A Study on Psycho-social Situation of Children with Autism

(This Dissertation is Submitted to the Institute of Social Welfare and Research, University of Dhaka as Fulfillment of the Requirement for the Degree of Master of Philosophy (M.Phil.) in Social Welfare)

M.Phil. Dissertation Israt Jerin

Registration No: 072 Session: 2018-2019



Institute of Social Welfare and Research University of Dhaka- 1205 Bangladesh

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October 2023

Dedication

This dissertation is dedicated to the memory of my beloved father Late Md. Ibrahim Sikder and my mother Mrs. Sohely Sultana who encouraged me to pursue my dreams and finish my dissertation.

Declaration

I hereby declare that the M.Phil. Dissertation entitled "A Study on Psycho-social Situation of Children with Autism" is an original report of my research, has been prepared by me under the guidance and supervision of Professor Dr. Mahbuba Sultana, Institute of Social Welfare and Research, University of Dhaka-1205. I am submitting this dissertation to the Institute of Social Welfare and Research, University of Dhaka - 1205, Bangladesh for the fulfillment of the requirements and official procedure for the award of the Degree of Master of Philosophy in Social Welfare. This dissertation is sui generis which was totally prepared with my own effort. This dissertation or any part of it is not used or submitted to anywhere in Bangladesh or abroad.

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Certificate of Approval from the Supervisor

This is to certify that **Israt Jerin** has effectively completed her dissertation entitled, **A Study on Psycho-social Situation of Children with Autism** under my proper and accurate supervision. This dissertation has not been submitted fully or partly to anywhere else for any other degree. To the best of my knowledge, it is an exclusive and original work done by her. I am recommending and forwarding this dissertation to the University of Dhaka, through Institute of Social Welfare and Research for further official formalities to accept for the requirements of the Degree of **Master of Philosophy**.

Prof. Dr. Mahbuba Sultana

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Abstract

Bangladesh is an independent and sovereign country from Southeast Asia having population of more than 16 million people. The rate of autism is increasing day by day. But there is not enough information about autism to increase public awareness. In this context, it is very important to explore the nature of psycho-social status of autistic children. Keeping this goal in mind, the current research work under the title **A Study on Psycho-social Situation of Children with Autism** has been conducted.

In the present study, data were collected and analyzed from both primary and secondary sources to explore the psycho-social condition of children with autism. A research design including rationale of the study, objectives, conceptual and theoretical framework, research methodologies, data collection tools and techniques has been formulated by reviewing various books, articles, journals and survey's supporting the research.

The main objective of the present study was to understand psycho-social situation of children with autism. Social Survey and Case Study methods were followed to illustrate the main objective of the research i.e. the psycho-social condition of autistic children. The social survey method used in the study was to collect data through structured interview schedule from parents of a total number of 60 autistic children from 2 "special education schools" to highlight the quantitative approach of the research. In addition data were collected through in-depth interviews with 10 stakeholders who are experts and who have knowledge of the subject matter to meet the goal of research objectives. Besides, 6 case studies have been done to apply the qualitative approach of the research as the methodology of the research work is based on mixed-method approach, both quantitative and qualitative.

The analysis of the data obtained from the two methods of this research shows that, it can clearly be seen that people's acceptance and awareness about autism has increased to a large extent. As a result, the diagnosis of autism is increasing. About 66 percent of children are diagnosed with autism within 1-2 years. But 100 percent awareness has not yet come among people. Analyzing data regarding receiving on autistic children's health and education services, about 55 percent of the respondents feel that their child's health is improved after receiving health services and about 63 percent of respondents feel that positive changes and improvements are being observed in their child after receiving education services. According to majority of the respondents, healthcare providers need skilled health workers. About 56 percent of the respondents feel that health workers are efficient but therapy support is not sufficient. About 65 percent are getting speech therapy, about 20 percent are getting occupational therapy; about 6

percent are getting other health services and therapies. Regarding education services, about 20 percent of the respondents are dissatisfied and about 50 percent of the respondents are fairly satisfied. Therefore, emphasis should be given on improving the quality of education and health services and ensuring adequate services. Exploring the psycho-social challenges of autistic children, it was found that, about 71 percent of the respondents think, the attitude towards autistic children of the family members and relatives are condescending. About 61 percent placed their opinion regarding the social attitude towards autistic children, society still consider autistic child as a curse. About 5 percent of the respondents think that, autistic children's are suffering from financial burden. About 70 percent of the respondent's think- having an autistic child made them socially isolated. Near about 86 percent thinks that-parents of children with autism have financial burden. About 40 percent of the respondents suffers from severe depression. Therefore, parents and children's counseling is needed. The study also shows that, the data obtained from the case studies, increasing awareness in order to ensuring social acceptance, rehabilitation, employment, accommodation, social security allowances etc. are very important for the autistic children. Moreover, social security allowances, banking facilities are utmost needed for the well-being of children with autism. The study explored that, about 90 percent of the respondents from the in-depth interview, think that- ensuring social inclusion is utmost important to bring the children with autism back to the mainstream of society for overall development of the autistic children. About 80 percent of the respondents placed their opinion that-monitoring, evaluation and accountability must be ensured in every organizations giving the services to the children with autism which will accelerate sustainable development. About 60 percent of the respondents think that, media can play an important role to increase awareness. Public awareness also can be increased through various government campaigns, and ensuring access to information through the implication of "RTI Act-2009".

This research study suggests that- in order to ensure the well-being of the children with autism, government, non-government and above all people from all levels of society should work together by following human rights model of disability and to ensure the implementation of existing policies and programs; monitoring, evaluation and accountability must be ensured in every government and non-government organizations so that autistic children can be brought back into the mainstream of the society through social inclusion which will accelerate sustainable development for the children with autism.

Key to Abbreviations

AAS	American Autism Society
ACWFB	Autistic Children's Welfare Foundation, Bangladesh
APA	American Psychology Association
ASA	Autism Society of America
ASD	Autism Spectrum Disorder
A2I	Access to Information
BCS	Bangladesh Civil Service
BD	Bangladesh
BPF	Bangladesh Protibondhi Foundation
BSMMU	Bangabandhu Sheikh Mujib Medical University
CDC	Centers for Disease Control and Prevention
CRI	The Centre for Research and Information
DNA	Deoxyribonucleic acid
DSS	Department of Social Services
DU	University of Dhaka
GOB	Government of Bangladesh
IPNA	Institute for Pediatric Neurodisorder and Autism
ISWR	Institute of Social Welfare and Research
KII	Key Informant Interview
MDG	Millennium Development Goal
NAS	National Autistic Society
NDD	Neurodevelopmental Disorder
NDF	National Disability Forum
NFOWD	National Forum of Organizations Working with the Disabled
NGO	Non-governmental organization
Q & A	Question and Answer
RTI	Right to Information
RTIA	Right to Information Act
SD	Sustainable Development
SDG	Sustainable Development Goal
SEASIA	Southeast Asia
SPSS	Statistical Package for the Social Sciences
SSRC	Social Science Research Council
SWAC	Society for the Welfare of Autistic Children

ToM	Theory of Mind
TTCT	Torrance Tests of Creative Thinking
UK	United Kingdom
UN	United Nations
USA	United States of America
WCC	Weak Central Cohesion
WHO	World Health Organization

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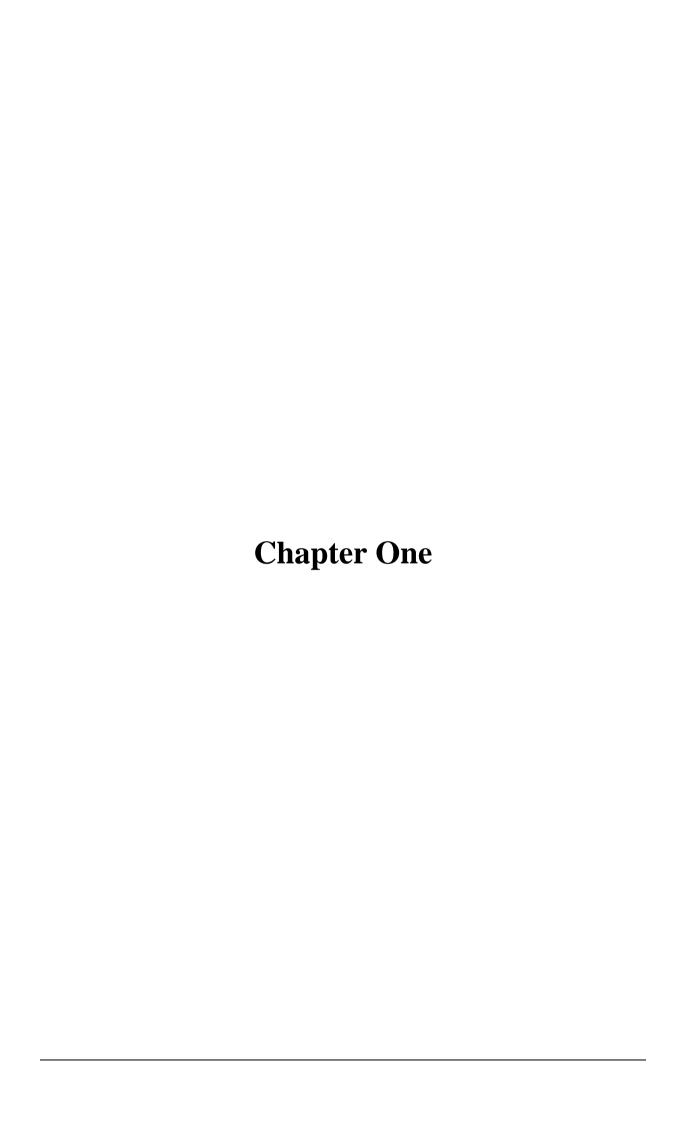
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Chapter One: Introduction

1.1 Background of the Study

Bangladesh is a developing country from Southeast Asia. In terms of population, Bangladesh is the 8th largest country in the world with more than 16 million people. According to statistics from "The Autism Society of the United States"- about one percent of the world's population is autistic. Seventeen out of every ten thousand people in Bangladesh have autism. A recent study conducted by "Institute for Pediatric Neurodisorder and Autism (IPNA) revealed this information- the number of autistic children is increasing in urban areas than in rural areas, fourteen out of every ten thousand children in the city have autism. According to the Ministry of Social Welfare- twenty eight percent of people with disabilities in the country have autism. There are still many families in Bangladesh who do not have a clear idea about autism. The rural people most of the time depends on traditional and religious healer's. According to a study, it was revealed that-more than 50% rural people have faith on traditional healers. The negative attitude of the society towards the children with autism has not changed yet. Many people in the society are still superstitious. They consider the birth of a children with any type of disabilities a curse. They treat the autistic children with contempt. As a result, children with autism and their parents or family suffers from psycho-social problems. To reduce these problems and reintegrate autistic children into the mainstream of society which will accelerate sustainable development, the Government and other service providing organizations needs to be together and must work for the betterment of children with autism and their parents.

1.2 Statement of the Problem

Autism is the most commonly found neurodevelopmental disorder characterized by deficits in three domains: social interaction, communication and problems related with behavior. It is a complex neurodevelopmental disorder that typically appears during a child's first three years. Most of the people are unfamiliar with the concept of autism. Although it was identified in 1943, autism is still a relatively unknown disability. In Bangladesh, neurodevelopmental disorder is now regarded as an issue with special concentration, distinguishing the issue as a national policy priority.

Bangladesh has a population of over 167 million people. Despite of being a developing country, we don't have enough data to estimate the actual number of population who are suffering from autism spectrum disorders. The availability of services to the autistic children are not enough to deal with the effects of autism. A study revealed that millions of children from around the world are suffering from this problem.

According to the European Epidemiologic Studies which was conducted in 60's and 70's, it is reported-1 is suffering from autism spectrum disorders in 25000 children in the population. A matter of concern is that by the 2000, it has increased terribly and 1%-2% of all children who are suffering from neurodevelopmental disorders like autism.

Bangladesh is now trying to develop a rights based paradigm for individuals with autism or other neurodevelopmental disorder. [The Centre for Research and Information (CRI), 2014]. A pilot study in Bangladesh which was conducted in 2013, reveals- The Prevalence of all kinds of neurodevelopmental disability is 7.1%. Although we have an upgraded health care system but unfortunately despite of being a developing country, we don't have adequate data and information to estimate the actual number of population of children or person with autism. Parenting a children with autism not only has an impact upon the parent's psychological well-being, but the family and marriage system as well. According to a research study, it was revealed that- depression and stress levels are significantly higher in parents of children with autism than the parents of typically developing children. Bringing up a children with autism can be challenging for parents, especially when other people do not understand the issues. Therefore, a systematic as well as scientific investigation is essential to this area and the present study is a step forward in this direction.

1.3 Rationale of the Study

Every research study is being conducted on the basis of some rationalities. This research project has also some potential rationalities. Children with autism are also our future of the country. If we can utilize their capacities effectively and can develop them properly, they can play an important role in our National Development. Therefore, the selection of the research study is very much rational because it has some social importance. Autism related research study is essential for better understanding of children with autism, their needs, wants and for improving their quality of life by ensuring their rehabilitation. So far, adequate research on autism has not been conducted yet in Bangladesh. Data on autism is scarce. Through the current research work, it will be possible to know the information about the psychosocial situation of children with autism, which will play a very useful role in formulating policies related to autism in the future. This research study will pave the way for ensuring access to mainstream development for autistic children, which will accelerate sustainable development.

1.4 Objectives of the Study

The general objective of this study is to understand psycho-social situation of children with autism. The specific objectives are as follows:

- To know the socio-demographic background and economic condition of children with autism;
- To gather knowledge about psycho-social developmental history of autistic children from birth to present;
- To identify the challenges faced by the autistic children from family, neighbors, relatives and social environment;
- To acquire knowledge about services received by autistic children from various organizations in terms of education, health, training and occupational therapy/vocational training and
- To recommends some way out to deal with the psycho-social problems faced by the children with autism and to understand the effectiveness of these suggestions while taking necessary initiatives in the light of existing policies to accelerate sustainable development for the betterment of children with autism and future policy formulation.

1.5 Research Questions

In this research study research questions are given bellow:

- 1. What are the socio-demographic background and economic condition of children with autism?
- 2. What are the psycho-social developmental history of autistic children from birth to present?
- 3. What are the challenges faced by the autistic children?
- 4. What kind of services are received by autistic children from various organizations in terms of education, health, training and occupational therapy/vocational training?
- 5. What are the recommendations for some way out to deal with the psycho-social problems faced by the children with autism and how these suggestions can play an effective role in taking necessary initiatives in the light of existing policies to accelerate sustainable development for the betterment of autistic children and formulating future policies?

1.6 Scope of the Study

The study is very much important and most relevant in the scope of Institute of Social Welfare and Research, University of Dhaka and Social Science Research Council (SSRC), Planning Division, Ministry of Planning, Dhaka. This research study was conducted under M.Phil. Research Programs of Institute of Social Welfare and Research, University of Dhaka and

M.Phil. Scholarships of Social Science Research Council (SSRC) on "A Study on Psychosocial Situation of Children with Autism".

1.7 The Organization of the Thesis

A total of seven chapters have been highlighted in this research report. The first chapter deals with introduction where background of the study, statement of the problem, rationale of the study, objectives of the study, research questions, scope of the study, organization of the report and limitation of the study are highlighted. The second chapter deals with literature review where some relevant literature is reviewed. Conceptual issues and theoretical framework is discussed in the third chapter, where the conceptual issues of current research, such as- autism, children with autism, psycho-social, situation etc. are discussed and various theories related to autism, such as- Executive Dysfunction Theory, The Theory of Mind, Weak Central Cohesion (WCC) Theory, Social Learning Theory of Autism, Social Motivation Theory, The Charity Model and Human Rights Model of Disability are discussed in the chapter of Theoretical framework. At the end of this chapter, the theory related to the current research and how this theory can be applied is mentioned. The fourth chapter reflects the research design and methodology, where research approach, method of the study, research area, population and unit of the study, method of sampling, method of data collection, key informant interview, structured interview schedule, translation of interview guideline and interview schedule, data processing and analysis, validity, reliability and generalizability, ethical consideration and limitations of the study are discussed. Chapter five presents the Global and Bangladesh perspectives of autism. Findings and analysis of the study is being discussed in the chapter six. The summary of findings is highlighted in the seventh chapter. Also, some relevant recommendations have been given by discussing the new knowledge gained through this research study. At the end, what kind of role this research will be able to play in the formulation of future policies, has been highlighted in this chapter.

1.8 Pre-Testing Data Collection Instruments

In this research study, intensive observation and Pre-Test has been conducted. In view of this, the structured interview schedule of the research work was partially revised and refined. In order to fulfill the main objective of the study, to understand the psycho-social situation of children with autism, five sample units from Bangladesh Protibondhi Foundation (BPF) Kalyani Inclusive School, Malibagh, Dhaka and five from Society for the Welfare of Autistic Children (SWAC), Adabor, Dhaka premises were Pre-Tested by collecting data. After analyzing the data obtained from ten sample units, the content of the questions, practical

aspects and respondent's inconsistencies were reviewed and finally the data were collected from the determined number of sixty samples from the field level.

1.9 Limitations of the Study

In Bangladesh, although autism awareness has increased and research on autism has started but still it is insufficient. While looking for academic research reports related to autism, it was found that there is no such research work related to it in Bangladesh. Main limitation of the current research work is that most of the area of Bangladesh has not been covered by this research work. Since this research study is only Dhaka based, it has not been possible to highlight the data related to the psychosocial status of rural autistic children. For that reason, the actual situation of children with autism in rural areas was not reflected in this research. Therefore, it was not possible to generalize the entire Bangladesh through this present study. But since this research work has been conducted by adopting a scientific and systematic method, both qualitative and quantitative methods have been used in the research method, i.e. mixed method approach has been applied, therefore, this research work has been relevantly representative.

1.10 Conclusion

Conducting research on autism is undoubtedly a challenging task. The main reason behind this is that until now there has not been much public awareness built up regarding autism. It is not yet possible to accurately calculate the number of patients suffering from autism in Bangladesh. Whereas, the rate of children with autism is constantly increasing day by day in the country. Along with the policies that already have been adopted for children with autism so that it can be possible to ensure while getting mainstream civic services like general people, the recommendations emerging from this research work will be able to contribute significantly to the formulation of more effective policies and taking necessary steps to accelerate sustainable development for the betterment of children with autism in near future.

Chapter Two

Chapter Two: Literature Review

2.1 Introduction

An important step in conducting a research work is to review the Literature from relevant documents, books, articles etc. which is related to the research topic. Various studies, books, and articles related to the psycho-social situation of children with autism were reviewed based on the research objectives. In the context of Bangladesh, there is almost no research paper available on the psycho-social condition of autistic children, therefore related documents, academic paper and books are scarce here. In this perspective, so many research work done in the global context has been studied and reviewed. Several search engines have been used in this regard, such as-Google Scholar, Academia.edu and ResearchGate. It has been possible to get a lot of information from those related sources which is very much helpful for the present study.

The relevant literature found are described below:

2.2 Relevant Literature Review

1. Study on Prevalence of Autism in Bangladesh by Prof. Dr. AKM Fazlur Rahman, Dr. Shaheen Akhter, Dr. Animesh Biswas, Abu Sayeed Md. Abdullah.

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder that is primarily observed in the first three years of birth which affect a person's ability to communicate and interact with others. In Bangladesh, autism has already been identified as a burden of disease and it has been assumed that the magnitude is high and majority cases have not diagnosed till now.

The study explored the Prevalence of autism among 18 months to 36 months of children in a rural community of Bangladesh. A Cross sectional study method has been applied where Qualitative data were collected from the household level by door to door visit in rural community of Bangladesh. In this study purposive sampling technique were chosen a total number of 255265 population residing in 55492 households of the six unions of Raiganj Upazila of Division of Rajshahi .The study covered all household of the unions. In this research study M-Chat, DSM-4, Structured Questionnaire methods used as Data collection tools.

In this research study finding shown that among 5286 children of 18 months to 36 months aged group in one Upazila consists with six unions, four cases were found with autism. Prevalence of the ASD in rural community was found 0.075%. Among the four ASD cases three were boys and one was girl. The findings also shown the parents in the rural community

still not much aware about the disease, mostly treatment are available in Governmental or at local level. Social stigma and barriers are also found as one of the key challenge in rural areas of Bangladesh.

2. Psychosocial Aspects of Parenting a Child with Autism by Cynthia A. Serrata.

This literature review examines the psychosocial aspects involved in parenting a child with autism. Parenting a child with autism not only has an impact upon the parent's psychological well-being, but the family and marriage systems as well.

In this research study findings shown that depression and stress levels are significantly higher in parents of children with autism than in parents of typically developing children. The study also shows that there is a negative coo-relation between stress and marriage quality for parents of children with autism. Financial stress is also common as treatments for autism are expensive.

From this study it is also found that 68% of parents gained support from their friends, 58% received support from close family, relatives and 47% received support from spiritual guidance. A large majority, as much as 93%, also gained strength in others who had children with a similar diagnosis.

Findings suggests the importance of rehabilitation counselors in assessing the social networks and social supports of parents of children with autism, as well as providing them with professional and educational support.

3. Psychosocial Support for Families OF Children with Autism by Ashum Gupta, Nidhi Singhal.

An article by Ashum Gupta and Nidhi Singhal entitled "Psychosocial Support for Families of Children with Autism" was published in 2005.

This article focuses on the stress levels and coping strategies used by families of children with autism. This article discusses the challenges faced by the parents and siblings of autistic children and how they deal with them.

In this research, the researcher highlighted how important it is to get psychosocial support for families of children with autism and what are the limitations in getting such support. In this research article the researcher also paid attention to the present situation of autism in India.

The researchers explored it that- 70% of mothers and 40% of fathers suffer from high level of distress among parents of autistic children which has a multifaceted effect on family functioning including with their social, behavioral and cognitive development. It is also found that autism is very much unique by its multifaceted characteristics. As a result, parents are often not receptive to deal with the challenges of an autistic child.

This research has shown that family members of children with autism often experience negative psychological effects. As a result, parents of autistic children go through with by several negative emotions such as- disbelief, helplessness, anger, deep sadness, severe depression, remorse etc. Because it effects everyone in the family in some way, it affects autistic children as well.

Despite India being a developing country, there is a paucity of autism related service provider organizations. Steps can be taken to overcome these problems- increasing public education programs, supporting role of mass media, vocational training and rehabilitation plans, positive support system for children with autism and his family, ensuring respect of autistic children as an individual. In this regard, service providing organizations can play a multifaceted role, such as- information provider, proper guidance, building awareness etc.

The most important step in this regard is to create an effective service provider system that will work for the development of autistic children and their families and will play a significant role in the overall development of the state.

4. The Effectiveness of Psychosocial Intervention on Challenging Behavior in Children with High Functioning Autism Spectrum Disorder by Farangis Demehri, Hamid Aliyade, Shahla Pezesk, Faranzis Kazemi, Noor Ali Farokhki.

An article named "The Effectiveness of Psychosocial Intervention on Challenging Behavior in Children with High Functioning Autism Spectrum Disorder" published in 2016, written by Farangis Demehri, Hamid Aliyade, Shahla Pezesk, Faranzis Kazemi and Noor Ali Farokhki. The main objective of the research study is to examine the impact of psychosocial intervention on challenging behavior in children with high functioning autism spectrum disorder.

A two group experimental design was chosen with pretest and posttest In light of research objectives. Study population 24 autistic children, age limit between 8-12 are divided into two groups from where only the experimental group and their parents participated in the training session and GARS checklist have been applied to evaluate the challenging behavior. Later the posttest were conducted to examine both groups along with their parents.

The result of the research study showed that a significant difference was observed between the two groups of the study in challenging behavior. The researchers revealed that psychosocial intervention with parents and children with autism has positive effects in reducing challenging behavior. Therefore, it can be concluded that intervention programs, taught techniques are very much useful to decrease challenging behavior.

5. Psychosocial and Financial Needs, Burdens and Support, and Major Concerns among Greek Families with Children with Autism Spectrum Disorder (ASD) by

Vassiki Ntre, Katerina Papnikolaou, kalliopi Triantafyllou, George Giannakopoulos, Maria Kokkosi and Gerasimos Kolaitis.

A research study entitled "Psychosocial and Financial Needs, Burdens and Support, and Major Concerns among Greek Families with Children with Autism Spectrum Disorder (ASD)" published in 2008 is another significant literature.

The objective of the research study is to explore the general concerns and the needs for support and information of Greek mothers of children with autism, their health problems and the family financial burden.

Data was collected through Questionnaire from 61 mothers of children with autism, age limit between 6-17 years. The research study finds that- if there are autistic children in the family, it brings financial burden. One more thing is observed here that- there is a lack of information about autism among mothers of children with autism.

The findings that emerge from this research work are that parenting autistic children has severe negative effects on physical and mental health among the parents of children with autism. Its impact on career decision, psychological wellbeing and social life is extensive.

In conclusion, the researchers provide some recommendations, which are: An informal support networks is essential. In order to prevent social isolation, there is a need to increase the awareness of autism in a large part of the population. The urgent need to provide support to autistic children and their families is to develop a well-organized health network system and the provision of education services, which will help to meet the lifelong needs of children with autism.

6. Psychosocial Adjustment Strategies among Typically Developing Adolescents of Siblings with Autism Spectrum Disorder by Aiza Masyati Mas'ut and Manisah Mohd. Ali.

An article named "Psychosocial Adjustment Strategies among Typically Developing Adolescents of Siblings with Autism Spectrum Disorder" published in 2023, written by Aiza Masyati Mas'ut and Manisah Mohd. Ali.

If a family has an autistic child, not only the parents, but also the siblings of the family have to face various obstacles in the process of psychosocial development. In families with autistic children, their siblings who are normal like typical children, have severe adverse effects on their psychological, educational and social functioning. In this context, the research project has been designed on the basis of qualitative approach. Case Study method has been applied as research method.

The main objective of this research study is to explore the psychosocial adjustment strategies taken by typically developing adolescents when dealing with ASD siblings.

Six participants who matched the study criteria were selected following snowball and purposive sampling techniques. In-depth interviews were conducted using semi-structured interview schedule as data collection tools.

In this research study finding shown that siblings of autistic children are all controlled by negative emotions such as- depression, frustration, annoyance, anger, confusion, restlessness, embarrassment etc. Research findings from the data analysis of this study also emerged- how society and medical professionals perceive typically developing adolescents who have siblings who are sufferings with ASD. Researchers believe that the passive type of coping approach will not only prevent them from becoming victims but also be very helpful for their mental health.

Finally, the recommendations of this research study are that-parents, community, medical and academic professionals can play an important role in dealing with and coping with the problems. Interventions programs, sibling training etc. various programs can be taken.

2.3 Conclusion

By reviewing these literatures, it is observed that all of these literatures are somehow connected with the present study. Directly or indirectly, these literatures have provided me enough ideas in determining the research objectives, methodology and above all research design of the entire research work. These literatures helped me a lot in getting clear understanding of autism. However, Because of unavailability of literatures related to this topic in Bangladesh context, most of the research work done globally had to review. In Bangladesh, there is a vast lack of adequate information and awareness about autism. Therefore, this literature review has played a very significant role in advancing the present study. The importance of literature review is immense to get an idea about autism and psycho-social conditions of autistic children. So in this context, the above mentioned literatures are quite justifiable. Adequate findings will emerge through these literature review which will play a helpful role in future policy making and necessary programs and initiatives for the well-being of children with autism.

Chapter Three

Chapter Three: Conceptual Issues and Theoretical Framework

3.1 Introduction

This chapter highlights some of the relevant conceptual issues and theoretical framework of this research study. A very important aspect of any research work is determining the theoretical framework. Because, the theoretical framework acts as a guide for a research study. Moreover, the conceptual framework is also very important in guiding the findings of a research. A conceptual or theoretical framework may vary depending on the nature and methodology of the research. A theoretical framework serves as a basic review of existing theories and a roadmap for developing arguments. On the other hand, conceptual framework helps to visualize the research work and execute it.

The study identified the need to construct a conceptual framework and a theoretical framework by referring to the relevant concepts and the contents of some theories related to autism and the psycho-social condition of autistic children and constructing a theoretical framework.

3.2 Conceptual Issues related to the Present Study

This study addresses the need for a conceptual base to develop more effective results on psycho-social situation of children with autism.

3.2.1 Autism

The word "Autism" comes from the Greek word "Autos" which means self. According to Autistic Children's Welfare Foundation, Bangladesh (ACWFB) - "Autism is a lifelong developmental disorder that causes Qualitative abnormalities is reciprocal social interactions, patterns of communication and rigidities in thinking and behaviors".

The three main areas of difficulty which all people with autism share are sometimes known as the trait of impairments, they are-difficulties with social communication, difficulties with social interaction and difficulties with social imagination.

Autism Spectrum Disorder (ASD) is a group of complex neurodevelopmental disorders. It is characterized by social impairment, speech impediments and restricted and repetitive behaviors. It is a brain disease that usually affects a person's ability to communicate with others.

Types of Autism Spectrum Disorders

Autistic Disorder: It is also known as classic autism. This is the common pattern of autism. Children with autistic disorder are mainly characterized by language barriers.

Asperger Syndrome: Mild symptoms of autistic disorder are observed in children with this Asperger Syndrome. Social behavioral disorders and abnormal behavior are observed among them.

Pervasive Developmental Disorder: This is called atypical autism. In this case, some symptoms of autistic disorder and Asperger's syndromes are seen. Children with pervasive developmental disorder only face problems in social and language communication.

Symptoms of Autism

Symptoms of autism are usually observed in a child before the age of three. It can last till the end of life. However, the severity of symptoms may decrease over the time. It turns out that a child goes through the process of normal development from eighteen to twenty four months of age, but then they are no longer able to acquire new skills and the previously acquired skills are forgotten.

Some of the symptoms observed in an autistic children are:

- Even at the age of twelve months, he or she does not respond when called by name.
- Can't even play at the age of eighteen months
- Can't make eye contact
- Cannot express or understand feelings
- Late talk
- Keep repeating the same sentence etc.

Causes of Autism

No specific cause of autism has yet been diagnosed. There is considerable disagreement among scientists. According to most scientists; there are two main reasons behind a child becoming autistic, namely: genetic problems and environmental problems. A child with autism carries an error named DNA Copy Number Variant. Also, some toxic chemicals are believed by scientists to be responsible for autism, such as-pesticides, mercury, lead, use of artificial colors in food, etc. In addition, scientists are of the opinion that there is a possibility that the child will be affected by autism due to structural defects of the brain, any accident or infection before or after the birth of the child.

Diagnosis of Autism

Medical Science has not yet discovered any test by which autism can be diagnosed. A doctor diagnoses the disease based on the behavior and growth of children with autism.

Management of Autism

Autism can be controlled and managed with medication, therapies and special education. A child's development can be accelerated if the child gets services through early intervention. Autistic children can improve their condition with the help of various therapies.

3.2.2 Children with Autism

Autism is a developmental disorders characterized by difficulties with social interaction, communication, and repetitive behavior. When these signs will be seen in the baby, they will be considered as the children with autism. These signs can be seen during the first three years of a Children's life. Autistic children tend to say the same things and do the same things over and over again. Their behaviors and sensory systems are different from normal children. Autistic children can be highly skilled in specific areas, such as- math, science, drawing, sports, music etc.

Characteristics of Children with Autism

- > If the baby does not laugh alone by the age of six months;
- ➤ Unable to speak little words by the age of twelve months;
- ➤ Inability to express thoughts using two or more words by age of twenty four months;
- Forgetting again after acquiring the use of language;
- ➤ Inability to engage in age-appropriate social behavior;
- > Difficulty forming social relationships;
- > Communication problems;
- ➤ Repetition of behavior, such as- clapping hands, twirling fingers, rolling around on the floor etc.

Children who exhibit these characteristics are considered as children with autism.

3.2.3 Psycho-social Approach

A psycho-social problem is a type of problem that disturbs the person mentally, takes the person away from his own place. Psycho-social problems reduce a person's judgment and impair their ability to perform social roles.

The psycho-social approach looks at individuals in the context of combined influence that psychological factors and the surrounding social environment have on their physical and mental wellness and their ability to function. This approach is used in a broad range of helping profession's in health and social care settings as well as by medical and social science researcher's. Psycho-social support is the provision of psychological and social resources to a person by a supporter intended for the benefit of the receiver's ability to cope with problems faced. Psychological theories and models for autism explain the underlying psychological process of autism, including:

- Social functioning;
- Stereotyped and repetitive behavioral patterns and
- Language and communication.

3.2.4 Situation

According to Cambridge Dictionary- "Situation is the set of things that are happening and the conditions that exist at a particular time and place".

For an example; like normal children, children with autism also have a difficult time in adolescence. Like other typical children, changes in body and mind occur between the ages of ten and nineteen. During this time their reproductive system changes, the tone of the voice begins to change, period starts etc. Autistic children also have to adapt to these changes in body and mind. This sometimes threatens their physical safety. So, everyone including parents, teachers and relatives of children with autism should be aware and some things are very important to look at, they are described below;

- Try to explain physical changes through stories or pictures;
- Trying to explain the physical differences between men and women;
- Ensuring physical and mental safety;
- Good touch and bad touch should be explained through pictures or practical training;
- Autistic children should be taught not to touch other people's bodies;
- Girls should be trained to change sanitary napkins during periods and
- Boys should be trained to shave their beards etc.
- One thing to always remember is that autistic children are also part of our society. So, having compassion for them is very important.

3.3 Theoretical Framework

Behavior, thinking and social characteristics of children with autism are different from normal children. A few theories that are consistent with current research are highlighted below:

3.3.1 Executive Dysfunction Theory

Executive function is the mental ability to coordinate thought and action to accomplish a goal. It is a type of cognitive process that we use to control our behavior. A test has been conducted on this subject which is called "Tower of Hanoi Test".

Tower of Hanoi Test

In 1999, Craig and Baron-Cohen conducted three studies using TTCT (Torrance Tests of Creative Thinking). They tested participant's creativity. The results showed that-concepts of the neurotypical person included a rich range of suggestions.

3.3.2 The Theory of Mind

The Theory of Mind has existed for some time and picked up interest in the 1980s. Premack and Woodruffs (1978) studied the theory of mind alongside Baron-Cohen, giving it more prominence.

The Theory of Mind is the ability to understand others mental states and how they may differ from others. The Theory of Mind (ToM) is a broad, complex and multifaceted construct, defined as the ability to attribute mental states (beliefs, desires, and intentions) to oneself and to others, making it possible to explain and predict behavior (Premack and Woodruff, 1978). Autism involves significant difficulties in understanding mental states. The Theory of Mind focuses on deficits in reasoning about mental states. Autism is not a single condition but a category of various disorders, which is why it is called "Autism Spectrum Disorders".

The Theory of Mind is a theory related to understanding other people's mental state, beliefs, intentions, feelings etc. Factors identified by Baron-Cohen, Lesley and Freeth in 1983 in autistic children and adults are: Autistic individuals often have trouble understanding others mental states, beliefs, intentions, feelings etc. In 1985 Baron-Cohen suggested that autism is caused by an absence or weak theory of mind or metalizing power in children. According to Baron-Cohen's Theory of Mind study, children diagnosed with autism significantly second lower in the belief questions, suggesting they had a lower theory of mind than typical children and children who diagnosed with downs syndrome.

3.3.3 Weak Central Cohesion (WCC) Theory

According to this theory, autistic individuals fail to make cognitive adjustments. They integrate local level information into global level spaces.

In an examination of this subject- participants are shown an irrelevant scene made up of many pictures and asked, can you pick out a shape that matches the small triangle in the picture? The results showed that individuals with autism found the shape faster than neurotypical people and focused on the details of the image to the exclusion of the whole scene, which accelerate spatial processing. While this may not be as important to a neurotypical person, it does cause anxiety in a person with autism. In this case, the autistic person may face problems in the process of putting together separate sentences to form a coherent story.

3.3.4 Social Learning Theory

The Social Learning Theory is the mirror neuron system. A mirror neuron system is a group of specialized neurons that can mirror actions that others can perform.

Social learning refers to the transfer of one person's knowledge or behavior to another through imitation and observation. When we observe another person's behavior, the mirror neuron system is then activated. But research has shown; mirror neuron system are not activated as frequently in individuals who are suffering with autism. It is more active in neurotypical individuals. Hence, it is observed from this theory that individuals with autism are hindered in understanding the behaviors and perspectives of others.

3.3.5 Social Motivation Theory

The Social Motivation Theory of autism states that autistic children are less interested in social engagement. As a result, they pay less attention to social information. What this theory explain is that children with autism are less likely to be influenced by social stimuli. The point can be explained with an example- Autistic children are more inhibited than neurotypical children in communicating with others and expressing emotions.

For example; autistic people often lack:

• Theory of Mind (TOM):

The ability to understand that other people think differently or to accurately guess what others are thinking and feeling.

• Initiative skills:

The ability to closely observed and copy the behavior of peers in various social situations.

• Communication skills:

The ability to use appropriate verbal and nonverbal language to communicate wants, needs and ideas.

• Play skills:

The ability to engage meaningfully with same age peers in age-appropriate games that require collaborations or shared creative thinking.

• Empathy:

The ability to put oneself into another person's shoes and imagine how they might be feeling (empathy is different from sympathy).

In addition to these deficits which, not surprisingly, make day-to-day life extremely challenging, people with autism are not motivated to action by the approval of others. However, one study showed mixed results. So, the reliability of this story is often questioned.

3.3.6 The Charity Model

Children and persons with disabilities have always been treated as objects of charity and pity. In the community in which they live, people always assume that people with disabilities only need help and sympathy. According to this model, no attempt is made to convert persons with disabilities into human resources. They are always considered as a burden to the society. Charitable resources are emphasized in this model as the only means of assisting persons with disabilities and dependence is more on donors than local resources. The Charity Model always portrays disabled people as marginalized groups in society who deserve only sympathy. This model focuses on providing assistance to persons with disabilities through social charity rather than undertaking sustainable development programs. This is why Charity Model is considered an outdated model.

3.3.7 Human Rights Model of Disability

This model is based on Human Rights Principles. Disability is part of human diversity. That is why this issue should be given importance in all areas. People with disabilities have equal rights to all those rights that people at all levels of society have, because, they are an integral part of the society.

The Human Rights Model is an important model to ensure all the rights for the people with disabilities. In 2006, it is stated in "The United Nations Convention on the Rights of Persons with Disabilities" which was developed by the United Nations, are:

- > Equality must be ensured for persons with disabilities around the world
- ➤ Government of every country in the world should focus on ensuring the rights of persons with disabilities and taking necessary steps.

This model states that disability cannot be used as an excuse to deny or person with disabilities cannot be denied civil rights. According to this model, the three things that emphasized are:

- Equality
- Human Dignity and
- Social Justice.

People from all walks of life should be empathetic towards people with disabilities. They must be accorded respect and dignity as "human beings".

3.4 Conclusion

By reviewing the above conceptual and theoretical framework, essential insights into autism and psycho-social aspects of autistic children have been found which are very helpful in this research work. The theoretical framework provides a direction as to which theories can play a helpful and effective role in this research study. I have discussed a total of five logical theories and two relevant models in my chapter. Among them, the model that seems to be the most relevant for my research study is "Human Rights Model of Disability". Since this model is based on human rights principles, that is why its role in ensuring the rights of disabled people is very important. Children with disabilities are part of our society. If they are to be brought back into the mainstream of society; equality, human dignity and social justice must have to ensure which will accelerate sustainable development.

Chapter Four

Chapter Four: Research Design and Methodologies

4.1 Introduction

Research is a scientific investigation process. The successful accomplishment of a research work depends on the research design and selection of methods. The present research study is a descriptive work. According to the nature of this research study, the research method which has been found to be the most appropriate are Mixed Method Approach by following both Qualitative and Quantitative Approach. To fulfill the main objective of the research, the widely used Social Survey Method of Quantitative Approach has been used, on the other hand for Qualitative Approach, Key Informant Interview (KII) and Case Studies has been done. In the present study, the primary data were collected from 60 sample unit using an accidental sampling method through a Structured Interview Schedule, Expertise interviews were taken from policy maker cum disability expert, NGO executives, pediatrician, academician, media personality and teacher and 6 Case Studies of children with autism has been done to collect data as a primary sources of data collection. Data has been collected from the secondary sources as well as, such as newspapers, journals, articles, books, websites including electronic news media, research studies, seminar articles etc. This chapter highlights various relevant issues including research design, research approaches and methodologies used in the study, sampling techniques, data collection tools and techniques, data processing, analysis and presentation methods, ethical considerations and limitations of the study.

4.2 Research Approach

Human nature is always curious. An insatiable desire to know the unknown or to delve deeper into what is already known has always driven man. Research is a scientific and systematic process of finding truth; the purpose of which is to investigate various questions.

Research is the process of making logical decisions by analyzing the facts and collecting objectives and accurate data to solve a particular problem by adopting scientific methods. Research can be different types of based on purpose, depth, analysis, time, data etc. According to the data used in the research, there are three types of research; they are: Qualitative Approach, Quantitative Approach and Mixed-method Approach.

4.2.1 Mixed-Method Approach

A mixed method approach is a research method in which researchers collect and analyze both quantitative and qualitative data within the same study. When a study uses both qualitative and quantitative data types to investigate the problem through interpretive analysis, it is called

mixed method approach. Data and results of mixed method are mathematical and unmathematical.

As both quantitative and qualitative methods have been adopted in the present research work, therefore, this present study has been carried out by using Mixed-method Approach to understand the Psycho-social Situation of Children with Autism. Social survey as quantitative approach through structured interview schedule and on the other hand, observation, key informant interview schedule (KIIs), Case Study Guideline as qualitative approach were applied for this research study to understand and evaluate different aspects of children with autism, including with socio-demographic condition, sex, religion, educational background, financial condition, occupation, psycho-social challenges faced by the children with autism, various services they are getting from the service providers, existing policies and initiatives and future necessary policy formulation and programs for the well-being of children with autism etc.

4.3 Research Methodology of the Study

The research study was carried out through Mixed-Method Approach.

Research methodology is the specific method or technique used to identify, select, process and analyze data about a topic. The purpose of research methodology is to explain the rationale behind selection of the research methodology, data collection methods, methods of analysis and supporting other key points of the work. Choosing an appropriate research method is a very important step in any research, because the use of proper methodology helps to fulfill the aims and objectives of a research work and plays a role in guiding the research in the right direction. The right choice of research method plays a very effective role in giving a scientific framework to the overall research work. Selection of wrong research method acts as a hindrance in accomplishing the objectives of the research work. Research methodology depends on the nature of research, objectives, situation, time, expected outcome etc. The present research study was carried out to understand the psycho-social situation of children with autism. The most effective research method for finding information about the psychosocial status of autistic children is the Mixed-Method Approach, using both Quantitative and Qualitative Method which provides in-depth information about social conditions, relationships, behavior, concerns, resources, needs etc., it plays a helpful role in formulating and implementing constructive social programs and formulating effective policies. Hence, Mixed-Method is used in this study as this technique is very useful to find out descriptive and informative data of the present study in a relevant manner.

4.3.1 Main Method

One of the most popular and widely used research techniques in modern social research is the social survey method.

In general, survey refers to collecting information on the ground about a subject or event. This method is a technique of gathering information about various social issues related to the mindset, attitude and lifestyle of the people of a geographical area.

Ernest W. Burgess said while defining the Survey Method- "It is the scientific study of conditions and needs of community for presenting a constructive program of social advance".

So, it can be said that social survey method is to collect specific data through structured interview schedule from some people representing the larger population concerned with the subject to achieve the objectives of the research.

The present study was carried out with The Social Survey Method of Quantitative Approach and data was collected through Structured Interview Schedule. On the other hand case study method was used for qualitative part of the study.

4.3.2 Research Area

In a research study, selection of the study area is very important stage. The Social Survey Research Method was carried out in Bangladesh Protibondhi Foundation (BPF) Kalyani Inclusive School, Malibagh, Dhaka and Society for the Welfare of Autistic Children (SWAC), Adabor; Dhaka premises.

4.3.3 Population and Unit of the Study

The children who are suffering from autism was considered as the population and the children with autism who are getting services by Bangladesh Protibondhi Foundation (BPF) Kalyani Inclusive School and Society for the Welfare of Autistic Children (SWAC), age limit between 4-18 was considered as the unit of the analysis.

4.3.4 Method of Sampling

In this present study, accidental sampling technique was followed which is a type of non-probability sampling. This process continues until the sample reaches to my expected volume. This method is used to arrive at a temporary decision immediately. For this research work, accidental sampling technique was followed to select study population of 60 autistic children from which 30 from Bangladesh Protibondhi Foundation (BPF) Kalyani Inclusive School and 30 from Society for the Welfare of Autistic Children (SWAC).

4.3.5 Key Informant Interview (KII)

Key Informant Interview is one of the most popular methods of social research. It is a widely used and reliable method of collecting information and data. In the light of the content and purpose of the research, data collection through in-depth interview is called Key Informant Interview (KII).

In order to make the current research work more reliable, face-to-face interviews with eight participants who have relevant information on the psychosocial situation of children with autism were conducted in light of the research objectives and content.

4.3.6 Case Study Method

The case study method is becoming increasingly popular in social science research. An important method of social research in studying social problems is the case study method. This method is used to find out details about a person, group or organization. This method has successfully contributed to the field of social work, law, medicine, psychiatry, education, sociology, economics, political science etc.

According to P.V. Young (1948): - "Case study is a method of comprehensive study of a social unit, be that unit a person, a family, institutions, cultural-group, or even an entire community". A case study is a method that analyzes a social unit in depth and thoroughly from different perspectives.

A total of 6 cases are reviewed as a supporting method for the present study considering the effectiveness of the case study method. Different areas of Dhaka South City Corporation were selected to carry out the Case Studies of children with autism.

4.3.7 Method of Data Collection

In this Research Study Methods of Data Collection tools is used as like as bellow:

Observation, Structured Interview Schedule, Case Study guideline and KII guideline. The Interview Schedule was used through face to face Question and Answer session for collection of data from the parents of the children with autism and Personnel from related stakeholders. Related Documents from Kalyani Inclusive School, Society for the Welfare of Autistic Children and other related books, journals, articles, newspapers, previous researches are also used for the tools of Data Collection.

4.3.8 Structured Interview Schedule

¹ Devi, K.B.L. (2020). Case Study Method. e-PG Pathshala INFLIBNET Centre Retrieved October, 2023 from https://www.researchgate.net/publication/344780835

An important data collection technique in social research is the interview schedule. According to Good and Hatt (1952) - "Schedule is the name usually applied to a set of questions which are asked and filled by an interviewer in a face to face situation with another".² The interview schedule is prepared with complex and advanced questions. Through this method it is possible to collect relevant information. Data obtained after conducting face-to-face interview session through an interview schedule is comparatively more accurate and reliable. In the present research study, the respondents were interviewed face to face through a structured interview schedule and it was recorded by the interviewer.

4.3.9 Translation of Interview Guideline and Interview Schedule

Most of the stakeholders during face-to-face in-depth interview session with interview guideline and all the parents of autistic children participating in the social survey were interviewed in Bengali through a structured interview schedule as their mother tongue is Bengali and they were comfortable giving interviews in Bengali. But since this is an academic research work and the medium is English, the interview schedule and guidelines were translated into English very carefully and efficiently after conducting the interviews.

4.3.10 Data Processing and Analysis

The next step after data collection is data processing. In the first stage of the research, data was collected from using various tools and techniques of data collection and collected data is processed according to order. The collected data was checked and organized to look across all respondents and their answers in order to identify differences. The accuracy of the information is determined. The data obtained from the survey method is entered into the widely used SPSS software in the computer. Then various types of statistical analysis are performed and the analyzed data is presented.

4.3.11 Validity, Reliability and Generalizability

Multiple methods such as- observation, interviews and recordings were employed towards generalizability of the research to enhance the reliability and validity of the research and to improve the analysis and understanding of construction of other research studies.

4.4 Ethical Consideration

Some ethical issues were strictly followed while conducting the present research. As no financial assistance or any other kind of assistance was provided to the respondents during

² Good, & Hutt. (1925). Methods of Social Research, New York: Mc-Graw Hill Book Company INC.

the data collection process, this matter has been clearly informed before conducting the interview session with the respondent. Prior consent was obtained from each respondent before conducting the interview. The respondents were assured that the collected data would be used for academic research purposes only. "The principle of confidentiality" has been strictly followed in the collection of data for this research work. It is also ensured that the results of the research will not have any negative impact on the personal and social life of the respondents. The research work is totally free from all forms of manipulation, lies, deception and biasness. This is an independent and unique research study, no part of this study which has been taken from any other research report and has not been used in any previous research work.

4.5 Limitations of the Study

Some limitations are observed in any research work. This research study is also no exception. Various problems which had to face while conducting research work on psychosocial situation of children with autism are highlighted below:

- ❖ During the process of data collection, a total number of 60 parents or guardian of children with autism were selected from 2 special education schools from which 30 respondents were selected from each school. But it would have been better if I could take more sample for the present study.
- ❖ This present study was conducted based on urban area of Bangladesh. But for further study, researchers can utilize this report as a guideline for their further research work in rural area also.
- ❖ I had to accomplish this research work within a planned timeframe. Therefore, with a keen interest I tried to overcome all those limitations. As a researcher always wants to go to the deeper of a study for intensive outcome of the research work. So, I had to limit my area and sample size.

4.6 Conclusion

This entire chapter is devoted to research design and methodology. This chapter discusses the various steps of research method. The present study was conducted by following Mixed-method approach. "The principle of Confidentiality" was strictly followed during data collection process. Interviews were conducted keeping ethical considerations in mind. Although data collection process was very time consuming and costly due to certain

limitations, but still the research work was carried out with very strategically and effectivel through overcoming the limitations of the study.		

Chapter Five

Chapter Five: Autism: Global and Bangladesh Perspectives

5.1 Introduction

Now a days everyone is more or less familiar with the term "Autism". Autism is a neurodevelopmental disorder. Autism is characterized by lack of functional communication skills, problems with social interaction and repetitive behavior patterns. Because of the behavioral diversity of autistic children, no single treatment approach can solve this problem. The number of children with autism is increasing day by day across the world. Scientists blame various factors behind it, such as-a competitive lifestyle due to urbanization, excessive stress, excess of fast food culture, junk food etc. Like other countries of the world, the number of children with autism is increasing at a significant rate in Bangladesh. But in dealing with this problem, rural areas face more difficulties than urban areas. The main reason behind this is that there is still no awareness about autism in the rural areas of Bangladesh; rather, there are many superstitions about autism. In most cases, children with autism are never brought under medical care. Hence, it is high time to formulate adequate and well-planned policies on autism, which will accelerate sustainable development.

5.2 Global Perspectives of Autism

Autism is a developmental brain disorder that impairs a child's ability to socialize and form relationships. The number of patients with autism is severely increasing worldwide and has become a public health problem. While previously there was little awareness of autism, over the past decade, public awareness of autism has grown significantly across the world. An epidemiological data shows that- 1 child in every 100 children in the world is affected by autism.

According to epidemiological data, the presence of autism is observed in about 52 million people worldwide, which supports the concept of 1% - 2% of children with autism worldwide. In May 2014, a resolution was adopted at the 67th "World Health Assembly" of "World Health Organization, where it is said that- "Comprehensive and Coordinated efforts for the management of autism spectrum disorders" (WHO, 2013); through which assistance is provided to 60 countries of the world.

According to the definition of "National Autistic Society"-"Autism is a lifelong developmental disability which affects how people communicate and interact with the world". A study found that around 700,000 children and individuals in the United Kingdom have autism.

According to the statistics of the "American Autism Society"- 1 percent of the world's population is affected by autism. The rate of children with autism is much higher in developed

countries than in underdeveloped countries. Some studies have shown that higher-income and single-parent families have relatively higher rates of autism compared to lower-income families and this disease is more among boys than girls, the ratio of which is 4:1. In 1943, American psychiatrist Leo Canner was the first to identify autism while working with children with psychological problems and coined the term "Autism".

In November 2017, the United Nations General Assembly adopted a resolution on the implementation of the "Convention on the Rights of Persons with Disabilities (CRPD)", drawing attention to the special challenges faced by women with disabilities. The United Nations General Assembly decided to observe April 2, 2007 as "World Autism Awareness Day" to highlight the need to help and improve the quality of life of children and adults with autism. The theme of the 15th "World Autism Awareness Day" in 2022 was-"Building a world that nurtures the talents of people with autism".

Table 1 highlights the autism rates by country from upper to lower order. If we take a look over the Table 1, it is seen that, Qatar has the highest rate of autism and prevalence rate of autism is 151.20 per 10000 children. One thing is noticeable here that autism rates are higher in Middle Eastern Countries. Bangladesh ranks 43 among all of the countries and the rate of autism is 85.30 in per 10000 children.

Table 1: Autism Rates by Country

Country	Prevalence per 10,00 Children
Qatar	151.20
United Arab Emirates	112.40
Oman	107.20
Bahrain	103.30
Saudi Arabia	100.70
Kuwait	97.70
Jordan	92.10
Syria	91.90
Afghanistan	91.20
Palestine	91
Sweden	90.80
Libya	90.60
Yemen	90.40
Iran	90.30
Sudan	90.10
Mexico	89.90
Lebanon	89.80
Egypt	89.40
Algeria	89.40

Iraq	89.40
India	88.50
Morocco	88.40
Bhutan	88.40
Australia	88.20
Honduras	88
Tunisia	87.90
Turkey	87.80
Costa Rica	87.70
Nicaragua	87.50
Panama	87.40
Venezuela	87
Pakistan	86.70
Kenya	86.50
Guatemala	86.50
Canada	86.40
Belize	85.90
Japan	85.80
Colombia	85.80
Grenada	85.60
New Zealand	85.50
Greenland	85.50
Bermuda	85.40
Bangladesh	85.30
Dominican Republic	85.30

Source: (World Population Review, 2023)

According to Table 2, it is explored the rate of autism based on gender. A Study which was conducted in 2018 explored that boys have a higher rate of autism than girls. The autism rate of boys is 36.5 per 1000 and 23.0 in girls which is respectively 3.7% in boys and 0.9% in girls.

Table 2: Prevalence Rates of Autism by Gender

Gender	Autism Prevalence in 8-	Percent
	Year-Olds (2018)	
Boys	36.5 per 1,000	3.7%
Girls	8.8 per 1,000	0.9%
Overall	23.0 per 1,000	2.3%

Source: (www.discoveryba.com)

Table 3 shows that the worldwide prevalence rate of autism is 1 in every 100 people which is 1 in every 36 people in the United States. Globally, the country with the highest autism rate is Qatar from the Middle East and the country with the lowest autism rate is France.

Table 3: Autism Prevalence Statistics:

Statistics	Data
Global Autism Prevalence	1 in 100
U.S. Autism Prevalence	1 in 36
Country with the Highest Autism Rates	Qatar
Country with the lowest Autism Rates	France

Source: (www.discoveryba.com)

5.3 Bangladesh Perspectives of Autism

It is not yet possible to accurately determine the number of children with autism in Bangladesh. Day by day the number of children with autism is increasing at an alarming rate in Bangladesh.

A study conducted by the CDC (Centers for Disease Control and Prevention) in 2018 revealed that-in 1980, 1 in every 2500 people was autistic and in 2010, 1 in every 110 people had autistic traits, which stands today; 1 in every 54 people.

According to a 2009 estimate- one percent of children in the country are affected by autism. A 2013 report showed; three percent of children in Dhaka city are affected by autism. According to the Ministry of Social Welfare, 2.87 percent of people with disabilities in the country have autism.

In a developing country like Bangladesh, once there was no idea about autism among common people. Autistic children and their families were subjected to severe contempt, negligence and deprivation. The fact that autistic children are also part of the mainstream of society is not considered at all. However, significant changes are being observed at a slow pace. "World Autism Awareness Day" is celebrated every year in Bangladesh like other countries of the world on 2nd April.

Bangladesh is moving ahead in autism related activities at an incredible speed. The National Task Force has been formed with 14 Ministries. National Steering Committee has been formed by 8 Ministries, including- Ministry of Social Welfare, Ministry of Health and Family Welfare, Ministry of Education, Ministry of Women and Children Affairs and Ministry of Primary and Mass Education.

Bangladesh's current Prime Minister Sheikh Hasina and prominent nuclear scientist Dr. Wazed Mia's daughter Saima Wazed Putul's contribution to the cause of autism is undeniable.

She is serving as the Chairperson of Bangladesh National Committee on Autism. Since 2008, she has been working tirelessly on issues related to autism and neurological complications in children. It was through her efforts that "The Neurodevelopment Disability Trust Act, 2013" was passed in Bangladesh. She is also working as a Goodwill Ambassador for the World Health Organization in South East Asia to set various policies on autism in Bangladesh. A number of autism treatment centers and support centers have been set up under the inspiration the inspiration of Saima Wazed Putul such as: Institute for Pediatric Neuro-disorder and Autism (IPNA), Bangabandhu Sheikh Mujib Medical University, Shahbagh, Dhaka, National Institute of Mental Health, Child Guidance, Sher-E-Bangla Nagar, Dhaka, Dhaka Shishu hospital, Shishu Bikash Kendra, various private institutions and specialized schools approved by the government; disability services and help center, National Disability Foundation etc. are notable.

The Government of the People's Republic of Bangladesh has taken various programs and steps for the overall development of all types of disabled persons including autistics. The ongoing activities carried out by the National Foundation for the disabled under the Government of the People's Republic of Bangladesh are:

Provision of Free Therapeutic Services through Disability Services and Centers

A total of 130 disability service and aid centers were launched in 64 districts and 39 upazilas in order to provide the necessary health services to all the disabled people in the remote areas of Bangladesh. All the services that are conducted under these are:

- Providing free therapeutics
- Counseling
- Referral service
- Providing supporting materials etc.

Mobile One Stop Therapy Service

Under this service free therapeutic services are being provided through 40 mobile therapy vans.

Free distribution of Supporting Materials

Under this program, through 103 disability service and help centers; support materials are distributed at free of cost such as- sewing machine, walking frame, standing frame, wheel chair, crutch, prosthesis etc.

Management of Schools for the Mentally Retarded

A total of 74 special schools are being run by the National Handicapped Development Foundation. At present these schools have 1103 teachers/staff and 10889 students.

Management of Special School for Children with Autism

A completely free special school was started in October 2011 at the National Disability Development Foundation campus. Later, a total of twelve schools are being run in Dhaka's Mirpur, Lalbagh, Uttara, Jatrabari and six divisional cities (one each in Rajshahi, Khulna, Chittagong, Barisal, Rangpur and Sylhet), one in Gaibandha district and one each in Biswanath upazila. Currently 160 children with autism are getting free education in these schools.

Autism Resource Center:

In 2010, the National Disability Foundation established a resource center on campus. The services provided through this resource center are:

- Occupational therapy
- Speech and language therapy
- Physiotherapy
- Counseling
- Group therapy
- * Referral service
- ❖ Providing counseling services to parents of children with autism etc.

Grant:

Donation at the Private Level: From 2003-2004 to 2020-2023 fiscal year, grants and loans of taka 16 crore have been disbursed to private charities from the Foundation's Welfare Fund.

Financial assistance at the Individual Level:

In the financial year 2021-2022 TK 9, 43,841 has been distributed to 135 persons with disabilities which is still ongoing.

There are also other programs which are being run by the national Disability Foundation; they are: Employment fair for persons with disabilities, skill development related training, working handicapped men and women hostel, home for disabled children who are orphan, international and national day of persons with disabilities is celebrated every year on December 3, setting up of marketing and exhibition centers etc.

To ensure the welfare and development of neglected, backward, poor, orphans, disabled and backward people as per Articles 19(1) and (3), 27, 28(1), (2) and (4) and 29(1) of the Constitution of Bangladesh and "The Neurodevelopmental Disability Protection Trust Act, 2013" and "The Disability Integrity Special Education Policy, 2019" to improve the quality of life of persons with all types of disabilities, including persons with neurodevelopmental disorders.

"The Neuro-Developmental Disability (NDD) Protection Trust" has provided online training services to 390 parents/guardians in 190 upazilas of 53 districts of Bangladesh on caring for children and individuals with autism during Covid situation. At the same time, 450 teachers

of 115 schools in 105 upazilas of 60 districts have been trained which is still ongoing. An application "Smart Autism Barta" has been developed to test for autism at home.

5.4 Conclusion

If children with autistic characteristics can be ensured effective health services including proper education, training, guidance, motivation and various therapies, then autistic children will also be able to enter into the mainstream development of Bangladesh. And in order to achieve this goal, it is very necessary to empathize with changing the negative attitudes of people from all walks of life towards autistic children and individuals.

Chapter Six

Chapter Six: Findings and Analysis of the Study

6.1 Introduction

The main focus of this chapter on the present research work is to analyze and present the results of the data obtained by applying the Social Survey, Case Study and KII method.

Analyzing psycho-social conditions is necessary to reintegrate autistic children into the mainstream of society and include them in the journey towards achieving the aspirational goals of sustainable development. In order to fulfill the purpose of the research, the researcher conducted a survey by interviewing the parents of 60 autistic children in 2022-2023. Moreover, in 2023, interviews were conducted with 10 prominent people who are experts and who have real information on the subject and data were collected from 6 case studies to investigate the psycho-social status of autistic children. Research findings were extracted from the collected data through survey, KII and case studies mentioned in this chapter and the findings have been analyzed. After that the analysis of the findings was presented accordingly.

6.2 Findings of the Social Survey

6.2.1 Introduction

The researcher conducted this study to understand the psycho-social condition of autistic children and based on that goal, information were collected from the parents of children with autism through the questionnaire.

Data were collected from 2 "Special Education Schools" of Dhaka division by following accidental sampling technique from 60 sample units through structured interview schedule. First of all pre-test was done and the reflections of a total of 10 respondents from 2 schools were observed to check the validity of the questionnaire. Then the consistency and inconsistency of the data was checked after pre-test and in the final stage the data was collected from the mentioned above numerical sampling unit by aiming to the fulfillment of research objectives.

In this part, based on the opinion of the respondent, the collected data and information were analyzed and presented.

6.2.2 General Demographic Information of Children with Autism Child Age

Analysis of survey data shows, the age distribution of autistic children receiving services in "Special Education Schools"; about 33 percent of students are in the age group of 13-16 years.

Children in the age group of 5-8 and 9-12 years have about 26 percent. The number of autistic children aged 17+ is about 13 percent. Most of the children are aged between 13-16 years according to the data obtained.

Categories	Frequency	Percent	Cum. Percent
5-8	16	26.67	26.67
9-12	16	26.67	53.33
13-16	20	33.33	86.67
17+	8	13.33	100
Total	60	100	

Table 4: Child Age

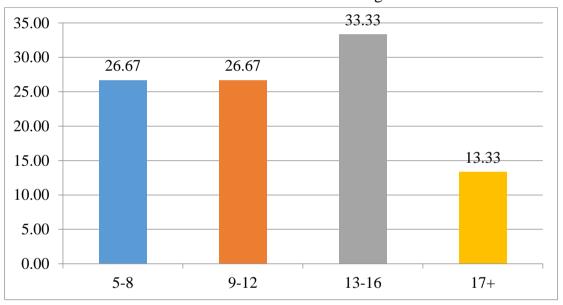


Figure 1: Child Age

Gender

The gender distribution of autistic children is roughly 65 percent boys and about 35 percent are girls.

Categories	Frequency	Percent	Cum. Percent
Body	39	65.00	65.00
Girl	21	35.00	100
Total	60	100	

Table 5. Gender

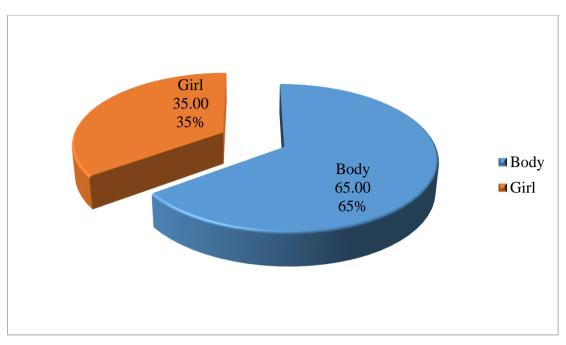


Chart 1: Gender

Religion

In terms of religion, about 93 percent of autistic children are Muslim and 6 percent are Hindu. Children of other religion has not been found in the survey.

Categories	Frequency	Percent	Cum. Percent
Muslim	56	93.33	93.33
Hindu	4	6.67	100
Total	60	100	

Table 6: Religion

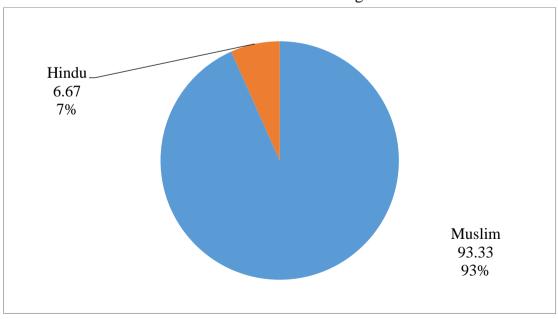


Chart 2: Religion

6.2.3 General Demographic Information of the Respondent

Age of the Respondent

According to the data obtained from the 60 respondents, about 45 percent of the respondents are aged between 35-44 years. About 26 percent are in age limit between 45-54 years. About 25 percent of the respondent's age limit between 26-34 and about 1 percent of the respondents are aged between <16-25 and 55-64>.

Categories	Frequency	Percent	Cum. Percent
<16-25	1	1.67	1.67
26-34	15	25.00	26.67
35-44	27	45.00	71.67
45-54	16	26.67	98.33
55-64>	1	1.67	100
Total	60	100	

Table 7: Age of the Respondent

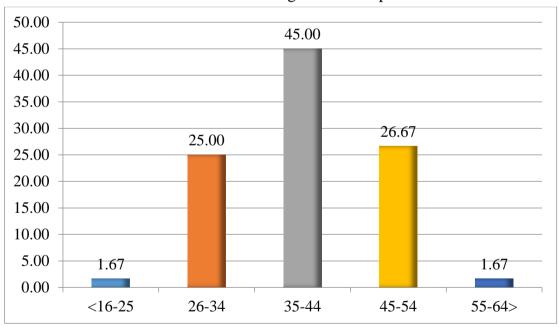


Figure 2: Age of the Respondent

Gender

According to the data collected from the survey, about 63 percent of the respondents are Female and about 36 percent are male.

Categories	Frequency	Percent	Cum. Percent

Male	22	36.67	36.67
Female	38	63.33	100
Total	60	100	

Table 8: Gender

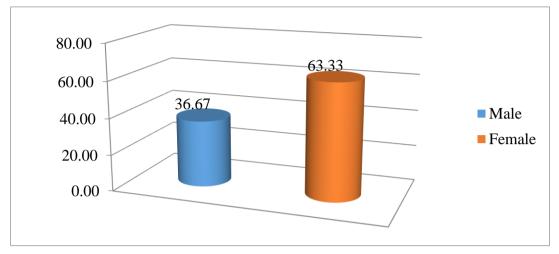


Chart 3: Gender

Marital Status

According to the data collected from the respondents, about 91 percent of the respondents are married. About 5 percent are widower and about 3 percent are divorced.

	Frequency	Percent	Cum. Percent
Married	55	91.67	91.67
Divorced	2	3.33	95.00
Widower	3	5.00	100
Total	60	100	

Table 9: Marital Status

Educational Qualification

A review of the educational qualifications of the respondents shows that, 43 percent of the respondents are Post Graduate. The second highest 25 percent respondents are Graduate. 10 percent are in Higher Secondary and Secondary level, 1 percent have literacy and 5 percent of the respondents who have not studied at all.

Categories	Frequency	Percent	Cum. Percent
Only can sign	1	1.67	1.67
Can Read	1	1.67	3.33

JSC	2	3.33	6.67
SSC	6	10.00	16.67
HSC	6	10.00	26.67
Graduate	15	25.00	51.67
Post Graduate	26	43.33	95.00
Other	3	5.00	100
Total	60	100	

Table 10: Educational Qualification

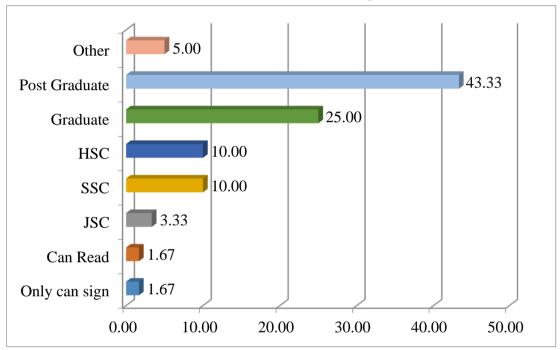


Figure 3: Educational Qualification

Religion

According to the information obtained by the respondents, 95 percent of the respondents are followers of Islam and 5 percent are followers of Hinduism. Respondents of other religion were not found in the survey.

Categories	Frequency	Percent	Cum. Percent
Islam	57	95.00	95.00
Hindu	3	5.00	100
Total	60	100	

Table 11: Religion

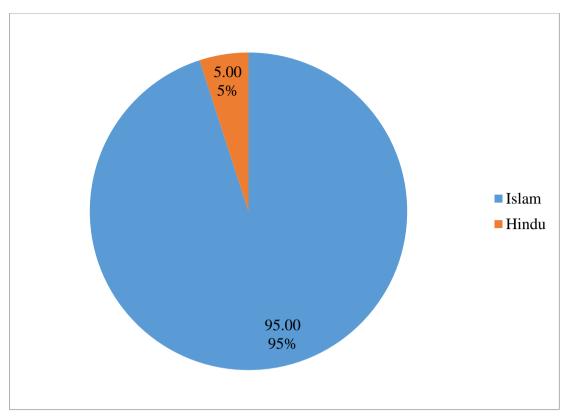


Chart 4: Religion

Number of Family Members

According to the information collected from the respondents, about 46 percent have 3-4 family members. About 38 percent have 5-6 family members. The number of families with 7 or more members is 10 percent and 5 percent are families with 1-2 members.

Categories	Frequency	Percent	Cum. Percent
1-2	3	5.00	5.00
3-4	28	46.67	51.67
5-6	23	38.33	90.00
More than 7	6	10.00	100
Total	60	100	

Table 12: Number of Family Members

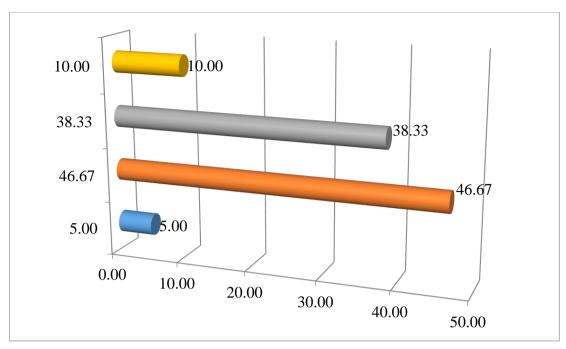


Figure 4: Number of Family Members

Occupation

As per the research survey, it is observed that, maximum 46 percent respondents are housewives. The number of businessman is 11 percent, Private sector employment is about 10 percent and Government sector about 6 percent. About 6 percent of the respondents are engaged in teaching profession. 3 percent are students. About 13 percent of the respondents are engaged in other professions including journalism, freelancing etc.

Categories	Frequency	Percent	Cum. Percent
Service (Government)	4	6.67	6.67
Service (Private)	6	10.00	16.67
Business	7	11.67	28.33
Student	2	3.33	31.67
Teacher	4	6.67	38.33
Small Business	1	1.67	40.00
Housewife	28	46.67	86.67
Other	8	13.33	100
Total	60	100	

Table 13: Occupation

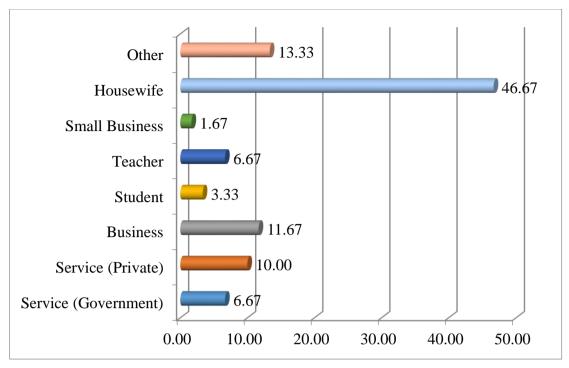


Figure 5: Occupation

Total Monthly Household Income

According to the survey, in terms of family monthly income of autistic children, 53 percent of the family have a monthly income of around 56000-640000or more. About 21 percent of the respondents have a monthly family income of approx. 440000-56000>. About 11 percent have the monthly income of the family is about 20000-32000; 6 percent of the respondent's family monthly income is approx. 3200044000 and family monthly income of 6 percent respondents is minimum <8000-20000.

Categories	Frequency	Percent	Cum. Percent
<8000-20000	4	6.67	6.67
20001-32000	7	11.67	18.33
320001-44000	4	6.67	25.00
440001-56000	13	21.67	46.67
56001-64000>	32	53.33	100
Total	60	100	

Table 14: Total Monthly Household Income

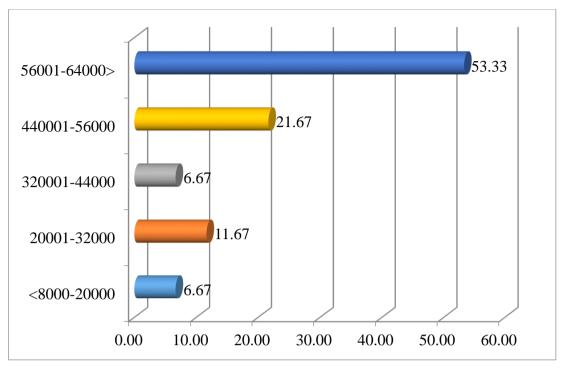


Figure 6: Total Monthly Household Income

6.2.4 Health Related Information of Children with Autism from Birth to Present

Diagnosis Year of Children with Autism

According to the survey, about 66 percent of children are diagnosed with autism at the age of 1-2 years. About 23 percent of children are diagnosed with autism by the age of 3-4 years. About 8 percent of children are diagnosed with autism at age of 5 or above. So, it is particularly observed here that many parents take the child to the doctor late due to lack of awareness.

Categories	Frequency	Percent	Cum. Percent
below 1 month	1	1.67	1.67
1-2 years	40	66.67	68.33
3-4 years	14	23.33	91.67
5 years more	5	8.33	100
Total	60	100	

Table 15: Diagnosis Year of Children with Autism

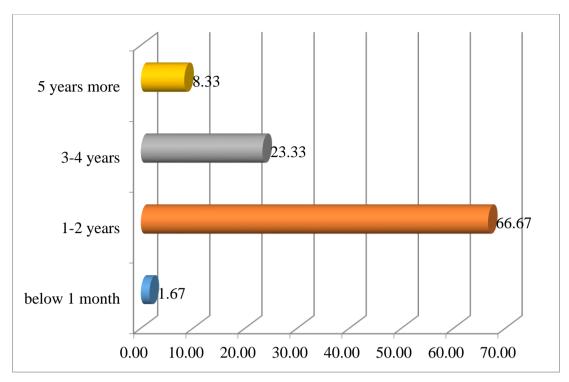


Figure 7: Diagnosis Year of Children with Autism

Years of having Autism

Analyzing the data obtained in the survey, it can be seen that about 43 percent of the children with autism have been diagnosed for about 5-10 years. About 31 percent of children aged 10-12 and 20 percent of children aged 0-5 were diagnosed with autism.

Categories	Frequency	Percent	Cum. Percent
0-5	12	20.00	21.05
5-10	26	43.33	66.67
10-12 Above	19	31.67	95
Total	57	100	

Table 16: Years of Having Autism

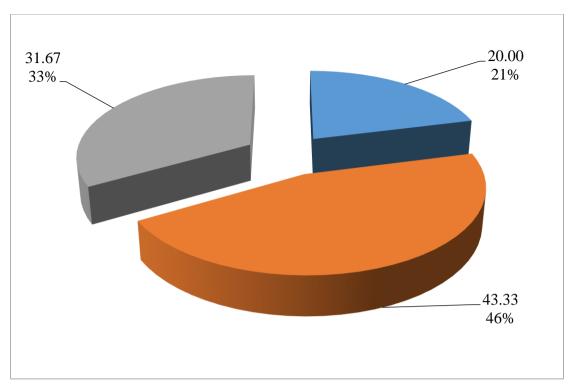


Chart 5: Years of Having Autism

Symptoms that are Observed in Children with Autism

About 33 percent of autistic children are unable to socialize with peer groups. 25 percent of children exhibit repetitive behaviors. About 23 percent of children do not make eye contact. 8 percent of children have speech problems. About 5 percent of children have extreme aversion towards social behavior. About 3 percent of children are severely hyper. Other symptoms are also observed in about 1 percent of children.

Categories	Frequency	Percent	Cum. Percent
Not to mingling with peers	20	33.33	33.33
Repetitive Behavior	15	25.00	58.33
Not to make Eye Contact	14	23.33	81.67
Speech Problem	5	8.33	90.00
Lack of Patience	2	3.33	93.33
Extreme Aversion to Social Behavior	3	5.00	98.33
Other	1	1.67	100
Total	60	100	

Table 17: Symptoms are Observed in Children with Autism

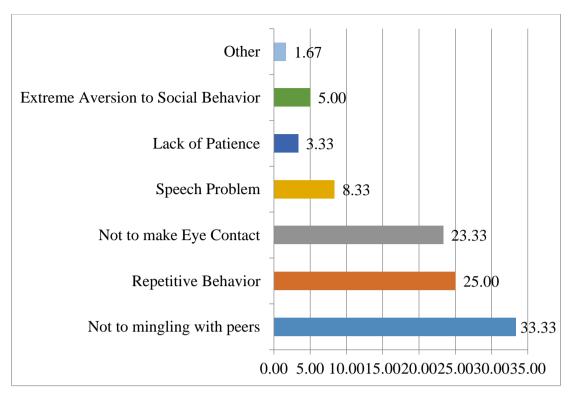


Figure 8: Symptoms are Observed in Children with Autism

6.2.5 Health Service Related Information Getting by the Children with Autism from the Service Providers

Information about the Treatment Receiving by the Children with Autism

About 93 percent of autistic children receives Allopathic treatment and about 6 percent are getting Homeopathy treatment. This information points to one thing, that is-families of autistic children are more aware and free of prejudice than before. When the symptoms are seen into children, they directly take the child to the doctor for early intervention much more than before.

	Frequency	Percent	Cum. Percent
Allopathic	56	93.33	93.33
Homeopathy	4	6.67	100
Total	60	100	

Table 18: Information about the Treatment Receiving by the Children with Autism

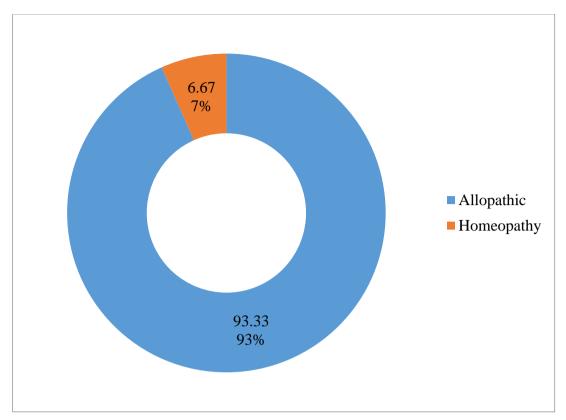


Chart 6: Information about the Treatment Receiving by the Children with Autism

Duration of Getting Treatment

According to the survey, about 33 percent of children are receiving medical care for more than 5 years. About 31 percent of children are getting for 3-4 years, about 28 percent children are receiving for 1-2 years and about 6 percent of children are getting health care services for near about 1-11 months.

Categories	Frequency	Percent	Cum. Percent
1-11 month	4	6.67	6.67
1-2 years	17	28.33	35.00
3-4 years	19	31.67	66.67
5 years more	20	33.33	100.00
Total	60	100.00	

Table 19: Duration of Getting Treatment

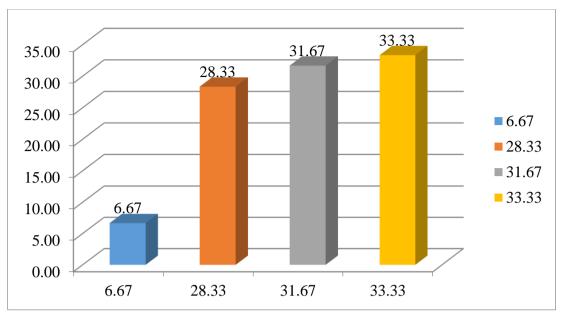


Figure 9: Duration of Getting Treatment

Types of Health Services Receiving by the Autistic Children

As per the survey findings- up to 65 percent of autistic children are having speech therapy. About 20 percent of children are receiving occupational therapy. About 8 percent of children are getting language therapy and about 6 percent are receiving other services such as medication, counseling etc. It is clearly seen that therapy and healthcare support for autistic children are not sufficient.

Categories	Frequency	Percent	Cum. Percent
Speech Therapy	39	65.00	65.00
Language Therapy	5	8.33	73.33
Occupational Therapy	12	20.00	93.33
Other	4	6.67	100
Total	60	100	

Table 20: Types of Health Services Receiving by the Autistic Children

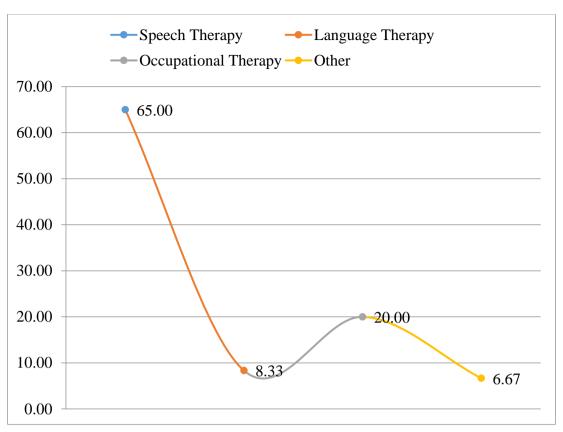


Chart 7: Types of Health Services Receiving by the Autistic Children

Doctor's Opinion about the Autistic Children

According to the opinion of about 56 percent of doctors- the disability of an autistic child will be partially okay. About 36 percent of the doctors said that the child's autism will improve. About 6 percent of the doctor's opinion is that the child will not improve at all. However, positive changes will come through autism management.

Categories	Frequency	Percent	Cum. Percent
Will be okay	22	36.67	36.67
Partially okay	34	56.67	93.33
Will not be okay	4	6.67	100
Total	60	100	

Table 21: Doctor's Opinion about the Autistic Children

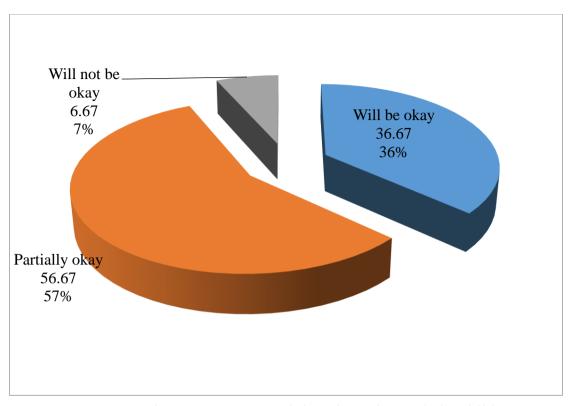


Chart 8: Doctor's Opinion about the Autistic Children

Efficiency of Doctor's and Health Service Providers

According to the opinion of the respondents-about 56 percent of Doctor's and Health Service providers are skilled. About 23 percent are fairly efficient, about 16 percent are very efficient and about 1 percent of Doctor's and Health Service Providers are inefficient.

Categories	Frequency	Percent	Cum. Percent
Very Efficient	10	16.67	16.67
Skilled	34	56.67	73.33
Fairly Efficient	14	23.33	96.67
Inefficient	1	1.67	98.33
Not Efficient at all	1	1.67	100
Total	60	100	

Table 22: Efficiency of Doctor's And Health Service Providers

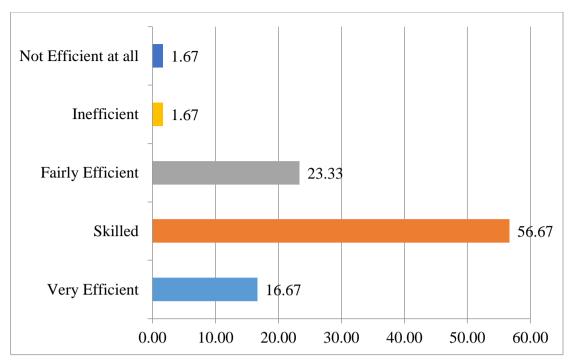


Figure 10: Efficiency of Doctors and Health Service Providers

6.2.6 Developmental History of Children with Autism after Getting the Health Services

Child's Progress after Receiving Healthcare Services

About 55 percent of children improved after receiving health care. About 25 percent of children remained the same as before. About 13 percent of children had partial improvement, about 5 percent of children's condition deteriorated and the condition remains unchanged for about 1 percent of children. This suggests that children should be referred for assessment as early as possible the symptoms are appeared into the children.

Categories	Frequency	Percent	Cum. Percent
Improvement from before	33	55.00	55.00
Same as before	15	25.00	80.00
Partial Improvement	8	13.33	93.33
Deterioration has occurred	3	5.00	98.33
Other	1	1.67	100
Total	60	100	

Table 23: Child's Progress after Receiving Healthcare Services

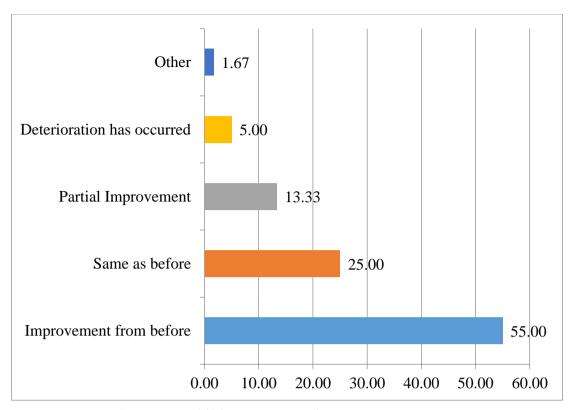


Figure 11: Child's Progress after Receiving Healthcare Services

Improvements have been Observed after Getting Health Services

About 31 percent of children improved in social behavior and speech after receiving health care. About 21 percent of children had increased eye contact. About 6 percent of children improved in communication. Agitation and restlessness decreased in about 3 percent of children and other improvements were seen in about 5 percent of children.

Categories	Frequency	Percent	Cum. Percent
Improvement in speaking	19	31.67	31.67
Improvement in social behavior	19	31.67	63.33
Increased Eye Contact	13	21.67	85.00
Improvement of communication	4	6.67	91.67
problems			
Reduced Fickleness	2	3.33	95.00
Other	3	5.00	100
Total	60	100	

Table 24: Improvements have been Observed after Getting Health Services

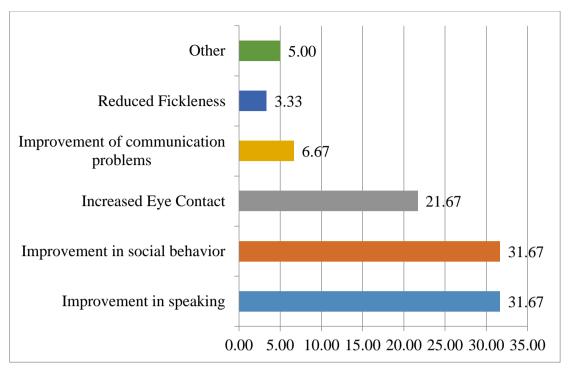


Figure 12: Improvements have been Observed after Getting Health Services

6.2.7 Information Regarding Access to Educational Services for Children with Autism

Children's Educational Institution

50 percent of the students are from Bangladesh Protibondhi Foundation (BPF) Kalyani Inclusive School and 50 percent from Society for the Welfare of Autistic Children (SWAC) to apply the survey method of the present research work.

Categories	Frequency	Percent	Cum. Percent
BPFKIS	30	50.00	50.00
SWAC	30	50.00	100.00
Total	60	100.00	

Table 25: Children's Educational Institution

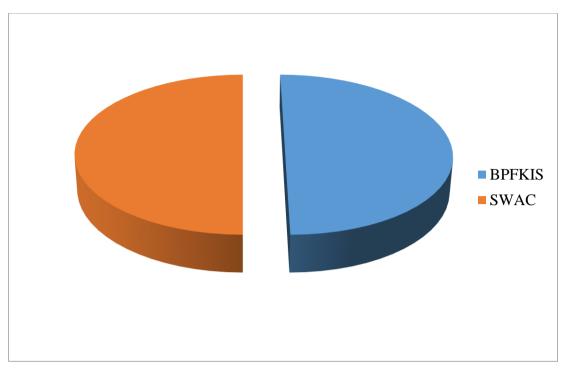


Chart 9: Child's Educational Institution

Duration of Getting Education Services from the Institution

About 40 percent of children are receiving education services for 3-4 years in these Special Education Schools. About 33 percent of children are receiving education for 1-2 years, 20 percent for 5 or more and about 6 percent children are getting services for 1 year or less.

Categories	Frequency	Percent	Cum. Percent
1 year below	4	6.67	6.67
1-2 year	20	33.33	40.00
3-4 year	24	40.00	80.00
5 year more	12	20.00	100
Total	60	100	

Table 26: Duration of Getting Education Services from the Institution

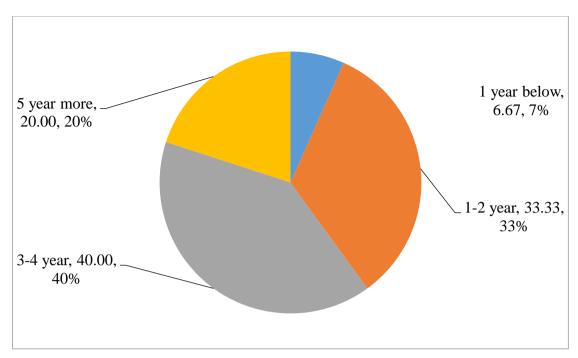


Chart 10: Duration of Getting Services from the Institution

Distance from Educational Institutions from Home

About 48 percent of children have a school distance of 2-3 km. from their home. About 23 percent children have the distance of less than 1 km. 15 percent children have 4-5 km. and 13 percent children's home to school distance are about 6 km or more from home to school. What is observed in this is that transportation services are very necessary for autistic children.

	Frequency	Percent	Cum. Percent
1 km below	14	23.33	23.33
2-3 km	29	48.33	71.67
4-5 km	9	15.00	86.67
6 km more	8	13.33	100
Total	60	100	

Table 27: Distance from Educational Institutions from Home

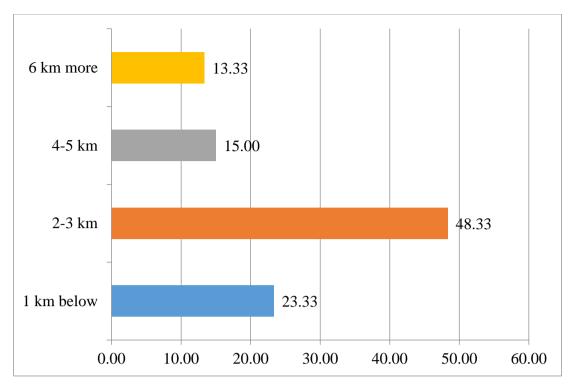


Figure 13: Distance from Educational Institutions from Home

Adequacy of Teaching Materials

According to the opinion of about 53 percent of the respondents, the educational materials of these special education schools are fairly adequate. About 26 percent of the respondents feel that educational materials are inadequate. About 20 percent of the respondents feel that there are adequate teaching materials in these special education schools.

Categories	Frequency	Percent	Cum. Percent
Adequate	12	20.00	20.00
Fairly Adequate	32	53.33	73.33
Inadequate	16	26.67	100
Total	60	100	

Table 28: Adequacy of Teaching Materials

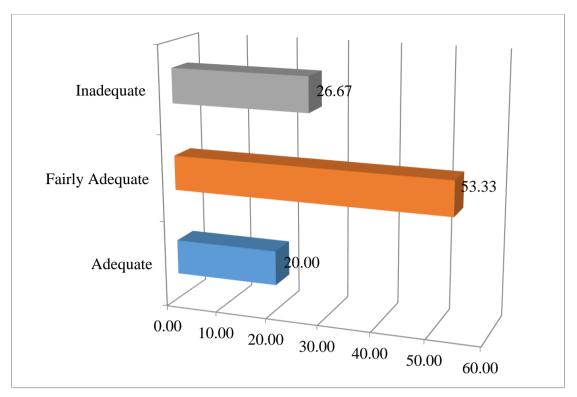


Figure 14: Adequacy of Teaching Materials

Satisfaction Level of Parents Regarding Classroom Environment

About 40 percent of the respondents are satisfied with the classroom environment of special education schools. About 35 percent are fairly satisfied, about 10 percent are very satisfied, 10 percent are dissatisfied and 5 percent are totally dissatisfied.

Categories	Frequency	Percent	Cum. Percent
Very satisfied	6	10.00	10.00
Satisfied	24	40.00	50.00
Fairly Satisfied	21	35.00	85.00
Dissatisfaction	6	10.00	95.00
Totally Unsatisfied	3	5.00	100
Total	60	100	

Table 29: Satisfaction Level of Parents Regarding Classroom Environment

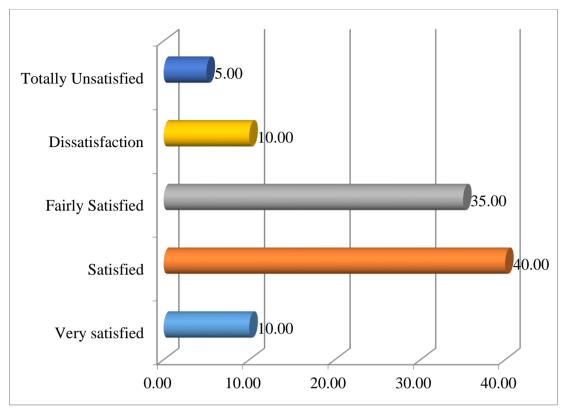


Figure 15: Satisfaction Level of Parents Regarding Classroom Environment

Efficiency of Teacher's on Providing Services to Autistic Children

Almost 50 percent of the respondents feel that the in-service teachers are fairly efficient. Second highest about 30 percent said teachers are skilled. About 13 percent think the teachers are very efficient, about 5 percent think inefficient and about 1 percent respondents think teachers are not at all efficient in providing services.

Categories	Frequency	Percent	Cum. Percent
Very Efficient	8	13.33	13.33
Skilled	18	30.00	43.33
Fairly Efficient	30	50.00	93.33
Inefficient	3	5.00	98.33
Not Efficient at all	1	1.67	100
Total	60	100	

Table 30: Efficiency of Teachers

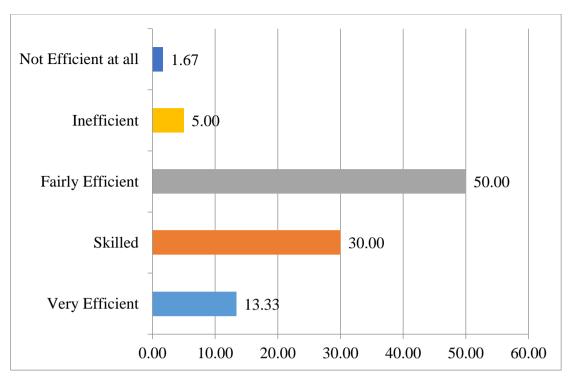


Figure 16: Efficiency of teachers

Satisfaction Level of Services Provided by the Educational Institutions

About 40 percent of the respondents are fairly satisfied, about 38 percent are satisfies and about 8 percent are dissatisfied after getting the services from the educational services by the children with autism.

Categories	Frequency	Percent	Cum. Percent
Very satisfied	8	13.33	13.33
Satisfied	23	38.33	51.67
Fairly Satisfied	24	40.00	91.67
Dissatisfaction	5	8.33	100
Total	60	100	

Table 31: Satisfaction Level of Services Provided by the Educational Institutions

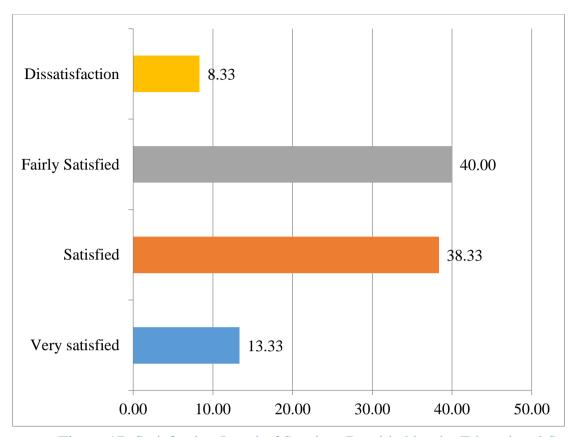


Figure 17: Satisfaction Level of Services Provided by the Educational Services

6.2.8 Developmental History and Information of the Autistic Child after Receiving Services from the Educational Institutions

Child's Progress after Admission and Receiving Services from the Institutions

About 63 percent of the respondents who participated in the survey felt that autistic children have improved than earlier. About 26 percent felt the autistic children are same as before. About 8 percent reported partial improvement are seen. According to about 1 percent of the respondents, the condition of the child has deteriorated than earlier.

Categories	Frequency	Percent	Cum. Percent
Improvement from before	38	63.33	63.33
Same as before	16	26.67	90.00
partial Improvement	5	8.33	98.33

Deterioration ha	s 1	1.67	100
occurred			
Total	60	100	

Table 32: Child's Progress

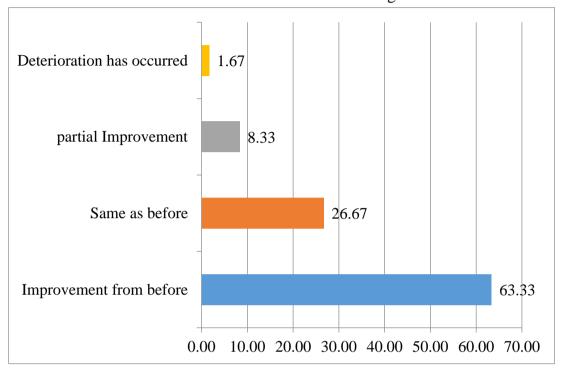


Figure 18: Child's Progress

Autistic Children Need Additional Facilities after Receiving Existing Educational Services from the Institution

Respondents expressed their views on the additional facilities that autistic children require after receiving existing educational services from their respected institutions. About 19 percent of the respondents felt that adequate and quality education services and 19 percent think that recreational activities should be increased for the well-being of autistic children. About 17 percent of the respondent thinks that Physical exercise and 15 percent gave their opinion in increasing sports facilities. About 11 percent of the respondents think that Vocational training is utmost needed for the autistic children and about 9 percent think that adequacy of quality treatment and therapy services should be increased.

Statements/Opinion	N	Percentage Rate
Quality Treatment and	25	9.33%
Therapy Services		
Adequate and Quality	52	19.40%
Education		

Physical Exercise	46	17.16%
Residential Facilities	2	0.75%
Recreational Activities	52	19.40%
Sports	41	15.30%
Vocational Training	31	11.57%
Other	19	7.09%

Table 33: Autistic Children Need Additional Facilities after Receiving Existing Educational Services from the Institution*Multiple Replies Have Been Received

6.2.9 Challenges Faced by the Children with Autism in terms of Family Life Attitude of Other Books in the Family towards the Autistic (

Attitude of Other People in the Family towards the Autistic Children

About 71 percent of the respondents think that, attitude of other family members towards the autistic children are condescending. About 10 percent respondents think that normal, about 6 percent's opinion are empathetic and 1 percent of the respondents think that attitude towards the children with autism are generous.

Categories	Frequency	Percent	Cum. Percent
Condescending	43	71.67	75.44
Normal	6	10.00	85.96
Generous	1	1.67	87.72
Empathetic	4	6.67	94.74
Other	3	10.00	100
Total	60	100	

Table 34: Attitude of Other People in the Family towards the Autistic Children

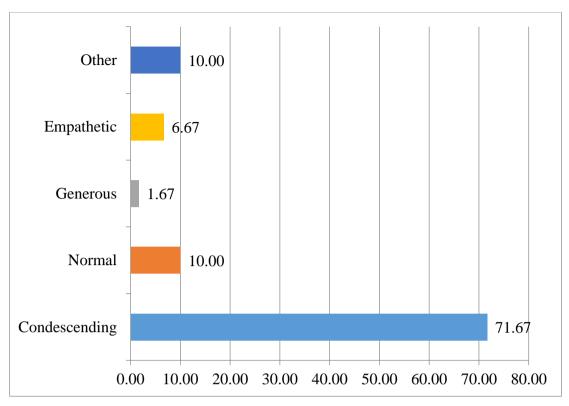


Figure 19: Attitude of Other People in the Family towards the Autistic Children

Problems Faced by the Parents of Children with Autism in Family Life

About 26 percent of the respondent's opinion is that they are isolated from the relatives. About 23% are suffering from family disorder. About 20% of the respondents said that they had to face family dispute with other family members. About 6% became the victim of misunderstanding with the family members and 8 percent of the respondents did not face any problem.

Statements/Opinion	N	Percentage Rate
Family Disorder	38	23.46%
Family Dispute	33	20.37%
Misunderstanding	11	6.79%
Isolation from the	43	26.54%
Relatives		
There was no problem	13	8.02%
Other	24	14.81%

Table 35: Problems Faced by the Parents of Children with Autism*Multiple Replies
Have Been Received

6.2.10 Social Challenges Faced by the Children with Autism Social Attitude towards the Children with Autism

According to the survey, about 61 percent of the respondents feel that society's view towards the autistic children is considered as a curse. About 18 percent of the respondents said that people in the society think of children's disabilities as ironic and only about 5 percent of the respondents think that social attitude towards the children with autism are normal.

Categories	Frequency	Percent	Cum. Percent
Curse	37	61.67	61.67
Fate	11	18.33	80.00
Natural things	3	5.00	85.00
Other	9	15.00	100
Total	60	100	

Table 36: Social Attitude towards the Children with Autism

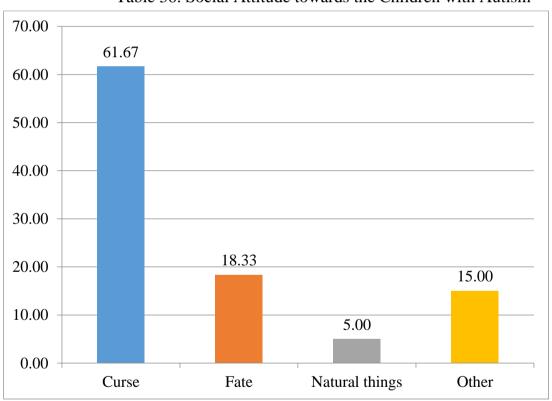


Figure 20: Social Attitude towards the Children with Autism

Challenges Faced by the Children with Autism in terms of Social Security Assistances and Services A Maximum of 51 percent of the respondents felt that autistic children faces barriers while getting healthcare services. About 16 percent thinks that autistic children are severely deprived of getting proper educational services and access to civil rights. About 13 percent think that autistic children are deprived of social security related assistances and 1 percent think that they are facing the social challenges in terms of social rights etc.

Categories	Frequency	Percent	Cum. Percent
Deprived of Educational Services	10	16.67	16.67
Healthcare	31	51.67	68.33
Access to civil rights	10	16.67	85.00
Social security	8	13.33	98.33
Assistances			
Other	1	1.67	100
Total	60	100	

Table 37: Challenges Faced by the Children with Autism in terms of Social Security

Assistance and Services

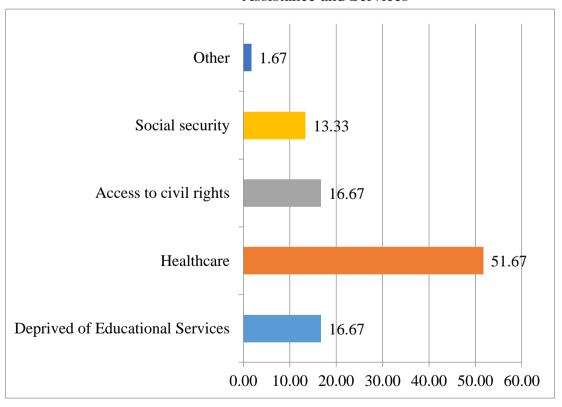


Figure 21: Challenges Faced by the Children with Autism in terms of Social Security

Assistance and Services

Problems Faced by the Children with Autism in Participating Social Events

About 41 percent of the respondents felt that people's attitudes towards autistic children are very negative when the matter of participation in social events comes regarding the autistic children. About 31 percent of the respondents think that autistic children become the victim of having adverse comments from the community. About 16 percent think that the participation of children with autism in social events are normal and near about 1 percent think attitude of the people are fairly normal.

Categories	Frequency	Percent	Cum. Percent
Normal participation	10	16.67	16.95
Peoples negative look	25	41.67	59.32
Victim of adverse	19	31.67	91.53
comments			
Other	5	8.33	100
Total	60	100.00	

Table 38: Problems Faced by the Child in Participating Social Events

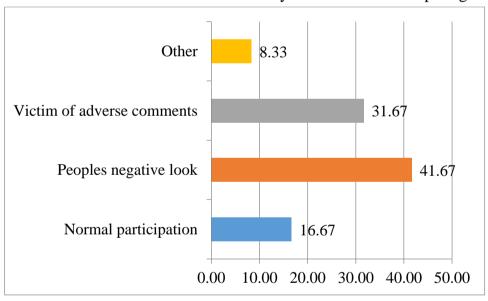


Figure 22: Problems Faced by the Child in Participating Social Events

6.2.11 Financial Constraints Having by the Children with Autism Financial Challenges Faced by the Autistic Children

About 25 percent of the respondents think that children with autism are getting difficulties in obtaining banking facilities. Because everyone in the society wants to be secure financially and for savings to fixed deposit which will ensure autistic children's future, there is no special facilities available for the children with autism so that banking system will be autism friendly which will make them financially secured. About 23 percent of the respondents think that autistic children are deprived of getting access to social security assistances or programs. about 22 percent respondents think that autistic children might be vulnerable and have to face the deprivation of access to wealth and about 18 percent of the respondent's opinion is autistic children have lack of employment opportunities.

Statements/Opinion	N	Percentage Rate
Deprivation of Access to	37	22.16%
Wealth		
Deprivation of Access to	39	23.35%
Social Security Programs		
Difficulty in obtaining	43	25.75%
banking facilities		
Lack of Employment	31	18.56%
Opportunities		
Other	17	10.18%

Table 39: Financial Challenges Faced by the Autistic Children*Multiple Replies Have Been Received

Financial Constraints are being Faced by the Parents of Children with Autism

About 75 percent of the respondents think that they are suffering from financial burden. About 24 percent of the respondents are sufferer in various types of economic losses such asworking sector, employment opportunities, economic burden due to maintaining autistic children's health treatment and therapies etc.

Statements/Opinion	N	Percentage Rate
Parents Economic Burden	50	75.76%
Having an Autistic Children		
Various Economic Losses	16	24.24%

Table 40: Financial Constraints are being Faced by the Parents of Children with Autism*Multiple Replies Have Been Received

6.2.12 Information on the Psychological Challenges Faced by the Parents of Children with Autism

Psychological Problems Faced by the Parents

About 40 percent of the respondents are suffering from severe depression. About 21 percent are always in hypertension and near about 13 percent of the respondents are suffering from anxiety due to having a children with autism.

Categories	Frequency	Percent	Cum. Percent
Frustration	13	21.67	21.67
Depression	24	40.00	61.67
Anxiety	10	16.67	78.33
Hypertension	13	21.67	100
Total	60	100	

Table 41: Psychological Problems Faced by the Parents

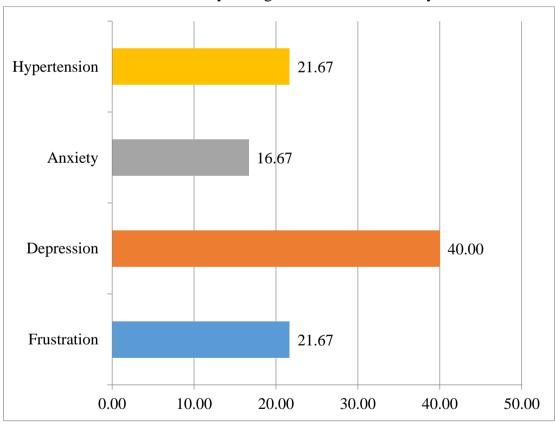


Figure 23: Psychological Problems Faced by the Parents

6.2.13 Parents Expectations Regarding Ensuring Social Security Assistances for the Well-being of the Children with Autism

About 20 percent of the respondents said that they want quality education services. About 14 % parents want quality health services from the health service providers. Near about 14% of the respondents seeks government allowances for the welfare of autistic children. About 13 percent of the respondents want their autistic children to get access to training in income generating activities. About 12 percent respondents want financial assistances due to their financial burden. About 7 percent of the respondents want employment of the children with autism so that parents can be assured that their children will be able to survive here in this world even after their death.

Statements/Opinion	N	Percentage Rate
Quality Education Services	46	20.26%
Quality Health Services	33	14.54%
Access to Training in	29	12.78%
Income Generating		
Activities		
Employment Facilities	17	7.49%
Government Allowances	34	14.98%
for the Welfare of Autistic		
Children		
Financial Assistances due	28	12.33%
to having the financial		
burden		
Access to Recreational	18	7.93%
activities		
Other	22	9.69%

Table 42: Parents Expectations Regarding Ensuring Social Security Assistances for the Well-being of the Children with Autism*Multiple Replies Have Been Received

6.2.14 Conclusion

Data from the current research work, survey have revealed several findings related to autistic children which will help understanding the psychosocial status of children with autism. Findings of the study show that, although autism diagnosis increased as parents became more aware than earlier, but still there are many barriers in ensuring service support for the children with autism. Autistic children are very talented. If adequate health, education and services are ensured from the related service providers, I believe that, in near future they will be able to equally involve in the developmental process of the country.

6.3 Findings of the Key Informant Interviews

6.3.1 Introduction

In the light of the nature, scope and purpose of the present study, the data was collected through in-depth interviews with experts and representatives of the concerned community along with other methods of data collection.

A total of 10 people including disability experts, NGO executives, academician, doctor, child psychiatrist, media personality and special educator were interviewed. Through the said interviews, information is obtained about the psycho-social condition, access to services, challenges, various programs and policies for the betterment of children with autistic. Recommendations and future guidelines are also obtained from the respondents. Among the information have been found, the similarities can be observed on those points from the statements of the respondents are briefly discussed.

6.3.2 Current Status and Overall Condition of the Children with Autism

Autism is a developmental disorder in which problems in social communication, social behavior, social imagination etc. are observed in children. Experts define it as Autism Spectrum Disorder (ASD). The exact reason or cause of autism is not yet known. But according to the opinion of some scientists, there are two reasons behind autism are genetic and environmental. According to **Dr. Ashish Kumar Chakraborty**, Consultant Hepatologist, Birdem General Hospital, Dhaka, Children with Autism carry errors called "Copy Number Variants" in their genes.

Most of the In-depth interview respondents felt that, Autism or any type of disability is nothing new. No specific cause of autism is known till now. But as the number of centers and resources have increased in Bangladesh, the prevalence is also increasing. But why the autism rate is increasing alarmingly, **Dr. Shamim Ferdous**, The Executive Director of Bangladesh Protibondhi Foundation (BPF), thinks that, currently, the number of autistic children is increasing at all levels. There can be two reasons behind this: people are more aware than before and assessment opportunities are now available more than before. Once there was a misconception in Bangladesh that, if any child can't talk, everyone used to think, the children have autism. But autism and other neurodevelopmental disabilities are not the same. The prevalence of autism is increasing in our country as the "Early Diagnosis" at government and private levels increases, therefore, identification and detection of children with autism are increasing.

According to the opinion of **Ferdousi Maula**, Child Psychologist, Clinic, Bangladesh Protibondhi Foundation, symptoms are usually observed between the ages of 1.5-3 years in autistic children. Common symptoms seen in children with autism are:

- ➤ No or poor eye contact
- > Speech problems
- > Communication problems
- ➤ Non responsive behavior etc.

Speaking about the rate of persons with autism, **Md. Kamrul Islam Chowdhury**, Joint Secretary, Director (Activities), Activities Department, Department of Social Services, Dhaka said- As per "Disability Identification Survey Program" conducted by Department of Social Services: Number of Persons with Autism are- (Male: 51959, Female: 32769 and Hijra: 54). Globally, a large proportion of individuals with autism have been identified in the Middle East. **Dr. Nafeesur Rahman**, Disability Expert, Director, National Forum of Organizations Working with the Disabled (NFOWD) said- Qatar has the highest rate of autism in the world. The Royal Families of the East have the highest number of person with autism.

6.3.3 Factors are Important in Autism Management and Development of the Children with Autism

Taking Pre-cautions while Family Planning

Answering in this context, **Dr**. **Shamim Ferdous**, The Executive Director of Bangladesh Protibondhi Foundation (BPF), said that-

- Age is an important factor in any type of disability including autism. However, now a days, 20 to 25 year old mother's children are also suffering from autism;
- If the mother is under a lot of stress during pregnancy, the child is more likely to be hyperactive;
- Malnutrition is one of the causes of having autism in a children. So, nutritious food should be given to mother during her pregnancy;
- A regular checkup is utmost needed before pregnancy and in the first trimester of pregnancy;
- Mother should get all the vaccines time to time etc.;
- Mother cannot do heavy work. Moreover, she should not be idle during pregnancy as well as. Mother can do light physical exercises and yoga. After eating food, she can take a nap; and
- Husband and In-law's mental support are very important for the well-being of mother's mental and physical health during pregnancy. These are the few pre-cautions which can be followed during pregnancy to avoid any unwanted disabilities in a child.

According to the opinion of **Dr. Ashish Kumar Chakraborty**, Consultant Hepatologist, Birdem General Hospital, Dhaka- Specific medications do not work well for autistic children, however, it is possible to manage autism through: Early Intervention, Education and Therapies.

Raising Awareness for Autism Diagnosis and Early Intervention

Speaking up about building up awareness, **Dr. Shamim Ferdous**, The Executive Director of Bangladesh Protibondhi Foundation (BPF), thinks that, awareness has increased a lot in urban areas but still not observed as much in rural areas. Every parent needs to go to the pediatrician immediately if child seems to be lagging behind other children. This will lead to early diagnosis.

Ferdousi Maula, Child Psychologist, Clinic, Bangladesh Protibondhi Foundation thinks that-The sooner an autism diagnosis is made, the sooner a child's autism management can begin. Autism diagnosis can be done by using M-Chat, IQ Test, and Screening etc. Hence parental awareness is very important.

Dr. Ashish Kumar Chakraborty, Consultant Hepatologist, Birdem General Hospital, Dhaka said- autistic children will fall behind if early intervention is not ensured. So, action must be taken quickly and the media has a huge role to play in raising awareness.

Media personality **Ameen Al Rasheed**, Editor, Current Affairs, Nexus Television placed his opinion in this regard- Bangladesh Television can play an important role in raising awareness. They can create various awareness building programs regarding autism. Apart from this, people from all levels including government and private organizations should come forward. **Subarna Chakma**, Chairperson, Society for the Welfare of Autistic children (SWAC) said in this regard- awareness is not built up yet in all levels of the society. But slowly it's increasing. To raise awareness, it is important to take necessary steps by the Government and Non-Government Organizations so that at once parents observe some unusual symptoms in children, they should immediately take the children to the doctor or other health service providers.

Autistic Children Should Be Brought under Social Inclusion in terms of Getting Educational, Health and Other Services

Disability Expert **Dr. Nafeesur Rahman**, Director, National Forum of Organizations Working with the Disabled (NFOWD) said- autistic children needs to bring under inclusion. Special education setup is necessary to achieve that goal. Special Education Schools should be brought under mainstream primary education. Infrastructural changes should be made in schools.

Child Psychologist **Ferdousi Maula** thinks that- Adjustment is the biggest barrier to inclusion of autistic children in mainstream education.

Dr. Shamim Ferdous, The Executive Director of Bangladesh Protibondhi Foundation (BPF), thinks that, there should be one special educator in every mainstream school in the community. A special resource room should be kept. When an autistic children becomes hyper, he or she should be taken to the resource room and calmed down. Thus inclusion in the mainstream of children with autism will be possible.

Dr. Ashish Kumar Chakraborty, Consultant Hepatologist, Birdem General Hospital had said-autistic children should be treated normally by bringing them under inclusion. Through Applied Behavior Analysis (ABA), autism management plan should be developed for the children after carrying out need assessment.

Wahida Banu, Executive Director, Aparajeyo Bangladesh placed her opinion in this regard, autism management requires an inclusive approach. Every institutions need to work with deeper perception.

Dr. Md. Aliur Rahman, Chairperson, Department of Journalism and Media Communication, Green University of Bangladesh expressed his opinion in this regard, Inclusive partnerships are emphasized in various parts of the United Nations Sustainable Development Goals. Therefore, we must build a livable world with inclusion of all the children including autism.

Creating Skilled Service Providers

According to Wahida Banu, Executive Director, Aparajeyo Bangladesh- We need technical persons and skilled human resources for autism management. To achieve this goal, proper foundation training is needed for service providers. Otherwise, unskilled staff will misguide in autism management which will be considered as one of the obstacles in proper development of autistic children.

Parent's counseling for creating acceptance and better autism management

Ferdousi Maula, Child Psychologist, Clinic, Bangladesh Protibondhi Foundation thinks that-When parent's come to the service providers with their children, they need to improve in the area of autistic management through counseling. Now a days in various training and workshop, it is often said that- first management and assessment should be done.

According to Disability Expert **Dr. Nafeesur Rahman- Parents** need to create an environment of social acceptance through counseling. They have to accept the fact that how far their children can go. Because if the parents of an autistic child expect too much, they can sink into despair when it turns out not to be possible. So, small milestones can be created. For example, the parent should plan what development they want to see into their child in the next

three months? It should be planned according to the children's ability. Therefore, early intervention and assessment are very important. Thus, acceptances will be created.

6.3.4 Steps Can Be Taken to Bring the Autistic Children Back into the Mainstream of Society without Considering them as a Burden to the Society

At this stage of the in-depth interviews, various dimensions were highlighted while answering this question. **Disability Expert Dr. Nafeesur Rahman**, Director, National Forum of Organizations Working with the Disabled (NFOWD) said- "Proclamation of Independence" was the first constitution of Bangladesh enacted on April 10, 1971 by the Mujibnagar Government. Three things are mentioned there. They are:

- > Equality;
- > Human Dignity and
- > Social Justice.

The new constitution enacted on December 16, 1972 spoke of Equity along with Equality. Therefore, Human Dignity and Social Justice must be ensured on the basis of equality and equity to bring the autistic children into the mainstream of society.

In this regard Md. Kamrul Islam Chowdhury, Joint Secretary, Director (Activities), Activities Department, Department of Social Services, Dhaka said- The Department of Social Services is implementing social protection programs to bring disables persons back into the mainstream rather than treating them as a burden on the society. Hon'ble Prime Minister Sheikh Hasina, daughter of Bangabandhu Sheikh Mujibur Rahman, invested heavily in social security sector of Bangladesh and gave a planned institutional form to the social security business to bring smiles to the faces of the poor people. A "National Social Security Strategy Paper" was launched in 2015 to reflect its far- reaching vision. The strategy is based on five life cycles from birth to death for the extremely poor and disabled. There are specific plans and procedures to ensure sustainable social security for each life cycle. A life cycle approach to Social Security Strategy is playing an effective role in achieving human development, job creation and economic growth.

Mahfuza Islam, Special Educator, Kalyani Inclusive School, Bangladesh Protibondhi Foundation opinioned on this- Social Inclusion is very important in bringing autistic children back into the mainstream of society. Early Interventions and Social Interaction are essential to ensure this.

Answering in this context, **Wahida Banu**, Executive Director, Aparajeyo Bangladesh, Dhaka said- we have to work with the resources we have in bringing the overall welfare of autistic children. The human resources that we have is insufficient compared to the requirement but

if every service provider from special education to every sector through adequate and quality training, then they will be able provide quality services to the children with autism. Serving autistic children should be considered as a motivational work because teachers and all level of service providers are at their best when they are motivated by themselves. Only then quality of service will be improved and if the quality is improved the condition of autistic children will be improved which will help them out to bring them back to the mainstream of society.

Ferdousi Maula, Child Psychologist, Clinic, Bangladesh Protibondhi Foundation placed her opinion in this regard. She said- Skilled manpower in providing services to autistic children is very scarce in Bangladesh. Therefore, government policies should be changed to create highly educated skilled persons. This should be done through various training and sessions. Moreover, the subject can be brought into the mainstream curriculum of the education so that a degree can be earned in the subject.

Ameen Al Rasheed, Editor, Current Affairs, Nexus Television said- adequate institutions for autistic children are very necessary and to implement that, people from all levels of society should come forward along with government.

6.3.5 Initiatives, Programs and Existing Policies Have Been Adopted by the Government and N.G.O's for the Betterment of Children with Autism

Government Initiatives and Programs

Md. Kamrul Islam Chowdhury, Joint Secretary, Director (Activities), Activities Department, Department of Social Services, Dhaka said- Department of Social Services has taken and implementing various programs and initiatives for the welfare of all types of disabled persons including autistic children.

Disability Allowance: The Disability Allowance Program was introduced from the financial year of 2005-2006 as part of the mandate under Article 15(D) of the Constitution. To cover 100% disabled persons under "Disability Identification Survey", 29 lac persons with disabilities are being provided allowance in the current financial year 2023-2024.

Financial Year	Amount per	Number of	Total Allocation(in
	person per month	Beneficiaries	crore)
	(Taka)		
2005-2006	200	1.04	25.00
2009-2010	300	2.60	93.60
2014-2015	500	4.00	240.00
2018-2019	700	10.00	840.00
2019-2020	750	15.45	1390.50

2020-2021	750	18.00	1620.00
2021-2022	750	20.08	1820.00
2022-2023	850	23.65	2429.1861
2023-2024	850	29.00	2978.71

Table 43: Disability Allowance Program Statistics

Education Scholarship Program for Students with Disabilities

The main objective of this program is to ensure commitment to the Constitution. An attempt has been made to bring disabled students into the mainstream through this program. Poor families cannot afford the cost of education for disabled students. Therefore, under this program, 112.74 crore rupees have been allocated for 1 lac disabled persons in the financial year of 2023-2024.

Identification of Persons with Disabilities

The Constitution of the People's Republic of Bangladesh enshrines the commitment to equal rights of citizens, human dignity, fundamental human rights and social equality. Nationwide, "Disability Identification Survey Program" was adopted to ascertain accurate statistics of disabled population.

Rehabilitation Programs for Burnt and Disables Persons

947872770 Taka have been allocated for 191130 in 493 upazilas for the rehabilitation of persons.

Training Center for Persons with Disabilities

Technical training centers have been established for orphans and disabled children.

N.G.O Initiatives and Programs

Bangladesh Protibondhi Foundation

Dr. **Shamim Ferdous**, Executive Director of Bangladesh Protibondhi Foundation (BPF) said in this regard- Bangladesh Protibondhi Foundation (BPF) was established in 1988. The mission and vision of this organization is: to bring the underprivileged children into the inclusion and mainstream of the society, who live at the lower level of the society.

Services provided by Bangladesh Protibondhi Foundation:

- > Assessment;
- Screening;
- Diagnosis;
- Counseling through Child Club;
- ➤ Counseling through Parent's Club;

- ➤ Home Visit;
- > Therapies;
- ➤ Music Therapy;
- > Dance Therapy;
- ➤ Vocational Training such as: Cooking, Handicrafts, running small business, Beautician course etc.
- > Teaching DLA (Daily Learning Activities) through Functional Activity; and
- > Scientific meeting and teacher's training etc.

Aparajeyo Bangladesh

Wahida Banu, Executive Director of Aparajeyo Bangladesh said in this context- Aparajeyo Bangladesh mainly works with street children. This organization works with all kinds children who are suffering from various problems including autistic and children with other disabilities. Aparajeyo Bangladesh believes that all children have same right. The journey of Aparajeyo Bangladesh started in 1995 with the aim of bringing all the children under inclusion.

Services provided by Aparajeyo Bangladesh

- ➤ This organization mainly works on Right Based Approach;
- The individual child is given priority in providing educational services;
- > Every individual child has individual file;
- > Case Management;
- ➤ Individual Motivational Session;
- > Group Motivational Session; and
- ➤ Vocation Training are given as per the children's need and interests such as-computer training, beautician course etc.

Existing Policies

Md. Kamrul Islam Chowdhury said in this regard:

- In 2001, the "Disability Welfare Act" was passed;
- Bangladesh signed the UN Charter "Convention on the Rights of Person with Disabilities (UNCRPD) 9 May, 2007 and ratified it on #0, November;
- Right and Protection of Persons with Disabilities Act, 2013;
- Rights and Protection of Persons with Disabilities, 2015 etc.

Disability Expert **Dr. Nafeesur Rahman** placed his opinion in this context- Bangladesh has legal framework but if 10% of the law is implemented, there will be a huge change. "The

Action Plan" was passed in 2019 but in the last 4 Budgets, not a single money has been given for implementation.

6.3.6 Steps Can Be Taken to Achieve the Sustainable Development Goals for the Well-being of Children with Autism

On 15 September, 2015, the Sustainable Development Goals (SDGs) were announced by the United Nations. The objective of the SDGs is to eradicate hunger and poverty from the world and make it equally livable for all.

Md. Kamrul Islam Chowdhury, Joint Secretary, Director (Activities), Activities Department, Department of Social Services, Dhaka said- The following measures should be taken to achieve the targets related to SDGs for autistic children are:

- ➤ By 2030, 100 percent of disabled persons should be covered under disability allowance:
- > Expanding social security programs;
- > Increasing awareness;
- > Poverty alleviation;
- ➤ Providing financial assistance through social service programs to the government hospitals;
- Promoting the care of institutionalized disabled children and
- Employment, rehabilitation and reintegration of person with disabilities including autism etc.

Wahida Banu said in this context- Government departments should do the mapping regarding ensuring sustainable development for the children with autism. Ensuring home visit, follow-up, treatment etc. We have to work with the minimum human resources we have. Individual cases should be highlighted. The entire system should be visualized. Every organization should be brought under monitoring.

Media personality **Ameen Al Rasheed**, Editor, Current Affairs, Nexus Television said that-If International organizations take up big projects to ensure sustainable development goals for autistic children, it will increase the business interest of television channels. In order to ensure SDGs, every government department must have a monitoring system. Accountability must be ensured not just on paper but in practice.

Disability Expert **Dr. Nafeesur Rahman** said that- Achieving the SDGs goals requires long term planning. Any government organization conduct a "Foundation Training Session" during after recruitment process, where the charity model is inculcated. But these are the rights of the disabled person. Those matters should be taken into consideration which will accelerate sustainable development for the children with autism.

According to the opinion of **Dr. Md. Aliur Rahman,** to ensure SDGs, public-private initiatives should be prioritized to achieve important goals such as-poverty, hunger relief, good health and welfare, inclusive and equity based quality education, gender equality and women empowerment as described in SDGs (Sustainable Development Goals) 1,2,3,4 and 5 no. Goals.

6.3.7 Conclusion

Analyzing the research findings that have emerged from the above discussion, it can be seen that genetic error is one of the reasons behind the child becoming autistic. The noticeable thing is that, there was lack of awareness earlier about autism. But now parents became more aware than earlier and at once they observe some problems in the child, without wasting time; immediately they consult with a doctor. Therefore, autism diagnosis increased a lot. But the problem is that awareness about autism has not yet been created among people of all walks of life. Therefore, most of the expert opinions reflected in one answer- to increase awareness. Another major problem in the context of our country is the lack of skilled service providers. Therefore, it is very necessary to create skilled special educators, health care workers, therapists etc. for overall development of autistic children. Because if it is ensured to provide quality services, autistic children can be brought back into the mainstream of society through inclusion. Policy implementation is essential to ensure sustainable development for autistic children. Therefore, implementation of the policies should be done through monitoring, evaluation and accountability which will accelerate sustainable development for the children with autism.

6.4 Findings of the Case Studies

6.4.1 Introduction

Considering the importance, advantages and applicability of Case Study Method, in the light of the purpose of studying the psycho-social condition of autistic children, the following 6 case studies have been conducted by choosing 6 autistic children, age limit between 4-18 was selected from Dhaka South City Corporation through collecting data from the parents of the children with autism and reviewed in the present study as a very effective method to get a practical understanding of the psycho-social problems, limitations and challenges faced by the children with autism. The respondents are determined as A, B, C, D, E, F.

6.4.2 Findings of the Case Studies

The data obtained in this study reflected various dimensions related to the psycho-social condition of children with autism. The findings from the case studies are analyzed which are described below:

Table 44: Sub-heading of the research findings

01	Children are diagnosed with Autism Faster than Ever
02	A Mother Needs Special Care during Pregnancy
03	Symptoms are Common often Observed into the Children with Autism
04	Services getting by the Children with Autism are not Adequate
05	The Attitude towards the Children with Autism from the Family Members
	are Positive
06	Social Attitude towards Autistic Children is Negative
07	Autistic Children's are Multi-talented
08	Autism friendly Banking Facilities is Utmost Needed
09	Raising Awareness is very much Important for Social Acceptance of the
	Children with Autism
10	Programs, Initiatives, Social Allowances, Rehabilitations are important to
	Ensure the Holistic and Sustainable Development of Children with Autism
	to bring them back into the Mainstream of the Society

Children are Diagnosed with Autism Faster Than Ever

As the awareness increases than earlier, therefore, autism is being diagnosed faster than ever. In this regard, the respondent A said,

"At the age of 2, me and my husband observed it that he was not making eye contact...We took him to the doctor... and he was diagnosed with mild autism".

Respondent B expressed his opinion in this regard,

"When my son was 1.5 years old, I observed that he was not making eye contact...I became suspicious...but we didn't take that issue seriously at that time...when he was 2.5 years old...we took him to the child psychiatrist...and he was diagnosed with autism".

Respondent C also expressed the same,

"When my daughter was at the age of 2.5 years...she was not making eye contact...me and her father took her to the child specialist...and she was diagnosed with autism".

Respondent D said,

"At the age of 3 years, my son was having severe trouble in sleeping...he had a poor eye contact...moreover, he was not being able to walk...we took him to a pediatrician...and he was diagnosed with autism".

Respondent E said about the diagnosis of children with autism,

"When my son was 1.5 year old...some symptoms were seen into him...which made us tensed...he was not making eye contact...and had extreme aversion to social behavior...we took him to a Shishu Bikash Kendra...and he was diagnosed with autism".

Respondent F placed her opinion in this regard,

"When my son was 2 years old...I observed that...he is not behaving like other typical children...he had speech problem...and poor eye contact...we took him to a pediatrician...and he was diagnosed with autism".

As per the above information, one thing is observed that autism awareness is increasing among parents of autistic children, if they observe any symptoms which is abnormal in the child, at once they take their child to the doctor. As a result, autism diagnosis is happening much faster than before. According to the respondents, the children was diagnosed with autism between the minimum age of 1.5 years and maximum age of 3 years.

A Mother Needs Special Care During Pregnancy

A mother's care during pregnancy is very important for giving birth to a healthy baby. Therefore, it is very important to take special care that the mother does not fall into any kind of accident, or suffer from any mental stress or any diseases.

Respondent E gave her opinion in this regard,

"I was suffering from bipolar disorder...during my pregnancy".

Respondent B shared her experience regarding this matter,

"When I was pregnant...one day I played Ludo for long time...and after that I had bleeding".

According to the opinion of respondent C,

"When my daughter was in my womb...I used to suffer from severe bloating...therefore...I had to go for premature delivery through C-section".

The research findings shows that, during pregnancy a mother needs special care so that her both physical and mental health remain sound which will help out to prevent giving birth of a children with autism in some extent.

Symptoms are Common Often Observed into the Children with Autism

The research study explored that symptoms are common which are usually observed in the children with autism.

According to the opinion of respondent A,

"My son was not doing eye contact...he is extremely hyper...and have extreme aversion to social behavior".

Respondent B placed her opinion in this regard,

"My son was not making eye contact...and he has speech problem as well". Respondent C said,

"When I observed my daughter...I saw...she is not making eye contact...she has troublesome in speaking...and she repeats words again and again".

According to the data obtained from the respondent D,

"My son had trouble in sleeping...along with poor eye contact...and he is extreme hyper".

Respondent E shared her observation in this regard,

"My son has speech problem...along with poor eye contact...and anger".

Respondent F said,

"My son has speech problem...and poor eye contact".

Findings from the respondent's data showed that the symptoms are observed into children with autism are common in most of the cases. The common symptoms are seen into autistic children are:

- > Speech problem;
- ➤ No or poor eye contact;
- > Extreme aversion to social behavior;
- > Hyper etc.

Services Getting by the Children with Autism are not Adequate

Autistic children are getting various services from various service providers in terms of education, health and other services from Government and Non-Government service providers. But getting these services, there are lack of having adequate and proper services.

According to the opinion of respondent E,

"From Shishu Bikash Kendra my son got occupational therapy...but he is not receiving speech therapy over there...which he needs the most. After enrollment in a special education school...my son is getting basic life skill training...along with education services...but the educational materials are not adequate".

Respondent D said in this regard,

"After diagnosis of autism...I took him to a child psychologist...who advised me to give my children a high protein diet...and some improvement were seen...but as we belong to a middle class family...due to financial problem...we couldn't continue the treatment...after that we admitted our son to a special education school...the quality of educational services are good here...but the education materials are not adequate here".

The Attitude towards the Children with Autism from the Family Members are Positive

Attitudes of other family members towards autistic children are quite positive. In this regard, most of the respondents shared the same opinion.

Respondent A said,

"My son is loved by everyone in the family...everyone has sincerity towards him...everyone loves him a lot...and all of them has a positive attitude towards him". Respondent B also expressed the same,

"My son is well-loved by all the family members...as he has no other siblings...everyone really cares him...My son gets along with everyone in the family...he respects elders very much...everyone is sympathized about my son".

Respondent E also placed her opinion in this regard,

"Everyone in my family has a positive attitude towards my son...but the problem is that...my in-laws...who are associated with my family...have a very negative attitude towards my son".

Analyzing the data collected from the respondents, it can be seen that although, the attitude of the family members towards autistic children are quite positive but still not completely has been formed.

Social Attitude towards Autistic Children is Negative

Social attitude towards autistic children are still negative. Awareness has not been built up yet in the society regarding autistic children that, they are our integral part of our society. Respondent F placed her opinion regarding this issue,

"I can't go to any social event with my son...people teases him...insults him...when they see him...that's why I don't take him to anywhere...not even we attend any social events...what's the necessary to take so much negativity".

Respondent E also said the same in her statement,

"Why my son became autistic, that is why no one wants to give us value...whenever I took my son to any social event...most of them starts giving him negative look...and stalks him...we feel pain to see all of these...therefore, we usually don't go to any social events now a days".

Respondent D expressed her opinion about this issue,

"The painful thing is that...when we get invitation for any social event...so many times it happened that...they told us to not to take my son to those events...which made us so saddened...and most importantly...nobody wants to give us respect...that time we took decision that...we will not attend any social events...and we stopped going there".

From the above discussion, it can be understood that the society's attitude towards autistic children is still very negative, therefore, steps should be taken to eliminate this negative attitude towards the children with autism.

Autistic Children's are Multi-talented

Findings from case studies explored that autistic children are multi-talented Respondents A gave her statement in this regard,

"When my son got admitted into a special education school...significant positive changes were seen into him...he is well spoken...he sings very well...he is also very good at sports...he participated in "Special Olympiad"...and received awards".

Respondents B gave her opinion,

"My son goes to Mosque on regular basis...he greets everyone...he goes to the bazar with me...he is very good at painting...he does his work himself".

So, from the above facts, it is assumed that, if autistic children gets adequate service support, they will be able to do better for the country.

Autism Friendly Banking Facilities is Utmost Needed

Most of the parents of the children with autism suffers from severe depression and hypertension to think it that, how their children will remain socially secured even after their death. Therefore, to make the children financially secure, banking facilities should be autism friendly.

Respondent B said,

"I am always in hypertension that...my son doesn't know the value of money...he can't do banking work...if we keep money for him even...how he will withdraw that amount from the bank".

Respondent F also said the same thing,

"My BP remains high all the time...my son is not like other children...how he will go to the bank...and will do so many banking procedures".

So, it is utmost needed to make the banking procedures disability friendly including autism so that their social security is being ensured.

Raising Awareness is very much Important for Social Acceptance of the Children with Autism

Respondent D gave the statement about this issue,

"I think...everyone needs to be aware...regarding autistic children...they need to be socially accepted".

Respondent A said that,

"Today my son is autistic...they can't say that...their children will not be autistic in near future...so, it is important to increase awareness...so that along with my child...every autistic child gets social acceptance".

One thing we have to remember that, awareness will not be created in one night. Slowly we have to work for increasing awareness which will bring social acceptance towards the children with autism.

Programs, Initiatives, Social Allowances, Rehabilitations are Important to Ensure the Holistic and Sustainable Development of Children with Autism to Bring Them Back into the Mainstream of the Society

The only way to ensure sustainable development for autistic children is to ensure adequate developmental programs for them.

Respondent B placed her opinion in this regard,

"To ensure development for the autistic child...Government should think about their rehabilitation...so that we...the parents of autistic child...can get rid of sever tension".

Respondent A said that,

"If media plays an effective role...regarding building up awareness...besides...Government can take steps to increase awareness through various programs".

Respondent C said about the issue,

"If Government and Non-Government Organizations ensured accommodation for our children...moreover, employment...and social allowances are needed".

The data obtained from the opinion of the respondents, it is clearly seen that; to ensure holistic and sustainable development for the children with autism, everyone at all level needs to work together and necessary steps should be taken for the well-being of autistic children.

6.4.3 Conclusion

In the present study, 6 case studies were conducted to find out about psycho-social status of autistic children, demographic information of autistic children, and their families, economic status, developmental history about autistic children, family, economic, social, psychological information of autistic children, access to services of autistic children, etc. This study explored various dimensions regarding autism and psycho-social condition of children with autism.

6.5 An Analysis of the Findings

6.5.1 Analysis of the Findings of Survey

Analyzing the findings of the research study reveals various psycho-social aspects of autistic children that will guide the way to taking initiatives for them. Those aspects are discussed below:

Rates of Autistic Children are Higher among Boys

A gender analysis of the demographic data of autistic children shows that about 65 percent of the children are boys and about 35 percent are girls. This means that, boys are more affected by the autism than girls in terms of the rate of autistic children.

Age of the Parents is a Factor Giving Birth of a Children with Autism

Analyzing the data on the age of the respondents, about 45 percent of the respondents are in the age group of 35-44. Moreover, about 26 percent and 25 percent are aged between 45-54 and 26-34 respectively. However, according to experts, children of younger parents may also be autistic. But the age of the parents is also a very important factor behind the child becoming autistic. According to the doctor's opinion. Therefore, it is very important to take a doctor's advice before doing family planning.

Children Develop Faster if Parents Take Care of the Child Together

As the survey was conducted in 2 "Special Education Schools", the gender analysis of the respondents shows that about 63 percent of the respondents are female. Only about 36 percent of the respondents are male. According to experts, children whose parents take care of their child together, develop very quickly. But from the perspective of Bangladesh, it can be seen that, fathers do their own work by imposing all the responsibilities on mothers. But every parent should share the responsibility towards the child which will speed up the development of children with autism.

Autistic Children and Their Families are Facing Economic Problems despite of Having Good Monthly Family Income

Analyzing the monthly family income data, it can be seen that about 53 percent of the respondents have a monthly family income of 56000-64000 or above. However, while

examining economic status data, most families suffer from financial crisis that hinder the autistic children's access to services.

Diagnosis of Autistic Children are Increasing Due to Increases Awareness of the Parents

Analyzing the findings, a maximum of 66 percent of children diagnosed with autism were at the age of 1-2 years. According to pediatricians, child psychologist and other service providers, the sooner the diagnosis of autism are made, early intervention will be made which will help to improve the condition of children with autism.

Access to Health Care is Helpful in the Autistic Child's Development

Analyzing the findings, it is seen that, the maximum development of about 55 percent of the children is observed after receiving health care, Therefore, parents should be aware of this so that their children gets related health services.

Required Adequate Learning Materials

After analyzing the data regarding the availability of educational materials for the children, it is explored that- according to the opinion of about 55 percent of the respondents, the educational materials are fairly adequate and about 26 percent of the respondents think that the educational materials are not adequate at all. Therefore, special education schools and government agencies service providers should take steps in this regard.

Necessary Steps Should Be Taken to Improve the Skills of Special Educators and Other Education Service Providers

Analyzing the rate of satisfaction level on receiving the services of the educational institution, it was revealed that, about 40 percent of the respondents are fairly satisfied. About 8 percent of the respondents are not at all satisfied. After analyzing the data, it was found that- there is a great need for skilled special educators and other service providers in terms of educational services related to the children with autism.

Access to Adequate Educational Services are Instrumental in the Development of Autistic Children

Analysis of respondent's data shows that- autistic children improve after receiving educational services. About 63 percent of the respondents said their children improved after receiving educational services from special education schools. Therefore, it is utmost important to improve the quality of education and create special educators through training.

Family Approach towards Autistic Children is Empathetic

Analyzing the data obtained from the respondents, it can be seen that the attitude towards the children with autism are condescending.

Social Attitude towards Autistic Children are Negative

According to the data regarding society's attitude towards the autistic children, about 61 percent of the respondents think that having an autistic children is still considered as a curse by the society. It is very necessary to change this attitude. And for that purpose, it is essential for the government to take necessary steps to make the people of all levels aware regarding autism and autistic children.

Strengthening Social Security Support for the Betterment of Children

About 51 percent of the respondents felt that autistic children are deprived from access to health services. About 16 percent said- autistic children are denied getting social security benefits and civil rights. According to about 13 percent of the respondents, they are deprived of social security assistances. Therefore, social security support should be strengthened for the holistic development of children with autism.

6.5.2 Analysis of the Findings of Key Informant Interview (KII)

10 Experts and stakeholders placed their opinion as a part of Key Informant Interview (KII) method to explore the various dimensions of Psycho-social situation of Children with Autism. During in-depth interview session, various dimensions were explored related to this topic which are described below:

Reason/Causes of Autism

The causes of autism is still not fully understood. But according to opinion of the doctor's-children who carry "Copy Number Variants" in their genes are usually diagnosed with autism. According to the scientists, two factors are generally responsible for the development of autism:

- 1. Genetic and
- 2. Environmental.

The Prevalence Rate of Autism is High

The prevalence rate of autism is increasing day by day. According to the opinion of the expertise, the reason behind the increase of autism rate is that- autism is being diagnosed more than ever before. Because awareness of the parents of the autistic children has increased more than earlier. Therefore, at once they observe their children's behavior are different from other, they rush to the doctor. And that is why autism is being diagnosed and the rate of autism is increasing day after day.

Symptoms are Observed Usually in Children with Autism

- ➤ No or poor eye contact
- Speech problems
- > Communication problems
- Non responsive behavior etc.

These are the common symptoms that are observed in autistic children according to the expert's opinion.

Autism Rate in Bangladesh

According to "Disability Identification Survey Program" conducted by Department of Social Services- Number of Persons with Autism are- (Male: 51959, Female: 32769 and Hijra: 54).

Taking Pre-cautions can Decrease Autism in a Children in Some Extent

According to the doctor's opinion- if the parents can take pre-cautions, in some extent possible to prevent giving birth of an autistic child. Doctors suggests that parents must have to consult a doctor before go for family planning. Moreover, during pregnancy, some necessary steps should be followed strictly which will help mother to give birth of a healthy child such as: ensuring proper nutrition, regular health checkup, mental support from husband and in-laws, not to take any antibiotics during pregnancy, light exercises and yoga etc.

Raising and Building up Awareness for Diagnosis and Early Intervention

The sooner an autism diagnosis is made, the sooner a child's autism management can begin. Diagnosis can be done by using M-Chat, IQ Test, and Screening etc. Hence parental awareness is very important.

Autistic Children Needs to Bring under Social Inclusion

Autistic children needs to bring under inclusion. Special education setup is necessary to achieve that goal. Special Education Schools should be brought under mainstream primary education. Infrastructural changes should be made in schools. Autism management requires an inclusive approach. Every institutions need to work with deeper perception.

Creating Skilled Service Providers

Proper foundation training is needed for service providers. Otherwise, unskilled staff will misguide in autism management which will be considered as one of the obstacles in proper development of autistic children.

Parent's Counseling Needed for Better Autism Management

Parents need to improve in the area of autism management through counseling. Now a days in various training and workshop, it is often said that- first management and assessment should be done.

Media can Play an Important Role in Building-up Awareness

As media is called the mirror of the society, therefore, media has an important role building up awareness. Media needs to change their typical way of presentation so that people feels interest to know about the children with autism. Media can create interesting short content or

cartoon like mina or sisimpur which will make positive vibes and awareness will be build up through this way.

Awareness can be Build-up through the "RTI ACT-2009"

According to the United Nations Charter, it is said that- Access to information is like Philosopher's stone.

Initiatives Needed while Providing Services by the Government and Non-Governmental Organizations for Ensuring Sustainable Development

We have upgraded legal framework. But problem is in implementation. To ensure implementing initiatives and programs, every organizations has to include under monitoring, evaluation and accountability. Because without these elements, good governance cannot be established and without good governance no programs and initiatives will sustain. Therefore, everyone from all levels of the state needs to work together for the betterment of children with autism which will accelerate sustainable development

6.5.3 Analysis of the Findings of Case Studies

Analyzing the research findings from the case studies, the points that emerge are discussed below:

Social Attitude towards Children with Autism is Negative

It can be seen from the case studies, social attitudes towards autistic children are still negative. To eliminate this negative view, awareness should be increased among mass people. Acceptance of autistic children is also need to increase.

Autistic Children are Multi-talented

The research findings shows that- most of the autistic children are multi-talented but those remain latent. That is why those qualities should be found out with the help of service providers and appropriate measures should be taken according to their needs assessment.

Autism Friendly Banking Facilities is Utmost Needed

Facilitating autism friendly banking facilities is very important to make the children with autism socially secure for the future.

Raising Awareness for Social Acceptance

Social awareness needs to be raised to increase acceptance of autistic children and that should be done through various programs in every community. For example-, this issue can be discussed in Mosques, Temple etc. Because the number of religious people in Bangladesh is high. Therefore, the speech given in the Mosque will play an important role in raising the awareness of the people.

Ensuring Adequate Education and Health Care Support for Autistic Children

Data obtained from case studies shows that, rapid improvements are seen and observed after receiving the health and education services. But lack of adequate educational materials and quality services, lack of health services such as- therapies, counseling, diagnosis etc. are considered as the barrier of the development of autistic children. Therefore, ensuring quality and adequate education and health services are essential.

Free Therapies, Medical Assistances and Allowances from the Government and Non-Government Organizations for the Needy People

According to the findings, many autistic children cannot continue medical care, especially, therapy services due to inadequate and high cost. It hinders the child's development. Therefore, free government and private service support should be ensured.

6.6 Conclusion

Autistic children are our integral part of our society. Without bringing them into the mainstream of the society, no development will be ensured for the betterment of the children with autism. This present study explored so many dimensions regarding psycho-social condition of children with autism which will help to take further initiatives for the well-being of the Children with Autism.

Chapter Seven

Chapter Seven: Summary of the Findings and Recommendations

7.1 Introduction

In Bangladesh, although some research work on autistic children has been conducted earlier, but yet no research was done related to psycho-social condition of children with autism. But one thing should be noted, if the overall development of the autistic children is to be insured as well as sustainable development, it will not be possible to ensure it without knowing the psycho-social condition of the autistic children. Therefore, related research work is absolutely essential and for that purpose, the present research work has been conducted. Social Survey Method is applied keeping in mind the subject of the research; where data was collected through the survey on 60 parents of autistic children from two "Special Education Schools". Besides, data is collected through in-depth interviews with 10 individuals who are subject matter experts and stakeholders who have information to fulfill the research objectives end 6 case studies have been carried out to help analyzing the psycho-social situation of children wait autism.

Based on the important data obtained from the aforementioned survey, in-depth interviews and case studies, this chapter presents the conclusions and recommendations which will help out to improve or modify the existing policies and future policy formulation.

7.2 Summary of the Major Findings Explored Through the Present Study

The present research work on "A Study on Psycho-social Situation of Children with Autism" explored various dimensions of psycho-social status of autistic children. In the light of research objectives, three methods- survey, in-depth interviews and case studies were followed in this study. The major findings that have emerged from this present study, are summarized and discussed below:

As per the research objectives, the study was able to uncover socio-demographic background and economic condition of children wait autism. According to the survey data about the age of autistic children, about 65 percent of autistic children are boys and 35 percent are girls. About 93 percent of autistic children are Muslims, about 6 percent are Hindus. Children of other religions were not found in the research study. According to the information obtained from the parents participated in the survey, about 63 percent of the respondents are female and about 36 percent are male. Analyzing the educational qualifications of the respondents, it can be seen that, most of them art Post graduate and graduate. Some of them passed SSC and

HSC. According to the findings of the respondents, it is observed that the highest number of about 46 percent respondents are housewives. In responses to the question of why they are unable to get involved in the working sector, the information came from all the methods applied here in the study are almost same. Since the mother has to take care of the child alone, along with households' chores and maintaining other family members, they are unable to utilize their education in working sectors. They are not being able to get into any job, which is causing financial burden.

According to data on the development of autistic children, symptoms of autism are usually observed between 1.5-2 years of age. Commonly observed symptoms are- reluctance to engage in in social behavior, difficulty in speaking; no or poor eye contact, extreme hyperactivity, communication problem etc. According to the data obtained from the survey, about 66 percent of children with autism are diagnosed at the age of 1-2 years. It can easily be understood from this information that, the awareness among parents is increasing than earlier.

As per one of the objective of the present study, while uncovering the psycho-social challenges of autistic children, it is discovered that- autistic children face multi-faceted problems and obstacles in various fields including familial, social, economic, psychological etc. According to survey and case studies, it is clearly seen that; the attitude of other family members and relatives towards autistic children are very negative. About 71 percent of the respondents think that, the attitude of other family members towards the autistic children are condescending. According to the survey, about 61 percent of the respondents feel that society's views and attitude towards the autistic children still considered as a curse. About 41 percent of the respondents think that people's attitude towards autistic children's are very negative, therefore, parents of children with autism makes them socially isolated. About 75 percent of the respondents think that they are suffering from financial burden. Parents of autistic children suffer from severe anxiety, depression, frustration and hypertension thinking about the future of their autistic children after their death.

According to the information regarding the access to services of autistic children, the awareness among people has increased more than before. There was a time, when children with disabilities; including autism, were referred to as Pagol (crazy). Now, it is not visible and changes has come. Moreover, if the presents see different symptoms than the normal children, they immediately take them to the child specialist. Therefore, the rate of autism is increasing day by day. The only reason behind this is - the diagnosis. Autism is diagnosed through - early intervention and screening. As a result, the percentage of autism diagnosis in the age of 1-2 years of children is the highest.

With the analysis of three research methods shows that- Bangladesh has now developed better healthcare and education services but it is not adequate. Moreover, the service providers are not skilled enough. To overcome this situation, skill development should be given the utmost priority through education, training and counseling. If human resources are not competent, they will misguide in providing services to autistic children which will disrupt the overall development of the autistic child. Moreover, the government organizations which are under undertaking various programs aimed at bringing autistic children into the mainstream of society, have policies on paper but they are not as much serious about implementation. Therefore, human perspective approach should be used.

One of the objectives of the present study was to know about the existing policies and to shed light on what other policies can be adopted in the future. Most of the experts who gave information, agreed on one thing- the disability policies in Bangladesh are enough and well planned but the main challenge is implementation. The awareness, positive attitude and sincerity should be increased in every department related to these issues. Monitoring, evaluation and accountability must be ensured in every department by ensuring these things, only then, the sustainable development of autistic children is possible which will help out bring the children with autism into the mainstream of society.

7.3 Relation with Social Policy Formulation and Implication

There is a lack of information related to autism. People's perception about autism is still not clear. Moreover, there is a lack of clear understanding; what types of psychosocial problems that autistic children suffers from and what steps can be taken to get rid of these problems.

All the laws enacted in the developed countries of the world are properly implemented by the government. Administration mainly works in the area of policy implementations. For that reason, equality, human dignity and social justice issues should be inputted through proper training in every government employees involved in the implementation programs; so that the issue of social responsibility is created among them.

Laws should not only be on the paper, they should be implemented in practice as well. All the Ministries and Departments should work together regarding implementing existing policies for the well-being of the children with autism. Monitoring, evaluation and accountability should be undertaken to ascertain the extent to which the law is being implemented in each area.

This research study will provide information about the psycho-social situation of children with autism to the program planner government and non-government organizations which will help them out to take suitable initiatives and proper steps for the betterment of the children with autism to bring them up into mainstream of the society which will accelerate sustainable development.

7.4 Recommendations for the Future Study

Based on the data on psycho-social status of children with autism following field survey indepth interviews and case studies review the following recommendations are formulated for the current research.

- 1. Every service providing organizations for holistic development of autistic children has to work in human perspective approach the main goal of that approach will be to ensure equality human dignity and social justice.
- 2. As many laws and policies are there for the development of all types of disabilities including autism must be implemented disability budget can be kept in the national budget allocation.
- 3. Every ministry department and nongovernmental organizations should work together to bring back autistic children to the mainstream of society through collaboration.
- 4. A major obstacle to any development path is lack of access to information to ensure sustainable development for autistic children the first step is to ensure access to information through RTI Act.
- 5. To ensure sustainable development every government department should have a monitoring system accountability must be ensured if monitoring evaluation and accountability are confirmed it will establish good governance which will accelerate sustainable development.
- 6. Media can play a significant role in raising awareness about autism suitable short content should be made for digital platforms media can create some entertained entertainment content and gives some info graphics on the subject of autism at end of the content thus the awareness will increase because of that the media has to change their way of presentation media has to create interesting digital content such as Mina cartoon or Sisimpur where autism issue can be included.
- 7. Every institutions who are providing services for autism or any type of disabilities should be brought under monitoring whether there is any kind of corruption exists in the system or not those things need to get the light and have to be visualized monitoring and accountability must be ensured.
- 8. Government departments should mapping the situation issues related to autism regular visit follow-up treatment must be ensured.

- 9. We need human resources to bring autistic children back to normal life so the authorities should give importance to this matter well trained human resources should be created through proper training and institutions.
- 10. Doctors and health care workers need to be trained through applying different approaches autistic children should be brought back to normal life by bringing them under social inclusion in terms of health education and if they spheres of life.
- 11. It is important to take steps for the autistic children so that they receive early interventions therefore the awareness of the parents is utmost important government can create awareness through various campaigns in this regard.
- 12. Sometimes in getting government allocated disability allows children has to face harassments to get rid of these problems seeds of social responsibility must be planted into every government employer it is autistic children's right these social values must be imputed.
- 13. Adequate and quality training should be done under government sponsorship to create skilled special educators there is a severe shortage of qualified special educators who will provide location services to the children with autism that is why it is necessary to bring some changes in the government's policies highly educated skilled persons should be created.
- 14. Few policy changes can be made for all types of disabilities including autistic children a certain percentage of persons with disabilities can be employed in every sector it will enable inclusion of autistic children and persons their employment Social Security and rehabilitations will be ensured.
- 15. Every autistic children has some spatial quality lying dormant inside him or her which needs to find out and developed through special education and training.
- 16. Parents of autistic children has to write assets in the name of the child through trust so that the autistic children's Social Security is being ensured strong bonding needs to be created between autistic child and his siblings from an early age responsibility should be taught so that they can look after their autistic brother or sister.

- 17. Awareness can be raised through various campaigns to create social acceptance and autistic children's parents and their family's acceptance can be created through counseling.
- 18. Employment opportunities can be created through vocational training in various subjects such as teaching garment work buttoning, shirt collaring etc. Handicrafts and cottage industries culinary arts computer training beautician course et cetera which will ensure Social Security and rehabilitations.

7.5 Concluding Remarks

Concluding remarks auto strict children are part of our society they are not outsider of the society Once Upon a time there was a barrier to the diagnosis of autism parents did not want to admit that their children have autism they wanted to hide the matter from relatives to society but in the present context the scenery has changed a lot autism diagnosis has increased more than ever before because of the increasing awareness among people but autistic children cannot be brought back into the main stream of society through drag diagnosis only it requires social inclusion autistic children should be included in every normal activity of the society only then we will be able to see the practical form of the policies related to autistic children which will ensure sustainable development and in this way autistic children will be established as an indispensable citizen of the society without being a burden to the society and rather they will live as a part of mainstream of the society the present study is only an initial attempt as a higher research to explore the nature of psychosocial status of children with autism despite several limitations this study has yielded sufficient data hopefully future researchers will be able to open new areas of more intensive research based on this data and then I will think my research effort will be worthwhile.

References

- Ahmed, Dr. A. (2020). Program Director (Deputy Secretary), Disability Detection Survey: A Key to inclusive development in Bangladesh. Department of Social Services, Ministry of Social Welfare. Retrieved October 2023 from https://jpuf.portal.gov.bd/sites/default/files/jpuf.portal.gov.bd/notices/50320753 a215 43bf 9ad5 1 613e/4143aa/Disability%20
- Bardhan, A. (2022). Family Care and Its Impact on the Life of Elderly People: A Study in Dhaka City. Ph.D. Dissertation. Dhaka University Institutional Repository. Retrieved May, 2023 from
- $\underline{https://repository.library.du.ac.bd:8080/browse?type=author\&value=BARDHAN\%2C+AN}\\ URADHA$

Bogardus. (1925). Bogardus Social Distance Scale: Definition, Survey Questions with Examples. Retrieved September 2023 from https://www.questionpro.com/blog/bogardus-social-distance-scale/

- CRI. (2014). Global Autism Movement and Bangladesh. Centre for Research and Information, Retrieved October 5, 2023 from https://cri.org.bd/2014/09/03/global-autism-movement-and-bangladesh/
- Cynthia, A., Serrata. (2012). Psychosocial Aspects of Parenting a Child with Autism. Journal of Applied Rehabilitation Counseling, Volume 43, DOI: 10. 1891/0047-2220.43.4.29
- Demehri, F., Alizade, H., Pezeshk, S., Kazemi, F., & Farokhi, N. (2016). The Effectiveness of Psychosocial Intervention on Challenging Behavior in Children with High-Functioning Autism Spectrum Disorder. Middle Eastern Journal of Disability Studies, 6: 56-61.

Retrieved from October 9, 2023 https://jdisabilstud.org/article-1-672-en.html

- Devi, K.B.L. (2020). Case Study Method. e-PG Pathshala INFLIBNET Centre. Retrieved October, 2023 from https://www.researchgate.net/publication/344780835 Case Study Method
- Elias, M., (2023). 51 Autism Statistics: How Many People Have Autism? Discovery ABA Therapy, Retrieved September 28, 2023 from https://www.discoveryaba-com.translate.goog.statistics/how-many-people-have-autism?
- Good, &Hutt. (1952). Methods of Social Research, New York: Mc-Graw Hill Book Company INC
- Green, J.C., Caracelli, & Graham, W. F., (1989). Toward a conceptual framework for mixed-method evaluation design. Educational Evaluation and Policy Analysis, 11, 255-274. doi: 10.3102/01623737011003255
- Gupta, Ashum., & Singhal, Nidhi. (2005). (PDF) Psychosocial support for families of children with autism. Asia Pacific Disability Rehabilitation Journal, Volume 16. Retrieved from http://www.researchgate.noe/publication/228355364 psychosocial support for families of childre n_with_autism
- Hahler, E. M., & Elsabbagh, M, (2015). Autism: A Global Perspective. Current Developmental Disorders Reports, 2(1).
- DOI: 10.1007/s 40474-014-0033-3
- Hartselle, S. (2023). Autism: Overview and More. Dotdash Meredith. Retrieved October, 2023 from https://www.verywealth.com/autism-overview-4582004
- Hossain, Anwar. (2008). An Overview of Autism in Bangladesh. The Dhaka University Journal of Psychology, Vol-3, p-111. Retrieved from https://studymoose.com/literature-review-on-autism-spectrum-disorder-essay (Accessed on 29.10.2020)
- IPNA. (2021). Autism, Institute of Pediatric Neurodisorder & Autism, Bangabandhu Sheikh Mujib Medical University (BSMMU). Retrieved October, 2023 from https://ipnabsmmu.edu.bd/autism/
- Masu't, A.M., & Ali, M. M. (2023). Psychosocial Adjustment Strategies among Typically Developing Adolescents of Siblings with Autism Spectrum Disorder. International

Journal of ACADEMIC RESEARCH IN BUSINESS & SOCIAL SCIENCES, 13(2), 1355-1376.

DOI: 10.6007/UARBSS/V13-12/16345

- Ntre, V., Papnikolaou, K., Triantafyllou, K., Giannakopoulas, G., Kokkosi, M., & Kolaitus, G. (2018). Psychosocial and Financial Needs, Burdens and Support, and Major Concerns among Greek Families with Children with Autism Spectrum Disorder (ASD). International journal of Caring Services, Volume 11. Retrieved October 5, 2023 from <a href="https://www.academia.edu/37688622/Psychosocial and Financial Needs-Burdens and Support and Major Concerns among Greek Families with Children with Autism Spectrum Disorder ASD
- Rahman, Prof. Dr. AKM. F., Akhter, Dr. S., Biswas, A., & Abdullah, A, A, S. (2016). Study on Prevalence of Autism in Bangladesh. Ministry of Health and Family Welfare, Government of the People's Republic of Bangladesh

DOI: 10.13140/RG.2.2.33709.33765

- Rabbani, Golam., A, Helal., Muzharul, M., & Chowdhury, W.A. (2014). Autism in Bangladesh: Window for Stigma Removal. Conference: 2014 International Meeting for Autism Research. Retrieved October 29, 2020 from https://www.researchgate.net/publication/268143329 Autism In bangladesh Window for Stigma Removal
- Rajmohan, V., & Mohandas, E. (2007). Mirror Neuron System. Indian J Psychiatry, 49(1), 66-69.

doi: 10.410310019-5545.31522

- SS. (2023). Theories of Autism: Social, Psychological. Retrieved July 18, 2023 from Study Smarter: https://www.studysmarter.co.uk/explanation/psychology/basic-psychology/psychological-theories-of-autism/
- WHO. (2013). Executive Board, 133rd session, provisional agenda item 6.1, EB133/4. Retrieved April 8, 2023 from https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders
- WPR. (2023). World Population Review. Retrieved September 28, 2023 from https://worldpopulationreview.com/country-rankings/autism-rates-by-country

Appendices

Appendix A Letter of Informed Consent

The present research work will be conducted as a part of M.Phil. Thesis under M.Phil. Programs, Institute of Social Welfare and Research, University of Dhaka. The research study will be conducted in strict accordance with all the ethical requirements applicable to social research. Therefore, some principles will be followed accordingly so that this study meets the ethical requirements of a good and effective research work. These principles are given below:

- The purpose of the research study will be clearly explained to the respondents.
- The respondents will be directly informed that this work is an academic research work and purely voluntary work and they will not get any benefit from it.
- Respondents will have full freedom to decide whether they will participate in the interview session as a part of data collection process or not.
- The collected information will be treated with utmost confidentiality.
- No unauthorized person shall have access to the collected information, therefore, the collected information will be strictly kept confidential

In addition, few more ethical consideration will be followed which are described below:

- Audio recorder will be used during the interview session which will help out later during the process of data documentation and analysis. This thing will be informed to the respondents.
- After accomplishment of the work, all the data will be erased.
- Respondents have all the right to take the decision, whether he or she will participate in the interview session or not.
- Interviewee's identity will not be revealed during publication of results from this study.

If you have any query further for more details you are welcome to contact me or my research supervisor.

Research Supervisor

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Appendix B

Structured Interview Schedule

A Study on Psycho-social Situation of Children with Autism

Institute of Social Welfare and Research University of Dhaka



[The collected data will be used for research purposes only and confidentiality of the collected data will be maintained accordingly]

				Na	me	of t	he l	[nte	rvie	ewe	e :					
				Dat	e o	f th	e In	terv	viev	v :						
				Mo	bile	e No	o.:									
0	1															
	0	0 1	0 1	0 1	Dat	Date o Mobile	Date of th Mobile No	Date of the In Mobile No. :	Date of the Intermediate Mobile No. :	Date of the Interview Mobile No.:	Date of the Interview : Mobile No. :	Mobile No. :	Date of the Interview : Mobile No. :	Date of the Interview : Mobile No. :	Date of the Interview : Mobile No. :	Date of the Interview : Mobile No. :

1. General Demographic Information of Children with Autism:

Name	:
Age	:
Date of Birth	:
Gender	:
Religion	:
Nationality	:

2. General Demographic Information of the Respondent

2.2Far	nily Details	5							
Seria l No.	Name of head of family and name of member s in upper to lower order	Relatio nship with the child	Marital Status Unmarried= 1 Married=2 Divorced=3 Widow/ Widower=4 Other=5	Age	Gende r Male= 1 Femal e=2	Education al Qualificati on (Enter the code below)	Main Occup ation (Enter the code below)	Seconda ry Occupat ion (Enter the Code Below)	Average Monthly Income
1	2	3	4	5	6	7	8	9	10
1									
2									
3									
4									
5									
6									
7									
8									
Total 1	Monthly H	ousehold I	ncome =					•	

2.1Location of the Respondent	
Name of Head of the Family	
Ward No.	
Holding No.	

Area	
Police Station	
District	
Division	

Illiterate=1, Only can sign=2, Can Read=3, Primary/elementary level=4, JSC=5, SSC=6, HSC=7,Graduate=8, Post Graduate=9, Other(Specify)=10

Main and Secondary Occupations: Service(Government)=1, Service(Private)=2, Business=3, Industrial Worker=4, Student=5, Unemployed=6, Retired=7, Teacher=8, Small Business=9, Housewife=10,Other(Specify)=11

2.3Number of Family Members Yes=1 Number: Type: Physical=1 with more special needs (If any) No=2Mental=2

2.4Religion of the Respondent	Islam=1, Hindu=2, Christian=3, Buddhist=4,
	Other(Specify)=5

3. Economic Status of Household Head or Respondent (Occupation, Income, Expenses, Wealth)

3.1List of Assets Type of Asset (there Yes (If Yes) (If Yes) Serial No No. could be more than one **Quantity/Number Estimated Price** (Taka) answer) 1. Cash Money 2. Invested (Capital Cash) 3. Land (Katha/Shotangsho) Flat 4. 5. House 6. Jewelry (Gold/Silver) 7. **Business**

8.	Furniture		
9.	Shop		
٥٥.	Other(Specify)		

3.2Sources of Family Income

Sources of	Job Specific Name	Yes=	No=	Monthly Gro	oss Income
Income		1	2	(Taka)	
Job/Work	1.Service				
	(Government/Private)				
	2.Garments				
	3.Business				
	4.Day laborer				
	&.Driving				
	(Rikswa/Van/Auto/				
	Motorcycle)				
	6. House/Shop Rent				-
	7. Small Business (Tea				
	Stall/Grocery Store)				
	8. Other (Specify)				
Social Assistance	9. Government Pension				
	10. Old Age Allowance				
	(Five Hundred Taka Per				
	Month)				
	11.Widow's Allowance				
	(Five Hundred Taka Per				
	Month)				
	12.Freedom Fighter				
	Honorary				
	(Twenty Thousand				
	Taka Per Month)				
	13.Disability				
	Allowance (Seven				
	Hundred and Fifty Taka				
	Per Month)				

	14. Other (Specify)				
Gross Monthly Income =					

3.3 Monthly Household Expenses					
Sector of Expenditure	Monthly Expenses (Taka)				
1. Home Rent					
2. Food					
3. Clothing					
4. Purchase of Furniture					
5. Land/Flat/Shop/Purchase of Vehicle					
6. Education					
7. Health/Healthcare costs of autistic					
children/Medicine					
8. Electricity/Water/Gas Bill					
9. Festival (Religious/Social/Cultural/ Hospitality)					
10. Mobile/Internet Bill					
11. Other (Specify)					
Total Monthly Expenses=					

4. Hea	4. Health Related Information of Children with Autism						
Birth	and Post-Natal-Developmental Histo	ory Related Information Regarding					
Autist	Autistic Children						
4.1 At	What Age is Your Children Diagnosed w	rith Autism?					
Answe	er:						
4.2	Is Your Child Congenitally Autistic?	Yes=1No=2					
4.3	If the answer is No, then what's the	Any Accident in Pre-Natal, Natal or					
	reason behind of being autistic	Post-Natal Stage=1, Any Particular					
	children?	Disease=2, Natural=3, Other					
		(Specify)=4					
4.4	How long has the children been	0-5=1, 5-10=2, 10-12/(Above)=3					
	autistic?						
4.5	Does your child have any disabilities	Yes=1, No=2					
	other than autism?						

4.6	If the answer is yes, please specify	Physical=1, Vision=2, Hearing=3, Speech=4, Intellectually Disabled=5,
		Other (Specify)=6
4.7	What are the symptoms that is observed	Not to mingling with peers=1,
	in children with autism?	Repetitive Behavior =2, Not to make
		Eye Contact=3, Speech Problem=4,
		Lack of Patience=5, Extreme Aversion
		to Social Behavior=6, Other(Specify)=7
	Health Services Related Information	
	getting by the Children with Autism	
	from the Service Provider	
4.8	What type of treatment receiving by the	Allopathic=1, Homeopathy=2,
	autistic children?	Kabiraji=3, Ayurvedic=4, Other
		(Specify)=5
4.9	Name of Service provider:	
	Duration of Services:	
4.10	What kind of health services do children	Speech Therapy=1, Language Therapy
	receive?	=2, Occupational Therapy=3, Other
		(Specify)=4
4.11	What is the Doctors opinion about the	Will be okay=1, Partially okay=2, will
	children's disability?	not be okay=3
4.12	How skilled are Doctors and Health	Very Efficient=1, Skilled=2, Fairly
	Service Providers?	Efficient=3, Inefficient=4, Not Efficient
		at all=5
	Developmental History of Children	
	with Autism after getting the Health	
4.10	Services	1
4.13	How is the child's progress after	Improvement from before=1, Same as
	receiving health care services?	before=2, partial Improvement=3,
		Deterioration has occurred=4
4.14	What type of improvements have been	Improvement in speaking=1,
	observed after getting health services?	Improvement in social behavior=2,
		Increased Eye Contact=3, Improvement
		of communication problems=4,

	Reduced	Fickleness=5,	Other
	(Specify)=6		

5.Information Regarding Access to Educational Services for Children with Autism		
5.1	Name of the Children's Educational	
	Institution:	
	Class Name:	
5.2	The duration of education services from	
	this institution:	
	Information regarding educational	
	services received from the institution:	
5.3	How far is the educational institution	0-1 km=1, 1-2 km=2, 2-3 km=3, 3-
	from your home?	4/Above=4
5.4	What services does your child usually	Treatment=1, Education=2, Physical
	receive from the institution? (There	Exercise=3, Residential=4,
	maybe more than one answer)	Entertainment=5, Sports=6,
		Training=7, Other(Specify)=8
5.5	Are the teaching materials adequate?	Adequate=1, Fairly Adequate=2,
		Inadequate=3
5.6	Are parents allowed to visit classrooms?	Yes=1 No=2
5.7	How satisfied are you with the classroom	Very satisfied=1, Satisfied=2, Fairly
	environment?	Satisfied=3, Dissatisfaction=4,
		Totally Unsatisfied=5
5.8	How efficient do you think the teachers	Very Efficient=1, Skilled=2, Fairly
	of the institution are in providing	Efficient=3, Inefficient=4, Not
	educational services to autistic children?	Efficient at all=5
5.9	How competent do you think the doctors,	Very Efficient=1, Skilled=2, Fairly
	therapists, psychologists and other health	Efficient=3, Inefficient=4, Not
	workers who provide care are?	Efficient at all=5
5.10	Are there counseling and training	Yes=1 No=2
	services for autistic children and autism	
	management for parents?	
5.11	If the answer is yes, please specify	

Developmental History and Information about the Children's progress after receiving Services from the Institution and Expected Furthermore Services from the Institution:

5.12	How is your child's progress after	Improvement from before=1, Same	
	admission and receiving services from	as before=2, partial Improvement=3,	
	the Institution?	Deterioration has occurred=4	
5.13	How satisfied are you with the services	Very satisfied=1, Satisfied=2, Fairly	
	of the Institution?	Satisfied=3, Dissatisfaction=4,	
		Totally Unsatisfied=5	
5.14	More services you want after receiving	Education services=1, Health	
	services from this institution: (Multiple	services=2, Access to training in	
	answers possible)	income generating activities=3,	
		Job=4, Government sponsorship=5,	
		Financial assistance=6,	
		Entertainment=7, Other(Specify)=8	

6. Information on the Challenges faced by the Children with Autism

	Challenges Faced by the	
	Autistic Children in Family	
	Life:	
6.1	What is the attitude of other people in the	Condescending=1,
	family towards the autistic children?	Normal=2Generous=3,
		Empathetic=4,
		Other(Specify)=5
6.2	What is the attitude towards acceptance of	No acceptance at all=1,
	autistic children compared to other family	Normal=2, Partial
	members?	acceptance=3
	Information about the Social Impairments	
	of Autistic Children	
6.3	How is the children's disability considered	Curse=1, Fate=2, Natural
	socially?	things=3, Other(Specify)=4

6.4	What kind of problems do children face	Deprived of Educational
	socially?	Services=1, Healthcare=2,
		Access to civil rights==3,
		Social security=4,
		Other(Specify)=5
6.5	What problems are faced by the children with	Normal
	autism in participating in social events and	participation=1,Peoples
	recreational activities?	negative look=2, Victim of
		adverse comments=3, no
		problem has to face=4,
		Other(Specify)=5
	Information on Financial Constraints faced	
	by the children with autism	
6.6	What are the financial challenges faced by the	Deprivation of access to
	autistic children? (There maybe more than one	wealth=1, Deprivation of access
	answer)	to social security programs=2,
		Difficulty in obtaining banking
		facilities=3, Lack of
		employment opportunities=4,
		Other(Specify)=5

7. Information on the Challenges Faced by the Parents of Children with Autism

	Information on Family Challenges	
	faced by the Parents of Children with	
	Autism	
7.1	Specify if the Problems faced in Family	Family Disorder=1, Quarrel=2,
	life by the parents of children with	Divorce=3, Isolation from the
	autism(Maybe more than one answer)	Relatives=4, No Problem=5,
	answer is yes	Other(Specify)=6
	Social Challenges faced by the	
	Parents of Autistic Children	
7.2	What problems are being faced by the	Social Isolation=1, Socially
	parents of autistic children in terms of	Degraded=2, Dishonor=3,
	social life? (There maybe more than one	Deprivation of Social
	answer)	Responsibilities=4,There was no
		problem=5, Other(Specify)=6

	Financial Constraints has to face by	
	the parents of autistic children	
7.3	What type of financial constraints are	Health=1, Education=2, Working
	being faced by the parents of children	sector=3, Economic=4,
	with autism?	Other(Specify)=5
	Psychological problems faced by the	
	Autistic Children's Parents	
7.4	Psychological problems faced by the	Frustration=1, Depression=2,
	parents of children with autism (There	Anxiety=3, Hypertension=4, Other
	maybe more than one answer)	(Specify)=5
8	Recommendations	

(Thank you so much for patiently participating in the Interview Session)

Appendix C

Key Informant Interview Guidelines

- 1. What is the current situation of the children with autism?
- 2. What factors are important in autism management?
- 3. What type of pre-cautions can be taken while family planning to give a birth of a child without any disabilities including autism?
- 4. What steps can be taken to raising awareness for ensuring diagnosis and early intervention?
- 5. What initiatives, programs and policies have been adopted by the Government and Non-Government Organizations?
- 6. It is said that-media is the mirror of society. How can the media play a role in raising public awareness for autistic children?
- 7. Autistic children are not a burden to society, rather they are integral part of this society. What steps can be taken to bring them back to the mainstream of society?
- 8. The United Nations Charter of Human Right states that the access to information is philosopher's stone. In which extent has the "RTI ACT-2009" been implemented for autistic children?
- 9. What steps can be taken to ensure sustainable development for the well-being of children with autism?

Introductory Information
Name
Designation/Organization
Contact Address
Mobile/Telephone No
E-mail
Transparency
Interview Time:Date:Place:
Question ID no.
Signature of Interviewer:Signature of Interviewee (optional)

Appendix D

List of Key Informant Interviewee's

A. Disability Expert

1. Dr. Nafeesur Rahman

Director, National Forum of Organizations Working with the Disabled (NFOWD)

B. Government Officials

2. Md. Kamrul Islam Chowdhury

Joint Secretary, Department of Social Service (DSS)

C. NGO Executives

3. Dr. Shamim Ferdous

Executive Director, Bangladesh Protibondhi Foundation (BPF)

4. Wahida Banu

Executive Director, Aparajeyo-Bangladesh

5. Subarna Chakma

Chairperson, Society for the Welfare of Autistic Children (SWAC)

D. Academician

6. Dr. Md. Aliur Rahman

Chairperson, Department of Journalism and Media Communication, Green University of Bangladesh

E. Media Personality

7. Amin Al Rashid

Editor, Current Affairs, Nexus Television

F. Special Educator

8. Mehfuza Islam

Special Educator, Kalyani Inclusive School, Bangladesh Protibondhi Foundation (BPF)

G. Child Psychologist

9. Ferdousi Maula

Child Psychologist, Bangladesh Protibondhi Foundation Clinic

H. Doctor

10. Dr. Ashish Kumar Chakraborty

MBBs MD (Hepatology), CCD (Diabetes)

Consultant Hepatologist, Birdem General Hospital, Dhaka

Appendix E

Case Study Interview Guideline

The Interview Schedule is designed as part of the data collection of the research to find out the information about psycho-social situation of children with autism.

(The information collected through this questionnaire will be used for academic purpose only. Confidentiality will be maintained accordingly. Questions will be asked in Bengali as the native language of all of the respondents is Bengali).

A) General Demographic and Socio-economic Information of the Autistic Children and Their Parents

(Name, Age, Gender, Marital Status, Religion, Address, Educational Qualification, Occupation, Monthly Income, Number of Family Members).

B) Information about the Birth and Developmental History of the Child

- 1. Did the autistic children face any problems or accidents during Pre-Natal, Natal or Post-Natal Stage?
- 2. At what stage the child diagnosed with autism?
- 3. What symptoms of autism are observed in children?

C) Information Regarding Health Services Getting by the Children with Autism

- 4. How is the child diagnosed with autism?
- 5. What kind of Healthcare services received by the autistic children? Are they adequate for the children with autism?
- 6. How skilled are healthcare service providers?
- 7. Is there any improvement observed into the autistic children after receiving healthcare services?

D) Information about Education Services Received by the Children with Autism

- 8. How many years has the children been receiving education services?
- 9. What types of services is the child receiving from the institution?
- 10. How are the skills of education service providers?
- 11. What improvement has been observed since the children received the education services?

E) Information about Psycho-social Challenges Faced by the Children with Autism and Their Families

- 12. What is the attitude of the family members towards the autistic children?
- 13. Which type of social constraints has to face the autistic children?
- 14. Does an autistic children face any financial constraints?
- 15. What kind of psychological problems faced by the children with autism and their families?

F) Information about the Expectations and Recommendations Regarding Services, Programs, Initiatives and Policies Taken by the Government and Non-Government Organizations for Ensuring Sustainable Development for the Children with Autism

- 16. What steps do you think should be taken to ensure the sustainable development for the betterment of children with autism?
- 17. Which type of initiatives can be taken to improve the quality of education and healthcare services?
- 18. What type of social security assistances are needed to receive by the children with autism?
- 19. What kind of initiatives can be taken to get rid of psycho-social challenges faced by the children with autism?
- 20. Do you have any suggestions to ensure holistic development of autistic children which will bring them back into the mainstream of society?

Appendix F

National Disability Policy, 1995 Ministry of Social Welfare

Government of the People's Republic of Bangladesh

National Policy on Disability:

A key element of Bangladesh's National Policy on Disability is "Ensuring full participation and equal opportunities for all".

International Resolutions and Declarations:

- ❖ The United Nations Resolution on the Rights of Persons with Disabilities (1975) states— "The attainment of goals relating to the prevention, rehabilitation and full participation and equal rights of persons with disabilities".
- ❖ ESCAP (United Nations Economic and Social Commission for Asia and the Pacific) Declaration (1993): Full participation and equal rights of persons with disabilities in Asia and the Pacific.

As the principles of ensuring full participation and equal rights of persons with disabilities are included in the Constitution of Bangladesh and International Declarations and Resolutions, the National Policy on Disability adopted by the Government of Bangladesh is described below:

1. Resistance:

Actions to be taken to reduce disability across Bangladesh, especially in rural areas:

- ➤ Adoption of immunization programs targeting the most backward and underprivileged sections of the society
- ➤ Health care and nutrition education through special education programs
- > Safe water supply
- > Supply of iodized salt
- ➤ Health care and sewage system etc.

2. Diagnosis and Prevention

Things to do for the diagnosis in identifying disabilities:

- a. Enumeration of persons with disabilities by type, sex and age during the National Census
- b. Disability related survey
- c. Informing the mass people about signs and patterns of disabilities

Things to do regarding ensuring preventing measures:

o Providing free public health services

- Ensuring free health care
- o Free support services for training and rehabilitation
- Provision of Disability Identification Card etc.

3. Advance Prevention:

- Information about remedial and preventive care facilities should be provided by disability health centers
- Advising on educational opportunities

4. Materials:

- ➤ Medical services and supplies of materials will be provided free or at low cost
- > Conducting training and demonstration on the use of equipment's
- ➤ Sales tax/VAT will be waived on locally manufactured materials
- Exemption from import tax/VAT on imported materials.

5. Education:

- Patterns of children with disabilities, impact integration with mainstream curriculum
- Conducting special education programs in special schools
- Providing free training and residential accommodation in special education centers
- To undertake the provision of better quality Braille system for the visually impaired etc.

6. Rehabilitation:

- o Diagnosis will be made through medical care to remove the disability
- o Medical care and rehabilitation will be provided by the Health Department
- o Ensuring Vocational Rehabilitation
- o Services to be provided by the Rehabilitation and Resource Centers:
 - Vocational and social rehabilitation counseling
 - Job identification and follow-up in the workplace
 - Support services for integrated rehabilitation programs etc.

7. Manpower Development:

- Undertake training for teachers and related manpower who are associated with special education and rehabilitation
- Providing disability related training to health workers, social workers and teachers etc.

8. Employment

- Identifying suitable workplaces and providing employment
- Undertake in-service training
- Awareness raising campaign to increase employment of persons with disabilities

• In case of disabled persons the prescribed age limit will be relaxed up to five years etc.

9. Research

- ➤ Health Centers, Resource Centers, Rehabilitation Centers and Workforce Training Centers will conduct research on disability prevention, rehabilitation and employment
- > Scholarships for group or individual research etc.

10. Ensuring Free Movement and Transportation Facilities:

❖ Ensuring special infrastructures and public transport facilities for the disabled such as- special facilities and building codes at government office buildings, railway stations, bus terminals, airports, hospitals, banks, cinema halls, parks etc. incorporation into law.

11.Information:

• Special programs for the disabled will be aired through Bangladesh Television and National Broadcasting Center.

12. Entertainment:

➤ Participation in sports and other recreational activities shall be made free for persons with disabilities.

13. Movement for and by the Disabled:

- Undertaking necessary training programs to develop leadership qualities and self-reliance programs
- Adoption and implementation of public and private self-awareness programs to eliminate exploitation, discrimination and indifference towards persons with disabilities

14.Implementation and Coordination:

➤ The overall responsibility for the implementation of the National Policy on Disability will be entrusted to the National Coordination Committee for Disability.

Appendix G

Bangladesh Disability Welfare Act, 2001, (Act No. 12 of 2001)

This Act repealed by The Persons with Disabilities Rights and Protection Act, (Act No. 39 of 2013).

This Act has been enacted to make provisions for the protection of the rights and dignity of persons with disabilities, their participation in state and social activities and ensuring overall welfare and related matters.

Short Title and Introduction:

- This Act shall be known as the "Bangladesh Disability Welfare Act, 2001".
- This Act will come into force on the day fixed by the Government through the Official Gazette.

Definition and Identification of the Person with Disabilities:

Person with Disability means a person who is physically handicapped or mentally unbalanced by birth, or by disease, or injury by accident or by maltreatment, or by any other reason and partially or totally disabled and unable to lead a normal life due to said impairment and imbalance.

Formation of National Coordinating Committee:

A committee named "National Disability Welfare Coordination Committee" was formed to fulfill the objectives of this Act.

Responsibilities and Functions of the National Disability Welfare Coordination Committee:

Duties and functions of coordination committee shall be as follows:

- ➤ To review the existing policies of the government in order to ensure the full participation of disabled people according to their abilities in social and state life and in the light of the reviewing prevailing reality, suggesting some recommendations to amend it and to recommend new policies if necessary;
- ➤ Advising the government to take various programs and projects for the implementation of disability related policies;
- ➤ Coordinating, reviewing and providing necessary instructions if needed, to the government and private organizations along with executive and district committee who are working for the welfare of disabled people in Bangladesh.

- > To protect the rights of person with disabilities, giving advises to the government and encouragement to other organizations
- ➤ Undertaking training initiatives for capacity building of persons engaged in activities related to disability;
- ➤ Establishment of National Information Center on Disability and to provide and promote the necessary information for the welfare of the person with disabilities through various media etc.

Appendix H

Persons with Disabilities Rights and Protection Act, 2013 (Act No. 39 of 2013)

An Act enacted to repeal and re-enact existing laws in this regard to ensure the rights and protection of persons with disabilities.

Since the constitution of the People's Republic of Bangladesh has expressed the commitment to establish equal rights, human dignity, basic human rights and social equality and since Bangladesh has ratified the UN Charter on the Rights of Persons with Disabilities (United Nations Convention on the Rights of the Persons with Disabilities) and since it is expedient and necessary to make provision for repealing the existing laws in this regard in order to ensure the establishment and protection of the rights of persons with disabilities; therefore, it is hereby enacted as follows:

Short Title and Introduction: This Act shall be known as the "Persons with Disabilities Rights and protection Act, 2013".

Definition: Disability means any long term or permanent physical, mental, intellectual, developmental or sensory impairment or disadvantage of any person and the interaction of attitudinal and environmental barriers to that person, which prevents that person from participating fully and effectively in society on an equal basis.

Types of Disability: In order to fulfill the objectives of this Act, taking into consideration the physical, mental, intellectual, developmental, sensory impairments and the diversity of the handicaps, the types of disabilities shall be as follows:

- a. Autism or Autism Spectrum Disorders;
- b. Physical disability;
- c. Mental illness leading to disability;
- d. Visual disability;
- e. Speech disability;
- f. Intellectual disability;
- g. Hearing disability;
- h. Deaf-blindness;
- i. Cerebral palsy;
- j. Down syndrome;
- k. Multiple disability and
- 1. Other disability.

Autism Spectrum Disorders: Individuals with the following symptoms will be considered as autistic:

- a. Limitations in verbal or non-verbal communication;
- b. Problems on social and interpersonal behavior, communication and imaginative activities:
- c. Repetition of similar or limited actions or behaviors;
- d. More or less sensitivity than others to hearing, sight, smell, taste, touch, pain, balance and movement;
- e. Mental retardation or any other or seizure;
- f. Exceptional skills in one or more specific subjects and uneven development within the same individual:
- g. No or less eye contact;
- h. Excessive agitation, incoherent laughing and crying;
- i. Abnormal body movements;
- j. A strong tendency to follow the same routine; and
- k. Any other feature prescribed by the Government time to time, vide Gazette Notification.

Rights of Persons with Disabilities:

Without prejudice to the provisions of any other law or instrument having the force of law for the time being in force relating to the rights of persons with disabilities, every person with a disability, according to the type of disability, shall have the following rights, such as:

- a. To live and thrive to the fullest;
- b. Equal legal recognition and jurisdiction in all cases;
- c. Inheritance
- d. Freedom of speech, expression and access to information;
- e. Living in community with parents, legal guardians, children or family, marriage and family formation;
- f. Accessibility
- g. Full and effective participation, according to the type of disability, in social, economic and governmental spheres;
- h. Participation in integrated education at all levels of education, subject to access to appropriate facilities in educational institutions;
- i. Employment in public and private institutions;
- j. In working life, the disabled person is engaged in work, otherwise, receiving appropriate rehabilitation or compensation;
- k. Protection from harassment and access to a safe and healthy environment;
- 1. Access to the highest quality healthcare, subject to availability;

- m. Obtaining "convenient environment and reasonable facilities for necessary comfort" in all relevant areas including education and workplace;
- n. Access to supportive services and rehabilitation facilities with a view to attaining physical, mental and technical capabilities and fully integrating into all aspects of social life;
- o. Provision of appropriate safe housing and rehabilitation if a disabled person dependent on parents or family or separated from the parents or family and has no proper accommodation or maintenance arrangements;
- p. Participation in culture, recreational, tourism, leisure and sports activities;
- q. Adoption of Bengali Sign Language as the first language, as far as possible, according to the wishes of hearing impaired and speech impaired persons;
- r. Confidentiality of personal information; and
- s. Formation and management of self-help organizations and welfare associations or societies.

Appendix I

Neurodevelopmental Disability Protection Trust Act, 2013

It is appropriate and necessary to establish a trust to protect the rights of persons with neurodevelopmental disabilities; it is hereby enacted as follows:

Short Title and Introduction:

- 1. This Act shall be known as the 'Neurodevelopmental Disability Protection Trust Act, 2013'.
- 2. It will be effective immediately.

Types of Neurodevelopmental Disabilities:

To meet the purposes of this Act, considering physical, mental, intellectual, developmental and sensory impairments and adversities diversity, the types of neurodevelopmental disabilities shall be as follows:

- a. Autism or Autism Spectrum Disorders
- b. Down Syndrome and
- c. Cerebral Palsy

Characteristics of Autism:

- a. Limitations in verbal and nonverbal communication
- b. Limitation of social and interpersonal behavior, communication and imaginative actions
- c. Repetition of behavior
- d. More or less sensitivity
- e. Convulsions or other impediment
- f. Not to make or less eye contact
- g. Unusual gestures
- h. Any other feature advised by the Government through Gazette notification.

Termination of Trust:

After the coming into force of this Act, as soon as possible, the Government shall establish a trust called the 'Neuro-Developmental Disability Protection trust' under the provisions of this Act.

Aims and Objectives of the Trust:

The aims and objectives of the trust shall be, to enable persons with neurodevelopmental disabilities to live with dignity as part of society and those are mentioned bellow;

- a. Providing physical, emotional and financial support as much as possible;
- b. Taking initiatives for appropriate education and technical knowledge and
- c. Ensuring social empowerment.

Functions of the Trust:

For the fulfillment of the purposes of this Act, the functions of the trust will be as follows:

- Taking initiatives to identify and determining the dimension of neurodevelopmental disabilities;
- Ensuring residence of persons with neurodevelopmental disabilities with their families;
- Providing support to the family of a person with a neurodevelopmental disability, in case he or she meets unnatural death;
- Engagement of public-private sector and community stakeholders in welfare activities for persons with neurodevelopmental disabilities;
- Taking necessary steps to obtain inheritance and taking possession of the inherited properties;
- Establishment of residential hostels or shelters for persons with neurodevelopmental disabilities etc.

Appendix J

The Rights and Protection of Persons with Disability Rules, 2015 (Ministry of Social Welfare

Government of the People's Republic of Bangladesh)

Title: these rules will be called as the name of "The Rights and Protection of Persons with Disability Rules, 2015.

Definition: Unless the subject or context contains anything to the contrary, in these rules – (1) "Act" means the Rights and Protection of Persons with Disabilities Act, 2013 (Act No. 39 of 2013).

Submission of the Reports by Committees:

- Latest status of registration and issue of Identity Cards of Persons with Disabilities;
- General information regarding the performance of its duties and functions;
- Complaints received from disenfranchised or discriminated persons with disabilities and action taken accordingly.

Registration of Disabled Person, Issue of Identity Card etc.:

According to section (31), for registration as a disabled person and receiving identity card, in the upazila or urban area in which the disabled person resides permanently, the upazila committee will fill up the organization form (4) of the disabled person along with the attestation of the doctor in charge of the concerned upazila health complex or government hospital will be submitted to the chairman of the committee of the city area.

Discrimination and Compensation to Persons with Disabilities etc.:

If any person, institution, authority or organization shows any kind of discrimination or discriminatory behavior towards the disabled person or they are being harmed in anyway, within thirty days from the date of the damage, according to Form-6, an application can be submitted to the authorized district

Committee by claiming appropriate compensation against the responsible person, institution, authority or organization.

Appendix K

Sustainable Development Goals (SDGs)

And

Bangladesh

The Sustainable Development Goals are some of the future global development goals that have revolutionized in development thinking and action around the world. After the expiry of the "Millennium Development Goals" in 2015, The United Nations adopted the "Sustainable Development Goals", with a time duration of 2016 to 2030. The "Sustainable Development Goals", 2030 have been formulated to fulfill 17 targets/aims and 169 specific targets/aims with five main agendas in mind. Sustainable Development Goal-3 states that-ensuring good health and well-being for all people of all ages. Goal no. 4 highlights to ensuring inclusive and equitable quality education for all and creating opportunities for lifelong learning. Goal no. 5 mentions-achieving gender equality and empowering all women and girls. Sustainable Development Goal 16 states- promote peaceful and inclusive societies for sustainable development.

Since the adoption of the sustainable development goals, there has been a global shift in development thinking and Bangladesh is no exception. Bangladesh is determined to achieve the Sustainable Development Goals, 2030.

In this journey to achieve the Sustainable Development Goals, the issues that have been emphasized for the development of persons with disabilities are:

- A reliable survey statistic to determine the number of persons with disabilities;
- Ensuring disability sensitive budgeting and education;
- Establishing sustainable lifestyles and human rights;
- ➤ Gender equality
- A new type of cultural practice for peace and elimination of all forms of discrimination, who's main driving force will be a positive attitude towards people with disabilities.

Appendix L Report of plagiarism Check