

**“Level of participation of Children with Autism at Home,
School and Community settings”**



By
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*This thesis is submitted in total fulfillment of the requirements for the subject
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Statement of authorship

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The ethical issues of the study has been strictly considered and protected. In case of dissemination the finding of this project for future publication, research supervisor will highly concern and it will be duly acknowledged as undergraduate thesis.

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Dedication

Dedicated to my honorable & beloved parents, two brothers & one lovely sister, my respected all teachers of Bangladesh Health Professions Institute (BHPI).

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List of Abbreviation

ASD- Autism Spectrum Disorder

CRP- Centre for Rehabilitation of the Paralysed

IRB- Institutional Review Board

OT- Occupational Therapy

CASP- Child and Adolescent Scale of Participation

SPSS- Statistical Package for Social Science

WHO- World Health Organization

DSM V- Diagnostic Statistical Manual

ICF- International Classification of Functioning

APA- American Psychiatric Association

MICS- Multiple Indicator Cluster Survey

UN- United Nation

BHPI- Bangladesh Health Professions Institute

ABSTRACT

Background: Participation is a very important element of everyday life. Children with autism needs proper guidance about their activity participation from their childhood period. In Bangladesh there have no related studies and resources available about participation in a Bangladeshi context at all.

Objective: The study identified participation level of students with autism at home, school and community settings. Finding out the socio-demographic picture of students with autism.

Methodology: The study was conducted through cross-sectional design in quantitative study among 110 children with autism who were selected from some selected area of Dhaka city. Participants were selected by using purposive sampling process.

Result: Participation level in the home, school and community settings of children with autism were somewhat limited according to (CASP) questionnaire. According to CASP questionnaire, overall participation level is 74.25%, level of participation in home is 83.75%, level of participation in community 74.25%, level of participation in school is 69.50% and level of participation in home and community living activities 69.50%. That means school participation was better than home and community participation as family members were supportive to their child.

Conclusion: The study explored the participation in home, school and community life of children with autism. The CASP scale is used to measure the participation level of children with autism at selected area of Dhaka district. OTs should encourage the children and parents about engage in the different life situation to enhance participation. Those findings provided useful information for clinicians to understand the participation that are faced by their client. It is possible to increase awareness of professionals and parents about the importance of the participation of children with autism that will helpful for therapist to plan, prioritize based on the greatest restriction and implementation strategies to enhance children's participation in the defined time period.

Key words: Autism, Participation level in home, school and community.

1.1 Background

When a child is born it is hoped that he/she will carry on the traditions of the family, but when a child is born with any disability, it is seen as bringing a curse upon his family and even the parents are treated as if it is the result of great sin. Now-a-days, this thinking has been changed in most of the countries of the developed world, but developing countries like Bangladesh are still not completely aware of the true causes of disability. According to World Health Organization (WHO) 10% of the populations of the developing countries have a disability and this includes Bangladesh, on the other hand, the United Nation (UN) suggests that 20% the population of the some developing countries have a disability. The estimate regarding Bangladesh, over the past twenty years show disability ranged from 0.5% to 10% (Christian, Mahmud & Bhuiyan 2007). According to Multiple Indicator Cluster Survey; Bangladesh (2006), children's disability rate is 18% of the total disability rate. There are many factors for childhood disability and disorder.

Autism is one of the developmental disorder. Smeardon (ed.1998) explained that, autism which is one kind of developmental disorder. Autism is found in every country and region of the world, and across all racial, ethnic, religious and economic background. Characteristics associated with autism, such as atypical ways of thinking, moving, interacting, and sensory processing (Walker 2015), may dispose children to participation restriction. Children with ASD and other disabilities may have restrictions that interfere with their frequency of participation, as well as the diversity of their activities. Participation is 'involvement in life situation' (World Health Organization 2007) and can have a positive impact on health and well-being (Low 2002). Participation in meaningful activities is an essential outcome in

clinical practice (Hemminhsson and Jonsoon 2005), and there is a subsequent need for valid and reliable participation measures (Resnik and Plow 2009) that target children with disabilities, a child's participation in various activities supports the development of their physical, cognitive and communication skills and create opportunities to make friendships

(Hoogsteen and Woodgate 2010; Law et al. 2004; Sylvestre et al. 2013). The construct of participation encompasses the larger context of a child's life by using the collective integration of their functional abilities, developed or regained through rehabilitation that factors community belonging (Coster and Khetani 2008). It may be that children on the autism spectrum do not simply have lower participation than their typically – developing peers (Hilton et al. 2008, Hochhauser and Engel-Yeger 2010, Potvin et al. 2013). Our findings are consistent with published studies describing poor outcomes in adults with ASDs. We observed a significant decrease in community participation from adolescence to adulthood (63–46 %). Our data support the anecdotal evidence that as individuals with ASDs exit the school system, they are at risk for losing community connections. Clubs, sports and other extracurricular activities that schools maintain during adolescence provide structured accessible opportunities for community participation.

Center for the Rehabilitation of the Paralyzed (CRP) is a unique and specialised rehabilitation center in Bangladesh for children with autism. The researcher completed clinical placement in the Pediatric Unit at CRP, and also completed advance placement in faith Bangladesh for one month where most of the patients were autism. Researcher observed that children with autism have participation restriction in their daily living activities as well as in home, school and community. Every year the number of children with autism is increasing in the world. Bangladesh is no exception than other countries. The World Health Organization states that one in every 500 people suffers from autism. According to Autism Society of America, the

most cited statistic is that autism occurs in 4.5 out of 10,000 live births. This is based on large-scale surveys conducted in the United States and England. In Bangladesh around 2.8 lakh children are affected by autism. This figure indicates that one in every 500 children in the country is affected by autism. In India, one in 500 Indian infants has this syndrome or condition. Autism is found in every country and region of the world, and in families, all of racial, ethnic, religious, and economic background (Sylvia, 2003). The prevalence of ASD in 4-year-old children in 13.4 per 1000 (Christensen et al. 2016).

After diagnosis there are many health professionals working in multidisciplinary teams for the autistic child e.g. doctor, Occupational Therapist, Speech & Language Therapist and clinical Psychologist, Dietician or Nutritionist, Special Educator. They maintain their roles most of the time, as a combination of treatment methods is more effective to meet the child's need. Among them the Occupational Therapist plays a vital role in treating the autistic child. To improve the child's developmental skills, early occupational therapy intervention is very effective. To develop important learning skills, it will need to start treatment from birth to 3 years (Law 2006).

Early interventions for children with ASD that target specific tangible improvements (e.g. skill development such as word acquisition, sharing of toys) must be placed within the larger context of participation in life events, which evolve as the child with ASD develops. Measures that support the evaluation of how children with ASD participate in the day-to-day activities of family and community activities within life situations have not yet been identified and reviewed in a systematic way.

Participation is a very important element of every day life. Children with autism needs proper guidance about their activity participation from their childhood period. Therapists concentrate on this issue in order to improve quality of life. Large numbers of international studies have

been done about participation of children with autism but in Bangladesh there have no related studies and resources available about participation in a Bangladeshi context at all so it is very important issue to conduct the study about the level of participation of autism child in different settings like home, school and community. That's why researcher is highly motivated to find out the actual participation level of autism child at home, school and community in Bangladesh.

1.2 Justification of the study

It is known about the measurement of participation of preschool children with ASD who are at a critical time in development for involvement with peers and the community. Previous reviews of participation The primary goal of current treatments for ASD, particularly early intervention, is to improve participation at home, in the community or at early education programs. Thus participation measures that support the selection of meaningful goals and outcomes for a pre- and post-delivered treatment plan for children with ASD in a variety of activities in real-life settings are important. Presently, little measurements have focused on cerebral palsy (Morris et al. 2005; Sakzewski et al. 2007), acquired brain injury (Ziviani et al. 2010), hand use (Chien et al. 2013) or disabilities generally (Adolfsson et al. 2011; Chien et al. 2014; Phillips et al. 2013). None have focused on ASD or preschool children with disabilities, yet the reviews are useful for identifying the breadth of measures available. The aim of the scoping review was to determine what participation measures are available for use with children with ASD.

1.3 Operational Definition

Autism Spectrum Disorder: Autism, or autism spectrum disorder, refers to a range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication, as well as by unique strengths and differences. The term

“spectrum” reflects the wide variation in challenges and strengths possessed by each person with autism.

Autism’s most-obvious signs tend to appear between 2 and 3 years of age. In some cases, it can be diagnosed as early as 18 months. Some developmental delays associated with autism can be identified and addressed even earlier.

Participation: The International Classification of Functioning, Disability and Health (ICF), defines participation as “involvement in a life situation”. Assessing someone’s level of participation is seen as essential to understanding the social impact of a disability on a person’s life. The definition of participation and participation restriction found in the ICF has been described as “intuitively satisfying” but “difficult to measure”. *People viewed participation is an expression of their values. Several themes related to core participation values and these are: (i) active and meaningful engagement/being a part of, (ii) choice and control, (iii) access and opportunity (iv) personal and societal responsibilities, (v) having an impact and supporting others, and (vi) social connection.*

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD), also known as Pervasive Developmental Disorders (PDDs). Its main characteristics are impaired communication and social interaction as well as restricted and repetitive interests and behavior (Larsson et. al. 2005).

Autism is a wide-spectrum disorder. This means that no two people with autism will have exactly the same symptoms. The term “spectrum” is used because, though all people with autism share three main areas of difficulty but the condition will affect them in very different ways. Children and adults with ASD usually have particular communication and social characteristics in common, but that the condition covers a wide spectrum e.g. severity- mild to severe, age, of onset, levels of functioning, and difficulties with social interaction (Autism Society Canada 2009).

- Autism Spectrum Disorder (ASD) is a complex disorder, lifelong condition that affects individuals from all walks of life, as well as their families, friends and caregivers. The word autism derives from the Greek word autos, which means self. Autism is a common neurological pediatric condition. In 1943, Leo Kanner first identified this disorder as Autism (Miller- Kuhaneck 2004, p.7).
- Autism is a pervasive developmental disorder is marked by profound deficits in social language, and cognitive abilities. There are some characteristics associated with autism including severe, complex and permanent behavioral and cognitive disabilities and affects all areas of performance (Case-Smith, Allen and Pratt 1996).

Most individual with autism appear is normal and have no physical disability. Sometimes this condition is accompanied by other handicapping conditions, such as seizures or significant intellectual delay. It is important to note that the symptoms which are displayed by an autistic child can change as the child matures and/or receive treatment (Autism Treatment Service of Canada 2009).

Types of autism spectrum disorder include Asperger syndrome, childhood disintegrative disorder, Rett syndrome, Pervasive developmental disorder and Classical autism. Characteristics of these types of autism include impaired social interaction and communication skills, and a partial choice of activities and interests (Types of autism 2014).

Initial sign and symptoms naturally seem in the early developmental period however, social deficits and behavioral patterns might not be known as symptoms of Autism Spectrum Disorder (ASD) until a child is unable to social, educational, occupational or other important life stage stresses. Functional limitations vary among persons with Autism Spectrum Disorder (ASD) and might develop over time (Rai et.al.).

ASD is characterized by four main categories: impairment in verbal and nonverbal communication, restricted, repetitive and stereotyped behavior, interests, and activities and developmental delay. According to DSM-5 criteria the characteristics are given below:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back and forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g. strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Autism is a physical condition linked to abnormal biology and chemistry in the brain. The exact causes of these abnormalities remain unknown. Smerdon (ed1998) mentioned that there are probably combinations of infectious, metabolic, genetic and environmental factors that lead to autism. Among these factors seem to be important. In some cases, maternal rubella, tuberous sclerosis and encephalitis which are the conditions affecting brain development may be associated with autistic spectrum disorder.

Chromosomal abnormalities and other nervous system problem are also more common in families with autism (Autism fact sheet 2014).

A number of other possible causes such as diet, digestive tract changes, mercury poisoning, and the body's inability have been suspected, but not proven (Autism Treatment Survey of Canada 2009).

- Autism Spectrum Disorder is a life-long condition found in all races and in all social classes. According to the National Autistic Society, over 500,000 people in the UK have

an ASD and prevalence rates suggest one in 100 children may have an ASD. ASD occurs about 4 times more often in males than females (Roberts 2004).

- An overview of prevalence rates of autism was provided in statistic by country of autism (2014) and mentioned that in the United State approximately 544,000 people have autism and in Bangladesh approximately 280,000 people have autism and its prevalence rate is 1 in 500.
- Autistic children have a problem in understanding communication and responding appropriately. This is clarified by Jordan & Morgan (n.d.) who identified that a few autistic children have a acquired speech at 5 years older and some show a lack of improvement in communication skills. Some children need social support, meaningful relationships, future employment opportunities or self determination or they need more time for their daily living activities and school work, because the autistic child shows a lack of interest in their environment, social interaction and others. As a result children will depend on caregivers at all time.

Recent evidence suggests that parents of children with ASD report lower participation in everyday life occupations among their children. For example, families of children with ASD ranging from the ages of 6 to 17 years reported that their children were less involved in after-school or weekend clubs or other organized events; they also were less involved in community activities when compared to families of children with typically developing children (Lee, Harrington, Louie, & Newschaffer, 2008). Findings from another study by LaVesser and Berg (2011) indicated that children from the ages of 3 to 6 years with ASD participated in fewer activities than typical children. The most commonly cited reasons for low participation among children with ASD were factors associated with behaviors, such as having tantrums, not following directions, showing no interest in an activity, and experiencing sensory issues. Family reasons, such as parents choosing not to participate

in activities with the child or not assigning chores, were considered to be another factor associated with low participation among children with ASD. The results of the LaVesser and Berg (2011) study also noted that participation in self-care activities was lower than for typically developing children because children with ASD may experience sensory and motor issues that interfere with such participation. Similarly, children with ASD participated in fewer sedentary leisure activities. Younger children with ASD may participate more in parent-child household activities (e.g., picking up toys, cleaning the room, having adult-child playtimes) and community activities, such as children's festivals and community celebrations (Little, Sideris, Ausderau, & Baranek, 2014). Rodger and Umaibalan (2011) have investigated the difference in routines and rituals between families of children with ASD and families with typically developing children. In their study, families of children with ASD established routines that were more child-oriented, geared toward meeting the demands of their child with ASD rather than the family as whole.

Another study show that children on the autism spectrum (6–13 years) with an IQ above 70 consistently show a lower overall frequency of participation in recreational activities than their peers (Hilton et al., 2008; Hochhauser & Engel-Yeger, 2010; Potvin, Snider, Prelock, Kehayia, & Wood-Dauphinee, 2013). Similar findings have also been reported for preschool-age children (LaVesser & Berg, 2011) and adolescents (Solish, Perry, & Minnes, 2010). Children on the autism spectrum have been shown to participate less frequently in formal (structured), informal, recreational activities, for example, playing with toys and watching TV, and social activities (Hilton et al., 2008; Hochhauser & Engel-Yeger, 2010). Less frequent participation in recreational and social activities, as measured by a purpose-designed instrument called the Activities Questionnaire, was also reported in adolescents on the autism spectrum (Solish et al., 2010). The selection of

activities may also be influenced by age. Little, Sideris, Ausderau, and Baranek (2014) compared three groups of children on the autism spectrum (5–6, 7–9, and 10–12 years) using the Home and Communities Activities Scale (adapted from Dunst, Hamby, Trivette, Raab, & Bruder, 2000) and found older children engaged more frequently in outdoor activities and faith-based activities, whereas younger children engaged more frequently in parent–child home activities. The importance of considering item-level profiles in children on the autism spectrum is highlighted by Potvin et al. (2013) who reported no difference in frequency of participation in social activities, and more frequent participation in recreational activities, when looking at domain scores. However, when explored at item-level, they found children on the autism spectrum generally participated in activities alone or with fewer people and more often with family members. Similar findings have been found in a number of studies (Hilton et al., 2008; Hochhauser & Engel-Yeger, 2010; Reynolds et al., 2011; Shattuck, Orsmond, Wagner, & Cooper, 2011; Solish et al., 2010). It is easy to assume that more participation is better (Liptak, Kennedy, & Dosa, 2011); however, this may not be the case, and little is known about caregiver views on their child's participation levels and whether this changes with age. A child may participate more or less frequently in certain activities than peers, but this may give little indication of whether it has a positive or negative impact on the child and whether this is perceived positively or negatively by those around the child. This study investigates the frequency and involvement in activities of children on the autism spectrum aged 5 and 9–10 years across home, school, and community contexts while also documenting caregivers' perceptions by asking about any desire for change in such behaviors.

3.1 Research Question

What is the participation level of students with autism at home, school and community settings?

3.2 Aim and specific objectives of the study**3.2.1 General objective**

To explore the level of participation of students with autism at home, school and community settings.

3.2.2 Specific objectives

1. To investigate the participation level of children with autism at home, school and community settings.
2. To explore the socio-demographic picture of the participation level of children with autism at home, school and community settings.

3.3 Conceptual framework

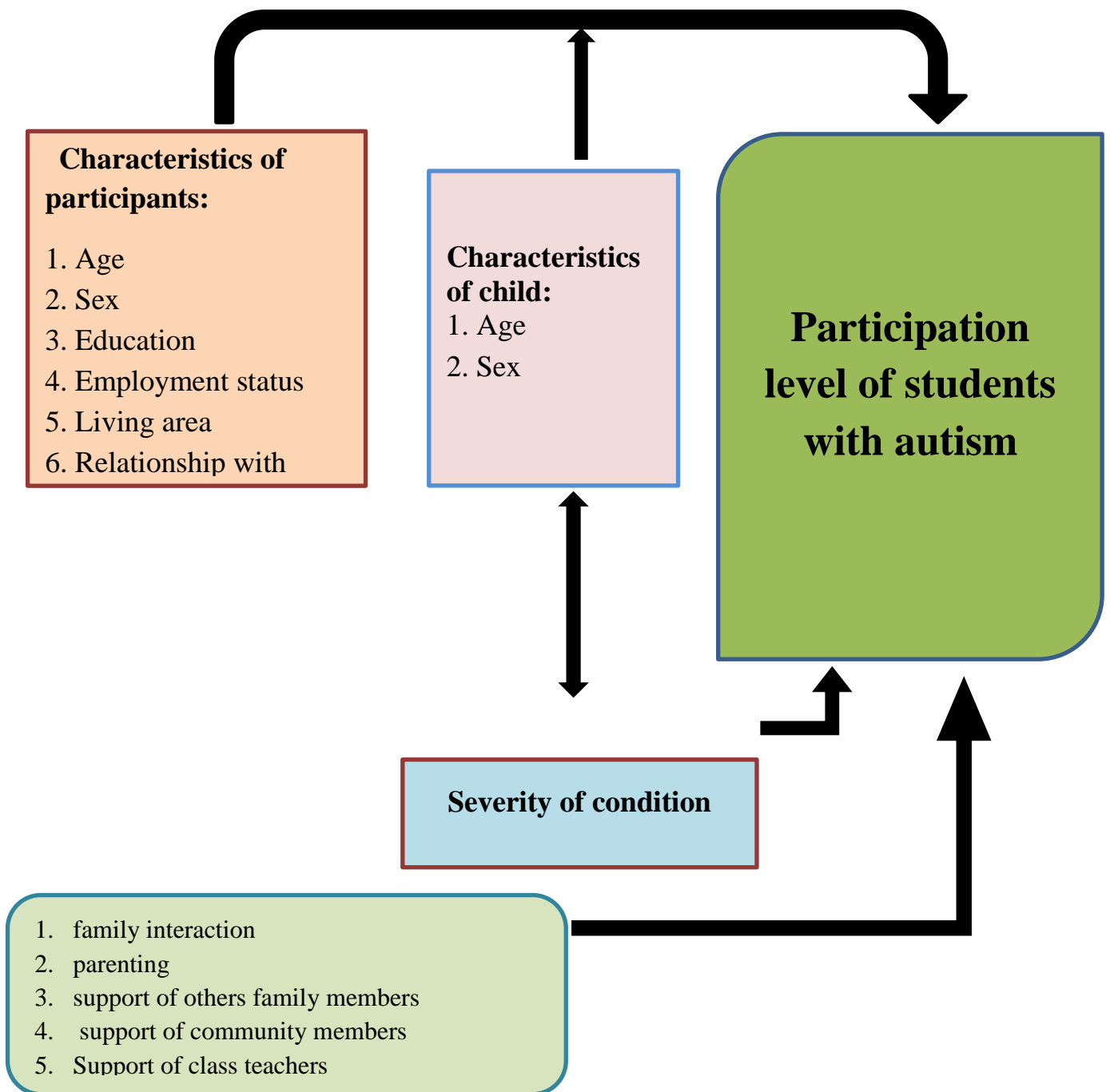


Figure 3.1 Conceptual Framework

3.4 Study design

In this study, researcher used quantitative research design. A quantitative method is an appropriate method to know the subject well-known, comparatively simple and clear. Quantitative method is an easy way to collect information among large participant. The investigator's intension was to measure the level of participation of students with autism at home, school and community settings and though using standardized tool. Cross sectional design to find out the quantitative information on different variable in this study. Data was collected from the participants in order to reveal the response and other variable of performance. Therefore the cross sectional study provide a snapshot of related characteristic in a population at a given point in time. In the article of Hall, 2013 stated that an interview guide focused on factual information as well as individual participation level and subject assessment.

3.5 Study population

The study participants were consisted of mother of children with autism of pediatric unit of Savar and Mirpur CRP, faith Bangladesh, Beautiful Mind school. The objective is to identify the participation level of students with autism at home, school and community settings. In addition, also explore the socio-demographic information's related to the question, participation level of students with autism.

3.6 Study settings

This study was conducted in four areas and these areas were:

CRP Savar

Pediatric Unit out patient of CRP Chapain, Savar, Dhaka-1343 is the head office for the Centre for the rehabilitation of the paralysed (CRP) and occupies approximately 13 acres of

land. CRP originally began its operation in 1979 from two cement storerooms of the Shaheed Suhrawardy Medical College Hospital, Dhaka. The size and complexity of the current CRP-Savar centre, establishment of the 9 additional CRP sub-centers across Bangladesh and extensive range of high quality services now provided to Persons with Disabilities. Bangladesh Health Professions Institute (BHPI), CRP Nursing College, William and Marie Taylor School and various other activities also operate from this centre.

CRP Mirpur

Plot A/5, Block A, Mirpur 1, Dhaka-1206 and CRP-Mirpur is located in a unique 13-storeyed building in Dhaka city, providing a wide range of services to maintain the financial sustainability of CRP. It was designed with an accessible wide ramp up to the fifth floor, visible gardens from each floor, and with an innovative use of light and space. About 450 patients receive daily services from various units at CRP-Mirpur. There is an inpatient and outpatient service offered for pediatrics similar to the service in Savar.

Beautiful mind

Beautiful mind: A special center for autistic and mentally challenged children is situated at plot# 1145, Road# 6/A Dolipara, Sector#5, Uttara Dhaka-1230, Bangladesh. It is built on a foundation of hope and commitment to helping children and families affected by Autism and other related development disorders. And also it is comprised of dedicated professionals that are passionate about helping families understand the complexities of the disorders so their children can reach their fullest potential.

faith Bangladesh

Foundation for Advancement of Innovations in Technology and Health, Bangladesh [faith Bangladesh] is a registered not-for profit organization based in Bangladesh which envisions a

planet where people living in resource-poor communities will enjoy advancement of innovations relating to health and technology.

faith Bangladesh supports innovative solutions to improve the health and livelihoods of people living in resource-poor communities in Bangladesh and beyond. They envision a planet where all people have access to comprehensive healthcare services delivered by competent and compassionate health professionals with appropriate means and technology. They research and build partnerships to support innovative solutions, including products, trainings and technologies, that improve the health and livelihood of people living in resource-poor communities in Bangladesh and beyond.

3.7 Study Period

The research study has been done as the part of the academic education of B.Sc. in Occupational Therapy. The period of the study was from October 2017 to March 2018. The study was conducted included data collection, data analysis and overall thesis writing. In particular, data collection was conducted from December 2017 to February 2018.

3.8 sample size

The study sample size is $n=110$ who were fulfill the inclusion criteria. Hicks (1999) stated that, “findings the appropriate number and types of people take part in the study called sampling”.

3.8.1 Sample size Calculation:

This is an essential part of good research design of any sort, whether it is surveys or experimental approaches. For quantitative research, it is better to meet as many subjects as possible relative to the size of the ideal population (Bowling, 1997). For calculating sample

seize the investigator used the principle of sample size determination: $n=(z)^2.pq/r^2$ (Hicks,2000). Sample size was estimated for this study according to the formula -95% confidence interval and 5% sampling error. Here the confidence interval is $(z)= 1.96$ and the sampling error is $(r)= 0.5$ Precise number of students with autism was unknown as well as prevalence of assumed $p= 0.5$ where $q= 0.5 (1-p)$ and then the sample size (n) it was stand for:

If this standard measurement as per the above formula was used to find out the sample size, it would be very difficult to collect data. Purposive sampling was chosen in this study and purposive sampling depends on the judgment of the researcher. As well as purposefully selected 110 numbers of students with autism of some selected areas of Dhaka city.

3.9 Inclusion criteria

- Children with autism who are school going.
- Children with autism who were at age between 5-22 years old.

3.10 Exclusion criteria

- Children with autism who were not school going .
- Children with autism below the age of 5 years and above the age of 22.
- Other.

3.11: Sampling Techniques:

Hicks (1999) stated that, “Findings the appropriate number and types of people take part in your study called sampling”. For quantitative data collection, purposive sampling technique is used. It is a nonprobability sampling. This study was conducted in the different selected areas of Dhaka city, between October 2017 to April 2018. In there is only which students are fulfilling the inclusion criteria and select in these study and participated.

3.12 Data collection tools

To fulfill the aim and objectives of the study researcher was used some tools during data collection period. These are:

- ❖ Information sheet and consent form.
- ❖ Child and Adolescent Scale of Participation (CASP)
- ❖ Paper, pen, pencil and eraser.

3.13 Information sheet

Information sheet is an important for the participants that make sure the participant to participate the research. An information sheet is necessary to inform the participant about identity of researcher, institute affiliation, research related information such as title, aim, period, duties and privileges of participants. To provide information about researcher and subjects, researcher developed an information sheet in Bangla {APPENDIX B} and English. Researcher was make sure about maintain confidentiality about their identity in this study by the information sheet. Data not shared to other person except research supervisor who was coordinating this study. The information sheet included that the participation was voluntary and this study was not any harm for the participant.

3.14 Consent form

Consent form is an essential part where the person consents to do something. A consent form is necessary for a study and it is a standard way to get clearance or agreement of participation legally which is important before initial the collect data of any kind of research. To take consent from subjects, researcher developed a consent form in Bangla and English. Researcher was set printed consent form for participants to confirm the level of accepting of the information sheet, awareness about the potential benefits and risks as participant of the

study. Researcher was taken permission from every single participant with signature on a written consent form. Volunteer participation of participants was permitted by signing.

3.15 Child and Adolescent scale of participation

The Child and Adolescent Scale of Participation (CASP) measures the extent to which children participate in home, school and community activities compared to children with same age as reported by family caregivers (Bedell,2004,2009). The CASP consist of 20 ordinal-scaled items and four subsections: 1)Home Participation (6 item), 2) Community Participation (4 item), 3) School Participation (5 items), 4) Home and Community living activities (5 items). The 20 items are rated on a four-point scale: “Age Expected (Full Participation),” “Somewhat Restricted,” “Very Restricted,” “Unable.” A “ Not Applicable” response is selected when the item reflects an activity in which the child would not be expected to participate due to age (work).

This score is the rating provided for each item (e.g., 1= Unable to participate, 2= very limited, 3= Somewhat limited, 4= Age expected/ Full participation).

3.16 Data collection

Data collection technique

The researcher fixed a date and time with the participant, according to his available time. At first, the researcher informed the participants about the contents of the consent form. Data collector collected data from those participants who gave consent. Researcher was used CASP questioner for find out the level of participation of Autism students in home, school and community settings. By using that questionnaire researcher got information about the level of participation among autism children, the details about actual situation of participation level in home, school and community settings. In a face to face interview, participant can

give information accurately and get clarification about any unclear question. Researcher collected data through face to face interview process in this study.

3.17 Data collection procedure

At first the researcher took permission from the head of the department of Occupational Therapy in CRP-Savar, CRP-Mirpur, from outpatient unit, faith Bangladesh and Beautiful mind to collect data. Researcher reviewed the schedule of patients with autism from unit in-charge and then makes a daily potential participant list to check the inclusion criteria. Before collecting data, researcher provided information sheets and consent forms to participant. Then, researcher was spent some time to build rapport with the participant. The interviewer explained the title and aim of the study to gain the trust of the participants. During an interview, trust is a very important element because if the participants felt uneasy to discuss sensitive issues then they may hide the truth. The questionnaire was based on participation level of students with autism at home ,school and community settings. Interview was conducted in Bangla so that participants could easily understand. Then the researcher collected the data from the participants by a face to face conversation and others trained volunteer who were helped researcher to collect data they were also followed this procedure. Through this process researcher and others volunteer asked question and filled up questionnaire or participant completed questionnaire. The participant was taken 10-15 minutes to fill up the questionnaire. The interviewer helped the interviewee by changing some word of same meaning to understand the questionnaire and when participant confused in some answer.

3.18 Data analysis procedure

Data analysis is essential that the data from any researcher is properly analysed. There are many statistical methods that might be useful but the researcher used descriptive statistics. Descriptive statistics are those that describe, organise and summarise the data and include think as frequencies, percentages, and description of central tendency and descriptive of relative relation. Data is analysed through data entry, and analysis was performed using the Statistical Package for Social Science (SPSS) version 20, by using descriptive statistic method and Microsoft excels spreadsheet. The presentation of data was organised in SPSS and in Microsoft Office Word. All data was inputted within the variable of SPSS. Specific findings were described in bar, graph, pie chart and in different tables which is easily understanding for reader.

3.19 Quality control and assurance

A field test was conducted with three participants. Before beginning the final data collection, it was necessary to carry out a field test to help the researcher refine the data collection plan. During the interview, researcher informed the participants about the aim and objectives of the study. From the field test the researcher became aware about which parts the participants found difficult to understand. It was helped to make a plan that how the data collection procedure can be carried out, sorting out the difficulties during questioning, making a basic plan of questioning and if there is needed any modification of the questionnaire. The questionnaires for the field test firstly transcribed from the English to Bengali. Then the transcription copy was translated again Bengali to English. And finally the transcription copy was corrected by the expertise person. The field test helped the researcher to make the plan on how the ways can be for collecting data, how a question can be asked on different ways

and what could be the probing question to find out the participant's actual response on the event.

3.20 Ethical consideration

Ethical considerations implemented to avoid ethical problem. The researcher granted permission from research supervisor and head of the department from the department of Occupational Therapy of Bangladesh Health Professions Institute (BHPI), an academic institute of CRP to conduct the study. Researcher got permission from head of Occupational Therapy department in both CRP-Savar, CRP-Mirpur, faith Bangladesh and Beautiful mind for data collection. Information sheet and consent form provided to each participant. Study purpose, aim and objectives were clearly describe in information sheet and consent form. Researcher informed verbally about the topic and purpose of the study to participant. The researcher assured them that confidentiality of personal information must strictly maintain in future. The researcher ensured that the service of patient will not be hampered by participants in this study. Participant had full right to withdraw their participation from this study at any time. The researcher also committed not to share the information given with others except the research supervisor. A written information sheet and consent form signed by each participant who participated in the study. The information gathered from the participants anonymously. The researcher had available to answer any study related questions or inquiries from the participants. All sources cited and acknowledged appropriately. The field notes and answer sheet not shared or discussed with others.

Table 4.1: **Socio-demographic characteristics of the participants**

Age of participants (child)	N%	
(5-10) years	93	84.5
Above 10 years	17	15.45
Mean± Std. Deviation	7.63±3.35	
Sex of Participants (child)		
Boys	85	77.3
girls	25	22.7
Mothers educational Background		
Less than secondary	4	3.6
Secondary completed	10	9.1
Higher secondary completed	15	13.6
Graduation Completed	41	37.3
Post Graduation	20	18.2
Others	20	18.2
Mother's Occupational status		
Housewife	80	72.7
Service holder	30	27.3
Parent's Monthly Income		
At least, (58,106) High Income group	61	55.5
At least, (18,404) Medium Income Group	45	40.9
At least (8,342) Low Income Group	4	3.6
Median	1.00	
Child's Community Type		
Urban	102	92.7
Semi-urban	8	7.3

Table 4.1 showed that this participant consider more boys than girls among the 110

participants of the study. Whereas 77.3% were boys and 22.7% were girls.

The majority of the participants age were 5-10 years, n=93;(84.5%). Therefore, here also above 10 years n=17 (15.45%).

In this study, here also include the child's mother education, occupational status, family income and community type. These individual characteristics also divided.

In addition, educational qualification of the autism children parents n=4; (3.6%) respondents were **less than secondary** and their children affected in autism, n=10; (9.1%) respondents were **secondary completed**, n=15; (13.6%) respondents were **higher secondary completed**, n=41; (37.3%) respondents were **graduation completed**, n=20; (18.2%) respondents were **post graduation**, n=20; (18.2%) were respondents who had **other educational qualification** and their children affected in autism.

This table also showed that the mothers of autism children were highly educated but due to their autism children they couldn't engage in service. Most of them were housewife n= 80 (72.3%) and only n=30 (27.7%) mothers were engaged in different service like doctor, lawyer etc.

In this table also showed that, monthly income divided into three parts and there are n=61; (55.5%) respondents who were living in **high income group**, n=45' (40.9%) respondents who were living in **medium income group**, n=4; (3.6%) respondents who were living in **low income group**.

Here n=102; (92.7%) respondents were living in urban area, n=8; (7.3%) respondents were living in semi urban area.

Table 4.2: Participation level of children with autism as reported by Child and Adolescent

Scale of participation

Participation	n (%)			
	Age expected	Somewhat limited	Very limited	Unable
Home participation				
Social, play, leisure, with family members at home.	19 (17.13)	63 (57.3)	28 (25.5)	-
Social, play, leisure, with friends at home.	11 (10.0)	48 (43.6)	47 (42.7)	4 (3.6)
Family chores, responsibilities and decisions at home.	26 (23.6)	56 (50.9)	20 (18.02)	8 (7.3)
Self-care activities.	11 (10.0)	67 (60.9)	29 (26.4)	3 (2.7)
Moving about in and around the home.	68 (61.8)	32 (29.1)	10 (9.1)	-
Communicating with other children and adults at home.	34 (30.9)	58 (52.7)	17 (15.5)	1(.9)
Community Participation				
Social, play or leisure activities with friends in the neighborhood and community	8 (7.3)	47 (42.7)	52 (47.3)	3 (2.7)
Structured events activities in the neighborhood and community.	14 (12.7)	55 (50.0)	39 (35.5)	2 (1.8)
Moving around the neighborhood and community.	6 (5.5)	63 (57.3)	38 (34.5)	3 (2.7)
Communicating with other children and adults in the neighborhood and community.	13 (11.8)	60 (54.5)	36 (32.7)	1 (.9)
School Participation				
Educational (academic) activities with other children in his or her classroom at school.	6 (5.5)	47 (42.7)	57 (51.8)	-
Social, play or leisure activities with other children at school.	5 (4.6)	56 (50.9)	48 (43.6)	1 (.9)
Moving around at school.	13 (11.8)	51 (46.4)	36 (32.7)	10 (9.1)
Using educational materials and equipment that are available to other children in his or her classroom or that have been modified for your child.	10 (9.1)	58 (52.1)	41 (37.3)	1 (.9)
Communicating with other children and adults at school	-	1 (.9)	73 (66.4)	36 (32.7)

Home & Community living activities				
Household activities.	5 (4.5)	39 (35.5)	52 (47.3)	14 (12.7)
Shopping and managing money.	1 (.9)	22 (20.9)	63 (57.)	24 (21.8)
Managing daily schedule.	17 (15.5)	27 (24.5)	48 (43.6)	18 (16.8)
Using transport to get around in the community.	35 (31.8)	38 (34.5)	21 (19.10)	16 (14.5)
Work activities and responsibilities.	16 (14.5)	50 (45.5)	28 (25.5)	16 (14.5)

Figure 1: Level of participation of children with autism at home, school and community settings

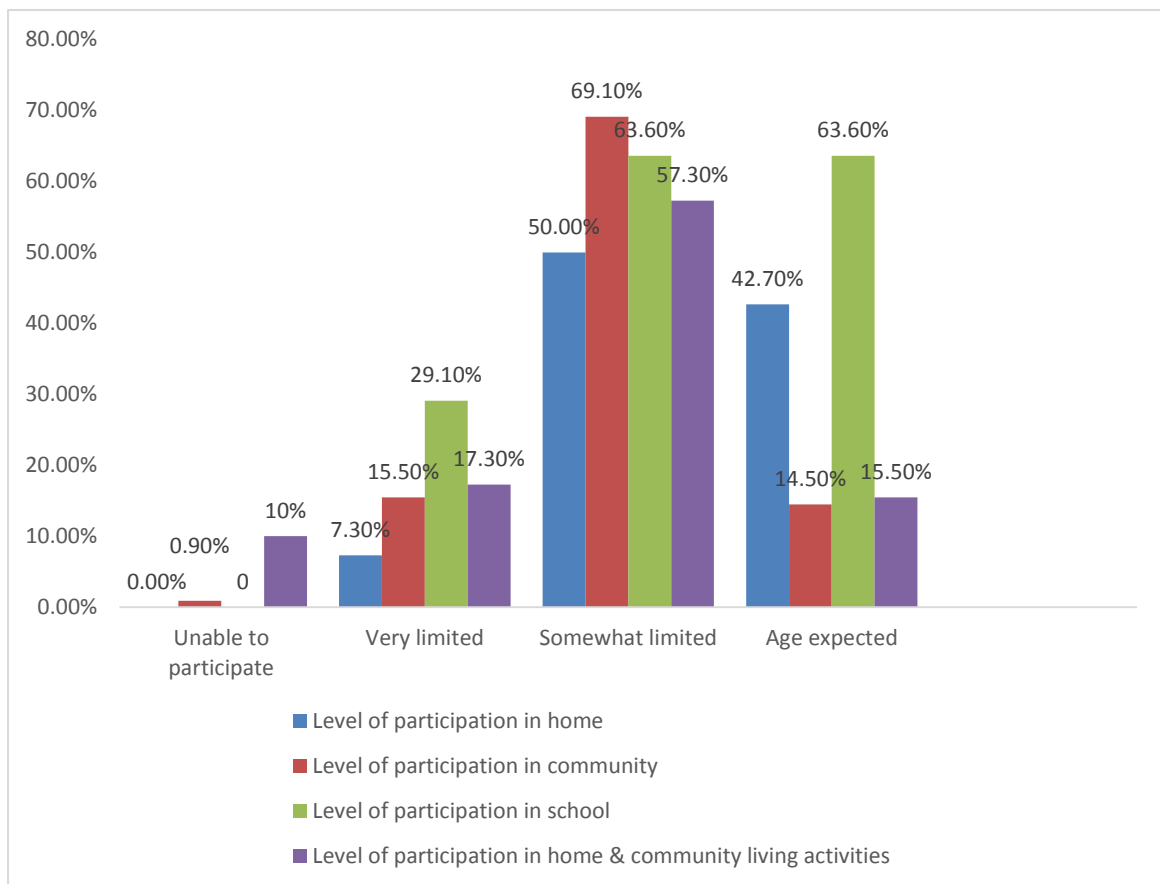


Figure 1 state that level of participation in home (7.30%) very limited, (50.0%) somewhat limited, (42.70%) age expected. Level of participation in community (15.50%) very limited, (69.10%) somewhat limited, (14.50%) age expected and only (0.9%) unable to participate in community. Level of participation in school (29.10%) very limited, (63.60%) somewhat limited, and (63.60%) participation level is age expected in school. Level of participation in home and community living activities (10%) unable to participate, (17.30%) very limited, (57.30%) is somewhat limited and (15.50%) participation level is age expected in home and community living activities.

Figure 2: Overall participation level of each domain of children with autism

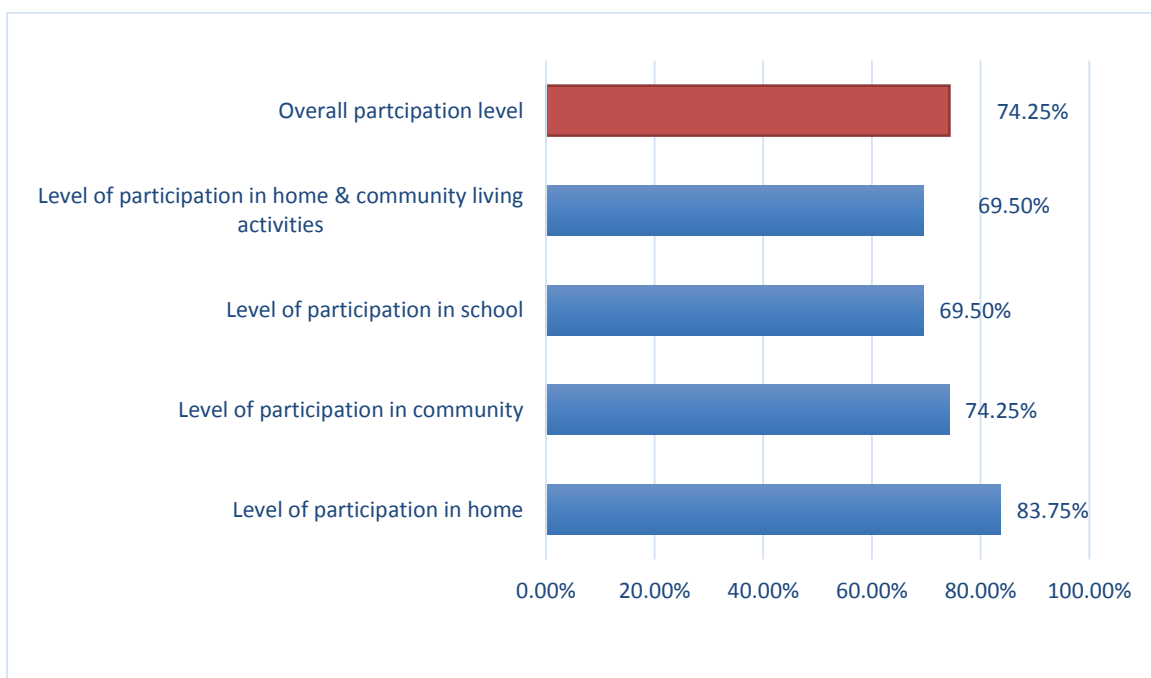


Figure 2 shows that, here overall participation level is 74.25%, level of participation in home is 83.75%, level of participation in community 74.25%, level of participation in school is 69.50% and level of participation in home and community living activities 69.50%. Through this figure, it is ensure that home participation (83.75%) is better than community and school participation because family members are more supportive than community and school.

5.1: Discussion

Autism Spectrum Disorders (ASD) are defined in the Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition; DSM-5) as a class of neurodevelopmental disorders that are characterized by persistent, complex and variable deficits in social communication and social interaction and restricted, repetitive patterns of behaviors, interests and activities (American Psychiatric Association, 2013). The symptoms present in early childhood, impair everyday function and may fluctuate throughout the lifespan.

Participation in daily life is crucial for human being at all ages to health and wellbeing, skill development and life satisfaction. It is the ultimate goal for pediatric rehabilitation practitioner. Participation is a new concept in the rehabilitation program and a growing number of tools are used by practitioners and researchers to measure participation with their peers in all aspects of daily life. This study used CASP scale to identify participation level of children with autism at home, school and community settings. The results from this study provide a valuable contribution to our understanding about patterns of participation across home, school, and in the community for children on the autism spectrum aged 5 and 9–10 years. The large sample size and analysis of participation at the item level of the CASP provides a rich source of information about participation levels in these age groups. Children in both age groups, most frequently participated in and were most involved in computer and video games, followed by watching TV, videos, and DVDs. Parents most desired a decrease in their child's participation in these activities. High levels of frequency and involvement were also reported in indoor play in the younger group.

Socio-demographic Characteristics of participants:

Through this socio-demographic characteristics we can see that there were more boys than girls among the 110 participants of the study. Whereas 77.3% were boys and 22.7% were girls.

The majority of the participants age were 5-10 years, n=93; (84.5%). Therefore, here also above 10 years n=17 (15.45%).

In this study, here also include the child's mother education, occupational status, family income and community type. These individual characteristics also divided.

In addition, educational qualification of the autism children parents n=4; (3.6%) respondents were **less than secondary** and their children affected in autism, n=10; (9.1%) respondents were **secondary completed**, n=15; (13.6%) respondents were **higher secondary completed**, n=41; (37.3%) respondents were **graduation completed**, n=20; (18.2%) respondents were **above graduation**, n=20; (18.2%) were respondents who had **other educational qualification** and their children affected in autism.

This table also show that the mothers of autism child were highly educated but due to their autism child they couldn't engage in service. Most of them were housewife n= 80 (72.3%) and only n=30 (27.7%) mothers were engaged in different service like doctor, lawyer etc.

In this table also showed that, monthly income divided into three parts and there are n=61; (55.5%) respondents who were living in **top income group**, n=45' (40.9%) respondents who were living in **middle income group**, n=4; (3.6%) respondents who were living in **bottom income group**.

Here n=102; (92.7%) respondents were living in urban area, n=8; (7.3%) respondents were living in semi urban area.

Overall participation level of each domain of students with autism:

Figure 2 shows that, here overall participation level is 74.25%, level of participation in home is 83.75%, level of participation in community 74.25%, level of participation in school is 69.50% and level of participation in home and community living activities 69.50%. Through this figure, it is ensure that home participation (83.75%) is better than community and school participation because family members are more supportive than community and school.

5.2 Limitation

- The researcher chose just 110 samples due to time limitation which is very small to generalize the result in all over the Bangladesh.
- The participants were taken from selected area which not generalizable for country perspective.
- Evaluate the children's community participation based on their current and temporary living area that is not representing permanent community environment.
- Researcher includes only autism children to measure the participation level that is more representative and comparative if there is include other disabled condition.

There are some limitations that should be kept in mind during conducting the study. The researcher always tried to consider these limitations. The following limitations have been identified during conducting the study.

- In this study purposive sampling was used to select the respondents. A small sample size is preferred when in-depth information is required. The findings of this study cannot be generalized to all children with autism. Because the sample size was small.
- Interview was conducted in Bangla. However the study is presented in English. Researcher had to translate interview information from Bengali to English.

Sometimes it may difficult to discover actual meaning of some information from the data translation. But researcher tried heart and soul to give the actual information of the data in the study.

- There were limited resources and information available about participation because it is a new study within Bangladeshi context.

5.3 Conclusion

The study explored the participation in home, school and community life of children with autism. The CASP scale is used to measure the participation level of children with autism at selected area of Dhaka district. OTs should encourage the children and parents about engage in the different life situation to enhance participation. Those findings provided useful information for clinicians to understand the participation that are faced by their client. It is possible to increase awareness of professionals and parents about the importance of the participation of children with autism that will helpful for therapist to plan, prioritize based on the greatest restriction and implementation strategies to enhance children's participation in the defined time period.

5.4 Recommendations for Therapist in Bangladesh

- Occupational therapist (OTs) should adopt a broader role and holistic treatment techniques on the fact of participation for children with autism.
- OTs need to update their knowledge in this area.
- OTs should motivate patients and their family to engage in participation as it is a major component of ICF and very essential for every human being.

Recommendations for further research

- To find out environmental challenges and barriers why the children with autism cannot properly participate in different settings like home, community and school.
- To compare participation level among girls and boys with autism sample size have to divided in equal two parts.
- Further research should be conducted with a large number of participants on this study design. If researcher conducts the study with large samples then it will be easy to generalize the result.

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Appendix1



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) Bangladesh Health Professions Institute (BHPI)

(The Academic Institute of CRP)

Ref.

CRP-BHPI/IRB/11/17/159

Date: 05/12/2017

To
Oliza Akter
B.Sc. in Occupational Therapy
Session: 2013-2014, Student ID: 122130126
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

Subject: Approval of the thesis proposal “Level of participation of students with Autism at home, school and community settings” by ethics committee.

Dear Oliza Akter,

Congratulations.

The Institutional Review Board (IRB) of BHPI has reviewed and discussed your application on 02/10/2017 to conduct the above mentioned dissertation with yourself, as the Principal investigator. The Following documents have been reviewed and approved:

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

Since the study involves “**participation of Autism students at home , school and community settings**” and “**The Child and Adolescent Scale of Participation (CASP)**” questionnaire that takes 10 to 15 minutes and 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 October 08, 2017 at BHPI.

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
Assistant Professor, Dept. of Rehabilitation Science
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 2



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই) BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)

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প্রতি
ইনচার্জ
পেডিয়াট্রিক ইউনিট
সিআরপি, সাভার, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) প্রসঙ্গে।

জনাব,

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী অলিজা আক্তারকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ২০.০১.২০১৮ তারিখ থেকে ২০.০৩.২০১৮ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরণ করা হলো।

তাই তাকে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে,

Su. muel
19/01/2018

শেখ মনিরুজ্জামান
সহকারী অধ্যাপক ও বিভাগীয় প্রধান
অকুপেশনাল থেরাপি বিভাগ
বিএইচপিআই।



Appendix 3



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)

BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)

(The Academic Institute of CRP)

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

BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178,8053662-3, Fax: 8053661

তারিখ : ১৯.০১.২০১৮

প্রতি
ইনচার্জ
পেডিয়াট্রিক ইউনিট
সিআরপি-মিরপুর, সাভার, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) প্রসঙ্গে।

জনাব,

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন অকুপেশনাল থেরাপি কোর্সের ছাত্রী অলিজা আক্তারকে তার রিসার্চ সংক্রান্ত কাজের জন্য আগামী ২০.০১.২০১৮ তারিখ থেকে ২০.০৩.২০১৮ তারিখ পর্যন্ত সময়ে আপনার নিকট প্রেরণ করা হলো।

তাই তাকে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে,

Su. Mridha
19/01/2018

শেখ মনিরুজ্জামান
সহকারী অধ্যাপক ও বিভাগীয় প্রধান
অকুপেশনাল থেরাপি বিভাগ
বিএইচপিআই।



Appendix 4



বাংলাদেশ হেল্থ প্রফেশন্স ইনষ্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)

(The Academic Institute of CRP)

CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178, 8053662-3, Fax: 8053661

CRP-BHPI/01/18/67

Date: 19.01.2018

To

Incharge

Department of Occupational Therapy

Faith Bangladesh

Mohammadpur, Dhaka.

Subject: Data Collection for Research Project.

Greetings from Bangladesh Health Professions Institute (BHPI). I would like to inform you that, BHPI, the Academic Institute of CRP is running B.Sc in Occupational Therapy Course, under Faculty of Medicine, University of Dhaka.

According to the content of 4th year of University course curriculum, the students have to do Research and Course work in different topics to develop their skills. Considering the situation, your institute will be the most appropriate place to collect data.

4th year students of BHPI Oliza Akter would like to collect data in your organization from 20.01.2018 to 20.03.2018.

We shall remain grateful to you if you could kindly allow her to collect data from your organization.

With regards,

Sk. Moniruzzaman
19/01/2018

Sk. Moniruzzaman
Assistant Professor & Head
Department of Occupational Therapy,
BHPI, CRP



Appendix 5



বাংলাদেশ হেল্থ প্রফেশন্স ইনস্টিটিউট (বিএইচপিআই)
BANGLADESH HEALTH PROFESSIONS INSTITUTE (BHPI)
(The Academic Institute of CRP)

CRP-Chapain, Savar, Dhaka, Tel: 7745464-5, 7741404, Fax: 7745069
BHPI-Mirpur Campus, Plot-A/5, Block-A, Section-14, Mirpur, Dhaka-1206. Tel: 8020178, 8053662-3, Fax: 8053661

CRP-BHPI/01/18/68

Date: 24.01.2018

To
Principal
Beautiful Mind
Uttara, Dhaka.

Subject: Data Collection for Research Project.

Greetings from Bangladesh Health Professions Institute (BHPI). I would like to inform you that, BHPI, the Academic Institute of CRP is running B.Sc in Occupational Therapy Course, under Faculty of Medicine, University of Dhaka.

According to the content of 4th year of University course curriculum, the students have to do Research and Course work in different topics to develop their skills. Considering the situation, your institute will be the most appropriate place to collect data.

4th year students of BHPI Oliza Akter would like to collect data in your organization from 24.01.2018 to 24.03.2018.

We shall remain grateful to you if you could kindly allow her to collect data from your organization.

With regards

Sk. Moniruzzaman
24/01/2018

Sk. Moniruzzaman
Assistant Professor & Head
Department of Occupational Therapy,
BHPI, CRP



Appendix 6

Information Sheet (English)

Information Sheet

The name of the researcher is Oliza Akter. She is a student of 4th year B.Sc. in Occupational Therapy in Bangladesh Health Professions Institute (BHPI), the academic institute of Centre for the Rehabilitation of the Paralysed (CRP). As a part of his academic issues, he has to conduct a research project in this academic year. So researcher would like to invite you to participate in this study. The title of the study is **“Level of participation of children with autism at home, school and community settings”**.

Your participation is voluntary in the study. You can withdraw your participation in anytime. There is not the facility to get any pay by this participation. The study will never be any harm to you but it will help the service user to know your experience, which is very important for the service provider to plan for their future activities.

Confidentiality of all records will be highly maintained. The gathered information from you will not be disclosed anywhere except the researcher and supervisor. The study will never published the name of participant anywhere.

If you have any query regarding the study, please feel free to ask to the contact information stated below:

Oliza Akter

Student of 4th year

B.Sc. in Occupational Therapy

Department of Occupational Therapy

Bangladesh Health Professions Institute (BHPI),

Centre for the Rehabilitation of the Paralysed (CRP),

Chaplain, Savar, Dhaka-1343

Appendix7

তথ্য পত্র

গবেষনাকারীর নাম: অলিজা আক্তার। সে পক্ষাঘাত পুনর্বাসন কেন্দ্র (সি আর পি) এর অধিনস্থ বাংলাদেশ হেলথ প্রফেশনাল ইনস্টিটিউটের অকুপেশনাল থেরাপি বিভাগ এর ৪র্থ বর্ষের একজন ছাত্রী। তার প্রাতিষ্ঠানিক কার্যের অংশ হিসেবে চলন্ত শিক্ষাবর্ষে তাকে একটি গবেষনামূলক কাজ করতে হবে। গবেষণাটির শিরোনাম “অটিজমে আক্রান্ত শিশুদের বাড়িতে, বিদ্যালয়ে ও সমাজে অংশগ্রহণের অবস্থা” গবেষণায় আপনার অংশগ্রহণ সম্পূর্ণ রূপে স্বেচ্ছায়। আপনি যেকোন সময় গবেষণা থেকে আপনার অংশগ্রহণ প্রত্যাহার করতে পারবেন। এই গবেষণায় অংশগ্রহণে গবেষক আপনাকে কোন ভাবে আর্থিক সাহায্য প্রদান করবেন না। এই অংশগ্রহণ কখনোই আপনার জন্য ক্ষতির কারণ হয়ে দাঁড়াবে না কিন্তু এই গবেষণার মাধ্যমে সেবা প্রদানকারী সদস্যগণ আপনার অভিজ্ঞতার কথা জানতে পারবেন এবং প্রাপ্ত তথ্য সমূহ সেবার মান উন্নয়নে সাহায্য করবে। আপনার কাছ থেকে প্রাপ্ত তথ্যসমূহের সর্বোচ্চ গোপনীয়তা রক্ষা করা হবে। গবেষক এবং গবেষণার সমন্বয়কারী ব্যতীত এই তথ্যগুলো অন্য কোথাও প্রকাশিত হবে না এবং গবেষণার কোথাও অংশগ্রহণকারীর নাম প্রকাশ হবে না।

গবেষণা সম্পর্কিত যেকোন ধরনের প্রশ্নের জন্য নিম্নলিখিত ব্যক্তির সাথে যোগাযোগ করার জন্য অনুরোধ করা যাচ্ছে।

অলিজা আক্তার

বিএসসি ইন অকুপেশনাল থেরাপি (৪র্থ বর্ষ)

অকুপেশনাল থেরাপি বিভাগ

বাংলাদেশ হেলথ প্রফেশনাল ইনস্টিটিউট

পক্ষাঘাত শিশুদের পুনর্বাসন কেন্দ্র (সি আর পি)

চাপাইন, সাভার, ঢাকা-১৩৪৩।

Appendix 8

(Consent Form – English)

Consent Form

Title : Level of participation of children with autism at home, school and community settings

Name of the Researcher: Oliza Akter

Please tick to confirm:

• I confirm that I have read and understand the information sheet for the above study	
• I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	
• I understand that participation is voluntary and that I am free to withdraw my child at any time, without giving any reason, without his/her medical or legal rights being affected.	
• I understand that relevant sections of any medical notes and data collected during the study may be reviewed by other individuals for the purposes of the study.	
• I agree to provide information to the researcher (s) on the understanding that my name will not used without my permission.	
• I agree to participate in this study under the conditions set out in the information sheet.	

Name of the child

Name of the parent/ Guardian Date

signature/ thumb impression

Researcher

Date

Appendix 9

সম্মতি পত্র

শিরোনাম : অটিজমে আক্রান্ত শিশুদের বাড়ি, বিদ্যালয় এবং সমাজে অংশগ্রহণ।

গবেষকের নাম : অলিজা আক্তার

দয়া করে নিশ্চিত করার জন্য টিক দিন

আমি নিশ্চিত করছি যে, আমি উপরোক্ত তথ্যপত্রের সবকিছু পড়েছি এবং বুঝেছি।	<input type="checkbox"/>
আমি তথ্যসমূহ বিবেচনা করবার, প্রশ্ন করবার এবং সন্তোষজনকভাবে উত্তর দেবার সুযোগ পেয়েছিলাম।	<input type="checkbox"/>
আমি বুঝতে পেরেছি যে, অংশগ্রহণটি স্বৈচ্ছাকৃত এবং আমি আমার শিশুকে অবাধে ফিরিয়ে নিতে পারি। এজন্য আমাকে কোনরকম কারন দর্শাতে হবে না বা তার চিকিৎসা বিষয়ক কোন অধিকার ক্ষুণ্ণ হবে না।	<input type="checkbox"/>
আমি বুঝতে পেরেছি যে, এই গবেষণার সময়কালীন যেকোন চিকিৎসা বিষয়ক টাকা বা তথ্য যেকোন প্রাসঙ্গিক বিভাগের যে কোন ব্যক্তি দ্বারা পর্যালোচনা হতে পারে।	<input type="checkbox"/>
আমি গবেষককে প্রয়োজনীয় তথ্য প্রদান করতে সম্মতি জ্ঞাপন করছি কারণ আমি জানি যে তিনি আমার বিনা অনুমতিতে আমার নামটি ব্যবহার করবেন না।	<input type="checkbox"/>
আমি তথ্যপত্রে উল্লেখিত শর্ত সাপেক্ষে এই গবেষণায় অংশগ্রহণ করতে সম্মতি জ্ঞাপন করছি।	<input type="checkbox"/>

শিশুর নাম _____

অভিভাবকের নাম _____

তারিখ _____

স্বাক্ষর/টিপসই _____

গবেষকের নাম _____

তারিখ _____

স্বাক্ষর _____

Appendix 10

Questionnaire (English)

(Demographic information Questionnaire – English)

Respondents Demographic Information

Day Month Year

Respondent name:_____ Code: _____ date of data collection:___/___/___

Age: _____ Profession: _____ Address: _____

Educational background

1. Informal education
2. Less than primary
3. Primary completed
4. Less than secondary
5. Secondary completed
6. Higher secondary completed
7. Graduation completed
8. Above graduation
9. Others _____

Type of community

1. Urban
2. Semi urban/small town
3. Rural
4. Others

Family monthly income(BDT)

1. At least 58,106 (Top income group)
2. At least 18,404 (Middle income group)
3. At least 8,342 (Bottom income family)

Autism Children's Information

Day Month Year

Name:_____ Age: _____ Date of birth:___/___/___

Gender : 1. Male 2. Female Name of school:_____ Grade:_____

Child's name _____

**Child & Adolescent
Scale of Participation
(CASP)**

- Instructions -

1. This scale asks questions about your child's participation in activities and events at home, school and the community. There also are a few questions that ask about strategies, assistive devices or modifications that are used or have been done to help your child participate if this is needed.
2. There are no right or wrong answers. You will have to choose, and in some cases write, the answer that best describes your child's participation and things that help or interfere with his or her participation. If you are not sure about how to answer a question, give your best guess.

Thank you

Your name _____

Your relationship to child _____

Date you completed survey _____

(Month / Day / Year)

We are interested in finding out about the activities that your child participates in at home, school and in the community.

You will be asked about your child’s current level of participation with activities as compared to other children his or her age. For each item, choose one of the following responses:

- **Age expected (Full participation)**, your child participates in the activities the same as or more than other children his or her age. [With or without assistive devices or equipment]
- **Somewhat limited**, your child participates in the activities somewhat less than other children his or her age [Your child may also need occasional supervision or assistance]
- **Very limited**, your child participates in the activities much less than other children his or her age. [Your child may also need a lot of supervision or assistance]
- **Unable**, your child can not participate in the activities, although other children his or her age do participate.
- Not applicable, other children your child’s age would not be expected to participate in the activities.

Please select one answer by placing an X in one of the boxes next to each item. If you are not sure, choose your best guess.

Compared to other children your child’s age, what is your child’s current level of participation in the following activities? HOME PARTICIPATION	Age expected	Somewhat limited	Very limited	Unable to participate	Not applicable
1) Social , play or leisure activities with family members at home (e.g., games, hobbies, “hanging out”)					
2) Social , play or leisure activities with friends at home (can include conversations on the phone or internet)					
3) Family chores, responsibilities and decisions at home (For younger children this ,may be getting things or					

putting things away when asked or helping with small parts or household chores; For older children this may be more involvement in household chores and decisions about family activities and plans)					
4) Self-care activities (e.g., eating, dressing, bathing, combing or brushing hair, using the toilet)					
5) Moving about in and around the home					
6) Communicating with other children and adults at home					
Compared to other children your child's age, what is your child's current level of participation in the following activities?					
NEIGHBORHOOD AND COMMUNITY PARTICIPATION					
7) Social, play or leisure activities with friend in the neighborhood and community (e.g., casual games, "hanging out," going to public places like a movie theater, park or restaurant)					
8) Structured events and activities in the neighborhood and community (e.g., team sports, clubs, holiday or religious events, concerts, parades and fairs)					

9) Moving around the neighborhood and community (e.g., public buildings, parks, restaurants, movies) [please consider your child's primary way of moving around, NOT his or her use of transportation]					
10) Communicating with other children and adults in the neighborhood and community					
Answers the following 5 questions if your child attends school or another structured educational programs such as an early intervention program or day care center. Please specify the type of program your child is attending here:					
Compared to other children your child's age, what is your child's current level of participation in the following activities? SCHOOL PARTICIPATION					
11) Educational (academic) activities with other children in his or her classroom at school					
12) Social, play and recreational activities with other children at school					

(e.g., “hanging out” sports, clubs, hobbies, creative arts, lunchtime, or recess activities)					
13) Moving around at school (e.g., to get to and use bathroom, playground, cafeteria, library or other rooms and things that are available to other children in his or her age)					
14) Using educational materials and equipment that are available to other children in his or her classroom/ or that have been modified for your child (e.g., books, computers, chairs and desks)					
15) Communicating with other children and adults at school					
Compared to other children your child’s age, what is your child’s current level of participation in the following activities? HOME AND COMMUNITY LIVING ACTIVITIES					
16) Household activities (e.g., preparing some meals, doing laundry, washing dishes)					
17) Shopping and managing money (e.g., shopping at stores, figuring out correct change)					

Appendix 11

Questionnaire (Bengali)

অংশগ্রহনকারীর তথ্য

অংশগ্রহনকারীর নাম: _____ কোড: _____ তথ্য নেওয়ার তারিখ: ____ / ____ / ____

বয়স:

পেশা:

ঠিকানা:

মোবাইল নং

অটিজম শিশুর সাথে সম্পর্ক

১. মা

২. বাবা

৩. অন্যান্য _____.

শিক্ষাগত যোগ্যতা

১. অনানুষ্ঠানিক শিক্ষা

২. প্রাথমিক থেকে কম

৩. প্রাথমিক সম্পন্ন

৪. মাধ্যমিকের চেয়ে কম
সম্পন্ন

৫. মাধ্যমিক সম্পন্ন

৬. উচ্চ মাধ্যমিক

৭. স্নাতক সম্পন্ন

৮. স্নাতকোত্তর

৯. অন্যান্য

সমাজের ধরন

১. শহর

২. অর্ধশহর/ছোট শহর

৩. গ্রাম

অন্যান্য _____.

পরিবারের মাসিক আয়

১. অন্তত ৫৮,১০৬ টাকা (উচ্চ আয়ের শ্রেণী)

২. অন্তত ১৮,৪০৪ টাকা (মধ্যম আয়ের শ্রেণী)

৩. অন্তত ৮,৩৪২ টাকা (নিম্ন আয়ের শ্রেণী)

অটিজম শিশুর তথ্য

নাম:

বয়স:

দিন মাস বছর

জন্ম তারিখ: ____ / ____ / ____

লিঙ্গ: ১. ছেলে

২. মেয়ে

বিদ্যালয়ের নাম: _____ শ্রেণী:

বাচ্চার নাম:

শিশু এবং বয়ঃসন্ধিকালে অংশগ্রহনের স্কেল

(সি.এ.এস.পি)

“নির্দেশনাবলী”

১. এই স্কেল প্রশ্ন **কণ্ডে** আপনার বাচ্চার বাড়িতে, বিদ্যালয়ে এবং সমাজে অংশগ্রহন সম্পর্কে, কার্যকলাপ এবং ঘটনা নম্পর্কে। এখানে আরো প্রশ্ন আছে যেটা জিজ্ঞেস করা হয় কৌশলগত সম্পর্কিত, সহায়তাকারী উপাদান অথবা পরিবর্তন যেটা ব্যবহার করা হয় আপনার বাচ্চার অংশগ্রহনের জন্য যদি তার প্রয়োজন পরে।
২. এখানে কোন সঠিক বা ভুল উত্তর নেই। আপনার বা তার অংশগ্রহনের সহায়তা বা হস্তক্ষেপের বিষয় সবচেয়ে ভালভাবে বর্ণনা করে। আপনি যদি কিভাবে উত্তর দিবেন তা সম্পর্কে নিশ্চিত না হন তাহলে আপনার সর্বোচ্চ অনুমান দিয়ে উত্তর দিন।

“ধন্যবাদ”

আপনার নাম:

উচ্চার সাথে আপনার সম্পর্ক:

জরিপ সম্পন্ন করার তারিখ:

(মাস /দিন / বছর)

আমার আপনার সন্তানের বাড়িতে, স্কুলে এবং সমাজে বিভিন্ন কার্যক্রমে অংশগ্রহন সম্পর্কে খুঁজে বের করতে আগ্রহী।

আপনি আমাদেও অবগত করবেন আপনার সন্তানের বিভিন্ন কাজের বর্তমান অংশগ্রহনের মাত্রা বিষয়ে যেটা কিনা সমবয়সী অন্যান্য বাচ্চাদেও সাথে তুলনা করে। নিম্নলিখিত অনুচ্ছেদ থেকে যেকোন একটি নির্ধারণ করতে হবে।

প্রত্যাশিত বয়স (পূর্ণ অংশগ্রহন), আপনার সন্তান সমবয়সী অন্য শিশুদেও ম তবা তাদেও তুলনায় বেশি বিভিন্ন কার্যক্রমে অংশগ্রহন কওে [সহকারী উপকরণ অথবা সামগ্রী সহ বা বাদে]

কিছুটা সীমাবদ্ধতা, আপনার সন্তান সমবয়সী ও অন্যান্য শিশুদেও জন্যও বিভিন্ন কাজে অংশগ্রহনে আশা যাবে না।

কলামে প্রতিটি আইটেম এর পাশে ক্রস - বসিয়ে একটি উত্তর নির্বাচন করুন। যদি আপনি নিশ্চিত না হন তাহলে আনুমান করুন।

নিম্ন লিখিত কার্যক্রমে আপনার সন্তানের বর্তমান অংশগ্রহনের মাত্রা কি, তার সমবয়সী অন্য শিশুদের তুলনায় বাড়িতে অংশগ্রহন	প্রত্যাশিত বয়সী	কিছুটা সীমাবদ্ধতা	খুব সীমাবদ্ধতা	অক্ষম	প্রয়োজন
১) বাড়িতে পরিবারের সদস্যদেও সাথে খেলাধূলা, অবসর বা দলবদ্ধকাজ (উদা- গেমস, শখ, ঘুরাফেরা)					
২) বাড়িতে পরিবারের সদস্যদেও সাথে খেলাধূলা, অবসর বা দলবদ্ধকাজ (ফোনে -- ইন্টারনেটে কথোপকথন অন্তর্ভুক্ত)					
৩) বাড়িতে টুকিটাকি পারিবারিক দায়িত্ব ও সিদ্ধান্ত (ছেটদেও জন্য যেমন কিছু নিয়ে আসা বা রেখে আসা বা পরিবাওে বিভিন্ন সিদ্ধান্ত, পরিকল্পনা এবং সাংসারিক কাজে জড়িত থাকা)					
৪) স্ব-যত্ন কার্যক্রম/ কাজ (উদাহরণ খাওয়া-দাওয়া, জামা কাপড় পড়া, গোসল করা, চুল আচড়ানো, টয়লেট ব্যবহার)					
৫) বাড়ির ভিতরে এবং চারপাশে ঘুরা					
৬) বাড়িতে বড়দের সাথে এবং অন্য শিশুদের সাথে যোগাযোগ রাখা।					

নিম্নলিখিত কার্যক্রমে আপনার সন্তানের বর্তমান অংশগ্রহণের মাত্রা কি, তার সমবয়সী----- নৈকট্য প্রতিবেশী এবং সমাজে অংশগ্রহণ	প্রত্যাশিত বয়সী	কিছুটা সীমাবদ্ধতা	খুব সীমাবদ্ধতা		প্রয়োজনীয় নয়
৭) বন্ধুদের সাথে সমাজে ও আশে পাশে খেলাধুলা, অবসর এবং দলবদ্ধভাবে কাজ করা (উদাহরণ আকস্মিক গেইমস, ঘুড়ে বেড়ানো এবং লোকস্থানে যাওয়া যেমন- সিনেমা হল, পার্ক অথবা রেস্টুরেন্ট)					
৮) আশেপাশে বা সমাজে বিভিন্ন কাঠামোবদ্ধ কার্যক্রম যেমন দলক্রীড়া, ক্লাব, ছুটি, ধর্মীয় অনুষ্ঠান, সংগীত অনুষ্ঠান এবং মেলা)					
৯) সমাজে এবং বাড়ির আশে পাশে ঘুরাফেরা (উদা- সরকারি বিল্ডিং, পার্ক, রেস্টুরেন্ট, সিনেমা হল) [বাচ্চার সাধারণ চলাফেরা বিবেচনা কওে, তার যোগাযোগ ব্যবস্থা নয়]					
১০) নৈকট্য প্রতিবেশী এবং সমাজে অন্যান্য শিশু এবং বয়স্কদের সাথে যোগাযোগ					

নিম্নে ৫ টি প্রশ্নের উত্তর দিতে হবে যদি আপনার সন্তান স্কুলে যায় অথবা অন্য কোন শিক্ষামূলক প্রোগ্রাম যেমন- প্রারম্ভিক চিকিৎসা প্রোগ্রাম অথবা ডে কেয়ার সেন্টার। দয়া কওে সুনির্দিষ্ট ভাবে উল্লেখ করুন আপনার শিশুটি কোন ধরনের প্রোগ্রামে অংশগ্রহণ:-----					
১১) তার স্কুল ক্লাসের অন্যান্য বাচ্চাদের সাথে তার শিক্ষামূলক (একাডেমিক) কার্যক্রম	প্রত্যাশিত বয়সী	কিছুটা সীমাবদ্ধতা	খুব সীমাবদ্ধতা	অক্ষম	প্রয়োজনীয় নয়
১২) স্কুলে অন্যান্য বাচ্চাদের সাথে তার খেলাধুলা, যোগাযোগ এবং বিনোদন মূলক কাজ (উদাহরণ ঘুরাফেরা, খেলা, ক্লাব, শখ, সৃজনশীল শিল্পকলা, দুপুরের খাওয়া অথবা ছুটির কার্যকলাপ)					
১৩) স্কুলে আশে পাশে ঘুরা (উদাহরণ বাথরুমে যাওয়া এবং ব্যবহার করা, খেলার মাঠ, ক্যাফেটেরিয়া, লাইব্রেরী, বিভিন্ন রুম বা তাদের বয়সী বিভিন্ন জিনিস য তার জন্য সহজলভ্য)					

১৪) ক্লাস রুমে অন্য বাচ্চাৰ জন্য সহজলভ্য যন্ত্ৰপাতি বা উপকরণ শিশুৱা ব্যবহার কৰে বা সেটা শিশুদেও জন্য পরিবর্তিত। (উদাহরণ বই, কম্পিউটাৰ, চেয়াৰ এবং					
১৫) স্কুলে অন্য শিশু এবং বয়স্কদেও সাথে যোগাযোগ					

নিম্নলিখিত কাৰ্যক্রমে আপনাৰ সন্তানৰ বৰ্তমান অংশগ্রহণৰ মাত্ৰা কি, তাৰ সমবয়সী অন্য শিশুদেও তুলনায়? বাডি এবং সামাজিক জীৱনৰ কাৰ্যক্রম?	প্রত্যাশিত বয়সী	কিছুটা সীমাবদ্ধতা	খুব সীমাবদ্ধতা	অক্ষম	পযোজ্য নয়
১৬) পাৰিবাৰিক কাৰ্যক্রম (উদাহৰন খাবাৰ তৈৰী কৰা, লন্ডি বা কাপৰ ধোয়া, থালাবাটি ধৌত কৰা)।					
১৭) কেনাকাটা এবং অৰ্থ ব্যবস্থাপনা (উদাহৰন দোকানে কেনাকাটা কৰা এবং সঠিক পরিবর্তন বুঝা)।					
১৮) দৈনন্দিন সময় তালিকা পরিচালনা কৰা (উদাহৰন সময়ৰ কাজ সময়ে শেষ কৰা এবং পয়োজনমত সময় এবং তালিকা সমন্বয় কৰা)					
১৯) পরিবহন ব্যবহার কৰে সমাজেৰ আশে পাশে ঘূৰা (উদাহৰন স্কুলে যাওয়া এবং আশা, বিনোদনমূলক কাজ কৰা)					
২০) দায়িত্ব এবং কাৰ্যক্রম (উদাহৰন কাজ, কাৰ্যনিবাহী সময় নিষ্ঠা, নিয়মিত এবং সহকৰ্মী ও সুপাৰভাইজাৰেৰ পাশাপাশি থাকে)					

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২১) উপরে উল্লেখিত কাজকৰ্মে অংশগ্রহণ কৰতে যা অধপনাৰ সন্তানকে সাহায্য কৰে তা অনুগ্রহপূৰ্বক বৰ্ণনা কৰুন (উদাহৰন যা বাচ্চা কৰে, যা তাৰ পৰিবাৰ, বন্ধুগণ অথবা শিক্ষামূলক বা পুনৰ্বাসন পেশাদাৰ ব্যক্তি কৰতে সাহায্য কৰে।)

২২) আপনাৰ সন্তান কি কোন এসিস্টিভ ডিভাইস বা সহায়ক দ্ৰব্য ব্যবহার কৰে যা তাকে অংশগ্রহণে সাহায্য কৰে। (উদাহৰন অভিযোজিত খাবাৰেৰ পাত্ৰ, গোসলেৰ চেয়াৰ, স্কুলেৰ টীকা সংগ্ৰাহক, দৈসিক পৰিকল্পক, কম্পিউটাৰ)।

হ্যা না

যদি হ্যা হয়, বৰ্ণনা কৰুনঃ

২৩) আপনি কি আপনার বাড়িতে, সমাজে, স্কুলে আপনার বাচ্চার অংশগ্রহনে সহায়তার জন্য কোন পরিবর্তন করেছেন ? (উদাহরণ দ্রব্যাদি বা আসবাবপত্র পূর্নবিন্যস্ত, আলো বা শব্দের মাত্রা সমন্বয় করা, ভবনে র‍্যাম্প বা কাঠামোগত পরিবর্তন)

হ্যাঁ না

যদি হ্যাঁ হয়, বর্ণনা করুনঃ