

**THESIS TITLE**  
**QUALITY OF LIFE OF PARENTS HAVING  
CHILD WITH AUTISM**

**BY**  
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**University of Dhaka**



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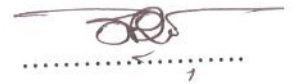
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## Declaration Form

- This work has not previously been accepted in substance for any degree and is not concurrently submitted in candidature for any degree.
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### **Key abbreviation**

**ASD**- Autism spectrum disorder

**QOL**- Quality of life.

**CSHCN**- Children with Special Health Care Needs

**HRQOL**-Health related quality of life

**WHO**-World Health Organization

**WHOQOL**-World Health Organization Quality of Life

**CDC**-Centers for disease control and prevention

**PDD**-Pervasive developmental disorder

**AS**- Asperger's syndrome.

**CRP**- Centre for the Rehabilitation of the paralyzed.

**CDD**-Child hood Distegrative Disorder

**DSM-5**Diagnostic and statistical Manual Disorder. **NS**-National Survey

**APA**-American psychiatric association

**USA**-United states of America

**BHPI**-Bangladesh Health Professions

**BSS**-Blessing child Special School Institute

**SAND**-School for Autism and neuro developmental disorder

**SCF**-Special care foundation

**MRS**-Masters in Rehabilitation Science

## Abstract

**Back ground:**-Bangladesh is on top the populated and progressing country. Among those population, 16 million people with disabilities. Autism spectrum disorder (ASD) mention to a group of complex neurodevelopment disorders distinguished by tedious and characteristic patterns of behavior and struggling with social communication and interaction. In Bangladesh, autism in children is a significant burden of condition among disabilities. Parents having child with ASD lead a stressful and ungraded quality of life (QOL). This Study has explored the challenges of QOL of parents and inspects their experiences and barrier as they face rising a child with ASD.

**Aims:**-To point out the challenges in quality of life of parents having child with Autism.

**Methodology:**-The study has revised with cross sectional prospective study with 80 participants who are parents having child with ASD. This is the design of a non-experimental study. The research has done in one time or in a little term. Maximum participants have selected from special school, Therapeutic clinic, Centre in Dhaka city where their child meet for education, intervention, treatment and training. Researcher has used organized structural questionnaire of WHOQOL-100 BREF with physical, psychological, social and environmental domain along with the socio demographic data. The data has presented on the basis of research objectives and research question. Data has arranged, entered and tabulated in computer SPSS to present the findings of the study. Simple descriptive statistics such as frequency, percentage, mean score, standard deviation has used for basic analysis of data.

**Results:**-In this study among 80 participants the researcher has trying to see association between age, gender, educational level with physical, psychosocial, social and environmental domains. Association between age and Physical well-being and Age and Social well-being of parents having child with Autism Spectrum Disorder examined by chi- square test and result .020, .012 which associations were significant ( $p < 0.05$ ). Other association between age, gender, educational level with psychosocial, physical, environmental well-being examined by chi-square test and result 0.119, 0.320, 0.746, 0.746, 0.454, 0.433, 0.892, 0.706, 0.603, 0.105 which associations were not significant ( $p > 0.05$ ).

**Conclusion:** -The findings may be hypothesized, if QOL can evaluate further and follow it for a few years. The result further suggests that the connection between variables with different domains at QOL levels is not universal. The study could

further enhance the initial campaign planning assumptions for rehabilitation professionals

**Key words : - Autism Spectrum disorder, Quality of life.**

Autism spectrum disorder (ASD) is a multiplex advancing disability; symptoms usually appear in early childhood and affect a person's ability to communicate and interact with others. ASD is defined by a convincing set of behaviors and a spectral condition that induces individuals individually and to varying degrees. There is no specific cause for autism, but awareness raising and early diagnosis and intervention and access to appropriate services leads to significantly improved outcomes. In Bangladesh, autism has already been detected as concern of neuro developmental condition and it has been estimated that the significance is high and mass cases, is undecided. In spite of that there was no epidemiological steady evidence on autism prevalence in Bangladesh. During 2013 a national level study in Bangladesh employed community health workers and formed eminence of autism; the study illustrates a prevalence of 1.5/1000 (30/1000 in Dhaka city and 7/10,000 in rural area) within 7200 population. Thus, the aim of this study is to explore the prevalence of autism in children aged 18 months to 36 months in a rural population of Bangladesh. The survey found that in one upazila (six unions) 5228686 children aged 18 months to 36 months.. 04 cases were found with autism spectrum disorder (Masum et al, 2016). The prevalence of ASD was found to be 0.075% in rural community population. According to a 2009 World Health Organization survey, 0.6% of children there suffer from autism spectrum disorder. However, children were not received treated with specialized facilities available ASD treatment and counseling in practice. This is the vulnerable consequence of the situation regards ASD in Bangladesh.

Parents of children with Autism Spectrum Disorder (ASD) take responsibility for diagnosis, advocacy and day-to-day care. There is evidence that it affects their quality of life (QOL). This systematic review examines the parental impact of a child with ASD on the parent's QOL. Evidence strongly suggests that poor parents generally have QOL compared to parents of both poorly developing children and children with disabilities.

The severity of the main features of ASD, the presence of Cumbered and especially the hyperactivity, affect the parental QOL, including anti-bias and behavioral difficulties, worry and sensitive features besides adverse level of behaviors. Several factors have been identified as general development and delays in the activities of self-care. Nevertheless the findings tested in this analysis have been incompatible results

regarding its contribution to QOL. It is advisable to test the effect of this part on their QOL. QOL is a multidimensional view that encompasses unlike realm of functionality.

The World Health Organization has defined QOL as the conception of a person's position in life in terms of their goals, expectations, values, right and concerns. Schalock et al. proposed a model for assessing QOL in the context of disabilities with eight core domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional wellbeing, physical wellbeing, and material wellbeing. Autism in a child affects not only the child's life but also the life of the family especially the life of the parents. Parents having children with autism lead a more stressful life in Bangladesh. They sometimes give up their daily and productive existence in order to assign parenting guidance and pay out large amount of time with their infants. Moreover, they also don't gather sufficient assistance or facilities from family, society and environment. Periodically parents become sufferer of social disgrace and social mortification, they touch in mind liable and assign guilt themselves as well as they do not have clear conception regards their child's disability. That is why this condition influence in charge of themselves and a child's disability impacts on their physical, psychosocial health, social relations and environment. There are no studies about how parents having children with autism are sensible, impression or understanding about their child's disability or about the challenges they face therefore, this study is to identify the impact on parents quality of life due to having a child with autism.

**1.1 Back ground of the study:** - Bangladesh is an over populated and developing county. Maximum people lead a life under poverty and literacy rate is also lower in the country. Disability or any other disorder is the major concern in Bangladesh as well as over the world. According to World Health Organization (2006) currently around 10 percent of the total world's population or approximately 650 million people live with disability. Female have a higher rate of disability than males.

Autism is one kind of neurodevelopmental disorder. Autism spectrum disorders (ASDs) constitute an extensive group of conditions that explicit in a range of deficits. Within this category of disorders, autism is the most prevailing (Linderman & Stewart, 1999). The Centers for Disease Control and Prevention (2010) estimated the prevalence of ASDs at around 1 in 110 children. The number and type of symptoms can differ extreme and range from mild to severe. Symptoms fall into a range of

categories, including problems with social interaction, somatosensory disturbance (i.e., constantly occupying in movement or rocking), atypical developmental patterns (Mayes & Calhoun, 1999). Dysfunction in perceptual and sensory processing as well as in communication and neurological functioning consequence in diverse functional behavior restriction (Watling, Deitz, Kanny, & McLaughlin, 1999). According to Rahman (2010) in Bangladesh almost 10.5 lakhs individuals have autism. In spite of the increase of this rate of prevalence of Autism, many researcher have studied the mental health of parents and the challenges in daily life and quality life of mothers having a child with autism. As parenting guidance and handling the child with autism is very strenuous and creating enormous stress for parents, they faces different challenges in their quality of life. In addition parents having a child with autism as showing significantly lower levels of quality of life than parents having children with other disabilities. In particular, it has stated by Kamei (2013) parents having children with autism showed lower physical health, difficulties in social relationships and lower psychological wellbeing than parents of children with other disabilities. Few movements parents are not aware about their child`s problem, its prognosis, therefore they accused themselves and think them responsible for their child`s disability. Moreover, there is very few awareness regards autism and its causes among the general people in Bangladesh and many Traditional views still exists .As a result the burden of the parents is also related to social rejection. They typically have the major care taking responsibility and they have face the challenges associated with their child`s disability (Ekas, 2009)

The researcher desire to carry out this study to explore the challenges of quality of life of parents having autistic child. This study will examine the parents understanding about their child`s problem and their experiences and challenges as they face raising a child with autism.

**1.2 Justification of the Study:** - As Autism is the prevalent issues now a day and after having children with autism the life style of parents become modify or adapted. In every part of survival transition, parents are thinking about the majority supreme part of a person's life. Parents can take part in a key role in the psychological, social and academic development of children. Studies for children with chronic disabilities have shown that children's well-being and growth consequences can significantly affect their parents' mental health(Hastings RP, Kovshoff H, Brown T, Ward NJ, Espinosa FD, et al. 2005) It can also influence their quality of life. On the other hand mother and father as parents had chosen for this study because it will contribute a better awareness regards the impact on their life of having the children with autism. This consciousness is very necessary to realize their difficulties, burden and needs. The result of this study can be effective for those parents who have children with this disability. This study is also helpful for the health professionals who are particularly working for children with Autism for understanding the needs and expectations of parents and how QOL are impacted after having an autistic child .It will also help professionals to support effective education to parents by increasing their knowledge about autism and changing their attitude towards autism.

This study will be also benefited rehabilitation professionals to explain regarding the provocations accepted by parents having child with autism. It will productive for other health professionals such as Social workers, Counselors, Psychiatrists and Physician, Occupational therapist, Physiotherapist, Speech and Language Therapist on this topic for formulate rehabilitation plan for those children`s well-being. The nature of this study is Cross sectional –prospective study addressing in order to represent the degree and synthesis of the experiences.



**1.3 Research question: - what are the challenges in quality of life of parents having child with autism.**

**1.4 Operational definition:-**

Autism Spectrum Disorder is a multiples neuro developmental condition that involves tireless difficulties in social interplay, speech and nonverbal communication, and restricted / repetitive behaviors. The effects of ASD and the severity of the index vary from person to person. Autism Spectrum Disorder (ASD) refers to a neurodevelopment disorder that is distinguished by strains with limited and repetitive patterns in social communication and social interactions and behaviors, interests, and activities.

By definition, symptoms appear early in development and affect daily functioning. The term 'spectrum' is used because of the presentation and severity of ASD symptoms as well as the level of skill and effectiveness of people with ASD

(American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, 5th et al. 2013)

**1.5 Quality of life :-**

Overall, the standard of living (QOL) is the value of a person's daily life, which is an assessment of their well-being .It covers every emotional, social and physical exposures of a person's life. Health-related quality of life (HRQL) is an analysis of how a person's well-being can be enhanced on top of time by disease, disability or disorder

The standard of living is a representation of unified purpose and individual criterion. Its life has a wide domain and unique worth. It get hold of a statement of concern that apparently obtained rules are not obligated be pertained in the absence of mentioning single variance. The elements that contribute to well-being differ just as individual preference however repeatedly adds economic guarantee, job pleasure, home lovingness, well-being and protection(WHO, 2013).

The Quality of life healthcare (WHO, 2012) curtains an eminent one of idea of health-associated welfare which admits the contents (like people, patient and survivors) bring their real case in liaison towards their own assumption. The following may differ up period, and act to outward impacts like extent and extremity of ill-health, assistance from home, etc. As with any case requiring vivid views, victims' and data accumulators grading of the alike purpose state of affairs have been found to vary

remarkably. Accordingly, health-linked standard of life is recently typically checked out applying survivor's survey form. Those are frequently compound and make up physical, social, emotional, cognitive, work- or role-related, and possibly spiritual aspects as well as a diverse range of disease related symptoms, therapy induced side effects, and even the financial impact of medical conditions in any complicated case. Though repeatedly cast-off compatible with the quantifying of state of health, both fitness-allied well-being and health standing appraisal of individual view (CDC, 2011).

## 2.1 Autism

Now-a-days Autism spectrum disorders are an urgent concern. Autism spectrum disorder is a condition related to brain development that affects how a person affects perception and socialization with others, causing problems in social communication and communication, including limited and recurrent patterns of behavior. Autism is a neuro developmental disorder which is distinguished by impeded and abnormal social interplay and communication, stereotype behavior and restrictive interest. Usually the symptoms of autistic behavior appear earlier to age three.

Pathappillil (2011) mentioned that in 1940's; Leo Kanner a psychiatrist and physician said that Autism is a collection of differences in social interaction, communication, and focused interests". According to Pathappillil (2011), it generally change the way of nerve cell and synapses connect and organize information and thus affects the normal processing in the brain. In addition autism is called pervasive developmental disorder (Bashir et al. 2014). The pervasive developmental disorders include: Autism, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), and Asperger's Syndrome (AS), and Rett's Disorder and Childhood Disintegrative Disorder (CDD) .All the disorders are known as Autism Spectrum disorder. However, In case of ASD's it is common characteristics that they have long-term impairments within the domains of social interaction, communication, play, imagination, and a restricted range of behaviors or interests.

According to the Mental Disorders Diagnostic and Statistical Manual (DSM-5), a guide developed by the American Psychiatric Association was used to diagnose mental disorders. People with ASD have

- Struggling with passing on information, internal voice and interplay with other people
- Constricted attentiveness, curiosity and tedious manners.
- Traits that hurt the individual's potentiality to task properly in school, work, and other areas of life

Autism is a disorder that is affecting more and more people because of the differences in the type and severity of the symptoms that people experience. ASD occurs in all ethnic, racial and economic groups. Although ASD can be a lifelong disorder,

treatments and services can improve a person's symptoms and ability to function (American psychiatric association APA, 2013)

## **2.2 Prevalence**

It has been increasing the prevalence of Autism spectrum disorder in world wide. According to Elfert (2004) lately in 2014, the prevalence of autism was 1 in 68 children and male: female ratio was almost 4.5:1 in world wide. In 2018, the CDC determined that about 1 in 59 children was diagnosed with Autism Spectrum Disorder (ASD). Boys are four times additional to be expected as detected with autism than girls. Most children are diagnosed after the age of 4, although autism can be reliably diagnosed at a young age of 2. Hartmann (2012) agrees with this that in USA approximately 1 child in every 110 children has autism and each year the rate is rising at a rate of 10% to 17% and it has seen that the prevalence is immensely toppe supposed to boys (1 in 70) rather than girls (1 in 315). In Bangladesh, there will be around 76,000 children under the age of five with ASD. It has certain by Ma (2012) that there is no consanguinity among contingency of autism with sprint, ethnicity, socioeconomic tradition. It is erected in all indigenous, tribal classes and socio economic groups.

## **2.3 Epidemiology**

It is estimated that one in every 160 people worldwide has an ASD. This estimate presents an average statistic and varies considerably throughout the reported spread study. Some controlled studies, however, have published statistics that are substantially higher. The prevalence of ASD is so unknown in many low-middle-income countries. Stand on epidemiological studies whose are leading over the past 50 years, the pervasiveness of ASD appears to be growing worldwide. There are plenty of credible statement for this evident expand counting rise consciousness, extension of diagnostic criteria, better diagnostic tools and enhanced outline.

## **2.4 Causes**

Autism is a panel, compound and progressively significant brain disorder. New data from the Centers for Disease Control and Prevention suggests that one in sixty-eight babies is born with some degree of autism. It is true that there is no biological test for autism that is particularly difficult to discuss in precise, final terms; Diagnosis is based on behavioral and the only verified treatment is intensive behavioral therapy. The researcher on autism, explore the prenatal factors that devote to the disorder.

The convenient research based document manifest that there are many factors that make a child more likely to have an ASD, including environmental and genetic factors. The obtainable epidemiological data draw to close that there is no proof of potency connecting with measles, mumps and rubella vaccine and ASD. Past studies proposing an uninhibited connection were found to be packed with methodological weakness.

Some studies administer the best evidence for a genetic basis of autism, then naturally occurring pathogen exposures offer the strongest evidence of environmental etiology. The best example of this is maternal rubella during pregnancy (German measles).

Before development and widespread broadcasting of efficient vaccines, major pandemics occurred every 10 to 30 years (Duszak RS, 2009). The last of these was from 1963 to 1965 and affected an estimated 10 percent of pregnant women, resulting in more than 13,000 fetal or early infant deaths; 20,000 infants born with major birth defects and 10,000 to 30,000 infants born with moderate to severe neurodevelopmental disorders. Stella Chess, a child psychiatrist at New York University, studied 243 children exposed to rubella during pregnancy (Chess S, 1977) and found that the largest category of neurodevelopmental disorder was intellectual disability, which infected 37 percent of the sample. Nine of these children also had autism; Another, other than intellectual disability, was a possible diagnosis; And eight are a partial syndrome of autism. These numbers would translate to more than 7,741 autism outbreaks per 10,000 rubella-exposed children. This is relatively attractive compared to the conventional rates published throughout the study, twice to thrice per 10,000 in the community. Fortunately, the widespread spread of the rubella epidemic is due to the widespread use of measles, mumps and rubella vaccines, and the association of autism with other viral or bacterial infections is weaker than that of rubella (Atladottir HO, et al. 2012).

However, there is relatively little evidence that the prevalence of today's highly infectious diseases such as influenza, ASD, significantly increases the risk of pregnancy. Perhaps the signal is weak because of gene by environment effects (Zerbo O, et al. 2015).

Attempts to understand the growing trend of autism spectrum disorder have led some to wonder whether the use of various drugs during pregnancy may be partly responsible. A recent concern has been the use of serotonin reuptake inhibitors for the treatment of depression during pregnancy. A recent review and meta-analysis of six

case-control studies and four cohort studies concluded that serotonin reuptake inhibitors use during pregnancy was significantly associated with increased risk of ASD in offspring (Kaplan YC, et al, 2016). Other postpartum experiences associated with the onset of ASD include deep social isolation among institution-raised children. Some environmental factors that matter to autism include certain foods, infectious disease, heavy metals, solvents, diesel tire out, phthalates and phenols used in plastic products, pesticides, alcohol, smoking, illegal drugs, vaccines and prenatal stress (Mandy W, Lai MC, 2016)

## **2.5 Prognosis**

Autism is a complex disorder that is associated with a variety of manifestations and is therefore called Autism Spectrum Disorder or ASD. There is no known cure for this condition. Children with autism can often grow up with a lack of social support systems, employment and meaningful relationships and families. Overall this leads to an acute lack of confidence. Symptoms become less severe with age, but most patients with severe autism are less likely to live an isolated life. Some children with autism may develop by 4-6 years of age, especially those with mild autism who were treated at an early age. These children may improve as they may be able to include them among their normal peers. The current education inclusion policy helps most ASD sufferers in mainstream schools. Results from surveys show that 49% of adults with autism still living with parents and only around 12% have full time employment. Parents with a growing awareness of autism are primarily interested in screening screenings, especially for high-risk children. It was further observed that the incidence of autism increased dramatically in the 1990s and early 2000s. This increase is largely responsible for improving diagnostic practice and public awareness. Other factors such as environmental toxins, improving parental age during pregnancy, etc. can also be important (Mandal, Ananya, 2019).

As parents are the responsible for taking care of autistic child and they have to manage burden of their own duties as well as nursing needs relevant to the child with autism. Thus parents QOL are afflicted in many ways after having a child with autism.

## 2.6 Quality of life

The WHO defines the quality of life as an individual's perception of their position in the context of their lives, cultures and values systems and as they become related to their aims, presumptions, values and agitates. The wide conviction of how a person's physical health, mental condition, personal beliefs, social correspondences, and their relationship with the characteristics of his environment are affected in a complex way. Health is defined in the constitution of the World Health Organization (WHO) as "A state of complete physical, mental, and social well-being not merely the absence of disease". According to Mohammadi et al. (2014) quality of life of the individual is defined by World Health Organization (WHO)

"The recognition, the individuals gain from their position in their lives in terms of their culture, value systems in which they live, goals, expectations, standards, and priorities".

## 2.7 The Structure of the WHOQOL-100

The structure of WHOQOL-100 reflects an issue that a group of scientific experts, as well as people at the center of each field, thought was important for the quality of life. The six broad domains of quality of life and the twenty-four aspects covered are shown below. Four items are included each aspect, as well as four common items covering thematic overall QOL and health, produced a total of 100 items in the evaluation. All items are rated on a five point scale (1-5)

## 2.8 Domains and facets incorporated within domains

### Overall Quality of Life and General Health

Physical Health	Psychosocial Health
<ul style="list-style-type: none"><li>• Spirit and tiredness</li><li>• Pain and uncomfortable</li><li>• Sleep and relax</li><li>• Self-care activities</li><li>• Reliance on medicinal inhalants and treatment aids</li><li>• Ability to move</li><li>• Performance capability</li></ul>	<ul style="list-style-type: none"><li>• Bodily reflection and presentation</li><li>• Bad feelings</li><li>• Happy feelings</li><li>• Self-assurance</li><li>• Thinking, learning, memory and concentration.</li><li>• Spiritual / religion / personal beliefs</li></ul>

<b>Social Relations</b>	<b>Environment</b>
<ul style="list-style-type: none"> <li>• Personal affairs</li> <li>• Social support and relationships</li> <li>• Sexual activity</li> </ul>	<ul style="list-style-type: none"> <li>• Economical assets</li> <li>• Flexibility, substantial protection and security</li> <li>• Health and social care: accessibility and quality.</li> <li>• Home environment.</li> <li>• Opportunities for acquiring new information and skills</li> <li>• Participation in and space for amusement/spare time</li> <li>• Physical environment (pollution/noise/traffic/climate)</li> <li>• Transportation</li> </ul>

The World Health Organization Quality of Life (WHOQOL) project began in 1991. It assesses the single approach regarding the background of their arts and worth structures and their private objectives, qualities and apprehensions. The instruments WHOQOL were thrived jointly within amount of figure of centers global and have been broadly field-tested. The lamina is applying swiftly in health sector. The WHOQOL-BREF instruments accept elements that evaluate the next wide domains: physical health, mental health, social relationships, and the environment. WHOQOL-BREF is a shortened model of the genuine material which may be more suitable to use in immense thesis studies or clinical trials. WHOQOL-100 is a grading scale where survivors ensure quality from 0 to 100. Better score defined better quality of life.

WHO (2014) introduce that the WHOQOL evaluation has standard where disease predicting to be expected to imply at most part of rehabilitation or repeal, execute which intervention be allowed extra shooting in lieu of healing. Hence, the WHOQOL appraisals will be granted comprehensive the standard of life data to be collected on a specific community, make possible the conception of diseases, and the evolution of remedy procedure. The global epidemiological investigations that on the make offacilitating by apparatus such as the WHOQOL- 100 and the WHOQOL-BREF will make it desirable to perform versatile quality of life, thesis, and to



numerous outcomes prevailed in diverse centers. Comparable thesis findings have major advantages, enable rehabilitation and additional pertinent variables.

## **2.9 Impact of quality of life of parents having children with autism**

### **2.10 Emotional impact**

The family members having autism child impacted by emotional ups and downs which start prior to the diagnosis and continue indefinitely. A study in the journal Pediatrics states that mothers of children with ASD often graded their status of mental health as fair or poor. Their stress levels were much higher than the general population. In addition to having higher stress levels, parents of autistic children may experience the following:

- Embarrassed about their child's behavior in public.
- Feeling socially isolated.
- Parents have experience in parenting and are frustrated with the difference between the ideas they hold.
- Thinking is guilty of thinking that they can be responsible for their child's challenges.
- Depression is a disorder that is influencing to a greater extends of people.
  
- Child dissatisfaction and guilt of their child due to anger.
- Be angry with yourself, physicians and husband.
- Reassurance because they have a name for their child's challenges.
- Of being engulf.

### **2.11 Marital impact.**

- A study in the Family Journal of Family Psychology found that parents of autistic children had a 9.7 percent chance of divorce compared to their peers. Marital stress can include the following
- Parents often diagnose their child's autism at different times and in different ways, causes friction.
- Commit many commitments and inconsistent schedules make it difficult to spend time together.
- The challenge of caring for autistic children is often.
- Economic tension can cause problems for spouses.

## **2.12 Sibling impact.**

A child with autism also affects his or her neuro-typical siblings. Siblings are under a lot of pressure from other family members. Moreover, parents may not be able to meet the needs of their autistic child and provide their full support as they are overwhelmed. In families where ASD-infected children as well as siblings usually develop, there is a more intense form of sibling competition. Siblings may feel deprived and upset because the autistic child needs more attention and time. But most families can overcome these challenges if they control other factors that lead to distress.

## **2.13 Financial impact**

Families of autistic children often face a huge financial burden. Expenses for the treatment and cure of autism are not covered by most private health insurers and are quite expensive. Parents often carry a huge financial debt for medications and office visits. According to a study featured in pediatrics, families with autistic children have lost an average of 14 percent of their total family income. Working full-time becomes very tough for both parents. Thus, even if the family income is low, the family will have to bear the increased expenses. Full-time employment is important for many parents for providing health insurance, and so, losing a full-time job may dramatically affect the family's financial condition (Christopher E. Nealy , Lindsey O'Hare , Joelle D. Powers & Danielle C.Swick,2012)

ASD can appear in a diversity of syndrome for juveniles. Those may add anomalous visual direction, constant body motion such as rocking or hand flapping, echolalia and defined field of interest (APA, 2000). These symptom can rank on a sequence from mild to severe. The general child development and daily functioning are adversely impacted through symptomology of challenges behavior. The detection of ASD clearly has the prospective to significantly affect the child's and functioning (Hall & Graff, 2011). The integrated family unit is likely to be broadly afflicted and individual members may capable expanded levels of stress (Meadan, Halle, & Ebata, 2010). In fact, study on parents of children with ASD has found the divorce rate to be nearly twice that of parents who do not have a child with a developmental disability (Hartley et al., 2010).

Families with a child diagnosed with ASD often face substantial challenges due to the disability that can glaring in multiple ways and matter of strain for the family (Smith

et al., 2010). Some of the common stressors reported by parents of a child with ASD include a sense of loss and depression, decline facilities for family vacation and fun outings, change in relationships resulting in loss of social support and personal and professional sacrifices.

Often families of teens with ASD might be owned through the inefficiency to holiday or relish feast out because of their child's aptitude explosion in feedback to over stimulation or break in routine. Concern up erratic and usually culturally undesirable behavior generally restrain the tribe from appreciating a lot recreational enterprises, so growing aloneness, fall off over all social support and likely conserving stress (Altiere & von Kluge, 2009b). This problem is further associated when family members cannot engage in social gatherings even without the analyzed child due to have need of decent care givers (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008)

#### **2.14 Changes in Social Relationships**

Another threat for families with a child diagnosed with ASD is a poor attention and education about the disorder from extended family and friends. Families report a loss of these relationships due to the time-consuming task of pay attention to their child that draw away from time shared with family and friends (Knapp, Romeo, & Beecham, 2009). Poor education and backing surely casts once annoying and irresistible burden of bring up a child with ASD. Caring for a child with ASD can desire meaningful time and finances, and parents often make personal and professional sacrifices to pursue quality resources (Knapp et al., 2009). For example, a lot parents depart from careers to give full-time child care and carry on the child's nursing. Although it is most often mothers who back off from careers to provide in-home care (Altiere & von Kluge, 2009b), for some women drop out a job is not a viable financial option. Altieri and von Kluge (2009b) found that many mothers viewed their incapability to afford added on care for the family as an expression of deficiency—thus possibly growing stress and strain for the family. Although the diagnosis of ASD is given to an individual child, the potential for consequential and adverse impact on the family is evident. Thus it is badly extensive to exceptional figure out more about the definite effects that having a child with ASD can have to better recognize and address the Family Impact of ASD.

Care for an autistic child is much asserted for every parent especially mothers. According to Hartmann (2012), taking care of those children is highly challenging

and stressful for parents. However, it takes some times for a new born baby to adjust with new circumstances but in case of child with disability and specially autistic child the situation become more difficult because they show unusual social behavior and difficulty in communicating in the society. Hartmann (2012) agrees with this that after having a child with autism the normal dynamics of a family become changed because parents need to give lots of time to take care of the special child that's why parents feel difficulties. Mothers take the major care-giving responsibility of the child and that's why they are more vulnerable in this perspective.

It has mentioned by about- Dagga (2013) that Mothers have to tolerate more care-giving burden rather than father. Mann (2013) reported that, now-a-days mothers are maintaining numerous roles and involving themselves in job sector but due to majority of childcare responsibilities, they may be most impacted by having a child with specialneeds .Care giving is a normal duty of mothers but an autistic child is needed high level of care which has a burdensome effect on the normal lives of mothers including physical, mental and social. According to Mann (2013), they can not expend time for their leisure and experience significantly more stressful events than mothers of typically developing children because of more care-giving responsibility. It has suggested by Motaghedi and Haddadian (2014) that mothers expend large amount of time with their children thus it hinders their possibilities to work outside for contributing to maintain family expenses. Sometimes mothers also leave their job for taking responsibilities of the special child. According to Karasavvidiset *al.* (2011), in case of Turkey mothers lose their jobs and usually work part-time because they are the only responsible for taking care of the special children. On the other hand, mothers also have to spend a large amount of time for receiving medical care for their children with autism that takes extra time and affecting their employment status. Sometimes mothers become insensitive about their own daily life activities to fulfill the needs of their special child. Finally, mothers have a lot of challenges in ADL's that affects their psychological aspects.

### **2.15 Parent`s psychological quality of life**

Parents of children with autism are always remaining in stress. According to Elfert (2014), they have to face high levels of parenting stress, depression, and anxiety. It is stated by Martins, Walker and Fouche (2013) that this ongoing stress has impact on their health. Poor mental health and lower level of well-being of mother is mainly

occurs for intense depression and stress. However, mothers have to face different mental health problems. According to Dehnaviet *al.* (2011), mothers of children with disabilities have experienced different mental illness problems. It has suggested by Martins, Walker and Fouche(2013) that mothers of children with autism remain in more stress rather than mothers with non-autistic child. They usually remain in stress due to child's maladaptive behavior, lack of educational opportunities and dark future. According to Ogston-Nobile(2014), mothers have to manage their child's challenging behavior, physical disabilities, inability to perform daily living skills, sleep problems, eating disturbances, those are very time consuming and thus mothers' become stressed. Moreover in Canada, mothers are experienced high level of stress than father. It has reported by Elfert (2014) that mothers are highly involved in child rearing then father that is why it may be the reason of elevate stress on mother. On the other hand, mothers are not enough aware about the reason of their children's disability therefore they strongly feel guilty on themselves for their children's disability. According to Ma (2012), many parents reported that they often feel intense anger, guilt, depression and anxiety. They are found low on ability to cope by maintaining their social system, self-esteem and psychological and physical stability.

### **2.16 Parents physical quality of life**

Mothers have to maintain high level of responsibility and have to spend lots of time with her special child that is why they always remain in mental stress that often affects their physical health. According to Abou-Dagga (2013), stress can become cause of many physical problems like headaches or backaches, muscle tension and stiffness, constipation, nausea, dizziness, insomnia, chest pain, rapid heartbeat, weight gain, loss of sex drive, frequent cold, lack of immunity and other health complications. Another study has reported that parents have mental distress due to burden and stress of responsibility of their special children and this usually affect the physical health. Generally like other kinds of disabilities a mother with autistic child feel more stress. Usually a mother with an autistic child feels more stressed than other types of disabilities.

Ma (2012) agrees with this that physical health problems are more common in case of parents with autistic children than parents of non-autistic children.

### **2.17 Parent`s family quality of life (spouse, siblings and other family members)**

Mothers have to spend high amount of time with their child with autism to provide

extra care and manage their challenging behavior that is why it creates an impact on their relationships with spouse and siblings. They often need extra close supervision from care-giver and also need to provide specialized medical care, and therapeutic interventions. According to Petrongolo (2014), mother as a primary caregiver, have to give much effort to fulfill the extra needs for their child with autism and make a balance between the demands of autistic children and other non-autistic children. Sometimes mothers cannot provide enough care towards the other child due to her child with autism. It has stated by Bashir et al. (2014) that sometimes mothers face difficulties to balance time between their other children and autistic children and that is why the siblings may feel that they are ignored or less important for parents. According to Hartmann (2012), siblings feel jealous towards their brother/sister diagnosed with autism because a large amount of time mothers spend with them. This behavior by siblings can create problems in family and create difficulties for parents as they are already passing through trauma and stresses.

This is an impact on relationship of mothers with their other children. Not only sibling's relationship sometimes marital relationship is also impacted in some cases. According to Martins, Walker and Fouche(2013), the role of caring for mothers also influence their nuptial bond. Bashir et al. (2014) stated that parents of children with disabilities have experienced more marital stress than parents with normal children, it is due to fulfill the extra demands of an autistic child, parents cannot get enough time to spend personal time as a result problems creates in relationship between parents, they remain depressed, and even it may leads to occur divorce. According to Elfert(2014), the prevalence of divorce is significantly higher in case of parents of children with ASD. In Asian culture, sometimes father's involvement in care-giving of the special child is less then mothers so that mothers become frustrated. Moreover, parents have also faced different troubles from society people too. They also show negative attitude towards those children's and their parents.

### **2.18 Parents' social quality of life**

Parents of a child with autism have to face troubles in society due to their child's challenging behavior. According to Ma (2012), they always adapt not only with their child's problems but also with stressful responses from others towards the child's behavior, as they have poorer knowledge about autism. Parents are often become the victim of social stigma and rejection due to society people are not aware and not supportive towards child's disability. Dehnavi et al. (2011) stated that in Iran,

Australia, and USA it is showed that social stigma is one of the main problem of mothers with autism. Dehnavi et al. (2011) reported that there is a natural tendency of society people to blame mothers for misbehaviors of children with autism. According to Altieri (2006), the parents often describe that their relatives are generally unhelpful towards them. The unhelpful attitude from family members and the stigma felt from members of the community increases the burden of mothers of a child with autism. Dzubay (2011) reported that mothers become psychologically depressed when they do not get enough support from society and lose the opportunity for social communications. When mothers feel stressed and cannot get enough support from society, then they began to use maladaptive behavior strategies such as avoidance. According to Johnson et al. (2011), parents usually try to take their child with autism out in the community. Parents also feel shy to take their kids into friends or relatives houses because of the child's challenging behaviors and thus sometimes parents become isolated from their friends, family and the community reported by Hartmann (2012). It has stated by Dehnavi et al. (2011) that social avoidance and isolation may lead to mental health problems of parents. Social support is very important for the parents of autism. Martins, Walker and Fouche (2013) mentioned that social support helps to reduce negative stress effect on parents of children with autism

At the end of literature review, it could be said that parents are more vulnerable position and their quality of life is affected after having a child with autism. They usually quit their own daily living, productive and leisure activities to give extra care and spend maximum time in care-giving to the child with autism. Moreover, they also don't get enough support from family and society. Sometimes they become the victim of social stigma. They also have not enough clear knowledge about their child's disability so they feel guilt and think they are responsible for their child's disability. Due to this reason, parents feel different physical, psychological, environmental challenges. The relationship with family members, siblings and relatives is also affected in many ways. By doing this study researcher wants to find the obstacles parents faced in social and overall quality of life after having a child with autism and their conception about their child's disability. This will be very helpful and will become important written evidence on this perspective.

### 3.1 Conceptual Frame work

Independent variable –Variable related to socio demographic status	Dependent variable
Age	Quality of life
Gender	Physical,
Occupation of parents	Social,
Financial status of parents	Psychological,
Living Area	Environmental
Autism Spectrum disorder	

**3.2 Aim of the study:** - To identify the challenges in quality of life of parents having child with Autism.

### 3.3 Objectives

To identify the parents understanding about the condition of autism.

To study if there are any challenges (physical, psychosocial, social and environment) in quality of life of parents having children with autism.

**3.4 Study design:** - The analysis has modified with Cross – sectional prospective Study. This is a non-experimental study design. The studies are done at one time or in a short period of time. The purpose of the study is descriptive, often used in the design of cross-sectional studies in the form of a survey. There is usually no such assumption, but the purpose is to illustrate a population or subgroup between a result and a population relative to an address of exposure aspects (Levin, 2006). Cross-sectional surveys are studied to determine the frequency of an event related to a definitive disclosure, illness or well-being in a characterized group for a specific number of times. Data can be collected on individual features as well as information about the results (Olsen & Marie, 2004).

In view of this study, no such assumption in that respect, yet the goal is to illustrate a community or subgroup within a population as a standard of living according to physical, social and psychological, environmental life. Data can be collected on individual features as well as information about the results .



In this way cross-sectional studies provide a snapshot of the outcome and the characteristics associated with it, at a specific point in time. The objectives of the study demanded a connection between demographic factors and quality of life, so cross-sectional study is the best way to find the relationship between them.

**3.5 Sample selection procedure**:-It is being worked for parents having child with autism for their quality of life and well-being. The researcher had chosen Dhaka city as a study area for collecting data. Researcher has met the participants at different special School, therapeutic clinic in Dhaka city. Researcher selected participants whose children are taking treatment, education and training in special Schools and institute. All the participants having child with autism were chosen for this study and that attained the inclusion criteria. Researcher spelt out each participant regards study aim and objectives. Researcher had taken sampling from those who willingly participated in this Study.

**3.6 Sampling technique** :-After receiving acceptance from the ethical body of BHPI Masters in Rehabilitation Science department and permission letter from study area the researcher had collected a list of participants having child with autism. Researcher also detected the parents having child with autism who had faced different challenges in quality of life. Investigator had selected them through convenience sampling that is feasible among the days of data collection. According to Koerber, and McMichael (2008), a health care researcher defined that convenience sample is a method by which participants are selected who are readily available and easy to contact for the researcher. Only 80 numbers of participants have found physically and collected data through face to face interview due to Covid-19 pandemic situation. Parents, who meet the inclusion criteria, are the study sample.

**3.7 Inclusion criteria** :-

Parents having child with ASD (girl and boy)

Parents are 20-50 years.

Parents with minimum higher secondary School certificate

Parents who were able to communicate and no hearing and mental problems had to be selected for the study.

**3.8 Sample size:** - Total population (N) = 80 parents having child with ASD

Sample size,

$$n = \frac{z^2 \times p \times q}{d^2}$$

$$n = \frac{(1.96)^2 \times 0.17 \times (1 - 0.17)}{(0.05)^2}$$

$$n = \frac{3.8416 \times 0.17 \times 0.83}{0.0025}$$

$$n = \frac{0.54204976}{0.0025}$$

$$n = 216.82$$

$$n = 217$$

**Where,**

**n** = required sample size

**z** = confidence level (95% = 1.96)

**p** = percentage of sample population (0.17)

**q** = prevalence of population (1-0.17)

**d** = degree of accuracy (5% = 5/100 = 0.05)

The researcher aimed to focus on the study by 217 calculations above. But in this study researcher collected data from parents having children with autism from Dhaka city only. Moreover, all the parents of children with autism had not been presented at the school or therapy center due to Covid-19 pandemic situation. So, researcher decided to limit with 80 parents as participants.

**3.9 Study population** –Parents having child with ASD

**3.10 Study time** :- 1 year.

**3.11 Study Area:** - Blessing child special School (BCSS), School for children with autism (SAND) and neurodevelopmental disorder (SAND), Special child care foundation (SCF).

The researcher has selected to collect data from those organizations due to non-profit, registered established organization. They are serving the people with Autism and other neurological disorder with all modern facilities since 2015. The aim of those organizations are facilitating child's capacity to make an inclusion to mainstream society. Those organization strives to bring about a positive change in the quality of life of the person with disabilities. They are committed to provide therapeutic interventions, rehabilitation, support services such as physical, emotional, social, psychosocial and economical.

**3.12 Data collection method:** -Prior to data collection, study goals, objectives, and study methods were explained to participants. They mentioned the benefits of asking questions and were asked to sign their written consent form once they were confirmed. When they sign the consent form, the researcher completes WHQOL-100 with demographic data. The researcher visited the institutes and special schools to

collect data. At this stage the researcher took permission from the chairman of the institute and the principal of the special school, the parents of the child with autism took part in the study. In this situation, the questionnaire may not be fully completed due to the person's assessed and acceptable language, psychological or mental health problems. In this case a person who is acquainted with the assessed person could fill up the form, provided that the person is present after the completion of the form.

**3.13 Data collection tools /materials:** Respondents' demographic information was collected using self-displayed demographic questions(appendix-2).

Demographic information included age, gender, and educational level, profession of parents, living area, and economical status. The participants have treated their child with autism at special school and therapeutic Centre whose are working for autism and neurodevelopmental disorder. That is why some extra information such as duration of school, diagnosis by whom and degree of gradation has put in the demographic questionnaire.

Physical, psychological and social, environmental domains of WHOQOL-BREF, WHOQOL-100 questionnaire: World Health Organization Measuring Quality of Life Scale have used in this study

**3.14 Procedure for data collection:** - The researcher has used self-administered questionnaire to collect the data. Questionnaires have distributed to approximate 5-6 respondents and asked to fill up the questionnaire within 20-30 minutes. All the questionnaires have collected after respondents fill up the questionnaires. Confidentiality of the respondent has maintained.

**3.15Data management and analysis:-** Data was accessed into Statistical Package for Social Science (SPSS) software Version 20.0.1 and excel spread sheet. Data also inspected by SPSS software. WHO-QOL 100 and Demographic questionnaire was investigated and talked about the demographic elements such as age, gender, occupation, educational level etc. WHO-QOL 100 questionnaire was also discussed about physical, psychological, social relation and environmental health of quality of life. In WHOQOL- 100, there are 30 questions.The scale is divided into classify 1-5 (very poor- very good) with overall the standard of life and level of health satisfaction.The domains have ranked with very poor, poor and fair.According to WHO guidelines, there are pages that convert from raw score to converted score

All modified scores are rated as good when the average is above average and there are multiple deviations from the average, and scores below the average are considered good if there is a value deviation between those scores that are considered fair. Olusina and Ohaeri (2008) used a similar method to assess the QOL of schizophrenia in Nigeria (Nuhu et al., 2013). It also divides the type of support and amount received by the affected person towards victims, the researcher looking for results by SPSS software that were examined through Excel and displayed in pie charts, bar graphs and columns. Data are presented through statistics and tables as a result and as applicable.

### **3.16 Data Presentation**

The data has presented on the basis of research objectives and research question. Data has arranged, entered and tabulated in computer to present the findings of the study.

### **3.17 Statistical test**

Simple descriptive statistics such as frequency, percentage, mean score, standard deviation has used for basic analysis of data.

The researcher has detected the outcomes by SPSS software which analyzed in Excel and showed in pie charts, bar graphs and columns. Discussed and presented the results through statistics and tables as applicable.

Parametric test (Chi square test)

### **3.18 Ethical consideration**

- Approval from MRS and CRP concerns
- Voluntary participation & taking informed consent.
- Avoid risk of harm of the participant.
- Maintain anonymity of the participant.
- Provide Confidentiality & privacy.
- Honestly report data, results, methods and procedures, and publication status.
- Be open to criticism and new ideas.
- Non-Discrimination.
- Researcher also gained permission from author bodies of WHOQOL for using their scale and by some terms and conditions researcher adapted with questionnaire and has gotten license to use it for one year. The permission has given from Geneva, Switzerland.

### **3.19 Reliability and validity**

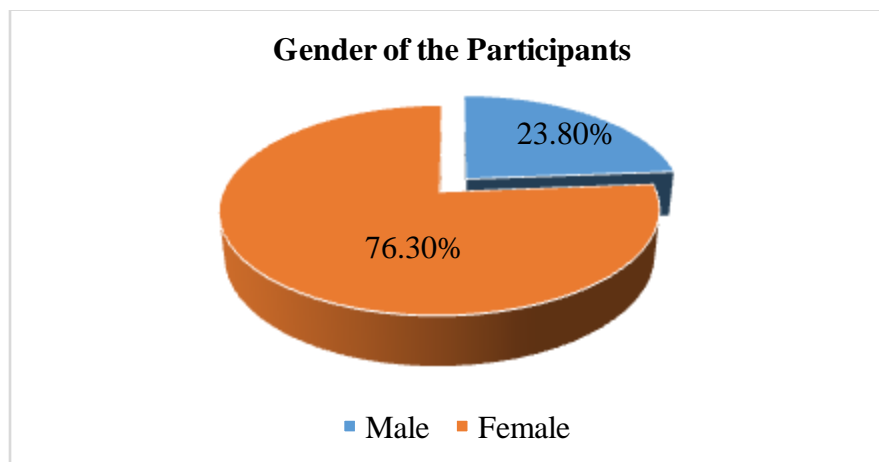
The World Health Organization Quality of Life (WHO-QOL 100) questionnaire is a reliable and valid material and has been used by various authors in their research. The WHO-QOL 100 Each participants was interviewed individually and given ample time to fill out their form for the questionnaire. The deadline for meeting the WHO-QOL 100 and socio-demographic questioners were 20-30 minutes in filling out. WHO-QOL questionnaire was translated manually.

WHO-QOL questionnaire is an ideal choice for evaluating person with physical disabilities who are put up with health associated well-being complications (WHO, 2013).

In this study, the investigator's aim was to determine the quality of life of parents having child with Autism Spectrum Disorder. So the investigator had collected 80 respondents and collected data from them. The data were analyzed by descriptive statistics and calculated as percentages and presented by using pie charts, column and tables.

#### 4.1 Demographic information

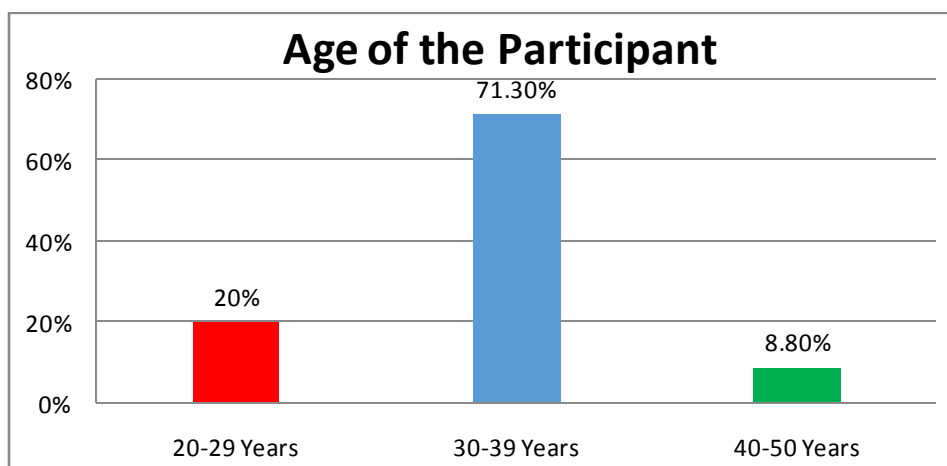
##### 4.1.1 Gender of the Participants



**Figure 4.1.1: Gender of Participants**

The chart shows that most of the participants 76.30% (61) were female and others Participants 23.80% (19) were male.

##### 4.1.2 Age of the Participants

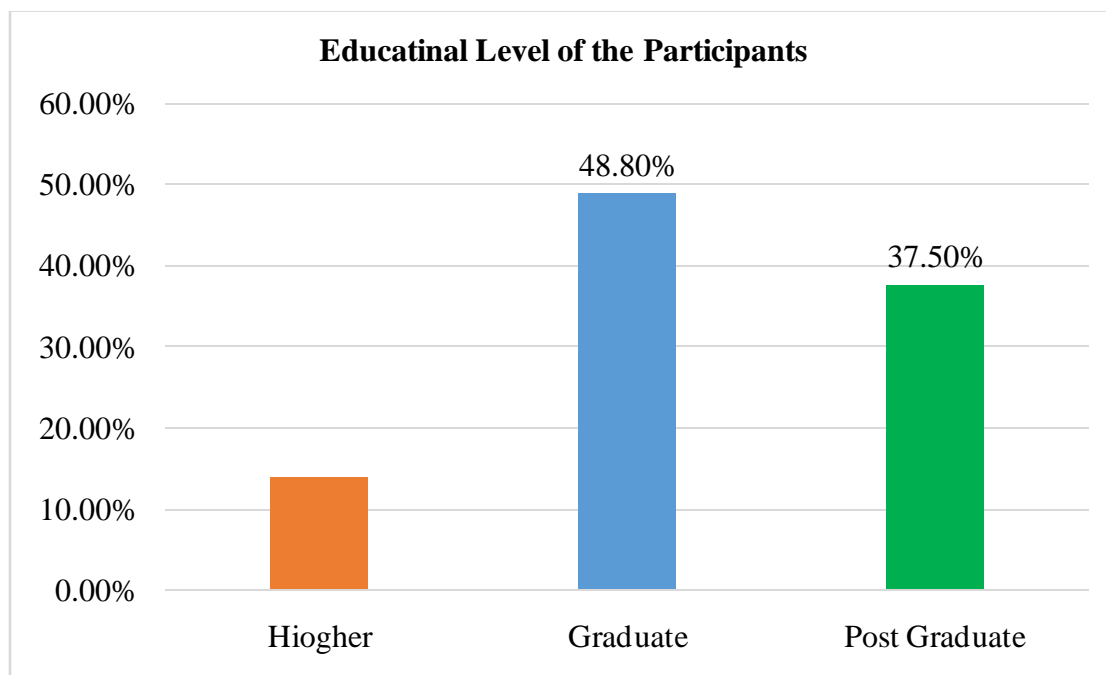


**Figure 4.1.2: Age of the Participants**

According to chart shows that the maximum number participants, 71.30% (57) were in the age range 30-39 years. It was found that 20% (16) participants those were in the

age between in the 20-29 years. Also, 8.80% (07) participants were in the age between 40-50 years.

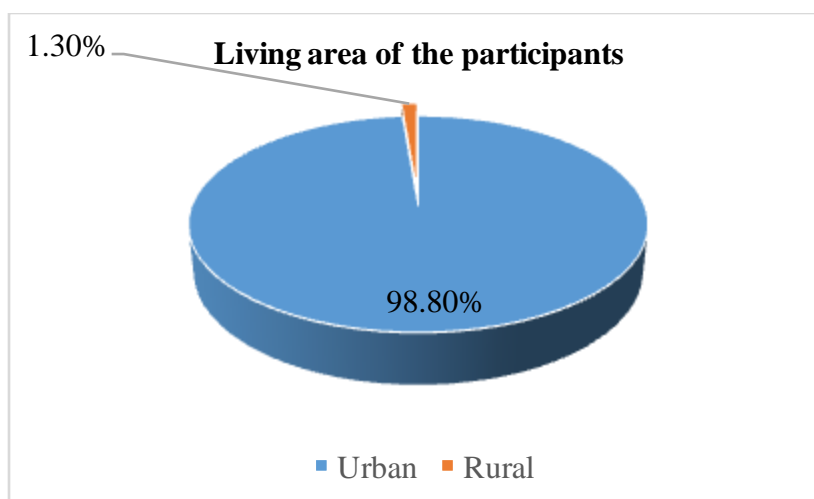
#### 4.1.3 Educational Level of Participants



**Figure 4.1.3: Educational Level of Participants**

The graph shows that the majority numbers of participants 48.80 % (39) were at graduate level education. It was found that 37.50 % (30) participants were post graduate level. Only, 13.80% (11) were at higher level education.

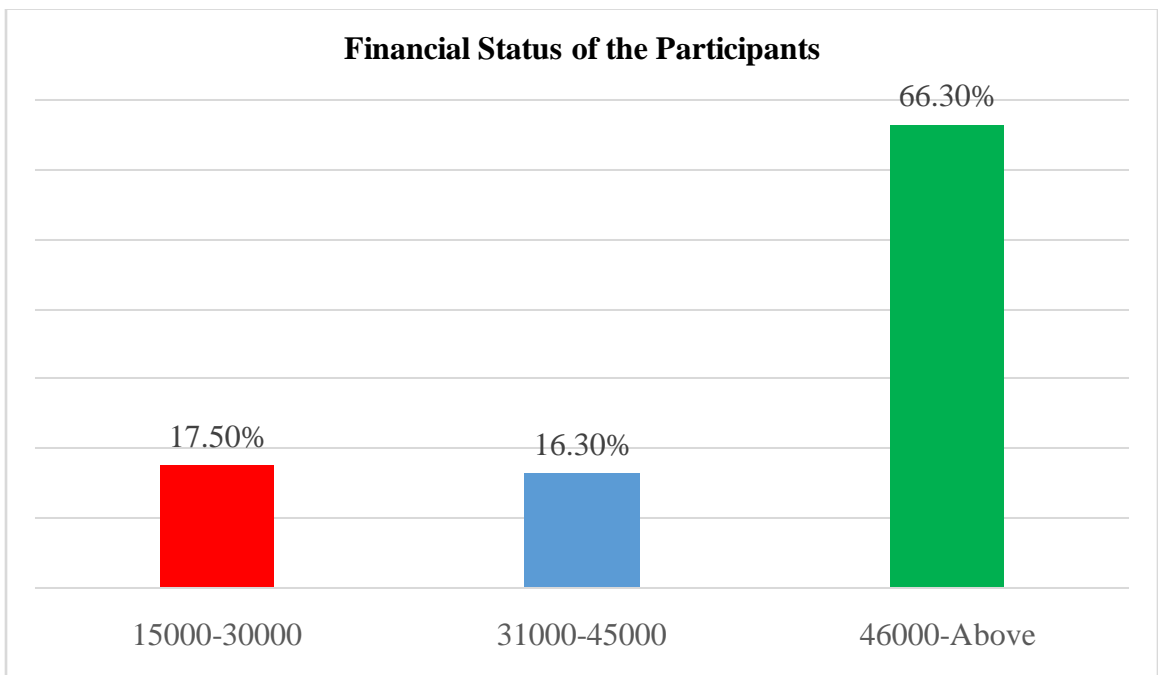
#### 4.1.4 Living area of the participants



**Figure: 4.1.4 Living area of the Participants**

This graph shows that the maximum number of participants 98.80% (79) was living in the urban area. And only 1.30 % (01) participants were rural area.

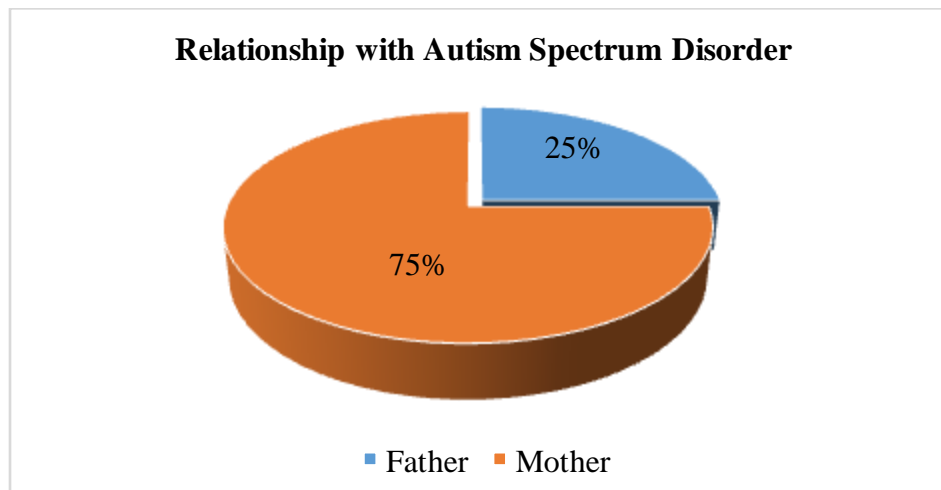
#### 4.1.5 Financial Status of the Participants



**Figure 4.1.5: Financial Status of the Participants**

Gathered data about monthly household income from participants are representing on bar chart where most frequent group is top income (46000-above) represent 66.30% (53), Also, second highest group is bottom income (15000-30000) that represent 17.50% (14) and another group represent mid income (31000-45000) is 16.30% (13) of total participants.

#### 4.1.6 Relationship with Autism Spectrum Disorder

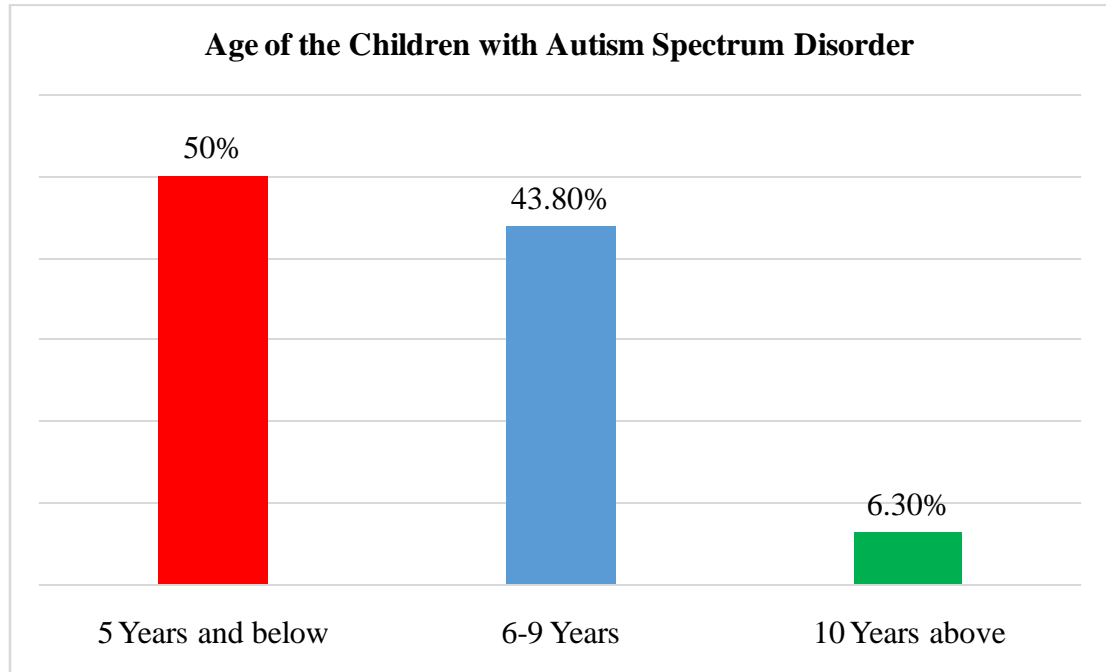


#### 4.1.6 Relationship with Autism Spectrum Disorder



Participant's relationship with the children is representing by pie chart whither mother of children is most frequent group that represent 75% (60) and another is lowest frequent group is father of children that represent 25% (20) of total participants.

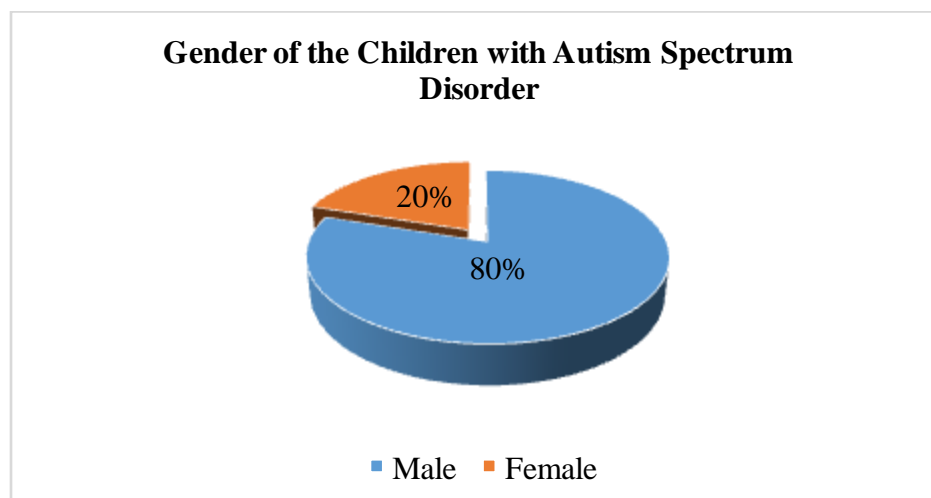
#### 4.1.7 Age of the Children with Autism Spectrum Disorder



**Figure: 4.1.7** Age of the Children with Autism Spectrum Disorder

According to chart shows that the maximum number of participants, 50% (40) was in the age range 2-5 years. It was found that 20% (35) participants those were in the age between in the 6-9 years. Also, 6.30% (05) participants were in the age between 10-Above years.

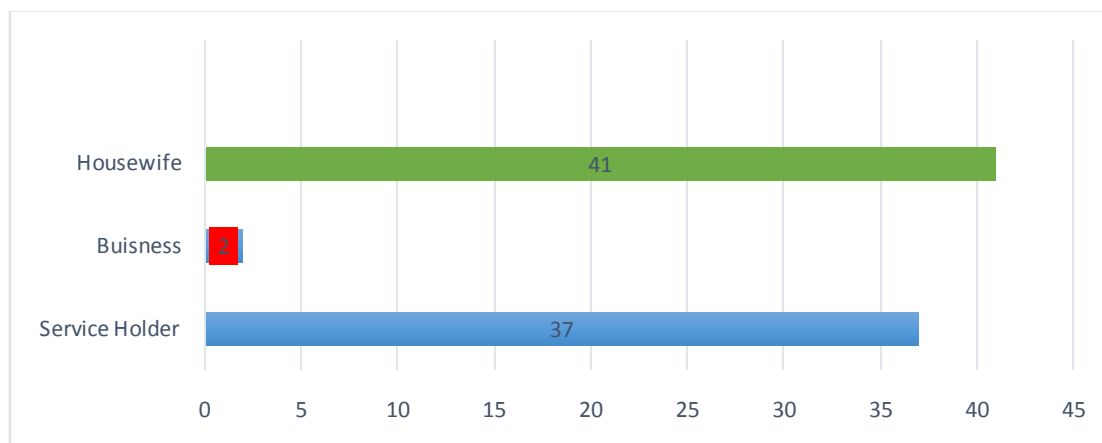
#### 4.1.8 Gender of the Children with Autism Spectrum Disorder



**Figure 4.1.8:** Gender of the Children with Autism Spectrum Disorder

The chart shows that most of the child 80% (64) was male and others Participants 20% (16) were female.

**Figure 4.1.9: Occupational level of parents having Children with Autism Spectrum Disorder**



In this chart mention that among the 80 participants 41% participants are housewives, 37 %participants are service holders and the rest 2% are in the area of business.

**4.2 Association between Variables:-**Researcher has used representative questions, Q1 from psychosocial, Q3 from physical, Q19 from social and Q20, Q23 from environmental domains to identify association to independent variable age, gender, and educational level, occupation, economic and living area.

**4.2.1(A) Association between Age and Physical well-being of parents having child with Autism Spectrum Disorder**

Age Vs Physical well-being of parents having child with Autism Spectrum Disorder	Physical well-being of parents having child with Autism Spectrum Disorder					Total
	Not at all	A little	A moderate amount	Very much	An extreme amount	
Age of the Participant 20-29	2	6	3	2	3	16
30-39	0	6	21	20	10	57
40-50	0	2	1	3	1	7
Total	2	14	25	25	14	80

**Chi-Square Tests**

	Value	Df	Asymp. Sig. (2-sided)
Pearson Chi-Square	18.173 <sup>a</sup>	8	.020
Likelihood Ratio	16.649	8	.034
Linear-by-Linear Association	3.273	1	.070
N of Valid Cases	80		

In evidence-based medicine, probability ratios are used to determine the value of diagnostic tests. They use the sensitivity and specificity of the test to determine if the test result effectively changes the probability that a condition exists.

Probability a person with the condition has a certain test result

Likelihood Ratio=-----

Probability a person without the condition has a certain test

The "linear by linear" test takes for ordinal (ordered) sections and captures equal and ordered intervals. The Linear by Linear Association test is a test for trends in a table larger than 2x2. Its value is shown as significant.

**Table: 4.2.1 Association between Age and Physical well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, physical wellbeing occurrences were found highest in 21 moderate amount participants in the age range of 30-39 years and also 20 very much participants were found physical wellbeing which age range in 30-39 years.

Association between Age and Physical well-being of parents having child with Autism Spectrum Disorder examined by chi- square test and result .020 which association was significant (p<0.05).

**4.2.2 (B) Association between Gender and Physical well-being of parents having child with Autism Spectrum Disorder**

Gender vs Physical well-being of parents having child with Autism Spectrum Disorder	Physical well-being of parents having child with Autism Spectrum Disorder					Total
	Not at all	A little	A moderate amount	Very much	An extreme amount	
Gender of the Participant Male	0	0	9	7	3	19
Participant Female	2	14	16	18	11	61
Total	2	14	25	25	14	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	7.346 <sup>a</sup>	4	.119
Likelihood Ratio	10.842	4	.028
Linear-by-Linear Association	1.366	1	.242
N of Valid Cases	80		

**Table: 4.2.2 Association between Gender and Physical well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, physical wellbeing occurrences were found highest in very much 18 participants who were female and 9 participants who were male.

Association between Gender and Physical well-being of parents having child with Autism Spectrum Disorder examined by chi- square test, result .119. The association was not significant ( $p > 0.05$ )

**4.2.3 (C) Association between Age and psychosocial well-being of parents having child with Autism Spectrum Disorder.**

Age vs psychosocial well-being of parents having child with Autism Spectrum Disorder	Psychosocial well-being of parents having child with Autism Spectrum Disorder					Total
	Very Poor	Poor	Neither poor nor good	Good	Very good	
Age of the Participant 20-29	3	2	8	2	1	16
30-39	7	13	23	13	1	57
40-50	0	0	3	4	0	7
Total	10	15	34	19	2	80

**Chi-Square Test**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	9.160 <sup>a</sup>	8	.329
Likelihood Ratio	10.447	8	.235
Linear-by-Linear Association	1.981	1	.159
N of Valid Cases	80		

**Table: 4.2.3 (C) Association between Age and psychosocial well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, psychosocial well-being occurrences were found highest in 23 participants in the age range of 30-39 years and also 8 participants were found psychosocial wellbeing which age range in 20-29 years.

Association between Age and psychosocial well-being of parents having child with Autism Spectrum Disorder examined by chi- square test, result .320. The association was not significant( $p>0.05$ ).

**4.2.4 (D) Association between Gender and psychosocial well-being of parents having child with Autism Spectrum Disorder**

Gender vs psychosocial well-being of parents having child with Autism Spectrum Disorder	Psychosocial well-being of parents having child with Autism Spectrum Disorder					Total
	Very Poor	Poor	Neither poor nor good	Good	Very good	
Gender of the Participant Male	2	2	9	5	1	19
Gender of the Participant Female	8	13	25	14	1	61
Total	10	15	34	19	2	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.945 <sup>a</sup>	4	.746
Likelihood Ratio	1.949	4	.745
Linear-by-Linear Association	1.008	1	.315
N of Valid Cases	80		

**Table: 4.2.4 Association between Gender and psychosocial well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, psychosocial wellbeing occurrences were found highest in very much 25 participants who were female and 9 participants who were male.

Association between Gender and psychosocial well-being of parents having child with Autism Spectrum Disorder examined by chi- square test, result .746. The association was not significant ( $p>0.05$ )

**4.2.5 (E) Association between Age and Social well-being of parents having child with Autism Spectrum Disorder**

Age vs Social well-being of parents having child with Autism Spectrum Disorder	Social well-being of parents having child with Autism Spectrum Disorder					Total
	Not at all	A little	Moderately	Mostly	Completely	
Age of the Participant 20-29	3	2	4	4	3	16
30-39	9	27	15	6	0	57
40-50	0	3	3	1	0	7
Total	12	32	22	11	3	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	19.607 <sup>a</sup>	8	.012
Likelihood Ratio	19.043	8	.015
Linear-by-Linear Association	3.010	1	.083
N of Valid Cases	80		

**Table: 4.2.5 Association between Age and Social well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, social well-being occurrences were found highest in 27 participants in the age range of 30-39 years and also 4 participants were found social wellbeing which age range in 20-29 years.

Association between Age and Social well-being of parents having child with Autism Spectrum Disorder examined by chi- square test, result .012. The association was significant ( $p < 0.05$ )

**4.2.6 (F) Association between Gender and Social well-being of parents having child with Autism Spectrum Disorder**

Gender and Social well-being of parents having child with Autism Spectrum Disorder	Social well-being of parents having child with Autism Spectrum Disorder					Total
	Not at all	A little	Moderately	Mostly	Completely	
Gender of the Participant Male	2	9	6	2	0	19
Female	10	23	16	9	3	61
Total	12	32	22	11	3	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.944 <sup>a</sup>	4	.746
Likelihood Ratio	2.658	4	.617
Linear-by-Linear Association	.196	1	.658
N of Valid Cases	80		

**Table: 4.2.6 Association between Gender and Social well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, social wellbeing occurrences were found highest in 23 participants who were female and 9 participants who were male.

Association between Gender and Social well-being of parents having child with Autism Spectrum Disorder examined by chi- square test, result .746. The association was not significant ( $p>0.05$ ).



**4.2.7 (G) Association between Age and Environmental well-being of parents having child with Autism Spectrum Disorder**

Age vs Environmental well-being of parents having child with Autism Spectrum Disorder	Environmental well-being of parents having child with Autism Spectrum Disorder					Total
	Not at all	A little	Moderately	Mostly	Completely	
Age of the Participant 20-29	5	2	7	2	0	16
30-39	14	25	14	3	1	57
40-50	1	2	3	1	0	7
Total	20	29	24	6	1	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	7.793 <sup>a</sup>	8	.454
Likelihood Ratio	8.640	8	.374
Linear-by-Linear Association	.001	1	.976
N of Valid Cases	80		

**Table: 4.2.7 Association between Age and Environmental well-being of parents having child with Autism Spectrum Disorder :-**In this study among 80 participants, environmental well-being occurrences were found highest in 25 participants in the age range of 30-39 years and also 7 participants were found social wellbeing which age range in 20-29 years.

Association between Age and Environmental well-being with Autism Spectrum Disorder examined by chi- square test, result .454. The association was not significant ( $p>0.05$ ).

**4.2.8 (H) Association between Gender and Environmental well-being of parents having child with Autism Spectrum Disorder**

Gender vs Environmental well-being of parents having child with Autism Spectrum Disorder	Environmental well-being of parents having child with Autism Spectrum Disorder					Total
	Not at all	A little	Moderately	Mostly	Completely	
Gender of the Participant Male	2	9	7	1	0	19
Female	18	20	17	5	1	61
Total	20	29	24	6	1	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	3.804 <sup>a</sup>	4	.433
Likelihood Ratio	4.401	4	.355
Linear-by-Linear Association	.465	1	.495
N of Valid Cases	80		

**Table: 4.2.8 Association between Gender and Environmental well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, environment wellbeing occurrences were found highest in 20 participants who were female and 9 participants who were male.

Association between Gender and Environmental well-being in Family of Children with Autism Spectrum Disorder examined by chi- square test, result .433. The association was not significant ( $p > 0.05$ )

**4.2.9 (I) Association between Educational level of the Participant and Physical well-being of parents having child with Autism Spectrum Disorder**

Educational level of the Participant vs Physical well-being of parents having child with Autism Spectrum Disorder	Physical well-being of parents having child with Autism Spectrum Disorder				
	Not at all	A little	A moderate amount	Very much	An extreme amount
Higher Graduate	0	2	2	5	2
Post Graduate	1	7	14	9	8
Higher	1	5	9	11	4
Total	2	14	25	25	14

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	3.592 <sup>a</sup>	8	.892
Likelihood Ratio	3.952	8	.861
Linear-by-Linear Association	.271	1	.603
N of Valid Cases	80		

In this study among 80 participants, physical well-being occurrences were found highest in 14 participants who were Graduate level of education and 9 participants who were Post Graduate.

Association between Educational level of the Participant and Physical well-being of parents having child with Autism Spectrum Disorder examined by chi-square test result .892. The association was not significant ( $p > 0.05$ )

**4.2.10 (J) Association between Educational level of the Participant and Psychological well-being of parents having child with Autism Spectrum Disorder**

Educational level of the Participant and Psychological well-being of parents having child with Autism Spectrum Disorder	Psychological well-being of parents having child with Autism Spectrum Disorder					Total
	Very Poor	Poor	Neither poor nor good	Good	Very good	
Higher	1	2	5	3	0	11
Educational level of the Participant Graduate	6	8	18	7	0	39
Post Graduate	3	5	11	9	2	30
Total	10	15	34	19	2	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	5.470 <sup>a</sup>	8	.706
Likelihood Ratio	6.083	8	.638
Linear-by-Linear Association	.924	1	.336
N of Valid Cases	80		

**Table: 4.2.10 Association between Educational level of the Participant and Psychological well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, psychological well-being occurrences were found highest in 18 participants who were Graduate level of education and 9 participants who were Post Graduate.

Association between Educational level of the Participant and Psychological well-being of parents having child with Autism Spectrum Disorder examined by chi-square test, result .706. The association was not significant ( $p > 0.05$ ).

**4.2.11 (K) Association between Educational level of the Participant and Social well-being of parents having child with Autism Spectrum Disorder**

Educational level of the Participant vs Social well-being of parents having child with Autism Spectrum Disorder	Social well-being of parents having child with Autism Spectrum Disorder					Total
	Not at all	A little	Moderately	Mostly	Completely	
Higher	2	2	4	2	1	11
Graduate	6	17	12	4	0	39
Post Graduate	4	13	6	5	2	30
Total	12	32	22	11	3	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	6.400 <sup>a</sup>	8	.603
Likelihood Ratio	7.859	8	.447
Linear-by-Linear Association	.014	1	.906
N of Valid Cases	80		

**Table: 4.2.11 Association between Educational level of the Participant and Social well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, social well-being occurrences were found highest in 17 participants who were Graduate level of education and 13 participants who were Post Graduate.

Association between Educational level of the Participant and Social well-being of parents having child with Autism Spectrum Disorder examined by chi-square test result .603. The association was not significant ( $p > 0.05$ ).

**4.2.12 (L) Association between Educational level of the Participant and Environmental well-being of parents having child with Autism Spectrum Disorder**

Educational level of the Participant vs Environmental well-being of parents having child with Autism Spectrum Disorder	Environmental well-being of parents having child with Autism Spectrum Disorder					Total
	Not at all	A little	Moderately	Mostly	Completely	
Higher	5	1	3	2	0	11
Educational level of Graduate	10	16	13	0	0	39
Post Graduate	5	12	8	4	1	30
Total	20	29	24	6	1	80

**Chi-Square Tests**

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	13.190 <sup>a</sup>	8	.105
Likelihood Ratio	16.376	8	.037
Linear-by-Linear Association	1.675	1	.196
N of Valid Cases	80		

**Table: 4.2.12 Association between Educational level of the Participant and Environmental well-being of parents having child with Autism Spectrum Disorder**

In this study among 80 participants, environmental well-being occurrences were found highest in 16 participants who were Graduate level of education and 12 participants who were Post Graduate.

Association between Educational level of the Participant and Environmental well-being of parents having child with Autism Spectrum Disorder examined by chi-square test result 0.105. The association was not significant ( $p > 0.05$ ).

### **5.1 Socio demographic attributes of the parents having child with Autism Spectrum disorder**

Social-demographic attributes are powerful predictors of wellbeing among survivors. In this study, the investigator had collected 80 respondents and collected data from them. The data were analyzed by descriptive statistics and calculated as percentages and presented by using pie charts, bar graphs, column and tables. Autism is a major cause of socio demographic features in parents having children born with gender. Related to the socio-demographic affair, this survey found the majority of participants 76.30% (61) were female and others Participants 23.80% (19) were male. In Bangladeshi cultural context maximum household activities, taking care of child, lift them into school and consult with any professionals regarding child`s problem ,mothers are more aware and sincere than male –father. Male are more responsible for earning and giving financial support to family. That is why they are quite busy with their official services, business and other earning sources. That is why they are quite busy with their official services, business and other earning sources. In this case female were more convenient participants in this study. Ogston et al. (2011) have raised questions about the content of mothers surveyed. In the surveyed mothers have discussed the stress caused by other aspects of their lives, which were not only related to their child's illness: household chores, relationships with other people, financial resources and employment. Based on these responses, the author mentions that these women are not only the parents of autistic children, they also play different roles in child care, take them into school, Centre and manage other problems of outside. Among all of the participants maximum number participants, 71.30% (57) were in the age range 30-39 years. It was found that 20% (16) participants those were in the age between in the 20-29 years. Further elements connected with parental age have an important role in describing the study findings. Father like age increases the risk of ASD for couples with increasing parental ages differences. In more than one geographical area, the prevalence of ASD is not limited to paternal or maternal age but also to the age of the parents, with or without the same type of elderly parents and significant elderly parents. Take caring of child with ASD also depends of parent`s health, energy, pain and discomfort. Couples of mothers aged 20-39 years and fathers aged 20-29 years produced 94.9% of all births. Of all children, 2.2% were under 20

years of age and 2.4% were 40 years of age or older. The father of 0.9% was over 50 years of age (D Schendel, CHltman, PSuren, ESusser, TGronborg, 2015).

In this study, the majority numbers of participants 48.80 % (39) were at graduate level education. It was found that 37.50 % (30) participants were post graduate level. Only, 13.80% (11) were at higher level education. As Autism spectrum disorders (ASD) are an array of long running neurodevelopmental disorder, it requires parents understanding, knowledge, education, attitudes and adaptability .It ought to think about how to take part in the autism group in the conceptualization of motive to encourage participation in all steps of the investigation circle. The autism community is made up of people living with autism and their families, healthcare professionals and educated people. The new era of autism research cast around to involve the autism group significantly, appreciating cooperation among investigator and community partners, so that person with autism spectrum and their households can share research priorities and agendas for research.

Community involvement in autism research can expand the move of science and build on the implementation of result in practice (Clark M, Adams D, 2020).

Parents perceptions of their children, on the other hand, shape their parents behavior and, as a result, children's self-perception, school coordination, and academic outcomes (Bandura, Barbaranelli, Ca-prara, & Pastorelli, 1996).). In fact, parents who hold high educational level and academic expectations have children who reveal better school outcomes than might be predicted based merely on their cognitive functioning or previous academic accomplishment (de Boer & van der Werf, 2015).

The maximum number of participants 98.80% (79) was living in the urban area. And only 1.30 % (01) participants were rural area. As the researcher has taken the participants from different special school, therapeutic Centre, clinic at Dhaka city in Bangladesh, maximum participants have found conveniently as urban residential members. According to Koerber, and McMichael (2008), a health care researcher defined that convenience sample is a method by which participants are selected who are readily available and easy to contact for the researcher. On the other hand all the rehabilitation institutes, Centre, clinics, hospitals are well organized and established in urban area. That is why people of urban area are more aware than rural areas people regarding their child`s condition and treatment and intervention. Few research has shown that very young babies born in the capital were at higher risk of being diagnosed with ASD than others (Mandell et al. 200; Fountain et al. 2011) and this



may indicate more awareness or attention to the disorder. Or better or more easily accessible diagnostic and medical services at hand in urban areas (Kalkbrenner et al. (2011).

An inscription from a community with an ASD-based region found that the median age of diagnosis of ASD was lower in children living in the region with more psychologists and specialist doctors, including neurologists and psychiatrists in variance to locale along mass elementary care of physician.

Gathered data about monthly household income from participants are representing on bar chart where most frequent group is top income (46000-above) represent 66.30% (53), Also, second highest group is bottom income (15000-30000) that represent 17.50% (14) and another group represent mid income (31000-45000) is 16.30% (13) of total participants.

The treatment procedures, education and training of ASD children highly cost in private sectors. That is why it is quite difficult to conduct their child's treatment and training expenses for bottom and middle income group parents except any financial discount or donation. Large number of children with ASD hurting for comprehensive, instructive, psychological, and healthcare indulgence which need remarkable numeric, moment, and responsibility strategic contributions for families. Usually, children with special health care needs (CSHCN) have more or more parents at risk of unemployment, financial stress, family burdens, poor quality of life, poor physical and mental health, and poor mental health.

For CSHCN with ASD in precise, data from the 2005-2006 Civil Audit of Children with Special Health Care Needs (NS-CSHCN) exhibit that Families with CSHCNs with other sensitive, growing, or attitude troubles have a greater danger of economic and business misunderstandings even other CSHCNs with families.

On the other hand, preventive known care was related to the economical tremble of lower households. In another national dataset, Montes and Halterman found that 39% of children with ASD had parents announcing that childcare difficulties contrived their employment decisions, compared to 9% of typically developing children (Katharine E. Zuckerman, Olivia J. Lindly, Christina D. Bethell, 2014). Caring of a child with ASD generally demands costly spending about family literacy and health care. The birth of autism infant not only divides the individual child, but also affects the whole family, including siblings. They often need extra close supervision from

care-giver and also need to provide specialized medical care, and therapeutic interventions (Tarek E.I Omar, Wafaa M Ahmed, Nehad S Basiouny, 2018)

Participant's relationship with the children is representing by pie chart whether mother of children is most frequent group that represent 75% (60) and another is lowest frequent group is father of children that represent 25% (20) of total participants.

Mothers have to spend high amount of time with their child with autism to provide extra care and manage their challenging behavior that is why it creates an impact on their relationships with spouse and siblings. According to Petrongolo(2014), mother as a primary caregiver, have to give much effort to fulfill the extra needs for their child with autism and make a balance between the demands of autistic children and other non-autistic children. Sometimes mothers cannot provide enough care towards the other child due to her child with autism. It has stated by Bashir et al. (2014) that sometimes mothers face difficulties to balance time between their other children and autistic children and that is why the siblings may feel that they are ignored or less important for parents.

In Asian culture, Sometimes father's engaging in taking care of atypical child is less than mothers so that mothers become frustrated. Moreover, mothers have also faced different troubles from society people too. They also show negative attitude towards those children's and their mothers. Parenting a child with a developmental disability is an debilitating effort specially for mom in the act of their more involving for offering care (Tarek E.I Omar, Wafaa M Ahmed, Nehad S Basiouny, 2018).

It has shown in the study that most of the child 80% (64) was male and others Participants 20% (16) were female. Among children who meet the norm for ASD, the actual boy-to-girl ratio is not 4: 1, as is often assumed; rather it is closer to 3: 1. A diagnostic seems to be gender bias, which means that girls who meet the criteria for ASD are at possibility of not getting a scientific investigation (Loomes R, Hull L and Mandy WPL. J Am Acad, 2017)

The maximum number of participants, 50% (40) was in the age range 2-5 years and 20% (35) participants those were in the age between in the 6-9 years. Also, 6.30% (05) participants were in the age between 10-Above years .The researcher has found 50% child's having age range between 2-5 years due to engage initial mediation care. Early intervention care is most effective for child among ASD and parents are now more concerns regarding this issue . Early intervention is desired as long as they do

not develop social, play, and in greater conditions language and cognitive region appearing in expected speed or in the expected multi-model, unified approach.

Learning incidentally when communicating, especially when interrupted by ASD-like vulnerabilities, especially those that specifically affect screening and social persuasion.

In fact, there has been reported a relationship between ASD and disability attention-learning in young children and learning incidental vocabulary (Yoder & McDuffie, 2006). The first intervention goals to expediting the grade of youngster -receiving, to develop advance progressing and generalizations of ingenuity, and to intensify the impact of ASD on growth by magnifying the benefits of incident-resting on synaptogenesis rapidly changes across the first 2-5 years (Rebecca J. Landa, 2018).

### **5.2 Interrelation between demographic factors and overall quality of life**

This study highlights concern about the association linking inclusive wellbeing, worry about pain, discomfort among physical wellbeing and characteristics of participants (age, gender, educational background) In this study among 80 participants, physical wellbeing occurrences were found highest in 21 a moderate amount participants in the age range of 30-39 years and also 20 very much participants were found physical wellbeing which age range in 30-39 years. Association between Age and Physical well-being of parents having child with Autism Spectrum Disorder examined by chi-square test and result .020 which association was significant ( $p < 0.05$ ).

Physical health affected by existence of persistent illness, bodily movement, working level, apprehension, and remaining lifetime. Parents have to maintain high level of responsibility and have to spend lots of time with their special child that is why they always remain in mental stress that often affects their physical health. According to Abou-Dagga (2013), stress can influence of many physical problems like migraine or stomachache, muscle strain and rigidity, ache, vomiting, vertigo, sleeplessness, acute myocardial infection, palpitation, fattening, deprivation of sex drive, frequent cold, lack of immunity and other health complications. Other study has reported that mothers affected mental distress due to burden and stress of responsibility of their special children and this usually attack the physical health. Parents having child with autism suffer unconditional pain in mind which affect their physical strength, endurance. Sometimes they express their nervousness and loss of their interest to do new work even their activities of daily living. They feel tired with in short time. Ma

(2012) agrees with this that physical health problems are more common in case of parents with autistic children than parents of non-autistic children.

Out of 60 participants in this survey, social welfare events were found to be highest among 227 participants aged 30-39 years and 4 participants found social well-being aged 20-29 years.

Association between QOL, support from others and friends as Social well-being and participants characteristics (age, gender, educational background) examined by chi-square test, result .012. The association was significant ( $p < 0.05$ )

Enduring a developmental impediment to a parent is a tedious task, especially for mothers, because they are more involved with care. Giving a parent a child with autism can be daring and growing parental tensely. With respect to social stressors in the current study, about half or more of the parents were upset with the lack of social travel to family and friends, the lack of recreational activities, and the negative impact of the child's position on the mental and physical functioning of their work. This can be explained by the fact that more than half of the mothers had to stay at home and could not come out due to the seriousness of their child's condition, being ashamed or awkward, storage of money, and ritual or traditional constraints. This is in line with Rosenthal et al. and Davis who found that parents may feel socially isolated and stigmatized because of child's status. Furthermore, Chibbaro found that negative feedback from others about redundancies could help break up a family at a time when support was needed.

Johnson and Deitz found that mothers of children with a physical handicaps or disfigurements had difficulties in leaving the house to participate or engage in social activities. They also speculated that this lack of social activity was due to the demand for parents to respond to the stigma of sick children, the stigma of society, and the negative behavior of others.

In this study there is no correlation between participant's age, gender, educational level with psychosocial, environmental well-being. The participant's quality of life does not depend upon their educational eligibility age, gender. Tsai et al. (2007) has revealed that there is a close association between level of mental health and educational qualification but in this study, researcher found those participants age, gender, educational qualifications has visible relation with their standard of life. If anyone ended graduation might be good or bad quality of life besides, someone higher secondary individual could give on to a poor or satisfaction standard of life.

Consequently, it may not express that the survival of the edified person is healthier than that of the unlettered. A young man in hand and man or woman can have a good or bad wellbeing of life.

Quality life of individual gather from their situation, in their lives in terms of their culture, believes values in which they reside, aim, prediction and priorities. It is a circumstance of complete physical, mental, social well-being without entirely the nonappearance of disease (WHO) .So it could be deliberates that person of QOL is not consistent on some factors. QOL could be changed on individual learning, leading, practicing and copying factors. This studies participants may convert their way of life by receiving of remediation facilities that include psycho-education and counseling, medical treatment, therapeutic service, vocational training of their child etc. These rehabilitation interventions may effective in helping to raise their wellbeing.

**5.3 Conclusion:** - Autism constitutes numerous challenges on the family. Thus parents having child with Autism have poorer QOL compared with other developmental child. In the cultural context of Bangladesh, parents have to maintain major care-giving liabilities of their children. In this case mother plays major roles of take care of their child and also has to manage their household restrains. In the study it has found that maximum participants are mother and occupations are house wife. As caring for a child with autism is so widespread that parents need to keep up the pressure. It often influences their daily life and comprehensive standard of living. The research has been overseeing to point out the parent's conception regarding autism and to study the challenges (physical, psychological, social and environment) they have been accepting in well-being. The QOL in the physical and social realms of the participants have reached significance but in case of environmental and psychosocial well-being they are still struggling. This study would be accommodating to associate specific problems area and challenges of parents and be prepared apposite emotional assist and education to multiplication their self-esteem, subsist skills. Moreover, they also dressing vivid physical, psychological, family and social barriers after having an autistic child and thus their quality of life is definitely decline greatly. The service mediation can be patented to boost up their welfare. The ministry and apprehension regulation, different national, international NGOs should take necessary measures and active step to implement the regulation by organizing awareness raising and promotional program about autism and its intervention to increase awareness in community just in case of indemnity, bear to parents, proceedings liabilities averse to those child with ASD. Different group of health and rehab professionals like physician, Therapist, social workers, counselors are working in multidisciplinary team members. They could become active entrepreneur. That is why the study is important for Rehabilitation professional for constructing Rehabilitation plan for those children's well-being as well as subsistence awareness and motivation of parents QOL.

#### **5.4 Recommendation**

The detection could be hypothesized, if QOL could evaluate once more and go after it for five to ten years. The results also suggest that association between variables with different domains in QOL dimensions is not universal. The study may expand on a number of implications for additional preliminary steps design. It could help to take further demand steps in intervention, treatment and healing affairs for making certain affordability. The information could be more constructive if more theses could observe their standard of life. Despite the impediments, this cross-sectional study may be a longitudinal study.

## **5.5 Limitation**

The researcher has to conduct this study as a part of course curriculum. Thus the researcher's skills in conducting interviews have limitation. If the researcher is a skilled person in conducting interview then she may be obtained more in- depth information. In this survey studies it requires .The researcher has to conduct this study as a part of course curriculum. Thus the researcher's skills in conducting interviews have limitations. If the researcher is a skilled person in conducting more participants but the researcher has abled to collect 80 participants due to Covid-19 pandemic period. Maximum Therapeutic Centers, Special schools have closed until Bangladesh Government opening declaration. In this situation, the researcher could not go outside of Dhaka to collect data in rural areas. Otherwise the study may become more generalized. Due to the limitations of the word, it was very difficult for the researchers to find similarities between the individual variables with each question in the physical, social, psychosocial, and environmental domains. In fact, researchers have selected representative questions from each domain. There are many studies in the world about autism but in the Bangladeshi context there have very few. The researcher had to use many secondary sources assessed by internet. It was difficult to discuss the findings in the Bangladeshi context. Researcher has always tried her best to consider these limitations. Though there are some limitations but still the study contains enough information about parents' way of quality of life.



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## **Appendix -1**

### **Consent form**

This is to inform that I am Sharoarea Jahan student of final year MSC in rehabilitation science at Bangladesh health professional institute. This study is conducted to know **Quality of life of parents having child with Autism Spectrum Disorder**. I am doing this study only for study purpose. So that, I will ask you to know any kind of physical, social, psychosocial, environmental challenges of you faces having child with autism. This will take approximately 20-30 min. You will have the opportunity to see the questionnaire before signing this consent form. There are no known or expected risks for participating in this study, except for the mild frustration associated with answering the questions. You may decide at any time to withdraw the study.

No payments will be made for participating in this study.

Any information about you that is obtained as a result of your participating in this research will be kept as confidential as legally possible. Your research records and test results, just like departmental records, may be inspected by federal regulatory authorities without your additional consent.

In addition, there are certain instances where the researcher is legally required to give information to appropriate authorities.

#### **Voluntary Participation**

Participating in this study is voluntary. You are free to withdraw your consent to participate in this study at any time. Refusal to participate or withdrawal will not affect and will involve no penalty to you.

You have been given the opportunity to ask questions about the research, and you have received answers concerning areas you did not understand.

I willingly consent to participate in this research.

Participant Name

Signature of participant..

Date \_\_\_\_\_ Time\_\_\_\_\_

Signature of Investigator

\_\_\_\_\_ Printed Name

Date \_\_\_\_\_ Time\_\_\_\_\_

## Appendix-2

### Socio demographic questionnaire for parents having child with autism

#### Part one

#### Respondent Identification

Code: - \_\_\_\_\_ Date.....

Name of respondent... ..

Age.....

Profession.....

Relation with Autism children: - Father /Mother

Educational background:- 1) Informal education

2) Less than primary

3) Primary

4) Secondary

5) Higher secondary completed

6) Graduation completed

7) Above graduation

8) Others

Address ...

Type of having community: - Urban/semi urban/ Small town/ Rural/ others

Income source:-

Family monthly income (BDT):-

1) At least 58,106( top income group)

2) At least 18,404(Middle income group)

3) At least 8342( Bottom income group)

#### Autism children information

Name:- \_\_\_\_\_ age:- \_\_\_\_\_ Date of birth:- \_\_\_\_\_

Gender: - Male/Female

Does the child go to School?: - yes/No

Duration of School:-

Does your child diagnosed as Autism?- Yes/No

By whom?:- Pediatrician/ MBBS/ specialist trainer/ Therapist

Degree of gradation of autism of your child: - Severe /Moderate/Mild

### Appendix-3

#### World Health Organization Quality of life (WHOQOL-100)BREF

The following questions ask how you feel about your quality of life, health or other areas of your life. I will lead out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standard, hopes, pleasures and concerns. We ask that you think about your life in the last 2 weeks

1	How would you rate your quality of life?	Very poor	Poor	Neither poor nor good	Good	Very good
		1	2	3	4	5
2	How satisfied are you with your health?	Very satisfied	Dissatisfied	Neither satisfied nor dissatisfied	satisfied	Very satisfied
		1	2	3	4	5
3	Do you worry about your pain or discomfort?	Not at all	A little	A moderate amount	Very much	An extreme amount
		1	2	3	4	5
4	How difficult is it for you to handle any pain or discomfort?	1	2	3	4	5
5	To what extent do you feel that (physical) pain prevents you from doing what you need to do?	1	2	3	4	5
6	How easily do you get tired?	1	2	3	4	5
7	To what extent does your quality of life depend on the use of medical substances or medical aids?	1	2	3	4	5
8	How much do you enjoy life?	1	2	3	4	5

9	To what extend do you feel your life to be meaningful?	1	2	3	4	5
10	How well are you able to concentrate?	1	2	3	4	5

11	How much do you value yourself?	1	2	3	4	5
12	Are you able to accept your bodily appearance?	1	2	3	4	5
13	Do you feel inhibited by your look?	1	2	3	4	5
14	Is there any part of your appearance which makes you feel uncomfortable?	1	2	3	4	5
15	How satisfied are you with your sleep?	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
		1	2	3	4	5
16	How healthy is your physical environment?	Not at all	A little	A moderate amount	Very much	Extremely
		1	2	3	4	5
17	Do you feel you are living in a safe and secure environment?	1	2	3	4	5
18	To what extend do you have problems with transport?	1	2	3	4	5
19	Do you get the kind of support from others that you need?	Not at all	A little	Moderately	Mostly	Completely
		1	2	3	4	5
20	To what degree does the quality of your home meet your	1	2	3	4	5

	needs?					
21	Have you enough money to meet your needs?	1	2	3	4	5

22	To what extend do you have the opportunity for leisure activities?	1	2	3	4	5
23	How much are you able to relax and enjoy yourself?	1	2	3	4	5
24	How satisfied are you with the support you get from your friends?	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
		1	2	3	4	5
25	How satisfied are you with your personal relationship?	1	2	3	4	5
26	How satisfied are you with your sex life?	1	2	3	4	5
27	How satisfied are you with the condition of your living place?	1	2	3	4	5
28	How satisfied are you with your access to health service?	1	2	3	4	5
29	How satisfied are you with your transport?	1	2	3	4	5
30	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	Never	Seldom	Quite often	Very often	Always
		1	2	3	4	5



Do you have any comments about the assessments?

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

The following table should be completed after the interview is finished

Equations for computing domain score		Row score	Transformed 4-20	score 0-100
Domain 1	$Q2 + Q3 + Q4 + Q5 + Q6 + Q15 + Q7$ $\square + \square + \square + \square + \square + \square + \square$	a.=	b.:	c :
Domain 2	$Q1 + Q9 + Q10 + Q11 + Q12 + Q13 + Q14 + Q28 + Q30$ $\square + \square + \square + \square + \square + \square$	a.=	b :	c :
Domain 3	$Q19 + Q24 + Q25 + Q26$ $\square + \square + \square$	a.=	b :	c :
Domain 4	$Q8 + Q16 + Q17 + Q18 + Q20 + Q21 + Q22 + Q23 + Q27 + Q29$ $\square + \square + \square + \square + \square + \square + \square + \square$	a.=	b :	c :

## Appendix-4

### সম্মতিপত্র

এই মর্মে জানাচ্ছি যে, আমি সায়োয়ারে জাহান, বাংলাদেশ হেলথ প্রফেসনস্ ইনিস্টিটিউটের এম.এস.সি ইন পূর্নবাসন বিজ্ঞানের শেষ বর্ষের শিক্ষার্থী। এই অধ্যয়নটি অটিজম স্পেকট্রাম ডিসঅর্ডার যুক্ত সন্তানের পিতামাতার জীবন মান সম্পর্কে জানতে পরিচালিত হচ্ছে। আমি এই অধ্যয়নটি কেবল অধ্যয়নের উদ্দেশ্যেই করছি। আমি আপনার অটিজমে আক্রান্ত শিশুর মুখোমুখি হওয়া যে কোন ধরনের শারীরিক, সামাজিক, মনোসামাজিক পরিবেশগত চ্যালেঞ্জ জানতে চাইব। এটি প্রায় ২০-৩০ মিনিট সময় নিবে। আপনি এই সম্মতি ফর্মটিতে স্বাক্ষর করার আগে প্রশ্নোত্তরটি দেয়ার সুযোগ পাবেন।

এই অধ্যয়নে অংশ নেওয়ার জন্য কোন প্রত্যাশিত বুকি নেই, কেবল মাত্র প্রশ্নের উত্তর দেওয়ার সাথে যুক্ত হালকা হতাশা ছাড়া। আপনি যে কোনও সময় অধ্যয়ন প্রত্যাহারের সিদ্ধান্ত নিতে পারেন।

এই গবেষণায় অংশ নেওয়ার জন্য কোনো অর্থ প্রদান করা হবেনা।

আপনার এই গবেষণায় অংশ নেওয়ার ফলাফল হিসাবে আপনার সম্পর্কে প্রাপ্ত যে কোনো তথ্য আইনীভাবে সম্ভব গোপন রাখা হবে। বিভাগীয় রেকর্ডের মতো আপনার গবেষণা রেকর্ড এবং পরীক্ষার ফলাফল গুলি আপনার অতিরিক্ত সম্মতি ছাড়াই ফেডারাল নিয়ন্ত্রক কর্তৃপক্ষ দ্বারা পরীক্ষা করা হতে পারে।

তদুপরি কিছু নির্দিষ্ট উদাহরণ রয়েছে যেখানে গবেষক আইনত যথাযথ কর্তৃপক্ষকে তথ্য দেওয়ার প্রয়োজন বোধ করেন।

#### সেচ্ছাসেবী অংশগ্রহন

এই গবেষণায় অংশ নেওয়া অংশগ্রহনকারী সেচ্ছাসেবী। আপনি যে কোনও সময় এই গবেষণায় অংশ নিতে আপনার সম্মতি প্রত্যাহার করতে পারেন। অংশগ্রহন বা প্রত্যাখ্যান অস্বীকার আপনাকে প্রভাবিত করবেনা এবং আপনাকে কোনো জরিমানাও করবে না।

আপনাকে গবেষণা সম্পর্কে প্রশ্ন জিজ্ঞাসা করার সুযোগ দেওয়া হয়েছে এবং আপনি যে অঞ্চলগুলি বুঝতে পারেননি সে সম্পর্কে উত্তর পেয়েছেন।

আমি সেচ্ছায় এই গবেষণায় অংশ নিতে সম্মতি জানাই।

অংশগ্রহন কারীরনাম:

অংশ গ্রহনকারীর স্বাক্ষর:

তারিখ:

সময়:

তদন্তকারীর স্বাক্ষর

মুদ্রিত নাম

তারিখ:

সময়:

পরিশিষ্ট-৫

অটিজমে আক্রান্ত বাচ্চার পিতামাতার জন্য সামাজিক গনতান্ত্রিক প্রশ্নাবলী।

প্রথম অংশ

প্রতিক্রিয়াশীল সনাক্তকরণ

কোড:

তারিখ:

উত্তর দাতারনাম:

বয়স:

পেশা:

অটিজম বাচ্চার সাথে সম্পর্ক: বাব/মা

শিক্ষাগতপটভূমি:

- ১। অনানুষ্ঠানিক শিক্ষা
- ২। প্রাথমিকের চেয়ে কম
- ৩। প্রাথমিক
- ৪। মাধ্যমিক
- ৫। উচ্চ মাধ্যমিকসম্পন্ন
- ৬। স্নাতক শেষ
- ৭। স্নাতকউপরে
- ৮। অন্যান্য

ঠিকানা:

সামাজিক অবস্থানের ধরন:-নগর/ আধানগর/ ছোটশহর/ গ্রাম / অন্যান্য

আয়ের উৎস:-পরিবারের মাসিক আয় (বিডিটি)

- ১। কমপক্ষে ৫৮,১০৬ (শীর্ষ আয়ের গ্রুপ)
- ২। কমপক্ষে ১৮,৪০৪ (মধ্য আয়ের গ্রুপ)
- ৩। কমপক্ষে ৮,৩৪২ (নিম্নআয়ের গ্রুপ)

অটিজম বাচ্চাদের তথ্য:

নাম:

বয়স:

জন্ম তারিখ:

লিঙ্গ: ছেলে / মেয়ে

সন্তানকি স্কুলে যায়? - হ্যাঁ / না

বিদ্যালয়ের সময়কাল:-

আপনার বাচ্চা কি অটিজম হিসাবে নির্ণয় করা হয়েছে? - হ্যাঁ / না

কাদেও দ্বারা?-শিশু বিশেষজ্ঞ/ এম বি বিএস/ বিশেষজ্ঞ প্রশিক্ষক/ থেরাপীস্ট  
আপনার সন্তানের অটিজমের থেডিংয়ের মাত্রা:- গুরুতর/ মাঝামাঝি/ হালকা

## Appendix-6

### World Health Organization Quality of life (WHOQOL-100) BREF

(WHOQOL-BREF) এ অংশের মূল্যায়ন আপনি আপনার জীবন, স্বাস্থ্য ও জীবনের অন্যান্য দিক সম্পর্কে কিভাবে, সে সম্পর্কে দয়া করে সবগুলো প্রশ্নের উত্তর দিন। যদি কোন প্রশ্নের উত্তর কি হবে না হবে না বুঝেন তবে সেটিকে আপনার মান, আশা, আনন্দ ও বিবেচ্য বিষয়সমূহ স্মরণ রাখুন। আমরা আপনার জীবনের গত ২ সপ্তাহের কথা স্মরণ করতে বলবো।

সবগুলো প্রশ্ন পড়ুন, আপনার অনুভূতি যাচাই কওে এবং পাশের ছকে যে উত্তরটি সচচেয়ে সঠিক মনে হবে সে নম্বরটিতে বৃত্ত তৈরী করুন।

### BANGLA

১.(G1)	আপনার গত ২ সপ্তাহের জীবনযাপন আনুসারে	খুবই খারাপ	খারাপ	খারাপও না ভালও না	ভাল	খুব ভাল
	আপনি আপনার জীবনযাপনের ধরণকে কত নম্বর দেবেন?	১	২	৩	৪	৫
২.(G4)	আপনি আপনার স্বাস্থ্যের উপর কতটুকু সন্তুষ্ট	খুবই অসন্তুষ্ট	অসন্তুষ্ট	সন্তুষ্টও না অসন্তুষ্টও না	সন্তুষ্ট	খুবই সন্তুষ্ট
		১	২	৩	৪	৫
৩.(F1.2)	আপনি কি আপনার ব্যথা বা অসুবিধা নিয়ে চিন্তিত?	একদমইনা	খুবঅল্প	কিছুটা পরমাণে	অনেক	অনেক বেশি
		১	২	৩	৪	৫
৪.(F1.3)	আপনার জন্য কোনো ব্যথা বা অসুবিধা সামলানো কতটুকু কষ্টকর?	১	২	৩	৪	৫
৫.(F1.4)	আপনি যা করতে চান আপনার ব্যথা (শারীরিক) সেটা আপনাকে কাজ করতে কতটুকু পরিমাণ বাঁধা দেয় বলে আপনি মনে করেন।	একদমই না	খুবঅল্প	কিছুটা পরমাণে	অনেক	অনেক বেশি
		১	২	৩	৪	৫

৬.(F2.2)	আপনি কত সহজে ক্লান্ত হন?	১	২	৩	৪	৫
৭.(F11.4)	আপনার জীবনযাপনের মান চিকিৎসা সামগ্রীর ওপর কতটুকু পর্যন্ত নির্ভর করে?	একদমই না	খুব অল্প	কিছুটা পরিমাণ	অনেক	অনেক বেশি
		১	২	৩	৪	৫
৮.(F4.1)	আপনি আপনার জীবন কতটুকু উপভোগ করেন?	১	২	৩	৪	৫
৯.(F24.2)	আপনি আপনার জীবন কতটুকু অর্থপূর্ণ মনে করেন?	১	২	৩	৪	৫
১০.(F5.3)	আপনি কতটুকু ভালভাবে মনোযোগ দিতে পারেন?	একদমই না	খুব অল্প	কিছুটা পরিমাণ	অনেক	অনেক বেশি
		১	২	৩	৪	৫
১১.(F6.1)	আপনি নিজেকে কতটুকু মূল্যায়ন করেন?	১	২	৩	৪	৫
১২.(F7.1)	আপনিকি আপনার শারীরিক আকৃতি/ গঠন মেনে নিতে পারছেন?	১	২	৩	৪	৫
১৩.(F7.2)	আপনিকি আপনার চেহারার জন্য অবহেলিত?	১	২	৩	৪	৫
১৪.(F7.3)	আপনার শারীরিক আকৃতির / গঠন কি এমন কোন অংশ আছে যা নিয়ে আপনি অসুবিধা বোধ করেন?	১	২	৩	৪	৫
১৫.(F3.3)	আপনি আপনার ঘুম নিয়ে কতটুকু সন্তুষ্ট?	খুবই অসন্তুষ্ট জনক	অসন্তুষ্ট জনক	সন্তোস জনকও না অসন্তুষ্ট জনকও না	সন্তোস জনক	খুবই সন্তোস জনক
		১	২	৩	৪	৫
১৬.(F22.1)	আপনার দৈহিক পরিবেশ কতটুকু স্বাস্থ্যসম্মত?	একদমই না	খুবই অল্প	কিছুটা পরিমাণে	অনেক	অনেক বেশি
		১	২	৩	৪	৫

১৭.(F16.2)	আপনি কি মনে করেন আপনি নিরাপদ ও সুরক্ষিত পরিবেশে বসবাস করছেন?	১	২	৩	৪	৫
১৮.(F23.2)	যানবাহন নিয়ে আপনার কতটুকু পরিমাণ সমস্যা রয়েছে?	১	২	৩	৪	৫
১৯.(F14.1)	আপনিকি আপনার প্রয়োজন মত অন্যদের থেকে সহযোগিতা পান?	একদমইনা	খুবইঅল্প	কিছুটা পরিমাণ	বেশিরভাগ	সম্পূর্ণ
		১	২	৩	৪	৫
২০.(F17.2)	আপনার বাড়ির অবস্থা আপনার চাহিদা বা প্রয়োজন কতটুকু পরিমাণে পূরণ করতে পারে?	১	২	৩	৪	৫
২১.(F18.1)	আপনার কি আপনার চাহিদাগুলো মেটানোর জন্য পর্যাপ্ত পরিমাণ টাকা আছে?	১	২	৩	৪	৫
২২.(F21.1)	আপনার অবসর কাজগুলো করার জন্য কতটুকু সুযোগ রয়েছে?	১	২	৩	৪	৫
২৩.(F21.2)	আপনি অবসর সময় কাটানোর জন্য এবং নিজেকে উপভোগ করার ক্ষেত্রে কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২৪.(F14.4)	আপনি আপনার বন্ধুদের কাছ থেকে সহযোগিতা পেয়ে কতটুকু সন্তুষ্ট?	খুবই অসন্তুষ্ট	অসন্তুষ্ট	সন্তুষ্টও না অসন্তুষ্টওনা	সন্তুষ্ট	খুবইসন্তুষ্ট
		১	২	৩	৪	৫
২৫.(F13.3)	আপনি আপনার ব্যক্তিগত সম্পর্ক নিয়ে কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২৬.(F15.3)	আপনি আপনার যৌনজীবন নিয়ে কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২৭.(F17.3)	আপনি আপনার বাসস্থানের অবস্থা নিয়ে কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫

২৮.(F19.3)	আপনি চিকিৎসা সেবার সর্বোপরিভায় কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
২৯.(F23.3)	আপনি আপনার যাতায়াত ব্যবস্থা নিয়ে কতটুকু সন্তুষ্ট?	১	২	৩	৪	৫
৩০.(F8.1)	আপনার নেতিবাচক মনোভাব যেমনঃ ডিপ্রেসন, দুশ্চিন্তা, মনখারাপ কেমন পরিমাণে হয়?	কখনই না	হঠাৎ	প্রায় সময়	বেশির ভাগ সময়	সব সময়
		১	২	৩	৪	৫



## Appendix-7

### Permission for using WHO Quality of Life Scale

#### User Agreement for “WHOQOL-100” and/or WHOQOL-BREF and related materials

This agreement is between the World Health Organization (“WHO”) and \_\_\_\_\_ . WHO hereby grants the User a nonexclusive, royalty-free license to use the World Health Organization Quality of Life Questionnaire and/or related materials (hereafter referred to as “WHOQOL-100” or “WHOQOL- BREF”) in User’s study outlined below. The term of this User Agreement shall be for a period of 1 year, commencing on

(Date)\_\_\_\_\_.

The approved study for this User Agreement is:

Study Title	
Principal Investigator	
Sample characteristics	
Sample size	
Treatment Intervention	
Total number of assessments	
Assessment time points	
“WHOQOL-100” or WHOQOL-BREF Version – Please specify language version(s) you would like to receive.	
Other measures	

This User Agreement is based upon the following conditions:

1. User shall not modify, abridge, condense, translate, adapt, recast or transform the WHOQOL-100 or BREF in any manner or form, including but not limited to any minor or significant change in wording or organization, or administration procedures, of the WHOQOL-100 or BREF. If User thinks that changes are necessary for its work, or if translation is necessary, User must obtain written approval from WHO in advance of making such changes.
2. User shall not reproduce WHOQOL-100 or BREF, except for the limited purpose of generating sufficient copies for its own uses and shall in no event distribute copies of the WHOQOL-100 or BREF to third parties by sale, rental, lease, lending, or any other means. In addition, User agrees that it will not use the WHOQOL-100 or BREF for any purpose other than conducting studies as specified above, unless agreed in writing by WHO. In any event, the

WHOQOL- 100 or BREF should not be used for research or clinical purposes without prior written authorization from WHO.

3. User agrees to provide WHO with an annual update regarding activities related to the WHOQOL-100 or BREF
4. User agrees to provide WHO with a complete copy of User's raw data and data code books, including the WHOQOL-100 or BREF and any other instruments used in the study. This data set must be forwarded to WHO upon the conclusion of User's work. While User remains the owner of the data collected in User's studies, these data may be used in WHO analyses for further examining the psychometric properties of the WHOQOL-100 or BREF. WHO asserts the right to present and publish these results, with due credit to the User as the primary investigator, as part of the overall WHOQOL-100 or BREF development strategy.
5. WHO shall be responsible for preparing and publishing the overall WHOQOL-100 or BREF results under WHO copyright, including:
  - a. the overall strategy, administrative set-up and design of the study including the instruments employed;
  - b. common methods used by two or more Users;
  - c. the data reported from two or more Users;
  - d. the comparisons made between the data reported from the Users;
  - e. the overall findings and conclusions
6. User shall be responsible for publications concerning information developed exclusively by User and methods employed only by User. Publications describing results obtained by User will be published in User's name and shall include an acknowledgement of WHO. User agrees to send to WHO a copy of each such paper prior to its submission for publication
7. WHO may terminate this User Agreement at any time, in any event. Should WHO terminate this User Agreement, User shall immediately cease all use of the WHOQOL100 or BREF and destroy or return all copies of the WHOQOL-100 or BREF. In the event of such termination, all other collateral materials shall be destroyed and no copy thereof shall be retained by User. Notwithstanding the return or destruction of the WHOQOL-100 or BREF and its collateral materials, User will continue to be bound by the terms of this User Agreement
8. It is understood that this User Agreement does not create any employer/employee relationship. User and its affiliates are not entitled to describe themselves as staff members of WHO. User shall be solely responsible for the manner in which work on the project is carried out and accordingly shall assume full liability for any damage arising therefrom. No liability shall attach to WHO, its advisers, agents or employees. Please confirm your agreement with the foregoing by signing and returning one copy of this letter to WHO, whereupon this letter agreement shall become a binding agreement between User and WHO.

**WHO:**



Dr. Somnath Chatterji  
Health Statistics and Health Information Systems  
(HSI) World Health Organization

Avenue

Appia

Geneva

27

CH 1211

Switzerland

Date:

**USER:**

By: \_\_\_\_\_

Title: \_\_\_\_\_

Institution: \_\_\_\_\_

Address: \_

Date: \_\_\_\_\_

Date: ~~10~~-2-21

The Institutional Review Board (IRB)

Bangladesh Health Professions Institute (BHPI)

CRP-Savar, Dhaka-I343, Bangladesh.

Subject: Application for Review and Ethical Approval.

Sir,

With due respect, I am Sharoarea Jahan, student of M.Sc. in Rehabilitation Science program at Bangladesh Health Professions Institute (BHPI) - an academic institute of CRP under Faculty of Medicine, University of Dhaka. I have to conduct a thesis entitled, "Quality of life of parents having child with Autism Spectrum Disorder" under the guidance of Associate Prof. Of Occupational Therapy Md Julker Nayan, BHPI & consultant & Head Occupational Therapy Department, CRP. The study involves use of standardized question that may take 15 to 20 min to collect the data.

A written consent will be taken prior and assured that all the participants' information would be kept confidential and the participants can withdraw themselves at any time according to their desire.

Therefore, I look forward to having your kind approval for the thesis proposal and to start data collection. I also assure you that I will maintain all the requirements for the study.

Sincerely



Sharoarea Jahan

Part-II, Roll No. 04

Student of M.Sc. in Rehabilitation Science

Session: 2018-2019

BHPI, CRP, Savar, Dhaka-I343

Recommendation from the thesis Supervisor



Md Julker Nayan BHPI,

Associate professor of Occupational Therapy

BHPI, CRP, Dhaka- 1343

Ref:

Date: 23/02/2021

CRP-BHPI/IRB/02/2021/444

Sharoarea Jahan  
5<sup>th</sup> Batch (Part-II) M.Sc. in Rehabilitation Science (MRS)  
Session: 2018-19, Student ID:181180113  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

**Subject:** Approval of the thesis proposal “Quality of life of parents having child with Autism spectrum disorder” by ethics committee.

Dear Sharoarea Jahan,

Congratulations.

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

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

The purpose of the study is to find out the challenges in quality of life of parents having child with Autism Spectrum Disorder (ASD). The study involves taking socio demographic information, social participation details by having face to face interview and find out the challenges of parents facing in quality of life having child with Autism by using standard questionnaires (WHOQOL100-BREF), which may take 20-30 minutes. There is 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 09.00 am on 17<sup>th</sup> February 2019 at BHPI (20<sup>th</sup>IRB Meeting).

The institutional Ethics committee expects to be informed about the progress of the study, any changes occurring in the course of the study, any revision in the protocol and patient information or informed consent and ask to be provided a copy of the final report. This Ethics committee is working accordance to Nuremberg Code 1947, World Medical Association Declaration of Helsinki, 1964 - 2013 and other applicable regulation.

Best regards,



Muhammad Millat Hossain  
Assistant Professor, Dept. of Rehabilitation Science  
Member Secretary, Institutional Review Board (IRB)  
BHPI, CRP, Savar, Dhaka-1343, Bangladesh

To

The principle and founder

Special child care foundation(SCF)

Uttara sector-7, road -11, house no-6, Dhaka

Subject:-Application for permission of data collection for MSc thesis

Sir,

With due respect I would like to draw your kind attention that I am a student of MSc in Rehabilitation Science course at Bangladesh Health Professions Institute (BHPI), academic institute of Centre for The Rehabilitation of the Paralyzed ( CRP) under the faculty of Medicine of University of Dhaka(DU).This is a 2 years full time course under the project of “ Regional Inter-professional scholarship MSc program in rehabilitation science funded by SAARC development Fund(SDF).I have to conduct a thesis entitled” Quality of life of parents having child with Autism spectrum disorder”-under honorable supervisor Md Julker Nayan, associate professor of Occupational Therapy Department ,BHPI.

The purpose of the study is to identify the challenges in quality of life of parents having child with autism, WHOQOL-100 BREF, structural questionnaire will be used to collect data.

The study will not cause any harm to the participants, verbal and written informed consents form each study participant will be collected prior to data collection. Any data collected will be kept confidential.

Therefore, I look forward to having your kind approval for the data collection of parents having child with ASD.

Yours sincerely

*Bahan*  
Sharoarea Jahan

MRS final year student

BHPI, CRP ,Savar, Dhaka.

*Permission is given  
for data collection*

**Md. Toufiq Hasan**  
B.ScOT (CRP DU), MHRL (DU)  
President  
Special Care Foundation

To

The principle and founder

School for children with Autism and neuro developmental disorder (SAND)

Uttara, Sector -12, road no -1, house no-66

Subject:-Application for permission of data collection for MSc thesis

Sir,

With due respect I would like to draw your kind attention that I am a student of MSc in Rehabilitation Science course at Bangladesh Health Professions Institute (BHPI), academic institute of Centre for The Rehabilitation of the Paralyzed ( CRP) under the faculty of Medicine of University of Dhaka(DU).This is a 2 years full time course under the project of “ Regional Inter-professional scholarship MSc program in rehabilitation science funded by SAARC development Fund(SDF).I have to conduct a thesis entitled” Quality of life of parents having child with Autism spectrum disorder”-under honorable supervisor Md Julker Nayan, associate professor of Occupational Therapy Department ,BHPI.

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Therefore, I look forward to having your kind approval for the data collection of parents having child with ASD.


Yours sincerely

  
Sharoarea Jahan

MRS final year student

BHPI, CRP ,Savar, Dhaka.

Received  
↓  
Permission is given for  
data collection

  
Md. Amrul Haque Chowdhury  
Certified Sensory Integration Therapist,  
BSc (Hon's) OT, (DU), CSI (USC,USA)  
Principal & Founder, SAND Uttara Dhaka

To

The principle

Blessing child special School

Rampura Aftabnagar, Jahurul Islam city, Block-G, road -4, house no-G-3, Dhaka

Subject:-Application for permission of data collection for MSc thesis

Sir,

With due respect I would like to draw your kind attention that I am a student of MSc in Rehabilitation Science course at Bangladesh Health Professions Institute (BHPI), academic institute of Centre for The Rehabilitation of the Paralyzed ( CRP) under the faculty of Medicine of University of Dhaka(DU).This is a 2 years full time course under the project of “ Regional Inter-professional scholarship MSc program in rehabilitation science funded by SAARC development Fund(SDF).I have to conduct a thesis entitled” Quality of life of parents having child with Autism spectrum disorder”-under honorable supervisor Md Julker Nayan, associate professor of Occupational Therapy Department ,BHPI.

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Therefore, I look forward to having your kind approval for the data collection of parents having child with ASD.


Yours sincerely

  
Sharoarea Jahan

MRS final year student

BHPI, CRP ,Savar, Dhaka

Accepted

  
10-9-2020