Mothers' Perceptions on Early care and Interventions for Developmentally Delayed Children in Bangladesh

By

Rumana Yeasmin 22255006

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

> 2024, Rumana Yeasmin All rights reserved.

Brac Institute of Educational Development Brac University October, 2024

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:

Rumana Yeasmin Student ID: 22255006

Approval

The thesis/project is titled **"Mothers' Perceptions on Early Care and Interventions for Developmentally Delayed Children in Bangladesh".** submitted by

1. Rumana Yeasmin (22255006)

of **"FALL 2022"** has been accepted as satisfactory in partial fulfillment of the requirement for the degree of Master of Science in Early Childhood Development in **"October 2024."**

Examining Committee:

Supervisor: (Member)	Mostak Ahamed Imran Lecturer & Child Play Therapist BRAC Institute of Educational Development (BRAC IED), BRAC University
Program Coordinator: (Member)	Ferdousi Khanom Senior Lecturer, ECD Academic Program Brac Institute of Educational Development Brac University
External Expert Examiner: (Member)	Nafisa Anwar Senior Lecturer, M. Ed BRAC Institute of Educational Development Brac University
Departmental Head: (Chair)	Dr. Erum Mariam Executive Director Brac Institute of Educational Development Brac University

Ethics Statement: <u>Mothers' perceptions on early care and interventions for</u> <u>developmentally delayed children in Bangladesh.</u>

Student name: Rumana Yeasmin

1. Source of population

Mothers of developmentally delayed children (5 to 8 years old) of the Institute of Special Education from urban areas in Dhaka city.

- 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 clearly informed about (yes or no)
 - a) Nature and purpose of the study (yes)
 - b) Procedures to be followed (yes)
 - c) Physical risk (n/a)
 - 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 for be required (yes or no)
 - a) from study participants (yes)
 - b) from parents or guardian (n/a)
 - c) Will precautions be taken to protect anonymity of subjects? (yes)
- 5. Check documents being submitted herewith to Committee:
 - a) Proposal (yes)
 - b) Consent Form (yes)
 - c) Questionnaire or interview schedule (yes)

Ethical Review Committee:

Authorized by: (Chair/Co-Chair/Other)

> Dr. Erum Mariam Executive Director Brac Institute of Educational Development Brac University

Abstract

Early childhood means from conception to five years when stimulations work most. But in the case of most children, the symptoms of developmental delays do not develop until 3 to 5 years, and the problem noticed by parents or caregivers is delayed speech, which means delayed identification of the problem. Besides, delayed admission due to trauma, fear of social stigma, lack of correct or adequate information, lack of parental awareness, or sometimes simply lack of parental knowledge as a result, delayed care-seeing or often no care-seeking.

The nature of the study is qualitative. The research findings are categorized into five themes (1). Mothers' understanding of developmental delay. (2). Ages at onset and symptoms of developmental delay (3). Problems or barriers faced to take immediate action. (4). Mothers' perceptions and experiences of early care and intervention 5. Mothers' suggestions for upbringing children

Keywords: Mothers' perceptions, early care and intervention, developmental delay.

Dedication

This thesis is dedicated to all the mothers of special needs children who are struggling and working hard for the betterment of their children.

Acknowledgment

I would like to show my gratitude to my thesis supervisor Mostak Ahamed Imran Lecturer & Child Play Therapist, IED, BRAC University, a person with nice cooperation, for his punctuality, guidance, and valuable time, Also, I would like to express my gratitude to all of the respected faculty members for their hard work, guidance, and dedication to us. I would like to thank all of my batch mates for their nice cooperation, and friendly behavior, for them the journey was very enjoyable. I am very much grateful to the mothers who participated in In-Depth Interviews as well as in the Focused Group Discussion, without their cooperation and participation it was not possible to complete my thesis work.

Finally, I would like to thank my beloved husband for his constant technical support, inspiration, and valuable time, my son who sacrificed and helped me a lot, and my daughter who is the source of my strength.

Contents

Declarationii
Approval iii
Abstractv
Dedicationv
Acknowledgmentvi
Chapter 11
Introduction and Background1
Statement of the Problem2
Purpose of the Study4
Justification of the Study
Research Questions
Operational Definitions of Key Terms7
Chapter II9
Literature Review9
Chapter III17
Methodology17
Validity and Reliability20
Ethical issues
Imitation of the study21
Chapter IV22
Findings and Discussion

Findings	22
Discussion	29
Conclusion	35
Recommendations	35
References	37
Annex 1	42
Annex 2	43
Annex 3	44
Annex 4	1

List of Acronyms

ECD	Early Childhood Development
ECI	Early Care and Intervention
SDG	Sustainable Developmental Goal
ECEC	Early Childhood Education and Care
EI	Early Intervention
FGD	Focused-Group Discussion
IDI	In-Depth Interview

Chapter 1

Introduction and Background

"Early stimulations and interventions work best in early childhood even in the case of cognitive delays by altering their developmental trajectories"..... (Guralnick, 2005).

Children with developmental delays are such condition of physical, mental or intellectual that limit the normal functioning of human beings (Islam & Juhara, 2021), a person can be affected by a single or multiple challenging issues at the same time such as motor skills, language, cognition, socio-emotional and behavior skills. Developmental delay happens when a child does not attain developmental milestones compared to peers of the same age range. Developmental delay can be further categorized as mild, moderate and severe (Choo et al., 2019).

Intellectual or cognitive delay is one of the most common types of developmental delay or disability (Smiley, 2024) which includes the growing capability to learn and think more complexly (Sultana, 2019). Lack of age-appropriate cognitive development may hamper other developmental areas such as language, social, and emotional development. It is supposed that delay in two developmental domains is related to delay over all domains evaluated (Riou et al., 2009).

Physically and mentally healthy children learn age-appropriate developmental matters, while Children with developmental delays are unable to understand and express, to put meaningful words or sentences (Prelock et al., 2008).

Developmental delays can be due to health problems, malfunctioning of the brain, parental exposure to alcohol, drugs, genetic conditions, environmental factors, and problems during pregnancy and birth. Genetic conditions such as Down syndrome, Attention Deficit Hyperactive Disorder (ADHD), Autism Spectrum Disorder (ASD), poor social skills, learning difficulties, etc. Early care includes early identification that helps to take necessary steps for early intervention by creating an Individualized Education Plan (IEP) for appropriate care-seeking such as speech therapy, physiotherapy occupational therapy, behavioral interventions, etc. can help the children. These special care and services enforce additional charges on the parents such as the economic burden, emotional outbursts, social harassment, etc. In our country bringing up children with a disability parents face the highest level of tension, worry, sorrow, and bitterness (Islam et al., 2022). The study will focus on developmentally delayed Children excluding physical impairments as they can be noticed and challenges are taken easily by parents or caregivers, but it takes a longer time to understand the problems with intellectual development as well as several factors that hinder the potential development of the children. Early care plays a crucial role in early identification and appropriate management which can positively alter their developmental trajectory (Choo et al., 2019).

Statement of the Problem

In the early years, the development of children in language, cognition, motor, social and emotional growth occurs rapidly, but it is also a time of vulnerability. Several factors such as biological, environmental, etc. crucially affect the structure and functioning of the brain by reinforcing learning as there are particular windows of opportunities during the early years of life. Sustainable progress has been noticed in reducing child mortality since 1990, and the death of under-five age children has decreased all over the world. However developmental disabilities have not been addressed to the same extent (Smythe et al., 2021). So, there is a chance to narrow the inequity gap by encouraging child development through early care and interventions in early childhood.

Early childhood is commonly known as zero to five years when stimulations work most (Knauer et al., 2019). But in the case of most children, the symptoms of intellectual disability do not develop until 3 to 5 years and the problem noticed by parents or caregivers is delayed speech (Sulkes, 2024) which means delayed understanding and delayed identification of the problem, Besides these several factors negatively affect early care and intervention e.g. delayed admission due to trauma, social stigma, lack of parental adequate knowledge, and lack of awareness. As a result, delayed care-seeking or often no care-seeking. Parental role in early care and interventions is crucial because they can heavily influence their children's development.

The additional demands such as speech therapy, occupational therapy, and behavioral interventions pose extra stress to the parents such as economically, on the other hand, parental denial due to social stigma, and trauma parents cannot accept disability that also affects their child's development, for example, due to economic burden, frustration, stress and depression reduce the capacity of social interaction and parental close involvement with their children while social interaction and working closely are very crucial for their overall development. Due to a lack of adequate knowledge or understanding regarding specialty after diagnosis parents have to give attention to understand everything, and sometimes it takes a long time to start intervention. Identifying delays as early as possible is crucial to start intervention and necessary support (Murphy & Harrison, 2022).

There is also a huge gap between the national policy and the implementation of that policy. We have several National Acts such as the National Children Policy of 2011, the Children Act of 2013, and the Rights and Protection of Persons with Disability Act of 2013, but there is no study to determine the prevalence of disabilities (Islam &

Juhara, 2021). Different studies show different results, for example, The National Census (2011) report presents disability prevalence as 1.4%, Bangladesh Bureau of Statistics (2010)" found a prevalence rate of 9.07%. World Health Organization estimates that 3 million children are disabled (Islam & Juhara, 2021). So, there is confusion about the reliability of the data. Lack of awareness, poor knowledge, and people's negative attitudes towards disability are still big concerns in protecting the rights of disabled persons in Bangladesh (Islam & Juhara, 2021). There is a lack of interventions or programs aimed at addressing these misconceptions and raising awareness of persons with disabilities at the community level. As a result, discrimination happens in the family and community (Thompson, 2020).

Finally, it is estimated that there is a high chance of increasing the prevalence of disability due to population growth, poverty, lack of knowledge and awareness, lack of trained and skilled personnel, and lack of adequate related care and service facilities which may be the major cause of poverty and underdevelopment (Islam & Juhara, 2021).

Purpose of the Study

The purpose of the study is to explore mothers' perceptions, knowledge and experiences about developmental delays specifically cognitive delays as well as their experiences with early care and interventions for their children with developmental delays or disabilities. Early childhood is the period of the first five years when the area of development such as language, cognitive, physical, social and emotional development happens swiftly as well as this is the time when the advancing brain is the fastest and most responsive to stimulation and care (Olusanya et al., 2018). Also, this is the time when development is treated as the basic for children that lasts for a long. The age ranges of the children were five to eight years as the early childhood period is treated from zero to five years, Children who are five to eight years old have an immediate history of the way of the journey through which they are gone. Mothers are the first and most important witnesses of the journey.

The study will emphasize raising parental or public knowledge and awareness of developmental delays or impairments. Often, it takes a substantially longer time to identify any such problems after the manifestations of related symptoms. Also, several factors hinder the potential development of developmentally delayed or disabled children, the aim of the study is also to explore those factors that negatively affect early care and intervention. Every parent indeed wants to ensure the healthy development of their children from early childhood but in many cases simply lack of parental knowledge or awareness works as a barrier to hinder special care and services for these special needs children.

Justification of the Study

Early childhood is when early stimulations and interventions work best to enhance children's growth even in the case of cognitive delays by altering their developmental trajectories and preventing many other difficulties that may occur (Guralnick, 2005). Cognitive development affects the standard of life and fruitfulness, not only for the affected children but also for families and communities as a whole. (Durkin et al., 2000). The study can help bridge this gap by providing scientific evidence supporting the benefits of early identification, recognition and early interventions. Children with developmental impairments are vulnerable and deprived of their basic needs including health, education, or other related care and services. Evidence shows that children who have disabilities begin their education at a later age and continue to lag behind other students of their age. (Ghosh et al., 2022). It is also found that the total primary school enrolment rate of school-age children in Bangladesh is 91%. while only 11%

of children with disabilities have access to education (Rahaman, 2011). The study would be helpful for policymakers and practitioners to reduce inequality between the laws and implementations of those laws by including every child who needs special care and services.

The study will highly focus on early identification and early stimulations because early identification helps early stimulations which support the development process, helping children obtain new skills and behaviors to bolster and strengthen learning. For example, in the absence of early intervention most children with Down Syndrome the continued decline happens significantly during the first five years of their life (Smythe et al., 2021). Sometimes simply lack of parental knowledge or poor knowledge is the barrier to reaching developmental potential. The study will positively influence parental care, high-level parental concern and closeness as well as help in providing information about the ideas, and symptoms of developmental delays as well as supporting early care and interventions for developmentally delayed children.

Finally, many families are unable to take proper care of members with disabilities due to economic reasons, and long-distance care. The study can narrow the inequity gap in early childhood as the Disability Act 2013 focuses on the right to have the highest quality of health care based on availability (Islam & Juhara, 2021).

Research Questions

- 1. What are the mothers' perceptions and knowledge about developmental delay?
- 2. How have early care and interventions positively influenced the development of children with developmental delays?

Operational Definitions of Key Terms

Mothers' perceptions: Perceptions are the ability to see, hear, or become aware of something through the senses (Cambridge University Press & Assessment, 2024). In a word, perception is a result of perceiving or experiencing how something is regarded and understood by parents. Mothers' perceptions of having children with developmental delays or disabilities refer to how mothers understand and interpret their understanding, realization, and experiences regarding their child's growth and development as they are the first and prime caregivers of their children.

Early care and interventions: The term" early care" refers to timely care that includes all universal services focused on enhancing developmental outcomes for all children (Learning, 2023). On the other hand, the term "early intervention" is more specific for targeted children, especially for those who have developmental delays. It is applied after addressing individual risks and protective factors. Identifying and addressing a child's need as early as possible and providing timely support can enhance protective factors and decrease risk factors that can positively influence a child's well-being. Early care and early intervention are both forms of support aimed at enhancing outcomes and preventing risks for children (Learning, 2023).

Developmental delays: Developmental delays or disorders are a set of conditions resulting from handicaps that may disturb physical, mental, cognitive development, or behavioral functioning, a single or multiple conditions may appear at the same time (Olusanya et al., 2018). Affected children may have sensory issues, seizures, Attention Deficit Hyperactive Disorder (ADHD), Autism spectrum Disorder (ASD), learning disorders, etc. Children with intellectual impairment are unable to receive and process information or learn slowly and face difficulties in daily living skills such as eating, dressing, socialization, participation with peers, etc., and are unable to fulfill the demands established by society compared to similar groups of children.

Mothers' Perceptions of Early Care and Interventions: Mothers' perceptions of early care and intervention can be what mothers have experienced or perceived after receiving early care and intervention for their developmentally challenged children in raising and supporting their children. Parental perceptions regarding care-seeking can be influenced by various factors such as fear of social stigma, religious beliefs and myths, cost of care and services, long-distance care, etc. All these may prevent early identification and recognition, and early decision for early care and interventions as time is very crucial for children with developmental disabilities that can influence the developmental trajectory of special needs children. Mothers' perceptions are very important and play a crucial role in parenting practices and supporting children with special needs as they are closely observing and closely connected with their children. Mothers' perceptions and experiences can also influence overall parents' well-being through knowledge sharing.

Chapter II

Literature Review

To understand the importance of Early Care and Intervention for developmentally delayed children, several pieces of evidence-based literature have been reviewed, following the key terms: Early Care and Intervention and its importance for developmentally delayed children, Early care and intervention in the global context, and early care and interventions in the Bangladeshi context.

Early care and intervention and the importance of early care and intervention

Developmental impairment includes some developmental circumstances particularly developmental disability, intellectual impairment, and autism spectrum disorder (ASD) (Sapiets et al., 2021). The appearance of developmental delays arises during the early years and keeps going around an individual's lifespan. Every child with special needs may be different from one another and their needs are also unique, intellectual impairment or cognitive disabilities increase the risk of other related issues such as behavioral problems and adaptive skills which are present as young as 3 to 5 years old (Sapiets et al., 2021).

Early care is very crucial for children with developmental delays, early care regarding cognitive delays includes early identification, recognition, and early intervention. Early identification as well as early intervention are two well-defined supportive complements for children with developmental delays, timely identification is a prerequisite for timely intervention that maximizes their developmental potential and their quality of life. Early stimulation enhances the accumulative process of development, assisting children with developmental delays to obtain new skills to strengthen learning (Smythe et al., 2021). Early Care and Intervention (ECI) programs

can be applied in different forms for children with developmental delays with their individual needs to support them such as mainstream ECD interventions, targeted intervention programs, etc.

Early care and intervention in the global context

The potential of intellectual impairments is a major concern globally, it is estimated that nearly 780 million can be affected between birth and 5 years of age (Guralnick, 2005). Early intervention can enhance the scope of results for children with special needs, and getting access to early stimulations has been recognized as a major concern for global research in developmental disabilities (Sapiets et al., 2021). Studies from global research show that parents play a key role in achieving desired outcomes, especially in the subject of child development. Parents' ideas, knowledge, and feelings about child-rearing in different contexts are supposed to be a fundamental part of their children's lives and well-being. The international argument on the issues related to development is not fulfilled in the absence of giving proper attention to child development, in the absence of assuring inclusive and impartial education for all. Early childhood development has been placed as a fundamental element of the Sustainable Development Goals (SDGs) to ensure education for all, as well as early childhood education and care (ECEC) has been recognized as one of the key interventions in human life and taking part in preschool is especially advantageous especially for children from underprivileged groups of society and the developing countries (Ghosh & Steinberg, 2022).

As developmental disability includes several groups of conditions such as sensory problems, cognitive delays, and physical impairments, all of these have a wide range of lifetime effects. It is estimated that 53 million children under five years old are

living with developmental disabilities, and developmental impairment is one of the most common causes of childhood impairment (Smythe et al., 2021).

In the early period of life, children communicate with the social environments or surroundings including communities, schools, and families which plays an important role in developmental ages that have long-term associations for their health, wellbeing and earning potential when (Akther et al., 2017) they grown-up. On the other hand, the inability to meet developmental potential comes with a universal round of poverty, inequity, and social isolation.

To distinguish and address the particular delays that an individual child may be undergoing, within an interactive structure, the things that need to be included are assessment, intervention, and evaluation activities targeting the basis of developmental measures, (Schiariti et al., 2021).

An assessment comes up with elaborate results such as the present level of functioning, weakness and strengths which leads to determining the individual's goals and interventions so timing is important for assessment because it makes it possible to start intervention as early as possible. If the identification can be done in early childhood it has long-established consequences. Identifying those differences in early childhood has long-lasting consequences. By early intervention programs, the positive outcomes can be arbitrated and long-lasting effects have been renowned as interrelated to the intellectual, behavioral and emotional development of children (Schiariti et al., 2021).

In advanced countries, early intervention focuses more on preparation for education through different initiatives such as preschool, home visit programs, etc. In the U.S., Turkey and Austria, Early childhood interventions have been structured starting at

birth, early intervention initiatives in these developed countries are formulated by national laws and legislations. (Schiariti et al., 2021).

The global recognition of the significance of the early childhood stages has been strongly accepted through decades of authoritarian investigation, evidence-based implementation, and indisputable confirmation. As a result, early childhood development has emerged as crucial in both national and global programs. Early periods have been defined as from birth to eight years old children when early stimulation enhances the accumulative process of development, assisting children with developmental delays to obtain new skills to strengthen learning (Smythe et al., 2021). Early identification as well as early intervention are two well-defined supportive complements for children with developmental delays, timely identification is a prerequisite for timely intervention that maximizes their developmental potential and their quality of life. Early Childhood Development includes cognitive, physical, language, social and emotional development. The area of Early Childhood Intervention (ECI) has been approved to give immediate specialized needs and interventions aimed at enhancing the maximum development of children with developmental disabilities. (Störbeck, 2024).

The effect of early care programs on child development has been inquired into by several authors, among them one study presents that for children who have participated in early care and education programs in a formal preschool setting the general effects have been found on cognitive development together with early intervention assist to overcome social inequality compared to those children who have not been cared for (Burger, 2010).

Early care and intervention in the Bangladeshi context

The prevalence of developmental disabilities is higher in low and middle-income countries due to high levels of poverty and illiteracy. In these countries, children with developmental impairments and their families are at high risk of social isolation, deprivation from education, and even dishonor and violence. Besides, looking after a child with developmental impairments parents and caregivers face high levels of tension, worry, frustration, extreme tiredness, and discrimination as available or accessible services are scarce here, so to support children with impairments and their families further amalgamates these risks. (Smythe et al., 2021).

In Bangladesh, significant improvements have been noticed in child survival and the prevalence of all sorts of disability is increasing where behavioral problems have been added as a new complaint with physical, sensory, and intellectual impairment (Khan et al., 2009). In Bangladesh, though there is a lack of dependable information about disabled children, intellectual impairment among people is almost double compared to high-income countries, evidence shows that the number of children with impairments in the country ranges between 1.4 % and 17.5 % (Islam et al., 2022). At the national level, Child disability data are captured by the Bangladesh Bureau of Statistics (2019), and an estimated 7 percent of children who are 2 to 17 years old have difficulty in at least one domain. The proportion of children with functional impairment increases with age, from almost 3 percent at 2-4 years to over 8 percent at 5-17 years (Grimes, 2021). The common factors for the burden are social stigma, lack of knowledge, lack of adequate services, high cost, and inadequate support systems to deal with the challenges of bringing up special children in developing countries like Bangladesh. It has been found from a research study that the developmental impairment rates among children under five years have been reduced in all countries but South Asia has the

top rate of prevalence of children with developmental disorders (Olusanya et al., 2018). Several factors are treated as barriers to seeking care and service for children with developmentally delayed or impaired in Bangladesh are mentioned below:

Religious myths and misconceptions

Under these circumstances, due to misinterpretations or misunderstood of religious and cultural beliefs by parents' effective communication can be compromised. Parents may look at their children's impairments as an act of God or as a punishment from God, as a blessing from God, or as a test of their faith. In our country impairments is socially or culturally less well accepted, so parents try to meet all of their disabled children's requirements alone, the idea of 'care in the society' is absent (Bola & Randhawa, 2013).

Social Barriers

In our society being parents of developmentally challenged children is viewed as a curse and it makes an ashamed for the entire family which leads to social isolation. It is commonly seen that society people utilize disrespectful words for those who are deaf, not able to speak or have any other disabilities that stop them from taking part in the community e.g., occasions and marketplaces, etc. Family members also think they are not productive so in most cases, they do not get significance even within the family. People with disability experience social isolation and lead their lives like a passive member of the family and society. Families also experience many bad conditions such as a lack of proper social entrance into resources, social isolation, and stigma that lower their capacity to reduce poverty (Hussain, 2021).

Lack of adequate health care and social services

Currently, the country's health sector is facing difficulties in ensuring healthcare delivery because of poverty, shortage of resources, etc. There is also a shortage of adequate support from social or developmental organizations. In a study, it was shown that 68.9 percent with a disability did not acquire any assistance from social or developmental associations (Hussain, 2021). Besides these, health care services, different kinds of therapy facilities, and service centers are city-based, so people who are living in rural areas face difficulties in managing the costs of related care and services. There is also a shortage of professionals or experts e.g. physiotherapists, professional therapists, specialized care, etc. that also affects healthcare services for children with developmental impairment in the country. The government's programs have been treated as very fruitful acts for poor vulnerable people but the scope is very low among the extremely poor with impairments. It is also found from the study that exclusion occurs from the stage of identification and registration to the implementation & evaluation stage. The programs are not rational in amplifying their ability to attain related care services (Hussain, 2021).

Lack of appropriate Education and Training Facilities

The education policy of Bangladesh (2010) emphasizes on education for special needs and inclusive education for children with different kinds of disabilities but the services are not adequate to cover a larger number of children with impairments (Akther et al., 2017). The factors which are treated as barriers to implementing inclusive education e.g. poverty, gender bias, race, regional disproportion and negative sides of climate change and natural disasters, etc. (Akther et al., 2017). Also, children with impairments experience limited facilities to study at educational institutes due to several factors such as the absence of excessive environment, special teaching curriculum, specialized teaching methods, etc. Lack of basic training for teachers on disabilities, application of government legislation regarding impairment or disability issues, etc. are the major barriers to the expansion of educational opportunities (Hussain, 2021).

From the above discussion, it is found that in our country bringing up special needs children raises different forms and levels of depression. It has been established from scientific evidence that early intervention may alter an individual's developmental trajectory and prevent secondary complications (Guralnick, 2005). So there is hope as early stimulation programs successfully minimize or prevent intellectual impairments during the intervention period itself or immediately, longer-term effects have also been noticed (Guralnick, 2005).

Chapter III

Methodology

Research Design: The chosen research design is a qualitative study that explores and analyzes mothers' perceptions and experiences about the early care and interventions of developmentally challenged children. The qualitative approach is the one that provides deeper, elaborative and detailed information about a phenomena (Oranga & Matere, 2023). Qualitative data collection methods such as interviews and focus groups provided an in-depth understanding by gaining insights into participants' experiences and understanding

Study Setting: The Qualitative study was conducted targeting mothers of developmentally delayed children in urban areas targeting an institute of special education in Dhaka city.

Study Population: In this study, participants were selected purposively. The research participants were mothers of developmentally delayed children between the age range 5 to 8 years old, from highly educational backgrounds and the same socioeconomic (upper-middle-class) backgrounds. Among 12 mothers, the age range of most of the mothers was 30-40 years only three mothers were from 25-30 years old. They were selected based on the convenience of the researchers. The children were aged 5 to 8 years because they immediately crossed early childhood periods which will be easily memorized by the mothers besides their developmental outcomes will be measured after just receiving the early care and interventions.

Sample size and selection process: In the study, total 12 mothers of developmentally challenged children participated, among them 6 mothers were selected for the Indepth interview, and 6 mothers for the Focus Group Discussion (FGD) were selected

separately as a different group, following some inclusion criteria: the same socioeconomic background (upper-middle-class) and the age range of the children 5 to 8 years. In the In-Depth interview, all the participants were mothers of male children and in the Focused Group Discussion there were mothers of 3 male children as well as mothers of 3 female children, they were chosen based on the convenience of the researchers. All the children were under the care and intervention of an institute of special education.

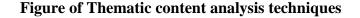
Data collection tool and methods: Two different data collection tools were used to conduct the research, thematic In-depth Interview (IDI) Questionnaires and Focused Group Discussion (FGD) guidelines. Data have been collected through face-to-face in-depth interviews and group discussions following IDI and FGD guidelines. The Focused Group Discussion (FGD) was conducted in an online group call via WhatsApp where 6 mothers joined, with the same questionnaires but in a little different setting to gain insights into parents' perceptions and experiences. After developing the IDI and FGD guidelines, the questions were checked by our academic expert before conducting the IDI as well as FGD, and then oral consent was taken from selected participants for a meeting, the date and time were fixed for the group session. After obtaining permission, both IDI and FGD were recorded, and field notes also were taken.

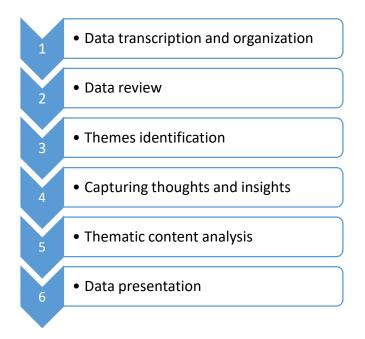
Data Management and Analysis: Thematic Content Analysis technique has been followed to manage and analyze the data; The thematic content analysis techniques have multiple stages that are described below:

Data transcription and organization: After data collection, the raw data were transcribed for each of the individual participants as well as a broad transcript

was done separately for FGD mentioning the names of the participants with the help of recorded files and field notes. For each transcript in the case of IDI, a serial number was given for recognition. Then data were translated from Bengali to English.

- Data review: After transcribing, the data has been written in narrative form.
 Data has been reviewed several times for theme identification,
- Themes identification: Then data from individual transcripts from IDI and group discussions were summarized and categorized according to themes.
- Capturing thoughts and insights: The thoughts and insights of the participants were captured through in-depth interviews and discussion.
- Thematic content analysis: After capturing the thoughts and insights of the participants data have been analyzed thematically.
- Data presentation: After finding out the themes and thematic analysis data has been presented according to the themes.





Validity and Reliability

For validity, the questionnaire was fixed after review and evaluation by the supervisor and other Academic Committee members of IED, BRAC. To keep the reliability of the research discreet, transparent and consistent data records were done. For triangulation, two different research tools have been used in IDI and FGD, to ask interviewees similar things differently. The data were constantly checked by utilizing sources to ensure correctness. To maintain reliability piloting has been done for the research tool as piloting is the first step that helps in the preparation of the main study. Finally, for incredibility recorded data were preserved as well as field notes were collected and that have been transcribed as soon as possible.

Ethical issues

Ethical guidelines have been followed in the qualitative study, and BRAC University approval, as well as plagiarism policy have been strictly followed. Participants' permission was considered to participate in an In-Depth Interview (IDI) and Focused Group Discussion. Verbal consent from the participants was taken first, then a written consent form was delivered to them, it was clear that personal information is only used for research. Only willing participants will participate in the study. Details about the research, such as purpose, objectives, and reasons were clear to them. A schedule was fixed for IDI and FGD after obtaining oral consent from the selected parents. An audio recorder recorded the In-Depth interview as well as the Focused Group Discussion after getting their permission. Field notes were taken also, and their knowledge, perception, experience and different terminologies have been quoted through notes. Participants had the right to exclude themselves from the study at any time.

Imitation of the study

As a limitation of the qualitative study, there may be some bias according to personal experiences as a parent of a developmentally delayed child. Another limitation was Focused Group Discussions were conducted through online platforms in a group call, it would be better if face-to-face discussions were conducted but all the mothers had children with special needs so it was difficult to sit with all the mothers together at the same time.

Chapter IV

Findings and Discussion

The result and discussion section are focused on In-depth Interviews as well as Focused Group Discussions on Parental perceptions, experiences in early care and interventions for developmentally delayed children in Bangladesh. Data was assembled from both face-to-face In-Depth-Interviews, and the Focused Group Discussion conducted via phone and online group call. The themes were categorized following the answers of IDI and FGD guidelines.

Findings

Demographic Details of the Participants

Annex 4 shows the demographic information of the participants where 12 mothers in total have participated in IDI and FGD, where all the participants were mothers of developmentally delayed children from a special educational institution in Dhaka city. The age range of half of the total mothers is between 35 to 40 years and the age range of another half is below 35 years. The age range of the children is between 5 to 8 years old. Participants' academic backgrounds are different, all of them have highly educational backgrounds, out of twelve mothers, only 2 mothers had HSC degrees, 2 mothers had BA, 2 mothers had MA, 2 mothers had MSC, 3 mothers had MBBS, and one of them have no mothers were housewives, among them 3 were doctors and one of them is govt. job holder, the occupation of the fathers of the children were doctor, ICT consultant, private service, nutrition coordinator in the public sector, textile engineer, police and business, types of disorder of the children, one of them is Down syndrome, 2 of them are Social Communication disorder (SCD), and 9 of the children have Autism Spectrum Disorder (ASD). In the In-depth interviews, all

mothers had male children and in Focused Group Discussion there were 3 male children and 3 female children. All the information found from participants has been categorized into five themes. These are presented below.

Theme 1. Mothers' Understanding of developmental delay

The study aims to explore mothers' knowledge, understanding, or experiences about developmental delays among children. Almost all of the mothers in In-depth Interviews and Focused Group Discussions acknowledged developmental delays as age-appropriate developmental matters.

One of the mothers mentioned developmental delay as "*Not having brain development according to age, for example, if a child's age is 8 years but his or her age of brain is like 2 years old children.*" (**IDI # 5, 10/07/2024**).

Another mother explained that "If there is the absence of age-appropriate matters such as speech, socialization activities, toilet training as self-care skills, etc. called developmental delay." (IDI # 4, 09/07/2024).

One of the mothers stated developmental delays mean a lack of both physical and mental age-appropriate matters, "*After birth, which is supposed to happen for a child when there is a shortage of either physical or mental development if anything is deficient, that is also called developmental delay.*" (**IDI # 2, 07/07/2024**).

Different reasons can interfere with children's development. In this regard, one of the mothers stated, "Developmental delay means slow development. For example, due to autism, development is not visible very fast. After a certain period, it is somewhat understandable that there has been a little development on a particular side." (FGD # 6, 12/07/2024).

On the other hand, one of the mothers picked up the differences between developmental delay and developmental disorder, she mentioned, "*I think the developmental disorder is never completely age-appropriate moving forward with time, will lag, and maybe the delay can sometimes be overcome. But in the case of disorder, it is very difficult to overcome those.*" (FGD # 1, 12/07/2024).

It is found that if there is an absence of age-appropriate speech, social communication, self-care skills, etc. called developmental delay. Different reasons may hamper development such as autism is one of them.

Theme 2. Ages at onset and symptoms of developmental delay

The symptoms were exposed and understood by parents between 16th months to 3 years. Common symptoms were e.g., no response by name-calling, inability to follow commands, poor eye contact, speech delay, hyperactivity, and staying like their own.

One of the mothers mentioned, "All types of development were fine till 14th months, some changes were noticed in the 16th months were self-indulgence, reduction of responses, little that was babbling is gone, inability to follow commands and recognize objects." (FGD # 1, 12/07/2024).

Another mother said, "When she was three years there was no eye contact, looked once after calling ten times." (FGD # 5, 12/07/2024).

Two participants acknowledged that their children's development was normal till a certain age, but after that gradually they went beyond one of the mothers mentioned, "In 2.5 years he became completely mute, the things he used to do such as uttering one word, toilet training that he learned, all forgotten, in the beginning, there was no hand flapping later hand flapping added." (FDG # 2, 12/07/2024)

Few of the mothers acknowledged that the subject of autism didn't come to their mind, one of the mothers mentioned, "It was identified when he was three years old, the subject of autism didn't come to mind before, he screamed abnormally, didn't sit in one place, didn't say any meaningful word, didn't sleep properly even at night."

(**IDI** # 1, 07/07/24).

According to another mother's statement "When he was 2.5 years old, we noticed speech delay, he was not saying anything except a word." (IDI # 2, 07/07/24)

It is also found that children may have specificity one of the mothers shared her experience, "When we identified his age was 2 years and 4 months, he didn't speak, did not respond when called, played alone, be like yourself, didn't say anything but he could give the call to prayer (Azan) very nicely." (**IDI # 5, 10/07/24**).

Almost all the mothers acknowledged that their children had poor eye contact, speech delay, social communication disorder and preferred to stay like their own.

Theme 3. Problems or barriers faced to take immediate actions

In the study, most participants were from upper-middle-income families, though all of them were aware of child development and took immediate action but some reasons have been identified for delayed interventions. Firstly, this is the group where many parents faced COVID-19, other factors identified were lack of awareness and lack of adequate knowledge about specialty, conflicts in self-acceptance, lack of correct information, long-distance care, parental denial due to trauma, and wasting time to understand everything,

One of the participants mentioned, "I didn't know assessment is an important thing, he was suggested a special school and three types of therapy, started only speech therapy as special schools remained closed for over one year due to COVID-19, If I could assess and start the earlier." (IDI # 2, 07/07/24).

Few parents acknowledged that their time was up to searching and going from one doctor to another doctor to understand everything. One of the participants stated, "*After being diagnosed we showed the child in many places then we found such a school (special school), all in all almost a year has passed, and we gave him special school when he was three years old.*" (**IDI # 3, 08/07/24).**

Some participants acknowledged they wasted time due to a lack of correct information. One participant mentioned, "*I was too late to reach the right place, everybody used to say many children speak late. I have been here (special school) since she was 4.5 years. I would have benefited more if I had given earlier.*" (FGD# 4, 12/07/2024).

Two mothers shared their personal experiences regarding normal school vs special school for these special needs children, according to one of the mothers' statements, "At first, I delayed sending him to a normal school but now I think it is better not to send a normal school because the same work is being done to each child but their problem is different." (IDI # 5, 10/07/24).

Sometimes due to trauma, fear of social exclusion hampers taking immediate actions, one participant shared, "*I could not accept myself; I didn't take him anywhere until I could accept it, my condition was worse I thought it might be okay. I am too late to overcome the traumatization; he is six years old now.*" (FGD # 2, 12/07/2024).

Two of the participants shifted to Dhaka due to better treatment, one of them acknowledged, *"We didn't get adequate and proper guidelines what I feel after coming to a special school in Dhaka, the labor that I give in if I could give in earlier,* he would go further I think so now. To gain knowledge about autism the age of development is gone." (FGD # 3, 12/07/2024).

Theme 4: Mothers' perceptions and experiences of early care and intervention

All the participants acknowledged the earlier the better because at that time everything can be taught quickly. Due to care and interventions, their child's understanding level has been increased, and the development of the children is happening little by little.

Most of the participants mentioned early intervention as, "speech therapy for speech development, activities for reducing hyperactivity, to associate with normal children as much as possible." (IDI # 5, 10/07/24).

All of the mothers acknowledged, "Due to early care and interventions volatility of my child has subsided, the sitting habit has arrived, and speech is also better now." (IDI # 1, 07/07/2024).

Another mother having a child with social communication disorder stated, "*His treatment was to be kept among more people, to play with children, interaction with teachers in a school environment. Now his sitting habit is better, eye contact is also normal, and speaking.*" (**IDI # 3, 08/07/2024**).

All the mothers mentioned due to speech therapy, physiotherapy, and interventions to reduce hyperactivity, the overall development of their children is better now.

Theme 5. Mothers' Suggestions for upbringing children

All of the participants in the study came to the point that if there is a problem parents should not delay and should talk to the expert necessary steps can be taken as early as possible because early periods are the most sensible time. The participants have given some hints on how to understand that children have problems regarding developmental issues.

One of the mothers mentioned, "In raising a normal child you will understand easily, but children will have behavioral issues if they are not normal. One or two normal children are playing together while children with problems will not play together, and may not have social activities." (IDI # 1, 07/07/24).

According to one of the participants' statements, "*Age-appropriate development* needs to be noted, if delays should take immediate action for better treatment without being frustrated because a child has an age limit of development, after that it slows down then stops." (**IDI # 3, 08/07/24**)

Another participant added, "Age-appropriate things such as speaking, responding by name calling, being interested in playing with others identifying those and talking to doctors also keeping the right environment because a normal child can be special due to environment." (IDI # 5, 10/07/24).

From another mother's experience, "*I will give two suggestions don't give the devices* to children. My child had a lot of screen time, this is a very bad one and giving quality time." (FGD # 5, 12/07/2024).

Two of the mothers were highly focused on assessment, and one mother stated, "*I* didn't know assessment is a very important thing even parents should do the same for normal children because a child's development is known at a certain age". (**IDI # 2**, **07/07/24**).

All in all, giving quality time, ensuring a child-friendly environment and exposure to screen time have been discouraged for overall child development

Discussion

The study aims to explore mothers' perceptions from their knowledge as well as experiences regarding early care and interventions of developmentally delayed children in Bangladesh from mothers of similar socio-economic backgrounds. According to the demographic profiles of annex 4 all the mothers who participated had one child with developmentally delayed within the age range of 5 to 8 years. All the participants are mothers with different highly educational backgrounds only two mothers had higher secondary education (HSC). From the demographic information, it is also seen from the fathers' occupation that all the families are from upper-middle-income backgrounds. From the study, it was found that among 12 mothers most of them didn't know about the symptoms of specialty, but all the mothers had an excellent acknowledgment of the importance of early care and interventions for child development.

Parental Understanding of developmental delays

In the study, it was found that child development was related to both physical and mental age-appropriate developmental matters. The physical development of all the children was fine except for two children whose physical development was a little late, one of them was a Down syndrome child and another one had Social Communication Disorder. Cognitive delay is interrelated to other developmental issues such as speech, social communication, emotional development, and behavioral problems. The literature review found that each skill's development influences others' development. For example, increased language capability contributes to the development of cognitive control, cognitive development encourages social

communication, and social communication promotes language development (Villagomez et al., 2019)

For some of the cases it is seen that their development was normal till a certain age, they were uttering one or more words but without understanding and suddenly stopped and gradually went beyond. The reviewed literature shows that its first signs appear at the end of the first year. Research has demonstrated that the signs of Autism Spectrum Disorder, such as reduced social interaction and communication slowly come out in the second half of the first postnatal year to become more obvious at the start of the second year. With growing age, most children with ASD gradually lose social and communicative capabilities that they had mastered earlier (Hadders-Algra, 2021).

In the study, we have also found that there is a difference between developmental delay and developmental disorder. Someone can overcome the developmental delay but it may be difficult to overcome developmental disorder.

It is found that Global Developmental Delay (GDD) (significant delays in two or more developmental areas such as speech, cognition, etc.) in children with Autism Spectrum Disorder (ASD) is worse compared to the group GDD without ASD though both have common features such as language delay in terms of the overall developmental level (Shan et al., 2022)

Ages at onset and symptoms of developmental delay

In the study, the symptoms of developmental delays were exposed and understood by parents between the months of the 16th to 3 years. Mothers of female children also participated along with the mothers of male children, but the symptoms were almost

the same for both male and female children, e.g., no response by name-calling, inability to follow commands, poor eye contact, speech delay, hyperactivity, staying like their own, etc.

It is found in a study that Early speech loss is associated with lower IQ, prominent communication deficiency, and poor language development, while the presence of useful speech at age 2 is associated with better performance in multiple domains (Rogers & DiLalla, 1990). Another study indicated that abnormalities in early development with autism often exist in the first year, including utmost temperament, poor eye contact and lack of response to the parents' voices or attempts to play and interact. Key symptoms such as speech delay and behavioral problems are often obvious in the second year, but these are not the crystal-clear symptoms of autism. But there is powerful evidence that autism is related to unusual brain development early in antenatal life (Zwaigenbaum et al., 2005).

Barriers to taking immediate action

In the research study, though all the participants were highly educated, there was a knowledge gap about developmental delay, most acknowledged they didn't know before or didn't come to their mind. But after realization and diagnosis, all the families gave importance to child development. in most cases, parents took immediate actions but due to lack of adequate knowledge, correct information, discouragement from family members as well as from surroundings, seat problems, religious beliefs (it would be fine, it can't be with me), traumatization, etc. for these, delays are noticed to reach right places. As a result, the waste of time as zero to five years is treated as the early childhood period. As all the participants in the study were from upper-middle-income, they didn't mention costs as a problem, few of them acknowledged that cost

is high. Some mothers mentioned that the cost is low compared to other special schools that's why they are here (current special school).

In the case of the first child, mothers understood the symptoms later because they claimed they didn't know about the child's developmental milestones. Few parents shifted to Dhaka city due to better care because they faced a scarcity of expertise, proper care, and services for their special needs children. So, the families who are capable of taking care and services shifted themselves toward city-based services, which is very difficult for many families. The study also indicates that in our country there is a lack of proper knowledge about specialized teaching because the study shows few parents sent their children to normal school but later mothers realized that was a waste of time and they discouraged not sending normal school in the case of these special needs children.

The results of a study disclosed that there is a lack of adequate resource allocation to continue the mainstream education system, inadequately trained teachers, transport problems and extra expenditure for children with special needs discourage parents from sending their children to school (Islam, 2021).

Our study also presents that when mothers share their children's problems with other family members as well as neighbors, they get feedback that it would be fine with ages. Thus, to understand everything most cases the developmental ages are almost gone. Self-acceptance sometimes works as a barrier to taking immediate action because understanding and recognizing one's limitations need to be done first, it is difficult for many people to accept negative things for themselves until their parents accept, their conditions were worse than the child's that were found in the study also.

It has been clear that the family is the keystone of early intervention. Families are the central environment of children, and family members are the key persons who may influence child development through daily interactivities during caregiving and play. More parental involvement is related to better outcomes for the family and young child (Hadders-Algra, 2021).

Parental understanding of early care and interventions

All of the mothers in the study agreed that early care and interventions have significantly positive impacts, they mentioned that the development of their child is becoming little by little, and their understanding level is much better now. Everyone has said if only I could have started earlier, then could have more benefits. In the study, we identified some common symptoms of developmental delays so early care and interventions for these symptoms can be speech therapy for speech development, activities to reduce hyperactivity, increasing sitting habits, working for eye contact, interacting with more people, outdoor playing, and talking a lot etc. Early care and interventions for these special needs children can only be in special schools, developmentally delayed children need special care and attention, and the environment in the special schools is welcoming for them. All the mothers were positive that the development of their children is gradually going forward though it is very slow, after a certain time positive changes are noticed. Early care and intervention also can be applicable to achieve daily living skills as well as activities for cognitive development. Their way of teaching is different explaining real objects by hand and giving basic ideas about everything. Many literatures support that there are certain periods when the brain is more responsive or vulnerable to biological and environmental impact which can influence the long-term path of the growing brain (Villagomez et al., 2019).

Another finding supports that earlier diagnoses help avoid the all-encompassing developmental delay and open up possibilities for early interventions (Levy, 2011).

Suggestions for upbringing children

All the participants from the study acknowledged that the early period is the most sensible time for up-brining children it has been suggested to give a child-friendly environment as well as spending quality time with children, too much screening time has been discouraged. As mothers closely observe their children, they know the strengths and weaknesses of their children, if there is something to be worried about should not delay because immediate actions create an opportunity for better treatment at the right time. Cognitive assessment has been highlighted by the participants in the research study, this assessment should be for all children in the country. For example, when people go to a vaccination center, they know which vaccination is given for which diseases. If there is a mandatory system for cognitive assessment with proper messages like, have to do an EEG, need therapies that can be helpful to build awareness among the public and many children will get the chance for early interventions. One study specifies that it is necessary to select children who need a more accurate or detailed assessment as early intervention is key for enhancing developmental progression in the delayed child (Oberklaid & Efron, 2005). Participants from the study suggested immediate actions because after a certain age, the chance of child development gradually decreases. Finally, acceptance is a very crucial one because whenever parents can accept then they can start working.

Early identification of developmental delay or disability is crucial to the well-being of children and their families and should lead to further evaluation, diagnosis, and

treatment. The terms delay development, developmental disorder," and "developmental abnormality" are used synonymously (Disabilities et al., 2006).

Conclusion

The research aimed to understand whether there were positive impacts of early care and interventions for children with developmental delays or not, from the study it has been profoundly proven that early care and interventions have significantly positive impacts on developmentally delayed children, though the progress of development is slow, but after a certain period positive changes are noticed in the developmental areas. There are several factors affecting early identification and taking immediate action such as poor knowledge and lack of conciseness are most common among them. The earlier the better, according to the study, all participants have experienced that early intervention works most during the early childhood periods. City-based expertise, high care and services have been found from parental experiences. In the research study, a cognitive assessment system has been strongly suggested for implementation at the national level as a mandatory system like existing vaccination activities in the country.

Recommendations

The research aims to understand the perceptions of parents regarding the developmental challenges of children. To improve the conditions some recommendations based on research findings and discussion are mentioned below:

 Further research is needed targeting a broader group, also addressing different socioeconomic groups such as low, middle and upper-income families. The research has been done on children who are under care and intervention, so, further research can be done on those who haven't reached under care and services.

- Awareness-building programs can be arranged for both parents and society people to convey proper information about developmental issues of children by Govt. and private organizations collaboratively.
- Special needs-related awareness programs including positive outcomes as a result of early care and interventions need to be broadcast on different media platforms such as television, radio and popular online platforms.
- In both Govt and private hospitals, clinics, and healthcare centers cognitive assessment-related activities with proper guidelines can be included as mandatory services.
- Expertise in the related fields should not only be confined to city-based but also given importance at the national level.
- Identifying the gaps between the national policies and realities up- to date plans and policies should be included to ensure the rights and safety regarding their early care and services within reasonable cost so that all classes of families can avail.

References

- Akther, N., Begum, M., Farah, S., Begum, N., Lata, N. M., & Sabnom, R. (2017).
 Child Care Practice of Mother of below Five Years Children in a Selected
 Semi Urban Area of Bangladesh. *Delta Medical College Journal*, 5(2), 76-82.
- Bola, K. K., & Randhawa, G. (2013). Role of Islamic religious and cultural beliefs regarding intellectual impairment and service use: a South Asian parental perspective.
- Burger, K. (2010). How does early childhood care and education affect cognitive development? An international review of the effects of early interventions for children from different social backgrounds. *Early Childhood Research Quarterly*, 25(2), 140-165.
- Cambridge University Press & Assessment. (2024). *Cambridge Dictionary*. https://dictionary.cambridge.org/dictionary/english/perception
- Choo, Y. Y., Agarwal, P., How, C. H., & Yeleswarapu, S. P. (2019). Developmental delay: identification and management at primary care level. *Singapore medical journal*, 60(3), 119.
- Disabilities, C. o. C. W., Pediatrics, S. o. D. B., Committee, B. F. S., & Committee,
 M. H. I. f. C. W. S. N. P. A. (2006). Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics*, *118*(1), 405-420.
- Durkin, M., Khan, N., Davidson, L., Huq, S., Munir, S., Rasul, E., & Zaman, S.
 (2000). Prenatal and postnatal risk factors for mental retardation among children in Bangladesh. *American journal of epidemiology*, *152*(11), 1024-1033.

- Ghosh, D., Khan, S. H., & Al-Mehedi, Z. (2022). Children with disabilities in an allinclusive education system.
- Ghosh, S., & Steinberg, H. (2022). Parents' attitudes and unequal opportunities in early childhood development: Evidence from Eastern India. *Journal of Early Childhood Research*, 20(3), 413-430.

Grimes, P. (2021). Disability-Inclusive Education Practices in Bangladesh.

- Guralnick, M. J. (2005). Early intervention for children with intellectual disabilities: Current knowledge and future prospects. *Journal of applied Research in intellectual Disabilities*, *18*(4), 313-324.
- Hadders-Algra, M. (2021). Early diagnostics and early intervention in neurodevelopmental disorders—age-dependent challenges and opportunities. *Journal of clinical medicine*, 10(4), 861.
- Hussain, M. M. (2021). Social exclusion of people with disability in Bangladesh: Dimensions and challenges. *Asian Social Work Journal*, 6(1), 12-21.
- Islam, A. (2021). *Mainstreaming education of the children with disability in Bangladesh* University of Dhaka].
- Islam, M. A., & Juhara, S. F. (2021). Rights and protection of persons with disabilities in Bangladesh: A critical review. *International Journal of Research and Innovation in Social Science*, 5(1), 331-335.
- Islam, M. A., Rahman, M. A., & Akhtar, S. (2022). Psychosocial impact of parenting children with intellectual disabilities in Bangladesh. *International Journal of Public Health*, 11(1), 211-219.
- Khan, N. Z., Ferdous, S., Islam, R., Sultana, A., Durkin, M., & McConachie, H.
 (2009). Behaviour problems in young children in rural Bangladesh. *Journal of tropical pediatrics*, 55(3), 177-182.

Knauer, H. A., Ozer, E. J., Dow, W. H., & Fernald, L. C. (2019). Parenting quality at two developmental periods in early childhood and their association with child development. *Early Childhood Research Quarterly*, 47, 396-404.

Learning, N. (2023). *Early help and early intervention*. The NSPCC. <u>https://learning.nspcc.org.uk/safeguarding-child-protection/early-help-and-</u> early-intervention

- Levy, Y. (2011). Developmental delay revisited. *Developmental disabilities research reviews*, 17(2), 180-184.
- Murphy, K., & Harrison, E. (2022). The weight of waiting: the impact of delayed early intervention on parental self-efficacy. *British Journal of Special Education*, 49(1), 84-101.
- Oberklaid, F., & Efron, D. (2005). Developmental delay: identification and management. *Australian family physician*, *34*(9).
- Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N.-Y., Nair, M., Halpern, R., Kuper, H., Breinbauer, C., De Vries, P. J., & Gladstone, M. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Global Health*, 6(10), e1100-e1121.
- Oranga, J., & Matere, A. (2023). Qualitative Research: Essence, Types and Advantages. *Open Access Library Journal*, *10*(12), 1-9.
- Prelock, P. A., Hutchins, T., & Glascoe, F. P. (2008). Speech-language impairment: how to identify the most common and least diagnosed disability of childhood. *The Medscape Journal of Medicine*, *10*(6), 136.
- Rahaman, M. M. (2011). Inclusive education practices for secondary school students with disabilities in Bangladesh.

- Riou, E. M., Ghosh, S., Francoeur, E., & Shevell, M. I. (2009). Global developmental delay and its relationship to cognitive skills. *Developmental Medicine & Child Neurology*, 51(8), 600-606.
- Rogers, S. J., & DiLalla, D. L. (1990). Age of symptom onset in young children with pervasive developmental disorders. *Journal of the American Academy of Child* & Adolescent Psychiatry, 29(6), 863-872.
- Sapiets, S. J., Totsika, V., & Hastings, R. P. (2021). Factors influencing access to early intervention for families of children with developmental disabilities: A narrative review. *Journal of applied Research in intellectual Disabilities*, 34(3), 695-711.
- Schiariti, V., Simeonsson, R. J., & Hall, K. (2021). Promoting developmental potential in early childhood: a global framework for health and education. *International Journal of Environmental Research and Public Health*, 18(4), 2007.
- Shan, L., Feng, J.-Y., Wang, T.-T., Xu, Z.-D., & Jia, F.-Y. (2022). Prevalence and developmental profiles of autism spectrum disorders in children with global developmental delay. *Frontiers in Psychiatry*, 12, 794238.
- Smiley, J. (2024). Intellectual Disability: Signs, Causes, and Support. <u>https://www.verywellhealth.com/types-of-intellectual-disability-in-children-and-adults-5210316</u>
- Smythe, T., Zuurmond, M., Tann, C. J., Gladstone, M., & Kuper, H. (2021). Early intervention for children with developmental disabilities in low and middle-income countries–the case for action. *International health*, *13*(3), 222-231.
- Störbeck, C. (2024). Early Childhood Development Is Not Enough: In Defense of Children with Developmental Delays and Disabilities and Their Right to

Family-Centered Early Childhood Intervention (In the Global South). *Children*, *11*(5), 606.

Sulkes, S. B. (2024). Intellectual Disability.

https://www.msdmanuals.com/home/children-s-health-issues/learning-anddevelopmental-disorders/intellectual-disability

- Sultana, R. (2019). *Parents' perception on responsive parenting during infancy* Brac University].
- Thompson, S. (2020). *Disability inclusive development situational analysis for Bangladesh.*

Villagomez, A. N., Muñoz, F. M., Peterson, R. L., Colbert, A. M., Gladstone, M.,
MacDonald, B., Wilson, R., Fairlie, L., Gerner, G. J., & Patterson, J. (2019).
Neurodevelopmental delay: Case definition & guidelines for data collection,
analysis, and presentation of immunization safety data. *Vaccine*, *37*(52), 7623.

Zwaigenbaum, L., Bryson, S., Rogers, T., Roberts, W., Brian, J., & Szatmari, P.
(2005). Behavioral manifestations of autism in the first year of life. *International journal of developmental neuroscience*, 23(2-3), 143-152.

IDI guidelines

Starting time:Ending time:Name of the parents:Age:Educational Qualification:Father's Occupation:Mother's Occupation:Securation:

Age of the child: Gender:

1. What is your understanding of children's developmental delay?

2. At which age do you find out your child has developmental difficulties?

3. What were the symptoms you noticed in your child?

4. At which age do you seek first care and services for your child?

5. After recognition did you take immediate actions for care and services or delayed? If delayed,

6. What types of problems did you face to take immediate action?

7. At which age your child went under schooling

8. Did you face any problems or barriers to reaching for related care and services? If yes, what was that?

9. What is your understanding of early care and interventions for developmentally challenged children?

10. Do you think early identification and early stimulation help in cognitive and other development? If yes, would you share your personal experiences?

11. In your suggestion what kind of knowledge should parents have for the upbringing of their children to ensure their development?

Focused Group Discussion (FGD) Guidelines Venue: Starting time Ending time: Total participants: Age of the child: Gender of children: Male/Female Mother's education Father's occupation

Date:

- 1. What is your understanding of developmental delays in children?
- 2. At what age did you discover your child has developmental difficulties? What were the symptoms?
- 3. At which age do you seek first care and services? Did you take immediate actions for care and services or were you delayed? If delayed, why?
- 4. What is your understanding of early care and interventions for developmentally challenged children?
- 5. What types of problems did you face in seeking related care and services?
- 6. How do early identification and early stimulations help in cognitive and other development? If yes, would you share your personal experiences?
- 7. In your suggestion what kind of knowledge should parents have for the upbringing of their children to ensure their development?

Consent Form

Title of the Thesis proposal: Parental Perceptions on Early Care and Interventions for developmentally delayed children in Bangladesh.

Name of the researcher: Rumana Yeasmin

Purpose of the research: The study will be a part of my Master's Degree requirement from the Institute of Educational Development (IED), BRAC University. The study aims to understand parental perceptions regarding care-seeking for children with developmental challenges.

Expectations from participants: If you agree, you will be expected to share your experiences, perceptions, thoughts, opinions, and beliefs regarding care-seeking for intellectually challenged children. The interview may take 30 to 60 minutes, depending on your response.

Risks and benefits: There is no risk for participating in this study, even if it is used for future research purposes. Directly or indirectly parents, children, and policymakers may be benefited in the future.

Privacy and anonymity: All information collected from you will be used only for research purposes, the privacy of your details will be maintained strictly.

Right not to participate and withdraw: Refusal to participate in the study will involve no penalty. You have the authority to decide for and against your participation in this study. If you agree to participate in my study, please indicate that by putting your signature in the specified space below-

Name of the parents:

Signature of the parents

Thank you for your nice cooperation. For further study queries, please get in touch with me at (<u>.....@gmail.com</u> or phn number).

Name of the researcher:

Signature of the researcher

Serial No Name of the Mothers' Fathers' Types of disorder Date of Educational Gender Age Age of Interview participants background occupation occupation children 07/07/2024 IDI#1 35 Male ASD B.A Govt. job Police 6 years 1 2 07/07/2024 40 MA Male ASD IDI#2 Housewife Business 7 years 3 08/07/204 IDI#3 36 MBBS Doctor Doctor 6 years Male SCD 09/07/2024 Private service 4 IDI#4 29 MSC Housewife 5 years Male ASD 5 10/07/2024 IDI#5 29 H.S.C Male ASD Housewife Business 8 years 11/07/2024 IDI#6 36 MA Male Down syndrome 6 Housewife IT Business 7 years

Demographic details of participants (In-Depth Interview)

Demographic details of participants (Focused Group Discussion)

Starting time: 7.45 pm Date of Focused Group Discussion				Ending time: 9.00 pm 12/07/2024				
1	Mother#1	33	MS in Nutrition and Food Science	Housewife	Nutrition Coordinator	5.5 years	ASD	Male
2	Mother#2	36	BDS	Dentist	Private service	6 years	ASD	Male
3	Mother#3	26	H.S.C	Housewife	Business	6 years	ASD	Male
4	Mother#4	38	MBA Finance and Banking	Housewife	ICT consultant	5.5 years	SCD	Female
5	Mother#5	32	MBBS, FCPS	Doctor	Doctor	5 years	ASD	Female
6	Mother#6	34	Masters in Journalism	Housewife	Textile Engineer	6 years	ASD	Female

Duration of

interview

35 mins.

50 mins.

45 mins.

40 mins.

50 mins.

40 mins.