

**‘Level of Participation of Children with Autism Spectrum Disorder in  
Family and Recreational & Self-care Activities’**



By

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## ABSTRACT

**Background:** Autism spectrum disorder is a neurodevelopmental disorder that affects a child's daily life activities participation. Participation in activities is very important in every children's life. Through participation children acquires skills and knowledge. But children with ASD have limited participation in activities and they need proper guidance to participate in activities. Parents also faces difficulty about their children participation in activities as they have to maintain the activities of their children.

**Objective:** This study identified the level of participation level of children with ASD in self-care, family and recreational activities and also explore the socio demographic factors of the parents and also children with autism.

**Methodology:** This study was conducted by cross sectional study design quantitative study. The cross sectional study was conducted among 40 participants who were selected from two selected areas of Dhaka city. The participants were selected by using convenience sampling procedure. The data was collected by using Child Engagement in Daily Life Measure with face-to-face interview. The data was analyzed by using SPSS.20 (Statistical Package of Social Science).

**Result:** The level of participation of children with ASD in self-care, family and recreational activities were average according to the Child Engagement in Daily Life Measure. Most children are not participated in self-care consistently and they need help to continue the self-care activities. However, children were more involved in recreational activities with their families. The frequency of participation of family and recreational activities is 57.2%, enjoyment of family and recreational activities is 62% and participation in self-care activities is 54%.

**Conclusion:** This study explored the level of participation of children with ASD in self-care, family and recreational activities. Child Engagement in Daily Life Measure scale was used to measure the participation level of children with ASD. The findings from this study provides information about the participation level of children with ASD and thus it will be helpful for rehabilitation professionals to plan according to the child's need. And it will also be helpful for parents to be aware of their children's participation.

**Key words:** Autism spectrum disorder, participation, self-care activities, recreational activities.

## **1.1 Background**

Bangladesh is a large and heavily densely populated country in South Asia. Bangladesh has an estimated 2019 population of 168.07 million, up from the 2013 estimate of 156.5 million. This makes Bangladesh the 9th most populous country in the world. (World Population Review, 2018). There is no accurate data or information on the exact number of persons with disabilities in Bangladesh. However, a total 15, 93,070 people with disability have been registered so far in Bangladesh, according to the National Taskforce on Disabilities-friendly Disaster Management Affairs (The Daily Star, 2018). The term “disability” broadly describes impairment in a person’s ability to function, caused by changes in various subsystems of the body, or to mental health.

Disability is a major concern in Bangladesh as well as all over the world. The prevalence of disability is increasing day by day. "Disability" is a word often used in daily conversations and holds different meanings for different people. The Disability Discrimination Act (DDA) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. (Disabled World, 2012). In 2005, Handicap International (HI) and National Forum of Organizations Working with the Disabled (NFOWD) conducted a survey on prevalence of disability in our country and they found 5.6 percent of the population living with disability in Bangladesh. But there was no survey particularly on children with disabilities. Since 2008 Child Sight Foundation (CSF) has been conducting a study on childhood disability in Bangladesh. The study reveals that about 2 percent children are living with severe form of disabilities in Bangladesh. (The Daily Star, 2011). The prevalence of childhood disability is increasing day by day.

Autism is one kind of disability and now-a-days the prevalence of this increasing day by day. A large number of children are born with Autism and neuro-developmental disorders. According the World health Organization supported survey 2009 there are 0.84% children are suffering from Autism Spectrum disorders. (Ahmed et al., 2014). At least 17 per 10,000 babies in the country have Autism Spectrum Disorder. The Centers for Disease Control and Prevention, USA (CDC) recognizes ASD as a major public health challenge as it is currently estimated to occur in significantly higher rates than pediatric cancer, HIV and heart disease combined. Unfortunately among all the major mental health disorders, autism is one of the least understood, and has the lowest amount of resources devoted to research and dissemination of best practices (Centre for Research and Information, 2014). According to Centre for Research and Information (CRI), the recent global trends of rising prevalence it can be asserted that on average, there is at least **1 person** challenged by an ASD in any country. The global prevalence of autism has increased twentyfold to thirtyfold since the earliest epidemiologic studies were conducted in the late 1960s and early 1970s. At that time, prevalence estimates from European studies were one in 2,500 children in the population and by the 2000s prevalence estimates from large surveys were 1%–2% of all children In 2014, the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network reported that approximately 1 in 68 children in the United States has an Autism Spectrum Disorder. This new estimate is roughly 30 percent higher than previous estimates reported in 2012 of 1 in 88 children. In the 1980's autism prevalence was reported as 1 in 10,000. In the nineties, prevalence was 1 in 2500 and later 1 in 1000. The latest prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. This means that over 695,000 people in the UK may have autism, an estimate derived from the 1.1% prevalence rate applied to the 2011 UK census figures (Centre for Research and Information, 2014). The prevalence is higher in urban areas and among boys. At least 17 per 10,000 babies in the country have Autism Spectrum Disorder, finds a new survey. (Molla, M.A.M., 2018).

Autism, a development disability, has a wide range of symptoms, including difficulty with social interaction and repetitive behavior. It is a lifelong condition. In 2013, Dhaka Shishu Hospital conducted a survey that reported autism prevalence to be 15 per 10,000 children aged below nine. In 2016, Institute of Pediatric Neurodisorder and Autism (IPNA) at Bangabandhu Sheikh Mujib Medical University (BSMMU) rural survey reported a figure of 7.5 per 10,000 children aged between 18 and 36 months. (Molla, M.A.M., 2018).

Recently, many studies found that, children with disabilities are less participated in everyday activities. Participation means involvement of an individual in life situation (World Health Organization, 2007) and it is very important for a child's development. For children and youth with disabilities, participation in activities is the context in which they learn and acquire skills, perform tasks and activities, develop friends, and find satisfaction of their lives. But children with disabilities are at risk for lower participation in everyday activities than children without disabilities (Law, 2002). Participation in activities is beneficial for children's health and development for children with ASD. (Askari, S. et al., 2015).

ASD children have limitations in their communication and social interactions, demonstrate restricted and repetitive behaviors, and may demonstrate hyper- or hypo-reactivity to sensory stimuli or unusual interests in sensory aspects of the environment (American Psychiatric Association [APA], 2013). This can be influenced in their participation in daily activities. ASD children have limitation in activity participation, and many studies have shown that children with ASD participate in activities less frequently and with less variety than other children with other developmental disabilities (DD) and typical development. According to LeVesser P., Berg C., (2011), it was said that, those who are preschoolers with ASD have participated less frequently in self-care, community mobility, vigorous leisure, and sedentary leisure than do children with typical development. Caregivers of children with ASD have reported that their children are less frequent and less diverse activity participation (Lam.S. F., Wong. B. P. H., Leung. D., Ho. D., Au-Yeung P, 2010). Rodger & Umaibalan, (2011) investigated that ASD children have limitation in special event activities, such as birthday parties & family vacations, have also been reported as less frequent among preschool and school-age children with ASD.

Participation is important for ASD children in everyday life as well as children with normal development. So children with ASD need proper family support and guidance to participate in everyday activities such as self-care, family activities, leisure or recreational activities as they less participate in these kind of activities. After diagnosis of children with autism, many health professionals provided treatment to the autism children according to their need. Health professionals work as a multidisciplinary team (MDT) to get a better outcome of the children e.g. doctor, occupational therapist, speech and language therapist, special educator, clinical psychologist, dietician or nutritionist. They provided services to the children with ASD as a more effective way to meet the children's need. Among them, the most important and vital role is Occupational therapy role to improve the quality of life and to improve the learning skills.

## **1.2 Justification of the study**

Children with ASD have impairment in social communication and interaction, restricted and repetitive type of behavior which has negative impact on participation in their daily activities such as self-care, family and recreational activities. Parents of autism children also complain these issues with health professionals. Children with ASD have limitations in activities to participate in self-care, family and recreational activities based on both personal and environmental context. Participation is an important issue for children with ASD and also for health professionals to the participation level of ASD children so that they can improve the treatment to get a better outcome. In Bangladesh, there is no study that measures the participation level of self-care, family and recreational activities of children with ASD. For a normal life, it is very important to participate in these activities. But ASD children have limitation in these activities to participate and parents are also worried about their children participation. In Bangladesh, there are some studies which focused on parents stress level, parents perception about their child on different issues, group therapy, and participation in home, school and community settings and others that are related to ASD but no study in self-care, family and recreational activities.

This study helps to explore the level of participation of children with ASD in self-care, family & recreational activities. Participation in self-care, family and recreational activities is a positive and desired outcome of treatment for children and youth with ASD. Besides, measuring participation is helpful for planning and providing treatment and also for rehabilitation program to know the gap of intervention which are provided to children with ASD. This study will help to develop a baseline to identify the effectiveness of intervention to improve the participation in activities of children with ASD.

This study will be done by using ‘Child Engagement in Daily Life Measure’ scale which is not used previously to measure the level of participation of children with ASD. So it will be very helpful for the health professionals who are involved in rehabilitation program for children with ASD, for parents and also for teachers. It will help to find out the specific problem or limitation for the children with ASD and based on the study findings it will be helpful to improve and design the treatment program.

### **1.3 Research Question**

What is the participation level of children with Autism Spectrum Disorder in self-care, family and recreational activities?

### **1.4 Study aim and specific objectives**

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

To explore the level of participation of children Autism Spectrum Disorder in self-care, family and recreational activities.

#### **Specific objectives**

The specific objectives of this studies are-

- To identify the level of participation of children with ASD in self-care, family and recreational activities.
- To identify the socio-demographic factors.

## **1.5 Operational Definition**

### **Autism Spectrum Disorder-**

Autism spectrum disorder (ASD) is a developmental disorder that affects communication and behavior. It refers to a range of conditions that is characterized by impaired social behavior, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively. (WHO, 2017). The effects of ASD and the severity of symptoms are different in each person. ASD begin in childhood and is tends to persist into adolescence and also in adulthood. But in most cases the conditions are present during the first 5 years of life of children. (WHO, 2017). In most cases, ASD can be diagnosed as early as 18 months of children. Some developmental delays associated with ASD can be identified earlier. Although ASD is a lifelong disorder, but treatments and services can improve children's symptoms and ability to function.

### **Participation-**

According to the International Classification of Functioning, Disability and Health (ICF), participation can be defined as involvement in life situation. It is a process in which children and youth get chance to involve in social and political processes and institutions. Through participation, it can be recognized the capacity and values of children and youth that they have to contribute to society, as well as is develop their potential. (Escobar. S. R., 2016). WHO defines meaningful participation as it requires an individual is entitled to participate in the decisions that directly affect that individual which includes in the design, implementation, and monitoring of health interventions.



### **Self-care activities-**

Self-care activity is any type of activity that we do deliberately in order to take care of our mental, emotional, and physical health. According to WHO (2013), self-care can be defined as it the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a health-care provider. It is a very active and powerful choice of an individual to engage in the activities that requires to gain or maintain an optimal level of overall health. This overall health includes not only just the physical health, but also the psychological, emotional, social, and spiritual components of an individual's well-being. (Money Crashers).

### **Recreational activities-**

Recreation means to all those activities that individual chooses to do to refresh his/her bodies and minds and makes the leisure time more interesting and enjoyable. Examples of recreation activities are walking, swimming, meditation, reading, playing games and dancing. (Khasnabis. C, Heinicke. M. K., Achu K, et al., 2010). Recreational activities are considered to be as fun and mainly done for enjoyment, entertainment, or pleasure.

## 2.1 Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a diagnostic condition which is familiar to many rehabilitation professionals. It can be described as a group of neurodevelopmental disorders in which an individual faces challenges with social engagement and age-appropriate play and fail to develop appropriate peer relationships according to his/her developmental level. (Memari. A.H. et al, 2015).

Autism spectrum disorder (ASD) refers to a group of complex neurodevelopment disorders which is characterized by repetitive and restricted patterns of behavior and have difficulties in social communication and interaction. In Bangladesh, now-a-days autism is a significant burden of disease. (Akhter. S., et al. 2018). It is a complex developmental disorder which involves persistent challenges in social interaction & communication, verbal and nonverbal communication, and restricted/repetitive behaviors. The effects of ASD and the severity of symptoms are different in each person. (American Psychiatric Association, 2018).

Autism appears to have its roots in very early brain development of an individual. The most common signs of autism and symptoms tend to develop between 2 and 3 years of age. Both children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities. (Autism Support of West Shore, 2019).

The word 'spectrum' describes the range of difficulties that children with autism spectrum may experience and the degree to which they may be affected. Some children may be able to live relatively normal lives, while others may have an accompanying learning challenges and require continued specialist support. Children with ASD may have following symptoms:

- Unusual sensory interests such as sniffing objects or staring at moving objects.
- Sensory sensitivities including avoiding everyday sounds and textures such as hair dryers, vacuum cleaners, music around them.
- Intellectual impairment or learning difficulties. (Autism Spectrum Australia, 2019).

ASD is a brain developmental disorder by four main characteristics: stereotyped, restricted and repetitive type of behavior, impairment in verbal and nonverbal communication; interests and activities and may have developmental delay of an individual.

## **2.2 DSM V criteria**

According to DSM-5 (Diagnostic and Statistical Manual of Mental Disorders), the diagnostic criteria of ASD are following:

- 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 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.

- 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 stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same 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 interests).
  4. Hyper- or hypo reactivity to sensory input or unusual interest 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. (American Psychiatric Association, 2013).

By using the previous version of the DSM, ASD was diagnosed with one of several separate conditions such as-

- Autistic disorder
- Asperger's' syndrome
- Pervasive developmental disorder not otherwise specified (PDD-NOS).

In the current revised version of the DSM (the DSM-5), these separate conditions have been combined into one diagnosis called is which “Autism Spectrum Disorder.” (National Institute of Mental Health, 2018).

There were many types of ASD include, over many years different diagnostic labels have been used include Autism, Autism Spectrum Disorder (ASD), Autism Spectrum Condition (ASC), Classic Autism, Kanner Autism, Pervasive Developmental Disorder (PDD), High-Functioning Autism (HFA), Asperger syndrome and Pathological Demand Avoidance (PDA). But now due to recent and upcoming changes to the main diagnostic manuals, 'Autism Spectrum Disorder' (ASD) is now likely to become the most commonly given diagnostic term. (National Autistic Society, 2016).

### **2.3 Etiology**

Though ASD is very common disorder at present but there is no known single cause for ASD. It is generally accepted that ASD is caused by some abnormalities in the structure brain or function. During brain scans, it shows the differences in the shape and structure of the brain in children with ASD which is compared to in neurotypical children. Even researchers do not know what the exact causes of ASD are but they are investigating a number of theories, including the links among heredity, genetics and medical problems. (Autism Society, 2016).

Amaral. G. D. (2017) refers that there may the combination maternal infection, maternal antibodies, drugs, environmental toxicants, postnatal factors, chemical imbalance which may be the cause of ASD. Chromosomal abnormalities and other nervous system are also more common in families with ASD. ASD tends to occur more often in people who have

certain genetic conditions such as fragile X syndrome or tuberous sclerosis .Older parents are also a higher risk for having autism child. Besides, parents who have a child with ASD have a 2- 18% chance of having a second child who is also affected by autism. Several studies have investigated that among identical twins, if one child has autism, than the other will also be affected about 36-95% of the time. In the non-identical twins, if one child has autism, then the other also is affected about 31% of the time. (Autism Speaks, 2019).

## **2.4 Participation of children with ASD**

ASD is a lifelong disorder which found in all races and in all social classes. According to Autism Speaks (2019), a study shows that, in 2018 the CDC investigated that there are approximately 1 in 59 children is diagnosed with (ASD). The ratio of boys and girls are 1 in 37 boys and 1 in 151 girls. So boys are risk four times more than girls. According to WHO (2017), worldwide 1 in 160 children are suffering from ASD. Based on epidemiological studies that was conducted over the past 50 years, the prevalence of ASD are increasing globally. And parents of children with ASD complain about lower participation in everyday activities of their children. King et al. (2003) found that children with ASD less participated leisure activities and that their participation is characterized by lower participation quiet recreational activities and fewer social activities. As children with disabilities are transitioned into adolescence and adulthood, their participation in everyday activities are appears to become more restricted.

There are many recent evidence which investigated that parents of children with ASD report lower participation in everyday life occupations of their children. For example, parent of children with ASD between the ages of 6 - 18 years reported that their children are less engaged in after-school activities, weekend clubs or even other organized event. They also are less participated in community activities rather than children with typically developing children. (Lee, L. C., Harrington, R. A., Louie, B. B., & Newschaffer, C. J., 2008). According to LaVesser, P., & Berg, C. (2011), a study showed that children with ASD ranges from the ages of 3-6 years are less participated in fewer activities rather than other typical children. This study also investigated that participation in self-care activities is lower than other typically developing children because children with ASD may

experience some or more sensory & motor issues which may interfere in participation in activities.

There may be many reasons for lower participation of children with ASD. The most common reasons for low participation among children with ASD are may be some factors associated with their behaviors e.g. having tantrums, do not following directions, having no interest in the activities, and experiencing sensory issues (hyposensitivity or hypersensitivity). Besides family reasons may be the cause for lower participation e.g. Parents of children with ASD are choosing not to participate in activities of their child or they are not assigning chores to their child to participate in activities (LaVesser, P., & Berg, C. 2011).

Similarly children with ASD are participated fewer in leisure or recreational activities. Younger children with ASD and also youth with ASD may participate more in parent-child household activities or family activities such as cleaning the room, picking up toys, having adult-child playtimes and community activities, such as children's festivals and community celebrations and religious program. (Little, L. M., Sideris, J., Ausderau, K., & Baranek, G. T., 2014). Rodger and Umaibalan (2011) have investigated that preschool and school-age children with ASD are less participated in special event activities, such as birthday parties and family vacations. This study also showed that there are differences in routines and rituals between families of children with ASD rather than families with typically developing children. In their study, families of children with ASD are established the routines that are more child-oriented by meeting the demands of their child with ASD rather than the family as normal developing children.

There may be some factors that influence or affect the participation of children with ASD in self-care, family and recreational activities. According to the Person-Environment Occupation-Performance (PEOP) model, (Christiansen & Baum, 2005), there may several factors that can influence an individual's participation in meaningful activities.

- Person-related factors e.g. as sensory processing (Brown & Dunn, 2010); cognitive skills (Zingerevich & LaVesser, 2009); social skills (Shattuck, Orsmond, Wagner, & Cooper, 2011), these may influence the participation of children with ASD in meaningful occupations within an environment.

- Environmental factors e.g. physical and social environment may also have an effect on children's ability to participate in activities within the home, school, and community (LaVesser, P., & Berg, C. (2011); Christiansen & Baum, 2005).
- Physical environment can create barriers to participation in activities e.g. a lack of toys and materials that may limit exploration in involving activities (Missiuna, C., & Pollock, N., 1991).
- According to Freitas. T. C. B., Gabbard. C., Caçola. P., Montebello. M. I. L., & Santos. D. C. C. (2013), a study investigated that there may be a significant positive relation between family income, parental education level, socioeconomic class, and the availability of motor affordances for children e.g. Physical space and play materials, within their environment.
- Social factors can also affect children participation include the availability and expectations of significant individuals, such as parents or caregivers, and the children's relationships with those individuals or their families. (American Occupational Therapy Association, 2008). The family members of a child with ASD plays a vital role in determining the type and number of activities in which the child will be given opportunities for participation in their everyday life.

A recent study according to Schaaf. R. C., et. Al (2011) investigated that children with ASD who are experiencing sensory-related behavioral problems, they have difficulty in performing morning and bedtime routines.

## **2.5 Role of Occupational Therapy**

Occupational therapy practitioners aim to enhance and improve the occupational performance of an individual. They are qualified to explore, to identify and to address the influence of the physical, social and cultural contexts on the daily occupations of individuals. Thus, occupational therapy practitioners must consider the home and the school contexts when designing interventions for children with autism. Environmental adaptations plays an important role in occupational therapy intervention for children and adolescents with ASD. For example, children with ASD may experience sensory



processing differences that influence their involvement in daily activities. (Brown. N. B., & Dunn. W., 2010)

Occupational therapy practitioners may embed sensory inputs within a child's daily routines to promote participation in everyday activities. Occupational therapists evaluate the sensory, motor, cognitive, social, and communication skills of children and adults with ASD that are related to their participation in everyday life activities. They identify the strengths and abilities, as well as needs and challenges that are important in the evaluation process, across the lifespan. The results of the occupational therapy evaluation helps to develop an appropriate intervention plan and intervention goals in collaboration with the family and children with ASD with a focus on what they need and want to do (American Occupational Therapy Association, 2018).

Occupational therapy interventions include:

- Sensory integration and sensory-based strategies treatment
  - Independent living skills training and modifications of their behavior
  - Motor development and motor planning skill development
  - Social emotional development and self-regulation strategies and programs.
  - Behavioral approaches, in collaboration with team members to support participation.
  - Engage in social participation activities.
  - Engage in ADL & play and/or leisure participation activities.
  - Visual supports such as schedules, timers, and video modeling.
  - Strategies to support personal responsibility and self-advocacy skills
- (American Occupational Therapy Association, 2018).

### 3.1 Conceptual framework

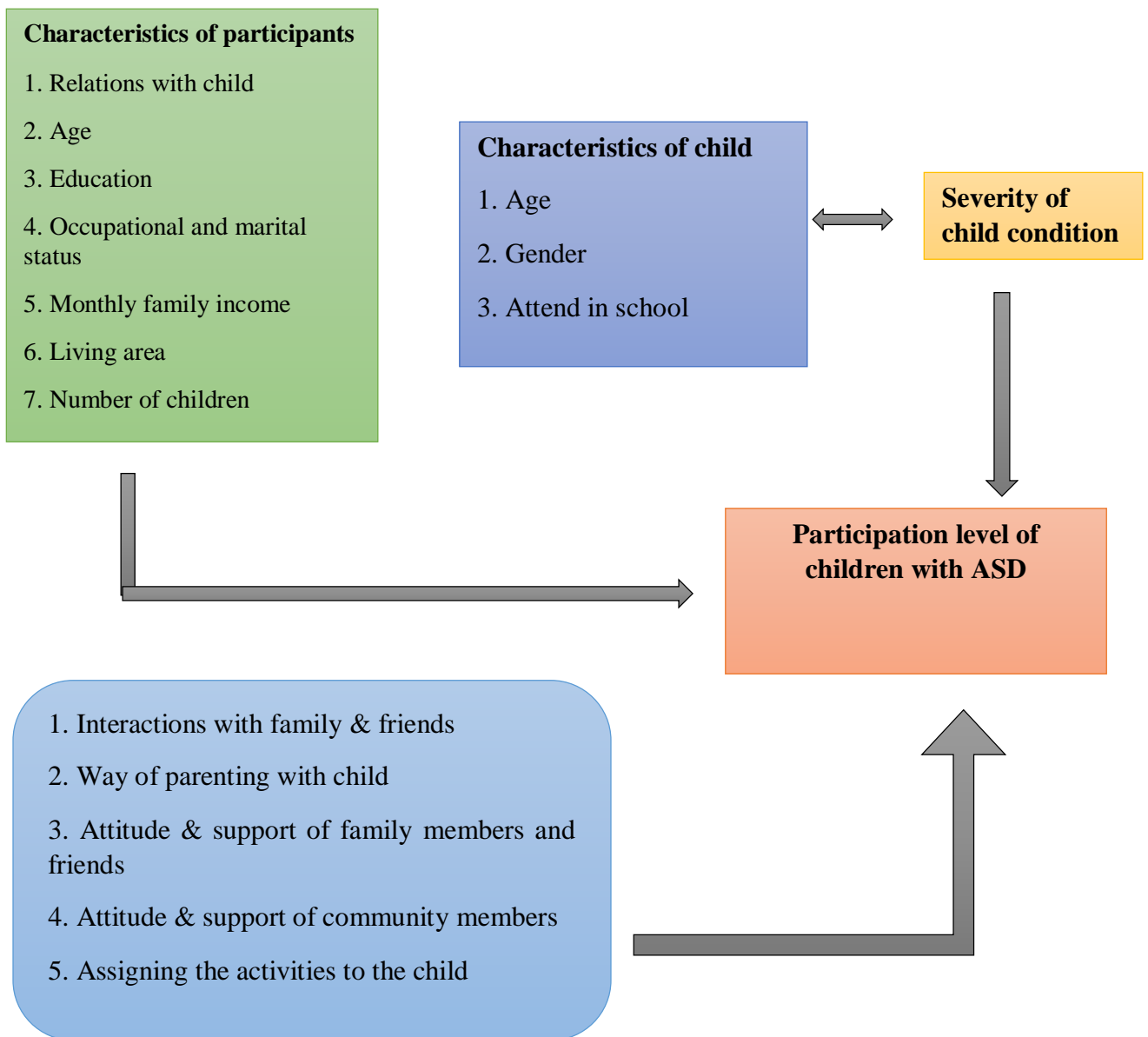


Figure 1- Conceptual framework

### **3.2 Study design**

In this study, researcher used a cross-sectional study to measure the participation level of children with ASD in self-care, family and recreational activities. Cross-sectional study is under the quantitative research design. A quantitative research design is a study design where the subject is well-known, comparatively clear and simple. Cross-sectional study is an easy way to collect data and information about research questions among the large participant. The researchers' intention of this study is to measure the participation level of children with ASD in self-care, family and recreational activities by using standard questionnaire. Data was collected from the participants to find out the response and level of participation. Creswell (2014) reported that cross sectional study helps to provide a snapshot of related characteristics in a large population at a given point of time. That's why researcher choose this study design for conducting study.

### **3.3 Study Population**

The study population for this study are consisted of mothers or person who remains close to the child and knows well about the participation of their child so that they can answer properly of the research questions.

### **3.4 Study Setting**

This study was conducted at two selected school of Dhaka District, Bangladesh- Pyoash Institute of Special Education & Research- Dhaka Cantonment and Faith Bangladesh- Iqbal Road, Mohammadpur.

### **3.5 Study period**

This study was conducted as a part of academic curriculum of B.Sc. in Occupational Therapy. So the study period of this study is short. The period of this study is from September 2018 to April 2019 including data collection, data analysis and discussion of this study.

### 3.6 Sample size

Sample size depends on some factors such as; the quality of data, the scope of the study, the nature of the topic, the amount of useful information obtained from each participant, the number of interviews per participant, and the Quantitative method and study design used. A sample size should be as large as the researcher obtains with a reasonable expenditure of time and energy. For conducting the study, investigator took sample according calculated numbers. Sample size could be large or small. Amount of sample size depends on study population and their participants (Bailey, 1997).

According to standard formula, sample size will be-

$$n = \frac{z^2 \times p(1-p)}{\alpha^2}$$

Here, n= sample size

z= 1.96 (Z-value) (e.g. 1.96 for 95 percent confidence level)

p= 0.17 (Prevalence of autism survivors in Bangladesh)

$\alpha$ = 0.05 (Level of significance / margin of error)

Putting these values in formula get n= 217

Here sample size is 217. Although, it is an academic research, data collection period was 2 months. Though this research was conducting by pre & post-test that's why it was impossible for investigator to take all samples in the limited time frame as well as it depended on the availability of sample. That's why investigator took 40 samples.

### **3.7 Inclusion and exclusion criteria**

#### **Inclusion criteria**

- Both boy & girl child who are diagnosed as ASD.
- Selected parents that have children with ASD.
- Children who are school going.
- Children with ASD whose age between 5-19 years.

#### **Exclusion criteria**

- Children who were not diagnosed as ASD.
- Children whose age under 5 or above 19 years.
- Unwilling parents.

### **3.8 Sampling technique**

To conduct this study the researcher collected data by using convenience sampling technique from the participants who met the inclusion criteria of this study. Convenience sampling technique is also known as availability sampling which is a specific type of non-probability sampling method that relies on data collection from participants who are conveniently available to participate in study (Explorable.com, 2009). It is a sampling technique where participants are selected because of their convenient accessibility and proximity to the researcher. (Mackey, A. & Gass, S., 2005)

### **3.9 Data collection tools/materials**

For conducting the study and data collection, the researcher used-

- Information sheet and consent form
- Bangla socio-demographic questionnaire and standard questionnaire (Child Engagement in Daily Life Measure)
- Paper file, pen, pencil, and eraser.

### **3.10 Data collection method**

At first, the researcher took permission from the Head of the Department of Occupational Therapy. Then took permission from the Head of the Department of Faith Bangladesh and Principle of Dhaka Proyash School to collect data. Researcher knew the schedule of children with ASD who came for receiving therapy of Faith Bangladesh and school time and indoor, outdoor services time of Dhaka Proyash. Then researcher went there to collect data. Researcher provided information sheets and consent forms to the parents of children with ASD. Researcher had to explain the research title, aim and objectives of this study, how this study can benefit for their children to the participants to gain the trust. Because trust is an important element of participants during data collection to find out the actual information regarding the research questionnaire. The research questionnaire was based on the participation level of children with ASD in self-care, family and recreational activities. Researcher collected data from participants through face to face interview. Interview was conducted in Bangla language so that participants can easily understand the questions and give actual answers. Each participant took 10-15 minutes to understand and response the questions of research questions. The staff of those organizations helped the researcher to conduct this data collection. They also introduced the researcher to the parents and told them to give time so that researcher can collect data appropriately.

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

Data management and analysis is important so that data from researcher is properly analyzed. There are many statistical methods that might be used but researcher used descriptive statistics. Descriptive statistics are useful to describe, organize and summarize the data and include frequencies, percentages and description of central tendency and description of relative relation. Data was being managed and analyzed by using Statistical Package for the Social Sciences (SPSS), version 20 to analyze the raw data. SPSS is suitable for analysis the Quantitative data. Nominal, Ordinal, & Scale data can be input in SPSS and able to analysis those data in different way. All data was inputted within the variable of SPSS. Specific findings were showed and described in bar graph, pie chart and in different table that is very easy to understand for the reader.

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

A field test was conducted with three participants before collecting data among participants. Researcher collected data from these participants by using all mentioned data collection instruments and following whole data collection procedure. Before beginning data collection from participants, it is necessary to conduct a field test. It is helpful because by conducting field test, researcher can understand whether participants can properly understand the questions or any change that need to be done. It is also helpful for the researcher to prove the validity of the questionnaire in this study. By conducting field test, researcher became aware about which part of the questionnaire finds difficult to understand. . By finding the difficulties of this questionnaires, the researcher had to check the questionnaire and change it to make it more understandable & clear for the participants to conduct the study. Before field test and collecting data, the English questionnaire was translated into Bangla. Then the translation copy was translated again Bangla to English. Then it was checked by the expertise person to correct the translation.

### **3.13 Ethical consideration**

The researcher maintained ethical consideration in all aspects of the study to avoid ethical problem. At first, the researcher took permission from the supervisor and the Head of the Department of Occupational Therapy Department of Bangladesh Health Professions Institutes (BHPI) which is the academic institute of CRP. After getting the permission from IRB, researcher went to the In-charge of Faith Bangladesh and the Principle of Dhaka Proyash with an application letter from BHPI to conduct the data collection. Then researcher got permission from the In-charge of Faith Bangladesh and Principle of Dhaka Proyash for data collection. The researcher provided information sheet and consent form to each participant. Researcher mentioned the title of the research, aim and objectives of the study by verbally. If any participant faced difficulty to understand the questions, researcher cleared about it. The researcher assured to all participants that confidentiality of all personal information will be maintained strictly in future. It was informed to all participants that there will be no risk or direct benefit to participate in this study. Researcher ensured to all participants that the service of the children will not be hampered during the

data collection time. In the data collection time, researcher used code no instead of name of participants so that their identity will not be published. The participants had the full right to withdraw their participant from this study at any time. Researcher had no right to force the participants to give information if they does not want to give. A written information sheet and consent form was signed by each participant who participated in this study. All the information was gathered from the participants anonymously. There was no biasness by the researcher to take information form the participants. Information that was provided by each participant was being confidential only to the researcher & supervisor have access to them. The field test notes and answer sheet was not shared or even discussed with others.



This section provides statistical analysis in a systematic way and interpretation of analyzed findings with the aim and objectives of the study. The aim of the study was to explore the level of participation of children Autism Spectrum Disorder in self-care, family and recreational activities. Findings of the study are presented by table and bar chart. Researcher gathered data from participants and then find out the findings of this study. Findings of the study are presented following by table and bar chart.

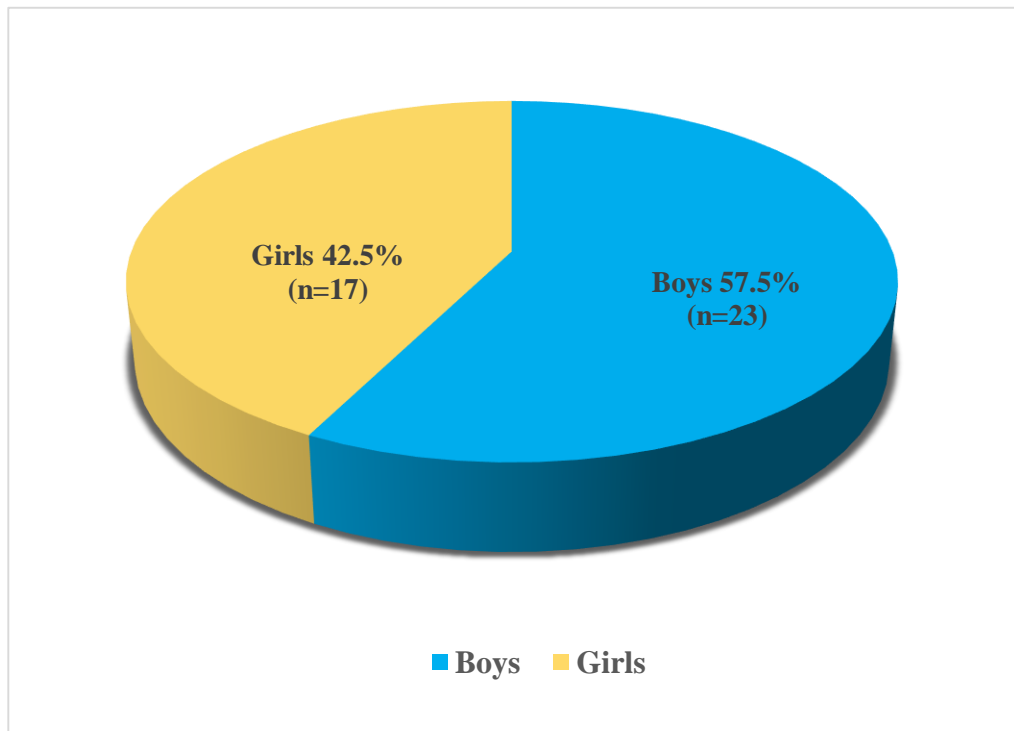
#### 4.1 Socio demographic characteristics of participants

In this study the researcher used many socio-demographic questions as researcher was interested to find out the socio demographic factors. Socio demographic questions include the information for autism children and participant's .The researcher categorized all the demographic characteristics in a table.

**Table 1: Distribution of respondents by child's age**

Age of the participants (child)	Frequency (n)	Percentage (%)
5-9 years	17	42.5
10-14 years	16	40.0
15-19 years	7	17.5
<b>Mean</b>	12.7	

Table 1 shows that, from all participants, about 42.5% (n=17) were 5-9 years of age group, 40.0% (n=16) were 10-14 years of age group and 17.5% (n=7) were 15-19 years of age.



**Figure 2: Distribution of respondents by child's gender**

Figure 2 shows that among 40 participants about 57.5% (n=23) were boys and 42.5% (n=17) were girls.

**Table 2: Distribution of respondents by relations with children, age of participants, educational status, occupation, marital status**

Socio demographic characteristics of the participants	n=40	
	Frequency (n)	Percent (%)
<b>Information provided by</b>		
Mother	35	87.5
Father	2	5.0
Others	3	7.5
<b>Age of the participants</b>		
20-30 years	8	20.0
31-40 years	23	57.5
>40 years	9	22.5
<b>Educational qualification of the information provider</b>		
Illiterate	1	2.5
Primary completed	1	2.5
Less than secondary	2	5.0
Secondary completed	2	5.0
Higher than secondary completed	3	7.5
Graduation completed	13	32.5
Above graduation	18	45.0
<b>Marital status</b>		
Married	38	95.0
Widow	2	5.0

Table 2 shows that, among (n=40) participants, about 87.5% (n=35) were mothers, 5.0% (n=2) were fathers and others were 7.5% (n=3). They were grandfather, grandmother and sister who takes care the child and knows well about the child's participation. Among all participants, the age range was also included in the demographic questions. . Among those 40 participants, about 20.0% (n=8) were 20-30 years age group, about 57.5% (n=23) were 31-40 years age group and 22.5% (n=9) were above 40 years old. From 40 participants, 2.5% (n=1) participant completed primary education, 5.0% (n=2) had completed their

education less than secondary and secondary completed, higher than secondary completed 7.5% (n=3) participants, 32.5% (n=13) participants completed graduation, post-graduation completed 45% (n=18) participants and 2.5% (n=1) were illiterate. Among all participants, 95% (n=38) were married and 5% (n=2) were divorced.

**Table 3: Distribution of respondents by occupation, monthly income, and living area, household.**

Socio demographic characteristics of the participants	n=40	
	Frequency (n)	Percent (%)
<b>Occupation</b>		
Housewife	26	65.0
Employee	6	15.0
Student	3	7.5
Business	5	12.5
<b>Monthly family income</b>		
31,000-40,000 /-	1	2.5
41,000-50,000/-	9	22.5
Above 50,000/-	30	75.0
<b>Living area</b>		
Urban	40	100.0
<b>Household</b>		
Own	25	62.5
Rented	15	37.5

Table 3 shows that from all participants of the participants, 65% (n=26) participants were housewife, 15% (n=6) were employee and 12.5% (n=5) were businessman. In this table, it also shows that monthly income were among all participants of their families, 2.5% (n=) had 31,000-40,000 taka, 22.5% (n=9) had 41,000-50,000 taka and 75.0% (n=30) had more than 50,000 taka. 100% (n=40) participants living area were urban and their household were 62.5% (n=25) had own house, 37.5% (n=15) had rented house.

**Table 4: Distribution of respondents by number of children, presence of any disability and presence of history among family members.**

<b>Socio demographic characteristics of the participants</b>	<b>n=40</b>	
	<b>Frequency (n)</b>	<b>Percent (%)</b>
<b>Number of children</b>		
One	14	35.0
Two	19	47.5
Three	7	17.5
<b>Any disability present in other children</b>		
No	40	100.0
<b>History of autism among family members</b>		
Yes	4	10.0
No	36	90.0

Table 4 shows that from 40 participants, 35.0% (n=14) had one children, 47.5% (n=19) had two children and 17.5% (n=7) participants had three children. Among those 40 participants, 100% (n=40) had no disability present in other children. In addition to all participants, 10.0% (n=4) participants complained that they had history of autism among family members and 90.0% (n=36) said that no history present of autism in their family members.

## 4.2 Participation level of Children with Autism Spectrum Disorder as reported by Child Engagement in Daily Life Measure Scale

In this study, researcher find out the participation level of ASD children in self-care, family and recreational activities. Researcher find out the family and recreational activities in two steps according to the scale:

**Table 5- Participation in family and recreational activities: Frequency**

Participation in family and recreational activities		N (%)			
How often?	Very often 5	Often 4	Once in a while 3	Almost never 2	Never 1
1. Family activities at home	2 (5.0 %)	25 (62.5 %)	9 (22.5 %)	4 (10.0 %)	-
2. Family outings in the community	-	17 (42.5 %)	19 (47.5%)	3 (7.5%)	1 (2.5%)
3. Indoor play with adults	6 (15.0%)	9 (22.5%)	15 (37.5%)	7 (17.5%)	3 (7.5%)
4. Indoor play with children	4 (10.0%)	12 (30.0%)	13 (32.5%)	7 (17.5%)	4 (10.0%)
5. Outdoor play with adults	2 (5.0%)	4 (10.0%)	10 (25.0%)	17 (42.5%)	7 (17.5%)
6. Outdoor play with children	4 (10.0%)	12 (30.0%)	10 (25.0%)	7 (17.5%)	7 (17.5%)
7. Quiet recreational activities	4 (10.0%)	17 (42.5%)	14 (35.0%)	4 (10.0%)	1 (2.5%)
8. Organized lessons, adapted sports, and arranged play groups	2 (5.0%)	9 (22.5%)	13 (32.5%)	3 (7.5%)	13 (32.5%)
9. Active physical recreation	4 (10.0%)	16 (40.0%)	19 (47.5%)	-	1 (2.5%)
10. Entertainment outings	-	4 (10.0%)	28 (70.0%)	6 (15.0%)	2 (5.0%)
11. Social activities	-	19 (47.5%)	15 (37.5%)	5 (12.5%)	1 (2.5%)

Table 5 shows that how often the child do the activity, family activities at home from all participants, 5.0% (n=2) were very often, 62.5% (n=25) were often, 22.5% (n=9) were once in a while, 10.0% (n=4) participants were almost never. Family outings in the community from all participants, 42.5% (n=17) participants were often, 47.5% (n=19) were once in a while, 7.5% (n=3) were almost never and 2.5% (n=1) participants were never according to the response of their parents. Indoor play with adults, 15.0% (n=6) were very often, 22.5% (n=9) had often, 37.5% (n=15) were once in a while, 17.5% (n=7) had almost never and 7.5% (n=3) were never participated. Indoor play with children, among all participants 10.0% (n=4) participants were very often, 30.0% (n=12) had often, 32.5% (n=13) participants were once in a while, 17.5% (n=7) participants were almost never and 10.0% (n=4) had never participated. Outdoor play with adults, 5.0% (n=2) participants were very often, 10.0% (n=4) had participated often, 25.0% (n=10) were once in a while, 42.5% (n=17) participants were almost never and 10.0% (n=4) had never participated. Outdoor play with children, 10.0% (n=4) participants were very often, 30.0% (n=12) participants had often, 25.0% (n=10) were once in a while, 17.5% (n=7) participants were almost never and 17.5% (n=7) participants had never participated.

Quiet recreational activities, 10.0% (n=4) participants were very often, 42.5% (n=17) participants had often, 35.0% (n=14) had once in a while, 10.0% (n=4) participants were almost never and 2.5% (n=1) participants were never participated. Among all participants, 5.0% (n=2) participants were very often participated, 22.5% (n=9) participants had often, 32.5% (n=13) were once in a while, 7.5% (n=3) had almost never and 32.5% (n=13) participants were never participated in organized lessons, adapted sports and arranged play groups. Active physical recreation, 10.0% (n=4) participants were very often, 40.0% (n=16) participants had often, 47.5% (n=19) participants were once in a while and 2.5% (n=1) participant had never participated. In addition to all participants, 10.0% (n=4) participants were often, 70.0% (n=28) participants were participated once in a while, 15.0% (n=6) were almost never and 5.0% (n=2) participants had never participated in entertainment outings. Social activities, 47.5% (n=19) participants were often, 37.5% (n=15) participants had participated once in a while, 12.5% (n=5) were almost never and 2.5% (n=1) participant had never participate in social activities.

**Table 6- Participation in family and recreational activities: Enjoyment.**

Participation in family and recreational activities		N (%)				
How much do you think your child enjoys the activity?	A great deal 5	Very much 4	Somewhat 3	Very little 2	Not at all 1	NA
1. Family activities at home	6 (15.0%)	14 (35.0%)	15 (37.5%)	3 (7.5%)	2 (5.0%)	-
12. Family outings in the community	8 (20.0%)	11 (27.5%)	15 (37.5%)	5 (12.5%)	1 (2.5%)	-
3. Indoor play with adults	13 (32.5%)	3 (7.5%)	14 (35.0%)	3 (7.5%)	7 (17.5%)	-
4. Indoor play with children	10 (25.0%)	13 (32.5%)	7 (17.5%)	5 (12.5%)	5 (12.5%)	-
5. Outdoor play with adults	6 (15.0%)	7 (17.5%)	7 (17.5%)	8 (20.0%)	9 (22.5%)	3 (7.5%)
6. Outdoor play with children	7 (17.5%)	15 (37.5%)	5 (12.5%)	4 (10.0%)	8 (20.0%)	1 (2.5%)
7. Quiet recreational activities	8 (20.0%)	12 (30.0%)	14 (35.0%)	3 (7.5%)	3 (7.5%)	-
8. Organized lessons, adapted sports, and arranged play groups	6 (15.0%)	10 (25.0%)	9 (22.5%)	2 (5.0%)	5 (12.5%)	8 (20.0%)
9. Active physical recreation	15 (37.5%)	13 (32.5%)	11 (27.5%)	-	1 (2.5%)	-
10. Entertainment outings	3 (7.5%)	20 (50.0%)	10 (25.0%)	5 (12.5%)	1 (2.5%)	1 (2.5%)
11. Social activities	11 (27.5%)	11 (27.5%)	9 (22.5%)	5 (12.5%)	4 (10.0%)	-

Table 6 shows the level of participation in family and recreational activities, how much the child enjoys the activity. According to the response of the parents of the children, among all participants, 15.0% (n=6) had a great deal, 35.0% (n=14) participants were very much, 37.5% (n=15) participants were somewhat, 7.5% (n=3) had very little and 5.0% (n=2) had participated in family activities at home. Family outings in the community, 20.0% (n=80



were a great deal, 27.5% (n=11) participants were very much, 37.5% (n=15) participants had somewhat, 12.5% (n=5) had very little and 2.5% (n=1) participants were not at all. Indoor play with adults, 32.5% (n=13) were a great deal, 7.5% (n=3) had very much, 35.0% (n=14) participants were somewhat, 12.5% (n=5) were very little and 17.5% (n=7) participants had not at all. Indoor play with children, among all participants, 25.0% (n=10) were a great deal, 32.5% (n=13) were very much, 17.5% (n=7) had somewhat, 12.5% (n=5) were very little and not at all. In addition from all participants, 15.0% (n=6) participants were a great deal, 17.5% (n=7) were very much and somewhat, 20.0% (n=8) participants were very little, 22.5% (n=9) had not at all and also 7.5% (n=3) were not applicable for their child. Outdoor play with children, 17.5% (n=7) participants had a great deal, 37.5% (n=15) were very much, 12.5% (n=5) had somewhat, 10.0% (n=4) participants had very little, 20.0% (n=8) had not at all and 2.5% (n=1) was not applicable.

In addition to all participants, quiet recreational activities, 20.0% (n=8) had a great deal, 30.0% (n=12) were very much, 35.0% (n=14) were somewhat, 7.5% (n=3) were very little and not at all. Organized lessons, adapted sports and arranged play groups, 15.0% (n=6) participants had great deal, 25.0% (n=10) were very much, 22.5% (n=9) were somewhat, 5.0% (n=2) had very little, 12.5% (n=5) were not at all and 20.0% (n=8) were not applicable. Active physical recreation, 37.5% (n=15) participants were a great deal, 32.5% (n=13) had very much, 27.5% (n=11) were somewhat and 2.5% (n=1) had not at all. Entertainment outings, 7.5% (n=3) participants were a great deal, 50.0% (n=20) had very much, 25.0% (n=10) participants had somewhat, 12.5% (n=5) were very little and 2.5% (n=1) were not at all and not applicable. Social activities, 27.5% (n=11) had a great deal and very much, 22.5% (n=9) were somewhat, 12.5% (n=5) were very little and 10.0% (n=4) had not at all.

### 4.3 Level of participation in self-care activities

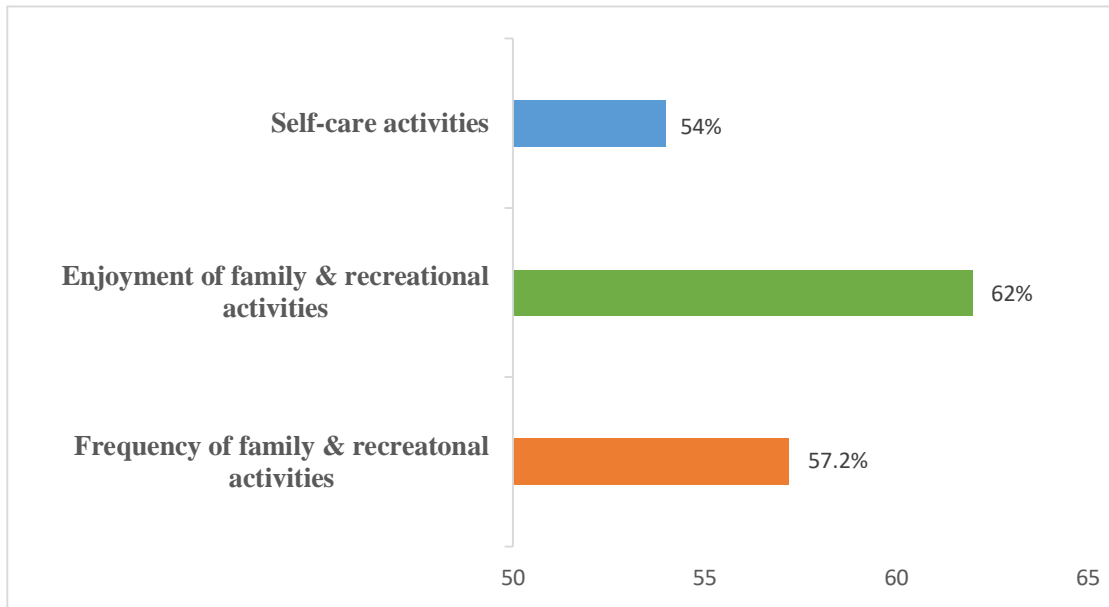
Table 7- Participation in self-care activities

Participation in self-care activities	N (%)				
	Yes, does the activity consistently	Yes, does the activity inconsistently	Yes, with help for part of the activity	Yes, with constant help	No, does not do the activity
Does your child safely participate in?	5	4	3	2	1
1.Feed self finger foods	4 (10.0%)	11 (27.5%)	12 (30.0%)	7 (17.5%)	6 (15.0%)
2.Feed self with spoon or fork	7 (17.5%)	9 (22.5%)	6 (15.0%)	3 (7.5%)	15 (37.5%)
3.Drink from a bottle or cup	26 (65.0%)	1 (2.5%)	12 (30.0%)	1 (2.5%)	-
4.Dress upper body	2 (5.0%)	5 (12.5%)	25 (62.5%)	5 (12.5%)	3 (7.5%)
5.Dress lower body	13 (32.5%)	5 (12.5%)	15 (37.5%)	5 (12.5%)	2 (5.0%)
6.Bathe/clean and tidy self	-	2 (5.0%)	16 (40.0%)	6 (15.0%)	16 (40.0%)
7.Use the potty or toilet	5 (12.5%)	1 (2.5%)	15 (37.5%)	13 (32.5%)	6 (15.0%)

Table 7 shows that among all participants, 10.0% (n=4) had does the activity consistently, 27.5% (n=11) had does the activity inconsistently, 30.0% (n=12) participants were with the help for part of the activity, 17.5% (n=7) were with constant help and 15.0% (n=6) were does not do the activity in feed self finger foods. In feed with spoon or fork, among all participants 17.5% (n=7) were does the activity consistently, 22.5% (n=9) were does the activity inconsistently, 15.0% (n=6) had with help for part of the activity, 7.5% (n=3) were constant help and 37.5% (n=15) were does not do the activity. From those 40 participants, 65.0% (n=26) were does the activity consistently, 2.5% (n=1) were does the activity inconsistently and with constant help and 30.0% (n=12) were with help for part of the activity. Among 40 participants, 5.0% (n=2) participants were does the activity

consistently, 12.5% (n=5) participants were does the activity inconsistently and with constant help, 62.5% (n=25) had with help for part of the activity and 7.5% (n=3) were does not do the activity. In addition to all participants, 32.5% (n=13) participants were does the activity consistently, 12.5% (n=5) were does the activity inconsistently and with constant help, 37.5% (n=15) had with help for part of the activity and 5.0% (n=2) participants were does not the activity of dress lower body. In bathe/ clean and tidy self, 5.0% (n=2) participants were does the activity inconsistently, 40.0% (n=16) had with help for part of the activity and does not do the activity, 15.0% (n=6) were with constant help. Among 40 participants, 12.5% (n=5) were does the activity consistently, 2.5% (n=1) were does the activity inconsistently, 37.5% (n=15) had with help for part of the activity, 32.5% (n=13) had with constant help and 15.0% (n=6) were does nor do the activity of use the potty or toilet.

#### 4.4 Overall level of participation of each domain of children with ASD



**Figure 3- Level of participation of each domain**

Figure 3 shows overall participation level of each domain. Here, frequency of family and recreational activities is 57.2%, enjoyment of family and recreational activities is 62% and level of self-care activities participation is 54%. Through this figure, it shows that children with ASD participate in family and recreational activities rather than self-care activities and the enjoyment is more than the frequency of participation.

## 5.1 Discussion

The purpose of the study is to explore the level of participation of children ASD in self-care, family and recreational activities based on parental reports. A total of 40 samples were participated in this study. This study identified the frequency and enjoyment of family & recreational activities and level of participation of children with ASD in self-care, family and recreational activities.

Participation in daily life activities is very important for every human at all ages to health and wellbeing, skill development and life satisfaction. Daily physical and recreational activities have an important role in the psychosocial development of children. Children with ASD are less participate in daily life activities than normal typical children. So increasing participation of children with ASD is the ultimate goal for rehabilitation program. This study used Child Engagement in Daily Life Measure to identify the level of participation in self-care, family and recreational activities. Results from this study provide an overall concept to the understanding about the patterns of participation across the self-care, family and recreational activities of children with ASD aged between 5-19 years old.

Socio- demographic characteristics of the children, boys was more than the girls in this study as participant group, mean was 12.7. From all participants, about 42.5% (n=17) were 5-9 years of age group, 40.0% (n=16) were 10-14 years of age group and 17.5% (n=7) were 15-19 years of age.

A total of 40 samples (parents) were included in this study. Among them, 35 respondents were mothers, 2 respondents were father, 1 respondent was grandfather, 1 respondent was grandmother and the remaining 1 was sister of children with ASD. And most of the parents were completed post-graduation, n=18 (45.0%) and graduation completed n=13 (32.5%). The mothers of children were highly educated and were engaged in job but due to their children, most of the mothers complained that they couldn't engage in job. Maximum participants respond that there family income is more than Tk. 50,000 and among 40

participants, 100% were living in urban areas. This study shows that about 62.5% respondents were having own house and 37.5% were rented house. The study showed that 47.5% respondents had two children, 35% respondents had one children and 17.5% respondents had three children. And all of them respond that there was no any disability present in other children. Among 40 respondents, 90% were history of autism among their family members 10% reported that they had history of autism among their family members.

Previous studies have identified that participation of children with ASD is lower in home and community activities (LaVesser & Berg, 2011; Little et al., 2014). Results from the current study indicates that most of the children with ASD do not have adequate activity participation in daily life activities. Many studies have investigated that individuals with ASD are more likely to be inactive and they are less likely to participate in activities when they are compared with the general children. A various number of factors can reduce the participation of children with ASD in daily life activities.

In this study, many parents expressed their opinion about their child participation in family and recreational activities and self-care activities. Parents expressed that their children more participated in doing chores, watching TV, video games, puzzle games, riding bicycle, engaging in indoor play rather than outdoor play. Most children attend in social activities like birthday party, marriage ceremony. Only few of them enjoys and some of them avoid because of auditory hyper-responsively. 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, browsing YouTube. High levels of frequency and involvement were also reported in indoor play in the younger group such as coloring, ball passing, matching cards, imaginative play etc. Children with high functioning ASD were reported by their parents to engage more frequently than typical children in family and recreational activities.

Most parents reported that their children mostly enjoy entertainment outings, active physical recreation, and indoor play with children. Some parents expressed that their children usually participated in those activities because they insisted the children to their children. And some of parents said that they didn't assign these tasks to their children because they think that their children don't enjoys the activities. But many parents wanted to participate in these activities of their children and they motivated their child to do the activities. Caregivers of these children wished that their children's participation level will increase and can lead a normal life as like normal typical developing children.

This study identified the level of participation of children with ASD. The overall participation of their participation showed in figure-10. It shows that among 40 children, their participation is better in family and recreational activities rather than self-care activities (54%). And those children had more frequency in family and recreational activities (62%) rather than their frequency of participation in family and recreational activities (57.2%). So by doing this study, it can be said that children with ASD have fewer participation in self-care activities. Many parents reported that, they didn't assign self-care activities to their child because they think that their children can't do the activity.

Parents of children with ASD are choosing not to participate in activities of their child or they are not assigning chores to their child to participate in activities (LaVesser, P., & Berg, C. 2011). So many parents expressed that their children couldn't eat independently as they didn't give opportunity to their children. Some children need help in self-care activities like feeding, dressing, bathing, toileting. Parents wished that their at least perform these activities independently as its personal issues in dressing, toileting and bathing. Parents of children above 10 years, wished that their children are growing up so they wanted that their children will become independent in self-care activities. Parents of children age between 5-8 years, they expressed that their children are still younger so they wanted to give more time to become independent in self-care activities.

The findings of this study will be helpful for the parents and also for the rehabilitation professionals who are working in pediatric settings especially with children with autism. By this study, the professionals can find out the gap of treatment and how the intervention can be improved to enhance the participation of children with ASD. Parents will be more conscious about their children and how they can involve their children in these activities more. It will be very helpful for the health professionals to improve the parents' knowledge and arranging awareness program for the parents to improve the participation of children with ASD.

## **5.2 Limitation**

Several limitations of this study have to be acknowledged. The limitation of this study are as following:

- In this study, researcher used cross-sectional data analysis. Therefore, the effects of children and family characteristics on activity participation among this sample over time is unknown.
- Researcher gathered data only from just 40 samples due to time limitation. It is very small to generalize the result in all over the Bangladesh.
- Researcher choose participants only from two selected places, so it is not generalizable for country perspectives.
- Researcher included the samples of children with autism to measure the level of participation level. It will be more representative and comparative if there was included other disable condition.
- There was limited resources and information available about participation level of children with ASD. As it is a new study in Bangladesh, so the resource was very limited.



There are more limitation in this study which should be kept in mind during conducting the study. The following limitations have been find out while conducting the study:

- For conducting interview, the scale was translated into Bengali from English. The author of this scale wanted the back translation of her scale from researcher. And researcher had to face difficulty as author gave feedback of this scale again and again.
- Though interview was conducted in Bengali but the study is presented in English. So researcher had to translate interview from Bengali to English and checked it by seniors and professionals. Sometimes it was very difficult to translate the actual meaning of some questions or words from the scale.
- The study was done by purposive sampling to collect data from the selected participants. The finding of this study can't be generalized to all children with ASD because of small sample group.

### **5.3 Conclusion**

Now a days Autism is a major concern in all over the world and as well as in Bangladesh. In Bangladesh, there have limited literature and research on participation level of children with ASD. The study explores the level of participation of children with ASD in self-care, family and recreational activities. Child Engagement of Daily Life Measure was used to measure the level of participation of children with ASD from selected two areas of Dhaka District. The findings from this study provided useful information about children participation for health professionals to understand about the level of participation and which area and treatment should be focused during planning rehabilitation program. Occupational therapists are working now to children with ASD mostly and they should encourage the children and their parents to engage in daily life activities in different life situations. Result of this study indicates that children with high functioning ASD differ from typically developing peers in both the quantity and type of activities in which they participate. Previous study in the area of participation for children with ASD has focused on home, school and community settings of children's level of competence. Data presented in this study provides evidence about the participation level of three areas of children and

adolescents aged 6 to 18 years with ASD. In conclusion, only a small part of children with ASD are physically active according to activity guideline and they participate in those activities. And parents are more concerned about their children's participation in self-care activities.

#### **5.4 Recommendation**

- In further research, the recommendation will be to compare the level of participation among boys and girls of children with ASD. Sample size have to be divided equally in two parts.
- Further research should be conducted with a large number of group on this study design so that a better result will be found and it will be easy to generalize the result.
- To identify the association between socio demographic factors and level of participation of children with ASD.
- To identify the factors and barriers that can influence and affect the participation level of children with ASD.