

**“IMPACT OF COMMUNITY BASED REHABILITATION (CBR)  
PROGRAM UPON PARENTS HAVING CHILDREN WITH  
CEREBRAL PALSY IN BANGALORE”**

By  
Doly Bokalial

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Submitted in Partial Fulfillment of the Requirements for the Degree of  
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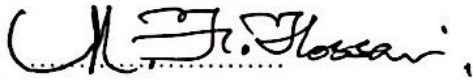


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## SUPERVISOR'S STATEMENT

As the supervisor of Ms Doly Bokalial's Thesis work, I certify that I consider her thesis "Impact of community based rehabilitation (CBR) program upon parents having children with cerebral palsy in Bangalore" to be suitable for examination.



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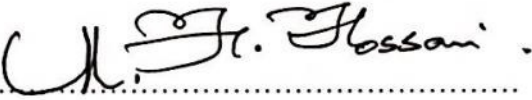
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- This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.
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## LIST OF ABBREVIATIONS AND ACRONYMS

APD: Association of People with Disability

BHPI: Bangladesh Health Professions Institute

CI: Confidence Interval

CP: Cerebral Palsy

CRP: Center for the Rehabilitation of Paralyzed

CRPD: The Convention on the Rights of Persons with Disabilities

GMFCS: Gross Motor Function Classification System

IBM: International Business Machine

ID: Intellectual disability

ILO: International Labour Organization

IRB: Institutional Review Board

PWD: Persons with Disabilities

QOL: Quality of Life

SPSS: Statistical Package for social science

UNESCO: The United Nations Educational, Scientific and Cultural Organization

WHO: World Health Organization

## **ABSTRACT**

Cerebral palsy (CP) is one of the most common causes of neurological impairment in children, and can be associated with lifelong disability (Pakula et al., 2009). Caring for a child with a disability affects the role of both parents, but the daily lives of mothers are often more affected, because they are usually the primary caregivers for the child. The estimated incidence of CP in India is around 3/1000 live births (Vyas et al., 2013). Community Based Rehabilitation (CBR) program aims to provide rehabilitation, reduce poverty, equalize opportunities and promote the inclusion of persons with disabilities in their communities and does this through a comprehensive and multi-sectorial approach that is aligned with the Convention on the rights of persons with disabilities (CRPD) (WHO, 2015).

Our aim of the study is to find the impact of CBR program on parent's life and to identify the challenges experienced by parents in raising their children with cerebral palsy at Bangalore area in India.

With the above aim and objective a cross sectional, descriptive study design was used to collect a sample of 100 parents of children with cerebral palsy; GMFCS level IV and V. These information were collected from various communities of Bangalore, Davanegere and Bijapur, India where APD services are available. Face to face interview was conducted with study subjects. Data were analyzed by SPSS using descriptive and inferential statistics to identify the impact of CBR program upon parents and have tried to establish association between various components of CBR matrix.

It has been observed that there is a positive impact of CBR program on parent's health, knowledge, social lives and empowerment. A binary logistic regression was done to find out the relationship between health, knowledge, social lives and assistive device uses. It was found that there is a strong association between health and knowledge ( $p=.001$ ); health and social lives ( $p<.001$ ); knowledge and social lives ( $p<.001$ ); GMFCS and assistive device ( $p=.004$ ) at 95% CI. The odds ratios between them are greater than 1 and shows high effectiveness of CBR program upon parents too.

**Key words:** Cerebral Palsy; CBR; Rehabilitation; GMFCS.

## CHAPTER I: INTRODUCTION

### 1.1 Introduction :

Community based rehabilitation (CBR) programs have been described as highly effective means of promoting the rights and opportunities of persons with disabilities (PWD). CBR principles and concept blend with home health care. Home health care is defined as “A component of comprehensive care whereby health services are provided to individuals and families in their places of residence for the purpose of promoting, maintaining or restoring health” (Hoeman, 1992). Although CBR programs are often the main way in which PWDs in low and middle income countries access rehabilitation services, there is little literature providing rigorous evaluation of their impact on people’s well-being.

Cerebral palsy (CP) is one of the most common causes of neurological impairment in children, and can be associated with lifelong disability (Brannen and Heflinger, 2006; Pakula et al., 2009). Sensory, motor, speech and other cognitive impairments are also experienced by children with CP (Pakula et al., 2009). Because of the functional limitations experienced, some children with CP are dependent on others for assistance with daily activities, which leads to long-term caregiving that far exceeds the usual needs of typically developing children (Resch et al. 2010). Providing the high level of care required by a child with long-term functional limitations can become burdensome, and may affect both the physical and psychological health of the caregiver (Dambi and Jelsma, 2014; Raina et al., 2005). Caring for a child with a disability affects the role of both parents, but the daily lives of mothers are often more affected, because they are usually the primary caregivers for the child. The estimated incidence of CP in India is around 3/1000 live births (Vyas et al., 2013). Being a developing country, the expected actual figure may be much more.

Research and evaluation on the conditions under which CBR programs are most effective for different populations is definitely needed, in the respect of both CBR principles and standards for effective research and evaluation (Grandisson et al., 2014). The CBR program method was found efficient in overcoming the economic, cultural and geographical barriers and was found to be more effective in retaining patients and their families in programs (Chatterjee et al., 2003).

## 1.2 Justification

Providing care for a child with a long-term health condition is often associated with negative health outcomes in caregivers, for instance, depression, stress, anxiety and low self-efficacy were reported in caregivers (Murphy et al., 2007). Cerebral palsy (CP) is the most common paediatric disability causing long-term functional limitations (Beckung and Hagberg, 2002). Children with CP most often present with multiple impairments, activity limitations and participation restrictions (Beckung and Hagberg, 2002). Most children require lifetime extensive assistance in functional day to day activities (Bjornson and McLaughlin, 2001). The level of required assistance depends on the severity of impairments, activity limitations and participation restrictions (Jette, 2006). Taking care of a child is part of normal parenthood; however, the excessive demands associated with taking care of a child with a disability may lead to increased burden/ strain (Green, 2007). Consequently, long-term caregiving for a child with CP may negatively affect the well-being of caregivers (Davis et al., 2010; Raina, et al., 2005). Mothers experienced social isolation and marital problems, as well as negative attitudes from family, friends, community members and health care professionals. The physical environment created access challenges because of a lack of sidewalks, ramps, functioning lifts and small indoor spaces. Mothers of children with IDs reported lower levels of happiness, self-esteem and self-efficacy than mothers of children without IDs (Emerson et al., 2006). Applying CBR programs in the rural and remote areas can be effective in improving the QOL of people with physical disability (Roghieh et al., 2015). Somewhere focus is only given to children with disability but as we know Parents and care takers are also co-related with the child as they are engaged with them 24 hours, so it is necessary to give importance to them also as it can directly influence the result of rehabilitation. Therefore, the purpose of this study is to find out how parents are benefited from CBR program and how their life change after implementation of CBR program. There are limited researches on impact of CBR program on parents with a disabled child not only in India but in entire South - Asian region, African region and in Middle East region. By collecting data from the parents about their life we will gain the insight of the CBR program. **The result and conclusion drawn from this study will help CBR programs to identify groups of persons (parents) who benefit less from specific activities and adopt strategies to improve their participation and can be used in further development of CBR program. Also more emphasize can be given to parents while designing a program.**

### **1.3 Research Question**

How CBR program change the life of parents with Cerebral Palsy children?

Whether parents are satisfied with CBR programs and according to them is there any steps/items that are lacking in the program?

Present health, knowledge, social live status of parents in the community.

### **1.4 Operational Definition**

#### **Community Based Rehabilitation:**

The measures taken at the community level to use and build on the resources of the community, including disable persons themselves, their families, and their community as a whole (Report of WHO Expert Committee on Disability, 2006).

According to WHO (2014) CBR focuses on enhancing the quality of life for people with disabilities and their families; meeting basic needs; and ensuring inclusion and participation.

The ILO/UNESCO/WHO Joint Position Paper defines CBR as a “strategy within general community development for the rehabilitation, poverty reduction, equalization of opportunities and social inclusion of all people with disabilities” (ILO/UNESCO/WHO, 2004).

#### **Cerebral palsy:**

Cerebral palsy is a physical disability that affects movement and posture.

Cerebral: of the brain and Palsy: lack of muscle control. Cerebral palsy is an umbrella term that refers to a group of disorders affecting a person’s ability to move. It occurs due of damage to the developing brain either during pregnancy or shortly after birth.

Cerebral palsy is primarily a disorder of movement and posture. It is defined as an “umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development” (Sankar and Mundkur, 2005).



## **CHAPTER II: LITERATURE REVIEW**

### **2.1 Community Based Rehabilitation (CBR)**

Most of the world's population with disabilities lives in low- and middle-income countries, facing stigma, discrimination, barriers to equal participation, and lack of appropriate services. Community-based rehabilitation (CBR), developed by WHO in the 1970s, has evolved over the years to address the wider needs of persons with disabilities, to maximize their participation and inclusion in society and to enhance their quality of life. CBR is currently implemented in over 100 countries around the World.

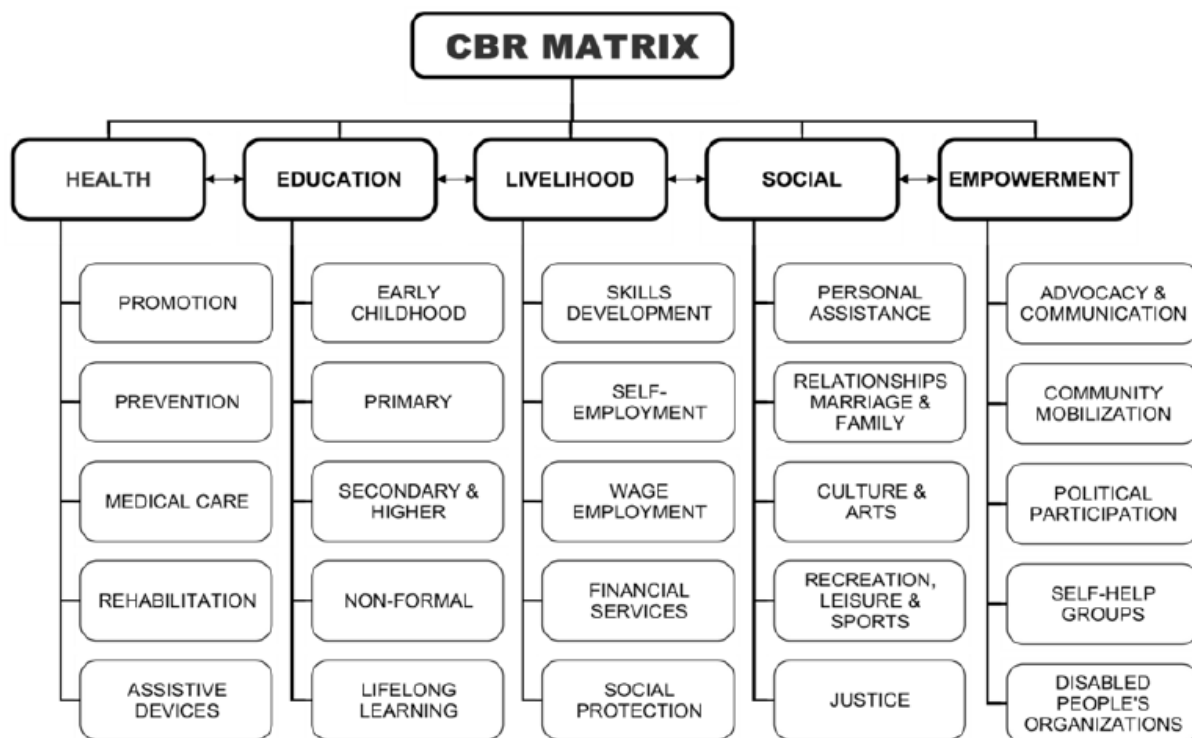
CBR is a strategy within general community development for rehabilitation, equalization of opportunities, and social inclusion of all children and adults with disabilities (ILO, UNESCO and WHO, 2004). The CBR concept is both simple and complex in nature. The simplicity has to do with its origins, i.e., delivery of rehabilitative services to people with disabilities in their communities. CBR's complexity is the result of the current concept of CBR programs as multi-disciplinary, i.e., visiting people with disabilities and their families in their homes; providing appropriate information, therapy and/or training; and facilitating rights and duties of people with disabilities, family, and community members (Vanneste, 2001). CBR programs in the rural and remote areas can be effective in improving the QOL of people with physical disability (Hatami et al., 2015).

The meaning of rehabilitation is not only concerned with physical or functional restoration/compensation of individuals disabled by injury or disease. Attention is also given to the total quality of life in terms of wellness, happiness and satisfaction in fulfilling the demands needs capacities of human existence in orientation, freedom of movement, independence, expression of self (with respect to age, sex and culture), relationship and ability to ensure independent economic existence. After a serious injury, illness or surgery, one needs to recover slowly. There is the need to regain strength, to relearn skills or find new ways of doing things one did before. This is the process of rehabilitation. Children who are born with disabilities need stimulation for development and adaptation – habilitation (Winnick, 1979), and those who acquire disabilities also need rehabilitation. Technically, therefore, rehabilitation is a creative procedure that includes the cooperative efforts of various medical specialists, and associates in other health, technical and environmental fields, to improve the physical, mental, social and vocational aptitudes of the disabled, with the

objectives of preserving and improving their ability to live happily and productively on the same level, and with the same opportunities as their neighbors (Krusen et al., 1971; Olaogun, 2007). In other words, it is a process of decreasing the dependence of the disabled person, by developing to the greatest extent possible, the abilities needed for adequate functioning in his individual situation in the community (Helinder, 1984).

CBR aims to provide rehabilitation, reduce poverty, equalize opportunities and promote the inclusion of persons with disabilities in their communities and does this through a comprehensive and multi-sectorial approach that is aligned with the Convention on the rights of persons with disabilities (CRPD) (WHO, 2015).

The CBR matrix has five key components which show the different sectors of the CBR strategy as a component of community development. They are health, education, livelihood, social and empowerment. In health, attention is focused on wellness promotion, disease prevention, medical care rehabilitation and use of assistive devices. The subsets of education are early childhood development, non-formal education, and formal. Livelihood is concerned with skill development, self-employment, waged-employment, financial services and social protection. The subsets of social components are personal assistance, relationship, marriage and family, culture, religion, arts, sports recreation, leisure and access to justice. On empowerment, the disabled individual is involved in social mobilization, political participation, self-help groups and disabled peoples' organizations (WHO, 2007). Lindoewood (2005) contended that by supporting and developing a network of disabled self-help groups, there is a systematic development structure through which medical therapeutics and other individualized services can be channeled with greater effectiveness. The disabled communities are enabled to become part of the solution rather than remaining the problem. It is important to stress those public offices and utilities should provide access and protection to the physically-disabled.



**Figure 1: CBR Matrix**

Measuring impact of CBR: Carrying out evaluations of CBR programs is essential in order to monitor its effectiveness and relevance. Hartley (2008) articulates that without evaluation the impact of CBR is not confirmed, which in turn could affect the integrity of a CBR program. Since the conception of CBR, there have been a considerable number of CBR evaluations worldwide (Chappell and Johannsmeier, 2009).

In the current study it appears that CBR have had an impact on families of PWD both directly and indirectly. For instance, direct interventions such as counseling and training with parents of children with disabilities and other family members had an impact on their self-esteem and confidence in dealing with their disabled family member. The study showed that the impact of CBR was not just the result of individual medical rehabilitation, but included aspects of community development, poverty reduction, social inclusion and equalization of opportunities, as set out in the joint position paper definition of CBR (Engle et al., 2011).

In a study it is found that the CBR program evaluated has a positive impact on access to services and the well-being of PWD who are particularly deprived on outcomes of interest (Mauro et al., 2014).

## **2.2 Situation of Parents having Cerebral Palsy children**

Caring a child with a disability affects the role of both parents, but the daily lives of mothers are often more affected, because they are usually the primary caregivers for the child. Mothers who care for their children with CP experience many challenges. Broadly, the challenges include psychological ones owing to caregiver demands and uncertainties (Glasscoe et al., 2007; Sajedi et al., 2010) and physical health challenges that emanate from excessive stress and through constantly assisting their children in activities of daily living (Tonga and Duger, 2008). In addition the mothers experience socio-economic challenges because many mothers lack employment opportunities (Borst, 2010) as well as marital problems (Vijesh and Sukumaran, 2007). The challenges could therefore be viewed within a bio-psychosocial model of disability (WHO, 2001). It is therefore evident that the quality of life of these mothers is negatively affected as a result of caring for their children with CP (Olawale et al., 2013; Yilmaz et al., 2013). Caring for a child with CP may be overwhelming, resulting in sorrow and grief as the reality of lost hopes and dreams becomes apparent (Huang et al., 2010). It has been reported that, in addition to the emotional problems parents have to deal with the negative attitudes of friends, relatives and the community at large (Lynch, 2007). These experiences have been described by mothers and caregivers of disabled children in developed countries as well as developing countries including Asia and Africa (Dambi and Jelsma, 2014; Geere et al., 2013; Sandy et al., 2013).

In a study in Africa, participants reported experiencing social isolation and negative attitudes from their friends, family and the community. In most cases their friends and family members failed to accept the children with CP. The negative attitudes experienced were partly as a result of traditional and cultural beliefs and partners who with or without their families blaming the mothers for the condition of their children. This led to discrimination and prejudice against the mothers and their children (Sandy et al., 2013). Besides there are believes that disability has a spiritual cause (Wegner and Rhoda, 2015) and so parents have also been accused of causing their children's disability (Ambikile and Outwater, 2012). This response from society causes parents of these children to isolate themselves and keep their children at home (Adegoke et al., 2013). The mothers with CP children experienced challenges which affect them physically as well as emotionally. They also experienced marital problems. As a result the mothers were isolated and lacked social support (Singogo et al., 2015).

Children with cerebral palsy and associated impairments are at higher risk of poorer health and family well-being. A family-centered approach to the care of children with cerebral palsy and their families is essential to ensure both receive adequate care and support (Parkes et al., 2009).

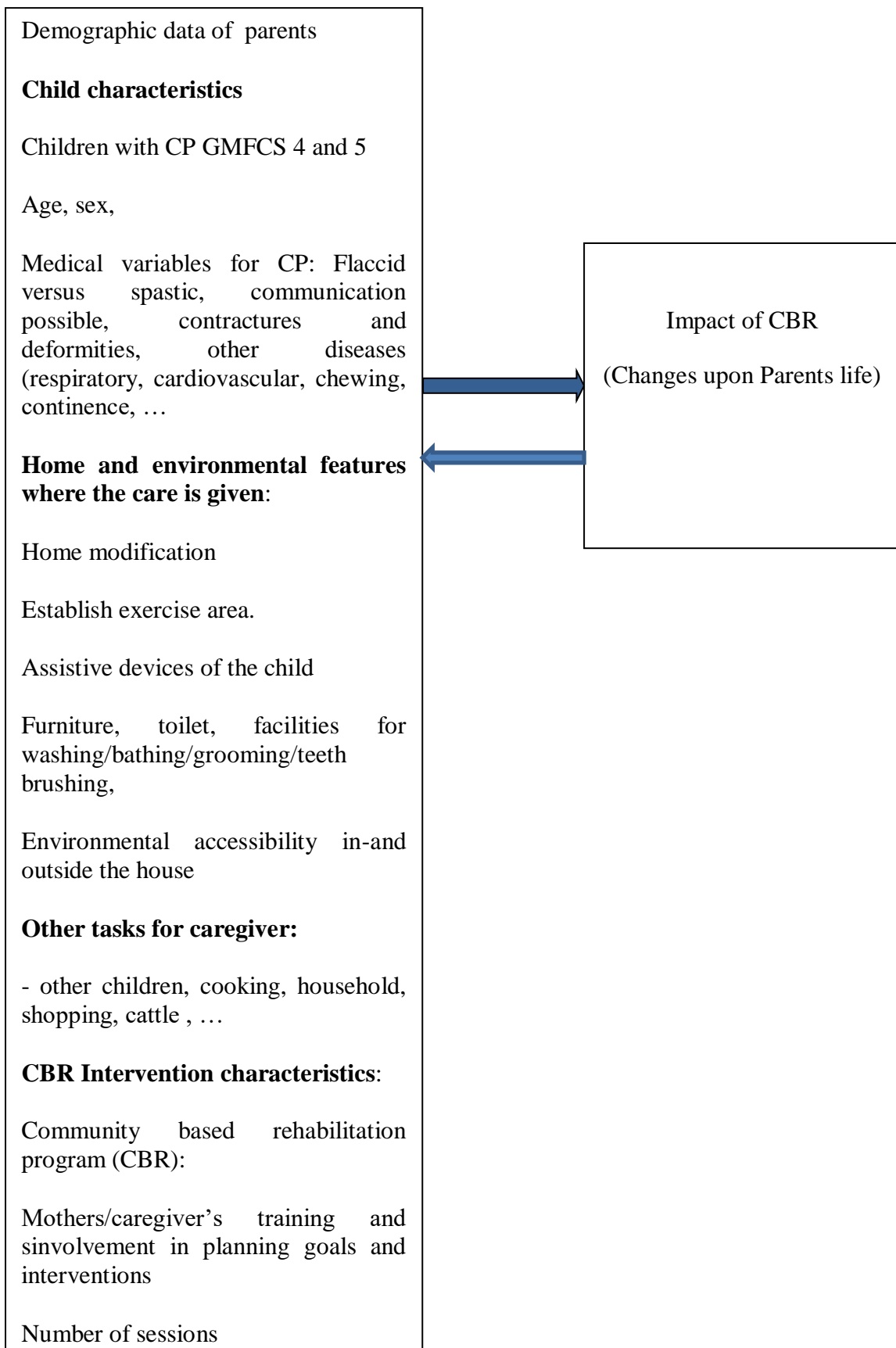
A child with CP in a family may lead to parents perceiving restrictions in family participation. These restrictions arise early in the life of a child with CP and may become more prominent as the child grows older (Rentinck et al., 2009).

In a study in India it is found that most of the parents quality of life was neither good nor bad. They stated that it may be because they would have learned to cope with the situation. The major affected domain was social followed by psychological domain. Majority of parents were satisfied with their own health. Most of the difficulties were due to lower socioeconomic class, limited finances, lack of awareness about the disease and the available health care facilities (Chalipat et al., 2016).

Some studies report that HRQOL of mothers with CP children is affected negatively (White-Koning et al., 2007; Arnaud et al., 2008). While HRQOL of mothers is reported to be associated with depression anxiety negatively, educational status, and functional levels, others assert that no correlation is present between HRQOL of mothers and functional levels of CP children (Yilmaz et al., 2013). In a study it was found that 70% of mothers with CP children were reported to have mild-to-moderate depression, and the depression was reported to have a negative effect on HRQOL of mothers (Diwan et.al, 2011).

## CHAPTER III: METHODOLOGY

### 3.1 Conceptual Framework



## **3.2 Study objectives**

### **3.2.1 General Objective**

To find out the Impact of Community Based Rehabilitation program on parent's knowledge, health and social lives having children with cerebral Palsy in Bangalore (urban, semi-urban and rural areas).

### **3.2.2 Specific Objectives**

- To identify the challenges those are overcome by parents after CBR program.
- To identify the improvements in parents lifestyle in 4 domains of CBR matrix
- To find out if any further changes required in the program for better result.
- To determine the family attitude, social inclusion, acceptance after implementing the program.

## **3.3 Study Design:**

It was a cross-sectional research mainly focusing on the impact of CBR program on parents and also to find the challenges and things that are needed to include in the CBR program in future for more effectiveness. Mixed (Qualitative and quantitative) study was applied to achieve the overall and specific objectives of this study. The investigator identified in-depth information about current CBR program. Participants were asked to provide information about their health, social, knowledge and empowerment status. Also suggestions were taken from them about how to improve the CBR program. Data were collected from individual mothers and fathers who were involved in children daily activities via interview as well completing questionnaire. The study was a cross-sectional design because it is effective design to collect quantitative as well as qualitative information about different variable that comes into play in the study. The study focuses to identifying the changes achieved by parents in their health, knowledge and social lives after implementing CBR program. Therefore, this study provides the impact of CBR program and its lacking's that could be address in near future by stakeholders.

### **3.4 Study population**

Mothers with CP children were the study target population. Investigator has used convenient sampling procedure to select the potential participants.

### **3.5 Study area:**

The study was conducted at Association of People with Disability at Bangalore in India. Data were collected from 3 districts of Karnataka they are Davangere, Bijapur and Bangalore.

### **3.6 Study period:**

December 2017 to May 2018

### **3.7 Sample Size:**

Sample size is 100.

### **3.8 Inclusion and Exclusion criteria**

#### ***3.8.1 Inclusion criteria***

- Mother / Father with CP children
- Child above 6 months and below 15 years
- GMFC - IV and V
- Covered under CBR program

#### ***3.8.2 Exclusion criteria:***

- Area not covered by CBR
- Those who did not received any training
- Children above 15 years

### **3.9 Sampling technique:**

Convenient sampling technique was used to collect data from the participants. It is a non-probability sampling method; it includes all the parents involved in the CBR program for more than two years.



### **3.10 Data collection tools/ materials:**

The survey questionnaire consisted of 44 questions inquiring about respondents' socio-demographic backgrounds, child's disability characteristics, health, knowledge, social lives and their empowerment status. It also includes the information of assistive device use and their home modification.

#### **3.10.1 Demographic Characteristics:**

Demographic characteristics were collected about the participant and their children. Maternal characteristics were defined such as mother's age, educational attainment, marital status, employment, occupation, number of family members living in the same household, and socio economic status. The child's characteristic includes age, GMFCS levels.

#### **3.10.2. Impact upon parent's health, knowledge, social lives and empowerment:**

The Impact Scale measured the impact of CBR program upon of parents in various dimensions. These are 16-item; five-point Likert-type scale consists of four domains: health, knowledge, social lives, and empowerment. Items are scored from one (low) to five (high), with higher scores indicative of greater positive impact of CBR program upon parents. This scale demonstrated acceptable reliability (Chronbach's  $\alpha = 0.83$ ) for this sample.

#### **3.10.3. Assistive devices and Modifications:**

The modification Scale measured the amount of modification done in various dimensions. These are 10-item; five-point Likert-type scale consists of three areas: home modification, established exercise area and assistive devices. Items are scored from zero (low) to four (high), with higher scores indicative of greater changes in home environment. This scale demonstrated acceptable reliability (Chronbach's  $\alpha = 0.77$ ) for this sample.

### **3.11 Data management and analysis:**

In this study all data are qualitative and quantitative.

#### **3.11.1 Quantitative data analysis**

Analyses were done by using Statistical Package for Social Science (SPSS) version 16 and Microsoft Excel spreadsheet. SPSS was used to enter data into variables and analyze statistically. Large data were re-coded to simplify data for easy analysis. For example age was classified in range to get concrete results. Reliability test on SPSS was done to ensure internal validity of the questionnaire.

#### **3.11.2 Qualitative data analysis**

Qualitative data will be analyzed by using Qualitative Content Analysis (QCA). This systemic tool will be used to reduce textual data for analysis. Priest et al., 2002 said that QCA facilitates to create a contextual meaning of text from the actual words through the development of emergent theme. The aim of data analysis is to find out actual meaning of information, which will be collected according to the participant's opinion. Data will be analyzed by 3 stages: coding, categorizing and generating themes. First level coding will be started with line-by-line analysis, where phrases, sentences or whole sections will be translated into categories. Then second level analysis will be done by indexing more detail and pieces of codes with similar meaning or insights will be grouped together to form a category. In third level, progressing reduction will be done through a process of interpretation to generate themes.

### **3.12 Quality control and quality assurance:**

The questionnaire used for the study is based on the literature review and some questions were adapted from the questionnaire used in similar study. Questionnaire was developed to find the impact of Community Based rehabilitation Program upon parents having children with cerebral palsy. To ensure and improve the quality of the study, the questionnaire was translated in the native language that is Kannada language following the standard procedure of linguistic validation. For translation, professional translator was hired. Before starting data collection procedures, pilot study was conducted on 5 parents having children with Cerebral Palsy who are under CBR program of Association of People with Disability. This was done

to ensure the face validity of the questionnaire. After reviewing the results of pilot study, changes were made to prepare final questionnaire. Filled questionnaires were kept safely. The data collected was reviewed, recorded and entered into the SPSS program in order to reduce the human errors that were likely to occur while entering and analyzing the data.

### **3.13 Ethical Consideration**

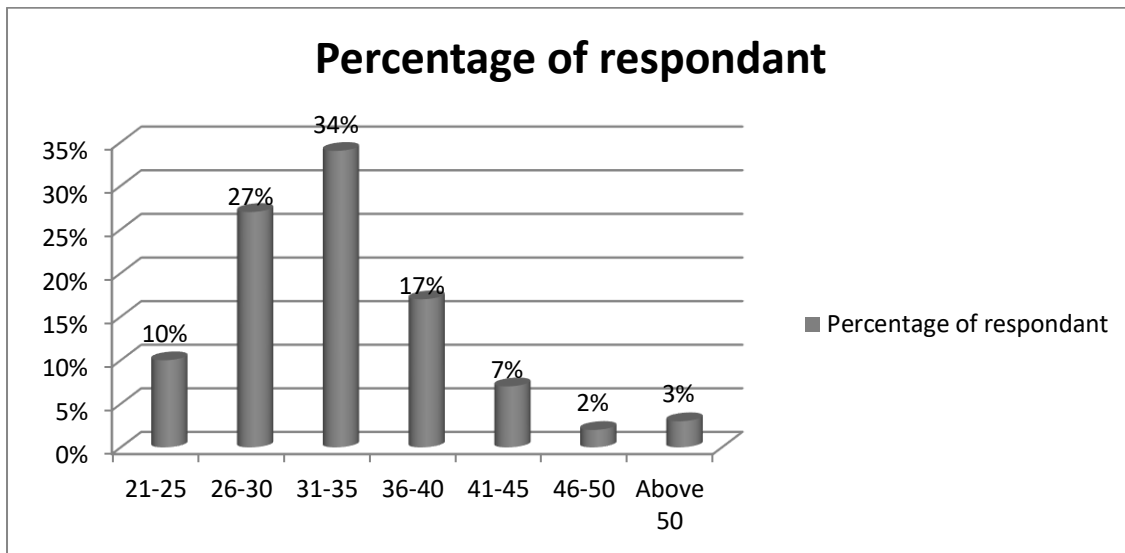
Study was conducted following the standard guidelines for ethical consideration. Ethical approval was taken from Institutional Review Board (IRB) of Bangladesh Health Professions Institute (BHPI) for conducting research. Informed consent as well as questionnaires in both English and Kannada language was submitted along with proposal. Then, a written permission from the concerned authority/managing authority of organization was obtained prior to the study. Individual informed consent was taken from respondent before starting data collection. The respondents were informed of his right to leave or not give answer if he/she is not willing to answer any question within the questionnaire. Participants were not forced or coerced to answer the questions if they were not willing to. Confidentiality and anonymity of the information provided by respondent was maintained. It is protected by the law “right to privacy” which prevents the researcher from disclosing any direct information about the participants of the research.

## CHAPTER IV: RESULTS

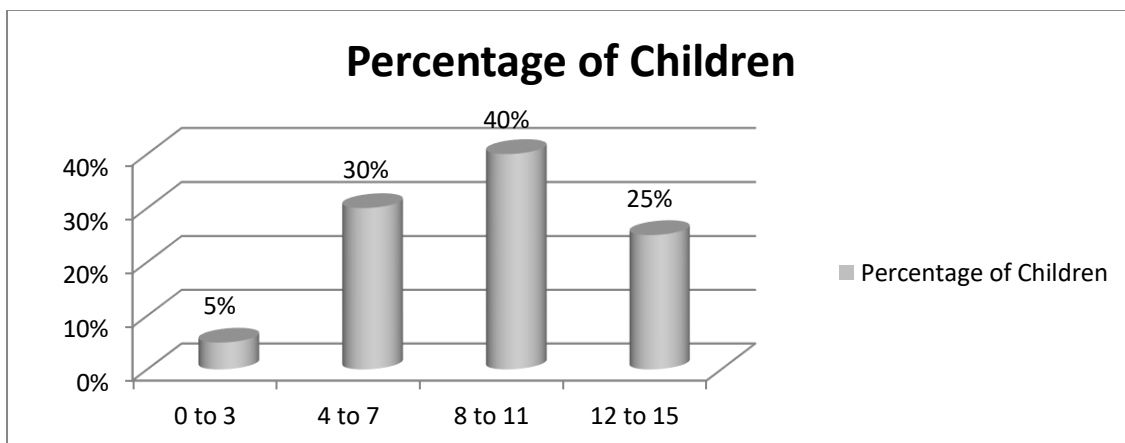
### 4.1 Socio-demographic findings:

#### 4.1.1. Respondent (Parents) age and Children age

Among 100 respondents, the highest 34 (34.0%) respondents were found between the age group of 31-35 years and the least two (2.0%) were found between the age group of 46-50 years. The mean age was 33.56 years with standard deviation 6.40, ranging from 23-54 years (Figure 2). Among those 100 children, the highest 40 (40.0%) were between the age group 8-11 years and the least 5 (5.0%) were found between the age group 0-3 years. The mean age was 8.99 years with standard deviation is 3.27, ranging from 6 months to 15 years (Figure 3).



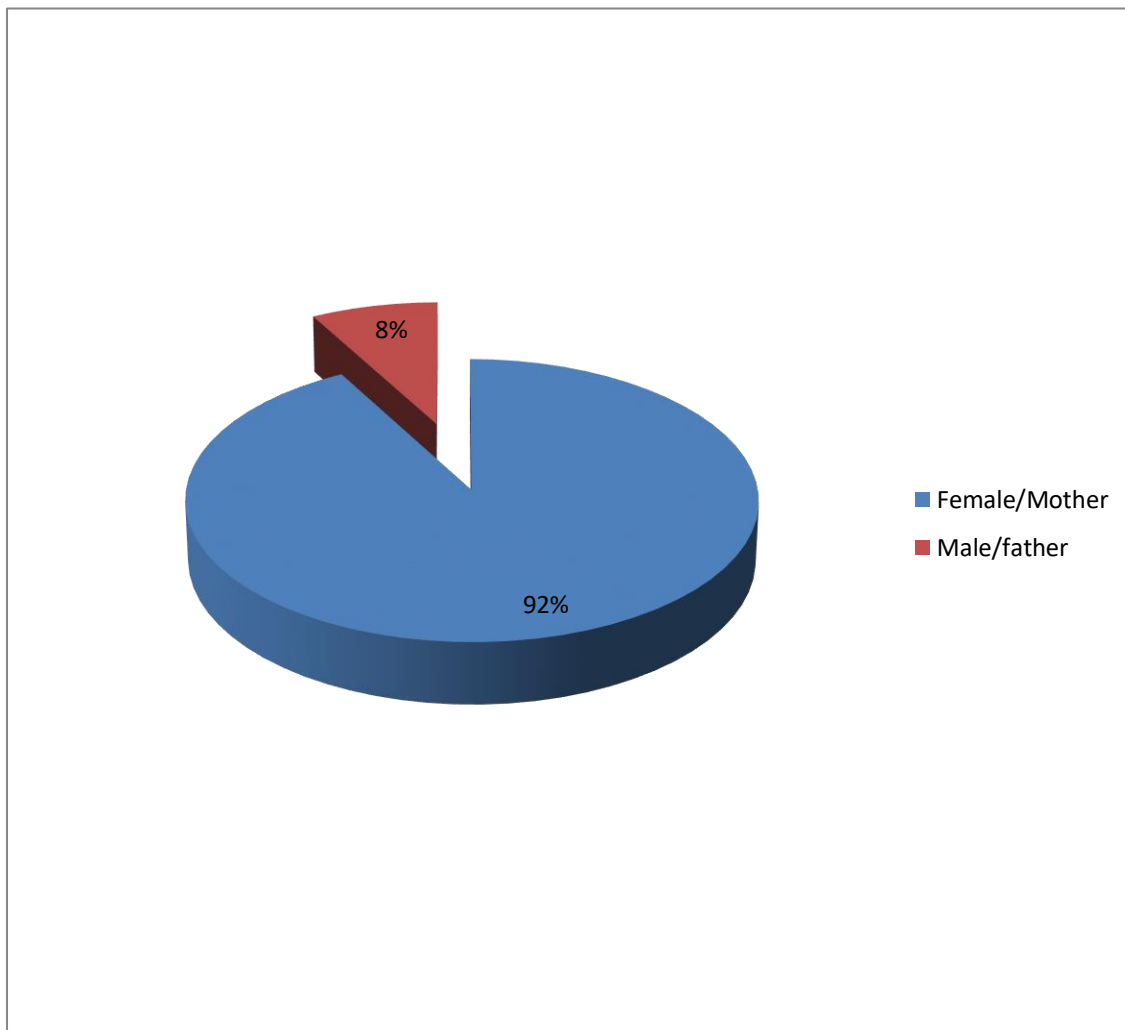
**Figure 2: Percentage of respondents (parents) according to age groups (seems to follow positively skewed distribution).**



**Figure 3: Distribution of children age group (seems to follow negatively skewed distribution).**

#### 4.1.2. Gender of respondents:

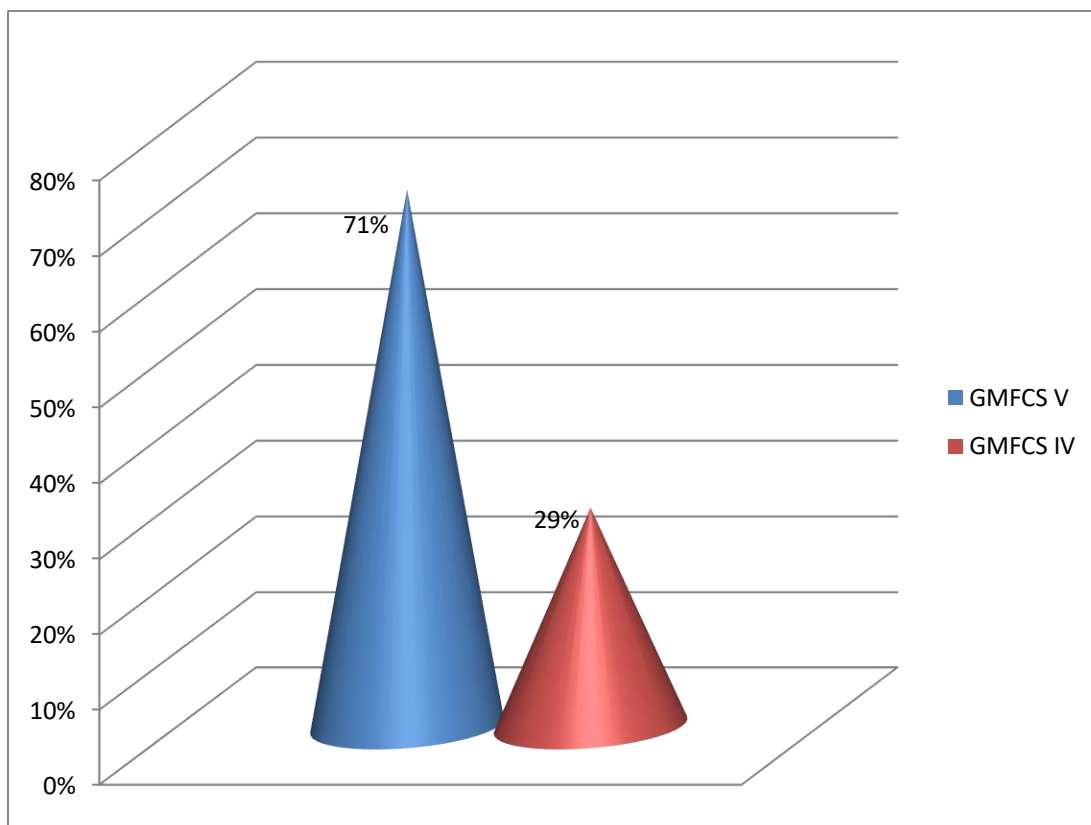
Out of the total respondents participating, 92.0 % were biological mothers and 8.0% were biological fathers. This means 92.0% respondent was female and 8.0% respondent was male. (Figure 4).



**Figure 4: Percentage of gender of respondent.**

#### 4.1.3. The Gross Motor Function Classification System or GMFCS levels:

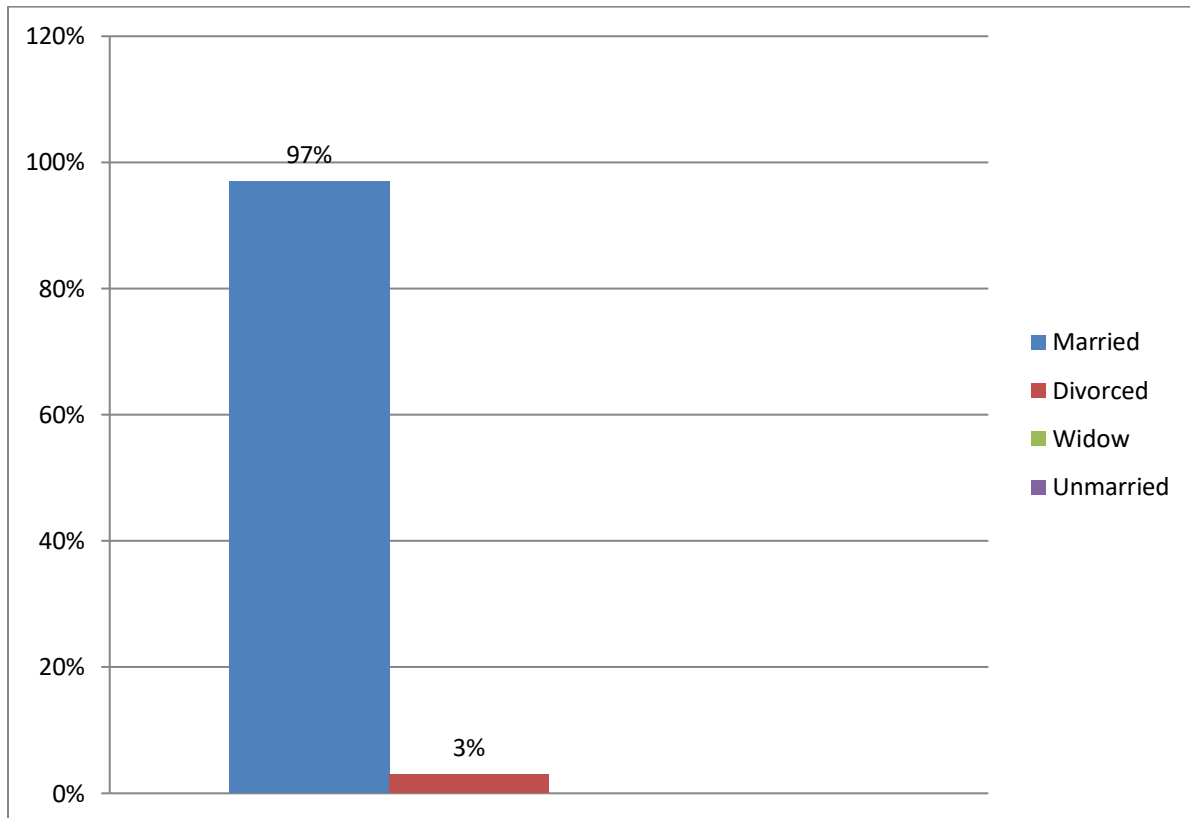
The Gross Motor Function Classification System (GMFCS) is internationally recognized classification system for assessment of the level of severity of cerebral palsy which grades the level of severity of cerebral palsy from 1-5. Out of the 100 children 29.0 % (29 children) were of GMFCS level IV whereas 71.0% (71 children) were of GMFCS level V. The complete description of the levels is attached in appendix I.



**Figure 5: Percentage of GMFCs of children**

#### 4.1.4. Marital status of respondents:

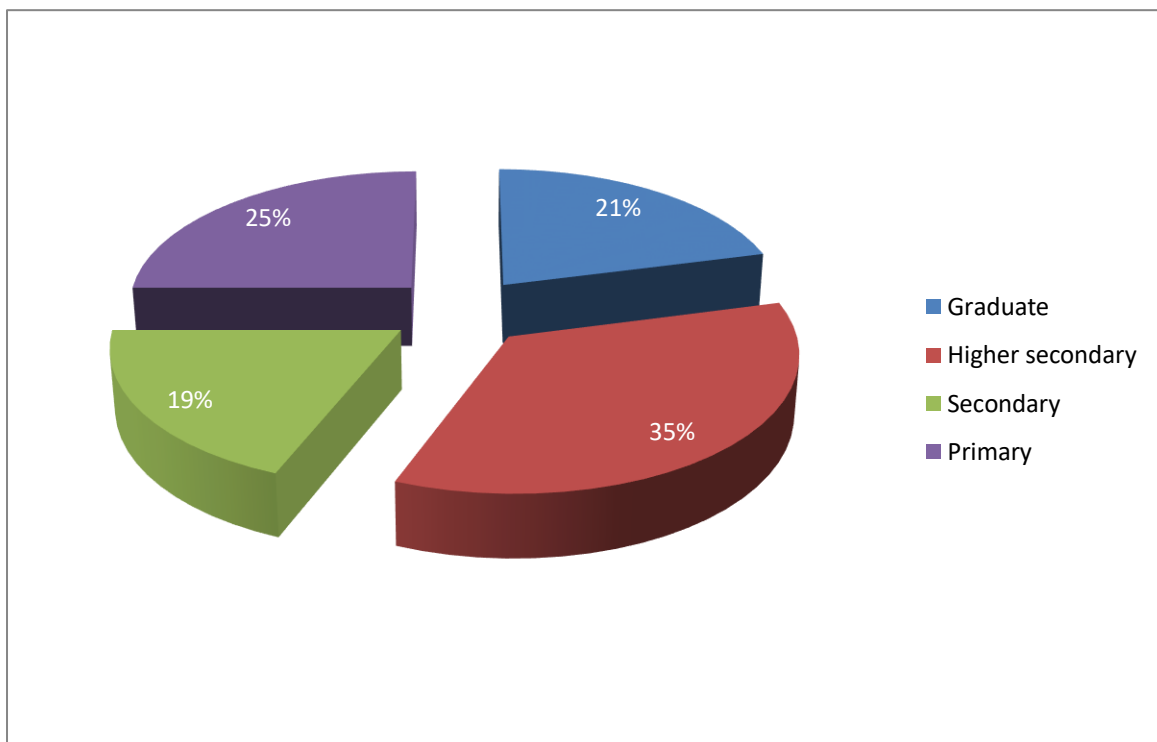
Out of the total 100 respondent 97% respondent are married and 3% respondent were divorce. None of the parents were widow or unmarried. (Figure 5)



**Figure 6: Marital status of respondents**

#### 4.1.5. Parents qualification and Occupation:

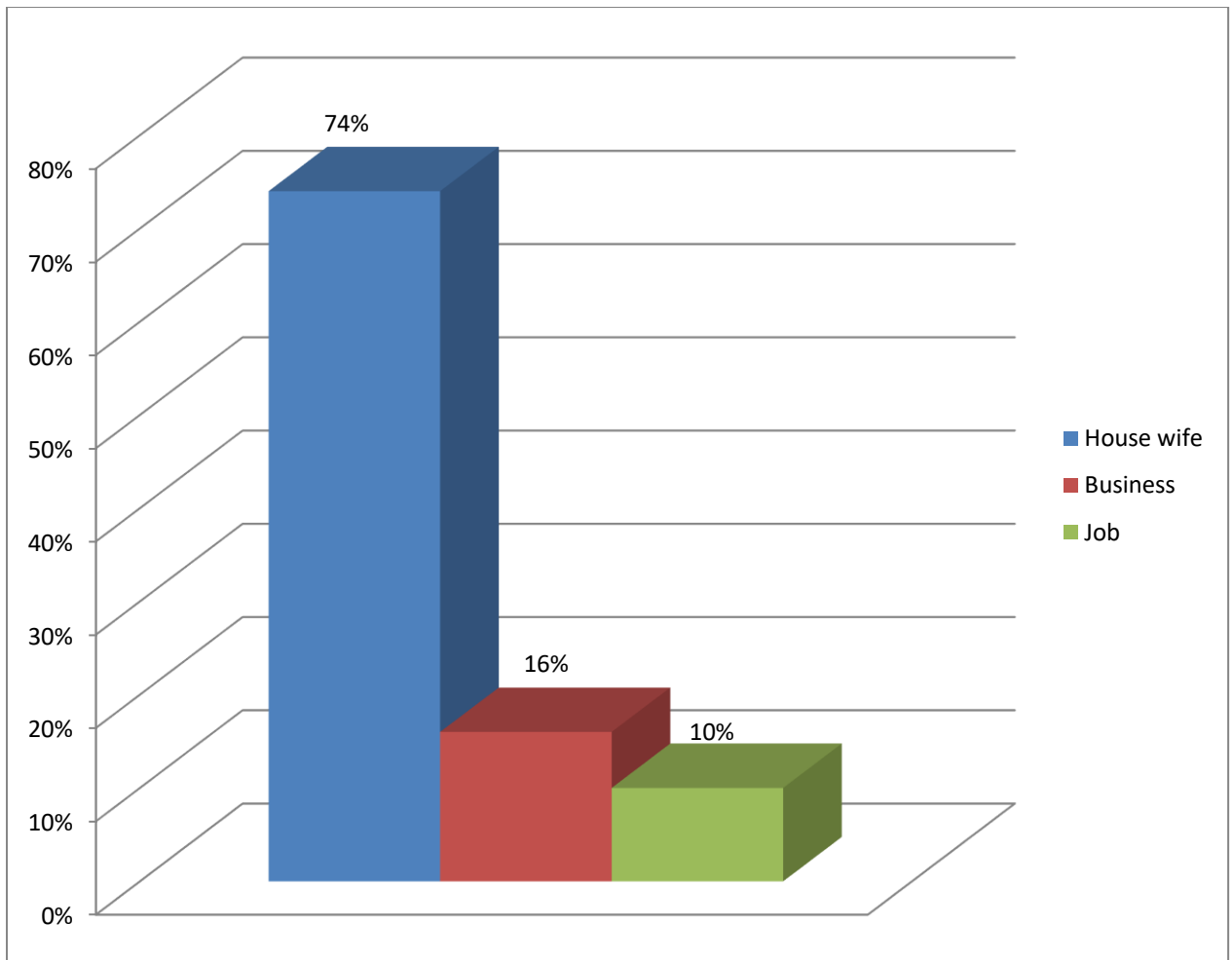
Among 100 parents 21 % respondent are graduate, 35 % respondent studied till higher secondary, 19% respondent studied till secondary level whereas 25 % respondent completed only their primary education (Figure 7). As per 2011 population census literacy rate of Karnataka is 75.36%. Of them, male literacy level was 82.47 % while female literacy level was 68.08 %. From the data we can assumed that female literacy rate is higher as compared to 2001 census as we can see that 75 % respondent completed their secondary education and 92% of them were female.



**Figure 7: Percentage of Parents Qualification**

74 % (74 mothers) of the total respondent are house wife (unemployed), 16 % are business personal which includes both father and mothers and 10% are job holders, these also includes both mother and father (Figure 8). From the data we can identify that large number of parents (mothers) are unemployed. The reason behind this could be many but as per our interaction with them most of them reveals that because of their children they are not capable of going out and get involved in income generated activities as they need to give full support and attention to their child. We have found various outcomes of CBR program which will be discussed later step by step.



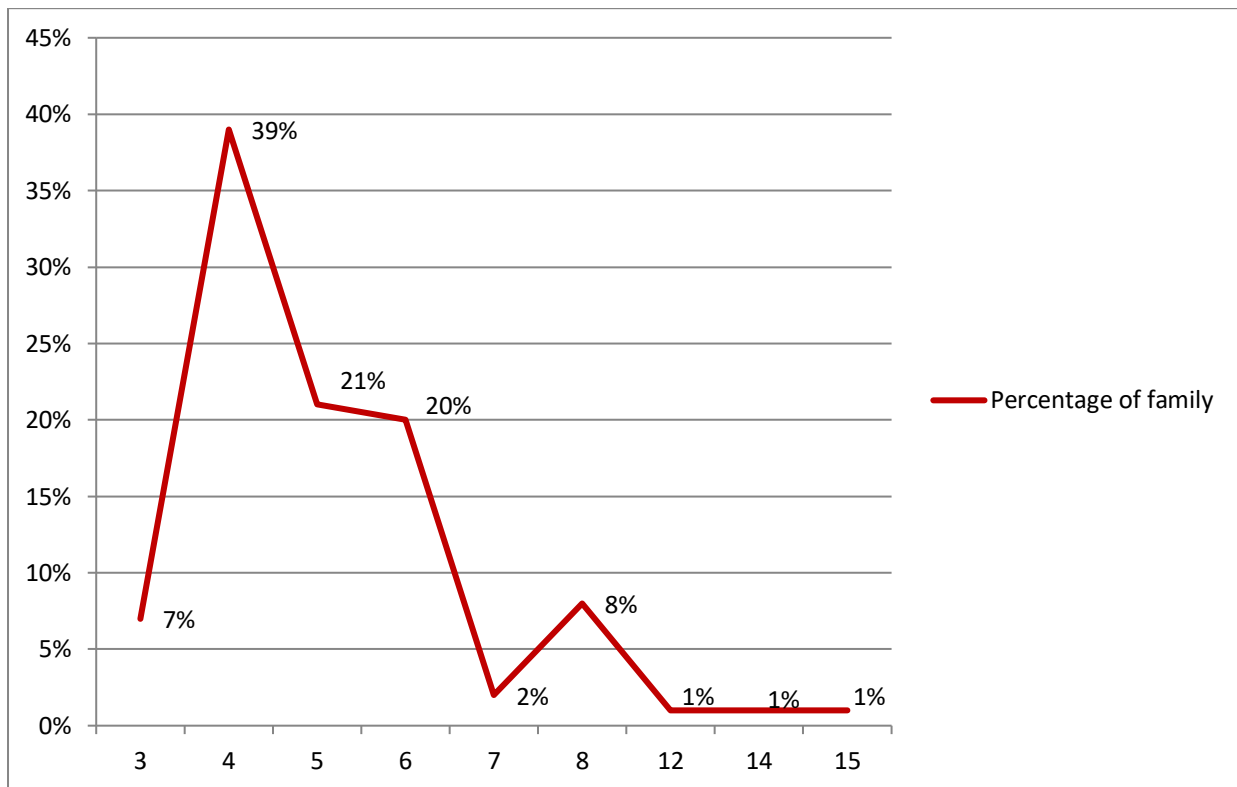


**Figure 8: Percentage of occupation**

#### 4.1.6. Respondents socio-economic status and number of family members.

Among 100 families, 86% economic status is stable and 14% are unstable.

Most of the family i.e. 39 % of respondent has 4 members in their family. The minimum i.e. 1 respondents has 15 family members, another 1 has 14 and 1 has 12 family members. The average family size is five with standard deviation 2 (Figure 9).

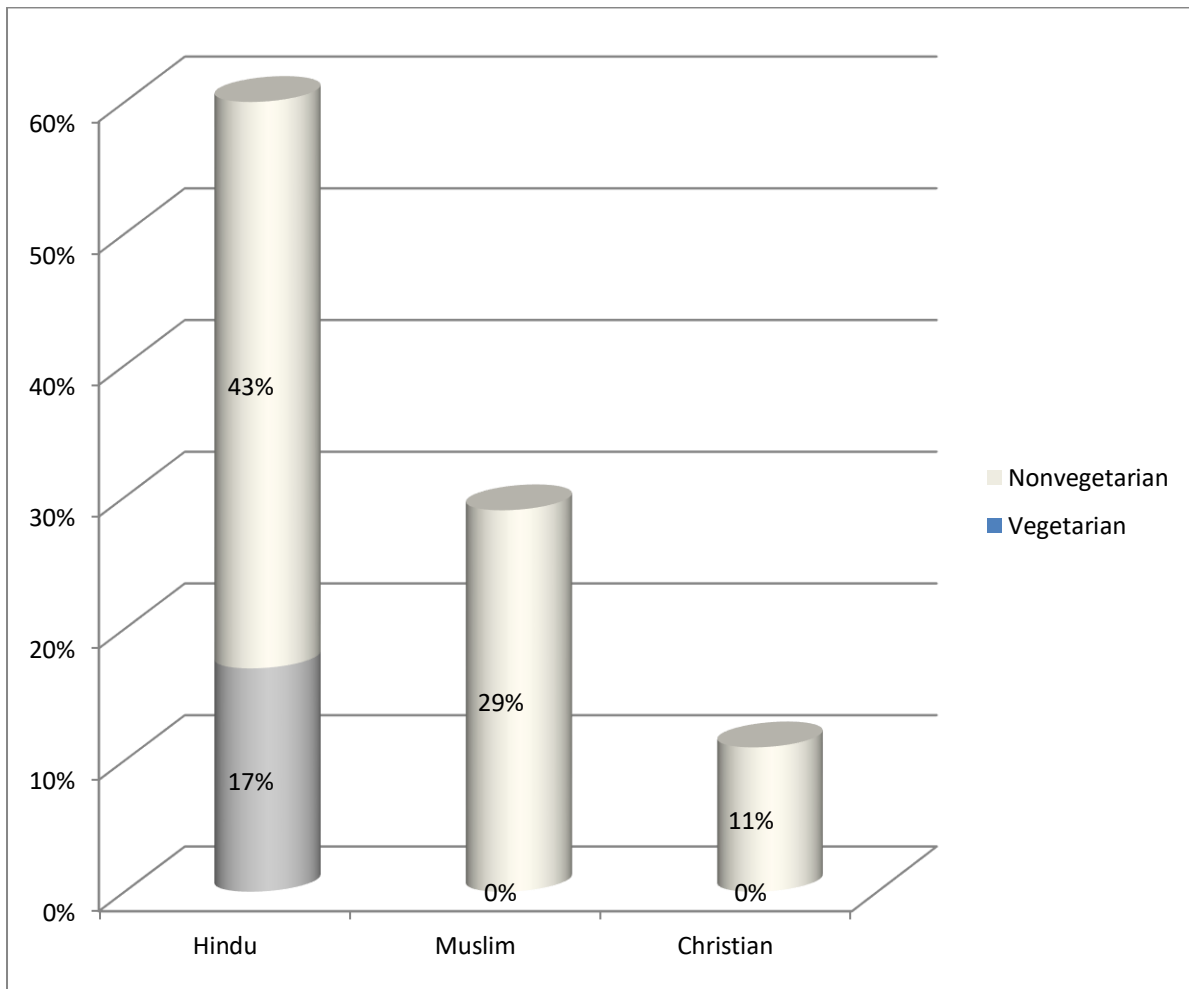


**Figure 9: Number of family members and its percentage (seems to follow positively skewed distribution)**

#### 4.1.7. Respondents religion and food habits:

Out of 100 respondent 60% were Hindu, 29% were Muslim and 11% were Christian. As per census 2011, Hindu are majority in Karnataka state. Hinduism constitutes 84.00% of Karnataka population. Muslims are minority in Karnataka state forming 12.92% of total population. From our result we can assume that Muslim and Christian populations are more vulnerable to Cerebral Palsy than Hindu population.

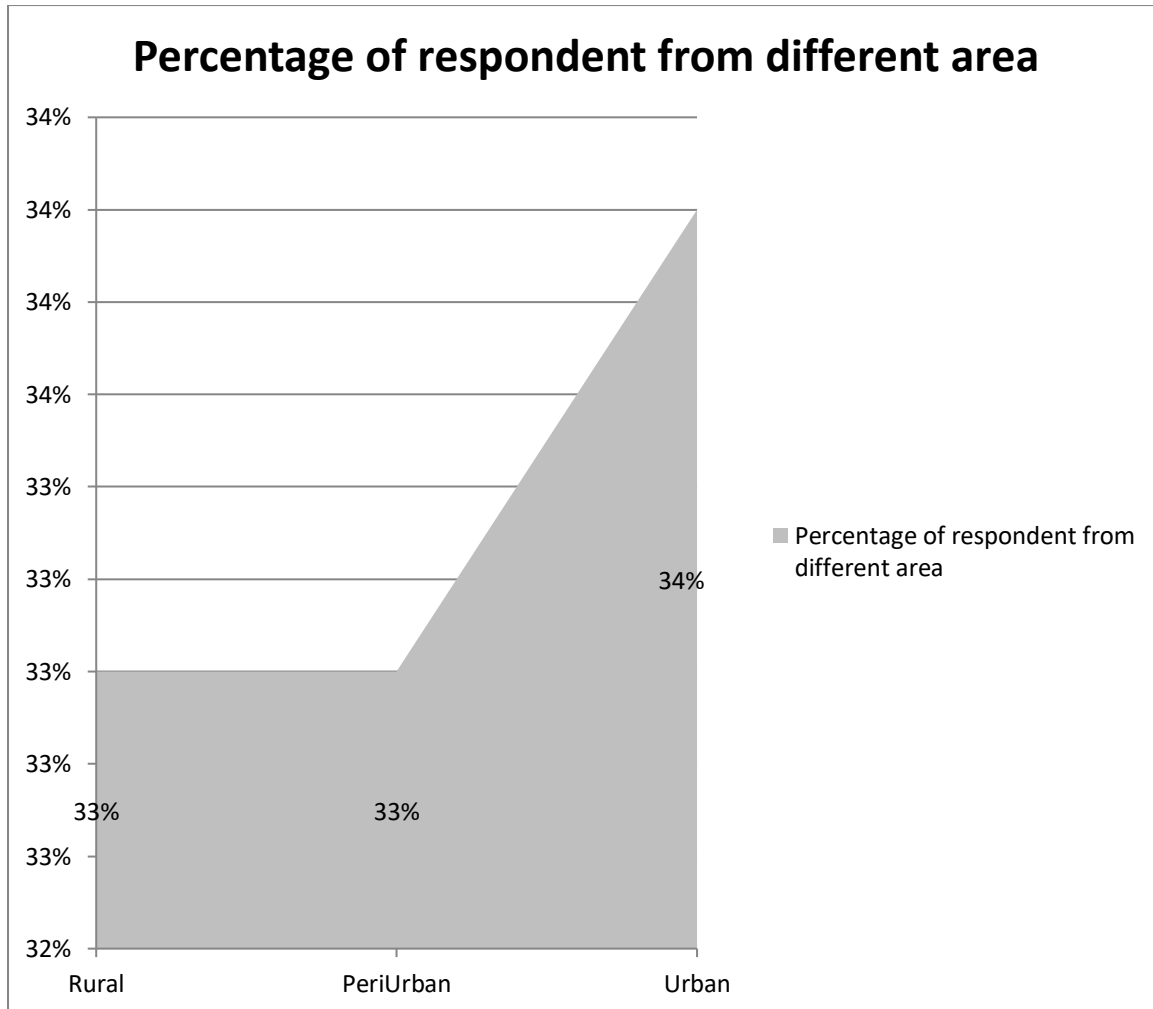
Among 100 respondents only 17 % were vegetarian and 83 % were non-vegetarian and vegetarians are from Hindu family (Figure 10).



**Figure 10: Religion and food habit**

#### 4.2. Area wise distribution of the respondent:

Out of 100 respondents 34% (34 cases) were taken from urban area, 33% (33 cases) were from semi-urban area and 33% (33 cases) were rural area (Figure 11).



**Figure 11: Percentage of respondent area wise.**

### 4.3. Distribution of frequencies (Impact) of each domain:

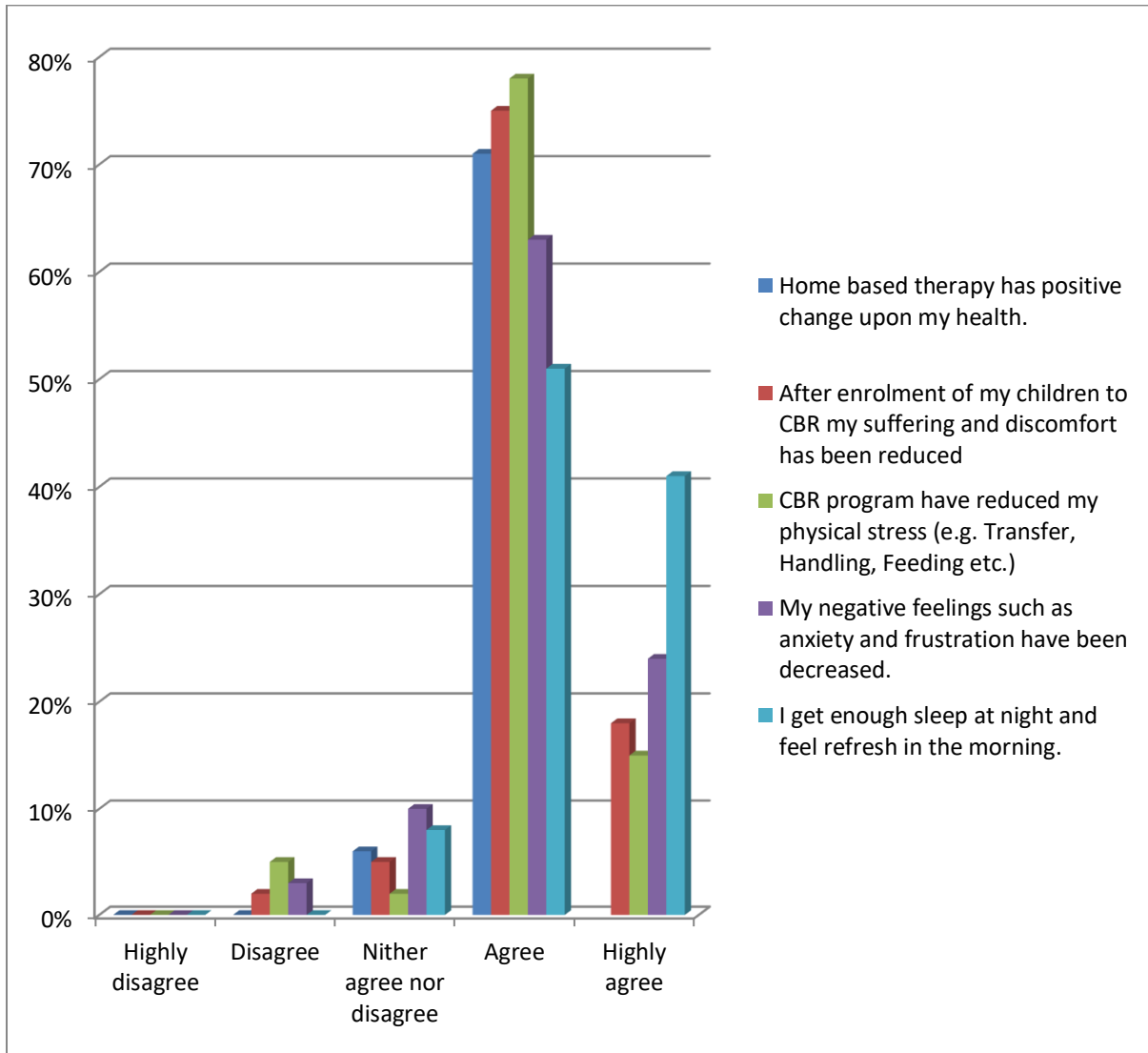
#### 4.3.1. Frequencies of Health:

**Table 1: Health Status of Mother after CBR**

	Highly disagree	Disagree	Neither agree nor disagree	Agreed	Highly agreed
Home based therapy has positive change upon my health.	-	-	6.0 %	71.0%	23.0%
After enrolment of my children to CBR program my suffering and discomfort has been reduced.	-	2.0%	5.0%	75.0%	18.0%
CBR program have reduced my physical stress (e.g. Transfer, Handling, Feeding etc.)	-	5.0%	2.0%	78.0%	15.0%
My negative feelings such as anxiety and frustration have been decreased.	-	3.0%	10.0%	63.0%	24.0%
I get enough sleep at night and feel refresh in the morning.	-	-	8.0%	51.0%	41.0%

In the domain “Health” five questions were asked to see the impact upon parents’ health after CBR. Out of 100 respondent 71% were agreed to the fact that home based therapy has positive change upon their health. 23% were highly agreed and six percent were neither agreed nor disagreed to this question. 75% were agreed that after enrolment of their children to CBR their suffering and discomfort has been reduced. 18% were highly agreed, five percent were neither agreed nor disagreed and two percent were disagreed to this question. 78% agreed to the fact that CBR program have reduced their physical stress (e.g. Transfer, Handling, Feeding etc.). 15% were highly agreed to this, five percent were disagreed and two percent were neither agreed nor disagreed to this. 63% were agreed that their negative feelings such as anxiety and frustration have been decreased after implementing CBR program. 24% were highly agreed, 10% were neither agreed nor disagreed and three percent were disagreed to this. 51% were agreed to that they get enough sleep at night and feel

refresh in the morning. 41% were highly agreed to this question and eight percent were neither agreed nor disagreed to this. From the above frequencies we can say CBR program has positive impact upon parent's health (Figure 12).



**Figure 12: Graph showing the health status of the parents.**

### 4.3.2. Frequencies distribution of Education/Knowledge (of respondent after CBR program training)

**Table 2: Status of knowledge of parents**

	Highly disagree	Disagree	Neither agree nor disagree	Agreed	Highly agreed
I am comfortable to take care of my child.	-	-	5.0 %	49.0%	46.0%
CBR program provided me training that have changed my life style.	-	-	8.0%	58.0%	34.0%
I gain knowledge about Cerebral Palsy/ handling techniques.	-	-	1.0%	62.0%	37.0%
I can perform Activities of Daily Living (ADLs) of my child without any difficulty.	-	-	8.0%	59.0%	33.0%

In the domain “Education/Knowledge” after the training from CBR program five four questions was asked to see the effectiveness of parents training. 49% were agreed that they are comfortable to take care of their children after the training, 46% were highly agreed and five percent were neither agreed nor disagreed to this question. 58% were agreed that the training provided by CBR program had changed their lifestyle, 34% were highly agreed, and eight percent were neither agreed nor disagreed to this question. 62% were agreed that they gained knowledge about cerebral palsy and how to handle them in a therapeutic way, 37%) were highly agreed, one percent was neither agreed nor disagreed to this question. 59% were agreed that they can perform ADLs of their children without any difficulty, 33% were highly agreed and eight percent were neither agreed nor disagreed to this question. So, we can say that there is a positive impact on knowledge of parents after CBR program.

### 4.3.3: Social lives after CBR program

**Table 3: Social lives of parents**

	Highly disagreed	Disagree	Neither agree nor disagree	Agreed	Highly agreed
CBR program made easier to participation in the social activities outside home.	-	-	13.0 %	60.0%	27.0%
Family and Society attitude is been positive to me after implementing CBR program.	-	4.0%	3.0%	68.0%	25.0%
I don't feel neglected from the community member.	1.0%	2.0%	5.0%	69.0%	23.0%
I get necessary time for my own needs and interest.	1.0%	4.0%	11.0%	64.0%	20.0%
My social participation has increased (e.g. Family gathering, marriage, religious social function etc.).	-	2.0%	6.0%	61.0%	31.0%

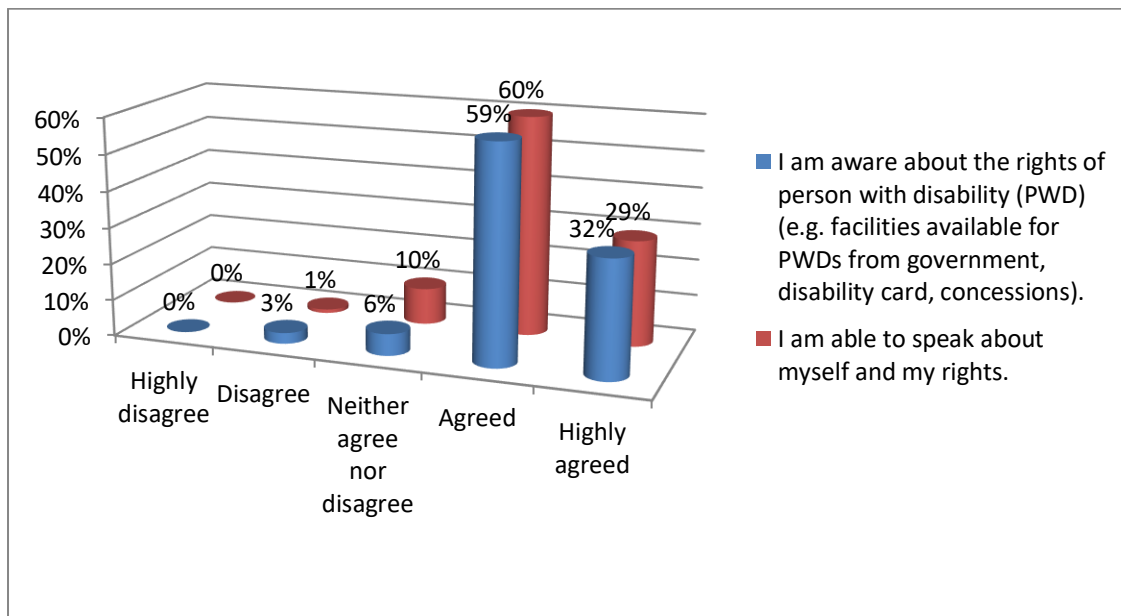
In the domain “social lives” after CBR program five questions were asked to see the amount of its impacts on social lives. 60% were agreed that CBR program made it easier to participate in social activities outside home. 27% were highly agreed and 13% were neither agreed nor disagreed to it. 68% were agreed that their family and society attitude is positive after implementing CBR program, 25% were highly agreed, four percent disagreed and three percent were neither agreed nor disagreed to it. 69% were agreed that they don't feel neglected by the community members, 23% were highly agreed, five percent neither agreed nor disagreed, two percent disagreed and one percent highly disagreed to it. 64% were agreed that they get necessary time for their own needs and interest, 20% were highly agreed, 11% neither agreed nor disagreed, four percent disagreed and only one percent highly disagreed to it. 61% of the total population was agreed that their social participation has increased (e.g. Family gathering, marriage, religious social function etc.), 31% were highly agreed, six percent neither agreed nor disagreed and two percent disagreed to it. From the above result we may comment that CBR program has positive impact upon the parents' social lives but still it is necessary to improve their social lives.



#### 4.3.4. Frequencies distribution of Empowerment after CBR program

**Table 4: Empowerment of parents**

	Highly disagree	Disagree	Neither agree nor disagree	Agreed	Highly agreed
I am aware about the rights of person with disability (PWD) (e.g. facilities available for PWDs from government, disability card, concessions).	-	3.0%	6.0 %	59.0%	32.0%
I am able to speak about myself and my rights.	-	1.0%	10.0%	60.0%	29.0%



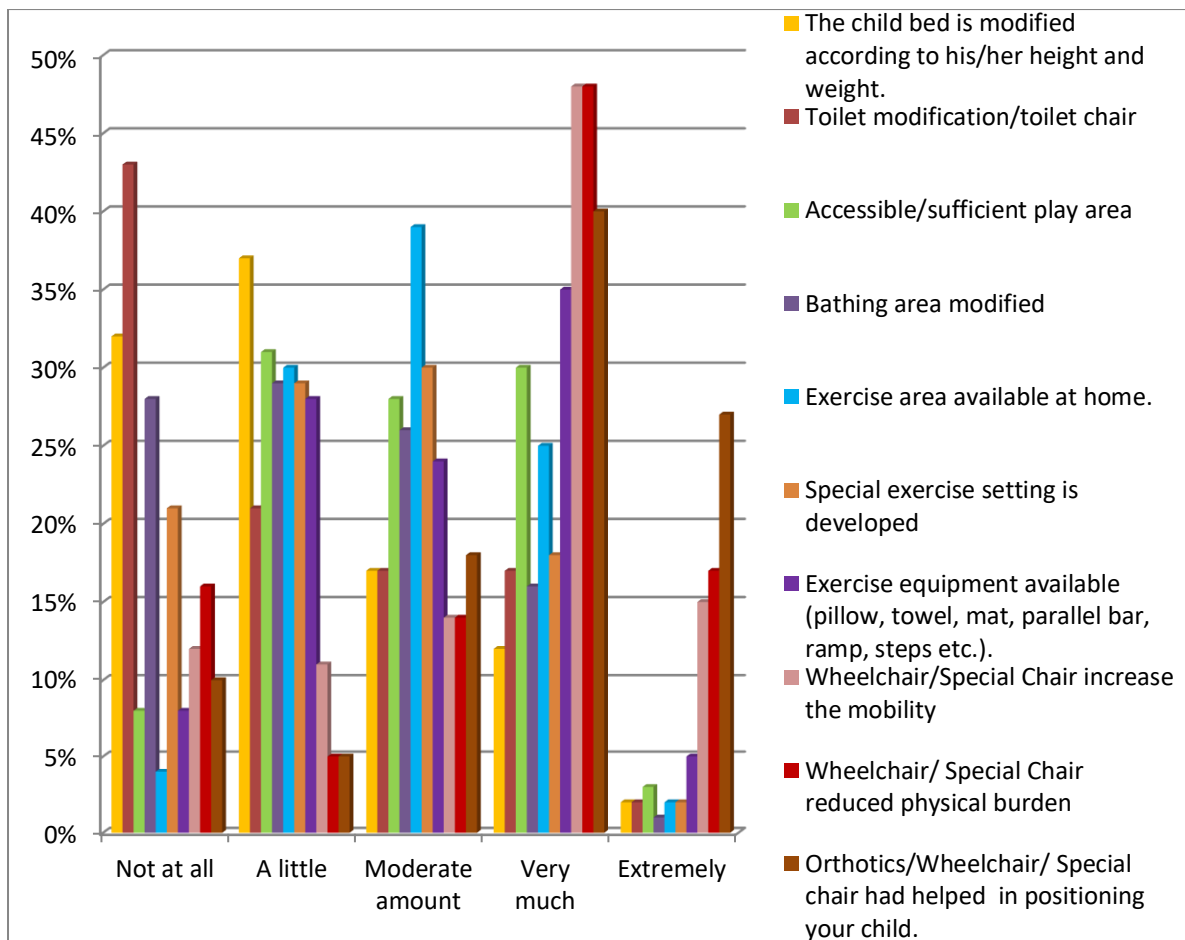
**Figure 13: Empowerment of parents after CBR.**

In the domain “empowerment” two questions were asked. 59% were agreed that they are aware about the rights of person with disability (PWD) (e.g. facilities available for PWDs from government, disability card, concessions). 32% were highly agreed, six percent were neither agreed nor disagreed and three percent were disagreed to this question. 60% were agreed that they are able to speak about themselves and their rights. 29% were highly agreed, 10% were neither agreed nor disagreed and only one percent was disagreed to this question.

#### 4.4. Frequencies distribution of changes in home modification, exercise area, assistive devices use.

**Table 5: Modification and use of assistive devices**

	Not at all	A little	A moderate amount	Very much	Extremely
The child bed is modified according to his/her height and weight.	32.0%	37.0 %	17.0 %	12.0%	2.0%
The toilet is modified or using toilet chair.	43.0%	21.0%	17.0%	17.0%	2.0%
Is there accessible and or sufficient play area available for your child?	8.0%	31.0%	28.0%	30.0%	3.0%
Is bathing area are modified?	28.0%	29.0%	26.0%	16.0%	1.0%
Area for exercise available at home.	4.0%	30.0%	39.0%	25.0%	2.0%
Special exercise setting is developed.	21.0%	29.0%	30.0 %	18.0%	2.0%
Exercise equipment available (pillow, towel, mat, parallel bar, ramp, steps etc.) based on needs.	8.0%	28.0%	24.0%	35.0%	5.0%
Using Wheelchair/Special Chair increase the mobility of your child.	12.0%	11.0%	14.0%	48.0%	15.0%
Wheelchair/ Special Chair reduced your physical burden in carrying the child.	16.0%	5.0%	14.0%	48.0%	17.0%
Orthotics/Wheelchair/ Special chair had helped you in positioning your child.	10.0%	5.0%	18.0%	40.0%	27.0%



**Figure 14: Frequencies distribution of changes in home modification, exercise area, assistive devices use.**

In part II of the questionnaire ten questions were asked about modification, exercise area and use of assistive devices. Following are the major findings. It looks a very much increasing in mobility use such as Wheelchair/Special Chair is used by 48% children, extremely in 15% children and moderate amount in 14% children. There is very much reduction in parent's physical burden in carrying the child after using Wheelchair/ Special Chair in 48%, extremely in 17% children and moderate amount in 14% children. Orthotics/Wheelchair/ Special chair had helped in positioning their child very much in 40% children, extremely to 27% children and moderate amount to 18% children. There were no major changes found in home and toilet modification of the children.

#### 4.5. Association between variables.

##### 4.5.1. Demographic vs. Socio cultural, health and knowledge Segments.

##### 4.5.1.1 Child Age vs. Parents Health

**Table 6: Association between child age and parents health**

	Health		Total	Chi- square $\chi^2$ /df	<i>p</i> value
	Poor Impact	Good Impact			
Age group of Children				2.620/3	.454
0-3	4	1	5		
4-7	17	13	30		
8-11	23	17	40		
12-15	11	14	25		
Total	55	45	100		

The result of chi square test for association between child age group and parents health was  $\chi^2$  (3, N=100) =2.620. *p*=.454. This result shows there was no significant association between child age and health of parents. The impact upon health of parents remains the same for all the age group of children following CBR training program. In some studies it was found that the burden of stress increases and QOL affects a lot in taking care of elder age group of children but we could find that CBR training has equal impact upon all the parents with different age group of children.

It could be also due to age limitation in our study till 15 years.

#### 4.5.1.2. Respondent age vs. Health:

**Table 7: Association between respondent age and health**

	Health		Total	Chi-square $\chi^2$ /df	<i>p</i> value
	Poor impact	Good Impact			
Respondent age group					
21-25	6	4	10	6.961/3	0.073
26-30	14	13	27		
31-35	24	10	34		
Above 35	11	18	29		
Total	55	45	100		

The result of chi square test for association between respondent age group and their health was  $\{\chi^2 (3, N=100)\} = 6.961$ .  $p = .073$ . This result shows at 10 % level of significant there was association between the age group of respondents and health.

#### 4.5.1.3 Respondent age vs. Knowledge:

**Table 8: Association between respondent age and knowledge**

	Knowledge		Total	Chi-square $\chi^2/df$	<i>p</i> value
	Poor Impact	Good Impact			
Respondent age group					
21-25	6	4	10	7.468/4	.080
26-30	9	18	27		
31-35	17	17	34		
36-40	12	5	17		
Above 40	8	4	12		
Total	52	48	100		

The result of chi square test for association between respondent age group and their knowledge was  $\{\chi^2 (4, N=100)\} = 7.468$ .  $p = .080$ . This result shows there was significant association at 10% of level of significance respondent age and their knowledge. It means all are receiving same quality and quantity of parents training irrespective of age but all respondent are not grasping it equally. The age group above 40 has low impact. It could be due to memory loss due to aging and other health conditions (Boseley, 2012).

#### 4.5.1.4. Respondent age vs. Social lives:

**Table 9: Association between respondent age and social lives**

	Social Lives		Total	Chi-square $\chi^2$ /df	<i>p</i> value
	Poor Impact	Good Impact			
Respondent age group					
21-25	6	4	10	0.824/4	.935
26-30	18	9	27		
31-35	25	9	34		
36-40	12	5	17		
Above 40	8	4	12		
Total	69	31	100		

The result of chi square test for association between respondent age group and social lives was  $\{\chi^2 (4, N=100)\} = 0.824$ .  $p = .935$ . This result shows that there was no significant association between respondent age and their social lives. Impact upon social live of all age group seems to be similar.

#### 4.5.1.5. Food habit and Health:

**Table 10: Association between food habit and health**

	Health		Total	Chi-square $\chi^2/df$	<i>p</i> value
	Poor Impact	Good Impact			
Food habit					
Vegetarian	12	5	17	2.011/1	.156
Non-Vegetarian	43	40	83		
Total	55	45	100		

Among 100 respondent 70.6% were vegetarian and has poor health. 29.4% who were vegetarian has good health. 51.8% who are non-vegetarian has poor health and 48.2% who are non-vegetarian has good health impact. The result of chi square test for association between food habit and health was  $\{\chi^2 (1, N=100)\} = 2.011$ .  $p = .156$ . This result shows that there was no significant association between food habit and their health. But the result shows percentage of poor impact on health is very high which is contradictory.

The overall health status was similar for the entire respondent. As we didn't enquire about the co-morbid diseases, it might be possible to get significant association between them if we ask details about their underlying health conditions.



#### 4.5.2. Association within Socio cultural, health and knowledge Segments.

##### 4.5.2.1. Health vs. Knowledge:

**Table 101: Association between health and knowledge**

	Health		Total	Chi-Square $\chi^2$ /df	<i>p</i> value
	Poor Impact	Good Impact			
Knowledge				11.422/1	.001
Poor	37	15	52		
Good	18	30	48		
Total	55	45	100		

Among 100 respondents 71.2% had poor impact upon health as well as upon knowledge, 28.8% had good impact upon health and poor impact upon knowledge whereas 37.5% had had poor impact upon health and good impact upon knowledge and 62.5 % had good impact upon health as well as good impact upon knowledge.

The result of chi square test for association between knowledge and health was  $\{\chi^2 (1, N=100)\} = 11.442, p = .001$ . This result shows there was significant association at 5% of level of significance. Therefore, it was concluded that knowledge and health of parents was associated.

It could be assumed that the health of parents improves along with increase in knowledge.

#### 4.5.2.2. Health vs. Social Lives:

**Table 112: Association between health and social lives**

	Health		Total	Chi-Square $\chi^2$ /df	<i>p</i> value
	Poor Impact	Good Impact			
Social Lives				15.471/1	<.001
Poor	47	22	69		
Good	8	23	31		
Total	55	45	100		

Among 100 respondents 68.1% had poor impact upon health as well as upon social lives, 31.9% had good impact upon health and poor impact upon social lives whereas 25.8% had had poor impact upon health and good impact upon social lives and 74.2 % had good impact upon health as well as good impact upon social lives.

The result of chi square test for association between knowledge and health was  $\{\chi^2 (1, N=100)\} = 15.471, p < .001$ . This result shows there was significant association at 5% of level of significance. Therefore, it was concluded that Social lives and health of parents was associated.

Web may comment based on our study that the social live of parents improves along with improvement in health.

### 4.5.2.3. Knowledge vs. Social Lives:

**Table 13: Association between knowledge and social lives**

	Social Lives		Total	Chi-square $\chi^2$ /df	<i>p</i> value
	Poor Impact	Good Impact			
Knowledge				23.161/1	<.001
Poor	47	5	52		
Good	22	26	48		
	69	31	100		

Among 100 respondents 90.4% had poor impact upon social lives as well as upon knowledge, 9.6% had good impact upon social lives and poor impact upon knowledge whereas 45.8% had had poor impact upon social lives and good impact upon knowledge and 54.2 % had good impact upon social lives as well as good impact upon knowledge.

The result of chi square test for association between knowledge and health was  $\{\chi^2 (1, N=100)\} = 23.161$ .  $p < .001$ . This result shows there was significant association at 5% of level of significance. Therefore, it was concluded that knowledge and social lives of parents was associated.

It could be assumed that the social live of parents improves along with improvement in knowledge.

#### 4.5.2.4. Home modification vs. Health:

**Table 14: Association between home modification and health**

	Health		Total	Chi-Square $\chi^2$ /df	<i>p</i> value
	Poor Impact	Good Impact			
Home Modification					
Poor	30	25	55	.010/1	.920
Good	25	20	45		
Total	55	45	100		

The result of chi square test for association between child age group and parents health was  $\{\chi^2 (1, N=100)\} = .010$ .  $p = .920$ . This result shows there was no significant association between home modification and health of parents.

But in a study it was found modifications to have moderate to very large effect on the child's mobility, self-care skills, and on social function. Furthermore, the modifications lightened the caregiving for mobility, self-care and for social function. Functional independence and care demands often benefited from different types of modifications (Ostensjo et al., 2005).

As there was very minimal modification done in this group of people they might not have idea about how their health could be benefitted from complete modification.

A very close study need to do to address this problem.

### 2.5.2.6. Assistive Device vs. Health:

**Table 15: Association between assistive device uses and health of parents**

	Health		Total	Chi-square $\chi^2$ /df	<i>p</i> value
	Poor impact	Good impact			
Assistive Device Less used	17	17	34	.520/1	.471
More used	38	28	66		
Total	55	45	100		

The result of chi square test for association between assistive device and health was  $\{\chi^2 (1, N=100)\} = .520$ .  $p = .471$ . This result shows there was no significant association between assistive device and health.

Assistive device has positive impact upon child as well as parents health as it reduces the burden of carrying children outside. Adaptations of housing and transportation facilitated effective use of assistive devices (Ostensjo et al., 2005).

The reason for not finding association could be small population size, lack of modifications as most of them stays in rented house or in top floors where modification is hardly possible.

### 2.5.2.7. Environment vs. Area:

**Table 16: Association between environment and area**

	Is your environment disable friendly		Total	Chi-square $\chi^2$ /df	p value
	Disable friendly	Not disable friendly			
Area					
Urban	17	17	34	.263/2	.877
Semi urban	18	15	33		
Rural	16	17	33		
Total	51	49	100		

The result of chi square test for association between environment and area was  $\{\chi^2 (2, N=100)\} = .263$ .  $p = .877$ . This result shows there was no significant association between environment and area where they live.

The attitude and accessibility of area did not vary. All three areas are equally affected as well as equally benefited. It was assumed that urban areas are more disabled friendly as compared to rural and semi - urban areas but we could not find any significant result. The result might be bias due to small population and most of them are from community living in rented houses, where modification for accessibility is possible.

**2.5.2.8. GMFCS vs. Assistive Device:**

**Table17: Association between GMFCS and assistive device.**

	GMFCS		Total	Chi- square $\chi^2$ /df	p value
	4	5			
Assistive Device				8.159/1	.004
Less used	16	18	100		
More used	13	53	100		
Total	29	71	100		

Among 100 respondents children 47.1% of GMFCs IV level had poor impact of assistive device and 52.9% of GMFCs V had poor impact of assistive device. 19.7% of GMFCs IV level had good impact of assistive device and 80.3% of GMFCs V had good impact of assistive device.

The result of chi square test for association between knowledge and health was  $\{\chi^2 (1, N=100)\} = 8.159$ .  $p = .004$ . This result shows that there exists significant association at 5% of level of significance. Therefore, we may conclude that GMFCs level and assistive device was associated.

The dependency or use of assistive devices increases along with the GMFCS level. In a study it was found that the limitations in achievement of activities, need for assistance, and use of assistive devices increased progressively with GMFCS level (Ostensjo et al., 2003).

## 4.6. Logistic Regression:

### 4.6.1. Health vs. Knowledge:

**Table 18: Binary logistic regression between health and knowledge**

		B	S.E	Wald	df	Sig.	Exp(B)
Step 1 <sup>a</sup>	Knowledge(1)	1.414	.427	10.946	1	.001	4.111
	Constant	-2.317	.681	11.574	1	.001	.099

Logistic model:  $\log \frac{\pi}{1-\pi} (C) = \frac{e^{\alpha+\beta x}}{1+e^{\alpha+\beta x}}$

$$\log \frac{\pi}{1-\pi} (C) = \frac{e^{-2.317+1.41x}}{1+e^{-2.317+1.41x}}$$

$$\Rightarrow e^{\beta} = e^{1.41}$$

If knowledge changes from poor to good category, health status increases by  $e^{\beta}$  unit.

Then, odds ratio  $e^{\beta}=4.096$ .

That is, odds of good health status are 4.1 times more than that of poor health status.



#### 4.6.2. Health vs. Social lives:

**Table 19: Binary logistic regression between health and social lives**

		B	S.E	Wald	Df	Sig.	Exp(B)
Step 1 <sup>a</sup>	Health	1.815	.485	14.008	1	.000	6.142
	Constant	-3.586	.821	19.077	1	.000	.028

Logistic model:  $\frac{\pi}{1-\pi}(C) = \frac{e^{\alpha+\beta x}}{1+e^{\alpha+\beta x}}$

$$\log \frac{\pi}{1-\pi}(C) = \frac{e^{-3.586+1.815x}}{1+e^{-3.586+1.815x}}$$

$$\Rightarrow e^{\beta} = e^{1.815}$$

If health changes from poor to good category, social live status will increase by  $e^{\beta}$  unit.

Then, odds ratio  $e^{\beta}=6.142$ .

That is, odds of good social live status are 6.14 times of good health status.

### 4.6.3. Knowledge vs. Social Lives:

**Table 20: Binary logistic regression between knowledge and social lives**

		B	S.E	Wald	df	Sig.	Exp(B)
Step 1 <sup>a</sup>	Knowledge	2.408	.552	18.996	1	.000	11.109
	Constant	-4.648	.984	22.299	1	.000	0.10

Logistic model:  $\frac{\pi}{1-\pi}(C) = \frac{e^{\alpha+\beta x}}{1+e^{\alpha+\beta x}}$

$$\log \frac{\pi}{1-\pi}(C) = \frac{e^{-4.648+2.408x}}{1+e^{-4.648+2.408x}}$$

$$\Rightarrow e^{\beta} = e^{2.408}$$

If Knowledge changes from poor to good category, social live status will increase by  $e^{\beta}$  unit.

Then, odds ratio  $e^{\beta}=11.11$

That is, odds of good social live status are 11.11 times of good knowledge status.

#### 4.6.4. GMFCS vs. Assistive device:

**Table 21: Binary logistic regression between GMFCS and assistive devices**

		B	S.E	Wald	df	Sig.	Exp(B)
Step 1 <sup>a</sup>	GMFCS	1.288	.462	7.752	1	.005	3.624
	Constant	-5.358	2.162	6.139	1	.013	.005

Logistic model:  $\frac{\pi}{1-\pi}(C) = \frac{e^{\alpha+\beta x}}{1+e^{\alpha+\beta x}}$

$$\log \frac{\pi}{1-\pi}(C) = \frac{e^{-5.358+1.288x}}{1+e^{-5.358+1.288x}}$$

$$\Rightarrow e^{\beta} = e^{1.288}$$

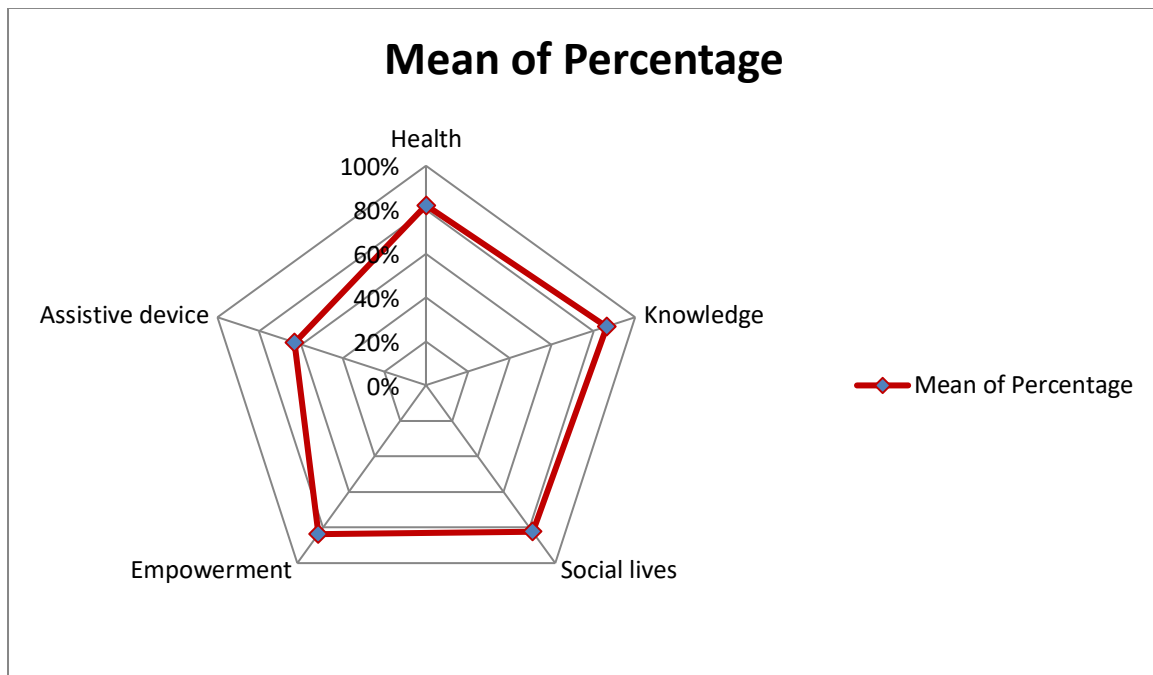
If GMFCS changes from IV to V category, assistive device use will increase by  $e^{\beta}$  unit.

Then, odds ratio  $e^{\beta}=3.62$

That is, odds of assistive device uses are 3.62 times of GMFCS level.

In 2003 Ostensjo found in regression analysis that the GMFCS was a good predictor of everyday functioning with age and learning problems as significantly contributing factors, particularly in self-care and social function (Ostensjo et al., 2003).

#### 4.7: Radar Graph:



**Figure 15: Radar graph for means of health, knowledge, empowerment, social lives and assistive devices**

Radar chart is a graphical way to compare data by displaying data in a "web-like" form looking like spider web. So it is also known as spider chart/graph. Usually, it is applied to evaluate multiple alternatives based on multiple criteria.

In our study we found that the mean of health (82%), knowledge (86.4%), social lives (82.32%), empowerment (83.70%) and assistive device (63.08%) which we put in the radar graph to draw a conclusion. Based on the graph we can see that assistive devices has lowest mean, that means this area need prioritization in near future followed by health of parents.

The reason for low impact could be lack of service, accessible house, roads and lack of awareness among the groups.

#### **4.8. Qualitative data analysis:**

In the qualitative part there were five major questions which were asked to individual parents and the interviews were conducted in the homes and various community centers as it was difficult to travel to all the houses due to limited time and lack of accessibility. The home visits enabled observation of the child and parents especially mother in their local context. On an average an interview lasted 45 minutes.

##### **4.8.1. Reasons for taking care of the child:**

The first question was asked to know about the reasons why that particular person is taking care of the child. It might be due to various reasons and as we can see that improvement of a child depends upon the quality of caregiving. Most of the respondent in this research were mother i.e. 92% and 8% were father. Usually we don't see father involvement in taking care of a child like mothers do. Most of the answers that we came across are

*“I am a mother and it's my responsibility to take care of my child like other abled children.”*

Whereas we found answers that states about the necessity of caring a child with cerebral palsy as it needs lots of effort due to presence of complications not only in one system of body but affects almost all the major systems of the body. These complications make a child partially to completely dependent on others for their daily activities.

*“I am taking care of my child because he is completely dependent and can't perform any activity of his own. And I am the only one to look after him.”*

Among the well-wishers parents come first and like other parents they also want their child to be happy and live a healthy life. All parents want to see a good future for their children. Most of the parents also said that they want their child to be educated and a good citizen of the country. And that's why almost all of them sending their child to inclusive schools. No matter how hard it is for them they are ready to do all those things and that's possible for them as a parent.

*“I am taking care of the child because he should improve physically and lead a happy life. I am also taking care of his education so that he can learn basic things and can spend quality time in school as well as with his friends.”*

*“We accept him as he is but we are worried about his future. We are trying to make him able up to possible extend so that in future he becomes less dependent on others.”*

**4.8.2.** The second question was asked whether they think it's their holy duty to take care of their child or there is another reason behind the caring. The result shows that seventy percent (70%) thinks it's their responsibility to take care of their child. The reasons stated were first they are the parents and those are their children. Secondly, they want to see their children happy and healthy. Thirdly, their children should be less dependent upon others. They also stated their fear about their children's future after they die. Twenty percent of them think it's their holy duty as well as responsibility to take care of the children. Ten percent thinks it's their holy duty to take care of their children.

*“It is my holy duty to take care of him because no one will take care of him after me as I am alone, my husband left me and I am scared of thinking about- in future who will take care of him.”*

**4.8.3.** The third question was asked about the challenges experienced by parents in taking care of a child with special needs. The answers were different based on their locality and needs. In rural as well as urban area the most challenging task was to find the right person for consultation. Parents said that it's really difficult for them to visits several doctors at several hospitals and not getting the right rehabilitation guideline to follow.

*“Carrying her to different hospital in public transport was difficult and the distance was very far from one hospital to another. After visiting various hospitals we could not find the answers that we were looking for. Finally one doctor suggested visiting APD; we came here and took appointment for rehabilitation. Now she has grown up and admitted to inclusive school within APD campus, here she gets rehabilitation as well as education. She uses wheelchair for mobility. I am here with her in school for whole day. I hardly get time for other things. Though the school is taking care of all the children still being a mother I cannot leave her alone.”*

Apart from these some of them find difficulty in performing activities of daily living as the child grows up.

*“Carrying the child outside for social gathering and doing her exercise at home is very difficult as her hands and legs are so tight and she feels pain and cry. No doubt we are*

*getting parents training but still it's really challenging to perform those exercises. I am giving my best cope up with all the difficulties.”*

In semi-urban and rural areas the most common challenges were using of assistive device, access to education, and service available for those children due to lack of accessibility. The durability of wheelchairs, Orthotics, and other assistive device is very less due to uneven or rough roads. Most of the children are homebound due to lack of accessibility outside as well as inside home.

*“My child name is registered in the school. Few days we took him to school but now we stop because we cannot carry him all the time as he is a grown up child and the wheelchair cannot move in this road. His class is in second floor and there is no ramp inside the school. Though we are getting facilities yet we cannot utilize it due to various problems. Inside home this wheelchair is helping us a lot as he is sitting in proper position and plays with his brother and sisters and it also helps me in feeding his meals. ”*

**4.8.4.** The next question was to find out whether any “reasonable adjustments” need to do to help mother with cerebral palsy children. But surprisingly ninety eight percentages said no and they are happy with the ongoing process of Community Based Rehabilitation. Two percent said that if the community worker visit increases it will be a great help for them.

*“We are happy with the service of APD in our community. It helps our children a lot; also it helps me to perform his activities in an appropriate way. The parental training that we are getting at APD helps us to learn a lot about our own children and also we can see the differences in our children activity. The training I got helped me a lot to do exercise for my child and I am also aware of the benefits of doing exercises and using assistive devices. Before the training I was completely unaware about cerebral palsy, its complications and the uses of assistive devices. Thanks to APD for providing us such training and helping us to take care of our children.”*

**4.8.5.** The final question was asked about specific training need to implement specifically for mothers. The answers were not very far from the ongoing training programs. The mothers were highly benefited from those training. In future they are expecting training specific to their child’s needs. They want to learn new skills and techniques so that they can give their full effort in taking care of the child.

*“I need training on specific exercise for my child because he is growing now and to cope with his physical growth I need to learn new exercises based on his condition so that I can do for him at home.”*

All the mothers were very much active and willing to explore new treatment protocol which can help their child to improve. They are very much hopeful that trainings will help them in future as well as their child grows. Overall we can see good response from parents and their involvement in training shows how much dedicated they are towards their children wellbeing.



## CHAPTER V: DISCUSSION

This section starts with a discussion of the sample. This study inspected impact of community based rehabilitation program upon parents having cerebral palsy children. The study sample consisted of 100 parents who are involved in day to day care taking of their children. Among the study subjects 92 were biological mothers and eight biological fathers. 34 cases were from urban, 33 from semi-urban and 33 from rural areas. The children age range from six months to 15 years. The study sample consisted of 71 cases of GMFCS level V and 29 cases of GMFCS IV. The female subjects were mostly housewives and they had mostly secondary level of education. Most of them are economically stable. The minimum number of members in a family was four and a maximum was 15. There was a significant relationship between socio-economic status and number of family members. The socio-economic status of the family decreases as family size increases. The associations between larger family size, poverty incidence and vulnerability to poverty are strong and enduring (Orbeta , 2005).

In the domain “Health”, among 100 respondent 71 were agreed to the fact that home based therapy has positive impact upon their health. 23 were highly agreed. 75 were agreed that after enrolment of their children to CBR program their suffering and discomfort has been reduced. 18 were highly agreed. 78 agreed to the fact that CBR program have reduced their physical stress (e.g. Transfer, Handling, Feeding etc.) and 15 were highly agreed to it. 63 were agreed that their negative feelings such as anxiety and frustration have been decreased after implementing CBR program and 24 were highly agreed. 92% informed that they get enough sleep at night and feel refresh in the morning

In the domain “Education/Knowledge” 49% was agreed that they are comfortable to take care of their children after the training and 46% were highly. 58% were agreed that the training provided by CBR program had changed their lifestyle and 34% were highly agreed. 62% were agreed that they gained knowledge about cerebral palsy and how to handle them in a therapeutic way and 37% were highly agreed. 59% were agreed that they can perform ADLs of their children without any difficulty, 33% were highly agreed. There were a huge number of agrees in social lives and empowerments. There were changes achieved after using assistive devices and had a great impact upon parents health.

To check association between different variables, a significant association was found between health of parents and knowledge of parents ( $p=.001$ ), health of parents and social lives of

parents ( $p<.001$ ), knowledge and social lives ( $p<.001$ ), GMFCS level and assistive device uses ( $p=.004$ ).

The odds of health is 4.1 times of knowledge, the odds of social live is 6.14 times of health, the odds of social live is 11.11 times of knowledge and the odds of assistive device use is 3.63 times of GMFCS.

So, we can say that there is a positive impact on health, knowledge, social lives and empowerment of parents after CBR training program.

The CBR program analyzed at Mandya and Ramanagara Districts of Karnataka state, India, has a positive impact on access to services and the wellbeing of PWDs (Mauro et.al, 2014).

Compared to hospitalized youth, home-based Multisystem Therapy (MST) for youth with serious emotional difficulties initially resulted in better outcomes (Henggeler. et al., 2003).

In a study in South Africa the results suggest that CBR program have had a positive impact, there are still a number of issues that need to be addressed (Chappell and Johannsmeier, 2009).

Considerable progress was recorded in activities of daily living (ADL) measures as well as social measures concerning family life and social participation outside the family in a study at Palestine, increased awareness about disability issues and attitude change were also clearly indicated ( Eide ,2006).

The CBR program in Palestine has had a pronounced impact on individuals with disabilities and their families. The program has also had a positive impact on awareness, attitudes and practice towards individuals with disabilities in their local communities (Eide, 2006).

The dependency or use of assistive devices increases along with the GMFCS level. In a study it was found that the limitations in achievement of activities, need for assistance, and use of assistive devices increased progressively with GMFCS level (Ostensjo et al., 2003).

Assistive device has positive impact upon child as well as parents health as it reduces the burden of carrying children outside. Adaptations of housing and transportation facilitated effective use of assistive devices (Ostensjo et al., 2005).

## **CONCLUSION:**

The aim of the study was to identify the Challenges that have overcome by the parents after CBR program; the improvements in parent's life at 4 domains of CBR program matrix; to find out whether there exist any further changes that would make in the program for better outcome and family attitude, Social inclusion, acceptance after implementing the program.

However, in order to attain this aim, the study determined: (i) parents 'health status (ii) knowledge gained by parents about CP and handling techniques (iii) Social live of parents after CBR training program (iv) Empowerment (v) Benefits of using assistive devices and home modifications (v) the association between the variables.

The overall findings say that there is a good (positive) impact of CBR training program on parent's health, knowledge, social lives and empowerment. There were benefits of using assistive devices. The use of wheelchair and other devices could be benefited much if there was accessibility around and within the house.

To trace the association between different variables, significant association were found between health of parents and knowledge of parents ( $p=.001$ ), health of parents and social lives of parents ( $p<.001$ ), knowledge and social lives ( $p<.001$ ), GMFCS level and assistive device use ( $p=.004$ ).

The odds of health is 4.1 times of knowledge, the odds of social live is 6.14 times of health, the odds of social live is 11.11 times of knowledge and the odds of assistive device use is 3.63 times of GMFCS.

CBR program does not only have positive impact upon PWDs, it also plays a vital role in parents' life. It contributes positive effects upon parents overall activity. The radar graph shows that priority should be given to the provision of assistive devices as it was the less benefited area among all the variables.

Based on the qualitative findings more hands-on training should be provided to parents so that they can take care of their children along with growing age. It is really hard to find professionals in rural community to provide rehabilitation to cerebral palsy children on day to day basis, therefore training of parents is in high demand.

## **RECOMMENDATIONS:**

Further studies should be done to find out the impact of each parents training in the community centers. So that it could help the CBR training provider to know how much parents have learnt and up to what extend they are using it practically and whether any improve method or new training item should be included to improve the training program

Further study must include those organizations and NGOs that are working in CBR program altogether to get a better impact result.

Socio-cultural factors have a big impact in perception study like this. So, if we could do similar study in other countries focusing upon parents and compare the findings then we could find out the interplay of sociocultural factors on CBR program impact.

The study describes the challenges from parents' point of view. Studies on challenges perceived by health care professionals will give a complete picture of real challenges and measures to be taken.

Monitoring of ongoing program will give us insight to fix errors at present which could lead to negative impact in future.

## **LIMITATIONS:**

**Performance bias:** Performance Bias from respondents' side may have been introduced during data collection as respondents were aware of what is to be asked to them. They may have sub consciously changed their choice to make themselves in better view and opinions of researcher. Key informant may have wished to keep quiet about actual status of CBR program. They may have altered their views and opinions regarding rehabilitation during interviews.

**Selection Bias:** Selection bias may have been introduced while selecting centers for undertaking study. The study has been done in focusing one organization of Bangalore and its branches within Karnataka state. If the study had been conducted including various organizations (NGOs), then we could have found more representative information.

**Language Barrier:** Due to language barrier for researcher, several data collectors had to be recruited. This could lead to some bias.

**Small sample size:** Although 100 samples were taken from three areas, still the results cannot be generalized to the whole population of Bangalore under CBR program. If the sample size could be increased sufficiently a more exact result may be extracted which could be more representation.

**Lack of prior research with similar type:** Lots of research focuses on impact upon PWD, challenges of PWDs and upon caregiver stress and burden. Very few studies focus on impact of CBR program, especially upon parents with cerebral palsy children.

**Measure used to collect data:** Both Qualitative and Quantitative measures were used to collect data as the number of participants is very less. Though mixed method enhances the quality of research still there could be gap in coding of qualitative data.

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## Appendix I

### Description of GMFCS:

	<p><b>GMFCS level I</b></p> <ul style="list-style-type: none"><li>• Children walk at home, school, outdoors and in the community.</li><li>• They can climb stairs without the use of a railing.</li><li>• Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.</li></ul>
	<p><b>GMFCS level II</b></p> <ul style="list-style-type: none"><li>• Children walk in most setting and climb stairs holding onto railing.</li><li>• They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces.</li><li>• Children may walk with physical assistance, hand held mobility aids or use wheel chair over long distance.</li><li>• Children have only minimal ability to perform gross motor skills such as running and jumping.</li></ul>
	<p><b>GMFCS level III</b></p> <ul style="list-style-type: none"><li>• Children walk using hand held mobility device in most indoor settings.</li><li>• They may climb stairs holding onto a railing with supervision or assistance.</li><li>• Children use wheeled mobility when travelling long distances and may self propel for short distances.</li></ul>
	<p><b>GMFCS level IV</b></p> <ul style="list-style-type: none"><li>• Children use methods of mobility that require physical assistance or powered mobility in most settings.</li><li>• They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned.</li><li>• At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.</li></ul>
	<p><b>GMFCS level V</b></p> <ul style="list-style-type: none"><li>• Children are transported in a manual wheelchair in all settings.</li><li>• Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.</li></ul>

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## Annexure II

### Information sheet

Namaste/Hello

I am Doly Bokalial, student of the Bangladesh Health Professions Institute (BHPI) which is the academic institute of the Centre for the Rehabilitation of the Paralyzed (CRP), Savar, and Dhaka. I am studying M.Sc. in Rehabilitation. In regards to the fulfillment of M.Sc. Degree, it is mandatory to conduct a research in final year of study. It will be very helpful if you accept my invitation and take part in my study.

From many literatures, I got information that community-based rehabilitation (CBR) programs help people with disabilities, for social integration, equalization of opportunities, and Physical upliftment. My research Title is “Impact of Community Based Rehabilitation program on parents having children with cerebral Palsy in Bangalore.” The specific objective is to identify the challenges overcome by parents after CBR program along with Family Social inclusion, acceptance after implementing the program.

This study result will be helpful to Result can help CBR programs to identify groups of persons (parents) who benefit less from specific activities and adopt strategies to improve their participation. Can be used in further development of CBR program. More emphasize can be given to parents also while designing a program. You can voluntary participate in this study. You have full right to withdraw from the study at any time without hesitation. You are free to not participate at all, despite consenting to take part earlier.

I will collect data by some questionnaire and some observation during home visits. Confidentiality of all records will be highly maintained and all details will be kept on a confidential database that is only accessible to me and my supervisor. The identity of you will not be disclosed in any presentation or publication without your agreement. If you have any queries now regarding this study please feel free to ask. I am accountable to answer all questions regarding this study.

Doly Bokalial

MRS, BHPI

Participant’s signature:

Date:

Investigator’s signature:

Date:

## Consent Form

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 above named study.

1. I confirm that I have read and understood the information sheet for the study or that it has been explained to me and I have had the opportunity to ask questions. Yes / No
  
2. I have satisfactory answers to my questions regarding with this study. Yes / No
  
3. I understand that participation in the study is voluntary and that I am free to end my involvement at any time, or request that the data collected in the study be destroyed without giving a reason. Yes / No
  
4. Information from interview and questionnaire, those will be collected by the investigator might be examined by research supervisor. However, all personal details will be treated as highly confidential. I have permitted the investigator and supervisor to access my recorded information. Yes / No
  
5. I have sufficient time to come to my decision about participation. Yes / No
  
6. I agree for quotations from my interviews to be used in the above study. Yes / No
  
7. I agree to take part in the above study. Yes / No

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

Date \_\_\_\_\_

### **Investigator**

I have explained the study to the above participant precisely and he/she has indicated a willingness to take part.

Investigator's signature \_\_\_\_\_

Date \_\_\_\_\_



**Annexure III**

*Please help us by providing below details.....*

**Socio-demographic data**

1.Name:	2.Age:
3.Gender:	4.Marital Status:
5.Education Qualification:	6.No.of family members:
7.Socio-economic status:	8.Religion:
9.Food habits (Veg,Non-veg):	10.Responsibilities:

**PART-I**

11. Why are you taking care of the child? ..... ..... ..... ..... ..... ..... ..... .....
12. Relationship between you and the child? ..... ..... ..... ..... .....
13. Do you think this is your holy duty to take care of him/her or there is other reason behind it? If yes please explain. ..... ..... ..... ..... .....

14. a) Year of implementation, b) Number of sessions per year, c) Total sessions obtained

a).....

b).....

c).....

**PART-II**

**How CBR (Community Based Rehabilitation) did affected the following:**

**Health status of mother after CBR**

		Highly disagree	Disagree	Neither agree nor disagree	Agreed	Highly agreed
15	Home based therapy has positive change upon my health.					
16	After enrolment of my children to CBR my suffering and discomfort has been reduced.					
17	CBR program have reduced my physical stress (e.g. Transfer, Handling, Feeding etc.).					
18	My negative feelings such as anxiety and frustration have been decreased.					
a)Child b)Mother						
19	I get enough sleep at night and feel refresh in the morning.					

**Educatons /Knowledge (of mother after CBR based on training)**

		Highly disagree	Disagree	Neither agree nor disagree	Agreed	Highly agreed
20	I am comfortable to take care of my child.					

21	CBR program provided me training that have changed my life style.					
22	I gain knowledge about Cerebral Palsy/ handling techniques.					
23	I can perform Activities of Daily Living (ADLs) of my child without any difficulty.					

### **Social lives after CBR**

		Highly disagree	Disagree	Neither agree nor disagree	Agreed	Highly agreed
24	CBR program made it easier to participate in social activities outside home.					
25	Family and Society attitude is been positive to me after implementing CBR program.					
26	I don't feel neglected from the community member.					
27	I get necessary time for my own needs and interest.					
28	My social participation has increased (e.g. Family gathering, marriage, religious social function etc.).					

### **Empowerment after CBR**

		Highly disagree	Disagree	Neither agree nor disagree	Agreed	Highly agreed
29	I am aware about the rights of person with disability (PWD) (e.g. facilities available for PWDs from government, disability card, concessions).					
30	I am able to speak about myself and my rights.					

**PART-III**

**How much change you see in the following:**

**Home modification:**

		Not at all	A little	A moderate amount	Very much	Extremely
31	The child bed is modified according to his/her height and weight.					
32	The toilet is modified or using toilet chair.					
33	Is there accessible and or sufficient play area available for your child?					
34	Is bathing area are modified?					

**Establish exercise area**

		Not at all	A little	A moderate amount	Very much	Extremely
35	Area for exercise available at home.					
36	Special exercise setting is developed.					
37	Exercise equipment available (pillow, towel, mat, parallel bar, ramp, steps etc.) based on needs.					

**Assistive device**

		Not at all	A little	A moderate amount	Very much	Extremely
38	Using Wheelchair/Special Chair increase the mobility of your child.					
39	Wheelchair/ Special Chair reduced your physical burden in carrying the child.					

40	Orthotics/Wheelchair/ Special chair had helped you in positioning your child.					
----	--	--	--	--	--	--

**Environment**

41. Is your environments disable friendly? YES NO

**PART-IV**

**Future Perspective**

42. What are the most challenging aspects as the parents of children with special needs?  
 .....  
 .....  
 .....  
 .....  
 .....

43. Are there any “reasonable adjustments” which should be made in the CBR program to help mother with disabled child?  
 .....  
 .....  
 .....  
 .....

44. Are there any specific training need to implement specially for mothers? If yes, please explain what type of training you are expecting.  
 .....  
 .....  
 .....

## Appendix IV

### Kannada Questionnaire

ದಯವಿಟ್ಟು ಈ ಕೆಳಕಂಡಂತೆ ವಿವರಗಳನ್ನು ಒದಗಿಸಿ ನಮಗೆ ಸಹಾಯ ಮಾಡಿ.

ಸಾಮಾಜಿಕ ಜನಸಂಖ್ಯಾ ವಿಜ್ಞಾನ ಅಧ್ಯಯನ (ಸೂಷಿಯಾಲ-ಡೀಮೋಗ್ರಾಫಿಕ್)

1. ಹೆಸರು:	2. ವಯಸ್ಸು:
3. ಙಗ:	4. ವೈವಾಹಿಕ ಸ್ಥಿತಿ:
5. ವಿದ್ಯಾರ್ಹ ತೆಗಳ:	6. ಕುಟುಂಬ ಸದಸ್ಯರ ಸಂಖ್ಯೆ:
7. ಸಾಮಾಜಿಕ-ಆರ್ಥಿಕ ಸ್ಥಿತಿ:	8. ಢತ:
9. ಆಹಾರ ಅಭ್ಯಾಸಗಳು (ಸಸ್ಯಹಾರಿ-ಮಾಂಸಹಾರಿ)	10: ಹೂಬೆಗಾರಿಕೆಗಳು

ಭಾಗ-1

11. ನೀವು ಮಗುವಿನ ಆರೈಕೆ ಏಕೆ ತೆಗೆದುಕೊಳ್ಳುತ್ತಿದ್ದೀರಿ? ..... ..... ..... .....
12. ನಿಮ್ಮ ಮತ್ತು ಮಗು ಮಧ್ಯೆ ಇರುವ ಸಂಬಂಧ? ..... ..... .....
13. ಅವನ/ಅವಳ ಆರೈಕೆ ತೆಗೆದುಕೊಳ್ಳುವುದು ನಿಮ್ಮ ಪವಿತ್ರ ಕರ್ತವ್ಯವಾಗಿದೆ ಎಂದು ನೀವು ಯೋಚಿಸುತ್ತೀರಾ ಅಥವಾ ಅದರ ಹಿಂದೆ ಬೇರೆ ಕಾರಣವಿದೆಯೇ? ಹಾದುದಾದಲ್ಲಿ ದಯವಿಟ್ಟು ವಿವರಿಸಿ. ..... .....

14. ಅ) ಕಾರ್ಯಾಗತಗೊಳಿಸುವ ವರ್ಷ, ಆ) ಪ್ರತಿ ವರ್ಷ ಅಧಿವೇಶನಗಳ ಸಂಖ್ಯೆ, ಇ) ವೆಚ್ಚದ ಮೊತ್ತದ ಒಟ್ಟು ಅಧಿವೇಶನಗಳು.

ಅ).....

ಆ) .....

ಇ) .....

#### ಭಾಗ-2

ಸಿಬಿಆರ್ (ಸಮುದಾಯ ಆಧಾರಿತ ಮನ್ವ್ಯತನಗೊಳಿಸುವಿಕೆ) ಇದು ಈ ಕೆಳಗಿನವುಗಳಿಗೆ ಹೇಗೆ ಛಾಧಿ ಸಿರುತ್ತದೆ:

		ಹೆಚ್ಚು ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪಿಕೊಳ್ಳುವುದಿಲ್ಲ ಅಥವಾ ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪಿದ್ದೇನೆ	ಹೆಚ್ಚು ಒಪ್ಪಿದ್ದೇನೆ
15	ಮನೆ ಆಧಾರಿತ ಷಿ ಕಿತ್ಲೆಂಒಂದ ನನ್ನ ಆರೋಗ್ಯದ ಮೇಲೆ ಸಕಾರತ್ಮಕ ಬದಲಾವಣೆ ಆ ಗಿದೆ.					
16	ಸಿಬಿಆರ್ ಇದಕ್ಕೆ ನನ್ನ ವುಕ್ಕಳನ್ನು ದಾಖಲಿಸಿದ ನಂತರ ನನ್ನ ನೋವು ಮತ್ತು ಅಸ್ವಸ್ಥತೆ ಕಡಿಮೆ ಆ ಗಿದೆ.					
17	ಸಿಬಿಆರ್ ಕಾರ್ಯಕ್ರಮವು ನನ್ನ ದೈಹಿಕ ಒತ್ತಡವನ್ನು ಕಡಿಮೆಯೂಡಿದೆ (ಉದಾಹರಣೆ: ವರ್ಗಾವಣೆ, ಸಿಛಾವಣೆ, ಆಹಾರಕೂಡುವುದು, ಮೂದಲಾವುದುಗಳು)					
18	ನನ್ನ ನಕರಾತ್ಮಕ ಅ) ಛಾವಣಿಗಳಾದ ಆತಂಕ ಮತ್ತು ಹತಾಶೆ ಇವುಗಳು ಇಳಿದಿದೆ. ಆ) ತಾಂಒ					
19	ರಾತ್ರಿಯಲ್ಲಿ ನನಗೆ ಸಾಕಷ್ಟು ಸಿದ್ಧ ಬರುತ್ತದೆ ಮತ್ತು ಬೆಳಿಗ್ಗೆ ಹೂವ್ ಬೇತನ ಕಾರುತ್ಲೇನೆ.					

ಶಿಕ್ಷಣಗಳು/ಜ್ಞಾನ (ತರಬೇತಿ ಮೇಲೆ ಸಿಐಆರ್ ಆಧಾರಿತ)

		ಹೆಚ್ಚು ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪಿಕೊಳ್ಳುವುದಿಲ್ಲ ಅಥವಾ ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪಿದ್ದೇನೆ	ಹೆಚ್ಚು ಒಪ್ಪಿದ್ದೇನೆ
20	ನನ್ನ ಮಗುವಿನ ಆರೈಕೆ ತೆಗೆದುಕೊಳ್ಳಲು ನನಗೆ ಆರಾಮದಾಯಕವಾಗಿದೆ					
21	ಸಿಐಆರ್ ಕಾರ್ಯಕ್ರಮವು ನನ್ನ ಜೀವನಶೈಲಿ ಬದಲಾಯಿಸಿದಂತಹ ತರಬೇತಿ ನನಗೆ ಒದಗಿಸಿದೆ					
22	ಸೆರೆಲ್ಲಾ ಪಾಲ್ಗೊಳ್ಳುವ/ನಿರ್ವಹಣೆ ತಂತ್ರಗಳ ಕುರಿತು ನನಗೆ ಜ್ಞಾನ ಸಿಗುತ್ತದೆ.					
23	ಯಾವ ತೊಂದರೆ ಇಲ್ಲದೆ ನನ್ನ ಮಗುವಿನ ದಿನನಿತ್ಯ ಜೀವಿಸುವ ಚಟುವಟಿಕೆ (ಎಡಿಎಲ್)					

ಸಿಐಆರ್ ನಂತರ ಸಾಮಾಜಿಕ ಜೀವನ

		ಹೆಚ್ಚು ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪಿಕೊಳ್ಳುವುದಿಲ್ಲ ಅಥವಾ ಒಪ್ಪುವುದಿಲ್ಲ	ಒಪ್ಪಿದ್ದೇನೆ	ಹೆಚ್ಚು ಒಪ್ಪಿದ್ದೇನೆ
24	ಸಿಐಆರ್ ಕಾರ್ಯಕ್ರಮವು ಮನೆ ಹೊರಗಡೆ ಸಾಮಾಜಿಕ ಚಟುವಟಿಕೆಗಳಲ್ಲಿ ಭಾಗವಹಿಸಲು ಸುಲಭ ಮಾಡಿದೆ					
25	ಸಿಐಆರ್ ಕಾರ್ಯಕ್ರಮ ಕಾರ್ಯಗತಗೊಳಿಸಿದ ನಂತರ ಕ್ರಿಯಾತ್ಮಕ ಮತ್ತು ಸಾಮಾಜಿಕ ಮನೋಭಾವಗಳು ನನಗೆ ಸಕಾರಾತ್ಮಕವಾಗಿವೆ.					
26	ಸಮುದಾಯದ ಸದಸ್ಯರಿಂದ ತಿರಸ್ಕಾರವಾಗಿದೆ ಎನ್ನುವುದು ನನಗೆ ಅನಿಸುವುದಿಲ್ಲ					
27	ನನ್ನ ಸ್ವಂತ ಅಗತ್ಯತೆಗಳು ಮತ್ತು ಹಿತಾಸಕ್ತಿಗೆ ಅಗತ್ಯ ಸಮಯ ನನಗೆ ಸಿಗುತ್ತದೆ.					
28	ನನ್ನ ಸಾಮಾಜಿಕ ಭಾಗವಹಿಸುವಿಕೆಯು ಹೆಚ್ಚುತ್ತಿದೆ (ಉದಾಹರಣೆ: ಕುಟುಂಬ ಸಭೆ, ಮದುವೆ, ಧಾರ್ಮಿಕ ಸಾಮಾಜಿಕ ಸಮಾರಂಭ, ಇತ್ಯಾದಿಗಳು)					



ಸಿಐಆರ್ ನಂತರ ಸಬಲೀಕರಣ

		ಹೆಚ್ಚು ಒಪ್ಪಂದಿಲ್ಲ	ಒಪ್ಪಂದಿಲ್ಲ	ಒಪ್ಪಿಕೊಳ್ಳುವುದಿಲ್ಲ ಅಥವಾ ಒಪ್ಪಂದಿಲ್ಲ	ಒಪ್ಪಿದ್ದಾನೆ	ಹೆಚ್ಚು ಒಪ್ಪಿದ್ದಾನೆ
29	ಅಂಗವೈಕಲ್ಯ ಹೊಂದಿರುವ ವ್ಯಕ್ತಿಯ ಹಕ್ಕುಗಳ ಬಗ್ಗೆ ನನಗೆ ಅರಿವಿದೆ (ಸರ್ಕಾರದಿಂದ, ಅಂಗವೈಕಲ್ಯ ಕಾರ್ಡ್, ರಿಯಾಯಿತಿಗಳು, ಇವುಗಳಿಂದ ಪಿಡಬ್ಲ್ಯುಡಿ ಇವುಗಳಿಗೆ ಸಿಗುವ ಸೌಕರ್ಯಗಳು).					
30	ನನ್ನ ಸ್ವತಃ ಮತ್ತು ನನ್ನ ಹಕ್ಕುಗಳ ಬಗ್ಗೆ ಮಾತಾನಾಡಲು ನನಗೆ ಸಾಧ್ಯವಾಗಿದೆ.					

ಭಾಗ-3

ಈ ಕೆಳಕಂಡವುಗಳಲ್ಲಿ ಎಷ್ಟು ಬದಲಾವಣೆ ನೀವು ಕಾಣುತ್ತೀರಾ:

ಗೃಹ ಮಾರ್ಪಡೆ:

		ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮ ಪ್ರಮಾಣ	ತುಂಬಾ	ಅತ್ಯಂತ
31	ಮಗುವಿನ ಹಾಸಿಗೆಯನ್ನು ಅವನ/ಅವಳ ಎತ್ತರಕ್ಕೆ ಮತ್ತು ತೂಕ ಅನುಗುಣವಾಗಿ ಮಾರ್ಪಡಿಸಿಮಾಡಿದೆ.					
32	ಶೌಚಾಲಯವನ್ನು ಮಾರ್ಪಡಿಸಿಮಾಡಿದೆ ಅಥವಾ ಶೌಚಾಲಯ ಕುರ್ಚಿ ಉಪಯೋಗಿಸಿದೆ.					
33	ನಿಮ್ಮ ಮಗುವಿಗೆ ಸಾಕಷ್ಟು ಆಟವಾಡುವ ಪ್ರದೇಶ ಲಭ್ಯವಿದೆಯೇ ಮತ್ತು ಪ್ರವೇಶಾವಕಾಶವಿದೆಯೇ					
34	ಸ್ನಾನದ ಪ್ರದೇಶ ಮಾರ್ಪಡಿಸಿ ಮಾಡಿದೆಯೇ ?					

ವ್ಯಾಯಾಮ ಪ್ರದೇಶ ಸ್ಥಾಪಿಸುವುದು:

		ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮ ಪ್ರಮಾಣ	ತುಂಬಾ	ಅತ್ಯಂತ
35	ಮನೆಯಲ್ಲಿ ವ್ಯಾಯಾಮ ಮಾಡಲು ಲಭ್ಯವಿರುವ ಪ್ರದೇಶ					
36	ವಿಶೇಷ ವ್ಯಾಯಾಮ ಸೆಷನ್‌ಗಳನ್ನು ಅಭಿವೃದ್ಧಿಪಡಿಸಿದೆ.					
37	ವ್ಯಾಯಾಮ ಉಪಕರಣಗಳು ಲಭ್ಯವಿದೆ (ದಿಂಬು, ಟೌವಲ್, ಚಾವಿ, ಸಮನಾಂತರ ಪಟ್ಟಿ, ಇಳಿಜಾರು (ರಾಂಪ್), ಮೆಟ್ಟಿಲುಗಳು, ಇತ್ಯಾದಿಗಳು, ಇವುಗಳ ಅಗತ್ಯಗಳ ಮೇಲೆ ಆಧಾರಿಸಿ					

ಸಹಾಯಕ ಸಾಧನ

		ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮ ಪ್ರಮಾಣ	ತುಂಬಾ	ಅತ್ಯಂತ
38	ಗಾಲಕುರ್ಚಿ/ವಿಶೇಷ ಕುರ್ಚಿ ಉಪಯೋಗಿಸುವುದು ನಿಮ್ಮ ಮಗುವಿನ ಚಲನೆಗಿಂತ ಹೆಚ್ಚುತ್ತದೆ					
39	ಗಾಲಕುರ್ಚಿ/ವಿಶೇಷ ಕುರ್ಚಿ ಇದು ಮಗುವನ್ನು ಕೊಂಡಯ್ಯುವುದರಲ್ಲ ನಿಮ್ಮ ದೈಹಿಕ ಹೊರೆ ಕಡಿಮೆ ಮಾಡಿದೆ					

		ಇಲ್ಲವೇ ಇಲ್ಲ	ಸ್ವಲ್ಪ	ಮಧ್ಯಮ ಪ್ರಮಾಣ	ತುಂಬಾ	ಅತ್ಯಂತ
40	ಅರ್ಥೋಕ್ಲೆ/ಗಾಲಕ್ರೂಡ್/ವಿಶೇಷ ಕೂರ್ಷಿ ಇದು ನಿಮ್ಮ ಮಗು ಸ್ಥಾನದಲ್ಲಿ ಇರಿಸುವಿಲ್ಲ ನಿಮಗೆ ಸಹಾಯಮಾಡಿದೆ					

ಪರಿನರ

41. ನಿಮ್ಮ ಪರಿನರಗಳು ನೋಹಮಾರ್ಗವಾಗಿ ಅನರ್ಹಗೊಳಿಸುತ್ತದೆಯೇ? ಹೌದು ಇಲ್ಲ

ಭಾಗ-4

ಭವಿಷ್ಯದ ದೃಷ್ಟಿಕೋನ

42. ವಿಶೇಷ ಆಗತ್ಯತೆಗಳೊಂದಿಗೆ ಮಕ್ಕಳುಗಳ ಮೋಷಕರಾಗಿ ಬಹಳ ಸವಾಲುಹಾಕುವಂತಹ ರೂಪಗಳಾವುವು?
.....
.....
43. ಅಂಗವಿಕಲನಾದ ಮಗು ಜೊತೆಗೆ ತಾಯಿಗೆ ಸಹಾಯವಾಗಲು ಸಿಐಆರ್ ಕಾರ್ಯಕ್ರಮದಲ್ಲಿ ಮಾಡಬೇಕಾದಂತಹ ಏನಾದರೂ "ಸಮಜಂಪ ಹೊಂದಾಣಿಕೆ"ಗಳನ್ನು ಇವೆಯೇ?
.....
.....
44. ತಾಯಂದಿರರಿಗೆ ವಿಶೇಷವಾಗಿ ಕಾರ್ಯಗತಗೊಳಿಸಲು ಯಾವುದಾದರೂ ನಿರ್ದಿಷ್ಟವಾದ ತರಬೇತಿಗಳಿವೆಯೇ? ಹೌದಾದಲ್ಲಿ, ಯಾವ ತರಹದ ತರಬೇತಿ ತಾವು ಆವೇಶಪಡುತ್ತೀರಾ ಎಂಬುದನ್ನು ದಯವಿಟ್ಟು ವಿವರಿಸಿ.
.....
.....
.....
.....

## Appendix V



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

Ref.

CRP-BHPI/IRB/11/17/157

Date: 05/02/2017

To  
DolyBokalia  
Part – II, M.Sc. in Rehabilitation Science  
Session: 2016-2017, Student ID: 181160069  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Subject: Approval of the thesis proposal – “Impact of Community Based Rehabilitation (CBR) upon parents having Cerebral Palsy children in Bangalore, India.”**

Dear Doly Bokalia,

Congratulations,

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on April 29, 2017 to conduct the above mentioned thesis, with yourself, as the Principal investigator. The Following documents have been reviewed and approved:

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

The purpose of the study is to find out the impact of community based rehabilitation upon parents having children with cerebral palsy. Data collectors will receive informed consents from all participants. Any data collected will be kept confidential. Participants will fill a questionnaire that takes 10 to 15 minutes and the study have no likelihood of any harm to the participants. The members of the Ethics committee have approved the study to be conducted in the presented form at the meeting held at 9.00 AM on 08-05-2017.

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*  
Muhammad Millat Hossain  
Assistant Professor, MRS  
Member Secretary, Institutional Review Board (IRB)  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

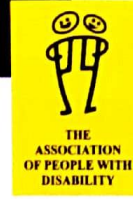


সিআরপি-চাপাইন, সাভার, ঢাকা-১৩৪৩, বাংলাদেশ, ফোন : ৭৭৪৫৪৬৪-৫, ৭৭৪১৪০৪ ফ্যাক্স : ৭৭৪৫০৬৯

CRP-Chapain, Savar, Dhaka-1343, Tel : 7745464-5, 7741404, Fax : 7745069, E-mail : contact@crp-bangladesh.org, www.crp-bangladesh.org

## Appendix VI

6th Cross, Hutchin's Road, Off. Hennur Road, Lingarajapuram, St. Thomas Town Post,  
Bangalore - 560 084, India. Phone : (+91-80) 25475165, 25489594, Fax : (91-80) 25470390  
e-mail : contact@apd-india.org Web : www.apd-india.org



Ref: APD/ HR/539/18

To,

The Principal  
Bangladesh Health Professions Institute  
Dhaka  
Bangladesh

This is to inform you that, **Ms. Doly Bokalial, student of Bangladesh Health Professions Institute in M.Sc in Rehabilitation Sciences has done research work in APD, from 29<sup>th</sup> January 2018 to 15<sup>th</sup> March 2018.**

During her research work, her project was on **“Impact of Community Based Rehabilitation upon parents having Cerebral Palsy children.”**

The research work on evaluation fulfills all the stated criteria and student's findings are her original work and we found her work satisfactory.

We wish her best wishes.

**For The Association of People with Disability**

*Archana Nayak*  
Archana Nayak  
Executive HR  
Interns & Volunteers



Place: Bangalore

Date: 16<sup>th</sup> March 2018