

**Carers' Views on Practicing Home Program  
Based on Towards on Inclusive World: A  
Guidebook for the Parents of Children with  
Cerebral Palsy**



By

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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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## Dedication

*Dedicated to my beloved parents and respected teachers of  
Bangladesh Health Professions Institute (BHPI).*

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## List of Abbreviations

ADLs	Activities of Daily Living
CP	Cerebral Palsy
CRP	Centre for the Rehabilitation of the Paralysed
HP	Home Program

## Abstract

**Background:** Cerebral Palsy (CP) is most common disability among the children in Bangladesh. Parents are play as carer to this child with CP. For better improvement Centre for the Rehabilitation of Paralysed (CRP) provide a guidebook to carer who take two week of inpatient rehabilitation service. Because this book helps the carer to practice home program (HP) easily with their child. This study was focused to explore the carer view of practicing HP with their child with CP by following the guidebook.

**Objective:** Objectives of the study were to find out the carer knowledge about the practicing the “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy”, to identify the facilitators to implement this guidebook for the carer, to find out the challenges to implement this guidebook at home for the carer, to find out the carers’ opinion and recommendation about the guidebook.

**Methodology:** The study was conducted by using qualitative thematic analysis method. Purposive sampling was used for selecting participants. Data was collected by using face to face interview with a semi structured question, data was analyzed by using thematic analysis.

**Result and discussion:** After analyzing data, it was found that carer have enough intelligence about the guidebook. The clear information help carer to participate in HP comfortably. Sometimes carer face difficulties to implement HP because they have less family support and lacking of therapeutic equipment. Carer are satisfied with this book and get benefit at the time of practicing. Carer recommendation to upgrade information that will be more helpful for them.

**Conclusion:** Rehabilitation process is more effective when carer participate HP regularly with their child with CP. “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy” has different home guidance for CP carer. Carer are aware about the guidebook and they get help from the book with satisfaction to implement HP. Child need variation on HP with their ages. So, it is necessary to include monitoring and educate the carer about the book with update HP in therapy session.

**Key words:** Cerebral palsy. Home program. Carer participation

## CHAPTER I: Introduction

Cerebral palsy (CP) is a common cause of disability in children that requires ongoing rehabilitation. CP is a neurological condition that causes mobility and postural difficulties and is caused by nonprogressive abnormalities in the developing fetus or infant brain. Physical activity and exercise-based rehabilitation for children with CP should enhance physical functionality, minimize secondary musculoskeletal deficits, and nurture the child's cognitive, social, and emotional development (Sadowska et al., 2020).

Children with disabilities, as well as their families, are impacted by disability (Burke & Hodapp, 2014). Parents of children with CP have a critical role in meeting these children's needs, pursuing therapy, and providing various forms of care for their unique demands (Hu et al., 2011).

The words 'carer' or 'caregiver' are commonly used to describe a person who gives significant amounts of help over long periods of time to a relative, friend or neighbor who is ill or disabled (Hughes et al., 2013).

Children with CP are particularly dependent on their carer. Children with CP are frequently cared for by their mothers (Vadivelan et al., 2020).

The primary goals of therapy for children with CP are to enhance function and eventually, social involvement. Motor learning and development occurs when a task is repeated numerous times in different situations. As a result, therapists have begun prescribing home programs for carer to use at home to practice tasks learned in therapy. As a result, HP are a therapy technique in which therapists and families collaborate to create a specific set of activities that focus on the child's pre-determined goals. In a

home setting, the activities are carried out by the family (“The use of home programs Cerebral Palsy as a therapeutic intervention”, 2022).

Novak (2010) reported a significant positive result of parents experienced benefits using partnership HP. Parents used these programs to help their child.

Qualitative study methods where semi-structured interview was conducted with 10 parents of children with cerebral palsy who had participated in HP. Again, 51.1 % of the carers carried out prescribed regularly and there was no significant association between any of the selected clinic-demographic variables and the level of compliance of the carers and this was selected by descriptive cross-sectional survey which involved 47 participant who regularly brought their children for therapeutic treatment (Olagunju et al., 2017).

Above all, it has seen that carer participation of HP is important for CP child. Every carer of CP child need to aware about HP participation for their childs’ better outcome. It is important for an occupational therapist to deal with carer about their active participation of HP. Because occupational therapist can work closely with CP child for their activities of daily living (ADLs) program with presence of carer. Again, during rehabilitation occupational therapist provide guidebook and education to carer that they practice at with their child. So, in order to ensure better rehabilitation service to CP, it is important issue for conducting this research. This study will be beneficial for an occupational therapist to understand about the carer participation of HP at home with their child.

## **1.1 Background**

Rehabilitation services are internationally recognized as one of the key components of health care (WHO, 2011). Presently only 2% of out of one million people with disabilities in Rehabilitation services (Ministry of health, 2003). CP is common

disability in children and young people. Occupational therapy HP for children with CP have been used for some time by families and therapist to increase the intensity of therapy, either between therapy session or during or during a break from therapy (Novak & Cusick, 2006). Prevalence of cerebral palsy is 3.4 per 1,000 children in rural Bangladesh and there are an estimated 233,514 children with CP in Bangladesh (Khandakar et al., 2018).

For this number of CP child paediatric department, CRP, in Bangladesh stabilize where children are referred to CRP after an initial assessment by multidisciplinary team and depending on child condition, they refer them out patient unit or inpatient unit in order to join the two-week residential program (Centre for the Rehabilitation of the Paralysed [CRP], 2022).

After completing two weeks intervention therapist are provide guidebook “Towards on Inclusive World – A guidebook for parents of children with cerebral palsy”. This is a guidebook for the parents of children with CP published by interprofessional project on Disability, Maternal and Child health. In this guidebook there are home guidance and occupational therapist provide education to the carer about occupational therapy home guidance from the part of this book such as hand skill training, daily life activities training (self-care, feeding, dressing, toileting, playing), communication skills training etc. All of these are important for their child to get better improvement. Therapist education assists carers in comprehending the HP and learning from the therapists’ activities. The carer must be able to carry out the HP with easy instruction. Complicated information makes it difficult to complete a HP. Again, mother wishes for the therapist to allow them to view the therapy process more closely. Therapist must observe and oversee the carer while they execute some of the exercises, and provide positive feedback to the carers. In addition to the carer, family members must assist in the

implementation of the HP. Because there are some obstacles that carers must overcome in order to establish a HP (Piggot et al., 2003).

As an occupational therapist has a great role in CP child and with the carer about performing HP. Every CP child need proper practice of HP. Every CP child need proper home-based intervention from their carer because carer plays an important role in HP. As the practicing of HP is important for CP child, CRP provides guidebook with home guidance through the therapist. So, it is need to include monitoring the carer participation about this guidebook. Also, therapist need to provide education to mark and update information for practicing HP in every therapy session. So, as an occupational therapy student researcher was interested to conduct this study.

## **1.2 Justification of the Study**

The student researcher broadly explained the carer perception and views of practicing the guide book at home with their CP child. Along with this, carer opinion and recommendation about this guidebook also be described. Carer also faces problem to implement HP that make carer to demotivated to practice HP. In Bangladesh, family members are the primary carer for children with disabilities (UNICEF Bangladesh, 2014). In Bangladesh, family members are the primary carers for disabled children. As a carer, family members play an important role in the rehabilitation of a child with a disability by providing ongoing intervention at home, hence increasing rehabilitation outcomes and lowering the need for ongoing professional visits (Siebes et al., 2007). An occupational therapist can work with CP child with their carer. Occupational therapy HP is a common approach used to provide intervention for the children with CP (Novak & Cuisick, 2006).

In Bangladesh there is not enough research regarding carer participation on HP for CP child. Though carer participation is important for every CP child and this guidebook

provides CRP only the use of carer that they practice easily home and get benefit. This study can be helpful for occupational therapy professional because it will provide a new insight of carer practicing the guidebook at home. As a result, it will develop confidence level of occupational therapist about providing education this guidebook to carer of CP child. This study will be a good resource for occupational therapy department that will help to develop more awareness about the guidelines of that book and also help to modify the occupational therapy part of the book if it will be needed. This study will be first study of occupational therapy profession in Bangladesh. So, the results of the study will be helpful for paediatric practitioners of CRP. The study findings can be helpful for upgrading occupational therapy service in Bangladesh and promote the professional development.

### **1.3 Operational Definition**

**CP:** Cerebral Palsy (CP) is one of the most frequent causes of motor disability in children. According to the up-to-date definition, CP is a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain (Sadowska et al., 2020).

**Carer of CP:** Parents are the carer for most often time for the child with cerebral palsy who are responsible for providing care for their child (Eloreidi et al., 2021).

**Home program:** Home-based programs are activities children and adults with cerebral palsy undertake at home to achieve certain goals. They are considered important for several reasons. One is that home programs increase the amount of practice of an intervention a person with cerebral palsy is getting.

Home programs are home-based activities that can improve the gross motor skills, arm and hand movements, self-care abilities, behavior and communication of a person with

cerebral palsy. Home programs are a way of increasing the amount of therapy for a child or adult with cerebral palsy (Alliance, 8 December).



## CHAPTER II: Literature Review

Literature review represented the relevant information of this study. The student researcher has explained the key term of this study by reviewing different related articles.

Novak (2011) published research about parents' experience of implementing effective HP at CP Institute, Darlinghurst, Sydney, Australia. This qualitative research, 10 participants were conduct with semi structured interview for achieving the parents' views about implementing effect of HP and practice recommendations. Parents view of HP was described as, one kind of advice and guideline that become the pathway of life for parents and their children. This study also defined HP for the children with CP. There was conducted a studied about HP intervention effectiveness evidence at CP. Study settings was Alliance, School of Medicine, University of Notre Dame, NSW, Australia on 2014. This study was quantitative randomized controlled trials, and discuss clearly about HP. In this study, HP describes as, HP is the treatment process that a parent or carer carried out in the home circumstance and if other health professional, therapist or special educator carried out the treatment at home environment for improvement, that time it will be excluded as HP (Novak & Berry, 2014).

Different literature defines HP in different way by conducting research in different areas of people. The similar result of the definition of HP is, HP performed by parents or carer at home following the guidance of home intervention with their child to get early better improvement. But one literature, where mentioned a very important view of HP that only parents or family member can provide HP with their child and if any

health professionals or educators or others provide intervention at home that will be excluded from HP (Novak & Berry, 2014).

Nahar (2015) conducted a research based on the views of findings the physiotherapy home exercise program of CP child's parents at Paediatric unit, CRP, Bangladesh. This was a qualitative study and 10 parents of CP child were participated. This was face to face interview with open-ended questions and analyzed data following content analysis process. The result said, mothers perform HP with their child and they think that HP is effective for getting improvement for their child with CP. Also said, mothers perform in HP as much as possible that they can do.

Based on the aim to describe the parents' perception about effective implementation of HP that inform to practice with therapist recommendation, Novak conducted a study at CP Institute, Sydney, Australia on 2011. This qualitative research was conducted with 10 parents who use partnership-based approach to participate HP. The data was analyzed by grounded theory. This study addressed that, parents get believe in the practice of HP and HP are part of life and can help to get maximum progress and to help to manage time. Again, it talked about benefits, including supports, realism, flexibility motivation, generalizable activities are provided by the partnership-based HP. Parents provided recommendation to other parents to follow HP and therapist to teach them these HP cooperatively. Parents also told, parents practice HP because parents get improvement by using partnership HP (Novak, 2011).

Mothers' perception about HP is very important to know for better rehabilitation process. Mothers' views help to continuing HP with their CP child. In different literature, mother perception was described by different way. The common perception about HP in these literatures that have discussed is as, mothers think that HP are effective to get better improvement for their child and they try their best to do HP with

their child at home. One literature that mentioned, HP is more effective when it performs with partnership-based HP (Nahar, 2015 & Novak, 2011).

At Nigeria there conducted a study to participation of HP with focusing the clinical and demographic factor with the informal carer of Nigerian children with CP on 2017. This was quantitative study and 47 informal carers are participated. Data was collected by face-to-face administrated questionnaire and was analyzed by descriptive statistics of means, mode frequency percentage and standard deviation and Chi-square test. The result is described as HP are regularly carried out by 51.1% of carers and among the informal carer of Nigerians' children with CP. There was no significant association compliance with HP (Olagunju et al., 2017).

A national survey was conducted by United Kingdom paediatric occupational therapy HP practice about on 2016. This study was done by survey questionnaire and number of participants was 123. The result told that, because of the parental business only about 49% participant reported that they did not perform HP regularly and their main focus was not to perform Occupational therapy HP and about 74.60 % participant perform occupational therapy HP (Milton & Roe, 2016).

Actively participation on HP is important for achieving childs' better outcome and there is some literature where discuss about the actively participation of HP. Qualitative and quantitative both researches had conducted to describe the participation of HP. In quantitative research it told that about 51.1% carer participate HP and among the Nigerian people (Olagunju et al., 2017). Another quantitative research it discussed about 74.60% perform Occupational therapy HP and 49% are avoid occupational therapy HP (Milton & Roe, 2016). Again, in qualitative research it told that parents follow HP regularly and perform collaboratively to get better improvement for child (Novak, 2011).

To identify the effectiveness of carer directed home based intensive bimanual training for children with CP, a study was conducted. This was quantitative randomized control trial study where 24 childrens' careers are participated. Children were randomized receive bimanual intensive home-based therapy of hand and arm or lower limb functional training. In result the greater improvement is showed hand arm bimanual intensive therapy on the box and blocks test rather than lower limb intensive functional training and also significant improvement of COPM (Ferre et al., 2016).

Improvement from performing home base intervention is discussed in some literature by differently. Continuing HP had significant improvement was showed for the child with cerebral palsy and also higher improvement was brought by home based bimanual intensive therapy (Ferre et al., 2016). Again, regular HP brought significant improvement of CP child with their function (Nahar, 2015). Though these two-research conducted with different area of population but both findings of improvement of HP was similar.

Associated factors that adherence to parents to continue in HP for the children with disabilities conducted at Spain, 2019. Data was collected from Murcia, Spain where 393 participants were participated. The result addressed about 34% parents who adherence to flexibility exercise and 50% of parent adherence by neurodevelopmental training exercise is adherence. Parents who had high self-efficacy and low perception of barriers, high level of knowledge were highly adherence to perform the exercise. Again, adherence to perform in different exercise is highly influence by the behavior of health professionals (Lillo-Navarro et al., 2019).

On 2013, published an article about the carers of children with cerebral palsy that adherence to perform home exercise program at Turkey. This was quantitative study and 147 participants were selected by survey. About 87.5% carers perform home

exercise program with good adherence and enhance the adherence to perform home exercise program and to the carers who had the severity of the functional limitation of children with cerebral palsy. Some negative impact is showed when carers were exhaustion and burnout (Basarn et al., 2014).

There was conducted a study for the young people with cerebral palsy based on factors that influence to adherence to perform home based strength training program on Australia. This was a qualitative study and 11 people were participated. The findings described by 2 types as personal and environmental factors like, motivation autonomy, ability to perform, understanding the exercise, family and emotional support, exercise equipment, exercise book etc. were influence to adherence to participate HP (Taylor et al., 2004).

Home exercise program may influence by both positive and negative factors. Some factors inspire and some factor create barriers to perform home program that was described some literature. The common findings were in positive factor that, parents' self-efficacy, motivation inspiration of HP. Again, common negative factor like, lack of time social supports family supports equipment's and understanding the guidance that affect to practicing HP. These factors are simply defined as personal and environmental factors. One literature mentioned that sometime health professionals' behavior affects to the carer to participate HP (Basarn et al., 2014). Environmental factors like lack of equipment or guidebook etc. highly affect to perform HP (Taylor et al., 2004).

Some literature discusses about the occupational therapy HP for CP child and they recommended to work with this topic and develop formal guideline for HP that is provided to the carer and also ensure the support of greater organization further education and skills development of this topics (Milton, & Roe, 2016).

Based on literature review there are only few researches in Bangladesh about HP.

Also, there is no study about HP following the “Towards an Inclusive World –A guidebook for parents of children with cerebral palsy”. So, it is need to study about HP following this guidebook that provided by CRP.

## CHAPTER III: Methodology

### 3.1 Study question, aim, and objective

#### 3.1.1 Study question

How the carer continuing home intervention based on “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy” after completing two weeks rehabilitation at the CRP?

#### 3.1.2 Aim and objectives

**Aim of the research:** To explore the carers’ views on practicing home intervention based on “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy” given from CRP after completing two weeks of in-patient rehabilitation.

**Objective of the research:**

- To find out the carer knowledge about the practicing the “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy”
- To identify the facilitators to implement this guidebook for carer
- To find out the challenges to implement this guidebook at home for carer
- To find out the carers’ opinion and recommendation about “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy”

### 3.2 Study design

Student Researcher used phenomenological qualitative research design to know about the experience of carer of CP child about their practicing home intervention following the guidebook. Qualitative research involves participants’ experiences of events in their life and the researcher capable to get insight into how another person feels and

understands the world through other experiences, because of this the researcher applied qualitative research (Austin & Sutton, 2014).

Phenomenological qualitative research focuses on an individuals' lived experiences, and phenomenological approaches are applied in every study where peoples' perspectives on their lives and experiences are needed (Neubauer et al., 2019). This research aim is to know the views on carer participant of home intervention following guidebook and it represented the participants own experience of perspective. So, the researcher used phenomenological approach of qualitative research design.

### **3.3 Study settings and period**

#### **3.3.1 Study settings**

This qualitative study was conducted from the carer of CP child at paediatric unit, CRP, Saver, Dhaka. For data collection the student researcher used that place which were recommended by the participants and where the participant feel comfortable to share their opinion.

#### **3.3.2 Study period**

The period of this study was from April 2021 to February 2022. However, the student researcher got time to collect data from December 2021 to January 2022.

### **3.4 Study participants**

#### **3.4.1 Study population**

The study population was the carer of CP child who came for follow up at CRP paediatric outdoor unit after taking 2 week of inpatient rehabilitation service from CRP paediatric inpatient unit.



### **3.4.2 Sampling techniques**

Purposive sampling technique was used in this study. Purposive sampling is a technique used in qualitative research to carefully select subjects depending on the study's aim, with the assumption, each participant gives unique and valuable information to the study (Suen et al., 2014).

### **3.4.3 Sample size**

The student researcher used purposive sampling for this qualitative study where participants were selected by judgmentally who meet the inclusion criteria. Eleven participants were selected by using purposive sampling according to criteria to conduct the study and the sample size was depended on data saturation. Data saturation in qualitative research refers to the point in the research process when no new information is discovered in data analysis, indicating to researchers that data gathering should be completed (Faulkner & Trotter, 2017). Sample size was very small as limited time duration and pandemic situation again, there is not necessarily representative of the vast population in qualitative research study (Vasileiou et al., 2018).

### **3.4.4 Inclusion and Exclusion criteria**

#### **Inclusion criteria:**

- Carer of CP Childs whose child had taken 2 weeks of in-patient OT rehabilitation from Paediatric inpatient unit of CRP
- Carer of CP child who came for follow-up after discharge from CRP paediatric inpatient unit taking 2 weeks of inpatient rehabilitation

#### **Exclusion criteria:**

- Carer who had received the two weeks in inpatient rehabilitation but not practicing following the guidebook

- Carer of CP Childs whose child had not taken 2 weeks of in-patient OT rehabilitation from Pediatric inpatient unit of CRP

### **3.4.5 Participant recruitment process**

The student researcher reached about eleven participants of CP child's carer who came for follow-up by going to Paediatric Unit, CRP, Savar and asked every carer of CP child that they had received 2 weeks inpatient rehabilitation and had have the guidebook.

### **3.5 Ethical consideration**

- The student researcher took permission from the Institutional Ethical Review Board through OT department, BHPI
- Student research took permission from authority of paediatric unit by showing the application letter of OT department, BHPI
- The student researcher maintained unequal relationship at the time of taking data from the population of the study
- Student researcher-maintained confidentiality about service information of the institute
- The student researcher ensured that the confidentiality is maintained about the participants
- All participant was informed about the aim of the study
- The student researcher was available to answer any study related questions or inquiries from the participants
- The student researcher was concern about the effect of biasness, as the study sample was selected based on inclusion and exclusion criteria
- Student researcher was ensured to the participant about there was no risk for giving information to the student researcher

- Student researcher was ensured to the participant that they didn't get any beneficence from student researcher

### **3.6 Data collection**

#### **3.6.1 Data collection methods**

All data was collected through face to face in depth interview by using a semi structured research question. In this study, student researcher has explored the views of carer practicing about the guidebook. In depth interviews are long duration face to face interviews that conducted to achieve desired goals. In depth interview participant explore their thoughts, feelings and beliefs about a particular topic (DeJonckheere & Vaughn, 2019).

This interview procedure would provide the opportunities to deserve the facial expression of participants and would help the student researcher to determine their understanding of the questions. The question was written in Bengali so it would be easily to understand for all participants. The student researcher started from initial stages of data collection procedure. At first, the student researcher would verbally present the details of the study such as aim, objectives and purpose of the study then explain the rights, roles, benefits and importance of the written consent form in a descriptive way and arranged with the interview in a suitable place. Before starting the interview, the student researcher asked the participant about the place of interview. When the participant agreed with the student researcher and they felt comfort with the place, then the student researcher started to interview. During the interview, a recorder was used to record the conversations and discussions between the participants and interviewer. Recorder, paper and pens also used during interview for writing the additional information from the participants.

**Field test:** A field test was conducted with two participants. Before the time of final data collection, it was necessary to conduct a field test to help the student researcher for purifying the data collection plan. During the interview, student researcher informed the participants about the aim and objective of the study. From the field test the student researcher was aware about which part of the question participant found difficulty or they did not understand properly. Student researcher observed the situation of the interview; participants' response thus helps to modify the question where necessary. Finally, the question was developed in Bangla.

### **3.6.2 Interview guide/ Survey tools**

- Audio recorder was used to record the conversation and discussion of the participant and the interviewer
- Paper, pen and pencil were used to write down the observation note or any other information that was obvious needed to research study
- To conduct this research, self-developed interview questions were created by student researcher. For developing these questions student researcher took help from different literature and self-ideas based on the research aim and objective. There were consisting of 7 questions related to carer participation of home program based on "Towards on Inclusive World: A guidebook for the parents with cerebral palsy"
- Consent form
- Information sheet
- Clip board

### **3.7 Data analysis**

Qualitative data analysis is a process that needs more to reading, thinking and reflection on the part of research. Thematic analysis is a method of analyzing qualitative data. It is usually applied to a set of texts, such as interview transcript. The student researcher closely examines the data to identify common themes – topics, ideas and patterns of meaning that come up repeatedly. The student researcher selected Qualitative Thematic Analysis method for analyzing data. There are various approaches to conducting thematic analysis, but the most common form follows a six-step process: familiarization, coding, generating themes, reviewing themes, defining and naming themes, and writing up (Caulfield, 2022). The analysis of data began from transcribe of interviews. At first, the student researcher would organize the interviews and transcribe the entire interview in Bengali from the audio tape recorder. Each of the transcript were translated from Bengali to English by 7 different individuals who did not know about the aim or objectives of the research question. Then the student researcher would verify all of the transcriptions and read it several times to find out what the participants wanted to say. Following that, the student researcher confirmed the data and found the actual themes of the study. When the student researcher would notice some similarities between the data, the student researcher would organize the data according to some major codes and under those codes, generated some theme and reviewed the theme under each objective. Then student researcher defining the theme under each objective and finally writing up the theme of the study.

### **3.8 Rigour**

This study was conducted through rigorous manner or trustworthiness. The entire study was conducted in a systematic way by following research step under the supervision of an experienced supervisor. At the time of data collection and data analysis the student

researcher never tries to influence the result by her own value or perspective. The student researcher accepted answers of the participants whether they would deliver. The student researcher prepared transcript from field notes and audio recording. Soon after the interview it was written. Translation has completed by 7 people to avoid biasness then student researcher completed the same translation and record to reduce mistake and compare it with the Bangla transcript. The student researcher has checked translated data for several times so that all information would be include. All of notes kept safe to maintain confidential it.

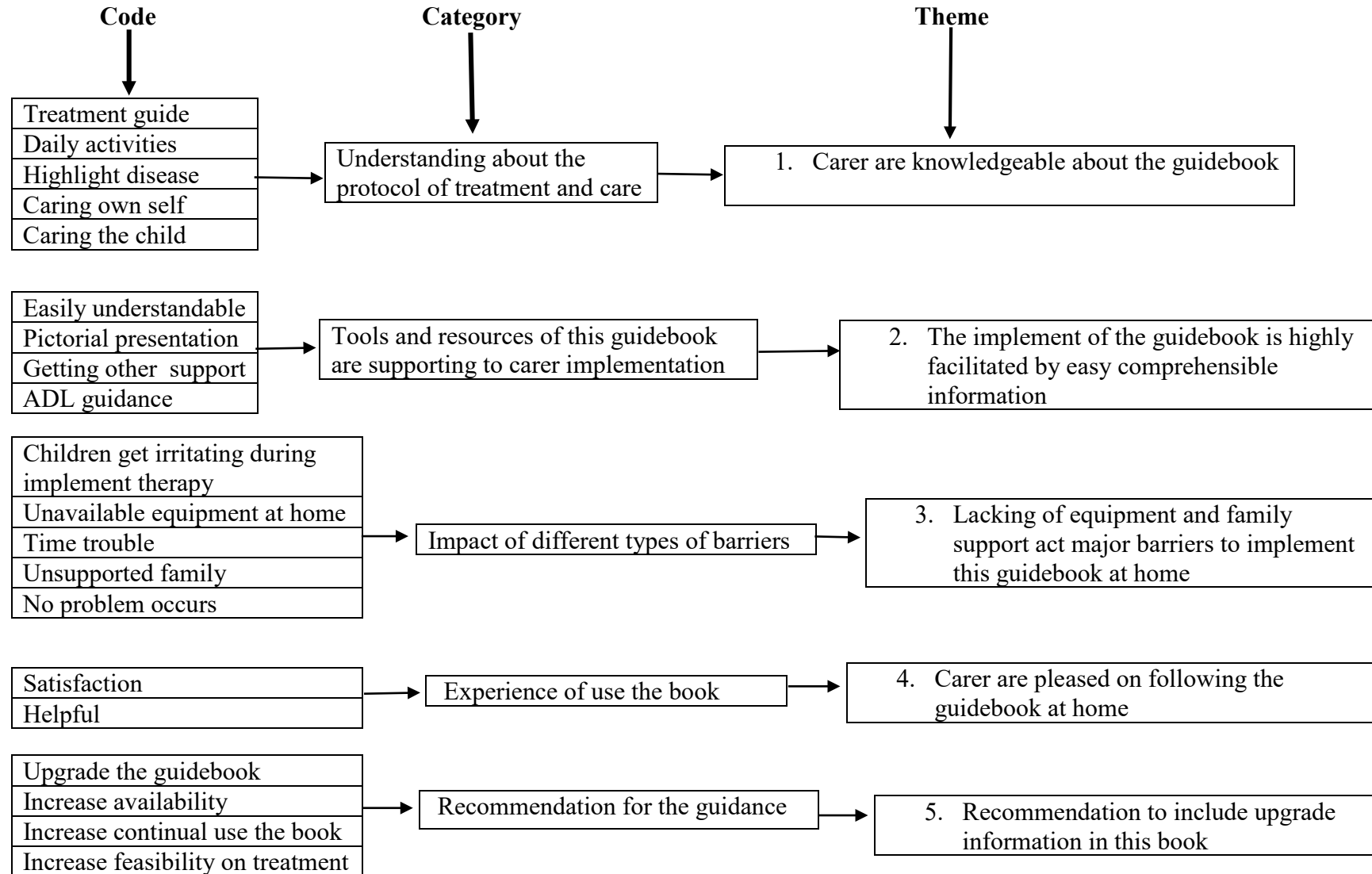
## **CHAPTER IV: Results & Discussion**

Result and discussion the findings that were reported in this chapter utilizing a variety of sources. In qualitative investigations, the most typical technique is to give the results and discussion in one section (Anderson, 2010).

The main findings of research are reported in the result section of this study. All relevant findings should be presented clearly and objectively in a logical order, with tables and graphs to demonstrate specific findings. The discussion part explains and evaluates the study findings, as well as offering a case in support of the general summary (Base & section, 2020).

The aim of this study was to explore the views of carer about the guidebook that provided from CRP. There were four objectives of this study. To fulfil these objectives, it has been emerged five major themes of this study.

Aim: To explore carer views on practicing home intervention based on “Towards on Inclusive World - A guidebook for the parents of children with Cerebral Palsy” given from CRP after completing two weeks of inpatient rehabilitation.



**Figure: Summary of the study**



**Theme 1: Carer are knowledgeable about home program of the guidebook “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy”.**

For the success of a home program, proper knowledge is essential. An educational program can assist carers improve their abilities to care at home (Mohammed & Kamel, 2015). All of the participant demonstrated the home program that contain in the guidebook. Most of the carer of CP child describe briefly about treatment protocol & every activitys’ guideline those are in the book. This theme means that carer of CP child has knowledge about this guidebook and they understand the guidance of the guidebook.

Every participant commonly mentioned that, “In this guidebook, there are treatment guidance like- occupational therapy, physiotherapy, speech and language therapy with strategies and purpose for practicing at home”.

Half of the participant said that, “This guidebook is the way of performing daily life activities for my child. This book has also instruction about different therapy that I need to practice with my child”.

The carer of CP child positively enlarge their knowledge of performing daily home care by the use of educational mobile application and according by this, they are knowledgeable about treatment of home program. Carer use this knowledge to deal with childcare management of daily life activities of child at any time anywhere. This application use as a supplement along with other treatment and rehabilitation practices of children with CP (Ghazisaeedi et al., 2016).

All of the participant demonstrated the home program that contain in the guidebook. Most of the carer of CP child describe briefly about treatment protocol & every activities guideline those are in the book.

One participant told that,

“This guidebook contains how to take care of my growing child with CP-what to do & how to do. The therapies like physiotherapy, occupational therapy, speech and language therapy also describe in this book. This book also has how to care myself, how to caring by child”.

Another participant told that,

“This guidebook contains the process of taking care about nutritious food and health of their child with CP. This book contains about my child condition, the process of how I take care of my child how I give my child therapy at home etc”.

Home programs are therapeutic activities that a child engages in at home with parental assistance in order to achieve targeted health outcomes (Novak et al., 2007). To complement therapy and/or discharge recommendations recommended by rehabilitation professionals. Therapeutic exercises, activities, and lifestyle behavior modifications are usually included. To improve a clients' safety, HP may also include activity and exercise measures (Riveland & Pettit, 2020). “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy” this book has involved with home guideline that the carer follows at home for their Childs' better improvement. This guidebook is provided professionals of CRP for CP Childs' carer. In this research showed that carer talked about the treatment protocol, daily living activities, recommendations etc. very clearly. Again, in this study it showed that carer

aware about all guidance in this guidebook including both about child and their self-care at home. All of these reported that they are knowledgeable about the guidebook.

**Theme 2: The implement of the guidebook is highly facilitated by easy comprehensible information.**

This theme highlighted the facilitator that help carer to participate home program with their child. Most of the participant said that they get help from this guidebook to practice home program for their child. The easier understandable instructions such as therapies, ADLs guidance and all over information with picture of this guidebook facilitates them to perform home program with their child.

One of the participants said, “Yes, the instruction of daily living activities such as, bathing, toileting, feeding, combing hair, playing activities all of them are very helpful to perform at home with my child”.

Another one of them shared, “When I practice daily living activities like feeding, bathing, sleeping, toileting, dressing always I look for the guidebook and it help me perform correctly”.

Home programs created by health professionals for the carer where mostly include therapeutic exercises, daily live activities, and different recommendation by different way. This home guidance helps the carer to perform home intervention with their child (Riveland & Pettit, 2020).

One of the participants said that, “During practice home program I see the instruction, read the instruction that are wrote in the book and I perform according with that”.

Another one of the participants said, “Pictures of this guidebook help me to practice treatment when I can’t understand how to do perfectly with my child”.

Another one of the participants said, “Guideline of home program describe clearly in this book, when I can’t remember how to do then I read the book and perform with my child”.

Paper versions are more commonly used by occupational therapists, who have reported to complement the handout with visual demonstration or direct training with feedback, as well as discussion of how to incorporate activities into routine as patient and carer understand easily and apply correctly at home (Brown & Fichter, 2017).

Facilitators are described as elements that improve functionality and increase the likelihood of a youngster participating in a physical activity when they are present or absent (World Health Organization, 2007). An important guideline, an accessible environment, available assistive technology, and good attitudes from individuals in the child’s environment, as well as programs, systems, and policies that aim to enhance participation, are examples of elements that improve functioning by their presence (Verschuren et al., 2012). Carer stated about facilitators that mostly help them to practice home program with their child. This study carer clearly mentioned that the information of the guidebook is very clear and easy to understand. They mostly get benefited from this easy understandable information. Carer reported significantly that the instruction of ADLs performing for their child are very nicely describe with understandable word with picture that also help them to practice home program perfectly.

### **Theme 3: Lacking of instrument and family support act major barriers to implement this guidebook at home.**

The third theme describe the major barriers that causes by lacking of instrument and family support that implement home program regularly with their child. It is necessary for therapists to understand the barriers in order to assist carers in actively participating in their childrens' rehabilitation at home (Abdullahi & Isah, 2020).

One of the participants said that, "I face difficulties during practicing activities at home as all instrument that need to practice are not available in our house. We have no money to buy experiment or others tools that help me practice therapy at home properly. I face difficulties because of that".

Another one of the participants discussed that, "Sometimes face problem because, some exercise showed in this book with different equipment. This equipment is not available to me".

One kinds of barriers to performing physical activity or continuing a home program or exercises for a non-progressive neurological condition is a lack of availability to exercise equipment such as different therapeutic equipment. (Mulligan et al., 2012).

This result showed that carer didn't have enough equipment that they use at the time of practicing home program. Carer mentioned that this lacking of equipment causes the barriers to implement home program.

One of the participants said,

"No one help me, I have to do everything for my child alone, again my family give pressure to me when I provide therapy to child and they said always as providing therapy to my child is waste of money and time".

Again, another one of the participants told, “No, no one helps me. I always did alone with my child. My family members never support me to do therapy at home”.

At the individual level the mothers perceived aches and pains due to the heavy physical activity of caregiving. They also suffered from a feeling of guilt about the child's condition. Due to the difficulty in balancing family and work, they had significant financial burdens. They also perceived a lack of knowledge and awareness about possible options for the treatment of their child. On a personal level, the mothers lacked support from their husbands and families while caring for their children. They also had to deal with the consequences of their husbands' drunkenness and physical violence. They had to make sacrifices in the care they gave to their other family members and children who did not have cerebral palsy. The women felt alienated from others in their town since they received little help from their neighbors (Vadevilan et al., 2020). Most of the carer reported that their family members didn't support and help them to continue home program with child. It's the big barriers to implement home program for carer at home.

The severity of a child's functional restriction appears to increase carers' commitment to home exercise programs. Carers' knowledge and assistance can enable them carry out a successful home program despite obstacles. For an effective home exercise program, carers should be socially and medically supported (Basaran et al., 2014).

#### **Theme 4: Carer are pleased on following the guidebook at home.**

Participants reflected their opinion as they are grateful and satisfied about this guidebook that provided from CRP. Carer are getting significant improvement from home program with their child with CP. This improvement gives carer great satisfaction to parent about home program (Novak et al., 2009).

One of the participants mentioned that,

“This guidebook is very helpful for me; it helps me practice treatment easily at home. If I have no this book, I will forget therapies. Because its s tough for me to memories all of this. So, this book helps me when I give therapy to my child”.

Another one of the participants said,

“This book is helpful to practice home treatment not only for me but also all parents like ours. This book is like a helping hand for me. Whenever I forget I see the book and give therapy. So, I think it is useful for all mother like me.”

For children with CP, home programs comprise the greatest available treatment. The most effective intervention for improving function, motor activity, and self-care performance is a home program. Carers are receiving assistance from home guidance in order to carry out successful interventions (Novak et al., 2013). Carer in this study mentioned specifically that this book helpful to implement home program.

One of the participants told, “Yes, I am fully satisfied with this book. This book has all guideline that always help me to provide treat at home”.

Another one of the participants said, “Yes, I am satisfied with this guidebook that give CRP to me. I am very grateful with this book”.

Parents have a high level of satisfaction, and the majority of parents see improvements in their children as a result of participating in the home program. Parents stated that observing improvements gave them satisfaction and that they felt less stressed as a result (Mullan et al., 2020). The result showed Carer are satisfied to get this book and use this book home.

**Theme 5: Recommendations to include the upgrade information in this book.**

The last theme of this research described the carer recommendation. Most of the carer specifically recommended to upgrade the guide book with more information that help more to practice home program.

Most of the participants said that, “This book is perfect but it will be more effective for me if the book has contained more therapies that are effective for my child”.

Another one of them explained, “The book is good but if there add some more information about the prognosis of child will more effective for me”.

Another one of them told,

“My child is growing and now she is in school. When I got this book that time my child was only 4. So, if the book contains what should I follow or practice with my child at home with her growing ages then it will be more effective for me”.

Children with cerebral palsy benefit greatly from home programs. Despite widespread agreement on the necessity of home program intervention, there is little evidence of efficacy and limited information on program parameters that may influence family engagement. There is some suggestion for home program that provide both professionals and carer. This literature reported that, clinical criteria for home programming must be developed through rigorous formal processes, and the impact of occupational therapy programs must be evaluated (Novak & Cusick, 2006). Result of this study suggest different recommendation to the other parents and therapists. But the most recommendation of the carer to add more information of therapies that help carer to implement home program. Home based intervention in children with CP is effective with various interventions that were carried out at different intensities and some of intervention suggest to perform as a home program during child daily living activities.



All effective center-based intervention that can be performed without therapist is applied as a home-based program for children with CP. These interventions may become more efficient if intensity and frequency can be increased at home. Developing comprehensive information and create guides for child and parents with limited resources may more effective rehabilitation for CP (Beckers et al., 2020). Upgrading instruction is highly recommended by parents for the “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy”.

## CHAPTER V: Conclusion

### 5.1 Strength and Limitation

#### Strength:

##### The strength of this study was:

- This study was the first study in Bangladesh that focus on carer participation about “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy”
- In this study participants were supportive and delivered appropriate data
- The purpose of the study was stated and student researcher achieved outcome of every objective successfully

#### Limitation:

Limitation is one kind of matter and incidence which may occur any time of conducting and constructing the study. Every study has some limitations which is not of student researchers' control (Simon & Goes, 2013).

During the time of conducting this study, there were some limitations presents. By considering these limitations the student researcher conducted this study. The limitations are given bellow:

- There was limited time duration and barriers for data collection and reach participant due to pandemic situation
- In this research study, only find out the carers' views of the home program based on the guidebook. So, it was not possible to measure the childs' outcome rate during continuing home program based on this guidebook

## 5.2: Recommendation

- **Recommendation for occupational therapist in Bangladesh**

Occupational therapist should address this carer practice about “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy” during the time of follow up treatment sessions. Occupational therapist should educate the parents about the book with update information that need for the child with growing age. In occupational therapy follow up session, it needs to include to provide instructions and education about the practice of the guidebook. If occupational therapists include home program based on this guidebook it will highlight the needs of book for the occupational therapy practice and carer participation. So, occupational therapist needs to give attention on this issue during rehabilitation period.

- **Recommendation for further research**

Occupational therapy needs to conduct various studies related to home based intervention. This study related to this topic maybe benefited to occupational therapy professional in Bangladesh. This may involve:

- Findings the outcome of CP child from home program based on this guidebook
- Findings the effectiveness of occupational therapy HP
- Find out the occupational therapy professional and students’ practice about carer active participation rate about the “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy”
- Occupational therapy needs to be addressed different studies about carer participation in HP in different areas like stroke, SCI etc.
- Further research should be conducted with large number of participants. It will help to generalize the result easily

### **5.3 Conclusion**

HP are widely used by occupational therapist as a strategy to address health and development needs of children with cerebral palsy (Novak, 2009). Carer are play the vital role for the home program for CP child. Carer active participation of home program by following “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy” is important. Because this is made with home guideline that helps the parents to practice easily. Regular practicing this guidebook with child also benefited for both CP child and carer. Though carers are positive and knowledgeable about the guidebook and its practice but sometimes they face barriers. Again, they didn't get enough support. All of these demotivated the carer to practice this guidebook at home. These kind of attitude of carer affect the outcome of the treatment program of their child and occupational therapy intervention.

Carer are aware and they feel the need of the book and also satisfied to get this guidebook and practice this guidebook. And that make the “Towards on Inclusive World- A guidebook for the parents of children with cerebral palsy” more valuable as a home guidance. Carer recommended in this study to added more information about therapies that will help them to practice HP. Therapist also need to monitoring and provide education to the carer about this book and practicing home guidance with the child. Because Childs are growing day by day and their therapy will be update with their ages. So, it is need to educate carer about home program following this book at every follow-up session.

Providing motivation and education about regular practicing the guidebook at home with their CP child are needed to be included on occupational therapy treatment session. It is hope that the better rehabilitation for CP Child will facilitate the quality of life through the proper home program based on this guidebook. Overall information

will help the carer and professional to ensure the best use of this book for CP child's outcome.

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# APPENDICES

## Appendix A

### Approval Letter of Institutional Review Board (IRB)



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

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Ref: Date:

CRP/BHPI/IRB/11/2021/530 17/11/2021

Israt Jahan Remi  
 4<sup>th</sup> Year B.Sc. in Occupational Therapy  
 Session: 2016-2017  
 BHPI, CRP, Savar, Dhaka- 1343, Bangladesh

**Subject:** Approval of the research project proposal “Carers’ Views on Practicing Home Program Based on “Towards an Inclusive World: A Guidebook for the Parents of Children with Cerebral Palsy” by ethics committee.

Dear Israt Jahan Remi,  
 Congratulations.

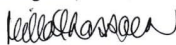
The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application to conduct the above-mentioned dissertation, with yourself, as the principal investigator and Kaniz Fatema as thesis supervisor. The Following documents have been reviewed and approved:

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

The purpose of the study is to explore the carers’ views on practicing home intervention based on “Towards an Inclusive World: A guidebook for the parents of children with cerebral palsy” given from CRP after completing two weeks of in-patient rehabilitation. Should there any interpretation, typo, spelling and grammatical mistakes in the title, it is the responsibilities of the investigator. Since the study involves questionnaire that takes maximum 30-40 minutes and have no likelihood of any harm to the participants, the members of the Ethics Committee approved the study to be conducted in the presented form at the meeting held at 9:15 AM on 15<sup>th</sup> September, 2021 at BHPI (29<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 Millat Hossain  
 Associate Professor, Dept. of Rehabilitation Science  
 Member Secretary, Institutional Review Board (IRB)  
 BHPI, CRP, Savar, Dhaka-1343, Bangladesh

## Appendix B

### Information Sheet and Consent From



### BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)

Department of Occupational Therapy

CRP-Chapain, Savar, Dhaka-1343, Tel: 02-7745464-5, 7741404, Fax: 02-7745069

Code no-

### Participants Information and Consent sheet

**Research topic:** Home based intervention to participate daily living activities following the “Towards on Inclusive world: A guidebook for the parents of children with Cerebral Palsy” provided by the CRP

**Researcher:** Israt Jahan Remi B.Sc. in Occupational Therapy (4<sup>th</sup> year), Session: 2016-2017, Bangladesh Health Professions Institute.

**Supervisor:** Kaniz Fatema, Lecturer in Occupational Therapy, Department of Occupational Therapy, Bangladesh Health Professions Institute.

**Place of Research:** The study will be conducted in the Paediatric unit CRP, Savar, Dhaka-1343.

#### Part-1 Information sheet:

#### Introduction:

I am Israt Jahan Remi, student of 4<sup>th</sup> year B.Sc. in Occupational Therapy session (20162017) studying under the Medicine Faculty of Dhaka University in Bangladesh Health Professions Institute. To complete B.Sc in Occupational Therapy from BHPI conduct a research project is mandatory. This research project will be done under the supervision of Kaniz Fatema, Lecturer in Occupational Therapy. The purpose of the research project is the collection of data and how it will be related to the research and this will be presented to you in detail through this participant paper. If you are willing to participate in this research, in that case the clear idea about the research topic will be easier for decision making. Of course, you do not have to make sure you participate now. Before taking any decision, you can discuss with your relatives, or guardian about this. On the other hand after reading the information sheet if the participant’s problem to understand the content or if you need to know more about something, you can freely ask.

#### Research Background and Objectives:

You are being invited to be a part of this research because in Bangladesh, there is no research on “Home based intervention to participate daily living activities following the “Towards on Inclusive world: A guidebook for the parents of children with Cerebral Palsy” provided by the CRP”. It will investigate the carers practice on homebased intervention by following “Towards on Inclusive world: A guidebook for the parents

of children with Cerebral Palsy”. Your information will be helpful to reveal the understanding of your knowledge and practice about this guidebook. The general



purpose of the study is to know the career's views on practicing home based intervention by following "Towards on Inclusive world: A guidebook for the parents of children with Cerebral Palsy" that given from CRP after completing two weeks of inpatient rehabilitation services.

**Let's know about the topic related to participation in this research work:**

Before signing the consent form, you, the details of managing the research project will be presented to you in detail through this participation note. If you want to participate in this study, you will have to sign the agreement. If you ensure the participation, a copy of your consent will be given. After a representative of collection data till by the researcher will go to you. At any given time taken from you by a question paper information will be collected. Your participation in this research project is optional. If you do not agree then you do not have to participate. Despite your consent, you can withdraw your participation at any time without giving any explanation to the researcher.

**The benefits and risks of participation:**

You will not get any benefit directly to participate in this research project. Participation in this study can lead to many difficulties in your daily work. However, we are hopeful that the benefits direct from the results of this research will remove the disadvantages. Don't worry about the questions that may know about your identity, it's a request. Patients name, address will not be included in the data analysis software to reduce the risk of uncover identity.

**Confidentialities of information:**

By signing this agreement, you are allowing the research staff to study this research project to collect and use your personal resources. Any information gathered for this research project, which can identify you, will be confidential. The information collected about you will be mentioned in a symbolic way. Only the concerned researcher and supervisor will be able to access this information directly. Symbolic ways identified data will be used for the next data analysis. Information sheets will be kept into a locked drawer. Electronics version of data will be collected in BHPI's Occupational Therapy department and researcher's personal laptop. It is expected that the results of this research project will be published and presented in different forums. In any publication and presentation, the information will be provided in such a way that you cannot be identified in any way without your consent. Data will be initially collected in papers.

**Information about promotional result:**

The result of this study will be published in various social media, websites, conference, discussion, and reviewed journals. **Participant's fees:**

There is no stimulus and remuneration for participation in this study.

**Source of funding to manage research:**

The cost of this research will be spent entirely by researchers own funds. This study will be done in small areas and no money come from external source.

**Information about withdrawal from participation:**

Despite your consent, you can withdraw your participation at any time without giving any explanation to the researcher. If the information can be used after the cancellation, its permission will be mentioned in the participant's withdrawal letter (application only volunteer withdrawal)

**Contact address with the researcher:**

If you have any question about the research, you can ask me now or latter. If you wish to ask question later, you may contact any of following: Israt Jahan Remi, Bachelor of Science in Occupational Therapy, Department of Occupational Therapy and Contact number: 01635523960 **Complaints:**

If there is any complaint regarding the conduct of this research project, contact with the Association of Ethics (77454645). This proposal has been reviewed by institutional Review Board (IBR), Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka-1343, Bangladesh, which is committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IBR, contact Bangladesh Health Professions Institute (BHPI), CRP, Savar, Dhaka1343, Bangladesh.

**Participant’s Withdrawal From**

(Applicable only for voluntary withdrawal) Reason

for withdrawal:

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

Whether permission to previous information is used?

Yes/No

Participant’s Name:

Participants Signature:

Date: .....

**Part-2 Consent Sheet:**

---

Code:

I have been invited to participate in the research titled “Home based intervention to participate daily living activities following the “Towards on Inclusive world: A guidebook for the parents of children with Cerebral Palsy” provided by the CRP”. I have read the previous letter or it has been read by me. There was an opportunity to ask my question about this and got a satisfactory answer to the all question. I voluntarily agree to be participated in this study.

Participant Name:

Participant Signature:

Date:

.....

**Researcher and consenting person statement:**

I have read the participant’s information from to the participant and according to my maximum capacity; the participants understand that the following topics will be done:

- 1) All the information will be used in the research work
- 2) Information will be totally confidential
- 3) Participant’s name and identity will not be published

I am sure that the participant has been given the opportunity to ask questions about this topic and accurate answer to these questions has been given as per my maximum capacity. I am convinced that no person has been compelled to give consent. He or she has freely or voluntarily agreed

**A copy of participant’s information and consent sheet has given to the participant** Researcher Name:

Researcher signature:

Date: .....



## Appendix C

### Information sheet and Consent form (Bangla)

## বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)

### অকুপেশনাল থেরাপি বিভাগ

সিআরপি- চাপাইন, সাভার, ঢাকা-১৩৪৩. টেলি: ০২-৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪, ফ্যাক্স: ০২-৭৭৪৫০৬

কোড নং:

### “অংশগ্রহণকারীদের তথ্য এবং সম্মতিপত্র

**গবেষনার বিষয়ঃ** সিআরপি দ্বারা প্রদত্ত “একীভূত পৃথিবীর পথেঃ সেরিব্রাল পালসি শিশুদের আভিভাবকদের জন্য পুনর্বাসন সহায়িকা” অনুসরণ করে দৈনন্দিন জীবনযাত্রার কাজসমূহ গুলো অনুশীলনের জন্য গৃহ ভিত্তিক চিকিৎসা।

**গবেষকঃ** ইসরাত জাহান রেমি বি.এস.সি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ), সেশন: ২০১৬-২০১৭ ইং, বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই), সাভার, ঢাকা- ১৩৪৩

**তত্ত্বাবধায়কঃ** কানিজ ফাতেমা, প্রভাষক, অকুপেশনাল থেরাপি বিভাগ, বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউট।

**গবেষনার স্থানঃ** শিশু বিভাগ, পক্ষাঘাতগ্রস্থদের পুনর্বাসন (সিআরপি), সাভার, ঢাকা-১৩৪৩ বাংলাদেশ।

### পর্ব ১ তথ্যপত্র:

আমি ইসরাত জাহান রেমি, ঢাকা বিশ্ববিদ্যালয়ে চিকিৎসা অনুষদের অধীনে বাংলাদেশ হেলথ প্রফেশন্স ইনস্টিটিউটে বি.এস.সি.ইন অকুপেশনাল থেরাপি বিভাগে ৪র্থ বর্ষের ছাত্রী হিসেবে স্নাতক শিক্ষাকার্যক্রম (২০১৬-২০১৭ইং) সেশনে অধ্যয়নরত আছি। বিএইচপিআই থেকে অকুপেশনাল থেরাপি বি.এস.সি শিক্ষাকার্যক্রমটি সম্পন্ন করার জন্য একটি গবেষণা প্রকল্প পরিচালনা করা বাধ্যতামূলক। এই গবেষণা প্রকল্পটি অকুপেশনাল থেরাপি বিভাগের প্রভাষক কানিজ ফাতেমা এর তত্ত্বাবধায়নে সম্পন্ন করা হবে। এই অংশগ্রহণকারী তথ্যপত্রের মাধ্যমে গবেষণার প্রকল্পটির উদ্দেশ্য, উপাত্ত সংগৃহণের প্রণালী ও গবেষণাটির সাথে সংশ্লিষ্ট বিষয় কিভাবে রক্ষিত হবে তা বিস্তারিত ভাবে আপনার কাছে উপস্থাপন করা হবে। যদি এই গবেষণায় অংশগ্রহণ করতে আপনি ইচ্ছুক থাকেন, সেক্ষেত্রে এই গবেষণার সম্পূর্ণ বিষয় সম্পর্কে স্বচ্ছ ধারণা থাকলে সিদ্ধান্ত গ্রহণ সহজতর হবে। অবশ্য এখন আপনার অংশগ্রহণ আমাদের নিশ্চিত করতে হবে না। যে কোন সিদ্ধান্ত গ্রহণের পূর্বে, যদি চান তাহলে আপনার আত্মীয়-স্বজন, বন্ধু অথবা আস্থাজন যেকারো সাথে এই ব্যাপারে আলোচনা করে নিতে পারেন। অপরপক্ষে, অংশগ্রহণকারী তথ্যপত্রটি পড়ে, যদি কোন বিষয়বস্তু বুঝতে সমস্যা হয় অথবা যদি কোন কিছু সম্পর্কে আরো বেশি জানার প্রয়োজন হয়, তবে নির্দিষ্ট প্রশ্ন করতে পারেন।

### গবেষনার প্রেক্ষাপট ও উদ্দেশ্য:

এই গবেষণাতে সেরিব্রাল পালসি বাচ্চার মা/ বাবা/ যত্নকারীদের অন্তর্ভুক্ত হবার জন্য আমন্ত্রণ জানানো হবে, এর জন্য আপনাকেও উক্ত গবেষণা প্রকল্পে অংশগ্রহণের জন্য আমন্ত্রণ জানানো হলো। এই গবেষণায় সিআরপি দ্বারা প্রদত্ত “একীভূত পৃথিবীর পথেঃ সেরিব্রাল পালসি শিশুদের আভিভাবকদের জন্য পুনর্বাসন সহায়িকা” অনুসরণ করে দৈনন্দিন জীবনযাত্রার কাজসমূহ গুলো অনুশীলনের জন্য গৃহ ভিত্তিক চিকিৎসা

সম্পর্কে জানার

জন্য আপনাকে গবেষণায় অংশগ্রহণের জন্য আমন্ত্রণ জানানো হলো। আপনার তথ্যসমূহ আপনার সহায়িকা বইটি ব্যবহার সম্পর্কে ধারণা দিতে সাহায্য করবে। কারণ আপনি জানেন যে “একীভূত পৃথিবীর পথেঃ সেরিব্রাল পালসি শিশুদের আভিভাবকদের জন্য পুনর্বাসন সহায়িকা” বইটি সিআরপি থেকে দেওয়া হয়ে থাকে যাতে বাচ্চার মা/ বাবা/যত্নকারী অনুসরণের মাধ্যমে বাসায় অনুশীলন করতে পারে এবং এই বিষয়ে কোন গবেষণা করা হয় নি। গবেষণাটির সাধারণ উদ্দেশ্য হল :সেরিব্রাল পালসি বাচ্চার মা,বাবা অথবা যত্নকারীদের বাসায় গৃহ ভিত্তিক চিকিৎসা চালিয়ে যেতে “একীভূত পৃথিবীর পথেঃ সেরিব্রাল পালসি শিশুদের আভিভাবকদের জন্য পুনর্বাসন সহায়িকা” যে বইটি সিআরপি ২ সপ্তাহ অন্তর্বিভাগ থেকে পুনর্বাসন সেবা নেয়ার পরে প্রদান করা হয় সেই বইটি অনুসরণ করা সম্পর্কে মতামত জানা। আপনার কার্যকরী অংশগ্রহণ গবেষণার উদ্দেশ্য পূরণে সহায়তা করবে বলে আমরা আশাবাদী।

### **এই গবেষণা কর্মটিতে অংশগ্রহণের সাথে সম্পৃক্ত বিষয়সমূহ কি সে সম্পর্কে জানা যাক।**

আপনার থেকে অনুমতিপত্র স্বাক্ষর নেবার আগে, এই অংশগ্রহণকারী তথ্যপত্রের মাধ্যমে গবেষণা প্রকল্পটির পরিচালনা করার তথ্যসমূহ বিস্তারিত ভাবে আপনার কাছে উপস্থাপন করা হবে। আপনি যদি এই গবেষণায় অংশগ্রহণ করতে চান, তাহলে সম্মতিপত্র আপনাকে স্বাক্ষর করতে হবে। আপনি যদি স্বাক্ষর জ্ঞান সম্পন্ন না হন বা অন্য কোন কারণে স্বাক্ষর প্রদানে ব্যর্থ হন, সেক্ষেত্রে আপনার কাছ থেকে একজন স্বাক্ষর উপস্থিতিতে বৃদ্ধাঙ্গুলির ছাপ সম্মতি পত্র নেওয়া হবে। আপনি অংশগ্রহণ নিশ্চিত করলে, আপনার সংরক্ষনের জন্য সম্মতিপত্রটির একটি অনুলিপি দিয়ে দেয়া হবে। পরবর্তীতে গবেষক কর্তৃক গঠিত তথ্য-উপাত্ত সংগ্রহের একটি দলের প্রতিনিধি আপনার কাছে যাবে। আপনার থেকে চেয়ে নেওয়া যে কোন একটি নির্দিষ্ট সময়ে একটি প্রশ্নপত্রের মাধ্যমে তথ্য সংগ্রহ করা হবে। এই গবেষণার প্রকল্পে আপনার অংশগ্রহণ ঐচ্ছিক। যদি আপনি সম্মতি প্রদান না করেন তবে আপনাকে অংশগ্রহণ করতে হবে না। আপনি সম্মতি প্রদান করা স্বত্বেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহণ প্রত্যাহার করতে পারবেন।

### **অংশগ্রহণের সুবিধা ও ঝুঁকিসমূহ কি?**

গবেষণা প্রকল্পটিতে অংশগ্রহণের জন্য আপনি সরাসরি কোন সুবিধা পাবেন না। এই গবেষণায় অংশগ্রহণে আপনার দৈনন্দিন কাজে সাময়িক অসুবিধার কারণ হতে পারে। তবে আমরা আশাবাদী যে, এই গবেষণার ফলাফল থেকে প্রাপ্ত উপকারীতা এই অসুবিধাকে অতিক্রম করবে। যে সমস্ত প্রশ্নের মাধ্যমে আপনার পরিচয় সম্পর্কে অন্যরা জানতে পারে, সেই বিষয়ে উদ্বিগ্ন না হবার জন্য অনুরোধ করা হচ্ছে। অংশগ্রহণকারীর নাম, ঠিকানা উপাত্ত বিশ্লেষণের সফটওয়্যারে উল্লেখ না করে পরিচয় উন্মুক্ত হবার ঝুঁকি কমানো হবে।

### **তথ্যের গোপনীয়তা কি নিশ্চিত থাকবে?**

এই সম্মতিপত্র স্বাক্ষর করার মধ্য দিয়ে, আপনি এই গবেষণা প্রকল্পে অধ্যয়নরত গবেষণা কর্মীকে আপনার ব্যক্তিগত তথ্য সংগ্রহ ও ব্যবহার করার অনুমতি দিয়েছেন। এই গবেষণা প্রকল্পের জন্য সংগৃহীত যেকোন তথ্য, যা আপনাকে সনাক্ত করতে পারে তা গোপনীয় থাকবে। আপনার সম্পর্কে সংগৃহীত তথ্যসমূহ সাংকেতিক উপায়ে উল্লেখ থাকবে। শুধুমাত্র এর সাথে সরাসরি সংশ্লিষ্ট গবেষক ও তার তত্ত্বাবধায়ক এই তথ্যসমূহে প্রবেশাধিকার পাবেন। সাংকেতিক উপায়ে চিহ্নিত উপাত্ত সমূহ পরবর্তী উপাত্ত বিশ্লেষণের কাজে ব্যবহৃত হবে। তথ্যপত্রগুলো তালাবদ্ধ ড্রয়ারে রাখা হবে। বিএইচপিআই এর অকুপেশনাল খেরাপি বিভাগে ও গবেষকের ব্যক্তিগত ল্যাপটপে উপাত্তসমূহের ইলেকট্রনিক ভার্সন সংগৃহীত থাকবে।

প্রত্যাশা করা হচ্ছে যে, এই গবেষণা প্রকল্পের ফলাফল বিভিন্ন ফোরামে প্রকাশিত এবং উপস্থাপিত হবে। যে কোন ধরনের প্রকাশনা ও উপস্থাপনার ক্ষেত্রে তথ্যসমূহ এমন ভাবে সরবরাহ করা হবে, যেন আপনার সম্মতি ছাড়া আপনাকে কোন ভাবেই সনাক্ত করা না যায়। তথ্য-উপাত্ত প্রাথমিক ভাবে কাগজপত্র সংগ্রহ করা হবে।

### ফলাফল প্রচার সর্পিকিত তথ্য

এই গবেষণার ফলাফল বিভিন্ন সামাজিক মাধ্যম, ওয়েবসাইট, সম্মেলন, আলোচনাসভায় এবং পর্যালোচিত জার্নালে প্রকাশ করা হবে।

### অংশগ্রহণকারীর পারিশ্রমিক

এই গবেষণায় অংশগ্রহণের জন্য কোন উদ্দীপনা ও পারিশ্রমিক দেবার ব্যবস্থা নেই।

### গবেষণা পরিচালনার ব্যয়কৃত অর্থের উৎস

এই গবেষণাটির খরচ সম্পূর্ণ গবেষকের নিজস্ব তহবিল থেকে ব্যয় করা হবে। এই গবেষণাটি ছোট পরিসরে করা হবে এবং এখানে কোন অর্থ বহিরাগত উৎস থেকে আসবে না।

### অংশগ্রহণ থেকে প্রত্যাহার সর্পিকিত তথ্যসমূহ

আপনি সম্মতি প্রদান করা স্বত্তেও যে কোন সময় গবেষককে কোন ব্যাখ্যা প্রদান করা ছাড়াই নিজের অংশগ্রহণ প্রত্যাহার করতে পারবেন। বাতিল করার পর তথ্যসমূহ কি ব্যবহার করা যাবে কি যাবেনা তার অনুমতি অংশগ্রহণকারীর প্রত্যাহারপত্রে (শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য) উল্লেখ করা থাকবে।

### গবেষকের সাথে যোগাযোগের ঠিকানা

গবেষণা প্রকল্পটির বিষয়ে যোগাযোগ করতে চাইলে অথবা গবেষণা প্রকল্পটির সর্পিকে কোন প্রশ্ন থাকলে, এখন অথবা পরবর্তীতে যে কোন সময়ে তা জিজ্ঞাসা করা যাবে। সেক্ষেত্রে আপনি গবেষকের সাথে উল্লেখিত ০১৬৩৫৫২৩৯৬০ (ইসরাত জাহান রেমি) নাম্বারে যোগাযোগ করতে পারেন।

### অভিযোগ

এই গবেষণা প্রকল্প পরিচালনা প্রসঙ্গে যেকোন অভিযোগ থাকলে প্রাতিষ্ঠানিক নৈতিকতা পরিষদের সাথে এই নাম্বারে (৭৭৪৫৪৬৪-৫) যোগাযোগ করবেন। এই গবেষণা প্রকল্পটি বাংলাদেশ হেল্থ প্রফেশনাল ইনস্টিটিউট, সাভারের প্রাতিষ্ঠানিক নৈতিকতা পরিষদ থেকে সিআরপি-বিএইচপিআই/আইআরবি/১০/১৮/১২৩৪ পর্যালোচিত ও অনুমোদিত হয়েছে।

## অংশগ্রহণকারীর প্রত্যাহার পত্র

(শুধুমাত্র স্বেচ্ছায় প্রত্যাহারকারীর জন্য প্রযোজ্য)

অংশগ্রহণকারীর নাম: .....

প্রত্যাহার

করার

কারণ:

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

পূর্ববর্তী তথ্য ব্যবহারের অনুমতি থাকবে কিনা?

হ্যাঁ/না

অংশগ্রহণকারীর

নাম:

অংশগ্রহণকারীর স্বাক্ষর:

তারিখ:

.....

যদি নিরক্ষর হয়\*

অংশগ্রহণকারীর

আঙ্গুলের ছাপ

কোড নং:

**পর্ব ০২ সম্মতি পত্র:**

" সিআরপি দ্বারা প্রদত্ত "একীভূত পৃথিবীর পথেঃ সেরিব্রাল পালসি শিশুদের আভিভাবকদের জন্য পুনর্বাসন সহায়িকা" অনুসরণ করে দৈনন্দিন জীবনযাত্রার কাজসমূহ গুলো অনুশীলনের জন্য গৃহ ভিত্তিক চিকিৎসা।"

- শীর্ষক গবেষণায় অংশগ্রহনের জন্য আমাকে আমন্ত্রন জানানো হয়েছে। আমি পূর্বলিখিত তথ্য পত্রটি পড়েছি বা এটা আমাকে পড়ে শোনানো হয়েছে। এই বিষয়ে আমার প্রশ্ন জিজ্ঞাসা করার সুযোগ ছিল এবং যে কোন প্রশ্নের আমি সন্তুষ্টিজনক উত্তর পেয়েছি। এই গবেষণায় একজন অংশগ্রহনকারী হবার জন্য আমি স্বেচ্ছায় সম্মতি দিচ্ছি।

অংশগ্রহনকারীর নাম:

অংশগ্রহনকারীর স্বাক্ষর:

তারিখ: .....

যদি

নিরক্ষর

হয়\*

অংশগ্রহনকারীর আঙ্গুলের ছাপ

সাক্ষীর

স্বাক্ষর:

তারিখ: .....

গবেষক ও সম্মতিকারীর বিবৃতি:

আমি অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্যপত্রটি পড়ে শুনিয়েছি এবং আমার সর্বোচ্চ সামর্থ অনুযায়ী নিশ্চিত করেছি যে, অংশগ্রহনকারীর বোধগম্য হয়েছে যে, নিম্নোক্ত বিষয়সমূহ করা হবে।

১) সকল তথ্য গবেষণার কাজে ব্যবহৃত হবে।

২)

তথ্যসমূহ সম্পূর্ণভাবে গোপনীয় করা হবে।

৩)

অংশগ্রহনকারীর নাম ও পরিচয় প্রকাশ করা হবে না।

আমি নিশ্চিত করেছি যে, এই বিষয় সর্ম্পকে অংশগ্রহনকারীকে প্রশ্ন জিজ্ঞাসা করার সুযোগ দেয়া হয়েছে এবং অংশগ্রহনকারী যে সকল প্রশ্ন জিজ্ঞাসা আমার সর্বোচ্চ সামর্থ অনুযায়ী, সেগুলোর সঠিক উত্তর প্রদান করা সম্ভব হয়েছে। আমি নিশ্চিত করেছি যে, কোন ব্যক্তিকে সম্মতি দান করতে বাধ্য করা হয়নি। তিনি অবাধে অথবা স্বেচ্ছায় সম্মতি দিয়েছেন।

*অংশগ্রহনকারীকে অংশগ্রহনকারীর তথ্য ও সম্মতিপত্রের একটি অনুলিপি দেওয়া হয়েছে।*

গবেষকের নাম:

গবেষকের স্বাক্ষর:

তারিখ: .....



## **Appendix D**

### **Questions**

#### **General information**

Interview date:

Time:

Duration:

Name of the patient:

Age:

Education:

Gender:

Contact number:

Address:

Relationship with children:

Total children numbers:

Have other children with disability:

### **Interview question**

1. Please explain what do you know about this “Towards on Inclusive World: A guidebook for the parents of children with Cerebral Palsy”?
2. Please describe how the “Towards on Inclusive World: A guidebook for the parents of children with Cerebral Palsy” facilitate you to continue home intervention for your child?
3. How the “Towards on Inclusive World: A guidebook for the parents of children with Cerebral Palsy” help you to practice daily living activities at home for your child?
4. Please explain is there anyone who help you at the time of practicing “Towards on Inclusive World: A guidebook for the parents of children with Cerebral Palsy”?
5. Please explain what types of challenges do you face at that time of providing home treatment following this guidebook “Towards on Inclusive World: A guidebook for the parents of children with Cerebral Palsy”?
6. Please describe are you satisfied about this home guidance of this book “Towards on Inclusive World: A guidebook for the parents of children with Cerebral Palsy” at the time of practicing home intervention?
7. Please explain do you have any advice about this guidebook “Towards on Inclusive World: A guidebook for the parents of children with Cerebral Palsy”?

## সাধারণ তথ্যাবলিঃ

সাক্ষাৎকারের তারিখঃ সময়ঃ স্থায়িত্বকালঃ

অংশগ্রহণকারীর নামঃ

বয়সঃ শিক্ষাঃ লিঙ্গঃ

ঠিকানাঃ

ফোন নাম্বারঃ

বাচ্চার সাথে সম্পর্কঃ

মোট বাচ্চার সংখ্যাঃ

প্রতিবন্ধি আর কোনো বাচ্চা আছেঃ

প্রশ্নঃ

- ✓ আপনি “একীভূত পৃথিবীর পথে” সহায়িকা বইটি সম্পর্কে কি জানেন দয়াকরে ব্যাখ্যা করুন।
- ✓ “একীভূত পৃথিবীর পথে” নির্দেশিকা বইটি আপনাকে আপনার সন্তানের জন্য বাড়িতে চিকিৎসা চালিয়ে যেতে কিভাবে সহায়তা করে? দয়াকরে বর্ণনা করুন।
- ✓ আপনার সন্তানের দৈনন্দিন কাজের অনুশীলনে “একীভূত পৃথিবীর পথে” বইটি আপনাকে কিভাবে সাহায্য করে?
- ✓ “একীভূত পৃথিবীর পথে” বইটি অনুশীলনের সময় আপনাকে কি কেউ সাহায্য করে? দয়াকরে ব্যাখ্যা করুন।
- ✓ “একীভূত পৃথিবীর পথে” সহায়িকা বইটি অনুসরণ করে বাড়িতে চিকিৎসা দেওয়ার সময় আপনি কি ধরনের প্রতিবন্ধিকতার সম্মুখীন হয়ে থাকেন? দয়াকরে ব্যাখ্যা করুন।
- ✓ বাড়িতে চিকিৎসাগুলো অনুশীলনের সময় আপনি কি এই “একীভূত পৃথিবীর পথে” সহায়িকা বইটি নিয়ে সন্তুষ্ট? দয়াকরে বর্ণনা করুন।
- ✓ “একীভূত পৃথিবীর পথে” সহায়িকা বইটি সম্পর্কে আপনার কোনো পরামর্শ/মতামত রয়েছে? দয়াকরে ব্যাখ্যা করুন।

## Appendix E

### Overall information of participants

<b>Code</b>	<b>Age</b>	<b>Sex</b>	<b>Education</b>	<b>Occupation</b>	<b>Living area</b>
P <sub>1</sub>	29	Female	Class 8	Housewife	Lokkhipur
P <sub>2</sub>	42	Male	MA	Business	Mymensingh
P <sub>3</sub>	30	Female	Class 8	Housewife	Savar
P <sub>4</sub>	30	Female	HSC	Housewife	Lokkhipur
P <sub>5</sub>	26	Female	B.Sc	Housewife	Noakhali
P <sub>6</sub>	20	Female	HSC	Housewife	Dhamrai
P <sub>7</sub>	22	Female	HSC	Housewife	Cumilla
P <sub>8</sub>	27	Female	B.B.S	Housewife	Noakhali
P <sub>9</sub>	25	Female	HSC	Housewife	Lokkhipur
P <sub>10</sub>	25	Female	HSC	Housewife	Savar
P <sub>11</sub>	22	Female	Class 8	Housewife	Savar

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