

**Barriers of Performance in Activities of Daily Living,
Academic and Social Functioning for Children and
Adolescents with Intellectual Disability: Parental
Perspectives.**



By
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*This thesis is submitted in total fulfilment of the requirements for the subject
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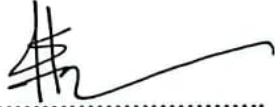
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Statement of Authorship

This is an affirmation that I, Fatema Jannat Tamanna, have completed the thesis project titled "Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for Children and Adolescents with Intellectual Disability: Parental Perspectives." to fulfil the requirements for earning a B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute, Savar, Dhaka, Bangladesh. There is no prior submission of this study for the award of any other degree or certificate.

I certify that nothing in this thesis has been published elsewhere or is being utilized to satisfy the criteria of any other academic program, except the instances where it is recognized explicitly in the text. This work does not contain any content that has been taken from a thesis given by me or anybody else for any academic reason.

I further declare that this study has been conducted with due diligence and that ethical considerations have been protected. Any future dissemination of the research findings will include proper acknowledgement of its origins as an undergraduate thesis. I acknowledge that my research supervisor has a strong interest in ensuring the responsible dissemination of the project's findings.

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Dedication

In the name of Allah, the Most Beloved, the Most Merciful

I dedicate this research to the Creator of all things, Allah; the Knower of the Seen and the Unseen, the Source of all knowledge and wisdom, whose guidance has been my guide through the journey of my entire life.

In addition, I dedicate my work to my father and everyone else in my family who raised me with humanity as a proper human being, to my thesis supervisor who helps me in every step of my writings by giving me proper guidance, and my friends, whose love and support have always been there for me and have never lost faith in my abilities. Your encouragement has kept me going through the challenges of this journey.

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List of Abbreviations

ADLs	Activities of Daily Living
AOTA	American Occupational Therapy Association
BBS	Bangladesh Bureau of Statistics
BHPI	Bangladesh Health Professions Institute
CRP	Centre for the Rehabilitation of the Paralysed
ICF	International of Functioning Disability and Health
ID	Intellectual Disability
IRB	Institutional Review Board
NHMRC	National Health and Medical Council
NSPD	National Survey on person with Disabilities
OT	Occupational Therapy
OTPF 4	Occupational Therapy Practice Framework 4
WHO	World Health Organization
WMA	World Medical Association

Abstract

Background: Cultural diversity significantly influences the barriers to being involved in the daily activities of individuals with a range of disabilities. In Bangladesh, children and adolescents with intellectual disabilities (IDs) are experiencing numerous barriers in their everyday lives, including difficulties in activities of daily living, academic and social participation, which are context dependent. It is essential to comprehend these obstacles and their overcoming strategies from the perspective of parents to establish support strategies and intervention which succeed.

Aim: This study aimed to explore the parent's perception regarding the potential barriers of performance while engaging in activities of daily living, academic and social functioning of children and adolescents with ID and generate the overcoming strategies.

Methods: The methodological framework of this thesis was conducted as a grounded theory approach in a qualitative research design. Participants were selected through non-probability, purposive sampling. Semi-structured interview was conducted among 11 parents of children and adolescents with ID from three different organizations in Bangladesh. To get this specific number of participants, the data saturation procedure was used. The grounded theory method was used to analyse and transcribe the data.

Result: Barriers were identified and described through five themes, including 1) Attitudinal barriers; 2) Physical barriers; 3) Financial barriers; 4) Institutional barriers and 5) Communication barriers. The sixth theme describes the overcoming strategies through three sub-themes, including 1) Awareness and advocacy; 2) Therapeutic support and other interventions; 3) educational reforms.

Conclusion: In the context of Bangladesh, the results of this study provide insight into significant barriers that impact children and adolescents with ID's involvement in ADL,

academic performance, and social functioning. Increasing awareness and advocacy, appropriate intervention and educational reform could be an important method of improving participation by minimizing barriers.

Keywords: Barriers, Performance, Activities of daily living, Academic functioning, Social functioning, Children, Adolescents, Intellectual disability.

CHAPTER I: INTRODUCTION

1.1 Background

According to the World Health Organization (WHO), since 2019, worldwide 970 million people were estimated to be suffering from a mental disorder (WHO, 2022). Statistics shows that 2.80 percent of people in Bangladesh live with disabilities, with 1.99 percent children in the country among the age of 5-17 years having a disability (including physical and mental). According to the Person with Disability Rights and Protection Act 2013, intellectual disability is one of the twelve categories or domains of disability and 0.14 percent of the population have intellectual disability (BBS, 2022). In accordance to the DSM-5, ID is a neurodevelopmental disorder that manifest in childhood and are expressed by intellectual and adaptive functioning deficit in conceptual, interpersonal and practical domain of everyday life along with intellectual issues (American Psychiatric Association, 2013). In Bangladesh, most of the people have negative perception about disability, particularly in rural areas where it is seen as a cultural curse. Usually attributed to the parent's sinful deeds and occasionally considered to be a communicable disease. Disability related stigma is so deep rooted that makes parents afraid of going anywhere with child (Islam & Jahan, 2018). Reducing this negative attitude among individuals to create social inclusion is essential for improving people's quality of life in Bangladesh.

During the developmental period, the onset is occurs with two significant symptom deficit in intellectual function such as thinking, reasoning, problem solving, planning, judgement, academic learning and deficit in everyday adaptive functioning in comparison to individuals age, gender and socio culturally matched peers in ID

(AmericanPsychiatricAssociation, 2013). ID is diagnosed before the age of 18 (Mark J. Hauser). There are 4 levels of ID depending on the IQ score. The average IQ score is 100. The person is considered intellectually challenged if they have an IQ of less than 70 to 75 (mild IQ 52-69, moderate IQ 36-51, severe IQ 20-35 and profound IQ less than 19) (Sulkes, 2022). In total, 85% have mild ID and less than 25% contain moderate, severe, and profound ID. Some research show that, 73.8 percent children with disabilities do not attend school and children with ID seems to be the highest risk of being excluded from school (Abrahamsson & Palmberg, 2016). Another study revealed that a poor number of children with ID received primary education and some of them received secondary education but there are no children with ID who received higher secondary or above education (Islam et al., 2022).

To minimize the participation problem in everyday activities and education and society, the barriers which exclude them from participation should be identified. And this study is about parents' perspective about the barriers of performance in activities of daily living, academic and social participation for children and adolescents with ID. Around the world many countries conducted research to identify the barriers of the community engagement or participation such as India, China, South Africa, The United Kingdom etc., (Ahmad, 2018; Mkabile & Swartz, 2020; Shi et al., 2022; Siperstein, Glick, & Parker, 2009). So, the result might not represent these populations with different cultures all over the world. There is still no evidence that a study of that sort (identifying the barriers) has been conducted in Bangladeshi context.

This study provides an in-depth understanding of the potential barriers of performance for children and adolescents with ID and solutions to overcome these barriers. This study findings will be helpful for the health professionals for further intervention plan according to individual needs and parents education, future researcher

will conduct other research related to these barriers, community people will have the understanding about difficulties that the children and adolescents with ID face from society and they can change their approach toward child and adolescents with ID and policymaker can understand those needs and difficulties and can change the policy for better engagement in different sectors. This study results will raise awareness among the community people and health professionals in Bangladesh.

1.2 Justification of the Study

This study will provide in-depth knowledge regarding the barriers of performance of children and adolescents with ID. According to Bangladesh Bureau of Statistics (BBS), 2022, the prevalence of ID in Bangladesh is 0.14% (*National Survey on Person with Disability*, 2022). It is such many populations for Bangladesh. Research finding from different socio-economic backgrounds/culture/context might not be appropriate to compare with the finding of another culture. According to my knowledge, this will be the first study about barriers of performance in activities of daily living, academic and social functioning for person with intellectual disability in Bangladeshi context.

The result of this research will demonstrate the identifiable barriers of the performance that will help the relevant health professionals including Occupational Therapist to minimize the barriers of performance related to attitude, physical, communication and institution. This study described the severity of barriers based on level of impairment and helps the Occupational Therapist to design specific intervention according to individual requirement and can ensure their support service with advocacy in the community to reduce negative attitude and social stigma. The result will change the Occupational Therapy practice beyond the current practice in Bangladesh for ID.

This research will help in community reintegration of children and adolescents with ID by addressing the identified barriers and implementing strategies to overcome them. The result of this research will inform policymakers, teachers, and academic authorities to lead to potential changes in both inclusive education policies and disability health service policies. As a part of dissemination, if the result of this research is published it will reduce the negative attitude and stigma from society. The research will provide a clear insight into the condition of ID and serve as a reliable resource in the field of Health Science. After implementing this research findings, it will hope to create a better Bangladesh for children and adolescents with ID.

1.3 Operational Definition

1.3.1 Barriers

Barriers are defined by the World Health Organization (WHO) as being anything more than just physical obstacles. Here is the WHO definition of barriers:

“Factors in a person’s environment that, through their absence or presence, limit functioning and create disability”(WHO, 2001).

1.3.2 Performance

The act of completing a selected behavior (performance skills), activities or occupation that is a consequence of a dynamic interaction among the client, the activities and the surrounding (Fisher, 2009; Fisher & Griswold, 2019).

1.3.3 Activities of Daily Living

Regularly performed activities that are focused on taking care of the body (Holm & Rogers, 2008). Living in society requires these activities to ensure basic survival and social well-being (AmericanOccupationalTherapyAssociation, 2020).

1.3.4 Academic Functioning

The phrase “academic functioning” is an umbrella term which is consist of both positive and negative indictors of a student’s academic experiences (Bélanger & Ratelle, 2021). Understanding academic functioning is essential and by better understanding it causes method and activities to improves student’s academic experiences can be described (Jeno et al., 2023).

1.3.5 Social Functioning

Social functioning refers to an individual’s interaction with their surroundings and the ability to perform in social context, at work and relationship with peers and family (Bosc, 2000).

1.3.6 Intellectual Disability

Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:

- The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work task.

(AmericanPsychiatricAssociation, 2013)

1.4 Aim of the Study

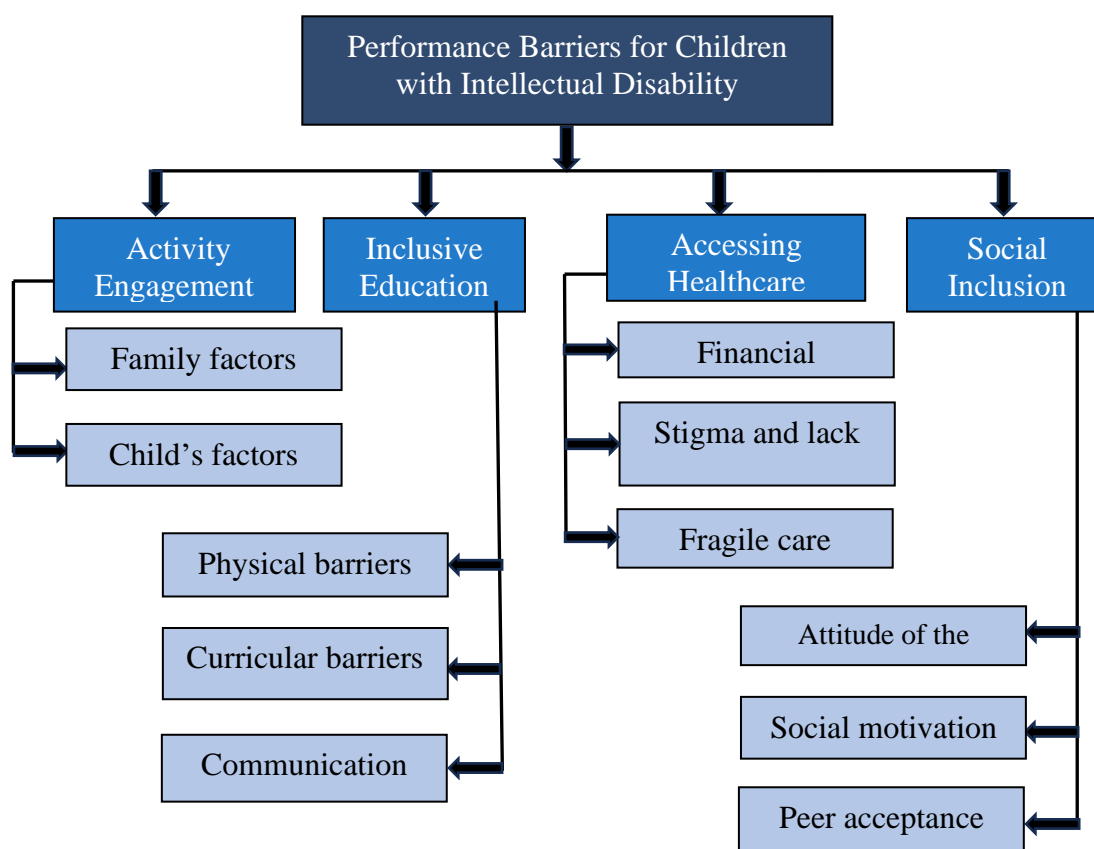
To explore the parent's perception regarding the potential barriers of performance for children with intellectual disability in different areas including engaging in activities of daily living, academic and social functioning and generate the possible recommendation to overcome these barriers of performance.

CHAPTER II: LITERATURE REVIEW

This chapter on literature review covered the synthesis of different research articles regarding caregivers' perspective about the barriers of performance for children and adolescents with ID. There are some different barriers for children and adolescents with ID and this chapter has information about it from previous literature. In Bangladesh, intellectual disability related research is significantly less and that is why some research article from e.g., India, South Africa, United Kingdom (UK), China is used for literature review. This study incorporated the relevant information from 11 research articles that were found through the first search strategies for 14 research articles on that topic. Because they may have empirical data relevant to the proposed study. In this chapter, a brief discussion is done on different domains from previous literature.

Figure 2.1

Overview of the literature review finding



2.1 Activity Engagement

This section of the literature review covered the information regarding the possible barriers for children with intellectual disability to engage in everyday activities. This includes two factors one is family factors and another child factors which is further divided into different sector (McGarty & Melville, 2018).

2.1.1 Family factors

Two studies show that the family structure of the children with intellectual disability also sometimes works as a barrier to children with ID being physically active. Insufficient knowledge of the caregivers about participation in everyday activities and inadequate skills about how to help in development of children with intellectual disability leads to the barriers of the family for children with ID (McGarty & Melville, 2018; Shi et al., 2022).

2.1.2 Childs factors

Child's factors include the child's cognitive abilities, psychological factors, behavioral problems, physical characteristics that is related to the child's disability and engagement in activity. Many of the barriers associated with child factor may be the results of parents perception and negative views relating to their child's competence due to the effect of their ID and how they believe other views the effect of their child's ID rather than actual competence and societal beliefs(McGarty & Melville, 2018). Limited physical and mental function and communication skills become the barriers for the children with intellectual disability to play with peers (Shi et al., 2022).

The abnormal behavior of children with ID is considered as a barrier to engaging in activity. 80% of the children hit others and 70% of children have stereotyped movement that was the 2nd common abnormal manner. Moreover 66% of patient had

verbal abuse problem while 60% belongs to self-injury nature (Islam et al., 2022).

Children with intellectual disability have other associated health problems. Among all associated health issues, sleep problem 44%, sensory impairment 22%, epilepsy 28%, dementia 37%, schizophrenia 41%, behavior impairment 32%, bipolar mood disorder 36%, hearing impairment 10% and obesity 7%. All those additional health issues considered as barriers to engage in activity for children with intellectual disability (Islam et al., 2022).

2.2 Inclusive Education

Local education authorities, schools and other organizations create inclusive culture policies and practice the inclusion process. All children with special educational needs can be successfully welcomed in mainstream education with the correct training, practice, and support. We are lacking in the inclusive education due to various barrier that interferes with its successful implementation (Woolley et al., 2006).

2.2.1 Physical barriers

The main barriers in school inclusion are physical barriers. Physical barriers such as ramps and toilets had been addressed in most school buildings, but no school had systematically or audited and acted upon an audit of the playground for inclusive play. It is necessary to access school buildings and classrooms independently but most of the schools and classrooms are not accessible for children with disabilities. Children face external barriers before coming to and getting enrolled in school such barriers could be physical location of a school, social stigmatization or economic condition of the children (Ahmad, 2018).

2.2.2 Curricular barriers

Together with environmental accessibility to children's curriculum must be facilitated

inclusive education too. Specialized modification and accommodation of teaching method, classroom and homework is required for inclusive education for children with intellectual disability. It is one of the significant barriers in case of inclusive education (Ahmad, 2018).

2.2.3 Communication and skills related barriers

One of the remarkable barriers in inclusive school or education is lack of communication among administration, teachers, specialist staff, parents, and students. Communication and coordination and planning between general education teachers and special education teachers are essential for inclusive education. Another barrier is inappropriate or inadequate skills of the specialized education teacher (Ahmad, 2018). Poor literacy and numeracy skills of the children with intellectual disability are considered one of the major barriers in case of inclusive education (Abbott & Mcconkey, 2012).

2.3 Accessing Healthcare Services

This section of the literature review covered the information regarding the barriers related to accessing healthcare services for children with intellectual disabilities.

2.3.1 Financial crisis

There are three pieces of literature that indicate this monetary crisis as a potential barrier for children and adolescents with ID to access healthcare services. In a research caregiver said that it cost ten times as much to raise a child with ID's as it did to raise a child with typical functioning. They cannot afford the cost of their child's healthcare needs (Shi et al., 2022). Even if the healthcare service cost is free for the children with intellectual disability, but the parents cannot afford the transportation cost for going to the service center (Mkabile & Swartz, 2020).

2.3.2 Stigma and lack of safety

The parents of other children called the children with intellectual disability as “retarded children” and they do not want to have a classmate with intellectual disability of their children. Sometimes the parents of the child with ID conceal their child's illness and face it negatively. They think that having a child children with intellectual disability is shameful in the society and God gave them curse that's why their baby was born with this condition (Mkabile & Swartz, 2020; Shi et al., 2022).

2.3.3 Fragile care network

A change in primary caregivers responsibilities for the children with ID affected their use of services (Mkabile & Swartz, 2020). The secondary caregiver did not take care of the child appropriately and it is one of the barriers of access to healthcare services.

2.4 Social Inclusion

Social inclusion has been largely defined in the fields of disability as greater participation in community-based activities and a border's social network, although in wider society it also embraces other dimensions such as acting as consumers of goods and services or participation in economy and socially valued activities, such as employment and child rearing (Burchardt et al., 2002). This section covers the literature review regarding inclusion in society.

2.4.1 Attitude of society

One of the biggest obstacles to the full inclusion of disabled individual in society is the attitude toward disability. Beyond discomfort, fear and sympathy to low expectations about what people with disability may achieve. People are not healed back by a negative stereotype or contribute attitude. The negative attitudes and stereotypes are often caused by a lack of knowledge and understanding because the general education teacher and

para educator are not enough trained and they have limitation in inclusive education (Ahmad, 2018).

2.4.2 Social Motivation

Activity was strongly motivated by social contracts. Peer interaction with siblings, peers with ID, and peers who are usually developing provide a reason to be physically active as well as a chance for peer modeling and support (McGarty & Melville, 2018).

2.4.3 Peers Acceptance and Social Relationship

The most common barrier for children with intellectual disability is the avoidance of peers in case of social inclusion. Other children without disabilities often do not choose them as friends, which hurts them and increases the avoidance of social gathering. It breakdown the social relationship with others children in the society (Siperstein, Glick, & Parker, 2009).

2.5 Strength and Weakness of these literature

2.5.1 Strength

- This research was conducted with a specific domain in a particular country, which is the reflects of this country's barriers or facilitator for children with IDs very well.
- All the studies were conducted in the community except one, so this gathered information is not only in a specific area based. It represents all over the country.
- This research was conducted by several professionals which contained detailed information, based on which the govt. can change the policy of the country.

2.5.2 Weakness or gaps of these literature

- Though this research was conducted in a particular country, it does not represent the world's condition.

- This research was conducted with a particular domain of a country and that is why it does not give us information about other domains of those countries.
- A couple of studies applied a cross-sectional approach with a quantitative design, but most of the remaining study used a qualitative design.
- There is no mention of professional staff, service facilities or support service and accessibility that can help support and intervene on behalf of children with intellectual disabilities.
- In Bangladesh only a few Research is conducted on intellectual disability but that is not enough resourceful.

2.6 How does my research fit in?

This literature review covered some specific domains individually in various country such as engaging in activity in China, accessing healthcare services in South Africa, inclusive education in India, engaging in recreational activity in UK But this research put together all domain in one thesis, that are gathered from literature review and additionally accessibility and support service for children with intellectual disability.

This research provided detailed information about the barriers of the community that a child and adolescents with ID faces and described the possible solution to overcome these barriers, which was not included in this literature. It will encourage the government to change disability service policies.

CHAPTER III: METHODS AND MATERIALS

3.1 Study Question, Aim and Objective(s)

3.1.1 *Overarching Study Question*

What are the parents' perspectives about the barriers of performance in activities of daily living, academic and social functioning for children and adolescents with ID?

3.1.2 *Aim*

To explore the parent's perception regarding the potential barriers of performance for children and adolescents with ID in different areas including engaging in activities of daily living, academic and social functioning and generate the possible recommendation to overcome these barriers of performance.

3.1.3 *Objectives*

- To find out the parent's perception about barriers towards their child and adolescents with ID's performance in activities of daily living.
- To identify the potential barriers of performance in academic functioning for children and adolescents with ID.
- To identify the barriers of performance in social functioning for children and adolescents with ID.
- To generate recommendations to overcome these barriers and increase performance for children and adolescents with intellectual ID.

3.2 Study Design

3.2.1 *Study Method*

A qualitative research method was used for this study as it explored the parent's

perspective through systematic enquiry about their child's (with intellectual disability) performance barriers. It provided an understanding of humans behavior and experiences based on description that they will shared and observation of the student researcher (Creswell & Poth, 2018).

Qualitative methods offer an effective way of understanding the complex reasoning of a perspective through inductive logic and it allows us to use multiple methods of collecting data at the same time such as interview and observation. It allowed the researcher to include or exclude any of the question based on the relevancy of the topic(Creswell & Poth, 2018; Liamputtong, 2017). Thus, the qualitative method suited this research most because it was helpful to in-depth exploration of the parent's experiences and perspective about the barriers of performance and generate the possible overcoming strategies in a particular setting.

3.2.2 Study Approach

The grounded theory approach suited this study most. The study used qualitative analysis of data inductively in a systematic way to gain the insight on individuals experiences (Creswell & Poth, 2018). The main aim of grounded theory approach was to move beyond description it means find out the root causes of a particular behavior or problem and to generate or discover a theory (Liamputtong, 2013, 2017). According to Strauss and Corbin, grounded theory is a qualitative research methodology whereby the researcher formulates a comprehensive explanation of a process, activity, or interaction that is informed by the perspectives from several participants. (Corbin & Strauss, 2008).

This study described the parent's experiences about their identifiable barriers of performance of their child and adolescents with ID regardless of their attitudinal, physical, social, and institutional perspective inductively. In this approach it gathered

the description of parent's experiences and unified this theoretical explanation to generate a theory about the barriers of performance of children and adolescents with ID (Creswell & Poth, 2018). This study was also to be helpful in finding out all the possible recommendations of the parents to overcome these barriers. This study developed a hypothesis based on participants' perspectives through using open coding, axial coding, and selective coding for data analysis (Creswell, 2018).

3.3 Study Setting and Period

3.3.1 Study Setting

The researcher conducted the interview at a mutually convenient time and place decided by both the researcher and participant while considering a quiet place. And the initial list of the participants was collected from inclusive school, special school, rehabilitation center and hospital (National Institute of Mental Health and Hospital) of Dhaka city.

3.3.2 Study Period

The study period was from May 2024 to January 2025. The data collection period was from 28th September 2024 to 27th October 2024.

3.4 Study Participant(s)

3.4.1 Study Population

The study population was the parents of children and adolescents with ID from Bangladesh.

3.4.2 Sample Size

There were 11 participants in this study (sample size, $n = 11$) who lived in Bangladesh.

3.4.3 Sampling Technique

Researchers used purposive sampling, which is a type of non-probability sampling to select the participants of the study. Participant was selected by subjective judgement

based on some inclusion and exclusion criteria, set by the researcher (Galloway, 2005). Purposive sampling was the deliberate selection of participants according to how well they can explain a particular theme, concept, or phenomenon (Banerjee & Chaudhury, 2010). The researcher used this sampling because there were some inclusion and exclusion criteria in this study and after judgment of all the criteria the researcher selected the participants.

3.4.4 Inclusion Criteria

- Parents (Father or Mother) of those children and adolescents with ID who are diagnosed clinically.
- Parents of those children and adolescents with ID between the age range 5-17 years. Because according to DSM-5, individuals over the age of 5 suspected of having an ID while under this age, child's feature might be overlapping with other conditions. As this study will be conducted with parents of children and adolescents, that is why the age ranges up to 17 years.
- Parents of school going children and adolescents with ID.

Exclusion Criteria

- Parents of those children and adolescents who have other disabilities associated with ID.
- Parents who are not primary caregivers.
- Participants who have psychiatric illness or cognitive impairment.

3.4.5 Participants Overview

One of the most important requirements in the qualitative study design phase is to select suitable participants. The subject sample must clarify significant aspects and possible relationships connected to the phenomena being investigated (Sargeant, 2012). This

study had 11 participants (parents), 9 of whom were mothers and 2 of them were fathers. Seven children of the eleven participants attended mainstream schools or madrasas, three attended inclusive schools, and one was enrolled in a special school. As an assistive device, one of them wore eyeglasses. Prior to this interview, eight out of the eleven children received rehabilitation services; the remaining only received medical services. They all belonged to the Islamic religion with one of them being Hindu and one being Christian.

Participants' confidentiality has been maintained by using a pseudonym in accordance with ethical standards (NHMRC, 2018). An overview of the identified participants is given below in table 3.1.

Table 3.1*Participant's overview*

Name of child with ID	Sex	Age (years)	Educational level	R_x received	Relationship with children with ID	Age (years)	Educational status
Mahin	M	11	Primary	Medical service	Mother	36	M.Sc.
Aritro	M	15	Secondary	Medical service	Mother	45	S.S.C
Nihan	M	10	Primary	Medical service, OT, SLT	Mother	34	B.B.A
Tithi	F	13	Primary	Medical service, SLT	Mother	30	S.S.C
Promi	F	13	Primary	OT, SLT	Mother	35	S.S.C
Fayaz	M	17	Primary	Medical service, Counselling, OT, SLT	Mother	55	Class-8
Kayeed	M	13	Primary	Medical service, Counselling, OT	Father	42	Class-8
Ifat	M	11	Primary	Medical service, Counselling, OT, SLT	Mother	45	S.S.C
Hafiz	M	15	Secondary	Medial service	Father	43	H.S.C
Zunaira	F	9	Primary	Medical service, Counselling, OT	Mother	29	Class-10
Rizwan	M	16	Secondary	Doctor, Counselling	Mother	50	Class-10

3.5 Ethical Consideration

In this research, ethics was maintained according to Helsinki Act's guideline (WorldMedicalAssociation, 2001).

3.5.1 Ethical Clearance

Ethical clearance was sought from the Institutional Review Board (IRB) of the Bangladesh Health Professions Institute (BHPI) through the department of Occupational Therapy.

3.5.2 Informed Consent (Information Sheet, Consent Form, Withdrawal Form)

- **Information Sheet/ Participant Explanatory Statement:** According to NHMRC guidelines, chapter 2.2, and clause 2.2.2, individuals' decision to participate in the research is voluntary. Depending on adequate information about the research, understanding the purpose and method & informed about the benefits and risks an individual will decide either participate in the research or not (NationalHealthandMedicalResearchCouncil, 2018). The Information Sheet (See Appendix-B) is a written document about the research that describes all these above points and describes when an individual can withdraw his participation from the research. The researcher will provide a clear explanation of the participant's explanatory statement and then recheck the understanding of the individual. There will be a chance to ask the researcher questions about the research that he did not understand. And after deciding to participate the researcher will take their consent in consent form as a written document.
- **Consent Form:** After deciding to participate, the researcher will take their consent in consent form as a written document. The researcher will take written

consent from the participants that are willing to participate in this research (See Appendix-D).

- **Withdrawal Form:** According to NHMRC (2018) declining consent and withdrawal consent guideline, participants can withdraw their participation at any stage from the research with reasoning (NationalHealthandMedicalResearchCouncil, 2018). Withdrawal form is a document that describes the procedure and condition of withdrawing participation. By using this form, the participant can voluntarily withdraw participation from the research (See Appendix-F).

3.5.3 Unequal Relationship

The student researcher did not have any dependent or unequal relationship with the participants. That means the participants had equal control and power as the researcher. If any types of power relationship identified during the research, the researcher took necessary steps to minimize potentially detrimental effects (NHMRC, 2018).

3.5.4 Risk and Beneficence

Student Researchers ensured that the participant was not at any risk or discomfort during their participation in this research such as emotional imbalance, sensitivity, and confidentiality. Though it was self-funded research, the participants will not have any benefits for their participation in this research such as gifts, reward, or money.

3.5.4 Confidentiality

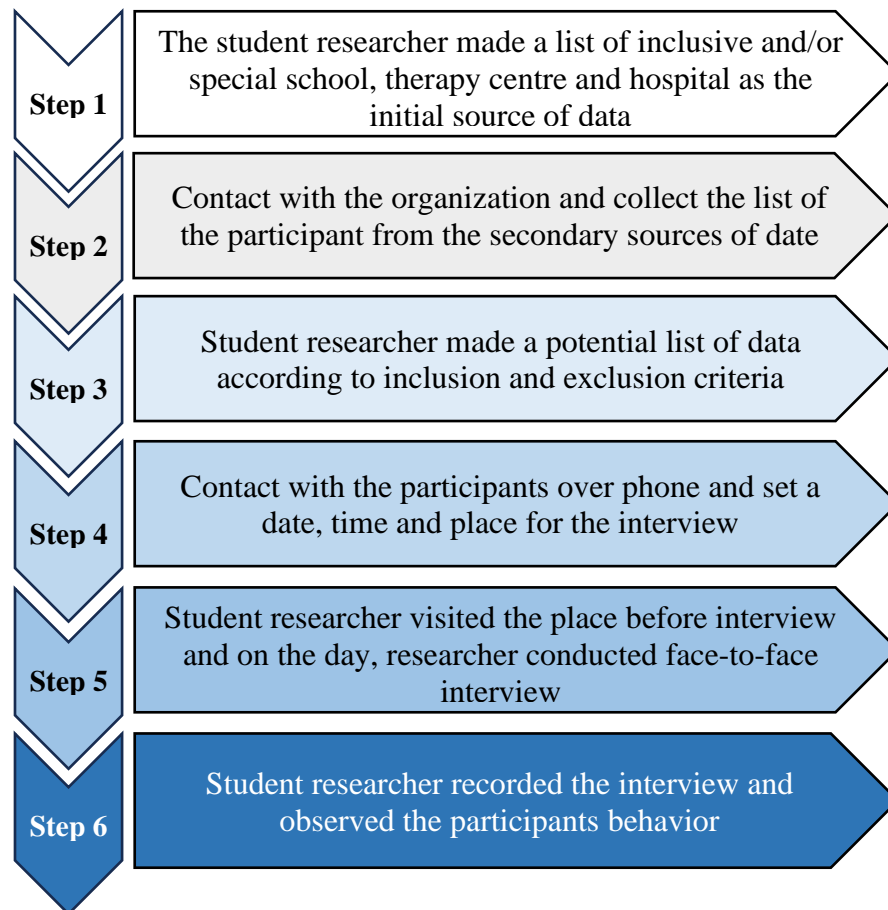
Only the student researcher, supervisor and subject teacher have access to information about the participants, and this is clearly stated in the participant explanatory statement. The researcher or anyone else could not disclose any of the information. Student researcher assured the participant that information will be kept private for future use

like publication or conference or any presentation.

3.6 Data Collection

3.6.1 Participant Recruitment Process

Because of the unique theory formation process, grounded theory is a widely preferred qualitative research tool in the social sciences. Participant selection is essential since the goal of grounded theory is to develop a theory based on the evidence. Therefore, choosing the right study participants is essential to any qualitative investigation that directly affects the rigor, credibility, and richness of the data generation and/or collection (Dahal et al., 2024). To conduct this research, 11 participants were recruited from different sectors of study setting and from different socio-economic and cultural backgrounds. The participant recruitment process is given below in figure 3.1.

Figure 3.1*Overview of participant recruitment process*

With the support of the study supervisor, the student researcher first compiles a list of institutions where there are children and adolescents with ID, such as schools, therapy centers, hospitals. After that, the student researcher contacts those institutions and gathers the participant list. The student researcher creates a participant list from the initial data list using subjective judgment and inclusion and exclusion criteria (for more information, see section 3.4.4). Then the student researcher contacts the participant and obtains their consent to participate and establishes a precise time, day, and location. Prior to the interview, the student researcher visited the site to ensure everything was in order, conducted a face-to-face interview as scheduled, and made observations during the session.

3.6.2 Data Collection Instrument

- **Demographic Variable:** Childs age, sex, level of impairment, family types, number of siblings, family economic status, educational status, environment and assistive technology.
- **Measurement Variable for Data Collection Tools:** The student researcher prepared a self-developed interview guide by reviewing literature related to this study and according to the research aim and objective. The Bangla version of this interview guide was used for collecting information on parent's perspective about barriers of performance related variables such as engaging in activity of daily living, academic and social functioning.

A phone recorder was used to record the interview of the participant & a pen, pencil, paper, and clipboard will be used to write down the observation note.

3.6.3 Data Collection Method

The researcher conducted a face-to-face interview through a semi-structured in-depth interview method. Semi-structured interview method allowed the researcher to in-depth exploration of participants' perspective. As this was a grounded theory approach of qualitative design, it is important to find out in-depth knowledge and information to conduct this research form a theory. A semi-structured in-depth interview method was used as primary data collection method. A self-developed interview guide was used in the study to conduct research. The interview guide has been developed through the literature review (Abbott & Mcconkey, 2012; Ahmad, 2018; McGarty & Melville, 2018; Mkabile & Swartz, 2020; Shi et al., 2022). Also, the student researcher developed a sociodemographic information sheet to collect general information like age, educational level, level of impairment and sex.

3.7 Data Management and Analysis

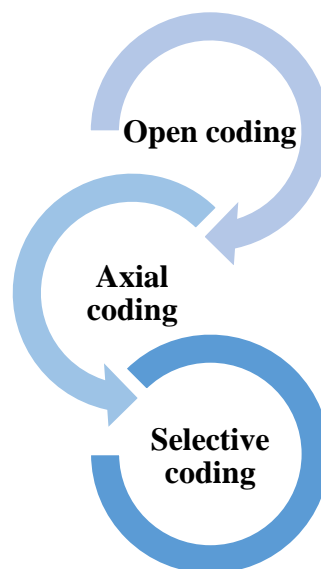
3.7.1 Data Management

Data was analyzed by the grounded theory method. Grounded theory provides a process for creating categories of information (open coding), connecting the categories (axial coding), building a "story" that connects the categories (selective coding), and concluding with a theoretical set of ideas (Creswell, John W. & Poth, 2016). The aim of open coding is to extract the categories from the data, while axial coding seeks to determine the relationships between the categories. The third stage, known as selective coding, involves identifying and characterizing the central category (Kasurinen, 2012).

3.7.2 Data Analysis

Figure 3.2

Data analysis steps



Stage 01: Open Coding

During the preliminary phase of research, the student researcher conducted a thorough examination of the collected data. Subsequently, the data was segmented into individual

components and concepts. The student researcher then proceeded to label these concepts with descriptive codes. Throughout the coding process, the newly acquired data was continuously compared with previously coded data to detect similarities and variances. The initial codes were an extensive list of codes that underwent a rigorous verification process by the supervisor to ensure their authenticity and accuracy.

Stage 02: Axial Coding

The axial coding process followed the generation of an extensive set of open codes. This process involved sorting and organizing the codes into broader themes by identifying the connections and interactions between them. Additionally, the researcher considered how these themes related to and influenced one another. After completing the axial coding process, the supervisor reviewed the list to ensure that the research was proceeding in the intended direction.

Stage 03: Selective coding

During the final stage of coding, the student researchers narrowed their focus to selective coding. They fine-tuned, merged the axial coding, and identified five main categories that best represent the study's core idea. Based on these categories, the student researcher created a comprehensive theoretical model that describes the relationships between the core category and other subcategories.

3.8 Trustworthiness and Rigour

Trustworthiness was maintained by methodological and interpretive rigour (Curtin & Fossey, 2007).

3.8.1 Methodological Rigour

- **Congruence:** For the research, a grounded theory approach with a qualitative study design was chosen, which appropriately matches the goals and objectives

of the study.

- **Responsiveness to social context:** A face-to-face interview occurred by manual convenience in an appropriate setting.
- **Appropriateness and adequacy:** The study employs purposeful sampling to select participants. In this study, nine participants were chosen based on a set of inclusion and exclusion criteria. Interviews were conducted in person to gather data.
- **Transparency:** The student researcher gathered and examined information. Because the supervisor actively participated in each stage of the data analysis process and provided a range of perspectives for the data, there was no chance of bias.

3.8.2 Interpretive Rigour

- **Authenticity:** The study findings and interpretation were presented with the participants' verbatim quotations. The student researcher asked the participants if they understood the explanation that had been given after their statements.
- **Coherence:** Data was adjusted to meet the aim and objectives. The student researcher translated the data from Bengali, their first language, into English by transcribing the information verbatim. After hearing the audio recording, the study supervisor went over each transcription to check once more, and the student researcher began data analysis.
- **Reciprocity:** The original data was not altered as the student researcher translated it verbatim. There was no discussion of data analysis with participants.
- **Typicality:** The student researcher provided a thorough description of the

study's context so that readers could grasp it.

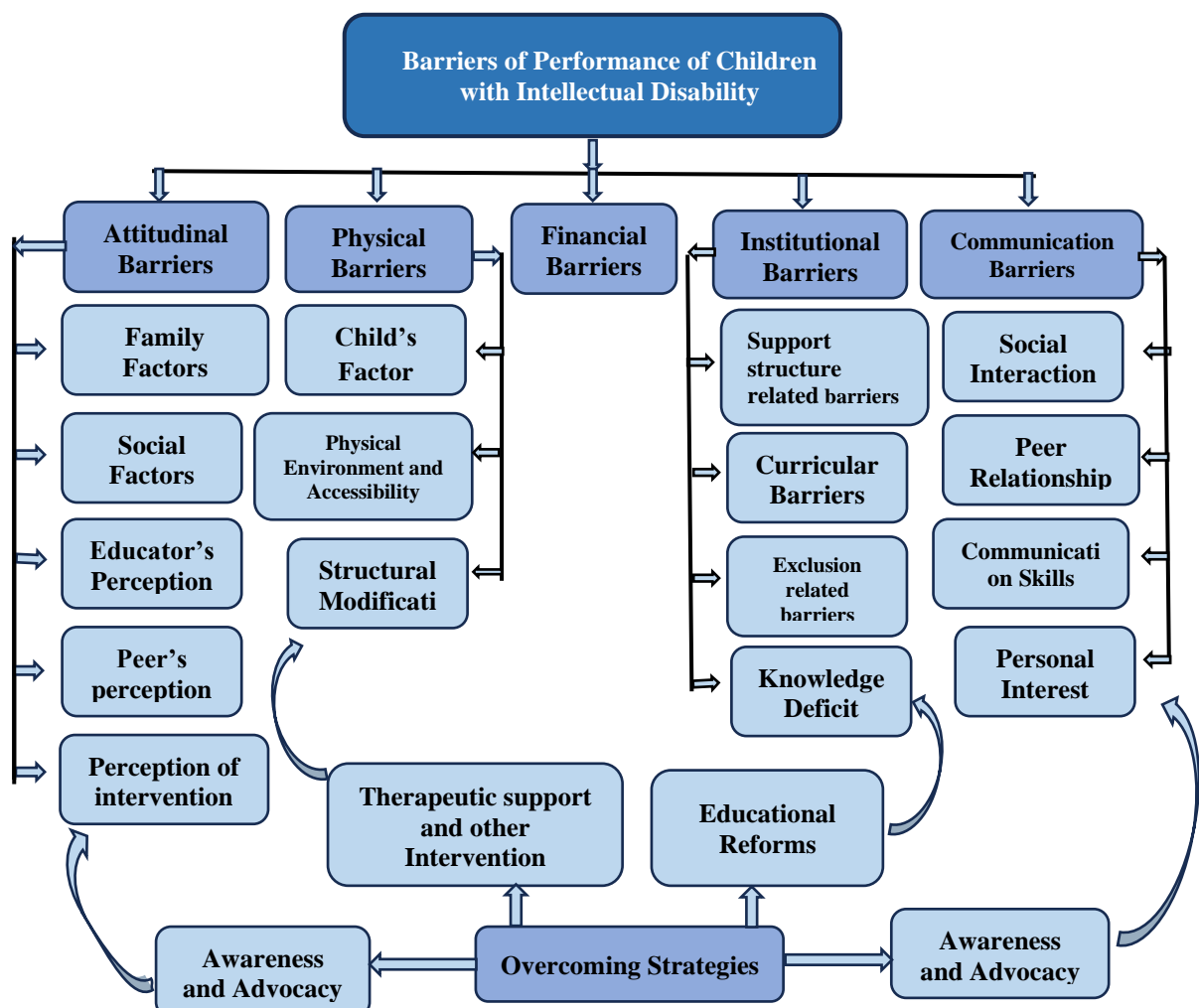
- **Permeability of the researcher:** The student researcher strictly followed the ethical guidelines. The student researcher finished the entire research strategy after consulting with the supervisor and making necessary checks to ensure the study's objectivity.

CHAPTER IV: RESULTS

This chapter represents the results of the current study on barriers of performance in ADLs, academic and social functioning for children and adolescents with ID that also provides a comprehensive analysis of the data gathered and generates a new perspective. All participants discussed their perspectives about the barriers faced by their children and adolescents with intellectual disability during performing the activities of daily living, academic functioning, and social functioning and how to overcome these barriers and challenges. An overview of the study findings is depicted below in figure 4.1.

Figure 4.1

An overview of the results generated from the study.



The study findings generated six themes including attitudinal barriers, physical barriers, financial barriers, institutional barriers, communication barriers and overcoming strategies and several sub-themes are generated from these interviews after analysis.

Theme one is further divided into five sub-themes or sub-categories including family factors, social factors, educator's factors, peer's perception, and perception of intervention where theme two has three sub-themes: child's factor, physical environment and accessibility and structural modification. There is no sub-theme under the theme three: financial barriers. The theme four institutional barriers are further divided into four sub-themes including support structure related barriers, curricular barriers, exclusion related barriers and knowledge deficit. Theme five have four sub-themes and these are: social interaction, peer relationship, communication skills and personal interest. The last theme overcoming strategies consists of three sub-themes: awareness and advocacy, therapeutic support and other interventions and educational reforms. Each of the sub-themes is described under their main theme with some direct quotes from the participants' interview.

4.1 Theme one: Attitudinal barriers

Attitudinal barriers are the first barriers that come from the family and society towards a person with intellectual disability. Participants responded to a wider range of perspectives when they were asked about the attitude of the extended family members, teachers, and other people of society towards their children and adolescents with intellectual disability. They explained how the behavior of society changes parallel to their child's development throughout time.

4.1.1 Sub-theme one: Family factors

Family factors encompass the attitudes, behaviors, interests, values, and beliefs of family members regarding their children and adolescents with ID. When the extended family members are expressed about their children, Majority explained it as extensive love and affection, helpful mindset, and best wishes for their children with ID. In the term of help, they are being overprotective and restrain their child to perform daily activity. For example, the mother of 8-year-old Mahin said that:

“Everyone pampers him a bit too much. Everyone takes extra care of him. They are extremely helpful and do not even let him work. If I get irate and say, let him do his task, especially his aunt says, no-no. He always does it. You make him do work under pressure. Now, we just offer a little assistance. This kind of behavior, I mean they show excessive affection.”

Only a small number of respondents indicate the dissatisfaction and preference of other children over the children with ID by their family members. One of the mothers said that her husband criticizes her by saying that the child will be fine if she could let him discipline her child. Tithi- the 13 years old adolescent, her mother was explaining about her helplessness situation in the family while supporting Tithi. She mentioned that,

“If I talk to her father, he gets angry and wants to hit her. But he does not understand that Tithi you should not talk to your grandmother like this. When I try to explain, he gets frustrated and says it is my fault that she is behaving badly. He tells me that I do not say anything to her and that I spoil her. He gets angry with me and ends up scolding her.”

4.1.2 Sub-theme two: Social factors

Participants were talking about and identified the socially influencing factors that

hinder the performance of their children and adolescents such as: social stigma, social isolation, indirect social rejection, and self-stigmatization. One of the key findings identified is that social stigma leads to social isolation and sometimes self-isolation. For example, Rizwan's her said that:

“In certain illiterate societies, people considered themselves superior and ask why should I allow my child to be around him? My child might also have a trouble consequently... Sometimes parents discourage their children by saying, 'do not hang out with Rizwan.' And there is such student.”

As children grow up, they get stigmatized by running with this attitude of society. They lose their confidence and consider themselves as a recipient of everyone's empathy. Even parents are also denied their condition in front of others and try not to expose it in the fear of stigmatization. Mahin's mother answered the question of required modification at school; She state that,

“I do not think so. What is already there is fine. Because if this is done, it will be a sense of discrimination that I am being more priority. This is that everyone will be equal, and he will be able to understand the thing.”

4.1.3 Sub-theme three: Educator's perception

When it comes to the perception of the educator about the children and adolescents with ID and their educational engagement, seven out of 11 participants identify positive attitudes of the teacher, and they save the children being bullied. One participant reported the teachers' attitude towards avoidance; Hafiz, a 15-year-old adolescent with superior complexity and the father of Hafiz described that:

“The teachers' attitude is not exceptionally good. His teachers, which means those who teach him, do not have a positive opinion of him. They say he points out the teachers' faults, meaning he identifies their mistakes and

complains about them to the senior teachers. Because of this behavior, even the teachers who are in the classroom do not get the opportunity to show him affection or accept him in that way. They tend to discipline him and keep their distance from him.”

4.1.4 Sub-theme four: Peer’s perception

A minority of participants indicated that peers’ behavior, negligence, rejection have a remarkable effect on children’s behavior and lead to isolation and less interaction. The father of a 13-year-old Kayeed explained the mental state of his child to make understand the perception of peer group. He stated that,

“He did not interact with them much because they would tease him. He preferred to keep his distance and stayed a bit reserved. He would not report it. Even if asked, he would not say anything. He would not mention it even if he struggled.”

4.1.5 Sub-theme five: Perception of Intervention

All the participants highlighted the ultimate purpose of the intervention for their children’s improvement. Out of 11 participants, one participant described her husband’s perception of intervention. Ifat is a as, “He calls him mad and says we have turned him into mad with medication by going to the mental hospital. He also says, ‘let’s see how many days you can roam from person to person for the boy.’”

4.2 Theme two: Physical Barriers

In this theme all the participants explained about the physical or environment related obstacles such as child’s factor which include child’s functional ability, emotional impact and behavioral impact, physiological environment and accessibility and structural modification and their impact on occupational

performance of children and adolescent with ID. Most of the participants described performance as instruction dependent performance out of laziness. There are three sub-themes under this theme: child's factors, physical environment and accessibility and structural modification.

4.2.1 Sub-theme one: Child's factor

All the participants described the functional abilities, emotional impact and behavioral impact of children and adolescents with intellectual disability. Seven participants reported that their children can perform ADLs, but two participants reported that their children face difficulties when getting water from the tube-well and in fine motor activity. Zunaira, the 9 years old madrasa going children; mother mentioned that:

“The things we have in our house, she can manage all of them, except for one thing. She cannot fill the water from the tubewell in our kitchen. She takes water from the sink instead. That is the only things; she can do everything else by herself.”

Another parent said that their children face difficulties in maintaining balance and toilet setting. Nihan's mother states that,

“However, this has not caused any serious issues yet. Even so his brain sends fewer commands, which affect his balance, and he falls frequently. He falls repeatedly, even when trying to run on a flat surface. He ends up getting cuts and bruises over his body throughout the year.”

Apart from that, respondents described emotional impact on performance for children and adolescents with ID including emotional impact of peers' rejection, unable to show age-appropriate behavior, performance anxiety, impact of stigmatization. While asking the question about peer's interaction, the mother said

that,

“He does not fully understand it. He just sits there feeling sad. I check on him every 10 or 30 minutes to see how he is feeling, and I often find him sitting quietly, upset. He does not complain about it. I tell other kids, ‘Please, try to interact with him, play with him a little. But I cannot oversee everything on my own.’”

(Aritro, 15-years-old)

4.2.2 Sub-theme two: Physical environment and accessibility

In this sub-theme, the participants were asked about their problems in the home, school and social environment related to accessibility and related obstacles. Participants explained that their child is facing difficulties in adapting to an unfamiliar environment, unable to understand the uneven surface. The mother of Promi mentioned that “No, she does not have any problem in her known place. There is a problem in the new place.”

Three of the participants discussed the accessibility of uneven surface means distinguishing the difference between high and lower surface. Zunaira’s mother expressed that, “She cannot walk alone, but it takes a long time. When holding my hand, she moves faster, but on her own, she is slow. She does not understand uneven surface at all- absolutely zero understanding.”

The mother of Nihan described the similar experience: “Has difficulty understanding high and low. He does not understand things like broken pieces, high and low, or pieces of break. In most cases, I must point it out to him. Once or twice explaining, and he understands.”

4.2.3 Sub-theme three: Structural Modification

When the participants were asked to discuss structural modification, the main area they are mentioned, home modification, structural modification at school, seating arrangement, modified seating cushion. Nine of the 11 participants explained that they need structural modification at home and school environment. Two participants report on home modification. For example, Promi, the 13-year-old girl, needs home modification. Her mother state that, “There is a faucet in the basin that needs to be twisted to open.”

The father of the Kayeed expressed the similar experiences: “One thing we have done is install a handle in the toilet because he could not sit down on his own. Now, he holds into the handle to sit and stand.”

Three of the participants were talking about the seating arrangement and setting cushions at the school and discussed why this special arrangement is needed for his educational arrangements. Kayeed’s father stated that,

“Yes, they did seat him at the front. In Madrasa, they do not have benches; students sit on the floor. They placed him at the front. Since he had difficulty sitting, I made a cushion for him to sit on. When he was younger, he could not sit properly and would sometimes fall because he did not have enough strength. If he fell on the hard floor, it could hurt him, so I made that cushion specifically for him. He used to sit on it, and no one else did. Now he has improved and can sit properly without any issues.”

4.3 Theme three: Financial Barriers

While talking about the causes of not taking intervention or not looking for inclusive school or special schools, four participants raised concerns about their financial

circumstances. From those four participants, Ifat's mother discussed the resilience for financial support means she must face verbal abuse and criticism from her family for not being any other financial support. She stated that:

“For instance, coming to this place costs 40 taka daily. Since I do not work, I ask him for the money. I do not have any support who would give me 100/200 taka on my own. That is why, I endure his words in return, but I do not mind.”

Tithi, a 13-year-old adolescent who studied in an inclusive school, lived with his family in a tin-shaded house. The mother of Tithi did not ensure a safe house for her child and stated that with guilt ,

“The place I live in, if I kept Tithi there, it would not be a good environment. And I do not have the financial means to move her to a better place. But if, in the future, Allah wills, I could place her in a safe place, like an apartment, then her going outside would be limited.”

Another participant said that she had to stop her “child's therapy because of monetary crisis. She is directly included that,

“My daughter can do all of it on her own, but in her case, she needs a little help. That is something I have been trying to address since she is a bit delayed. However, I have not been able to provide her with a lot of physical therapy because of financial constraints.”

4.4 Theme four: Institutional Barriers

By the term of institution, participants responded the more than others area of performance and it might be in the centre of their discussion and area of concern for their child. They described the institution of their child and addressed its facilities and challenges; while talking about the institution, their feelings were

reflected on their face. This theme is further divided into 4 sub-themes: support structure related barriers, circular barriers, exclusion related barriers and Knowledge deficit.

4.4.1 Sub-theme one: Support structure related barriers

The participants discussed the schooling type, teachers support, teachers training on special education, individualized attention in this whole sub-theme named support structure related barriers. They said it is most important for the determination of their child's future activity. Out of 11 participants, seven said they had been enrolling their child in mainstream school and madrasa, while three participants reported that they had been sending their child to an inclusive school and last one participant said that she admitted her child into a special school. Though the inclusive and special school has their individual education plan and inclusive curriculum for children with disability. Despite that, two mothers said they did not think about sending their child to an inclusive or special school. For example: Rizwan's mother mentioned that,

“He is doing well in the current school, getting along with everyone, and handling everything. The teachers and his private tutor at home say he is a good student. They advise me to provide extra care so that he can excel further in life. I have arranged for private tutors at home, and they have mentioned that he is performing well in subjects like math and finance. Since I see him managing, I have never considered transferring him.”

Most of the participants explained that there is not such training for the teacher on inclusive education and lack of individualized attention to their children. Ifat a 11-year-old boy, his mother state that,

“The other teachers do not pay attention, and they say, 'we cannot focus on

just one child '. If I bring it up, the teacher says 'your son cannot manage as it is; we already guide him through writing and let him pass. do not bother the principal about this. They also want the principle to treat them differently if I arise the issues. So, I remain silent.”

4.4.2 Sub-theme two: Curricular barriers

In this sub-theme the participants discuss the curricular load on the children and adolescent with ID that remark as a barrier, changing education system, resistance to adaptation and reluctant to parents' concern. Most of the participants said that the curriculum of the school is overwhelming for their child. For example: Tithi's mother said that “No, I do not think it is suitable for her. The reason is that the lessons and tasks they provide can be completed by the other normal children, but she cannot manage it.”

4.4.3 Sun-theme three: Exclusion related barriers

In this sub-theme the participants are explained about the uncertainty of services, deprived of the opportunity that affect the performance of children and adolescents with ID. Parents claim that their children are deprived of their proper rights in the educational institute. Tithi's mother mentioned that,

“She does not want to work, does she? She does participate in events, though when there is a function, she is there. But she does not get the chance to volunteer. Also, she has not made to participate in that kind of role because she does not understand it.”

4.4.4 Sub-theme: Knowledge deficit

The findings reveal a significant knowledge deficit among parents and communities regarding the needs and proper care of children with intellectual disabilities. This lack of awareness often contributes to barriers in providing effective support and

understanding for these children. Many parents expressed uncertainty about the resources available for their children or the interventions that could help address specific challenges. Fayaz's mother admitted, "I wonder if there is any treatment to help him overcome this fear. Does occupational therapy help reduce fear?" This highlights the gap in understanding therapeutic options that could enhance their child's quality of life.

In some cases, parents were unaware of how to manage behavioral or developmental challenges effectively. She also said, "We did not realize earlier that he had these issues. We thought he would gradually improve, but now, at 12 years old, everything seems to have gone the opposite way".

4.5 Theme five: Communication barriers

Communication is the most highlighted area of the children and adolescents with Id that they are problem with. When talking about the communication status of the children and adolescents, participants are explained about child's social, institutional, peer's and familial communication and their interest. There are four sub-themes identified under this main theme including: social interaction, peer's relationship, communication skills and personal interest.

4.5.1 Sub-theme one: Social interaction

Social interaction is defined as the core part of the social life of a person, and this is identified by all participants of this study. Social interaction barriers are identified by the name of limited social interaction, social isolation, and rejection, unable to initiate social interaction, lack of interaction with teacher. While explaining the social interaction of child, Nihan's mother mentioned that:

"If they ask him something, he answers it. At home, he tells me or sometimes

discusses it with the teachers online. His social communication is... well, he does not initiate communication with classmates or teachers. For example, if there is a program happening, he will not ask, “Who’s signing up?” He does not stand up and inquire about it or take the initiative to find out.”

4.5.2 Sub-theme two: Peer’s relationship

The findings highlight the notable challenges in the development and maintenance of peer relationships for children and adolescents with ID. The key patterns emerging from the information gathered include preference for younger peers, challenges in peer relationships, and reduced peer interaction. The results indicate that some children with ID show a clear preference for interacting with younger peers. This preference seems to stem from the perception that younger children are less judgmental and more accepting. For example: The mother of Ifat mentioned that: “His friends are good, but he does not play with older or same-aged children. He plays with younger children.”

11-year-old Mahin’s mother explained the similar experience, she said, “He does not play with children of his age. He does not go. Even if I said, he does not go. He does not go with them.”

4.5.3 Sub-theme three: Communication skills

While talking about the communication skills of the children with ID, the parents described the communication skills through verbal communication and non-verbal communication. Many of the participants reported that their children are comprehension to non-verbal and verbal communication except one. The mother of the Mahin shared that Mahin are incomprehension to non-verbal communication. Another participant said that her child can understand the non-verbal gesture but does not use them. She mentioned that: “Yes, he can understand them, though he does not use them

much himself.”

Challenges in sustaining conversations emerged as a prominent issue. While children could respond to questions, they found it difficult to extend or initiate dialogue. Aritro’s mother explained that, “Yes, he can interact. He enjoys it when someone comes to our house, and he also mingles with others when he visits their houses. His main problem is that he cannot keep the conversation on topic. That is his main issue.”

4.5.4 Sub-theme four: Personal Interest

This research findings illustrate a varied range of personal interests among children with intellectual disabilities, highlighting their preferences and areas of engagement as well as their disinterest in specific domains such as academic or volunteer work. All the participants identify some key areas of the children’s personal interest and disinterest such as interest in helping others, interest in voluntary activities, engaged in extracurricular activities and disinterest in volunteer work. Hafiz, a 15-year-old adolescent, the father of Hafiz said that his son is willing to perform any activity after instruction. For example, he stated that,

“No, he is not involved in any voluntary work. However, he might be inclined towards it. For example, on the fifth, students were assigned to traffic police duties, and he thought to himself, 'If I were given the chance, I would have gone too.' He participates in various competitions, and in those, there are specific rules, which he understands and follows.”

4.6 Theme six: Overcoming strategies

This study emphasized diverse strategies adopted by parents for dealing with the obstacles confronted by children and adolescents with ID. All the participants discussed those strategies while they were asked to search for a solution. These strategies are

further divided into three sub-themes including awareness and advocacy, educational reforms and therapeutic support and other interventions.

4.6.1 Sub-theme one: Awareness and advocacy

This study revealed that to lessen stigma and advance inclusivity, parents actively advocate for their children and raise awareness. Participants talked about addressing societal and familial stereotypes of children and adolescents with ID through a variety of strategies, such as social therapy, praising, and awareness campaigns, awareness-increasing video, counselling. Most of the participants supported the arrangement of an awareness program that will be conducted by health professionals to make people aware of their child's condition. For example, the mother of Promi said:

“How can I do it alone? Suppose if there were 5 more people like me,,,,,, if I only say, it will never change. If I ask them to come, our therapists will say something, but everyone will be interested in listening. Thus, may change.”

The mother of Aritro (a 15-year-old mainstream school going child) explained similar strategies. She mentioned:

“People need to understand that this is a condition. If they say this in front of the child, it can worsen their mental state, hurt the parents' feelings, and hinder the child's progress. People need to be compassionate and change their perspectives. That way, the child can integrate well into society.”

4.6.2 Sub-theme two: Educational reforms

The interviews' analysis made clear how important it is to have an inclusive educational system that can better serve students with intellectual disability. To foster social connection and inclusion, parents emphasized the value of establishing learning environments where children with special needs can study with their classmates who

are usually developing. Many of the participants discussed teachers' training on special education that may help to improve their child's performance. The mother of Ifat stated that,

“What is needed is teacher training. Teachers need to learn how to teach and interact with such children. There are schools like where I went twice to get my daughter's certificates. I saw they teach even physically disabled students, who perform well when given extra time. They write beautifully and achieve satisfactory results.”

Two of the participants reported that these barriers can be overcome by changing the education system or making the education system inclusive. Another participant is optimistic to expanding long term schooling programmes. For example:

“Schools like this should be extended long-term. I mean, we already worry about where he will go after grade five. If he goes to a general school, he will not be treated the same way. This needs to be done long-term, at least up to the SSC level. If it is extended up to the HSC level, that would be even better. A balance between the two—he should study as much as he can, and it should be practical, so he can survive with the knowledge he gains.”

(Mother of Nihan, a 10-year-old inclusive school going children)

4.6.3 Sub-theme three: Therapeutic support and other interventions

While asking the question about what types of intervention they received or taken, most of the participants replied that they did not get any services, some of them received therapeutic intervention and cherished to get more opportunity to receive this intervention. Zunaira, a 9-year-old madrasa going child, her mother shared that,

“At the day center, the way the teachers collaborated with her was highly effective. If there were more such centers or if her time there could have been

extended, it would have benefited her even more... When I did start going, I saw noticeable improvements in her. That is why I believe that if more centers like this are established and if children like her can spend more time there, their development will be much better. If these programs were extended for a longer duration, it would contribute even more to her improvement.”

Another participant, the mother of Aritro discussed similar experiences that:

“I would say that the services being provided here (Mental Health Daycare Center) should be extended for a longer term. This will allow them to become a bit more mature. If the service hours here could be extended a bit, and if we reduced our entertainment time to discuss the children's needs more, I think it would be better.”

CHAPTER V: DISCUSSION

This chapter describes the exciting new interpretations that the study has brought to the field of research and practice and discusses the findings of the study in relation to the relevant literature that is currently available. To the best of my knowledge, this study is the first to address the barriers of performance that children and adolescents with ID face in their everyday lives through activities of daily routine, academic functioning, social functioning, and to develop a theory to help overcome these difficulties. This study's findings are categorized into six themes: familial and societal attitudinal issues, physical barriers, financial barriers of the child's family, institutional barriers, communication barriers and conquering techniques to overcome those barriers. The parents' perspectives provided insights into the current cultural status of Bangladesh regarding barriers of children and adolescents with ID, as well as proposed solutions from the parents of this demographic while also highlighting the knowledge gap and the differences compared to prior literature. Every subject is analyzed, with references to associated sources of literature.

The results of this study are consistent with previous literature that emphasizes the significant challenges that children and adolescents with ID encounter in a variety of contexts, such as social inclusion, physical activity, academic engagement, and participation in everyday life (Mkabile & Swartz, 2020; Mprah et al., 2023; Shi et al., 2022). A qualitative study conducted by Linjun Shi, Granlund and two others, found that knowledge deficiency of primary caregivers, negative attitude, lack of caregiving skills, public and self-stigma hinder the participation of children with ID in everyday activities (Shi et al., 2022). While another literature stated, the attitude of healthcare professionals and educators affect badly on child's encouragement in engagement with

activities (Mprah et al., 2023). This study produced results which corroborate the findings of a great deal of the previous work in this field which include the following: parents' dissatisfaction and criticism, social stigma, and teachers' and peers' perceptions of work as a hindrance to children's and adolescents' performance. One unanticipated finding which differs from earlier research, was that the child's encouragement of participation in activities was impeded by the family members' overprotectiveness.

According to a qualitative critical study based on the COM-B model, children with ID find it challenging to engage in activities due to a variety of factors, including a lack of physical abilities; respiratory and cardiac conditions, decreased mobility, low muscle tone, exhaustion, and a low level of cardiorespiratory fitness and psychological abilities; struggle to understand and pay attention (McDermott et al., 2022). It is interesting to note that in all cases of this study addresses the functional factors, physical environment, and accessibility of children and adolescents in relation to physical barriers that restrict their performance. The results of this study are consistent with two other pieces of literature that claim that a child's low functional abilities, lack of use of the physical environment, and lack of environmental adaptation all impair activity performance (Mprah et al., 2023; Shi et al., 2022). This finding was unexpected and suggests that some children require structural modifications to participate in an activity, which minimizes the child's performance.

The most important clinically relevant finding was the financial crisis, it is considered as the most powerful performance barrier. As an example, one participant stated, "My daughter needs a little help to do his work, and I have been trying to address her since she is a little bit delayed, but I have never been able to continue the therapy session out of financial constraints." This study finding is parallel to the result of some literatures where it was stated that financial crisis is the potential barriers for child's

performance with ID, parents cannot afford the cost of their child's healthcare needs even if the service is free for them, but they cannot afford the transportation cost (Mkabile & Swartz, 2020; Shi et al., 2022; Varghese & Mathias, 2015).

Social engagement poses a significant barrier for children with intellectual disabilities, as noted by Abbott and McConkey (2012), who reported restricted interaction in verbal communication with others and utilization of community facilities, and participation in recreational activities (Abbott & McConkey, 2012). This study discovered that teachers and classmates rarely try to involve students with intellectual disabilities in group activities, resulting in social isolation for these students. The study found stigma and ignorance, which highlights the need to raise awareness and encourage inclusive behaviors to assure social engagement.

The study also mirrors findings from Ethiopia, where children with intellectual disabilities experience challenges in participating in everyday life activities (Krupa et al., 2022). Their independence and growth are hampered in both situations by the lack of support from families and schools. However, this study also reveals another aspect in which parents show a desire to adjust but do not have access to academic infrastructure and specialized resources. This illustrates the necessity of a cooperative strategy that involves communities, families, and schools to facilitate meaningful engagement.

These findings are consistent with findings that were found in previous research. In addition, with other conclusions, the current study found ways to overcome some of those obstacles from the viewpoint of the parents. In terms of awareness and advocacy, educational reformation, securing therapeutic assistance, and other interventions, those tactics will enhance the involvement of children and adolescents with ID.

Conclusively, the results of this investigation align with worldwide studies

about the challenges encountered by children and adolescents with intellectual disabilities. Inadequate training, stigma, and systemic restrictions are common themes in healthcare, social, physical, and everyday life contexts. To address these issues and foster inclusive environments and fair opportunities for people with intellectual impairments, a concerted effort across disciplines is needed.

CHAPTER VI: CONCLUSION

6.1 Strength and Limitation

6.1.1 Study Strength

- The Institutional Review Board (IRB) granted the study's ethical approval.
- Culture is acknowledged as a unique contextual component in occupational therapy. Hence, the countries which have a similar context, for example, China, South Asia, Nepal, Sri Lanka, and Pakistan would be benefitted from this study.
- A grounded theory analysis was used to analyze the findings. This is appropriate considering the research methods used for this study.
- Face-to-face interviews were conducted to gather information, which was then strongly preserved on the password-protected laptop.
- Research is strengthened by examining parents' viewpoints as significant stakeholders, as they play an active role in caring for and supporting children with intellectual disabilities. This provides a thorough understanding of strategies and challenges.

6.1.2 Study Limitation

- One highlighted limitation of the study was the small sample size, comprising parents of children and adolescents with intellectual disabilities.
- This study did not include back-translation of the instrument (semi-structured questionnaire) and the collected data from Bangla to English, as per the International Test Commission (ITC) requirements.
- As this study used probability sampling, this study cannot be generalized.
- The researcher faced difficulty collecting the data and they are sometime

inpatient OT.

6.2 Practice Implication (Recommendation for Future Practice and Research)

6.2.1 Recommendation for future practice

Theoretical Implications:

- The current research identifies significant challenges encountered by children and adolescents with intellectual disabilities, as seen by their parents. They contribute specific obstacles to the existing structure of literature.
- This study's conclusions also provided solutions to mitigate hurdles in the theoretical domain.

Practical Implications:

- Clinical occupational therapists and other healthcare professionals will be concerned about their performance barriers and will develop interventions accordingly.
- The government can introduce an inclusive school with intervention facilities for children with intellectual disability.
- The laws and policies related to the rights of individuals with disabilities and inclusive education are fragmented. To ensure that people with disabilities, including those with ID, have equal access to education and engagement in society, officials must therefore enhance existing legislation and their execution.
- In the future, based on the result of this study, any organization can run a successful schooling program with children and adolescents with intellectual disability.

Methodological Implications:

- This study provided rich and contextual data from open-ended questionnaires, and qualitative research using semi-structured interviews allowing for an in-depth examination of parents' perceptions.
- This study's grounded theory methodologies concentrated on developing a conceptual framework using data.
- A quantitative cross-sectional study approach would be used to ascertain the prevalence of barriers and pinpoint the most significant ones that require everyone's attention.

6.2.2 Recommendation for future research

- Further research should be conducted on the quality of life of a person with ID.
- Further research can be conducted to identify the accessibility issue of the children with ID.
- To meet the unique needs and preferences of diverse cultural groups, it is important to develop and assess culturally relevant occupational therapy interventions.

6.3 Conclusion

The purpose of the present study was to be to explore the parent's perspective regarding the potential barriers of the performance in activities of daily living, academic and social functioning of children and adolescents with ID. The goal of the study is to develop a theory by examining the way children and adolescents with ID deal with difficulties and what might be done as a coping mechanism. To create an inclusive environment that supports the performance of children and adolescents with intellectual disabilities, this study emphasizes the significant barriers that these individuals face in

academic, social, and everyday living contexts. It also emphasizes the necessity of systemic changes in the attitudes of family members and the community, as well as in educational practices and teacher training. The findings reveal a lack of teachers training, understanding, resources, and environmental modification in schools, negative attitude, stigma from society, physical inability, inaccessible environment and financial crisis, which hinder their development and integration in society.

Occupational therapy plays a crucial role in bridging the gap between these children's needs and the available support systems. The recommendations focus on empowering teachers and families, promoting social inclusion, advocating for policy changes, and ensuring intervention to address these issues. Through the implementation of these strategies, educators, therapists, and legislators can work together to guarantee that children with intellectual impairments receive the opportunity they need to succeed in school, in their social lives, and in their everyday lives. Along with helping children, these reforms will help create a society that is more inclusive and egalitarian.

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APPENDICES

Appendix A: Approval Letter and Permission Letter

Approval Letter



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
Bangladesh Health Professions Institute (BHPI)
(The Academic Institute of CRP)

Ref: CRP-BHPI/IRB/09/2024/961

Date: 18.09.2024

To
 Fatema Jannat Tamanna
 4th Year B.Sc. in Occupational Therapy
 Session: 2019-20, Student ID: 122190360
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

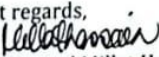
Subject: Approval of the thesis proposal "Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for Children and Adolescents with Intellectual Disability: Parental Perspectives" by ethics committee.

Dear Fatema Jannat Tamanna,
 Congratulations.
 The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, as the principal investigator and Kaniz Fatema as thesis supervisor. The Following documents have been reviewed and approved:

Sl. No.	Name of the Documents
1	Thesis Proposal
2	Self-Developed Interview Guide (English & Bengali version)
3	Information sheet & consent form.

The purpose of the study is to explore the potential barriers of performance for children and adolescents with intellectual disability in activities of daily living, academic and social functioning and generate possible recommendations to overcome these barriers. The study involves use of a Self-developed Interview Guide to explore the potential barriers of performance for children and adolescents with intellectual disability and generate possible recommendation to overcome these barriers that may take 40 to 50 minutes to answer the Interview Guide and there is no likelihood of any harm to the participants and no economical benefits for the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 8.30 AM on 4th September, 2024 at BHPI (45th IRB Meeting).

The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964 - 2013 and other applicable regulation.

Best regards,

 Muhammad Millat Hossain
 Associate Professor, Project and Course Coordinator, MRS
 Member Secretary, Institutional Review Board (IRB)
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ। ফোন: +৮৮ ০২ ২২৪৪৪২৪৬৪-৫, +৮৮ ০২ ২২৪৪৪১৪০৪, মোবাইল: +৮৮ ০১৭৩০ ০৫৯৬৪৭
 CRP, Chapain, Savar, Dhaka-1343, Bangladesh. Tel: +88 02 224445464-5, +88 02 224441404, Mobile: +88 01730059647
 E-mail: principal-bhpi@crp-bangladesh.org. Web: bhpi.edu.bd

Permission Letter

Date: 03/10/2024

To
The Principal,
William & Marie Taylor School
CRP-Chapain, Savar, Dhaka-1343.

Subject: Regarding permission for data collection for undergraduate research.

Dear Sir,

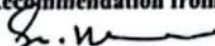
With due respect, I would like to state that I am a 4th year student of B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). I am seeking permission to conduct a thesis titled "**Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for Children and Adolescents with Intellectual Disability: Parental Perspectives**" with myself as the principal investigator and Kaniz Fatema as my thesis supervisor. The study aim is to explore the potential barriers of performance for children and adolescents with intellectual disability. I have obtained the ethical clearance from the BHPI Institutional Review Board (IRB) (reference number: CRP-BHPI/IRB/09/2024/961). The study participants will be the caregiver of children and adolescents with intellectual disability with age range 5-17 years. I kindly request you to provide me with the name and contact numbers of caregivers of children and adolescents with intellectual disability. The data collection period is from 28th September 2024 to 31st October 2024. I assure you that the collected information will be used solely for academic purposes and confidentiality will be maintained in accordance with ethical guidelines. Your permission and support would be invaluable in facilitating the successful completion of my research.

I sincerely appreciate your consideration of this request and would be grateful if you could guide me to the necessary steps to obtain this information. Thank you for your attention and cooperation.

Sincerely,

~~Tamanna~~
Fatema Jannat Tamanna
4th year, B.Sc. in Occupational Therapy
Session: 2019-2020, Student ID: 122190360
Bangladesh Health Professions Institute (BHPI)
CRP, Savar, Dhaka-1343, Bangladesh

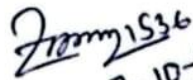
Recommendation from the Head of the Department:


Sk. Moniruzzaman
Professor & Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Savar, Dhaka-1343, Bangladesh

Permitted for data
Collection from WMTS.

Attachment:

- A Copy of the IRB Approval Letter
- A Copy of Research Proposal


7-10-24
MD. ABDULLAH AL ZUBAYER
Principal
William and Marie Taylor School
CRP-Savar, Dhaka-1343

Date: 07/10/2024

To
The Project Manager,
Meaningful Social Access for Persons with Mental Health Needs
CRP, Chapain, Savar, Dhaka-1343

Subject: Regarding permission for data collection for undergraduate research.

Dear Sir,

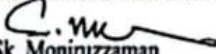
With due respect, I would like to state that I am a 4th year student of B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralyzed (CRP). I am seeking permission to conduct a thesis titled "Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for Children and Adolescents with Intellectual Disability: Parental Perspectives" with myself as the principal investigator and Kaniz Fatema as my thesis supervisor. The study aim is to explore the potential barriers of performance for children and adolescents with intellectual disability. I have obtained the ethical clearance from the BHPI Institutional Review Board (IRB) (reference number: CRP-BHPI/IRB/09/2024/961). The study participants will be the caregiver of children and adolescents with intellectual disability with age range 5-17 years. I want to collect data from Rabia Noor Mental Health Day Centre and the data collection period is from 28th September 2024 to 31st October 2024. I assure you that the collected information will be used solely for academic purposes and confidentiality will be maintained in accordance with ethical guidelines. Your permission and support would be invaluable in facilitating the successful completion of my research.

I sincerely appreciate your consideration of this request and would be grateful if you could guide me to the necessary steps to obtain this information. Thank you for your attention and cooperation.

Sincerely,

Tamanna
Fatema Jannat Tamanna
4th year, B.Sc. in Occupational Therapy
Session: 2019-2020, Student ID: 122190360
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Recommendation from the Head of the Department:


Sk. Moniruzzaman
Professor & Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Savar, Dhaka-1343, Bangladesh

Attachment:

- i. A Copy of the IRB Approval Letter
- ii. A Copy of Research Proposal

*Permitted for data collection
but be aware about
giving points for
Mental health program
Project (2020)*

Date: 03/10/2024

To

The Head of the Pediatric Department,
Centre For the Rehabilitation of the Paralysed (CRP)
CRP-Chapain, Savar, Dhaka-1343.

Subject: Regarding permission for data collection for undergraduate research.

Dear Sir,

With due respect, I would like to state that I am a 4th year student of B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). I am seeking permission to conduct a thesis titled "**Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for Children and Adolescents with Intellectual Disability: Parental Perspectives**" with myself as the principal investigator and Kaniz Fatema as my thesis supervisor. The study aim is to explore the potential barriers of performance for children and adolescents with intellectual disability. I have obtained the ethical clearance from the BHPI Institutional Review Board (IRB) (reference number: CRP-BHPI/IRB/09/2024/961). The study participants will be the caregiver of children and adolescents with intellectual disability with age range 5-17 years. I kindly request you to provide me with the name and contact numbers of caregivers of children and adolescents with intellectual disability. The data collection period is from 28th September 2024 to 31st October 2024. I assure you that the collected information will be used solely for academic purposes and confidentiality will be maintain in accordance with ethical guidelines. Your permission and support would be invaluable in facilitating the successful completion of my research.

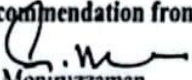
I sincerely appreciate your consideration of this request and would be grateful if you could guide me to the necessary steps to obtain this information. Thank you for your attention and cooperation.

Sincerely,

Tamanna
Fatema Jannat Tamanna
4th year, B.Sc. in Occupational Therapy
Session: 2019-2020, Student ID: 122190360
Bangladesh Health Professions Institute (BHPI)
CRP, Savar, Dhaka-1343, Bangladesh

*She will collect data
from this Department
please help her.*

Recommendation from the Head of the Department:


Sk. Moniruzzaman
Professor & Head of the Department
Department of Occupational Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Savar, Dhaka-1343, Bangladesh

Thanks

HP

8-10-24

Mosneara Perveer
Head of Department
Department of Paediatric
CRP, Savar, Dhaka

Attachment:

- i. A Copy of the IRB Approval Letter
- ii. A Copy of Research Proposal

গণপ্রজাতন্ত্রী বাংলাদেশ সরকার
 পরিচালক ও অধ্যাপকের কার্যালয়
 জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট ও হাসপাতাল
 শেরে বাংলা নগর, ঢাকা- ১২০৭

স্মারক নং-এনআইএমএইচ/একাজেডিক/২০২৪/১৭৬২

তারিখ ২৪/০৭/২৪

বহুবিধ

এসকে, মনিরুজ্জামান
 অধ্যাপক এড অকুপেশনাল থেরাপি
 বাংলাদেশ মেলুর্ন প্রফেশনাল ইনস্টিটিউট
 সিআরপি, সাভার, ঢাকা।

বিষয়: গবেষণা সংক্রান্ত তথ্য সংগ্রহের অনুমতি প্রদান প্রসঙ্গে।

উপরোক্ত বিষয়ের আলোকে বাংলাদেশ মেলুর্ন প্রফেশনাল ইনস্টিটিউট অকুপেশনাল থেরাপি বিভাগের ২০১৯-২০২০ শিক্ষাবর্ষের শিক্ষার্থী ফাতেমা জাহান্না তামান্না কে ১০/১০/২০২৪ হতে ৩০/১১/২০২৪ পর্যন্ত জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, শেরে বাংলা নগর, ঢাকায় "Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for Children and Adolescents with Intellectual Disability: Parental Perspectives" বিষয়ক গবেষণা সংক্রান্ত তথ্য উপাত্ত (ডাটা) সংগ্রহের জন্য অনুমতি প্রদান করা হলো।



(অধ্যাপক ডা. আব্দুল্লাহ আল-মামুন)

পরিচালক ও অধ্যাপক

জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।

তারিখ

স্মারক নং-এনআইএমএইচ/একাজেডিক/২০২৪/

অনুসিপি অবগতি ও প্রয়োজনীয় ব্যবস্থা গ্রহণের জন্য প্রেরণ করা হলো :-

- ১। সম্বন্ধে অধ্যাপক, চাইল্ড, এডভোকেট এড ফ্যামিলি সাইকিয়াট্রি বিভাগ, এনআইএমএইচ, ঢাকা।।
- ২। সহযোগী অধ্যাপক, জেরিয়ট্রিক এড অর্গানিক সাইকিয়াট্রি, এনআইএমএইচ, ঢাকা।
- ৩। ড. মোঃ জহির উদ্দিন, সহকারী অধ্যাপক, ডিউনিক্যাল সাইকোলজি, এনআইএমএইচ, ঢাকা।
- ৪। মোঃ জামাল হোসেন, সাইকিয়াট্রিক সেসল ওয়ার্কর, এনআইএমএইচ, ঢাকা।
- ৫। রেসিডেন্ট সাইকিয়াট্রিস্ট, এনআইএমএইচ, ঢাকা।
- ৬। প্রশাসনিক কর্মকর্তা, এনআইএমএইচ, ঢাকা।
- ৭। পরিচালক মহোদয়ের ব্যক্তিগত সহকারী, জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।
- ৮। সহকারী লাইব্রেরিয়ান, এনআইএমএইচ, ঢাকা।
- ৯। অফিস কপি।



(অধ্যাপক ডা. আব্দুল্লাহ আল-মামুন)

পরিচালক ও অধ্যাপক

জাতীয় মানসিক স্বাস্থ্য ইনস্টিটিউট, ঢাকা।

Appendix-B Information Sheet, Consent Form and Withdrawal Form

Information Sheet (English Version)

I am Fatema Jannat Tamanna, a 4th year student of B.Sc. in Occupational Therapy Department at Bangladesh Health Professions Institute (BHPI) the educational institution of Centre for the Rehabilitation of the Paralysed (CRP).

To fulfill the requirements of the course, I must conduct research as a part of the 4th year course curriculum.

This research is about “Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for children and adolescents with intellectual disability; Parental Perspective.” The purpose of this study is to explore parental experience about their child’s performance barriers, identifying the attitudinal barriers, educational participation, and social participation.

I would like to invite you to participate in this research, your valuable participation will strengthen my research. Your participation in this research is voluntary. You are free to not participate at all or withdraw from research any of the time. All the details of the research are given on this sheet. After reading this if you want to know more about something, you are welcome to ask a question.

During the interview, your answer will be recorded on a phone / tape recorder. Neither any gift/reward nor money is given to you for your participation in this research. The confidentiality of your information given will be highly maintained.

Where to contact to know about this research?

If you have any question/enquiry or any objection and if you want to know the result of the research, you can contact the student researcher:

Fatema Jannat Tamanna
 Phone no: 01679670644.
 Email: tamanna.bhpi.ot@gmail.com

Or the Supervisor of the research:

Kaniz Fatema
 Lecturer
 Department of Occupational Therapy
 BHPI, CRP, Savar
 Email: kanizot@gmail.com

Information Sheet (Bangla Version)

আমি ফাতেমা জান্নাত তামান্না, পক্ষঘাতগ্রস্তদের পুনর্বাসনকেন্দ্র (সিআরপি) এর শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেলথ প্রফেশনস ইন্সটিটিউট (বিএইচ পি আই) এর অকুপেশনাল থেরাপি বিভাগে চতুর্থ বর্ষে অধ্যয়নরত। কোর্সের প্রয়োজনীয়তা পূরণ করতে, আমাকে চতুর্থ বর্ষের অধ্যয়নের অংশ হিসেবে একটি গবেষণা পরিচালনা করতে হবে। এই গবেষণাটি হলো " বুদ্ধিপ্রতিবন্ধী শিশু ও কিশোরদের দৈনন্দিন কাজ, বিদ্যালয়ের কাজ এবং সামাজিক কাজের প্রতিবন্ধকতা নিয়ে পিতামাতার ধারণা"। এই গবেষণাটির উদ্দেশ্য হলো তাদের সন্তানের সম্পর্কে পিতামাতার অভিজ্ঞতা অন্বেষণ করা, মনোভাবগত বাধা, শিক্ষাগত অংশগ্রহণ এবং সামাজিক অংশগ্রহণে বাঁধা খুঁজে বের করা।

আমি আপনাকে এই গবেষণায় অংশগ্রহণের জন্য আমন্ত্রণ জানাতে চাই, আপনার মূল্যবান অংশগ্রহণ আমার গবেষণাকে শক্তিশালী করবে। এই গবেষণায় আপনার অংশগ্রহণ সেচ্ছাসেবী, আপনি সাক্ষাৎকারের পর যেকোনো সময় আপনার অংশগ্রহণ গবেষণা থেকে প্রত্যাহার করতে পারবেন। গবেষণার সমস্ত বিবরণ এই শীটে দেওয়া আছে। এটি পড়ার পর আপনি যদি কিছু সম্পর্কে আরো জানতে চান তবে আপনি প্রশ্ন জিজ্ঞাসা করতে পারেন। সাক্ষাৎকারের সময়, আপনার উত্তর একটি ফোন/টেপ রেকর্ডারে রেকর্ড করা হবে। এই গবেষণায় আপনার অংশগ্রহণের জন্য আপনাকে কোন উপহার/পুরস্কার বা অর্থ দেওয়া হবে না। আপনার প্রদত্ত তথ্যের অত্যন্ত গোপনীয়তা বজায় রাখা হবে।

এই গবেষণা সম্পর্কে জানতে কোথায় যোগাযোগ করবেন?

আপনার যদি কোন প্রশ্ন/অনুসন্ধান বা আপত্তি থাকে এবং আপনি যদি গবেষণার ফলাফল জানতে চান তবে আপনি গবেষকের সাথে যোগাযোগ করতে পারেন।

গবেষকের তথ্যঃ

ফাতেমা জান্নাত তামান্না

মোবাইল নংঃ ০১৬৭৯৬৭০৬৪৪

ই-মেইলঃ tamanna.bhpi.ot@gmail.com

অথবা গবেষণার তত্ত্বাবধায়কের তথ্যঃ

কানিজ ফাতেমা

লেকচারার

অকুপেশনাল থেরাপি ডিপার্টমেন্ট, বি এইচ পি আই

ই-মেইলঃ kanizot@gmail.com

Consent Form (English Version)

Research Title: Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for children and adolescents with intellectual disability: Parental Perspective

Student investigator: Fatema Jannat Tamanna

I have been asked to take part in the research of Bangladesh Health Professions Institute (BHPI). I have been asked to read the information sheet and hereby I consent to participate in this project.

Consent of the following	Yes	No
Participating in one semi-structured in-depth interview	<input type="checkbox"/>	<input type="checkbox"/>
Audio recording of interview	<input type="checkbox"/>	<input type="checkbox"/>
Being able to participate in future research related to this research	<input type="checkbox"/>	<input type="checkbox"/>

Name of participant: _____

Signature of participant/ Thumb print: _____

Date: _____

Consent Form (Bangla Version)

গবেষণার শিরোনাম: বুদ্ধিবৃত্তিক প্রতিবন্ধী শিশু ও কিশোরদের দৈনন্দিন কার্যক্রম, শিক্ষাগত এবং সামাজিক কার্যক্রমের প্রতিবন্ধকতা নিয়ে পিতামাতার দৃষ্টিভঙ্গি।

ছাত্রী গবেষক: ফাতেমা জান্নাত তামান্না

আমাকে বাংলাদেশ হেলথ প্রফেশনস ইন্সটিটিউটের (বিএইচপিআই) গবেষণায় অংশ নিতে বলা হয়েছে এবং আমি এই গবেষণায় অংশ নিতে সম্মতি জানাচ্ছি।

নিম্নলিখিত সম্মতি	হ্যাঁ	না
একটি অর্ধ-কাঠামোগত সাক্ষাতকারে অংশগ্রহণ করা	<input type="checkbox"/>	<input type="checkbox"/>
সাক্ষাতকারের অডিও রেকর্ডিং	<input type="checkbox"/>	<input type="checkbox"/>
সম্পর্কিত ভবিষ্যতের অন্য কোনো গবেষণায় অংশগ্রহণ করতে সম্মতি জানাচ্ছি	<input type="checkbox"/>	<input type="checkbox"/>

অংশগ্রহনকারীর নামঃ

অংশগ্রহনকারীর স্বাক্ষরঃ

তারিখঃ

Withdrawal Form (English Version)

I _____ (the participant),
wish to withdraw my consent to the use of data arising from my participation. The data
gathered from my participation must not be used in this research as described in the
Information sheet and Consent form.

Patient's Name:

ID Number:

Reason for Withdrawal:

.....
.....
.....
.....
.....

Participant's Name:

Participant's Signature:

Date:

Withdrawal Form (Bangla Version)

আমি.....(অংশগ্রহণকারী), আমার অংশগ্রহণ থেকে উদ্ভূত ডেটা ব্যবহারে আমার সম্মতি প্রত্যাহার করতে চাই। তথ্য পত্র ও সম্মতি ফর্মের বর্ণনামতে আমার অংশগ্রহণ থেকে সংগৃহীত তথ্য এই গবেষণায় ব্যবহার করা উচিত নয়।

শিশুর নামঃ

আইডি নম্বর:

প্রত্যাহারের কারণ:

.....

.....

অংশগ্রহণকারীর নামঃ

অংশগ্রহণকারীর স্বাক্ষরঃ

তারিখঃ

Appendix-C Interview Guide

Sociodemographic Question (English Version)

Participants Identification Information

Participant's name:

Participant's phone no:

Age:

Relationship to child with ID:

Educational status:

Employment status:

Date of interview:

Sociodemographic Question

Age of child:

Sex:

Number of siblings:

Family type:

Socioeconomic status:

Residential area:

Educational level:

Assistive Technology:

Services Received:

Interview Guide (English version)

Semi structured Interview:

The aim of this study is to explore the parent's perception regarding the potential barriers of performance for children and adolescents with intellectual disability in different areas including engaging in activities of daily living, academic and social functioning and find out the possible recommendation to overcome these barriers of performance.

Question 1: How do you think other family members feel about your child?

Question 1.1: Does this attitude of the family affect your child's daily activities?

-If yes, please explain in detail how it affects them.

-If not, please explain in detail why it does not affect them.

Question 1.2: Can your child independently complete daily tasks (such as eating, bathing, using the toilet, maintaining cleanliness, etc.)?

-If yes, please explain in detail how they do it.

-If not, please explain in detail why they cannot do it and what challenges they face.

Question 1.3: Have you made any infrastructural changes at home for your child?

-If yes, please describe in detail what changes have been made.

Question 2: What type of school does your child attend?

Question 2.1: If it is a regular school, why does your child study there?

Question 2.2: What kind of benefits does your child receive from a regular/inclusive school?

Question 3: How do you perceive the attitude of your child's teachers at school? Please explain in detail.

Question 3.1: How does this attitude of the teachers affect your child's behavior?

Question 3.2: How do your child's classmates behave towards them at school?

Question 4: Has any modification been made in the classroom for your child?

-If yes, what modifications have been made?

-If not, why hasn't any modification been made?

Question 4.1: How does the school's infrastructure impact on your child's functionality? Please explain in detail.

Question 5: How does your child communicate with their teachers? Please explain in detail.

Question 5.1: How does your child communicate with their classmates? Please explain in detail.

Question 6: Does the current school curriculum meet your child's overall needs?

-If yes, please explain how it meets their needs in detail.

-If not, please explain why it does not meet their needs.

Question 7: Has the school administration provided proper training to teachers regarding educating children with disabilities?

-If yes, please explain in detail.

-If not, why hasn't the training been provided? Please explain.

Question 8: What is society's general perception of your child? Please explain in detail.

Question 9: Does your child understand social cues or body language?

-If no, what difficulties do they face in understanding them? Please explain in detail.

Question 10: Are there any infrastructural barriers in society that affect your child's social activities?

-If yes, please describe in detail what kind of barriers exist.

Question 11: Does your child want to participate in any kind of voluntary activities?

-If yes, what is their opinion about it?

-If not, why don't they want to participate? Please explain in detail.

Question 12: What steps can be taken to create an inclusive society for your child? Please explain in detail.

Question 13: What changes do you think should be made in the school environment to support your child's education?

Question 14: In which areas do you think more focus should be given for the overall development of intellectually disabled children? Please explain in detail.

Sociodemographic Questions (Bangla version)

অংশগ্রহণকারীর নামঃ

মোবাইল নম্বরঃ

অংশগ্রহণকারীর বয়সঃ

শিশু/কিশোরের সাথে সম্পর্কঃ

অংশগ্রহণকারীর শিক্ষাগত যোগ্যতাঃ

কর্মসংস্থানঃ

শিশু/কিশোরের বয়সঃ

লিঙ্গঃ

ভাই বোনের সংখ্যাঃ

পরিবারের ধরনঃ

আর্থসামাজিক অবস্থাঃ

বাসস্থানের ঠিকানাঃ

শিশু/কিশোরের বর্তমান শিক্ষাগত অবস্থাঃ

প্রতিবন্ধিতার স্তরঃ

ব্যবহৃত সহায়ক উপকরণসমূহঃ

পূর্বে যে সকল সেবা সমূহ গ্রহণ করেছেনঃ

Interview Guide (Bangla version)

প্রশ্ন-১: আপনার সন্তানের প্রতি পরিবারের অন্যান্য সদস্যদের মনোভাব কেমন বলে আপনি মনে করেন?

প্রশ্ন- ১.১: পরিবারের এই মনোভাব আপনার সন্তানের দৈনন্দিন কার্যক্রমে প্রভাব ফেলে?

- উত্তর হ্যাঁ হলে দয়া করে আমাকে বিস্তারিত বলুন।

- উত্তর না হলে, কেন প্রভাব ফেলে না দয়া করে তা বিস্তারিত বলুন।

প্রশ্ন-১.২: আপনার সন্তান তার প্রতিদিনের কাজগুলো (যেমনঃ খাবার খাওয়া, গোসল করা, পায়খানা ব্যবহার করা, পরিষ্কার পরিচ্ছন্ন থাকা ইত্যাদি) সম্পূর্ণভাবে করতে পারে কিনা?

-উত্তর হ্যাঁ হলে দয়া করে আমাকে বিস্তারিত বলুন কিভাবে করে?

-উত্তর না হলে দয়া করে আমাকে বিস্তারিত বলুন কেন করতে পারে না এবং কিভাবে বাঁধার সম্মুখীন হয়?

প্রশ্ন-১.৩: আপনার সন্তানের জন্য আপনার বাড়িতে কোন ধরনের অবকাঠামোগত পরিবর্তন করেছেন কি?

-উত্তর হ্যাঁ হলে কি ধরনের পরিবর্তন করেছেন বিস্তারিতভাবে বলুন।

প্রশ্ন-২: আপনার সন্তান কি ধরনের বিদ্যালয়ে লেখাপড়া করে?

প্রশ্ন-২.১: যদি সাধারণ বিদ্যালয় হয় তবে কেন সে সাধারণ বিদ্যালয়ে লেখাপড়া করে?

প্রশ্ন-২.২: সাধারণ /একীভূত বিদ্যালয় থেকে সে কি ধরনের সুবিধা পেয়ে থাকে?

প্রশ্ন-৩: আপনার সন্তানের প্রতি বিদ্যালয়ে তার শিক্ষকদের মনোভাব আপনার কাছে কেমন বলে মনে হয়? দয়া করে বিস্তারিত বলুন।

প্রশ্ন-৩.১: শিক্ষকদের এই মনোভাব আপনার সন্তানের আচরণে কি ধরনের প্রভাব ফেলে?

প্রশ্ন- ৩.২: আপনার সন্তানের প্রতি বিদ্যালয়ে তার সহপাঠীদের মনোভাব কেমন?

প্রশ্ন-৪: আপনার সন্তানের শ্রেণীকক্ষে কি তার জন্য কোন ধরনের পরিবর্তন আনা হয়েছে?

- উত্তর হ্যাঁ হলে কি পরিবর্তন আনা হয়েছে?
- উত্তর না হলে কেন পরিবর্তন করা হয়নি?

প্রশ্ন-৪.১: বিদ্যালয়ের অবকাঠামো আপনার সন্তানের কার্যক্ষমতা কে কিভাবে প্রভাবিত করে দয়া করে বিস্তারিত বলুন?

প্রশ্ন-৫: আপনার সন্তান তার শিক্ষকদের সাথে কিভাবে যোগাযোগ করে দয়া করে বিস্তারিত বলুন।

প্রশ্ন-৫.১: সে তার সহপাঠীদের সাথে কিভাবে যোগাযোগ করে দয়া করে বিস্তারিত বলুন।

প্রশ্ন-৬: বিদ্যালয়ের বর্তমান পাঠ্যক্রম আপনার সন্তানের সামগ্রিক প্রয়োজন গুলো পূরণ করতে পারছে?

- উত্তর হ্যাঁ হলে প্রয়োজনগুলো কিভাবে পূরণ করছে বিস্তারিত বলুন।
- উত্তর না হলে কেন পূরণ করতে পারছে না দয়া করে বিস্তারিত বলুন।

প্রশ্ন-৭: প্রতিবন্ধী শিশুদের শিক্ষাদানের বিষয়ে বিদ্যালয়ের কর্তৃপক্ষ তাদের শিক্ষকদের যথাযথ প্রশিক্ষণের ব্যবস্থা করেছে কি না?

- যদি করে থাকে তবে দয়া করে বিস্তারিত বলুন।
- যদি না করে থাকে তবে কেন করা হয়নি বিস্তারিত বলুন।

প্রশ্ন-৮: সমাজের অন্যান্য লোকজনদের আপনার সন্তানের প্রতি ধারণা কেমন বিস্তারিত বলুন।

প্রশ্ন-৯: আপনার সন্তান সামাজিক সংকেত বা বাচনভঙ্গি বুঝতে পারে?

- উত্তর না হলে বুঝতে কি ধরনের সমস্যা হয় বিস্তারিত বলুন।

প্রশ্ন- ১০: সমাজে এমন কোন অবকাঠামো গত প্রতিবন্ধকতা রয়েছে যা আপনার সন্তানের সামাজিক কার্যক্রমকে প্রভাবিত করে?

- উত্তর হ্যাঁ হলে কি কি ধরনের প্রতিবন্ধকতা রয়েছে আমাকে বিস্তারিত বলুন।

প্রশ্ন-১১: আপনার সন্তান কি কোন ধরনের স্বেচ্ছাসেবামূলক কর্মকাণ্ডে অংশগ্রহণ করতে চায়?

- উত্তর হ্যাঁ হলে এই বিষয়ে তার মতামত কি?

- উত্তর না হলে কেন করতে চায়না বিস্তারিত বলুন।

প্রশ্ন-১২: আপনার সন্তানের জন্য একীভূত সমাজ তৈরি করতে কি কি পদক্ষেপ নেয়া যেতে পারে দয়া করে বিস্তারিত বলুন।

প্রশ্ন-১৩: আপনার সন্তানের পড়ালেখাকে চলমান রাখার জন্য বিদ্যালয়ের পরিবেশে কি কি পরিবর্তন করা যেতে পারে বলে আপনার ধারণা?

প্রশ্ন-১৪ বুদ্ধিভিত্তিক প্রতিবন্ধী শিশুদের সার্বিক উন্নয়নের জন্য কোন ক্ষেত্রে আরো বেশি মনোযোগ দেয়া উচিত বলে আপনি মনে করেন? দয়া করে বিস্তারিত বলুন।

Appendix-D Supervision Sheet

Bangladesh Health Professions Institute
Department of Occupational Therapy
4th Year B. Sc in Occupational Therapy
OT 401 Research Project

Thesis Supervisor- Student Contact; face-to-face or electronic and guidance record

Title of thesis: *Barriers of Performance in Activities of Daily Living, Academic and Social Functioning for Children with Intellectual Disability: Parental Perspective.*











Name of student: *Fatema Jannat Tamanna*

Name and designation of thesis supervisor: *Kariz Fatema, Lecturer of department of Occupational Therapy*

Appoint ment No	Date	Place	Topic of discussion	Duration (Minutes/ Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	19.08.24	Office building, BHPI	Research title, aim and objective checkout.	15 min	Got a proper idea about my research topic	<i>Tamanna</i>	<i>Kariz</i>
2	25.08.24	Office building, BHPI	Clearance of aim, objective and discussion about self- developed interview guide. Check the interview guide	30 min	Effective feedback	<i>Tamanna</i>	<i>Kariz</i>
3	28.08.24	Office building, BHPI	Modification of interview guide	15 min	Need to correction	<i>Tamanna</i>	<i>Kariz</i>
4	29.08.24	Office building, BHPI	Overall feedback of research proposal	35 min	Need to more correction	<i>Tamanna</i>	<i>Kariz</i>
5	02.09.24	Office building, BHPI	Correction of proposal after IRB presentation	30 min	Calculating sample size for quantitative research	<i>Tamanna</i>	<i>Kariz</i>
6	05.09.24	Office building, BHPI	Need to connection of the proposal	15 min	Need to connection of the proposal	<i>Tamanna</i>	<i>Kariz</i>

Bangladesh Health Professions Institute
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 4th Year B. Sc in Occupational Therapy
 OT 401 Research Project

Thesis Supervisor- Student Contact; face-to-face or electronic and guidance record

7	03.10.24	Office building BHPi	Check the application and discuss about data collection procedure.	30 min	Proper guidance on data collection	Tamanna	
8	30.12.24	Office building BHPi	Guideline about how to transcribe and translation	1 hour	Have to be rewrite the translation	Tamanna	
9	31.12.24	Office building BHPi	Grounded theory coding from translation	2:30 hour	Need to three types of coding	Tamanna	
10	04.01.25	Office building BHPi	Check the coding	1:30 hour	Rearranging the coding	Tamanna	
11	14.01.25	Office building BHPi	Ho Guideline on theme formation	1 hour	Have to be work on theme	Tamanna	
12	15.01.25	Office building BHPi	Check the theme formation	30 min	Rethink the theme	Tamanna	
13	20.01.25	Office Building BHPi	Discuss about result and conclusion	1:20 min	Constructive feedback	Tamanna	
14	26.02.25	Library Building BHPi	First draft feedback	4 hours	Sequential feed back (chapterwise)	Tamanna	
15	08.03.25	Office Building BHPi	Individual first draft feedback	3 hours	Works on major feedback	Tamanna	
16	10.03.25	Office	Literature review checking	3 hours	Need to correction	Tamanna	

Bangladesh Health Professions Institute
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 4th Year B. Sc in Occupational Therapy
 OT 401 Research Project

Thesis Supervisor- Student Contact; face-to-face or electronic and guidance record

	Building					
17	Library Building BHP I	Methodology checking and feedback	2:30 min	Works on major feedback	Tamanna	<i>[Signature]</i>
18	Office Building BHP I	Result checking, feedback and discussion	3 hours + 20 min	Construction of theme and writing style	Tamanna	<i>[Signature]</i>
19	Office Building BHP I	Discussion and conclusion writeup	4 hours	Works on major Feedback	Tamanna	<i>[Signature]</i>
20	Office Building BHP I	Overall feedback for 2 nd draft	4 hours	less correction	Tamanna	<i>[Signature]</i>
21	Office Building BHP I	Overall feedback on E-mail	1 hours	Overall feedback	Tamanna	<i>[Signature]</i>

Note:

1. The appointment number will cover at least 40 hours; it is applicable only for face-to-face contact with the supervisors.
2. Students will be required to submit this completed record while submitting their final thesis.