don't let the child be with anyone." (IDI # 3, 18.04.2024)*

On the other hand, the mothers felt more socially anxious than the father according to the data. Each and every mother (from FGD and IDIs) stated about the avoidance of social gathering whereas fathers didn't mention more about this.

#### ***Sub-theme 5: Panic Attacks***

Some mothers or their depression reported panic disorder in addition to anxiety. They said their panic attacks increased. Now there were a lot of problems, the heart beat increases, the body trembles. It was difficult to breathe felt like dying at any moment.

Some mothers experience several panic attack symptoms. According to their discussion, they always had some type of entity. Panic attacks occurred when thinking about their children. Some said that before he had no symptoms of being senseless in thought or fear. Now it could be seen that if a child had a fever, or if the child had any problem, the body trembled in tension. Not only with the child, now was it seen that panic-like symptoms appeared in them at any time. Some people thought they would die of a heart attack anytime.

*A mother said, "When the attack comes, it felt like I am dying just right now. My consistent daily life pressure doesn't support me to keep calm and quite although doctor suggested me to stay calm and relax." (IDI# 4, 18.04.2024)*

#### ***Sub-theme 6: Mental Stress and Anger***

Most of the parents talked about stress in their lives. Everyone said the pressure was on. The pressure was not reducing at all. Worries and worries increased the pressure. Life became more stressful. Stress was taking its toll both personally and professionally.

Most of the parents (From both FGD and IDIs) said they found it very difficult to control their anger. It was not possible to control anger like before. The tendency to get angry at the slightest has increased a lot. As a result of anger there was so much impact in the family and marital life. It affected relationships.

*A mother said, “My tolerance was higher before marriage. After the birth of the child, I become stressed to fast and loss my temper quickly. Even sometimes I misbehaved with my child and I felt than guilty.” (FGD, 15.05.2023)*

On the other hand, a father said, *“I know I am loosing temper day by day but I always tried to keep myself calm. Life became so difficult and stressful after having child with special needs.” (IDI # 6, 22.04.2024)*

### ***Sub-theme 7: Obsession and Compulsion***

One mother said (From FGD) her obsession started since her child was diagnosed with special needs. The tendency to do the same thing over and over again has increased. Especially being cleaned all the time, washing the same thing over and over again, doing things over and over again. By this, it could be seen that she is in mental turmoil and she thought that the child was not taken care of properly.

### **Theme 3: Challenges of the Parents during Child rearing**

Majority of the parents thought that parenting was a very complicated job. But if it was the parenting of special needs child then it becomes more and more difficult. From the time of birth to the diagnosis of the child to raising the child, everything required different energy, mental capacity which was always very difficult to maintain. A kind of uncertainty surrounded. Walking in society, socializing or many things gradually decreased. A child thought differently and it was

something to keep trying despite the uncertainty of how much progress can be made. Parents considered every moment a challenge. All the parents said that since the birth of the child, there have been many changes in their life activities, time management. A lot of time had to be given to take care of the child separately. According to most of the mothers, time management became difficult while taking care of the housework and raising children.

A mother said, *“There is challenge in every steps. I just feel tired. Taking care of the child with special need, try to keep focus on other children, family demands as well as finishing daily households all the activities are challenging for me. I am just as I need to do.”* (FGD, 15.05.2023)

A Father Said, *“When there is uncertainty, life become more challenging. Having child with special needs is a challenges. After finishing office work and getting back to home and taking care of the children is to an easy task.”* (IDI 8, 23.04.2024)

Family support was much needed by all. However, some have been seen to have received this assistance, while many have not. Family relatives, husbands, in-laws, own people did not help. Mentally at this time it was very difficult to hold yourself without help. No one has told them where to go to take care of the child.

#### **Theme 4: Coping Mechanism of the Parents of CSNs**

Every parent said that coping was very difficult. Every parent knew that it took a lot of time and patience. Everyone had a hard time accepting it at first. Felt like accepting over time. But they were very skeptical about how much they can do with time. They said they tried hard to take care of themselves, took time for themselves, listened to music, prayed, etc. Some people said they

wanted to go for a walk but they can't. Others have talked about going out with their families. They were trying to adapt.

Most parents said this situation was very difficult to accept. But the sooner the parents accept the situation and think of a solution, the easier it was. They thought that the more difficult it was to accept, the more the emotional pain would increase and the child would be neglected.

One mother said, *“If you accept it, your life will be easier and it will be easier to plan about the child.”* (IDI # 1, 15.04.2024)

Another Mother said, *“I took counselling from an expert. She advised me to ensure self-care. From then, I am trying to do the things I love to do e.g., listening music, reading books and watching movie and obviously 5 times prayers.”* (IDI# 4, 18.04.2024)

Few parents were not aware of how to cope with the situation till now. They were struggling to manage all the things.

A Father said, *“I have no idea how we will cope with the situation in future. Every night i go to sleep and i pray to almighty and wish for a good start from the next day.”* (IDI # 7, 23.04.2024)

## **Discussion**

The purpose of the study was to explore the mental health issues and caregiving practices among the parents of special need children. 8 participants were selected for the IDIs and a group of 8 members for the FGD were selected for this qualitative research. Content analysis method was followed to analyze the qualitative data.

### **Caregiving Practices of Parents of CSNs**

The first object of the research was to understand the caregiving practices of the parents of special need children. Among the most important findings that emerged from conducting FGDs and IDIs, it was significantly stated by the parents about the importance of parent-child attachment. According to them, the better the child's caregiving ensured, the stronger the bond with their children. Understanding the child and responding according to the child's needs was considered an important aspect by the parents. They said that understanding and observing children was very important. Attending to interests or needs with the child was considered a part of caregiving. Besides, following a daily routine for the child in all-day child care, playing sports with the child, spending quality time with the child is considered part of their caregiving. In addition, they nurtured children by ensuring their safety and security, including whether the child was getting enough to eat, meeting nutritional needs. Building relationships with other family members, especially those with other siblings, has been shown to be a part of relationship building and caregiving. Finally, in most of the time, the parents needed to be more authoritarian rather than the authoritative parents because of children condition. Results are discussed with reference to past studies. Developed in the unique conditions of the parent-child relationship, parental acceptance-rejection behavior may be very important in assessing the level of the emotional bond between parents and children (Aydın, A. & Yamaç, A. 2014). On the other hand,

according to the study done by Bayu1 & Kusmariyatni (2019) that To be an ideal parent of children, it is important to prioritize discipline in guiding them. Additionally, instilling religious and moral values early on, maintaining open and enjoyable communication with certain boundaries, and avoiding negative actions towards children are crucial steps in implementing an appropriate parenting approach for children with special needs.

### **Mental health of the Parents of CSNs**

The second object of the research was to understand the mental health issues of the parents who have special need children. According to the findings from both IDIs and FGD it was seen that after the birth of the study parents perceived their children's mental health to have deteriorated since they realized they had special needs. Most parents talked about depression, anxiety, panic, OCD, social anxiety, etc. They highlighted how hopeless, depressed they are in life and how it affected their daily lives. One of the most important problems that everyone had was sleep problems. Everyone said their sleep was greatly reduced. Apart from this, the tendency of suicide among some parents had also come up. This result was congruent with some other studies.

Moderate depression affected the majority of parents of children with intellectual disability. In the meanwhile, most parents of children without intellectual disabilities experience occasional emotional changes (Akhtar et al., 2021). In many, the level of the problem was so high that many had long-term symptoms of mental illness. Most of the parents spoke of excessive stress. They said the stress was so high that it was very difficult to manage most of the time. As a result of mental stress, various physical problems are occurring in them. Also, everyone said that they found it very difficult to control or manage their anger. Always their mental state was at such a level that they often expressed anger which further worsens their mental state. Kayesh and Kazi Imrul (2021) found their study that many people say they can't manage anger despite knowing a



little about anger management. In terms of anxiety, depression, and stress, there was a big difference between fathers and moms of autistic children. It was also found that there were no significant differences in anxiety, depression, and stress levels among parents of autistic children based on their job status.

Among the issues afflicted parents had were dependency, poor communication, behavioral issues, financial limitations, stress and worry, and a limited social life. (Aditi et al, 2019)

### **Challenges and Coping of the Parents of CSNs**

All parents said that raising children with special needs was very challenging. They all thought it was not easy at all. They have been facing challenges since the birth of the child. Nurturing the child, responding to the child with understanding. Managing children's behaviors was challenging for each of them. It became more difficult to raise a child as family or social support is not available much of the time. Coping with mental health issues finds it difficult to focus on caregiving as there was social pressure among them which made it very difficult to move in society or maintain networking. The development of autistic children has been significantly affected by social negligence and a lack of understanding, which has further exacerbated the suffering and uncertainty experienced by their parents. Based on the analysis, ideas have been generated. (Rozina Khanam, 2018)

Managing one's time, doing other tasks and taking care of other children in the family also became challenging. Coping with all these challenges and adapting to the situation was not always possible, parents said. But each followed a number of ways to cope with anger, stress and the situation. According to some data, all of whom said that the sooner they accepted the situation, the sooner they could cope. To cope with the situation, they said, it was necessary to seek support from those who can support. Many said that they seek support from those who

supported them. Some had given some responsibilities to others in the family to manage their time some have in-home support staff who said they don't have to worry about certain tasks. In addition, some parents followed several strategies for self-care, such as: keeping a time for themselves throughout the day, trying to give time when there was no work pressure, listening music, reading books, going out with the whole family, in this way they tried to keep themselves well. Some said they seek help from specialists for mental health problems. Many people said that they tried to learn about how to raise special needs children which helps them cope with the situation. Noelle Cauda-Laufer (2017) found that There was no significant correlation between coping techniques and distress, and positive adaptive coping did not lead to improved mental health outcomes. Parents consistently reported feeling socially alienated, financially pressured, and emotionally drained when raising a children with a disability, based on their own personal experiences.

## **Recommendations**

The most important aspect observed in discussions with parents was that there was knowledge gap among all. They had gaps in knowledge about raising special needs children. Therefore, first of all, they should have a clear idea about the diagnosis of their children (Gede Wira & Kusmariyatni<sup>2</sup>, 2019). The government and non-government groups should demonstrate social awareness, intensify their efforts, and implement effective strategies to disseminate knowledge about autism. Providing responsive caregiving is crucial for fostering the child's development.

But in most cases, they think that their children couldn't do everything by themselves, as a result of which they themselves impose many things on the children. In this case too, it seems that every parent needs to understand their children (Antonio et al., 2013). Some recommendations are given below based on the findings:

- Parents should have a clear orientation about the needs of their children.
- Parents should be given information about responsive caregiving and a proper caregiving practices.
- It is necessary to make parents aware about the mental health issues and to open up.
- Parents should be given about the clear idea about mental health professional support and benefits and proper referral pathway
- Institutional care (day care, counselling unit) are required for the parents
- Creating a training program to teach parents and other stakeholders how to deal with special needs children is essential.
- Rights and Protection of Persons with Disabilities Act, 2013 may be reviewed and modified
- The government and non-government organizations should demonstrate social awareness, intensify their efforts, and implement appropriate measures (skills training, day care, special needs) to spread knowledge of children with special need.

## **Conclusion**

The study suggested that every parents followed and tried their best to give a best caregiving to their child and also following tailored method. Parenting should be seen as a relationship between parents and children, rather than a characteristic. Findings indicated that MHPSS is very much needed to overcome mental health issues. It is essential for mental health professionals, such as psychiatrists, psychologists, social workers, therapists, and nurses working in institutions that cater to children with special needs, to possess the necessary qualifications for managing treatments related to anxiety, depression, and stress in parents with autistic children. This is

because there is a recognized need for counseling services that, if provided, can assist parents in coping with these challenges. Family and friends can be utilized more efficiently as valuable sources of information and support. The Bangladesh Government and various Non-Government Organizations (NGOs) should implement more impactful efforts to assist families with children who have special needs.

To fill-up the gap of knowledge and address the issues, a proper holistic approach including parental care, Family support, social services, institutional care and Govt., NGO and other organization can be possible solution to meet up the challenges and give the child and the caregiver a healthy living. .

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**Annex A**  
**IDI Guideline (English Version)**

**Demographic Information**

Name:

Age:

Educational Qualification:

Occupation:

Children:

Number of Children and their age:

Area:

Socio-economic status:

Husband/Wife Occupation:

Husband's/Wife's Educational Qualification:

Family Structure:

.....

## **Consent Form**

**Salam/Adab,**

Welcome to our interview. I am a student of “Early Child Development” master’s program at BRAC University. Thank you very much for agreeing to participate in our interview. I have come to interview you today for a study in my master's program. The topic of my assignment is, “A Qualitative Study on Mental Health and Caregiving practices of Parents of Children with Special Needs”. During this interview I will ask you some questions to try to get to know. If you give consent, please give a signature here.

.....

Participant’s Signature & Date

1. How is your relationship with your child?
2. How has your life changed after having a child with special needs as compared to before?
3. How are you upbringing your child?
  - How do you respond to your child when h/she needs anything?
  - What are the strategies that you have been following that you think work best in your caregiving your child?
4. What problems are faced by you in day to day life in the upbringing of your child?
  - What has been the best part of parenting a child with special needs?  
What has been the most challenging part of parenting a child with special needs?
5. What kind of feelings do you experience for yourself or for your child?
  - When do you feel stressed?
  - When do you feel depressed?
  - How is your sleep?
6. What are the kinds of worries you face for the future of your child and for yourself?
7. Tell me about part of your daily routine that has been going well.
  - Is there a part of the routine that has been more challenging?
8. What is the effect of the current status of your child on your day to day work/personal life/occupation?
9. What is the kind of support that you have obtained from your family, general community, neighbors, teachers, and health care providers?
10. How do you manage with all the issues?
11. How do you cope with your feeling and mental health issues?
12. What do you do when you feel stressed or depressed?

13. Can you describe moments during which you have felt happiness or satisfaction related to your child?
14. What would you suggest about caregiving to other parents who have children with special needs?
15. Can you quote some instances which you might have experienced when your child has been discriminated against, in any way?

## IDI Guideline (Bangla Version)

অংশগ্রহণকারীর তথ্যঃ

নামঃ

বয়সঃ

শিক্ষাগত যোগ্যতাঃ

পেশাঃ

শিশুর বয়সঃ

ছেলেমেয়ের সংখ্যা ও বয়সঃ

এলাকাঃ

আর্থসামাজিক অবস্থাঃ

স্বামী/স্ত্রীর পেশাঃ

স্বামী/স্ত্রীর শিক্ষাগত যোগ্যতাঃ

পরিবারের গঠনঃ

.....  
.....



## সম্মতিপত্র

সালাম/আদাব,

আপনাকে/আপনাদেরলে আমাদের এই সাক্ষাতকারে স্বাগতম। আমি ব্র্যাক বিশ্ববিদ্যালয়ের” শিশুর প্রারম্ভিক বিকাশ”মাস্টার্স প্রোগ্রাম এর একজন ছাত্র। আমার সাক্ষাতকার অংশগ্রহণে সম্মতি প্রকাশের জন্য আপনার/আপনাদের কাছে আন্তরিকভাবে ধন্যবাদ জ্ঞাপন করছি। আমার মাস্টার্স প্রোগ্রামের একটি গবেষণার কাজের জন্য আপনার সাথে আজ আমি সাক্ষাতকার গ্রহণের জন্য এসেছি। আমার এসাইনমেন্ট এর বিষয় হলো, “বিশেষ চাহিদা সম্পন্ন শিশুর বাবামায়ের মানসিক স্বাস্থ্য ও শিশুর যত্ন নেওয়ার পদ্ধতি অনুধ্যান”। এই সাক্ষাতকারে আমি আপনাকে/আপনাদেরকে কিছু প্রশ্ন করব যার মাধ্যমে আমি আপনার সম্বন্ধে জানার চেষ্টা করব। আপনি সম্মতি প্রদান করলে, নিচে আপনার একটি সাক্ষর প্রদান করুন।

.....

অংশগ্রহণকারীর সাক্ষর ও তারিখ

১. আপনার শিশুর সাথে আপনার সম্পর্ক কেমন?
২. আপনার শিশুর জন্মের পর আপনার জীবনে কী কী ধরনের পরিবর্তন এসেছে আগের তুলনায়?
৩. আপনার শিশুকে আপনি কীভাবে লালন পালন করছেন?
  - আপনার শিশুর যখন কোন কিছুর প্রয়োজন হয় তখন আপনি কীভাবে সাড়া দেন?
  - আপনি যে সকল উপায় অনুসরণ করে শিশুকে বড় করছেন আপনার মতে কোন উপায়গুলো সবচাইতে ভালো কাজ করছে?
৪. শিশুকে লালনপালনের ক্ষেত্রে কী কী ধরনের সমস্যার সম্মুখীন হচ্ছেন?
  - শিশু লালনপালনে সবচেয়ে ভালো দিক কোনটি?
  - শিশু লালনপালনে সবচেয়ে কঠিন দিক কোনটি?
৫. শিশুকে লালন পালন করতে গিয়ে আপনি মানসিকভাবে কেমন অনুভব করেন?
  - কখন আপনি মানসিক চাপ অনুভব করেন?
  - কখন আপনি হতাশবোধ করেন?
  - আপনার ঘুম কেমন হয়?
৬. আপনি কী কী ধরনের দুশ্চিন্তাবোধ করেন যখন আপনি আপনার শিশুর ভবিষ্যৎ নিয়ে চিন্তা করেন?
৭. আপনার দৈনন্দিন রুটিন সম্বন্ধে বলুন যা খুব ই ভালোভাবে অতিবাহিত হচ্ছে?
  - আপনার রুটিনে এমন কোন বিষয় আছে যা খুব ই কঠিন?
৮. শিশুকে লালন পালন করতে গিয়ে এর কোন প্রভাব আপনার দৈনন্দিন কাজ বা পেশায় বা ব্যক্তিগত জীবনে পড়ছে কিনা? সেটা কী ধরনের?
৯. আপনি কী কী ধরনের সহায়তা আপনি আপনার পরিবার, সাধারণ কমিউনিটি, প্রতিবেশি, শিক্ষক এবং স্বাস্থ্য সেবা দানকারীর কাছ থেকে?
১০. আপনি কীভাবে আপনার সমস্যাগুলো মোকাবিলা করছেন?
১১. আপনার অনুভূতি বা মানসিক স্বাস্থ্য সমস্যার সাথে আপনি কীভাবে মানিয়ে নিচ্ছেন?
১২. আপনার যখন মানসিক চাপ অনুভব হয় আপনি তখন কী করেন?
১৩. সন্তান লালনপালন করতে গিয়ে আপনি যখন খুব আনন্দিতবোধ করেন কিংবা সন্তুষ্টি বোধ করেন আপনি কি ঐ মুহূর্তের কথা খুলে বলতে পারবেন?
১৪. যেসব বাবামায়ের বিশেষ চাহিদা সম্পন্ন শিশু রয়েছে আপনি তাদের সন্তান লালনপালন নিয়ে কী পরামর্শ দিবেন?

১৫. আপনি কি এমন কিছু দৃষ্টান্ত উদ্ধৃত করতে পারেন যা আপনি হয়তো অনুভব করেছেন যখন আপনার সন্তানের সাথে কোনোভাবে বৈষম্য করা হয়েছে?

**FGD Guideline (English Version)**

**Demographic Information**

Sl.	Participant's Name	Age	Education	Occupation

1. How is your relationship with your child?
2. How has your life changed after having a child with special needs as compared to before?
  - How are you upbringing your child?
  - How do you respond to your child when h/she needs anything?
3. What are the strategies that you have been following that you think work best in your caregiving your child?
  - What problems are faced by you in day to day life in the upbringing of your child?
4. What has been the best part of parenting a child with special needs? What has been the most challenging part of parenting a child with special needs?
5. What kind of feelings do you experience for yourself or for your child?
  - When do you feel stressed?
  - When do you feel depressed?
  - How is your sleep?
6. What are the kinds of worries you face for the future of your child and for yourself?
7. Tell me about part of your daily routine that has been going well.
  - Is there a part of the routine that has been more challenging?
8. What is the effect of the current status of your child on your day to day work/personal life/occupation?
9. What is the kind of support that you have obtained from your family, general community, neighbors, teachers, and health care providers?
10. How do you manage with all the issues?
11. How do you cope with your feeling and mental health issues?
12. What do you do when you feel stressed or depressed?

13. Can you describe moments during which you have felt happiness or satisfaction related to your child?
14. What would you suggest about caregiving to other parents who have children with special needs?
15. Can you quote some instances which you might have experienced when your child has been discriminated against, in any way?

## FGD Guideline (Bangla Version)

ক্রমিক নং	অংশগ্রহণকারীর নাম	বয়স	শিক্ষাগত যোগ্যতা	পেশা

১. আপনাদের সাথে আপনাদের শিশুর সম্পর্ক কেমন?
২. শিশুর জন্মের পর আপনার জীবনে আপনাদের কী কী ধরনের পরিবর্তন এসেছে আগের তুলনায়?
৩. শিশুকে আপনারা কীভাবে লালন পালন করছেন?
  - শিশুর যখন কোন কিছুর প্রয়োজন হয় তখন আপনারা কীভাবে সাড়া দেন?
  - আপনারা যে সকল উপায় অনুসরণ করে শিশুকে বড় করছেন আপনারা মতে কোন উপায়গুলো সবচেয়ে ভালো কাজ করছে?
৪. শিশুকে লালনপালনের ক্ষেত্রে কী কী ধরনের সমস্যার সম্মুখীন হছেন?
  - শিশু লালনপালনে সবচেয়ে ভালো দিক কোনটি?
  - শিশু লালনপালনে সবচেয়ে কঠিন দিক কোনটি?
৫. শিশুকে লালন পালন করতে গিয়ে আপনি মানসিকভাবে কেমন অনুভব করেন?
  - কখন মানসিক চাপ অনুভব করেন?
  - কখন হতাশবোধ করেন?
  - আপনাদের ঘুম কেমন হয়?
৬. আপনি কী কী ধরনের দুশ্চিন্তাবোধ করেন যখন আপনি আপনার শিশুর ভবিষ্যৎ নিয়ে চিন্তা করেন?
৭. দৈনন্দিন রুটিন সম্বন্ধে বলুন যা খুব ই ভালোভাবে অতিবাহিত হচ্ছে?
  - রুটিনে এমন কোন বিষয় আছে যা খুব ই কঠিন?
৮. শিশুকে লালন পালন করতে গিয়ে এর কোন প্রভাব দৈনন্দিন কাজ বা পেশায় বা ব্যক্তিগত জীবনে পড়ছে কিনা? সেটা কী ধরনের?
৯. আপনি কী কী ধরনের সহায়তা আপনারা আপনাদের পরিবার, সাধারণ কমিউনিটি, প্রতিবেশি, শিক্ষক এবং স্বাস্থ্য সেবা দানকারীর কাছ থেকে?
১০. কীভাবে আপনাদের সমস্যাগুলো মোকাবিলা করছেন?
১১. অনুভূতি বা মানসিক স্বাস্থ্য সমস্যার সাথে আপনি কীভাবে মানিয়ে নিচ্ছেন?
১২. যখন মানসিক চাপ অনুভব হয় আপনি তখন কী করেন?
১৩. সন্তান লালনপালন করতে গিয়ে যখন খুব আনন্দিতবোধ করেন কিংবা সন্তুষ্টি বোধ করেন আপনি কি ঐ মুহূর্তের কথা খুলে বলতে পারবেন?
১৪. যেসব বাবামায়ের বিশেষ চাহিদা সম্পন্ন শিশু রয়েছে তাদের সন্তান লালনপালন নিয়ে কী পরামর্শ দিবেন?



১৫. এমন কিছু দৃষ্টান্ত উদ্ধৃত করতে পারেন কিনা যা আপনি হয়তো অনুভব করেছেন যখন সন্তানের সাথে কোনোভাবে বৈষম্য করা হয়েছে?