

**Level of Competence & Importance in  
Daily Living of Mothers of Children with Disability:  
A Cross-Sectional Study**



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

Except where it is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis presented by me for any other degree or seminar. No other person's work has been used without due acknowledgement in the main text of the thesis. This thesis has not been submitted for the award of any other degree in any other tertiary institution. The ethical issue of the study has been strictly considered and protected. In case of dissemination of the findings of this project for future publication, the research supervisor will be highly concerned, and it will be duly acknowledged as an undergraduate thesis.

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## List of Abbreviations

ADHD	Attention Deficit Hyperactive Disorder
ADL	Activities of Daily Living
ASD	Autism Spectrum Disorder
BHPI	Bangladesh Health Professions Institute
CRP	Centre for the Rehabilitation of Paralysed
CRPD	Convention on the Rights of Persons with Disabilities
CWD	Children With Disability
DS	Down Syndrome
IADL	Instrumental Activities of Daily Living
ID	Intellectual Disability
IRB	Institutional Review Board
OSA-DLS	Occupational Self-Assessment -Daily Living Scale
OT	Occupational Therapy

## Abstract

**Background:** Mothers play a central role in caregiving for her child's well-being. Their daily living provides understanding of the intricate demands and coping strategies within the context of raising a child with a disability. The researcher included in the study Cerebral Palsy, Autism Spectrum Disorder, Attention Deficit Hyperactive Disorder and Down syndrome. The study focused on the mothers of the children with disability faced challenges to maintain time for their own self-care, productive works and leisure.

**Aim:** The study aimed to find out the level of competence and importance in daily living activities of the mothers of children with disability.

**Methods:** The study followed a cross-sectional quantitative study design by conducting face-to-face survey using purposive sampling among 202 participants who were the mother of child who taking treatment in rehabilitation center and therapy center through standardized questionnaire Occupational Self-Assessment-Daily Living Scale (OSA-DLS). Descriptive analysis was used by SPSS 20 version to analyze the data. The Mann Whitney U test and Kruskal wallis test was used to test the association of socio-demographic factors with competence and importance.

**Results:** The score of competence was median (IQR) = 26.00 (21.00-30.00) which indicated high level of competence in daily living of participants according to OSA-DLS. The score of importance was median (IQR) = 27.00 (23.00- 33.00) which indicates high level of importance in daily living of participants. There was a significant association between competence and living area, educational level, age of child, diagnosis of child, number of children with disability and monthly income.

**Conclusion:** The study find out the higher level of competence and importance of the mother of children with disability. The study also contributes to a gross understanding of the status of socio-demographic and mother of children with disability. This study helps Occupational therapist to promote the mothers' daily living in managing with children with disability.

**Keywords:** Mother of Children with disability, Daily living, Occupational therapy, Level, Competence, Importance.

## CHAPTER I: INTRODUCTION

### 1.1 Background

A mother has a lot of duties and responsibilities in her family. But when a mother has a child with any disability, her responsibility is being more than the mother who have typical child. There is adequate evidence that mothers of Children with disability have poorer health, well-being, and quality of life than the typical mothers (Sim at al.2021).

According to the scoring, which is higher than the previous score and is based on a more inclusive and meaningful understanding of disability that considers a number of functioning domains, including those connected to psycho-social well-being, there are currently about 240 million children worldwide who have some kind of disability (Children With Disabilities-UNICEF Data, 2023).

According to the Persons with Disability Rights and Protection Act of 2013 in Bangladesh, 1.7% of children and 2.8% of adults in the country have some form of disability. Disability is defined as a "long-term or permanent physical, psychological, intellectual, developmental, or sensory impairment of a person and the interaction of perceptual and environmental barriers that hinders their smooth and effective participation in society on an equal basis with others" (BBS, 2022).

According to the CRPD "Those who have long-term physical, mental, or intellectual, sensory impairments that interaction with various barriers may hinder their full and effective participation in society on an equal basis" are classified as children with disabilities. The CRPD states that the following categories of CWD in Bangladesh- Autism, Physical, Psycho-social, Visually Challenged, Speech

Disability, Intellectual Disability, Hearing Disability, Hearing-Visual Disability, Cerebral Palsy, Down Syndrome, Multiple Disabilities.

The researcher include in the study such as- Cerebral Palsy, Autism Spectrum Disorder, Attention Deficit Hyperactive Disorder, Down syndrome, Brain injury and Intellectual disability.

Mothers are the central persons of the family. They do a lot of works to manage and balance their family. During playing their roles, they face many challenges, barriers. The religious and cultural contexts have also obstructed the occupations for mothers of CWD. Caregiving is a natural and important part of motherhood, but if the children have any disability, the mothers may need to assist the children with basic tasks such as feeding, hygiene, dressing, transportation, communication, body mobilization, play, and communication for more hours per day (Ranehov & Hakansson, 2018).

Traditionally, mothers have been the primary caregivers of their CWD. In addition to, taking care of children, mothers need to manage their self- care, leisure, and regular job, the situations become hard. In many cases, mothers leave their paid productive works to focus on the children care, and this has a major impact on their daily life, requiring a greater investment of time and resources. This circumstance can increase mental stress and health problems in these mothers as well as the impact on their physical health and the impact on occupational performance (Cantero-Garlito et al., 2020).

Basic Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) are the two categories into which the activities of daily living are divided. The skills needed to handle one's basic physical needs, such as eating,



clothing, using the restroom, transferring, or walking, and personal hygiene or grooming, are known as the basic ADLs or physical ADLs. The more difficult tasks associated with being able to live freely in the community are known as IADLs. This would cover things like handling money and prescriptions, cooking, cleaning, and laundry, among other things. The IADL is different from the ADL in that individuals frequently start requesting outside help when these tasks become challenging to complete on their own (Edemekong, Bomgaars, and Levy 2019).

Basic ADLs and IADLs are the two categories into which the activities of daily living are divided. The skills needed to handle one's basic physical needs, such as eating, clothing, using the restroom, transferring, or walking and personal hygiene or grooming, are known as the basic ADLs or physical ADLs. The more difficult tasks associated with being able to live freely in the community are known as IADLs. This would cover things like handling money and prescriptions, cooking, cleaning, and laundry, among other things. The IADL is different from the ADL in that individuals frequently start requesting outside help when these tasks become challenging to complete on their own. (Edemekong, Bomgaars, and Levy 2019)

In the study researcher measure the level of competence & importance of ADLs & IADLs (bathing, dressing, grooming (washing face, washing hands, brushing teeth, hair care, shaving face/applying makeup), meal preparation, toileting, walking, maintaining balance while walking, climbing stairs, driving, house cleaning, laundry, grocery shopping) of mothers of CWD.

Mothers are the primary caregiver of a child. When a child has any disability then definitely it impact on mothers daily life. The study can enhance knowledge of this

topic among academics and pave the way for additional research and advancements in the areas of family support and studies of disabilities.

## **1.2 Justification of the Study**

This study explored the level of competence & importance in daily living of mothers of CWD. The study focused on their challenges in maintaining self-care, productive work, and leisure activities. These mothers often give up other roles in society due to increased responsibilities for childcare, leading to a loss of empathy and understanding within the community. Mother is the primary or main care giver of a child. If the mothers had negative experiences in their daily life this must affect their child caring.

Occupational therapy places a strong emphasis on patient-centered care. By studying the experiences of mothers, can promote a more holistic and patient-centered approach to therapy. This information can inform therapeutic interventions and support strategies, potentially improving the quality of life for both mothers and their children. When Occupational Therapists come to know the difficulties of a mother with her CWD child, then they could provide appropriate interventions, for example: recommendations, modifications, and suggestions to minimize if they have any challenges and help them to lead a better daily live.

This study contributed to the academic understanding of this topic, potentially leading to further studies and advancements in the field of disability studies and family support.

## **1.3 Operational Definition**

### ***1.3.1 Activities of Daily living (ADLs)***

The term “Activities of Daily Living” (ADLs) refer to a group of basic abilities including eating, bathing, and moving around that are necessary for self-care on an independent basis. Sidney Katz first used the term "activities of daily living" in 1950 (Edemekong et al. 2019).

### ***1.3.2 Instrumental Activities of Daily Living (IADLs)***

The term "Instrumental Activities of Daily Living" (IADLs) describes activities that are focused on engaging with your surroundings and supporting everyday living. In general, IADLs are more complicated than ADLs. Though they are easily assigned to another person, they are essential components of family and community life (Mlinac and Feng 2016).

### ***1.3.3 Self-care activity***

The activities we have to do every day for our self-care are known as self-care activities. For example- washing hands & mouth, brushing teeth, combing hair, dressing, shaving, taking meal, having shower etc (“Self-care,” 21).

### ***1.3.4 Productive activity***

The activities we need to do every day to accomplish our job and house holding activities are known as work and productive activities. Example- meal preparations, shopping, take care of others, cleaning, job performance etc (Reid & Riddick Grisham, 2015).

### ***1.3.5 Leisure activity***

Activities which are done by the people for their personal interest and to spent their spare time in their everyday life are known as play or leisure. Example- Painting in

leisure period to spend the spare time, play football in the leisure, gardening etc ("Leisure activity," n.d.).

### ***1.3.6 Children with disability***

In accordance with the CRPD, children with disabilities "include those who have long-term physical, mental or intellectual, sensory impairments that interaction with various barriers, may hinder their full and effective participation in society on an equal basis."

### ***1.3.7 Quality of life***

According to the WHO, quality of life an individual's perspective of where they belong in life in relation to their objectives, standards, expectations, and anxiety as well as the culture and value systems in which they live, their represents (Zhu et al. 2022).

### ***1.3.8 Competence***

Competence in daily living activities refers to an individual's ability to perform essential tasks necessary for independent living. Competence in these activities indicates a person's capability to manage their basic self-care needs and maintain a certain level of independence in their daily life.

### ***1.3.9 Importance***

The term "importance" in daily living refers to the significance or relevance of something in one's everyday life. It encompasses the value that a particular activity to achieve personal goals, fulfilling needs, maintaining well-being or contributing to overall satisfaction and happiness. The importance of various aspects of daily living helps individuals prioritize tasks, make decisions and allocate resources effectively to enhance their quality of life.

#### **1.4 Aim of the study**

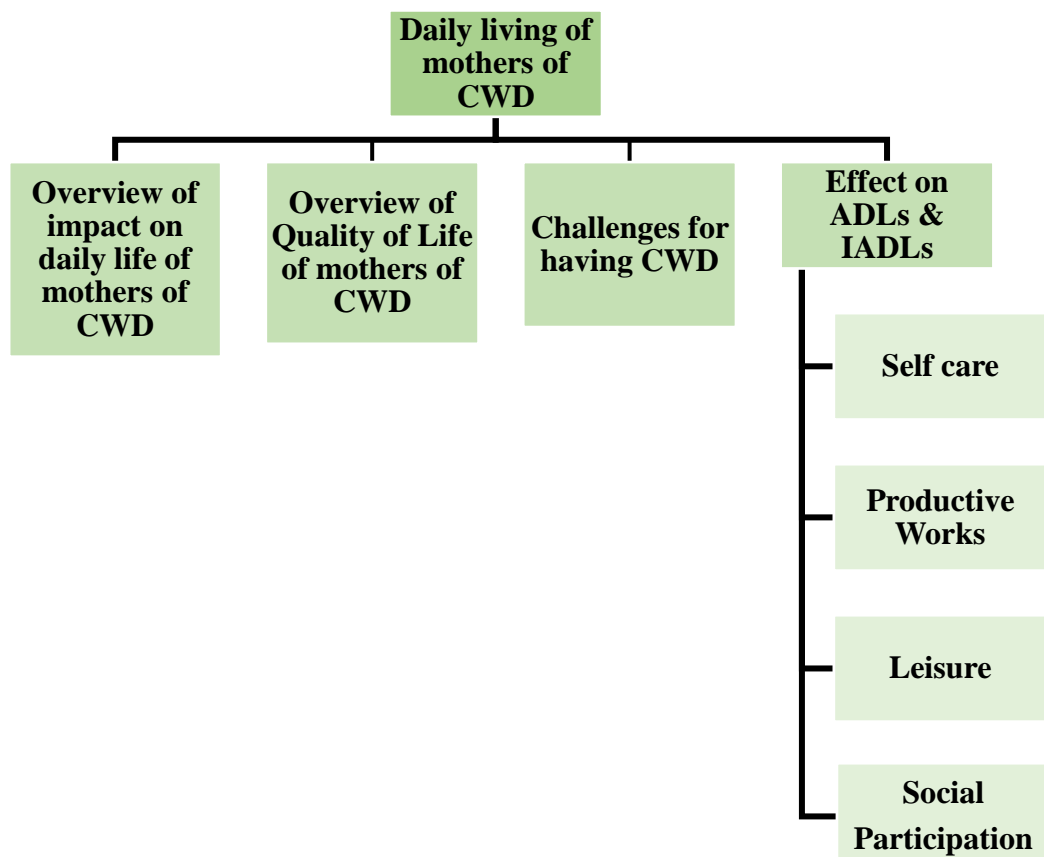
The study aimed to find out the level of competence and importance in daily living activities of the mothers of CWD.

## CHAPTER II: LITERATURE REVIEW

The chapter has represented the relevant information of the study. It covers the review of existing literature regarding daily living of mothers of CWD. Relevant literature has been included a review of impact on daily life, quality of life, challenges and effect on ADLs & IADLs.

**Figure 2.1**

*Overview of literature review findings*



## **2.1 Overview of impact on daily life of mothers of CWD**

Mothers are the main caregiver of a child. When a child has disability then its must be impact on mothers daily life. This study explores the challenges faced by mothers in fulfilling their crucial role as caregivers for CWD. Participants noted various difficulties related to the child, family, services, and community. Mental health problems and emotional discomfort were reported, and caring responsibilities can be demanding. Here also discusses the clinical implications of occupational therapy for supporting mothers and their children (Bourke-Taylor et al., 2010; Singogo et al., 2015; Courtney et al., 2018).

An article examined the effect of mothers of children with intellectual disabilities, focusing on maternal and family vulnerability and protective resources preliminary analyses showed significant differences in maternal stress levels and perception of the family's adaptability. The study supports hypotheses about the differential predictive role of maternal and familial resources in explaining mothers' affect. Here show the positive and negative impact of a mother of children with intellectual disabilities (Al-Yagon and Margalit 2009). Another article explores the challenges faced by mothers caring for in Zambia. Interviews with sixteen mothers revealed social isolation, marital problems, and negative attitudes from family, friends, community members, and healthcare professionals. Access challenges due to limited facilities and lack of sidewalks, ramps, and lifts further exacerbated these issues. The study highlights the need for improved support and support for mothers with CP (Singogo, Mweshi, and Rhoda 2015). An examined the experiences of twelve mothers with a life-limiting neurodevelopmental disability. The findings suggest constant struggle, negative impacts on family life, but also resilience and coping. The study suggests implications for service provision (Courtney et al. 2018).

## **2.2 Overview of Quality of Life of mothers of CWD**

A study looks at the quality of life (QOL) of parents of children with cerebral palsy who are between the ages of three and eighteen. It also looks at whether the impact differs as the child gets older. A qualitative study revealed that parental QOL varied across physical, social, freedom, independence, family, and financial stability, with no differences observed between subgroups. Parents frequently felt that the services they used did not support them.

A parent's life can be affected by raising a child with cerebral palsy in both positive and negative ways. (Davis et al. 2010). This study used the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) to investigate factors that influence the quality of life of caregivers for children with cerebral palsy. The World Health Organization Quality of Life-BREF-Taiwan version was used to assess the QOL of 167 children and their caregivers who took part in the study. The study discovered that the variables influencing quality of life were multifaceted and included aspects related to children, caregivers, and the surrounding environment. This information may help develop interventions to enhance the quality of life for caregivers of children with cerebral palsy by guiding a comprehensive approach to evaluation and intervention (Tseng et al. 2016).

An article analyzes variables associated with the effects of caregiving on parents of children with cerebral palsy. According to a thorough review of internet databases, parents who are caring for someone with cerebral palsy typically experience higher levels of stress and despair along with a lower quality of life. Higher levels of stress and depression are regularly associated with factors including low caregiver self-efficacy, poor social support, and behavioral and cognitive issues



in children. The findings' ramifications are examined, with a focus on measures meant to improve parents' capacity and resources to handle the difficult work of providing care (Davis et al., 2010; Singogo et al., 2015).

A study aim was to explore the impact of financial strain, social and familial responsibilities, psychological burdens, and stress-reduction strategies on the anxiety, depression, and overall quality of life of mothers raising disabled children. The study included 50 disabled children and their mothers. All parameters, except for coping, showed a moderate correlation with the mothers' anxiety and depression levels (Yarar et al. 2021).

According to the budget guidelines, parents should spend more money each week than they are able to in order to provide for their kids' needs. The study emphasizes how much more expensive it is for parents to raise a disabled child than a child without a disability. Benefits for children with disabilities have grown, but there is still a gap between maximum entitlements and funding needs. By creating a new paradigm for family life, parents can overcome the new experiences and financial worries they face. To meet the needs of both parents and their children, services must be dependable, sensitive, and responsive. Planning for a child's care requires parental involvement as well. By using their knowledge to improve resource utilization, parents and professionals can both benefit (Dobson, Middleton, and Beardsworth 2001).

### **2.3 Challenges for having CWD**

Caring for a child with disability is a challenging journey for parents. A qualitative study was conducted to understand how caregivers manage severe developmental disabilities in children in rural Africa. Following permission, individual interviews

were carried out using a semi-structured interviewing method after each individual digital story was recorded. To analyze the data, pre-established key categories were employed. Here the findings demonstrated that children with developmental disabilities had less autonomy and needed ongoing care. Due to learning disabilities or an inability to pay for specialized education, schooling had either not been attempted at all or had been discontinued. Parents experienced ongoing financial, emotional, and physical strain. Their income from their jobs dropped. To make ends meet, some families sold their possessions. Others started depending on their family. Knowing the effects of developmental disabilities makes it easier to decide where social support needs to be strengthened and concentrated (Castellani et al. 2022). This study explores the experiences of single mothers raising CWD in South Africa, focusing on their complex realities and practices. Four themes developed from the thematic analysis of interviews with twelve moms, ages 7 to 18. The study emphasizes the diverse stress of caring for a disabled child, which has a big influence on the social, economic, and emotional facets of single mothers' lives. Understanding the needs of single mothers in this situation, such as the need for psychosocial support and specific knowledge about their child's disability to enable them to make better accommodations for both them and their child is made possible by the findings. The results are critical to creating a thorough understanding of the needs and experiences of single mothers. (Mbanjwa and Harvey 2023)

#### **2.4 Effect on ADLs & IADLs**

Mothers of CWD face challenges to perform their ADLs such as their own ADL & IADL due to spend a lot of time to look after their children. CWD are completely dependent on their mothers due to their physical and cognitive developmental delays,

which prevent them from performing self-care activities (Wayne and Krishnagiri 2005). Here mentioned that raising a child with special needs is challenging for the mothers in maintaining a balance among work, leisure and daily living activities. Impacts on mothers' daily life with CWD impacts on social participation Experiences of performing self-care, productive and leisure activities.

#### ***2.4.1 Self care***

Self-care includes eating, bathing, dressing and grooming and all health decisions people make for themselves to get and stay physically and mentally fit. In addition to eating healthily, maintaining proper hygiene, avoiding health risks, and exercising to maintain mental and physical fitness, self-care also entails these activities. These moms struggle to keep up a schedule for their own self-care, particularly when it comes to eating and taking showers (Wayne and Krishnagiri 2005). also stated that because they have to spend more time caring for their children, mothers of CWD find it difficult to maintain the energy or power to properly manage their own self-care.

#### ***2.4.2 Productive works***

It was difficult for mothers of people with cognitive disabilities to continue doing productive tasks like taking care of the home and working. They devote the majority of their time to raising their kids. It said that a mother of a child with special needs must devote the majority of her time to caring for her child and minimal time to productive work. It has been demonstrated that these moms have less time for services or paid work. Outside-the-home employment is a protective and positive factor for mothers of CWD. Despite the additional demands of work, childcare, and family, working mothers report lower levels of stress and greater life satisfaction (Wayne & Krishnagiri, 2005)

### ***2.4.3 Leisure***

Leisure is very important for a person and specially the mothers of CWD because they feel more income (Wayne & Krishnagiri, 2005). Stress than the mothers of the typically developed children. Mother find it difficult to find time for themselves after giving a lot of time to caring for the CWD along with other responsibilities. These mothers spend most of their time with their CWD and have minimal free time because they are always worried about their children. They faced prejudice, social barriers, and poor service when performing leisure activities for another reason. Some parents internalized the negative views that others had about their children, and in other situations, they experienced shame when they were seen in public. The sensation of being judged turned into a barrier that prevented them from leisure participation and increased their social isolation. (Hsieh 2013).

### ***2.4.4. Social participation***

Social participation means carrying out one's life habits in one's environment such as school, workplace, and neighborhood. Carrying out these life habits depends especially on the age of the person, expectations of the living environment and cultural aspects. It has mentioned that social participation is an individual's involvement in activities that provide interaction with others in society or the community such as different social contact with community people, attending in different social function, social relationship and involve in social activities (Piskuret al. 2014). A study conducted and found that these mothers are unable to take the necessary time to prepare for achieving any functions at times because they have dedicated a significant amount of their time to caring for their children, running their homes, and other tasks. Additionally, the stigmatizing beliefs of members of society

contribute to the impediment of DS mothers' complete social inclusion (Abbeduto et al. 2004). It has showed that the mothers of the DS children experience different social stigma and negative attitudes from the community which make them isolated from the social participation (Hsieh 2013).

## **2.5 Key Gap of the Study**

- Small sample size in maximum articles, most of the studies are qualitative.
- Most of the data was collected by the online survey method.
- Limited study was found that focused competence and importance on daily living of mothers of CWD.
- Majority of the study was conducted in the hospital or rehabilitation centre. There was no data from the community.
- Limited information about socio-demographic characteristics of mothers and children.
- Most of the studies were conducted impact on daily life of mothers of CWD in Spanish region, South Africa, Australia, Canada, UK, USA. But there were limited study on this topic had been conducted in Asia.

## CHAPTER III: METHODS

### **3.1 Study question and aim, objectives**

#### ***3.1.1 Study questions***

What is the level of competence and importance in daily living activities of the mothers of CWD?

#### ***3.1.2 Aim***

The study aimed to find out the level of competence and importance in daily living activities of the mothers of CWD.

#### ***3.1.3 Objectives***

- To identify the level of competence on ADLs & IADLs of the mothers of CWD.
- To identify the level of importance in daily living activities of the mothers of CWD.
- To identify the association of socio-demographic information with competence and importance on daily living of mothers of CWD.

### **3.2 Study Design**

#### ***3.2.1 Study method***

The study followed the quantitative research to find out the level of competence and importance in daily living activities of the mothers of CWD. Researcher selected a population of mothers who have CWD.

Quantitative research, in contrast to qualitative research, deal with data that were numerical or could be converted into numbers. Statistical techniques were being

used for organizing, analyzing and interpreting the numerical data for this study (Sheard, 2018).

### ***3.2.2 Study Approach***

Cross-sectional studies assess the cause (exposure) and the effect (outcome) simultaneously (Gad, 2023).

In a cross-sectional study, the researcher simultaneously assessed the participants' exposures and outcomes. After choosing the study subjects, the researcher conducted the study in order to evaluate the exposure and results. The association between these can be examined by the researcher (Setia, 2016). So here, the exposure was disability and the outcome was their daily living. The researcher chose this approach because in the context of daily living of mothers of CWD, a cross-sectional design involved assessing their competence and importance in individuals at a particular moment. This approach helped researchers to capture a snapshot at a specific point of time when they were rearing their child. This design allows researchers to examine relationship between exposures and outcomes. So that, Cross sectional study was absolutely perfect for this study.

## **3.3 Study Setting and period**

### ***3.3.1 Study Setting***

The researcher conducted survey at the pediatric department of CRP, Savar and CRP, Mirpur. Ingenious Care Limited and Prottasha Center for Autism Care in Dhaka.

### ***3.3.2 Study Period***

The study period was between May 2023 to February 2024 and data collection period was between 1 December, 2023 to 31 December, 2023.

### **3.4 Study Participants**

#### ***3.4.1 Study Population***

The population of the study was the mothers whose children has disability (different types of disability like- Cerebral palsy, Down syndrome, ASD, ADHD, etc) & fulfill the inclusion and exclusion criteria of this study.

#### ***3.4.2 Sampling Techniques***

Purposive sampling is an intentional selection of participants based on their ability to explain a certain theme, concept, or phenomenon (Roeters 2014). In this research, the researcher had set some inclusion and exclusion criteria to meet the exact population for the study. So purposive sampling was the best way for the study to sample participants.

#### ***3.4.3 Inclusion Criteria***

- Mothers who were the primary caregiver of the CWD.
- Participants were the mother of child who taking treatment in rehabilitation center and therapy center.
- Participants who were willing to take part in the study.

#### ***3.4.4 Exclusion Criteria***

- Mothers were not in contact with her child regularly.
- Mother had any physical illness or physical disabilities were excluded.
- Mothers with diagnosed cognitive problem or mental illness.

#### ***3.4.5 Sample Size***

The population in study was the mother of child with disability in Bangladesh.

Sample size was estimated by using Cochran formula  $n = z^2 / 4d^2$  (as sample population and population proportion is unknown).



P= 50%

Sample size= n

Confidence Interval= 95%

Z value = 1.96

d= 5%

Sample size=  $(1.96)^2/4(0.05)^2=384.16$

Adding 10% non-response data to the actual sample size= 422.576~423

According to this equation, the sample size was 423, but the researcher collected 202 data from the population of the study because of the short time duration and cost limitation of the study. All participants willingly participated in this study.

### **3.5 Ethical Consideration**

#### ***3.5.1 Ethical approval from IRB***

The ethical issues were sought from the Institutional Review Board (IRB) with the explanation of aim, objective and purpose of the study through the Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI). The IRB number CRP/BHPI/IRB/10/2023/749. Permission from Head of the Occupational Therapy department, BHPI. The pediatric department of CRP Savar and Mirpur, Ingenious Care Limited and Prottasha Center for Autism Care had taken for data collection. The ethical process was followed according to (World Medical Association, 2014).

#### ***3.5.2 Informed consent***

The researcher explained the aim, objective, and purpose of the study to the participants through an information sheet. The participants, who felt willingly

interested to participate in the study, their data were collected. Written consent was obtained from the participants during the face-to-face survey.

### ***3.5.3 Unequal and power relationship***

- The population participated voluntarily.
- Researcher did not have any unequal or power relationship with the population.

### ***3.5.4 Right to refusal to participate or withdrawal:***

Participants had complete freedom to choose whether to participate or not in this study. The withdrawal form was attached with the consent form so that the participants could withdraw their participation from the study within two (2) weeks from the time of collecting data.

### ***3.5.5 Risk and Beneficence***

- The population did not have any risk to participate in the study.
- The population did not get any beneficence for giving data.

### ***3.5.6 Confidentiality***

The researcher was highly concerned about the confidentiality of the participants' information. The researcher did not include any personal information in the questionnaire about their identity, such as their name or address. Their information was kept private, except for supervision, which the information sheet made very clear. Furthermore, the same participant data did not be applicable for any future reporting, publishing, conferences, media, or written or spoken discussions. An information sheet provided the participants with clear information about confidentiality.

### 3.6 Data Collection Process

#### 3.6.1 Participant Recruitment Process

**Figure 3.6.1**

*Overview of participants recruitment process*



Figure 3.6.1 above explained the participant recruitment process. The researcher took study population from pediatric department of CRP, Savar and CRP, Mirpur, Ingenious Care Limited and Prottasha Center for Autism Care who came with her child to take intervention from inpatient (CRP, Savar & CRP, Mirpur) and outpatient during the data collection period.

#### 3.6.2 Data Collection Method

The data was collected by face-to-face survey through a socio-demographic questionnaire, the Occupational Self-Assessment-Daily Living Scales (OSA-DLS). The researcher was physically present to ask the survey questions and to help the respondent if they had faced any kind of problem to understand the question with

their responses in a face-to-face survey. Face-to-face survey maintained the quality of data and decreased the potential biasness (Everitt and Howell 2005).

### ***3.6.3 Data Collection Instrument***

#### **Occupational Self Assessment – Daily Living Scales (OSA-DLS)**

The OSA-DLS is a two-step assessment that was used to measure occupational performance based on 12 daily activities. The client was initially asked to score the difficulty of each task by choosing one of four options, ranging from "I have a lot of problems doing this" to "I do this extremely well," during the administration of this assessment. The client was then asked to rate the level of importance each activity has in the client's daily life by selecting one of four options ranging from "This is not so important to me" to "This is the most important to me". To score this assessment, the total score was added up for all 12 activities for each part. The score range was 0-48, with 48 indicating the client has no difficulty completing the 12 occupations and they feel all 12 activities were very important in their daily lives. This assessment was used to gain a better understanding of the client's perceptions on their daily occupations (Scott, 2016).

### ***3.6.4 Field Test***

The researcher translated the questionnaire into Bengali the native language of Bangladesh, after getting permission from Office Technology Management at UCL. The researcher conducted the field test with three mothers of cerebral palsy. Through the field test some changes in the socio demographic were fixed later which helped maintain that questions quality.

### **3.7 Data Management and Analysis**

Data management was the most important process in cross-sectional studies that aims to integrity of the collected data and ensure the validity. The process began with the development of a well-designed data collection form, which taking all relevant variables and information. Once the data was collected, it needed to be entered into a computerized database with careful attention to avoid errors during data entry. Numerical data entered in Microsoft Excel and analyzed by using Statistical Package for Social Science (SPSS) Version 20. Based on the results of the Kolmogorov-Smirnov test the distributions of the scores from scale, did not follow a normal distribution. As a result, Mann Whitney U test and Kruskal Wallis test was used to identify the association of socio-demographic information with competence and importance on daily living of mothers of CWD. Data cleaning was then conducted to identify and correct any inconsistencies, errors, or missing values. This involved checking for outliers, duplicates, and invalid entries, and applying validation rules and logic checks. Categorical variables were coded and transformed as necessary to facilitate analysis and interpretation. Data entry validation was performed by cross-checking a subset of the entered data against the original forms to ensure accuracy. Comprehensive documentation of the data management process was maintained, including a data dictionary or codebook that describes variables and any transformations. Quality assurance checks are conducted to ensure data quality, including data quality reports, range checks, and consistency checks. Data security measures were implemented to protect confidentiality and comply with ethical guidelines. Regular data backups and secure storage procedures were followed to prevent data loss. Finally, the cleaned and validated data was analyzed by using Mann Whitney U test and also Kruskal Wallis test.

That descriptive analysis was carried out to find out the level of competence and importance of mother of CWD. The Kruskal Wallis test was done to find out the association between competence and educational level, age of child, diagnosis of child, number of CWD and monthly income. And Mann Whitney U test to find out the association between competency level and urban and rural mothers of CWD.

### **3.8 Quality Control and Quality Assurance**

The proper quality of data assurance measures was essential in cross-sectional studies that managed by the researcher. This was important to guarantee the reliability and of the study's findings. The study was designed to assess the level of competence and importance in daily living activities of the mothers of CWD utilizing optimal research methodology and approach. The participants were deliberately chosen based on predetermined inclusion and exclusion criteria.

The standardized questionnaires OSA-DLS were employed to assess the levels of competence and importance in daily living activities among the mothers of CWD. The available literature indicates that the questionnaires exhibited favorable levels of validity and reliability. Conversely, the questionnaires underwent translation and field testing before formal data collection.

The entire study was conducted in a systemic way by following research steps under the supervision of an experienced supervisor. That data was input in SPSS version 20. Missing data was checked properly. At the time of data collection and data analysis, the researcher never tries to influence the result by her own value all perspectives. The researcher accepted answers of the participants whether they would deliver. All the data was input properly and assured by the researcher.

## CHAPTER IV: RESULTS

### 4.1 Socio-Demographic Characteristics

**Table 4.1**

*Socio-demographic characteristics of the participants (n=202) [Table 1 extends from page 25-26]*

<b>Variable</b>	<b>Category</b>	<b>Frequency (n=202)</b>	<b>Percentage (%)</b>
Mother's age	16-23 years	58	28.7
	24-31 years	71	35.1
	32-39 years	64	31.7
	40-47 years	9	4.5
Religious	Muslim	190	94.1
	Hindu	9	4.5
	Buddhism	1	.5
	Christianity	2	1.0
Living area	Urban	98	46.5
	Rural	108	53.5
Living with family	Yes	199	98.5
	No	3	1.5
Educational level	Illiterate	12	5.9
	Primary	46	22.8
	Secondary	48	23.8
	Higher secondary	25	12.4
	Graduate	22	10.9
	Postgraduate	49	24.3
Mother's Occupation	Housewife	182	90.1
	Employee	13	6.4
	Business	3	1.5
	Health Professional	1	.5
	Teacher	2	1.0
Suffering any Disease	Yes	54	26.7
	No	148	73.3
Duration of Household chores	Less than 5 hours	125	61.9
	5 to 10 hours	57	28.2
	more than 10 hours	20	9.9

<b>Variable</b>	<b>Category</b>	<b>Frequency (n=202)</b>	<b>Percent(%)</b>
Age of child	1-4 years	126	62.4
	5-8 years	66	32.7
	9-12 years	10	5.0
Diagnosis of child	Cerebral Palsy	124	62.3
	ASD	39	19.6
	ADHD	23	11.6
	Down Syndrome	5	2.5
	Brain Injury	4	2.0
	ID	4	2.0
Number of CWD	1	191	94.1
	2	9	4.4
	3	2	1.0
Spend hours with CWD	5 to 10 hours	23	11.4
	10 to 12 hours	30	14.9
	more than 12 hours	149	73.8
Monthly income	1000-10,000	32	16.6
	11,000-20,000	51	26.4
	21,000-30,000	30	15.5
	31,000-40,000	16	8.1
	41,000-50,000	15	8.0
	above 50,000	49	25.4

Table 4.1 shows an overview of the social-demographic status of mothers of CWD.

These socio-demographic status includes the participant's age, religious, living area, living with family, educational level, mother's occupation, associated disease, sleeping period, duration of household chores, age of child, gender of child, diagnosis of child, number of CWD, spend hours with CWD, monthly income status. There were 4 age groups, 16 to 23 years which was 28.7% (58), 24 to 31 years which was 35.1% (71), 32 to 39 years which was 31.7% (64), 40 to 47 years which was 4.5% (9) of all the participants. Out of 202 participants 94.1% (190) was Muslim, 4.5% (9) was Hindu, .5% (1) was Buddhism and 1.0% (2) was Christianity. Among all the participants most of them lived in rural 53.5% (108) and 46.5% (98) and was lived in urban. There were 98.5% (199) lived with her family and 1.5% (3) were single mother. The educational level of the participants was illiterate 5.9% (12), primary 22.8% (46), secondary 23.8% (48), higher secondary 12.4% (25), graduate 10.9%



(22), post graduate 24.3% (49). Among all the participants mother's occupation was housewife 90.1% (182), employee 6.4% (13), business 1.5% (3), health professional .5% (1) and teacher 1.0% (2). Among the participants 26.7% (54) were suffering any disease for a long time and 73.3% (148) were not suffering any disease for a long time. The participants spend their time in household most of the less than 5 hours 61.9% (125) then 5 to 10 hours 28.2% (57) and more than 10 hours 9.9% (20). There were 3 groups of participant's child; most of the children were 1 to 4 years 62.4% (126) then 5 to 8 years 32.7% (66) and 9 to 12 years 5.0% (10). In this study we can see most of the CWD were boy 67.3% (136) and girl 32.7% (66). Most of the children were diagnosed as Cerebral Palsy 62.3% (124), ASD 19.6% (39), ADHD 11.6% (23), Down Syndrome 2.5% (5), brain injury 2.0% (4) and ID 2.0% (4). Most of the mothers have one CWD 94.1% (191), two 4.4% (9) and three 1.0% (9). This study found most of the mothers spend their time with their child more than 12 hours 73.8% (149), then 10 to 12 hours 14.9% (30) and 5 to 10 hours 11.4% (23). Monthly income of the participants most of the 11,000 to 20,000 26.4% (51), then 49 participants had monthly income above 50,000 and only 15 participants' monthly income 41,000 to 50,000 taka.

## 4.2 Individual responses of competence in daily living activities

**Table 4.2**

*Individual responses of competence*

<b>Competence of daily living</b>				
<b>Variable</b>	<b>A lot of problems doing this</b>	<b>Some difficulty doing this</b>	<b>Do this well</b>	<b>Do this extremely well</b>
<b>Percentage (Frequency) % (n)</b>				
<b>Bathing</b>	25.2% (51)	36.1% (73)	35.1% (71)	3.5% (7)
<b>Dressing</b>	16.3% (33)	30.7% (62)	42.6% (86)	10.4% (21)
<b>Grooming (washing face, washing hands, brushing teeth, hair care, applying makeup)</b>	19.8% (40)	27.2% (55)	43.6% (88)	9.4% (19)
<b>Meal preparation</b>	30.7% (62)	33.7% (68)	31.7% (64)	4.0% (8)
<b>Toileting</b>	16.3% (33)	34.7% (70)	45% (91)	4.0% (8)
<b>Walking</b>	22.3% (45)	30.7% (62)	36.1% (73)	10.9% (22)
<b>Maintaining balance while walking</b>	22.8% (46)	22.3% (45)	40.6% (82)	13.9% (28)
<b>Climbing stairs</b>	27.2% (55)	24.3% (49)	36.1% (73)	12.4% (25)
<b>Driving</b>	3.0% (6)	4.5% (9)	1.5% (3)	1.0% (2)
<b>House Cleaning</b>	8.9% (18)	44.6% (90)	40.6% (82)	5.9% (12)
<b>Laundry</b>	9.9% (20)	44.6% (90)	40.1% (81)	5.4% (11)
<b>Grocery shopping</b>	37.1% (75)	40.6% (82)	19.8% (40)	2.5% (5)

The results presented a comprehensive view of the competence of mothers of CWD in various daily living activities. Each activity has been evaluated based on the reported difficulties and struggle experienced by these mothers. The result shows that a significant number of participants 36.1% (73) report some difficulties with bathing, indicating it as a challenging ADL, with only 3.5% (7) participants feeling competent. Fewer mothers experience severe difficulties with dressing 16.3% (33), and a majority

42.6% (86) manage this activity well and 10.4% (21) can extremely well, suggesting relatively higher competence in this area. Grooming also seems challenging, with 43.6% (88) of respondents reporting they do it well and 9.4% (19) extremely well, and only 19.8% (40) facing a lot of problems. Meal preparation appears to be challenging for a larger segment of mothers, with over 33.7% (68) reporting problems or some difficulty. This activity appears to be challenging for a notable portion 30.7% (62) of the mothers, presenting a lot of problems in this area. Toileting shows a better competence level, with a majority indicating they do this well 45% (91) and face some difficulties 34.7% (70). Only a few participants, 16.3% (33) facing a lot of problem and do extremely well 4.0% (8). Walking shows a mixed response but leans towards competence, with 36.1% (73) reporting they do it well and 30.7% (62) have some difficulties, despite 22.3% (45) having a lot of problems, 10.9% (22) reporting extremely well. Maintaining balance while walking, this activity sees a relatively better competence level, with 40.6% (82) doing it well, 22.8% (46) face a lot of problems, though a similar proportion face some problems 22.3% (45) and 13.9% (28) doing extremely well. Climbing stairs is challenging for 27.2% (55) have a lot of problems and 24.3% (49) of respondents face some problem, yet 36.1% (73) manage it well and 12.4% (25) indicate extremely well competence in this activity. Driving shows a markedly lower level of reported competence, which might be due to the specific demands of driving or less frequent need/ability to drive. Most of the participants skip driving activity, only 4.5% (9) have some problem, 1.0% (2) perform extremely well. House cleaning task where a majority of mothers report having some problem 44.6% (90) and only a small portion 5.9% (12) can do extremely well. Laundry task where a majority of mothers report having a lot of problems 9.9% (20) and able to perform well 40.1% (81), despite a significant portion 44.6% (90) facing

difficulties. Grocery shopping appears to be notably challenging with a high percentage 37.1% (75) reporting problems and 40.6% (82) indicating some difficulties.

### 4.3 Individual responses of importance in daily living activities

**Table 4.3**

*Individual responses of importance*

<b>Importance of daily living</b>				
<b>Variable</b>	<b>This is not so important</b>	<b>This is important</b>	<b>This is more important</b>	<b>This is most important</b>
<b>Percentage (Frequency)</b>				
<b>% (n)</b>				
<b>Bathing</b>	13.4% (27)	48.0% (97)	34.7% (70)	4.0% (8)
<b>Dressing</b>	9.9% (20)	47.5% (96)	38.6% (78)	4.0% (8)
<b>Grooming (washing face, washing hands, brushing teeth, hair care, applying makeup)</b>	11.4% (23)	31.2% (63)	49.5% (100)	7.9% (16)
<b>Meal preparation</b>	13.4% (27)	36.1% (73)	36.6% (74)	13.9% (28)
<b>Toileting</b>	6.4% (13)	35.1% (71)	46.5% (94)	11.9% (24)
<b>Walking</b>	5.9% (12)	43.1% (87)	43.6% (88)	7.4% (15)
<b>Maintaining balance while walking</b>	7.4% (15)	43.6% (88)	43.1% (87)	5.9% (12)
<b>Climbing stairs</b>	10.9% (22)	43.1% (87)	41.1% (83)	5.0% (10)
<b>Driving</b>	97.0% (196)	2.0% (4)	1.0% (2)	0.0% (0)
<b>House Cleaning</b>	13.4% (27)	37.1% (75)	45.5% (92)	4.0% (8)
<b>Laundry</b>	13.4% (27)	39.6% (80)	42.1% (85)	5.0% (10)
<b>Grocery shopping</b>	51.5% (104)	33.2% (67)	12.4% (25)	3% (6)

The data provided outlines the perceived importance of various daily living activities among mothers of CWD. Each activity is categorized based on the respondent's perspective, ranging from "Not so important" to "Most important." The result shows that a significant portion 48.0% (97) of respondents bathing as important and 34.7% (70) respondents bathing as more important. Dressing is similarly valued, with 47.5%

(96) considering it as important and 38.6% (78) as more important. This emphasizes the acknowledgment of the role of clothing in maintaining personal dignity and appearance. Grooming activities are widely recognized as more important, with 49.5% (100) expressing their significance. Only 11.4% (23) considering it not so important. Meal preparation is viewed as important by 36.1% (73) and only 13.9% (28) as most important of respondents. While this is a crucial aspect of daily living, the varied responses indicate a spectrum of priorities in this area. Toileting is considered more important by 46.5% (94) and important by 35.1% (71) of respondents, highlighting the recognition of its fundamental role in maintaining personal comfort and health. Walking is valued as important by 43.1% (87) of respondents and as more important 43.6% (88) is emphasizing its importance for mobility in daily activities. The importance of maintaining balance while walking is recognized as important by 43.6% (88) and more important by 43.6% (87) of respondents, indicating an understanding of its impact on overall mobility and safety. Climbing stairs is perceived as important 43.1% (87) and more important by 43.1% (83) of respondents. The overwhelming majority 97.0% (197) view driving as not so important, underlining a potential consensus that driving may not be a critical daily living activity for this demographic. House cleaning is considered more important by 45.5% (92) of respondents and 37.1% (75) as important. Laundry is seen as important 39.6% (80) and more important by 42.1% (85) of respondents, indicating a recognition of its role in maintaining personal hygiene and cleanliness. The importance of grocery shopping by 51.5% (104) as it not so important and only 3% (6) respondents as most important the activity which indicating mothers of CWD face many challenges that influence their priorities and affect prioritize tasks like grocery shopping.

#### 4.4 Level of competence in daily living activities of the mothers of CWD.

**Table 4.4**

*The level of competence in daily living (n=202)*

Variable	Frequency (n)	Percentage (%)
Competence A lot of problems doing this	8	4.0
Some difficulty doing this	81	40.0
Do this well	105	52.0
Do this extremely well	8	4.0
Median (IQR)= 26.00 (21.00-30.00)		

This table shows four levels of competence in daily living among participants using Occupational Self-Assessment-Daily Living Scale (OSA-DLS). To determine the frequency distribution of competence on daily living, raw scores were converted to a scale of 0 to 100. Participants were then categorized based on their responses using a four-point Likert scale, ranging from "A lot of problems doing this" to "Do this extremely well". In this study the total sample size was 202. The score was Median (IQR) = 26.00 (21.00-30.00) which indicates high level of competence in daily living of participants. The result indicated that a majority of participants reported "well" in performing daily tasks, with 52.0% (105). However, a significant proportion of participants reported "Some difficulty" with 40.0% (81). Only a small percentage of participants reported "a lot of problems" with 4.0% (8) and performing tasks "extremely well" with 4.0% (8). These findings indicated higher competence levels among mothers in managing daily activities related with CWD.

#### 4.5 Level of importance in daily living activities of the mothers of CWD.

**Table 4.5**

*The level of importance in daily living (n=202)*

Variable	Frequency (n)	Percentage (%)
Importance		
This is not so important	3	1.5
This is important	67	33.2
This is more important	120	59.4
This is most important	12	5.9
Median (IQR)= 27.00 (23.00- 33.00)		

This table shows four levels of importance in daily living among participants using Occupational Self-Assessment-Daily Living Scale (OSA-DLS). To determine the frequency distribution of importance on daily living, raw scores were converted to a scale of 0 to 100. Participants were then categorized based on their responses using a four-point Likert scale, ranging from "This is not so important" to "This is most important". In this study the total sample size was 202. The score was Median (IQR) = 27.00 (23.00- 33.00) which indicates high level of importance in daily living of participants. The result indicated that a majority of participants reported "This is more important" in performing daily tasks, with 59.4% (120). However, a significant proportion of participants reported "This is important" with 33.2% (67). "This is most important" in performing daily tasks, with a frequency of 5.9% (12). Only a small percentage of participants reported " This is not so important " 1.5% (3). These findings indicated higher importance level among mothers in managing daily activities related with CWD.

#### 4.6 Associations between socio-demographic status and competence

**Table 4.6**

*Association of competence between educational level, age of child, diagnosis of child, number of CWD and monthly income (Kruskal wallis test).*

Variable	Category	Frequency (n=202)	Mean rank	df	P Value
Mother's age	16-23 years	58	98.01	3	.732
	24-31 years	71	100.08		
	32-39 years	64	104.02		
	40-47 years	9	117.28		
Educational level	Illiterate	12	103.25	5	.000
	Primary	46	86.00		
	Secondary	48	80.33		
	Higher secondary	25	115.96		
	Graduate	22	131.89		
	Postgraduate	49	115.34		
Mother's Occupation	Housewife	182	101.35	4	.377
	Employee	13	113.04		
	Business	3	79.83		
	Health Professional	1	49.00		
	Teacher	2	49.00		
Duration of Household chores	Less than 5 hours	125	102.40	2	.567
	5 to 10 hours	57	103.61		
	more than 10 hours	20	89.83		
Diagnosis of child	Cerebral Palsy	124	89.86	5	.001
	ASD	39	128.37		
	ADHD	23	115.04		
	Down Syndrome	5	85.60		
	Brain Injury	4	71.88		
	ID	4	97.38		
Number of CWD	1	191	103.06	2	.012
	2	9	54.83		
	3	2	132.88		
Spend hours with CWD	5 to 10 hours	23	117.02	2	.315
	10 to 12 hours	30	100.22		
	more than 12 hours	149	99.36		
Monthly income	1000-10,000	32	80.43	5	.004
	11,000-20,000	51	79.46		
	21,000-30,000	30	81.62		
	31,000-40,000	16	97.65		
	41,000-50,000	15	111.50		
	above 50,000	49	114.76		



## Association of competence with living area (Mann Whitney U test)

Variable	Category	n	Mann Whitney U test	Mean Rank	P Value
Living area	Urban	98	3501	84.74	.000
	Rural	108		116.08	

According to 95% confidential interval, statically significant when p-value < 0.05 and esthetically not significant when P value > 0.05. So there was no association between competence with mothers's age, occupation, Duration of household chores and spend hours with CWD because P value > 0.05.

There is a significant association between competence and educational level, age of child, diagnosis of child, number of CWD, monthly income and living area. To evaluate the differences in competence of mothers of CWD with educational level, age of child, diagnosis of child, number of CWD monthly income were tested using Kruskal Wallis Test. The test revealed insignificant association in educational level, here P=.000. The result indicate that competence is necessarily influenced by the formal education level of the mother. The distribution of educational levels ranged from illiterate to postgraduate, showing a broad spectrum of educational backgrounds among the participants.

The test revealed significant association in age of child here, P=.002. This association indicates that the competence of mothers may vary according to the developmental stage of their child, potentially reflecting the changing care demands and challenges as children grow.

The test revealed an insignificant association in diagnosis of child here, P=.001. This could indicate that the type of disability does directly impact the mother's

competence in providing care, or that mothers adapt differently across different types of disabilities.

There was an insignificant association regarding the number of CWD in the family. Whether mothers had one, two, or three CWD did significantly alter the perceived competence levels, here  $P=.012$ .

A significant association was found with monthly income, indicating that financial resources might play a role in the competence levels of mothers. This could be due to the ability to access better resources, support, and services with higher income levels. The test revealed significant association in monthly income ( $P=.004$ ).

There is a significant difference in Competency level between urban and rural mothers of CWD. To evaluate the difference between urban and rural mothers of CWD for competence level, Mann-Whitney U Test was utilized. The test revealed significant differences in the level of competence of Urban (Median = 2,  $n = 94$ ) and Rural (Median = 3,  $n = 108$ ),  $U = 3501$ ,  $z=4.263$ ,  $p=.000$ , Suggests that the living environment significantly impacts the competence of mothers in caring for their CWD. The higher competence level in rural mothers might reflect different community support structures, resilience levels, or access to resources compared to their urban counterparts.

#### 4.7 Associations between socio-demographic status and importance

**Table 4.7**

*Association of competence between educational level, age of child, diagnosis of child, number of CWD and monthly income (Kruskal wallis test).*

Variable	Category	Frequency (n=202)	Mean rank	df	P Value
Mother's age	16-23 years	58	97.84	3	.836
	24-31 years	71	100.15		
	32-39 years	64	105.58		
	40-47 years	9	106.67		
Educational level	Illiterate	12	96.42	5	.959
	Primary	46	102.28		
	Secondary	48	98.68		
	Higher secondary	25	106.96		
	Graduate	22	108.00		
	Postgraduate	49	99.07		
Mother's Occupation	Housewife	182	99.96	4	.468
	Employee	13	116.50		
	Business	3	68.00		
	Health Professional	1	130.00		
	Teacher	2	130.00		
Duration of Household chores	less than 5 hours	125	102.40	2	.522
	5 to 10 hours	57	103.61		
	more than 10 hours	20	89.83		
Diagnosis of child	Cerebral Palsy	124	99.01	5	.088
	ASD	39	112.22		
	ADHD	23	92.09		
	Down Syndrome	5	129.50		
	Brain Injury	4	60.13		
	ID	4	60.13		
Number of CWD	1	191	101.98	2	.735
	2	9	88.94		
	3	2	107.13		
Spend hours with CWD	5 to 10 hours	23	116.07	2	.309
	10 to 12 hours	30	103.48		
	more than 12 hours	149	98.85		
Monthly income	1000-10,000	32	95.36	1	.615
	11,000-20,000	51	106.84		
	21,000-30,000	30	90.18		
	31,000-40,000	16	102.00		
	41,000-50,000	15	97.82		
above 50,000	49	95.73			

Association of importance with living area (Mann Whitney U test)

<b>Variable</b>	<b>Category</b>	<b>n</b>	<b>Mann Whitney U test</b>	<b>Mean Rank</b>	<b>P Value</b>
Living area	Urban	98	5066.500	101.40	.979
	Rural	108		101.59	

According to 95% confidential interval, statically significant when p-value < 0.05 and esthetically not significant when P value > 0.05. So there was no association between socio-demographic status and importance because P value > 0.05.

## CHAPTER V: DISCUSSION

The cross-sectional study on the daily living of mothers of CWD provides valuable insights into their competence levels and perceived importance of managing daily activities. The findings indicate that a majority of the 202 participants demonstrated a high level of competence in performing daily tasks related to their children, with 52.0% (105) performing well. This suggests a commendable ability among these mothers to handle the challenges associated with caring for CWD. A remarkable portion of the participants 40.0% (81) encountered some difficulty in performing these daily tasks. This highlights the nuanced nature of the experiences faced by mothers, showcasing the need for a more comprehensive understanding of the challenges they navigate on a day-to-day basis. A small percentage of participants 4.0% (8) reported facing "a lot of problems," while another 4.0% (8) performed tasks "extremely well." These divergent experiences within the sample suggest a considerable variability in the mothers' abilities and underscore the importance of activities of daily living.

In terms of perceived importance, a majority of participants 59.4% (120) expressed that performing daily tasks related to their CWD was "more important." This underscores the significance attached to these responsibilities, reflecting a strong commitment among mothers to actively engage in the well-being of their children. Additionally, 33.2% (67) of participants considered these tasks "important" emphasizing a widespread recognition of the value associated with managing daily activities for CWD. Furthermore, 5.9% (12) regarded the tasks as "most important," showcasing a subset of mothers who prioritize these responsibilities to a higher

degree. Also a minimal percentage of participants 1.5% (3) reported that performing these tasks was "not so important". While this proportion is small, it signals the existence of diverse perspectives and priorities among the study participants. In conclusion, the study sheds light on the intricate dynamics of mothers' experiences in managing daily activities related to CWD. The varying levels of competence and differing perceptions of importance underscore the need for targeted interventions and support systems that acknowledge the individualized nature of these challenges. The findings contribute to the existing body of knowledge in understanding and addressing the unique needs of mothers in this specific caregiving context.

According to 95% confidential interval, statically significant when  $p\text{-value} < 0.05$  and esthetically not significant when  $P\text{ value} > 0.05$ . So there was no association between competence with mothers's age, occupation, Duration of household chores and spend hours with CWD because  $P\text{ value} > 0.05$ . There is a significant association between competence and educational level, age of child, diagnosis of child, number of CWD monthly income and living area.

According to Crowe & Michael (2011), require more care and supervision than children without disabilities. These mothers dedicate the majority of their time to their children and devote less time to other activities. The majority of mothers have found it difficult to maintain their productive work because they spend so much time caring for their children. Their professional and personal lives are both burdened and difficult. They don't have enough time or scope to properly maintain their work (Crowe & Michael, 2011).

These mothers face difficulties to engage in their leisure activities. The main barrier of leisure activities is time restriction. These mothers don't have time for

themselves. They have limited their leisure participation due to a feeling of restriction in time for their workload (Cantero-Garlito et al., 2020).

One study's findings showed that, compared to mothers of CP children with elementary education, mothers of CP children with secondary education had a statistically substantially worse quality of life, only in the area of familial relationships ( $p=0.006$ ). Another study found opposite, suggesting that a mother's level of education affects her children's quality of life if the child has cerebral palsy. In contrast to the group of mothers whose children could move independently, the quality of life related to the health of mothers of children with cerebral palsy whose children did not move, in their own assessment, was statistically significantly worse ( $p=0.038$ ) only in the area of social functioning. Additionally, Keller and Honig indicate that a child's impairment lowers the mother's social involvement (Glinac et al. 2017).

Most of the mothers of CWD can't maintain their daily living activities properly due to extensive care responsibilities to their family and CWD. And for the working mothers, it's so difficult to maintain their daily life (McAuliffe et al., 2018).

## CHAPTER VI: CONCLUSION

### 6.1 Strengths and limitations

#### 6.1.1 *Strength of the study*

- OSA-DLS culturally validated; author permitted to use the tool.
- Researcher used forward and backward Bengali translated questionnaire in order to align it with cultural context and did a field test for validity and reliability.
- To ensure the quality of data, data life cycle management had been followed. The data collection process and data entry process was non-biased.
- Data was collected in face-to-face survey method and stored in the personal laptop which was highly secured.
- Ethical approval for the study was granted by the Institutional Review Board IRB, BHPI.
- The researcher followed the proper method to achieve the aim and objectives.
- Maximum participants were co-operative when information were taken from them.
- For data safety and validation, all the data used in this study will be destroyed.



### ***6.1.2 Limitations of the study***

All research has certain limits that are outside the researcher's control. Limitations are a type of issue that can arise at any point during the study's conduct and construction ("Research guides," 2021). There are some limitations of the study. They are,

- The study was not time effective. The sample size was 423, but the researcher collected 202 data due to the time limit of data collection duration.
- Some participants were not comfortable to share their information.
- The researcher was used only these online databases Google Scholar, Google Web page, PubMed, as others online databases weren't possible to access from this country.
- There would be any mistakes due to little experience of student researcher.

## **6.2 Practice Implication**

### ***6.2.1 Recommendation for the future practice***

- Establishing a consistent daily routine can provide stability for both the mother and her child.
- Explore respite care options to provide the mother with occasional breaks.
- Formation of support networks within the community for mothers of CWD to share experiences and increase awareness.
- Motivating mothers to fulfill their own daily life tasks such as- self care and recreation activities.

### ***6.2.2 Research Recommendation for Further Research***

Some research recommendations are as follows:

- Further research identify the stress level of mothers of CWD.
- Further research includes the perspectives and experiences of fathers of CWD.
- Find out the impact on other family members of CWD.
- Explore the life satisfaction of the mothers of CWD.
- Identify the maternal depression among parents of CWD.

### **6.3 Conclusion**

The purpose of the study was to find out the level of competence and importance in daily living activities of the mothers of CWD. The study contributes to our understanding of the socio-demographic characteristic and current situation of the population. The study has found that the level of competence and importance of daily living is high. This findings of the study show that the mothers of the CWD face challenges to maintain time for their own self-care, productive works and leisure. They have to spend a lot of time to look after their children. The study is important for the Occupational therapist to work with mothers having CWD. The Occupational therapist could provide recommendations and education to the mothers on basic care requirements which will help the children's own self-care. Occupational therapist could also promote the mothers' coping strategies in managing with CWD.

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## APPENDICES

### Appendix A: Approval Letter and Permission Letter

#### IRB Approval Letter



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

Date: 18-10-2023

Ref: CRP-BHPI/IRB/10/2023/719

To  
 Jannatul Ferdous Jerin  
 4<sup>th</sup> Year B.Sc. in Occupational Therapy  
 Session: 2018-2019; Student ID: 122180336  
 Department of Occupational Therapy  
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Subject:** Approval of the thesis proposal "A Cross-Sectional Study on Daily Living of Mothers of Children with Disability" by ethics committee.


Dear Jannatul Ferdous Jerin,  
 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 Sk.Moniruzzaman & Monika Singha as thesis supervisor. The Following documents have been reviewed and approved:

Sr. No.	Name of the Documents
1	Dissertation/thesis/research Proposal
2	Questionnaire (English & / or Bengali version)
3	Information sheet & consent form.

The purpose of the study is to measure the level of performance in daily living activities of the mothers after having child with disability. The study involves use of Standardized scales (Occupational Self Assessment-Daily Living Scales (OSA-DLS)) to measure the level of performance in daily living activities about 10 to 15 minutes to fill in the questionnaire for collection of specimen 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 23<sup>rd</sup> September 2023 at BHPI 38<sup>th</sup> 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 Milat Hossain**  
 Associate Professor  
 Project & Course Coordinator  
 Dept. of Rehabilitation Science  
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Member Secretary  
 Institutional Review Board  
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh.

সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ। ফোন: +৮৮ ০২ ২২৪৪৪৫৪৬৪-৫, +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: 19.10.2023

To

The Head of the Pediatric Department  
Centre for the Rehabilitation of the Paralysed (CRP)  
Savar, Dhaka-1343, Bangladesh

Subject: **Application for permission to collect data for the research project.**

Sir,

With due respect, I would like to draw your kind attention that I am a 4<sup>th</sup> year student of B.Sc. in Occupational Therapy at Bangladesh Health Professionals Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfilment of the degree of Bachelor of Science in Occupational Therapy. My research title is "A Cross-Sectional Study on Daily Living of Mothers of Children With Disability". The aim of this study is study to assess the level of performance in daily living activities of the mothers after having child with disability. As it is a cross sectional study, Quantitative research, I would like to take interviews with mothers of children with disability at CRP, Savar. That is why I need permission to start my research project. I assure you that anything of my project will not be harmful for the participants, and any data collected will be kept confidential.

So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,

*Jerin*  
Jannatul Ferdous Jerin  
4<sup>th</sup> Year B.Sc. in Occupational Therapy  
Session: 2018-2019, Student ID: 122180336  
Bangladesh Health Professions Institute (BHPI)  
CRP-Savar, Dhaka-1343, Bangladesh

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

*Thanks  
sk  
22-10-23*

**Signature and comments of The Head of The Department**

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

**Mosneera Perveer**  
Head of Department  
Department of Paediatrics  
CRP, Savar, Dhaka

Date: 19.10.2023

To

The Head of the Pediatric Department  
Centre for the Rehabilitation of the Paralysed (CRP)  
Mirpur, Dhaka-1343, Bangladesh

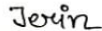
Subject: **Application for permission to collect data for the research project.**

Sir,

With due respect, I would like to draw your kind attention that I am a 4<sup>th</sup> year student of B.Sc. in Occupational Therapy at Bangladesh Health Professions Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfilment of the degree of Bachelor of Science in Occupational Therapy. My research title is "**A Cross-Sectional Study on Daily Living of Mothers of Children With Disability**". The aim of this study is study to assess the level of performance in daily living activities of the mothers after having child with disability. As it is a cross sectional study, Quantitative research, I would like to take interviews with mothers of children with disability at CRP, Mirpur. That is why I need permission to start my research project. I assure you that anything of my project will not be harmful for the participants, and any data collected will be kept confidential.

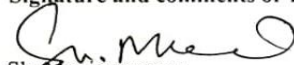
So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,



Jannatul Ferdous Jerin  
4<sup>th</sup> Year B.Sc. in Occupational Therapy  
Session: 2018-2019, Student ID: 122180336  
Bangladesh Health Professions Institute (BHPI)  
CRP-Savar, Dhaka-1343, Bangladesh

**Signature and comments of The Head of The Department**



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

To

Principal

Prottasha Center for Autism Care

Dogormora, CRP road, Savar, Dhaka.

**Subject: Application for permission to collect data for the research project.**

Sir,

With due respect, I would like to draw your kind attention that I am a 4<sup>th</sup> year student of B.Sc. in Occupational Therapy at Bangladesh Health Professionals Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfilment of the degree of Bachelor of Science in Occupational Therapy. My research title is "**A Cross-Sectional Study on Daily Living of Mothers of Children With Disability**". The aim of this study is study to assess the level of performance in daily living activities of the mothers after having child with disability. As it is a cross sectional study, Quantitative research, I would like to take interviews with mothers of children with disability at Prottasha Center For Autism Care, Dogormora, Savar. That is why I need permission to start my research project. I assure you that anything of my project will not be harmful for the participants, and any data collected will be kept confidential.

So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,

*Jerin*

Jannatul Ferdous Jerin  
4<sup>th</sup> Year B.Sc. in Occupational Therapy  
Session: 2018-2019, Student ID: 122180336  
Bangladesh Health Professions Institute (BHPI)  
CRP-Savar, Dhaka-1343, Bangladesh

**Signature and comments of The Head of The Department**

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

*Principal*  
Principal 22.10.2023  
Prottasha Centre for Autism Care  
CRP Road, Savar, Dhaka.

Date: 19.10.2023  
To  
The chairperson  
Ingenious Care Limited.  
Pallabi, Mirpur, Dhaka

Subject: **Application for permission to collect data for the research project.**

Sir,

With due respect, I would like to draw your kind attention that I am a 4<sup>th</sup> year student of B.Sc. in Occupational Therapy at Bangladesh Health Professionals Institute (BHPI). I have to submit a research paper to the University of Dhaka in partial fulfilment of the degree of Bachelor of Science in Occupational Therapy. My research title is "**A Cross-Sectional Study on Daily Living of Mothers of Children With Disability**". The aim of this study is study to assess the level of performance in daily living activities of the mothers after having child with disability. As it is a cross sectional study, Quantitative research, I would like to take interviews with mothers of children with disability at Ingenious Care Limited, Pallabi, Mirpur, Dhaka. That is why I need permission to start my research project. I assure you that anything of my project will not be harmful for the participants, and any data collected will be kept confidential.

So, I look forward to having your permission to start data collection to conduct a successful study as a part of my course.

Sincerely yours,

*Jerin*

Jannatul Ferdous Jerin  
4<sup>th</sup> Year B.Sc. in Occupational Therapy  
Session: 2018-2019, Student ID: 122180336  
Bangladesh Health Professions Institute (BHPI)  
CRP-Savar, Dhaka-1343, Bangladesh

**Signature and comments of The Head of The Department**

*Sk. Moniruzzaman*

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

*Approved*  
*7/12/23*

**Appendix B: Information Sheet, Consent form, Withdrawal Form  
(English Version)**

**Bangladesh Health Professions Institute (BHPI)**

**Occupational Therapy Unit**

**CRP, Savar, Dhaka-1343**

**Information Sheet**

**Research Title:** Level of Competence & Importance in Daily Living of Mothers of Children with Disability : A Cross-Sectional Study.

**Name of researcher:** Jannatul Ferdous Jerin, 4<sup>th</sup> year, B.Sc. in Occupational Therapy.

**Supervisor:** Sk.Moniruzzaman, Associate Professor & Head of the Department ,Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka & Monika Singha, Lecturer, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI),CRP, Savar,Dhaka.

Me, Jannatul Ferdous Jerin, want to invite you to participate in research study. Before deciding to participate, it is crucial that you understand the purpose of the study, what will be asked of you, and how you are related to it. Please read the information below and feel free to ask any questions that you may have.

**Who am I and what is this study about:**

I am Jannatul Ferdous Jerin , a student of 4th year, B. Sc in Occupational Therapy, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). As a part of my academic course curriculum, I am obliged to conduct a dissertation this academic year. The title of my research is " A Cross-Sectional Study on Daily Living of Mothers of Children With Disability". The aim of this study is to

find out the level of performance in daily living activities of the mothers after having child with disability.

**What to do to participate in the study?**

I will be measuring the level of performance in daily living activities of mothers of children with disability with their socio-demographic factors. For which I will use OSA-DLS. Also sociodemographic data will be collected by using a self-developed questionnaire. Participants will be answering all the questions. Time taken will be taken for 10-15 minutes.

**Why are you invited to participate in this study?**

Participants who are willing and meets the inclusion criteria of the study are invited to participate.

**Do you have to participate?**

Participation in the study is entirely voluntary and consent will be taken. After participating, they will be accounted to answer all the questions. You have the right to withdraw your consent and discontinue participation after two weeks of conducting survey without any repercussions.

**What are the possible risks and benefits of participation?**

The participant will not get any direct benefit for participating in this research, however the information gained from this research will be contributed for future development and improvement of rehabilitation services. Participants will not face any type of problem or harm, participating in the research but can feel psychological discomfort while sharing their tough experience. If this problem arises during the

interview the research will take a break or discuss re-scheduling the interview. Participants can also withdraw their consent according to their wish.

**Will the participation be confidential?**

All information collected during this study will be strictly kept confidential by maintaining secrecy. No information will be shared with anyone else outside of the study unless it is required by the law. Only the researcher and supervisor are allowed to access the data here. The participants will not be named in any reports, publications, or presentations that may come from this study. Information paper will be locked in a drawer, in the personal laptop of the researcher and lock cloud system.

**What will be the result of the study?**

The findings of this research will help the health professionals to better understand the level of performance in daily living activities of the mothers after having children with disability and will also explain their experiences and challenges. The findings will also help direct Occupational therapist to also consider the mothers in providing treatment to the children with disability. The results will help the Department of Occupational Therapy by studying the experiences of mothers, can promoting a more holistic and patient-centered approach to therapy. My research can contribute to the academic understanding of this topic potentially leading to further studies and advancements in the field of disability studies and family support considering their socio-demographic factors for ultimately improving the quality of rehabilitation outcome in a holistic way. The result of the study may be published in a scientific journal.

**Promotional result:** The results of this research will be published and presented through print media, electronic/ social media, conferences and criticism.

**For more information, please contact the address below**

**Student researcher: Jannatul Ferdous Jerin**

B.Sc. in Occupational Therapy

Session: 2018-19, Roll: 39

BHPI, CRP, Savar, Dhaka.

Contact number: 01939201041

Email: [jarinjannatul66@gmail.com](mailto:jarinjannatul66@gmail.com)

**Supervisor:**

Sk.Moniruzzaman,

Associate Professor & Head of the Department

Department of Occupational Therapy

BHPI, CRP, Savar, Dhaka.

Contact number: 01716-358212

E-mail: [sk.moniruzzamam@crp-bangladesh.org](mailto:sk.moniruzzamam@crp-bangladesh.org)

&

Monika Singha

Lecturer

Department of Occupational Therapy

BHPI, CRP, Savar, Dhaka.

Contact number: 01997-631361

E-mail: [monikamoni.ot.edu@gmail.com](mailto:monikamoni.ot.edu@gmail.com)



### Consent Form

I am Jannatul Ferdous Jerin, continuing B.Sc. in Occupational Therapy, Bangladesh Health Professions Institute under the Medicine Faculty of Dhaka University, an academic institute of Centre for the Rehabilitation of the Paralyzed. As a part of B.Sc. course curriculum, I'm going to conduct a research activity which is supervised by, Sk. Moniruzzaman, Associate Professor & Head of the Department, Department of Occupational Therapy, Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka. & Monika Singha, Lecturer, Department of Occupational Therapy, BHPI, CRP, Savar, Dhaka. The title of the research is "Level of Competence & Importance in Daily Living of Mothers of Children with Disability : A Cross-Sectional Study."

The aim of this study to find out the level of performance in daily living activities of the mothers after having child with disability.

Please read the following statements and put tick (✓) on yes or no to say that you understand the content of the information sheet, your involvement, and that you agree to take part in the abovenamed study.

I confirm that I have read and understood the participant information sheet for the study or that it has been explained to me and I have had the opportunity to ask questions \_\_\_\_\_ Yes/No

I have satisfactory answers to my questions regarding this study.  
\_\_\_\_\_ Yes/No

I understand that participation in the study is voluntary and that I am free to end my involvement till November, or request that the data collected in the study be destroyed without giving a reason. \_\_\_\_\_ Yes/No

However, all personal details will be treated as highly confidential. I have permitted the investigator and supervisor to access my recorded information.

\_\_\_\_\_ Yes/No

I have sufficient time to come to my decision about participation

\_\_\_\_\_ Yes/No

I agree to take part in the above study. \_\_\_\_\_ Yes/No

Participant's signature \_\_\_\_\_ Date \_\_\_\_\_

### **Withdrawal form**

Title of the research: "A Cross-Sectional Study on Daily Living of Mothers of Children With Disability".

I \_\_\_\_\_, confirm that I wish to withdraw my consent to the use of data arising from my participation.

Reason for withdrawal:

Name of the participant \_\_\_\_\_

Signature of participant \_\_\_\_\_

Date \_\_\_\_\_

## Appendix B: Information Sheet, Consent form, Withdrawal From (Bangla Version)

বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই)

অকুপেশনাল থেরাপি বিভাগ

সিআরপি, চাপাইন, সাভার, ঢাকা-১৩৪

### তথ্যপত্র

**গবেষণার শিরোনাম:** প্রতিবন্ধী শিশুদের মায়েদের দৈনন্দিন জীবনযাপনের উপর একটি ক্রস-সেকশনাল গবেষণা।

**গবেষকের নাম:** জান্নাতুল ফেরদৌস জেরিন, ৪র্থ বর্ষ, বি.এসসি.অকুপেশনাল থেরাপি।

**সুপারভাইজার:** শেখ মনিরুজ্জামান, সহযোগী অধ্যাপক ও বিভাগীয় প্রধান, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সিআরপি, সাভার, ঢাকা। এবং মনিকা সিংহ, প্রভাষক, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), সিআরপি, সাভার, ঢাকা। আমি জান্নাতুল ফেরদৌস জেরিন, আপনাকে একটি গবেষণায় অংশগ্রহণের জন্য আমন্ত্রণ জানাতে চাই। অংশগ্রহণ করার সিদ্ধান্ত নেওয়ার আগে আপনার এই গবেষণার উদ্দেশ্য, আপনাকে কী জিজ্ঞাসা করা হবে এবং আপনি কীভাবে এর সাথে সম্পর্কিত তা জানা খুবই গুরুত্বপূর্ণ। নীচের তথ্যগুলো পড়ুন এবং কোনো বিষয়ে জানার থাকলে নির্দিধায় যে কোনো প্রশ্ন জিজ্ঞাসা করুন।

**আমি কে এবং এই গবেষণাটা কী সম্পর্কে:**

আমি জান্নাতুল ফেরদৌস জেরিন, ৪র্থ বর্ষের একজন ছাত্রী, বি.এসসি ইন অকুপেশনাল থেরাপি। বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই), দ্য একাডেমিক ইনস্টিটিউট অফ সেন্টার ফর দ্য রিহেবিলিটেশন অফ দ্য প্যারালাইজড (সিআরপি)। আমার একাডেমিক কোর্স পাঠ্যক্রমের একটি অংশ হিসাবে, আমি এই শিক্ষাবর্ষে একটি গবেষণামূলক প্রবন্ধ পরিচালনা করতে যাচ্ছি। আমার গবেষণার শিরোনাম হল " প্রতিবন্ধী শিশুদের মায়েদের দৈনিক জীবনযাপনের উপর একটি ক্রস-সেকশনাল গবেষণা।" এই গবেষণার লক্ষ্য হল প্রতিবন্ধী শিশুর মায়েদের দৈনন্দিন জীবনযাত্রার কর্মক্ষমতার মূল্যায়ন করা।

**গবেষণায় অংশগ্রহণের জন্য কী করতে হবে?**

আমি প্রতিবন্ধী শিশুদের মায়েদের দৈনন্দিন জীবনযাত্রায় কর্মক্ষমতার লেভেল এবং তাদের সামাজিক-জনসংখ্যাগত কারণগুলির সাথে পরিমাপ করবো। যার জন্য আমি “অকুপেশনাল সেলফ অ্যাসেসমেন্ট-

ডেইলি লিভিং স্কেল ব্যবহার করতে যাচ্ছি। এছাড়াও নিজের তৈরি কিছু প্রশ্নাবলী ব্যবহার করে সামাজিক- জনসংখ্যা সংক্রান্ত তথ্য সংগ্রহ করা হবে। অংশগ্রহণকারীরা সব প্রশ্নের উত্তর দিতে হবে যার জন্য ১০-১৫ মিনিট সময় নেওয়া হবে।

### আপনাকে কি অংশগ্রহণ করতে হবে?

গবেষণায় অংশগ্রহণ সম্পূর্ণরূপে স্বেচ্ছায় এবং আপনার সম্মতি নিয়ে করা হবে। অংশগ্রহণের পরে, তাদের সমস্ত প্রশ্নের উত্তর দেওয়ার জন্য হিসাব করা হবে। আপনার সম্মতি প্রত্যাহার করার এবং কোনও প্রতিক্রিয়া ছাড়াই জরিপ পরিচালনার দুই সপ্তাহ পরে অংশগ্রহণ বন্ধ করার অধিকার রয়েছে।

### অংশগ্রহণের সম্ভাব্য ঝুঁকি এবং সুবিধাগুলি কী কী?

অংশগ্রহণকারী এই গবেষণায় অংশগ্রহণের জন্য সরাসরি কোনো সুবিধা পাবেন না, তবে এই গবেষণা থেকে প্রাপ্ত তথ্য ভবিষ্যতের উন্নয়ন এবং পুনর্বাসন সেবার উন্নতির জন্য অবদান রাখা হবে। অংশগ্রহণকারীরা গবেষণায় অংশগ্রহণ করে কোনো ধরনের সমস্যা বা ক্ষতির সম্মুখীন হবে না কিন্তু তাদের কঠিন অভিজ্ঞতা শেয়ার করার সময় মানসিক অস্বস্তি অনুভব করতে পারে। সাক্ষাৎকারের সময় যদি এই সমস্যাটি দেখা দেয় তবে শিক্ষার্থীর গবেষণায় একটি বিরতি নেবে বা ইন্টারভিউ নিয়ে পুনরায় সময়সূচী ঠিক করে আলোচনা করবে। অংশগ্রহণকারীরা তাদের ইচ্ছা অনুযায়ী তাদের সম্মতি প্রত্যাহার করতে পারবেন।

### অংশগ্রহণের গোপনীয়তা কিভাবে নিশ্চিত হবে?

এই গবেষণার সময় সংগৃহীত সমস্ত তথ্য গোপনীয়তা বজায় রাখা হবে। আইনের প্রয়োজন না হলে অধ্যয়নের বাইরে অন্য কারো সাথে কোনো তথ্য শেয়ার করা হবে না। শুধুমাত্র গবেষক এবং সুপারভাইজারের কাছে সকল তথ্য সংরক্ষিত থাকবে। এই গবেষণা থেকে আসা কোনো প্রতিবেদন, প্রকাশনা বা উপস্থাপনায় অংশগ্রহণকারীদের নাম দেওয়া হবে না। তথ্য কাগজ একটি ড্রয়ারে লক করা হবে, গবেষকের ব্যক্তিগত ল্যাপটপে এবং লক ক্লাউড সিস্টেমে।

### গবেষণার ফলাফল কী হবে?

অকুপেশনাল থেরাপিস্টকে প্রতিবন্ধী শিশুদের চিকিৎসা দেওয়ার ক্ষেত্রে মায়েদেরও বিবেচনা করতে সহায়তা করবে। ফলাফলগুলি মায়েদের অভিজ্ঞতা জেনে অকুপেশনাল থেরাপি বিভাগকে সাহায্য করবে, থেরাপির জন্য আরও সামগ্রিক এবং রোগী-কেন্দ্রিক পদ্ধতির প্রচার করতে পারবে। আমার গবেষণা অকুপেশনাল থেরাপির একাডেমিক বিভাগেও অবদান রাখতে পারে, ভবিষ্যতে এই বিষয়ে আরো ব্যাপকভাবে জানার জন্য এবং বিস্তৃতভাবে পরিচালিত করতে এবং সামগ্রিক উপায়ে পুনর্বাসন ফলাফলের গুণমান উন্নত করার জন্য তাদের সামাজিক-জনসংখ্যাগত কারণ বিবেচনা করতে পারবে। গবেষণার ফলাফল একটি বৈজ্ঞানিক জার্নালে প্রকাশিত হতে পারে।

**প্রচারমূলক ফলাফল:**

এই গবেষণার ফলাফল প্রিন্ট মিডিয়া, সোশ্যাল মিডিয়া, সম্মেলন এবং সমালোচনার মাধ্যমে প্রকাশ ও উপস্থাপন করা হবে।

আরও তথ্যের জন্য নিচের ঠিকানায় যোগাযোগ করুন।

**ছাত্রী গবেষক: জান্নাতুল ফেরদৌস জেরিন**

বি.এসসি. ইন অকুপেশনাল থেরাপি

সেশন:২০১৮-১৯, রোল:৩৯

বিএইচপিআই, সিআরপি, সাভার, ঢাকা।

যোগাযোগের নম্বর: 01639201041

ইমেইল: [jarinjannatul66@gmail.com](mailto:jarinjannatul66@gmail.com)

**সুপারভাইজার: শেখ মনিরুজ্জামান**

সহযোগী অধ্যাপক ও বিভাগীয় প্রধান

অকুপেশনাল থেরাপি বিভাগ

বিএইচপিআই, সিআরপি, সাভার, ঢাকা।

যোগাযোগের নম্বর: 01716-358212

ই-মেইল: [sk.moniruzzamam@crp-bangladesh.org](mailto:sk.moniruzzamam@crp-bangladesh.org)

**সহ-সুপারভাইজার: মনিকা সিংহ**

প্রভাষক অকুপেশনাল থেরাপি বিভাগ

বিএইচপিআই, সিআরপি, সাভার, ঢাকা।

যোগাযোগ নম্বর: 01997-631361

ই-মেইল: [monikamoni.ot.edu@gmail.com](mailto:monikamoni.ot.edu@gmail.com)

### সম্মতিপত্র

আমি জান্নাতুল ফেরদৌস জেরিন, বি.এস.সি. ইন অকুপেশনাল থেরাপিতে, ঢাকা বিশ্ববিদ্যালয়ের মেডিসিন অনুষদের অধীনে বাংলাদেশ হেলথ প্রফেশনস ইনস্টিটিউটে অধ্যয়নরত আছি, যেটি সিআরপির একটি একাডেমিক ইনস্টিটিউট। বি.এস.সি কোর্স পাঠ্যক্রম এর অংশ হিসেবে, আমি একটি গবেষণা কার্যক্রম পরিচালনা করতে যাচ্ছি যেটির তত্ত্বাবধানে আছেন শেখ মনিরুজ্জামান, সহযোগী অধ্যাপক ও বিভাগীয় প্রধান, অকুপেশনাল থেরাপি বিভাগ, বিএইচপিআই, সিআরপি, সাভার, ঢাকা। এবং মনিকা সিংহ, প্রভাষক, অকুপেশনাল থেরাপি বিভাগ, বিএইচপিআই, সিআরপি, সাভার, ঢাকা। গবেষণার শিরোনাম “প্রতিবন্ধী শিশুদের মায়েদের দৈনন্দিন জীবনযাপনের উপর একটি ক্রস-সেকশনাল গবেষণা।” এই গবেষণার লক্ষ্য হল প্রতিবন্ধী শিশুর মায়েদের দৈনন্দিন জীবনযাত্রার কর্মক্ষমতার মূল্যায়ন করা।

অনুগ্রহ করে নিম্নলিখিত বিবৃতিগুলি পড়ুন এবং হ্যাঁ বা না-তে টিক (✓) বসিয়ে বলুন যে আপনি তথ্য পত্রের বিষয়বস্তু বুঝতে পেরেছেন কিনা, আপনার সম্পৃক্ততা, এবং আপনি উপরোক্ত গবেষণায় অংশ নিতে সম্মত কিনা।

আমি নিশ্চিত করি যে আমি গবেষণার জন্য অংশগ্রহণকারীদের তথ্য পত্রটি পড়েছি এবং বুঝেছি বা এটি আমাকে ব্যাখ্যা করা হয়েছে এবং আমি প্রশ্ন জিজ্ঞাসা করার সুযোগ পেয়েছি। \_\_\_\_\_ হ্যাঁ/না

এই গবেষণা সংক্রান্ত আমার প্রশ্নের সন্তোষজনক উত্তর আছে। \_\_\_\_\_ হ্যাঁ/না

আমি বুঝিতে পেরেছি যে এই গবেষণায় অংশগ্রহণ সম্পূর্ণ স্বেচ্ছাসেবী এবং আমি নভেম্বর পর্যন্ত আমার সম্পৃক্ততা শেষ করতে পারবো। \_\_\_\_\_ হ্যাঁ/না

সমস্ত ব্যক্তিগত বিবরণ অত্যন্ত গোপনীয় হিসাবে বিবেচিত হবে। আমি গবেষককে এবং সুপারভাইজারকে আমার তথ্য রাখার অনুমতি দিয়েছি। \_\_\_\_\_ হ্যাঁ/না

অংশগ্রহণের বিষয়ে সিদ্ধান্ত নেওয়ার জন্য আমার কাছে যথেষ্ট সময় আছে। \_\_\_\_\_ হ্যাঁ/না

আমি গবেষণায় অংশ নিতে সম্মত। \_\_\_\_\_ হ্যাঁ/না

অংশগ্রহণকারীর

স্বাক্ষর \_\_\_\_\_ তারিখ \_\_\_\_\_

প্রত্যাহার ফর্ম

গবেষণার শিরোনাম: প্রতিবন্ধী শিশুদের মায়েদের দৈনন্দিন জীবনযাপনের উপর একটি ক্রস-সেকশনাল গবেষণা।

গবেষকের নাম: জাম্নাতুল ফেরদৌস জেরিন, ৪র্থ বর্ষ, বি.এসসি. অকুপেশনাল থেরাপি, রোল-৩৯

আমি \_\_\_\_\_ নিশ্চিত করছি যে আমি এই গবেষণায় আমার অংশগ্রহণ প্রত্যাহার করতে চাই।

অংশগ্রহণকারীর নাম :

প্রত্যাহারের কারণ:

অংশগ্রহণকারীর স্বাক্ষর/ আঙ্গুলের ছাপ :

## Appendix C: Questionnaire

(English)

### Socio-demographic variable:

- Mother's Age:
- Religion: 1) Muslim 2) Hindu 3) Buddhism 4) Christianity
- What area do you live in? 1)Urban 2) Rural
- Are you live with your family? 1)Yes 2) No
- Educational level: 1) Illiterate 2) Primary 3) Secondary 4) Higher Secondary  
5) Graduate 6) Post Graduate
- Mother's occupation:1) Housewife 2) Employee 3) Business 4) Health professional 5) Teacher
- Are suffering any disease for a long time? 1)Yes 2) No
- How many hours do you sleep every day? 1) 8 hours or less 2) more than 8 hours
- How many hours do you do household every day? 1)Less than 5 hours 2) 5 to 10 hours 3) more than 10 hours
- Age of the children with disability:
- Gender of the child: 1) male 2) female
- Diagnosis of your child-1) Cerebral Palsy 2) ASD 3) ADHD 4) Spinal Cord Injury 5) Spina Bifida 6)Down Syndrome 7)Muscular Dystrophy 8) Brain Injury 9) ID  
10) Others
- Number of disable child: 1)1 2)2 3)3 4)4
- How many hours do you spend with your child? 1)5 to 10 hours 2)10 to 12 hours 3)more than 12 hours
- Monthly income of your family:
  - [ ]1000-10,000/-
  - [ ]11,000-20,000/-
  - [ ]21,000-30,000/-
  - [ ]31,000-40,000/-
  - [ ]41,000-50,000/-
  - [ ]Above 50,000/-





## Appendix C: Questionnaire (Bangla Version)

### সামাজিক-জনসংখ্যা সংক্রান্ত তথ্য-

- মায়ের বয়স:
- ধর্মঃ ১) মুসলিম ২)হিন্দু ৩)বৌদ্ধ ৪)খ্রিস্টান
- আপনি কোন এলাকায় থাকেন? ১)গ্রামীন ২)শহর
- আপনি কি পরিবারের সাথে থাকেন? ১)হ্যাঁ ২)না
- শিক্ষাগত যোগ্যতাঃ ১)নিরক্ষরতা ২)প্রাইমারি ৩)মাধ্যমিক ৪)উচ্চমাধ্যমিক ৫)স্নাতক ৬)স্নাতকোত্তর
- মায়ের পেশাঃ ১)গৃহিনী ২)চাকুরি ৩)ব্যবসা ৪)চিকিৎসাসেবা ৫)শিক্ষকতা
- আপনি কি কোন দীর্ঘস্থায়ী রোগে ভোগছেন? ১)হ্যাঁ ২)না
- প্রতিদিন আপনি কত ঘন্টা ঘুমান? ১) ৮ ঘন্টা বা তার কম ২) ৮ ঘন্টা বা তার বেশি
- দৈনিক কত ঘন্টা গৃহস্থালির কাজকর্ম করেন?- ১) ৫ ঘন্টার কম ২) ৫ থেকে ১০ ঘন্টা ৩) ১০ ঘন্টার বেশি
- প্রতিবন্ধী বাচ্চার বয়সঃ
- প্রতিবন্ধী সন্তানের লিঙ্গঃ ১)ছেলে ২)মেয়ে
- আপনার সন্তানের প্রতিবন্ধকতার ধরনঃ ১) সেরেব্রাল পালসি ২) অটিজম স্পেকট্রাম ডিজঅর্ডার ৩) অ্যাটেনশন ডেফিসিট হাইপার অ্যাক্টিভিটি ডিজঅর্ডার ৪) স্পাইনাল কর্ড ইনজুরি ৫) স্পাইনা বাইফিডা ৬) ডাউন সিনড্রোম ৭) মাস্কুলার ডিসট্রফি ৮) ব্রেইন ইনজুরি ৯) বুদ্ধিগত প্রতিবন্ধকতা ১০) অন্যান্য
- প্রতিবন্ধী সন্তানের সংখ্যাঃ ১/২/৩/৪
- প্রতিবন্ধকতার স্বীকার বাচ্চার সাথে আপনি দৈনিক কত ঘন্টা সময় ব্যয় করেন? ১) ৫ থেকে ১০ ঘন্টা ২) ১০ থেকে ১২ ঘন্টা ৩) ১২ ঘন্টার বেশি
- সংসারের মাসিক আয়ঃ
  - (১) ১০০০/-থেকে ১০,০০০/-
  - (২) ১১,০০০/- থেকে ২০,০০০/-
  - (৩) ২১,০০০/- থেকে ৩০,০০০/-
  - (৪) ৩১,০০০/- থেকে ৪০,০০০/-
  - (৫) ৪১,০০০/- থেকে ৫০,০০০/-
  - (৬) ৫০,০০০/- এর উর্ধ্ব

### Occupational Self Assessment–Daily Living Scales (OSA-DLS)-বাংলা ভার্সন

অনেক বেশি সমস্যা= ১	তেমন গুরুত্বপূর্ণ নয়=১
কিছু সমস্যা=২	গুরুত্বপূর্ণ =২
ভালো=৩	অনেক গুরুত্বপূর্ণ =৩
অত্যন্ত ভালো=৪	অত্যন্ত গুরুত্বপূর্ণ =৪



## Appendix D: Permission letter for use tool

### **PERMISSION TO USE (PTU)**

**Requester:** Jannatul Ferdous Jerin  
 Bangladesh Health Professions Institute (BHPI)  
 Savar, Dhaka-1343, Bangladesh  
[jariniannatul66@gmail.com](mailto:jariniannatul66@gmail.com)

**Signing Authority Information (if different than above)**

Signing Authority Name: \_\_\_\_\_  
 Title: \_\_\_\_\_  
 Email: \_\_\_\_\_

**Material requested:** Tech ID: UIC-1998-031, Copyright ID: UIC-1998-031-24, Occupational Self Assessment/OSA Short form (OSA/OSA-SF)

**The “Translation” is defined as the work created by translating the Material.**

**Language is defined as the language into which the Requester desires to translate the Material. The Language requested for Translation is: Bengali**

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The authorization provided is valid only to the extent that all of the activities undertaken are consistent with the understanding and conditions as described. The authorization is void unless Requester strictly adheres to all conditions stated herein.

This letter embodies the entire understanding between Requester and the University of Illinois. There are no contracts, understandings, conditions, warranties or representations, oral or written, express or implied, with reference to the subject matter of this letter that are not merged in this letter.

Sincerely,

Accepted By:

*Suseelan Pookote*

*Jerin*

Board of Trustees of the  
University of Illinois  
Suseelan Pookote

Institution: Bangladesh Health Professions Institute (BHPI)  
Name: Jannatul Ferdous Jerin  
Title: A Cross-Sectional Study on Daily  
Living of Mothers of Children With Disability.

Director, UIC-OTM

Date: 03.10.2023

Date: 10/06/2023

## Appendix E: Supervision Contact Schedule

Bangladesh Health Professions Institute  
Department of Occupational Therapy  
4<sup>th</sup> 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: Level of Competence & Importance in Daily Living of Mothers of Children with Disability: A Cross-Sectional Study.

Name of student: Jannatul Ferdous Jerin

Name and designation of thesis supervisor: Sk Moniruzzaman, Associate Professor and Head of Occupational Therapy Department, BHPI, CRP, Savar, Dhaka.

Co- Supervisor: Monika Singha, Lecturer, Department of Occupational Therapy, BHPI, CRP, Savar, Dhaka.

Appointment No	Date	Place	Topic of discussion	Duration (Minutes/Hours)	Comments of student	Student's signature	Thesis supervisor signature
1	19.08.2020	BHPI	Discussion about the topic	2.5 hour	Got an idea about research topic	Jerin	Sk. Moniruzzaman
2	19.08.2020	BHPI	Discussion about the title, aim, objective	2 hour	Learning & understanding of aim & objective	Jerin	Sk. Moniruzzaman
3	19.08.2020	BHPI	Discussion about the tool (scale to be used)	1 hour	clear idea about the scale	Jerin	Sk. Moniruzzaman

4	20.09.23	Online	Introduction of research for proposal presentation	2 hour	Understand the guideline for introduction	Jerin	Moin Singh
5	21.09.23	Online	Significance, methodology for proposal presentation	1.5 hour	Got clear idea about methodology	Jerin	Moin Singh
6	22.09.23	online	How to proper proposal presentation	2.5 hour	Got proper guideline	Jerin	Moin Singh
7	03.10.23	DHPI	Feedback from proposal presentation	2 hour	Understand how to elaborate	Jerin	Moin Singh
8	04.10.23	DHPI	Feedback on consent form, withdrawal form, information sheet	1 hour	Got idea how to organize and	Jerin	Moin Singh
9	05.10.23	DHPI	Discussion on the translated survey form	1 hour	Effective discussion	Jerin	Moin Singh
10	06.10.23	DHPI	Data collection	2 hour	Helpful feedback	Jerin	Moin Singh
11	05.10.23	DHPI	Permission procedure to collect data from different organization	1 hour	Understand the permission procedure	Jerin	Moin Singh
12	06.10.23	DHPI	Feedback on field test	2 hour	Effective guideline	Jerin	S. V. S.
13	23.01.24	DHPI	Feedback on introduction write up for 1st draft submission	3 hour	Find extensive guideline	Jerin	Moin Singh
14	24.01.24	DHPI	Feedback on 1st draft	2.5 hour	Understand the mistake	Jerin	Moin Singh

15	02.09.24	DHPI	Feedback on result	4 hour	Got clear idea to solve mistake	Jerin	Jerin
16	04.09.24	DHPI	feedback on analysis & conclusion	2.5 hour	Effective guideline	Jerin	Jerin
17	06.09.24	DHPI	feedback on strength & limitation	2 hour	Got idea how to organize	Jerin	Jerin
18	10.09.24	DHPI	Feedback on 2nd draft submission	2 hour	To correct mistakes	Jerin	Jerin
19	23.09.24	DHPI	Discusses about correction of 2nd draft	2 hour	Helpful feedback	Jerin	Jerin
20	01.10.24	DHPI	Feedback from powerpoint presentation	1.5 hour	Effective feedback	Jerin	Jerin

Note:

1. Appointment number will cover at least a total of 40 hours; applicable only for face to face contact with the supervisors.
2. Students will require submitting this completed record during submission your final thesis.