

**The Understanding of Mother's in regards to their Child's Diagnosis
of Autism Spectrum Disorder (ASD)**

A research submitted to the
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APPROVAL

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DECLARATION

I state that the work presented here is my own. All sources used have been cited properly. Any mistakes or inaccuracies are my own. I also want to make sure that any single discussion of the study will not be unsafe to any participants.

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DEDICATION

To my beloved parents and my elder sister

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ABBREVIATIONS

DSM-IV: Diagnostic and Statistical Manual of Mental Disorders – 4th Editions

DSM-V: Diagnostic and Statistical Manual of Mental Disorders – 5th Editions

ASD: Autism Spectrum Disorder

SLT: Speech and Language Therapy

OT: Occupational Therapy

GP: General Practitioner

EEG: Electro Encephalogram

EXECUTIVE SUMMARY

Government of Bangladesh has taken many steps to improve condition of person or children with neuro-developmental disorders, Autism Spectrum Disorder (ASD) still remain a mysterious diagnosis for parents with much confusion especially for mothers because in context of Bangladesh mother spend more time with her child.

To get a clear sense about mothers understanding regarding their child's diagnosis of ASD the study has been conducted over 18 mothers lives in Dhaka city and attending in special school where different therapy services are available besides special education. In this study participants has been interviewed using a structured open-ended questionnaire where there are sixteen questions included consisting of defining ASD diagnosis, features of ASD and mothers experience about different health care services whom they consulted to get exact diagnosis as well as for further help. After data collection those are analyzed using qualitative method and data analyzed through content analysis process. At the time of analysis three different themes and six different categories have been emerged. Several causes and features reported by mothers when they tried to define ASD diagnosis in brief and very few were able to give an accurate and clear explanation. Most of the participants could not described all the characteristics of ASD but showed satisfactory understanding on any one or two particular features. A greater amount from the participants have been consulted more than 3 different health professionals to get the exact diagnosis and most of the participant reported dissatisfaction on health professionals as they did not find health professionals procedure of screening and suggestions helpful and effective. All most all mothers expressed satisfactory comments about services of special school and all of them found speech therapy and occupational therapy very effective for their child and also reported that after joining special school they knew more about characteristics of ASD diagnosis than the health professionals outside school they consulted for help.

Most mothers demonstrated poor understanding regarding ASD diagnosis and it is a matter of concern because it takes time to improve condition of children with ASD regarding learning new skills or shaping behavior pattern and if mother is confused about child's condition then it becomes more crucial for child to improve and also will result in more frustration for

parents. On the other hand this study also concludes with that a greater professional training is highly needed for all health professionals as prevalence of ASD is increasing in Bangladesh day by day but these children can lead a normal life if proper care and environment given but often professionals failed to give appropriate suggestion to mothers and they struggles to help their child.

1.1 Introduction

Autism Spectrum Disorder (ASD) is a developmental disorder which is characterized by significant impairments in social interactions, impairments in communication, lack of imaginative play as well as stereotyped patterns of behaviour and interests. According to Ellis (1990) “Social impairment, far more than other such problems, has a particularly devastating effect because it cuts off those affected from the ordinary sources of learning and emotional support other beings can provide.”

Unless the natures of these impairments are understood and skilled teaching and care are provided, children or people who are socially impaired are psychologically isolated in a world they unable to understand.

According to Smeardon (1999) “An autistic spectrum disorder (ASD) is a complex developmental disability that affects the way a person communicates and relates to people around them. The term spectrum is often used because the condition varies from person to person; some people or children with the condition may also have accompanying learning disabilities, while others are much more able to function with average or above average intelligence.”

ASD is a lifelong disorder. The word 'autism' is a compound of two Greek words — 'aut', which means 'self', and 'ism', which implies 'orientation or state', and can therefore be defined as the condition of somebody who is unusually absorbed in him or herself (Reber, 1985). This captures how children with ASD fail to show interest in other people, but misses many other features of non-verbal cues. Parents often go through severe levels of stress after obtaining a diagnosis for their child. In Bangladesh most of the time health professionals do not fully clarify and explain the characteristics and nature of the disorder, further they do not inform parents and what treatment programs are available and what they can do to help their child at home. As a result of these insufficiencies mothers and carers often find it difficult to cope with the challenging situation and lose motivation with seeking help for their children with special needs.

In Bangladesh ASD is “treated” in a variety of ways as professionals do not provide parents with accurate information about the diagnosis and treatments which have sound research evidence. In comparison to other physical and mental disabilities, Parents of children with ASD are often misdiagnosed and misguided by professionals in Bangladesh. There have been many reports of misdiagnosis, unethical treatments and treatments that do not have much evidence been used to treat children with ASD in Bangladesh. In these circumstances a research study is highly needed on mothers understanding about the diagnosis of ASD.

1.2 Background and Literature Review

Autism Spectrum Disorder (ASD) is characterized by severe behavioral, social and communication difficulties. As the disorder has affects a child multidimensionally, parents need to know clear and accurate informations to take proper care of these childs. On the otherhand prevalence of ASD is rapidly increasing in Bangladesh. It should be noted that there is no literature specifically on this topic but there have been research studies with similar objectives and have been reviewed this study. Osborne & Reed (2008) conducted a research on “*Parents’ perceptions of communication with professionals during the diagnosis of autism*” this research is important because it concludes that understanding and knowledge about ASD depends highly on how well professionals are able to explain it to the parents. In this article the authors found that at the time of diagnosis, most of the parents wished for a quicker and easier process in receiving information about ASD and wanted information on treatment approaches, parents also expected better outcomes from treatment approaches within a short period of time, suggesting that parents may not have been told what to expect. They also requested greater training for professionals on up to date and accurate knowledge on ASD in order to develop better interpersonal skills due to the sensitivity surrounding a diagnosis.

Harrington, Patrick, Edwards, and Brand (2006) conducted a study with sixty two families in the US titled “*Parental beliefs about autism implications for the treating physician*” In this study the authors tried to find out what the parental beliefs in regards for the cause, diagnosis, prognosis and treatment of ASD. Parents of children with ASD completed a questionnaire during the study which covered different perspectives related to the diagnosis of ASD (for example “when did you first notice developmental and behavioural problems? and how confident they were about the ability of their child’s physician to recognize autism?”). From the responses authors concluded that parents who tried different types of therapies and who

experienced greater delay in receiving a diagnosis had less confidence in physicians. For this reason the authors recommended that physicians should inquire about parental beliefs concerning etiology and know what treatments a child is receiving so that they can provide appropriate information and suggestions that are needed for the child.

From this study we are able to get an understanding that even in industrialized countries with more advance health care systems and better access to trained professionals, parents still struggle with getting a correct diagnosis and also information on treatment suggestions if needed. In Bangladesh the issue is more serious, particularly in remote areas and thus research is needed to help better understand context in order to improve it.

Midence and O'Neill (1999) conducted a research titled "*The Experience of Parents in the diagnosis of autism- A pilot study*" the authors conducted this research because literature on experiences of parents seeking a diagnosis for their child's behavioural abnormality is few in number. The authors surveyed parents using a semi structured interview format to document their experiences. Analysis was done using a grounded theory approach in this study. The authors divided all data received from parents into six categories here in this study these include difficulties with understanding their child's behaviours and the confusion that results from their inability to make sense of these behaviours and issues with obtaining a diagnosis. Findings in this research reflect the experiences of parents after receiving a diagnosis for their child. This helpful with accepting their limitations as a result of "autism".

In Bangladesh medical practitioners continue to struggle with providing an appropriate diagnosis and to provide the right level of support to reduce lack of knowledge about ASD as well as how other health professionals can help and a contributing factor to why parents face difficulties with having a clear understanding about the diagnosis of ASD. This research study will help to find out how mothers gather knowledge about the diagnosis, which professional they find most helpful, and finally accuracy of the knowledge that they possess.

Alqahtani (2011) conducted a research study named "*Understanding Autism in Saudi Arabia: A qualitative analysis of the community and cultural context.*" Alqahtni's study found that healthcare providers mostly have less understanding about causes and treatments of autism in Saudi Arabia. Parents of children with ASD, on the other hand, obtain contradictory information about ASD diagnosis from multiple formal and informal sources. The objective of this study was to evaluate qualitatively the beliefs of parents of children with ASD in Saudi Arabia. A purposive sampling method for recruiting typical sample was applied with

47 parents interviewed. Several causes of autism were reported by parents in this study, a vaccine was the most causative sources reported. Some parents feel guilty that they caused their child's ASD. Others believed that nonmedical or cultural reasons such as evil eye and black magic could cause ASD. Some parents reported using alternative medical intervention, such as dietary programs and hyperbaric oxygen therapy to heal their children from ASD. In Alqahtni's study it is recommended that health professionals should be aware and sensitive to these different beliefs and provide proper multidisciplinary interventions including behavioural and educational interventions. The results Alqahtni's study highlight the need to improve the knowledge and awareness about autism among medical sectors and for all paediatricians and health care professionals in order to improve health care and the quality of life of children with ASD.

As this ongoing study is on the understanding of mothers about ASD diagnosis and this research is also based on parental understanding so, findings of this research can be compared to ongoing study. On the other hand Saudi Arabia is a Muslim country like Bangladesh so this research can be compared to the findings the findings as well.

Dale, Jahoda and Knott's (2006) study "*Mothers' attributions following their child's diagnosis of autistic spectrum disorder*". Dale, Jahoda and Knott's study consists of two phases. First one is piloting phase which involved a focus group with parents of children with ASD to help inform the development of a semi-structured interview. Second one is main phase, in this section interview was conducted with more participants and formal measures of stress, depression and expectations about the child were also administered. The formal scales were

Parenting Stress Index (3rd edition; Abidin, 1995), *Child Expectations Scale* (Dunst and Trivette, 1986), *Beck Depression Inventory* (2nd edition; Beck et al., 1996).

According to Krueger, (1994) "A focus group is recognized as being a useful format for exploratory research" This process was used to explore the concepts and ideas that parents mentioned regarding their child's diagnosis in order to inform the development of the semi-structured interview for the main study. According to assumption of authors parents in the focus group described making attributions about their child's ASD which could be related to the stress and future expectations. The semi-structured interview was included questions relating to experiences preceding diagnosis, reactions and perceptions at diagnosis, feelings and beliefs about cause, action and beliefs about what may be helpful for their child and perceptions and concerns regarding their child's future. Questions were asked in an open-

ended format in order to develop a good rapport with mothers so that they could discuss their experiences openly, at the same time ensuring that key topic areas were covered across all the participants. After examining the attributions made by mothers about children with ASD shortly after diagnosis has showed some changes on understanding and their experiences of this process getting ASD diagnosis that was previously assumed by the authors. Every participant described different assumptions about the cause of their child's ASD but most did not mention a particular cause. Most of the participants suffered from uncertainty about cure but about half believed that change was possible with this diagnosis.

In Bangladesh mothers also face the same type of problems in regards to attribution. In this ongoing research study there were similar types of questions asked so results of Dale et al's (2006) study can be compared with ongoing research and also a research study is needed to reduce mothers feeling of confusion about child's diagnosis of ASD and to found effective sources of help.

Young, Brewer and Pattison's (2003) study "*Parental identification of early behavioural abnormalities in children with autistic disorder*" identified early behavioural abnormalities in children later diagnosed with ASD. It was argued that early identification should allow the diagnosis to be based on what might be considered to be the core deficit-linked behaviours, as opposed to secondary behavioural manifestations of the disorder. Core deficit-linked behaviours are more likely to reflect the underlying neurological problem(s), whereas secondary manifestations may be a product of an individual's approach to coping with the disorder or other disorders that may coexist (for example "intellectual disability"). Overall, parents identified several areas of behaviour that caused them concern in the first years of their child's life. Prior to their child's first birthday, parents were primarily concerned with difficulties related to social awareness and understanding, reflected in a lack of shared enjoyment or feeling and poor eye contact, however ninety-five percent of respondents had noticed anomalies in social development before 2 years.

In the context of Bangladesh research is needed where parents are asked questions about 'when they noticed an abnormality first and what types of abnormality?' because early notification signs lead parents to seek help from different types of health professionals and at times they may be misguided so in this way it is relevant to this study. Accurate identification of such deficits also has implications for the early diagnosis, intervention and prognosis.

Chamak, Bonniau, Oudaya, and Ehrenberg's (2010) study "*The autism diagnostic experiences of French parents*" mainly this study was conducted by using survey type study under mixed method (qualitative & quantitative) study design. The survey focused on French parents' views of the diagnostic process relating to their child with autism. Questions were focused on the age at diagnosis, the time taken to obtain a diagnosis and the difficulties encountered. In this study the average age of the child when parents first sought help was 26 months. 20% before 1 year of age, 40% between 1 and 2 years, 29% between 2 and 3, 9% between 3 and 4, and 2% after 4. The first professionals from whom parents sought help were paediatricians (42.5%), psychiatrists (23%) and GPs (17.5%). Generally it is not a paediatrician who gave the diagnosis but a child psychiatrist (83.3%), and the first specialist approached was often reluctant to give a firm diagnosis, especially when the child was still very young. The results showed that the mean delays between first consultation and diagnosis were reduced than before. Regarding the way the diagnosis was announced, 63% of the parents of children with autism and 93% of the parents of adults with autism were dissatisfied.

One of the focuses of this research study was a question on 'when child was first diagnosed and what information was given to you about the diagnosis?' it is therefore hope that links can be drawn to this study. By this process it is easier to identify the gaps in health professionals' knowledge as well as in their ways of describing it to parents. This study also can reduce misunderstanding of mothers about diagnosis of ASD after completing data collection.

1.3 Justification of the study

One estimation is that one child in 500 in Bangladesh has autism, meaning that the approximate number of children with ASDs in Bangladesh is no less than 280,000. *Education for the underprivileged (n.d.)*

The general attitude towards ASD is mostly negative and it is seen as a social barrier. Even today, ASD is considered a God-given curse and children with ASDs are taken as possessed by the Devil. Also bad parenting is accused: mothers going out to work still get the blame.

There is a lack of knowledge about ASDs even among doctors. Very often, children are misdiagnosed and given antipsychotic drugs by psychiatrists.

In these circumstances it has been assumed that there is lack of understanding about the diagnosis of ASD among parents in Bangladesh and as there is no existing study till now so a research study should be carried out on this topic to represent a picture of current condition.

1.4 Operational Definitions:

1.4.1 Autism Spectrum Disorder (ASD):

Autism Spectrum Disorder (ASD) is a lifelong neuro-developmental disorder appearing during early childhood. Typically occurring before three years of age, ASD is characterized by significant social difficulties associated with varying degrees of communication, behavioural problems and sensory. In the *DSM-IV*, autistic disorder is defined by three distinct domains: impairment in social interaction skills, impairment in communication, restrictive or repetitive behaviour or interests (Psych Central Professional, 2014).

1.4.2 Understanding:

Generally the word 'Understanding' means to comprehend or to develop anticipation about a certain thing. But in this study understanding means to comprehend every term accurately related to ASD diagnosis.

1.4.3 Diagnosis:

In general diagnosis is the identification of a disease by means of its symptoms. But in this study the word 'Diagnosis' refers to the diagnosis of ASD specifically.

1.5 Aim

The main aim of this study is to explore mothers' understanding about diagnosis of autism.

1.6 Objectives

There are some three objectives of this study-

1. To identify mothers knowledge about Autism Spectrum Disorder (ASD).
2. To identify gaps in the knowledge of mothers of children with ASD.

2.1 Study design

The focus of this study was on the mothers of children with ASD and their understanding of their child's diagnosis. The accuracy of knowledge of the mothers as well as their attitude towards diagnosis and sources of help was investigated. A qualitative method was selected for this study as it is the most appropriate design for the study. According to Hicks (1999) '*Qualitative research is exploratory in nature by which researcher can gain insight into another person's view, opinions, feelings and beliefs within their own natural setting.*' As the aim of the study has to determine the accuracy of knowledge, identify the gaps between knowledge and how the professional represented the diagnosis to mother, the information was collected using a survey. According to Hammell and Crepenter (2000) '*Qualitative research aims to describe the experiences of people in particular settings and to understand their perspective.*' The main objective of this study was to explore understanding about the diagnosis of autism amongst mother of children with ASD.

2.2 Study Population

Mothers of children with autism spectrum disorder (ASD) whose child currently attends a special school in Dhaka city were selected to conduct the study. Two special schools (Proyash and Beautiful Mind) in Dhaka city were selected for this study.

2.3 Sample Size

20 participants (mothers of children with ASD) who had children attending Proyash or Beautiful Mind were selected. These sites were selected due to availability of participants and also in accordance to their willingness. A limited number of participants were selected due to the time constraints of this dissertation. Limits were also placed based on the necessary numbers needed to help provide insight into the research question.

2.4 Sampling Procedure

A purposive non probability sampling method was used to select participants for this study. According to Depoy & Gitlin (2000) *'In purposive sampling criteria sample selection procedure is based on predefined criteria which represents insight of a larger group'*. In this study the inclusion criteria and exclusion criteria are listed below:

2.5 Inclusion Criteria

- Willing mothers who have a child diagnosed with ASD and attending in a special school.
- The child has to have had the diagnosis for greater than 6 months.

This two criteria have been included because if mothers are not willing to participate then data couldn't be collected within short period of time and in 6 months mother may get opportunity to visit more than one professional and also opportunity to gather correct and appropriate information regarding the diagnosis.

2.6 Exclusion Criteria

- Children with additional diagnosis those are not typically associated with ASD such as Down syndrome or Cerebral Palsy.
- Mothers who are not literate.

These criteria are selected because if child has got any other diagnosis associated some information might be overlapped and if mother is illiterate then couldn't be able to provide information according to questions.

2.7 Data collection Tool

A structured open-ended questionnaire was used to collect data for this study. To determine the knowledge of the mothers about their child's ASD questions were based on the DSM-V and DSM- IV criteria, the DSM-IV criteria was included due to the fact that the DSM-V was only released in 2013. The interview was conducted in Bangla to make it easier for all participants to understand but also allowed them to respond more freely as English is not

their first language. Answers were recorded on a recorder and notes were also taken. Consent forms, questionnaires, tape recorders, pens and papers were used for data collection.

2.8 Data collection Procedure

For the purpose of this data collection face-to-face interviews were used. All the answers were recorded for more comprehensive analysis of the data. According to Bailey (1997) interviews conducted face-to-face are more intimate, allowing the interviewer to interact directly and develop rapport with the interviewee which help put them at ease, face-to-face may encourage more candid responses. The disadvantage however face- to-face interview has the requirement of certain amount of effort to set up the interview and the logistics of time and locations.

2.9 Data analysis

Content analysis process was used to analyze data collected from all interviews. The main objective of data analysis is to find out the genuine significance of collected information. Data analysis is the process which gives the guidelines of the data arranging and presenting. According to Fraenkel & Wallen (2000) *“In qualitative studies data analysis is usually used to synthesize the information that was obtained from a variety of sources (for example “content analysis and interviews”) into logical description of what is collected”*. In this study all qualitative data was analyzed using content analysis. Bailey (1997) mentioned that content analysis is a process where repetitive words and concept are analyzed. In this study transcripts of interviews were recorded and other associated materials were organized in a systematic way. To analyze the data entire interview was transcribed from Bangla to English from audio recording in mp3 format. Transcripts were peer checked by two non-associated assistants, this is implied for better outcome of the study. During this process the moderator read the transcriptions in order to understand what the participants wanted to say in response to a particular question, beside this the moderator also listened to the recording and checked the questionnaire to again ensure the validity of the data. After properly checking, the data was then tabled according to each participant’s response. The themes were picked from the response and then codes were made under each category. Finally analysis was made from the

categorized data in relation to the understanding of mothers in regards to the ASD diagnosis of her child. The last stage involved the actual theme interpretation of the data.

2.10 Rigor of the Study

In this study all the steps were followed sequentially and the study was conducted in a systematic way. For example study design, data collection and analysis. Rapport was built with every participants and a neutral tone was used during the interview. The Bangla interviews were transcribed in English and were checked after translation; then again recorder was played to check the transcripts. At the time of interview researcher tried use simple language because this helped participants to better understand the question sometimes the investigator provided explanations and simple examples for the more difficult question.

2.11 Ethical Consideration

The project protocol of this study was presented in front of the ethics committee for approval. Permission was granted for this study. Permission was also provided by the head of the institutions from where the researcher collected data. Each and every participant in this study was informed about the purpose of the study. Participants were assured that they have right to refuse to answer any question during interview session if they are not comfortable with the question. All information and the personal identity of participants were kept confidential. The participants were informed that their participation in this study would not cause any harm to the child or her family. The mothers were also assured that the study had no connection with authorities at the school and it would not affect their child's education.

3.1 Analysis

In this section of the study all the findings will be discussed and objective of the study will be explored in accordance to participants' response and opinions against every specific questions of the questionnaire.

Both the mothers' opinions and thoughts have been presented together for easier conceptualization of their understanding about ASD diagnosis. This section also focuses on the findings as well as explains and explores the needs of mothers and also the difficulties they are facing due to their understanding and find out gaps of knowledge and needed resources to improve current condition. In this study responses are divided into three themes according to question pattern and participants answers and then subdivided into six different categories according to nature of the answers.

First theme is about defining autism with its causes and cures and in response of such kind of questions very few mothers were able to answer correctly or nearly correct. It happened due to irresponsibility of responsible health professional that first ensured the diagnosis and sometimes due to mothers' unwillingness towards knowing more about her child's diagnosis often they are more busy in seeking help and effective treatment rather than gathering knowledge more accurately about the diagnosis of ASD.

Second theme was about different characteristics of ASD in this portion half of the participants showed awareness about one or more features of ASD but do not have a clear concept and for this they cannot explain any feature in an elaborative manner. One fourth of the participants demonstrated their concern about all common characteristics of ASD with short explanation.

Third and the final theme was about experience of mothers about different treatment approaches that are used for their child and their opinions about different health professionals they consulted for help. Most of the participants expressed dissatisfaction on their health professional whom they met earlier for help before joining special school. Almost all mothers reported that they found the therapy services (OT & SLT) very much helpful and effective for progress of their child.

In this study all the answers divided into some general themes and brief descriptions about all themes have discussed and elaborative description with implications about those themes are given below-

Theme 1: Defining Autism Spectrum Disorder (cause and problems)

This theme focuses on how mothers define or interpret ASD. Under this theme there are two categories, including giving definitions of ASD and also give descriptions about causes and cures of ASD. These questions were placed under this theme because these reflect primary or basic knowledge about ASD. If a participant has a lack of knowledge in this part, she supposed to have poor understanding about whole ASD diagnosis as participant does not have the basic knowledge about the diagnosis. Under this theme two categories were made, one is about defining the ASD diagnosis and another focused on the cause and cure. Participants' opinions are discussed below-

Category 1.1:

Most of the participants reported difficulty when asked to define ASD. Almost all participants defined ASD by its features (for example if a child showed unexpected behaviours, did not interact or play with others, had difficulty communicating, preferred to be alone, then the child is affected by ASD). Only 2 mothers stated that ASD is a neuro-developmental disorder and another one said that it is a problem of brain. One of the participants told that she did not believe that it is a neuro-developmental disorder because the child had normal EEG report.

Mothers were also questioned about whether they asked health and medical professionals about the condition in detail at the same time, most of them answered that they did not receive very clear or accurate information from their health professionals. Mothers who gave appropriate responses all have had specific training on autism and some had attended workshops on ASD, finally one of the participants was a general physician. From the responses it is clear that mother who does not attended any workshop or training on ASD and who does not studied further for knowing about the diagnosis cannot give proper answer when asked to define. So a huge gap of knowledge about diagnosis of ASD is present among mothers of this country who has a child with ASD.

A health professional should define the diagnosis of ASD to parents that can prevent mothers or parents from any faulty expectations, even after joining special school Occupational

therapist and Speech therapist should discuss about ASD diagnosis with accurate information in a descriptive way at the time of first meeting.

Category 1.2:

13 participants were not able to answer questions about cause of ASD, Only 5 mothers among 18 responded with exact cause is unknown, 2 of them had training in autism, 1 mother mentioned she searched it in internet and learned that information, 1 mother is told by her child's health professional and mother who had a medical background reported she read about 18 books on autism and after that got a clear sense about ASD. Most of the participants reported that they do not know anything about the cause but they expressed their thoughts about the causes. These included that it may be caused by for any complication during pregnancy, marriage between blood relations, parental distress, If parents have problem in thyroid gland, Black magic, Pre-term baby and genetic causes may be responsible.

Most mothers reported that they wanted their child to be independent in activities of daily living when asked about a cure. They also told that if the child was properly trained in suitable learning environments their child may recover a lot from diagnosis. 3 participants had a good understanding of the prognosis, however 2 participants reported that there is possibility of full recovery from ASD, such that their child would be normal.

There is a large number of diverse responses noticed in the mothers' knowledge about the cause and cure of ASD. This is due to health professionals lacking about knowledge of autism and sometimes mothers unwillingness to know deeply about diagnosis.

It indicates that mother do not have a good understanding about cause of ASD nearly 28% mothers could answer correctly about the cause.

According to Alqahtani's (2011) study, "parents most likely believes that autism in their children might be caused by nonmedical reasons. Three-fourths of the sample viewed cultural causation as the source of their children's autism.

Surprisingly none of the parents in this study believed that genetics might contribute to autism in their children. This lack of acknowledgement about genetic contribution to autism is more likely to arise from confounding genetic causes in its widest sense on the other hand

in Saudi Arabia stigma could play a main role in ignoring genetic causes or to except that the real cause is still unknown genetics is a factor only.”

As like Saudi Arabia mothers of Bangladesh demonstrated incorrect thinking about the cause of ASD and stigma is also noticed in a participant while answering about the cause so this lacking of knowledge about ASD is need to be sorted out immediately to develop a clear sense about ASD among mothers and to help the child as well.

As there is lacking in parents or mothers knowledge about causation and cure, due to healthcare professionals misguided short and unclear description about diagnosis of ASD. So there should be predefined instructions for health professionals to develop quality of future practices.

According to Harrington et al (2006) concluded their study by saying that “many parents in their survey expressed a belief in one or more specific causes of their child’s autism, and most of them had tried numerous treatments.”

Like Harringtons study in Bangladesh parents also trying more than two or three treatments but most of the time reported that they got less help from various health professionals with no clarification about the cause and cure about ASD before joining special school.

Mothers who are taking individual Speech and Language Therapy sessions from clinic responsible therapist should give proper and accurate description about the diagnosis, cause and prognosis of ASD in very first session. Speech therapists who are working on different special schools should make arrangement of a group therapy session every week where mothers will share their views and ideas regarding the diagnosis of ASD and therapist will play role as a facilitator in this discussion and give corrections to mothers if they get any wrong or invalid information about the diagnosis. By this type of program mothers will also get an opportunity to share the progress of the child after taking Speech therapy service.

Theme 2: Knowledge about the features

This theme is based on mothers' description about different characteristics of children with ASD. In this theme there are three categories where mothers asked about sensory problems, repetitive and restricted behavior, verbal and non-verbal communication. Researcher put these categories under this theme because if mothers know about these features of ASD very well, then they can carry out therapy activity properly in home thus therapy services other treatments will become effective for child more quickly than expected and also mother will control any context if it goes wrong or unsuitable for child. In this section most of the participants' demonstrated good understanding on any specific characteristics rather than all common features those are mostly seen in children with ASD.

Category 2.1:

In this category mothers answers about sensory problems in children with ASD have been discussed.

3 participants out of 18 participants knows about sensory problems, 2 of them told directly that they do not know anything about sensory problem another one told that as her child do not have any sensory problem she does not know anything about it. Only 4 of the participants defined the problem properly, others have concept about the problem but not clear. Mothers reported different types of sensory problems (for example child bites everything, does not want to take bath, does not likes cutting his/her hair, does not likes if anyone touch his body, does not likes to hold anything in hand.)

In most cases mothers thinks only their child problem as only one sensory problem and does not know about other sensory problems children may have.

According to Midence and O'Neill (1999) "The comments of the parents highlight the need for early diagnosis and better awareness of developmental problems in young children among health professionals, especially GPs. The invisible nature of autism makes it more difficult for parents to explain the nature of their child's behavioural problems or to accept the conclusion themselves. Parents in this study felt that once they knew what was wrong with their child, and a label or diagnosis was given, they were able to understand their child's behaviour, accept the condition, and plan for the future." As like this study, parents in

Bangladesh also facing difficulty after getting the diagnosis of ASD. Participants reported that they thought their child naughty due to these unexpected behaviors as they do not know the actual reasons of such kind of behavior and suffering from stress and feeling ashamed or uncomfortable to join social parties or to go outside with child.

Patterns of maximum data in this section indicate that the mothers understanding and knowledge is limited due to lack of interest and also health professionals did not provide accurate explanations. Mothers' understanding needs to be developed regarding sensory problem as most of the children with ASD generally experience sensory problems. Responsible Speech & Language Therapist should clarify about sensory problems to mothers with applicable techniques to reduce the problem and can make a referral to Occupational therapist for further help if needed.

Category 2.2:

In this category mothers answers about repetitive and restricted behavior in children with ASD have been discussed.

Only 4 participants did not know anything about repetitive and restricted behavior and interest in this study, all of them reported they do not noticed any type of repetitive behavior in their children. Rest of the participants almost correctly told about this feature, 9 of them gave more accurate answers. Some examples given by mothers are likely- child likes to spin the wheel of toy car all the time, child need to go toilet after every 1 hour.

According to Chamak (2010)“In most cases, the diagnosis provides a degree of explanation for the behaviour of the child, and helps parents accept that they are not to blame for the condition. Many parents are relieved that someone else could corroborate what they initially suspected. Speech and Language therapist can play an important role to relieve the parents from negative feelings in context of Bangladesh as these professionals knows the actual causes of this type of behaviour and can manage the behaviours successfully. Speech therapist need to promote visual schedule and social stories to parents and other professionals in managing this type of difficulties and need to design these resources according to child's need and existing strengths.

It can be said that knowledge about repetitive behaviour among samples are quite satisfactory. Around 82% mothers have had a sound knowledge about repetitive behaviours

among the participants. Mothers' understanding regarding this is sufficient but there is no arrangement from the school authority or therapists to acknowledge the mothers about this behaviour who do not know about it.

Category 2.3:

In this category mothers answers about verbal and non-verbal communication and learning style in children with ASD have been discussed.

Mothers who have joined workshop on ASD and also got training and the mother who is doctor as well as 2 other total 5 mothers fairly knows about different ways of communication and learning style of ASD affected children. Rest of the samples do not know anything clearly about verbal and non-verbal communication and answered different things about learning style (For example:- By reinforcement, auditory learner, by playing they learns best, by songs and rhymes, from parents and people whom he likes most, by watching videos and cartoons, by practical demonstration of any task, by instruction and training)

2 of the samples could not answer anything about learning style. The school which has qualified Speech Therapist, samples of that school answered better.

The findings are around 80% of participants do not have a clear knowledge about the learning style of children with ASD. If mother is not aware of child's learning style she cannot help her to learn new skills in home environment effectively.

Here for all three categories the implication is that the responsible therapist always need to discuss about the feature/ characteristics and should help the mother to learn how control or minimize the difficulty and how she can carry out the therapy activity and techniques in home environment.

Theme 3: Experience about getting the diagnosis, satisfaction on responsible health professional.

Here in this theme discussed about when child first diagnosed with ASD. How the professional described the diagnosis to mother and what is mothers' experience about different treatment approaches applied on her child.

According to Chamak (2008) "currently, the diagnosis is obtained earlier than in previous decades but 8% among the 6–12 age group and 22% among the 13–17 age group had not yet received diagnosis in our sample. Some barriers to early and appropriate diagnosis remain. Psychiatrists with a psychoanalytic background were often reluctant to give an autism diagnosis to parents. They considered it could prevent the therapeutic process of their patient and might be too stressful for the parents."

This part is helpful to find out which health professionals are giving the diagnosis to parents in most cases in context of Bangladesh, what they actually told to parents about ASD as well as how easily parents got other sources of help immediately after diagnosis and finally how much they struggled to get a better understanding about ASD and know about possible effective services for child.

Category 3.1:

In this category mothers answers about which professional gave first diagnosis and satisfaction about different treatment approaches as well as dissatisfaction also for their children with ASD have been discussed.

Most of the children have been diagnosed by neurologist and child specialist. Some are diagnosed by general practitioner, psychologist and psychiatrist. Only 2 samples reported that their responsible health professional elaborated on what about ASD. Other samples did not find the health professional much helpful after getting the exact diagnosis. Even some professional did not give any specific diagnosis to the child only told parents to admit their child into a special school. Some of the professional wrote down some general strategies on a piece of paper and asked parents to follow it in home after initial screening. Two of the mothers took their child abroad for better treatment as well as develop a better understanding about the diagnosis.

According to Osborne & Reed (2008) “The parents would like better trained and better informed teachers and professionals working within the local authorities, and also felt that they would benefit from a list of reputable private providers of interventions and educational programmes.” In the ongoing research participant expressed similar types of expectations as like as Osborn’s study.

One third portion of the samples expressed satisfaction on their health professional that diagnosed and still visits them for follow up. Others told that they think special school and different therapy services more helpful for their child and most of them also reported they knew about many features of ASD after admitting their child in the special school.

Government or medical practitioner council can provide a clear instruction guide that a health professional should clarify the cause, features and prognosis of this type of neuro developmental disorder precisely to the parents and carers.

After analyzing all data and put them into different theme and categories it is found that only 30-40% participants in this study has had a sound knowledge and understanding about ASD diagnosis. In 90% cases it found that health professionals did not explained all features of ASD clearly after giving the diagnosis to parents and sometimes they also did not tell where to go for further help and what treatment approaches might be helpful for the child. Mothers have different types of assumption about ASD diagnosis and most of the participants possess unrealistic expectations about child's future in regards with diagnosis of ASD.

Due to lack of understanding and knowledge about diagnosis of ASD mothers often faced difficulty to find out source of help and those who receiving different therapies failed to carry over therapy techniques and apply the rules properly in home environment when needed.

It resulting in slows improvement of child's behavior and learning process and also remain confusing for mother's.

In Bangladesh medical professionals usually interested to get specialized training or higher degree in common cases or disease that could benefit them a lot economically in future and generally do not demonstrated sound knowledge about ASD as well as other neuro-developmental disorders.

There are some mother thinks special school and its services will do everything in improving their child and for this reason sometimes they feel less interest to know precisely and accurately about the diagnosis and it hampers child improvement rate even after getting quality therapy services.

The aim of the study was to explore mothers understanding regarding the diagnosis of ASD of their child. From the responses it is clear that mothers without any training on ASD demonstrated lots of lacking in their knowledge about ASD in various areas of the diagnosis. ASD is a matter of concern in Bangladesh now a day's among all of the neuro-developmental disorders. Mothers or parents of children with ASD are the most informed people about ASD diagnosis as well as other people of the community as it became a national issue in Bangladesh after prime minister's daughter showed her concern about neuro-developmental disorders where ASD is on special focus and she also proposed a act in UN for this children

which was accepted and after that a law was established in our country for these children which followed a disability act. Qualitative method was selected as the ideal approach for preliminary exploration of such complicated issue and obtain the understanding of personal beliefs and as well as opinions about understanding of mother's in regards to their child's diagnosis of Autism Spectrum Disorder (ASD).

In first theme most of the mothers' reported difficulties defining ASD diagnosis, they mentioned some of the features when asked to defined ASD. Mothers' gave different type of opinions about cause and cures of ASD. Less than around one fourth could not answer properly. This condition refers to a poor understanding as most participants could not answer basic questions about ASD diagnosis.

In second theme participants asked about different characteristics of ASD. Here participants gave mixed response. Some participants described sensory problems but failed to explain different ways of communication and repetitive behaviors as well. On the other hand participants who answered different ways of communication showed difficulty to explaining sensory problems. Very few of them has had a good understanding about all characteristics about all characteristics.

In third theme participants asked about their experience from different health professionals and from whom and when they got the diagnosis of ASD first. Parents visited more than 3 or 4 different health professionals to get a clear view about the diagnosis of their child but in most cases they are still dissatisfied with health professionals as they could not clarify the diagnosis descriptively to the parents. All the mothers are happy and satisfied about special school and therapy services that provided. It is a matter of concern that although occupational therapy and speech therapy is available in both special schools all mothers did not properly give answer while asked about sensory problems, repetitive behavior and different ways of communication. Point to be noted here one of the school do not have any qualified Speech therapist.

According to Osborne & Reed (2008) "The parents would like better trained and better informed teachers and professionals working within the local authorities, and also felt that they would benefit from a list of reputable private providers of interventions and educational programmes." In the ongoing research participant expressed similar types of expectations as like as Osborn's study.

According to Chamak (2010)“In most cases, the diagnosis provides a degree of explanation for the behaviour of the child, and helps parents accept that they are not to blame for the condition. Many parents are relieved that someone else could corroborate what they initially suspected. Speech and Language therapist can play an important role to relieve the parents from negative feelings in context of Bangladesh as these professionals knows the actual causes of this type of behaviour and can manage the behaviours successfully.

Above all most of the mothers reported that they knew about these features after joining to special school and from the therapy service providers not from the health professional they consulted for diagnosis as well as professional who first diagnosed.

There are some limitations to conducting the research study. Time and resources were limited which have a great deal of impact on the study. If adequate times and resources were available, then knowledge on this area could be extended. In this study participants were only taken from to renowned of Dhaka city special school where all facilities and support are available. Participant should be taken from different places or as many places as possible for any future study. The information was collected from books, Google search, journal and annual report but on this topic there was no relevant study. So it was difficult to compare the results of the study with other work. The interview schedule and interviewing skills were not in depth to get deeper information from the participants, as it was first attempt for the research. Due to the small sample it was difficult to generalize the study. The entire interview was conducted in Bangla and then it was translated in English. So during translation there might be possibility to loss the original theme of the information. The interview was not conducted in naturalistic setting. Participants' information was collected from school settings. So it may hamper to get the real picture of the situation.

Some recommendations which arise from this study likely that there should be an arrangement of discussion about features of ASD diagnosis where Occupational therapist, Speech therapist, Psychologist will be included in every special school setting. In this discussion project mothers' will share their ideas about ASD diagnosis and health professionals of school will provide them appropriate information. Because of this process parents as well as mothers knowledge about ASD diagnosis will be enriched and they can easily carryout a therapy activity in home environment, can modify the home environment and can help the child more than ever before. Future study could be "Developing a ASD guide in Bangla for parents" where features and process of assessment and some general guideline should be given in bangla and also need to find out how to make it available to all class of people in society as there is no books on ASD diagnosis in Bangla covering all area of ASD and which can give better ideas and clear concept about ASD to parents as well as to all the readers. Moreover Resources and therapy materials needed to developed in accordance with Bangladeshi context and resources from other countries need to be culturally adapted because there are some resources available in our country to use with children with ASD but all of them are suitable for foreign cultural context and it is less effective sometimes for children with ASD in Bangladesh even after modification. To address these problems norm referenced and culturally appropriate resources are crying need to help these children.

The prevalence of ASD has increased in all over the world in last few decades and as well as in Bangladesh but sources of help not increased in proportion to affected children especially in the remote areas. According to (Filipek et al., 1999) the prevalence of autistic spectrum disorder in childhood now exceeds that of Down's syndrome, diabetes, or cancer.

Bangladesh is a highly populated country and along with other countries of the world rate or incidence of autism is increasing in this country. It is relatively a new area for a research project in Bangladesh which may help to create a wide area for future research. Mothers' understanding about autism diagnosis is explored in this study, so further study could be done to find out what are the main barriers, what help best to get sound knowledge about autism in Bangladesh. Due to time limitation small number of sample was taken. In further study large group of participants should be chosen for generalizing the result.

Parents or mothers in Bangladesh sometimes affected with or believes in stigma as their child has got ASD and often the family treated differently in the society. On the other hand people of society and sometimes members of family thinks that ASD is occurred because of parents committed any great sin. These stigma and prejudices are needs to be addressed immediately and for this more and more awareness programs need to be arranged in our country to improve this condition particularly in the remote areas.

There is lack of support groups in our country for parents and mothers who have children with ASD. Only one or two support groups established in Dhaka city but it is insufficient to provide support to all families who have children with ASD and further more there is need of availability of a support group in every community.

At present government and different NGO's are now providing services to children with autism but still there are so much lacking in providing quality service to mothers as well as affected child. In this study researcher took data from two renowned special schools of Dhaka city but found variety of beliefs and opinions from the mothers and often they did not have a clear concept about the diagnosis and professional gave them unrealistic hope to maintain their motivation towards treatments that are not very effective. Most of the special school doesn't occupy qualified Speech Therapist as well as Occupational Therapist for their

economic benefit. As condition in capital city is still not suitable for mothers as well as for child so it can be easily assumed that condition in remote areas are more vulnerable. As most of the parents got diagnosed from neurologist so there should be arrangement of specialized training on autism is highly needed for them, and also a parent's guide should be developed for proper guideline and also need to make it feasible for every mother or parents.

Parents or mothers presented diversity in giving answer of same question and most of the time failed to give exact or accurate answer about ASD diagnosis as health professional did not provide enough information to them with features, even after getting different therapy services sometimes mothers could not answer properly because health professionals may not realize the importance of giving proper description to parents about diagnosis or may they do not have enough knowledge about the diagnosis.

For high functioning children with ASD who are continuing their study in any main stream school or college, for them there should be arrangement of quota to give them job opportunity and make them functional and give them a chance to contribute in the main stream society and also address their economic needs.

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ANNEXURE

Annexure: I Questionnaire (English)

These questions answers will be about the understanding of mother's regarding the diagnosis in their children with ASD.

Participant's name:	Age:
Occupation:	Mobile No.:
Educational Qualification:	Present Address:
Date:	

Questionnaire

Part 1: General Understanding

1. How do you define Autism Spectrum Disorder?
2. Please describe the main characteristics of autism spectrum disorder.
3. What causes autism?
4. What are the most common problems in autism?
5. Are you aware of any cures for Autism? (please provide details)

Part 2: Characteristics of Autism

6. What do you know about social impairments in Autism
7. What do you know about stereotyped or repetitive behavior? Can you explain Restricted, Repetitive patterns of behavior, interests, or activities?
8. What do you know about verbal and non-verbal communication and what is the pattern of communication in children with autism?
9. What do you know about sensory problems?
10. Are you aware of other problems that people with ASD may have? (sleep problems, intellectual disabilities, seizures, fragile X, gastrointestinal problem, ADHD) Can you explain about these problems?
11. How does autism affect behavior?
12. How can persons with autism learn best?

Part 3: Experiences

13. What sources of help you used so far and how could these sources cure your Childs problems? What was your experience in using these sources of help?
14. Who gave you the formal diagnosis of autism? What the professional describe you then about the diagnosis?

Annexure: II
Questionnaire (Bangla)

নামঃ	বয়সঃ
পেশাঃ	মোবাইলঃ
শিক্ষাগত যোগ্যতাঃ	বর্তমান ঠিকানাঃ
তারিখঃ	

প্রথম অংশ

- ১। অটিজম স্পেকট্রাম ডিজঅর্ডার কে আপনার নিজের ভাষায় সংজ্ঞায়িত করুন
- ২। অটিজম এর প্রধান বৈশিষ্ট্য গুলো সম্পর্কে যা জানেন বলুন
- ৩। অটিজম কি কারনে হয়? নিজের ভাষায় বর্ণনা করুন
- ৪। অটিজম আক্রান্ত শিশুর প্রধান সমস্যা সমূহ কি কি? নিজের ভাষায় বর্ণনা করুন
- ৫। অটিজম আক্রান্ত শিশুর সুস্থ হয়ে ওঠার ব্যাপারে আপনি কি জানেন বিস্তারিত বলুন

দ্বিতীয় অংশ

৬। শিশুর ক্ষতিগ্রস্ত সামাজিকতা সম্পর্কে আপনি কি জানেন বর্ণনা করুন

৭। কোন আচরণের অপরিবর্তনশীলতা ও পুনরাবৃত্তি বলতে আপনি কি বোঝেন? বাধা-ধরা আচরণ

ও কাজের প্রতি বিশেষ মনোযোগ এবং পুনঃপুনঃ ঘটনের প্রবণতা সম্পর্কে যা জানেন বলুন

৮। শব্দ সহ এবং শব্দ ব্যতীত যোগাযোগ সম্পর্কে আপনি কি জানেন? অটিজম আক্রান্ত শিশুর

যোগাযোগের ধরন কেমন হয় ?

৯। সেনসরি সমস্যা সম্পর্কে আপনি কি জানেন বর্ণনা করুন

১০। অটিজম স্পেকট্রাম ডিজঅর্ডারএর সাথে আর কিকি সমস্যা (শারীরিক ও মানসিক) বাচ্চার

থাকতে পারে? এ সম্পর্কে যা জানেন বলুন

১১। অটিজম শিশুর আচরণকে কিভাবে প্রভাবিত করে?

১২। অটিজম আক্রান্ত শিশুরা কোন মাধ্যমে/পদ্ধতিতে সবচেয়ে ভালভাবে শিখে? কেন?

১৩। শিশুকে সুস্থ করে তুলতে কোন কোন চিকিৎসা পদ্ধতির সাহায্য নিয়েছেন? এগুলো আপনার

বাচ্চাকে সুস্থ করে তুলতে কতটুকু ভূমিকা রেখেছে?

১৪। এইসব সাহায্যও মাধ্যমগুলো সম্পর্কে আপনার অভিজ্ঞতা কি?

১৫। সর্বপ্রথম কোন চিকিৎসক আপনার বাচ্চার রোগ নির্ণয় করে?

১৬। চিকিৎসক এই রোগের ধরন ও বৈশিষ্ট্য সম্পর্কে জানতে আপনাকে কি তথ্য ও উপদেশ বা

পরামর্শ প্রদান করেন এবং কোন সাহায্যের কথা বলেন?

Annexure: III

সম্মতিপত্র

এই গবেষণা স্পীচ এন্ড ল্যাঙ্গুয়েজ থেরাপি বিভাগের অধ্যয়নের একটি অংশ এবং গবেষকের নাম এজাজ আহমেদ। তিনি বাংলাদেশ হেলথ প্রফেশনস ইন্সটিটিউটের বি.এস . সি ইন স্পীচ এন্ড ল্যাঙ্গুয়েজ থেরাপি

বিভাগের ৪র্থ বর্ষের অধ্যয়নরত একজন ছাত্র এবং তার গবেষণার বিষয় অটিজম আক্রান্ত শিশুর মায়েরা এটি সম্পর্কে কতটা সঠিক তথ্য জানেন। এই গবেষণায় আমি-----
----- একজন অংশ গ্রহণকারী এবং আমি এই গবেষণার উদ্দেশ্য পরিষ্কারভাবে জানতে পেরেছি। আমি যে কোন সময় এবং গবেষণার যে কোন পর্যায়ে আমার অংশগ্রহণ প্রত্যাহার করতে পারি। এ জন্য আমি কারো কাছে জবাবদিহি করতে বাধ্য নই। এই গবেষণায় অংশগ্রহণ করলে তা আমার ও আমার সন্তানের বর্তমান এবং ভবিষ্যতে কোন প্রকার প্রভাব ফেলবেনা।

সাক্ষতের সকল তথ্য যেগুলো গবেষণার কাজে ব্যবহৃত হবে, সেগুলো সম্পূর্ণভাবে গোপন থাকবে। শুধুমাত্র গবেষকের তথ্যসমূহে প্রবেশাধিকার পাবে। কোন প্রকার নাম প্রকাশ হবেনা।

আমি গবেষণার পদ্ধতি এবং জটিলতা অথবা সাক্ষতের ব্যাপারে বা গবেষণার তত্ত্বাবধায়কের সহিত আলোচনা করতে পারব।

আমি উপরিউক্ত সকল তথ্যগুলো সম্পর্কে জানি এবং আমি এই গবেষণায় অংশগ্রহণে সম্মতি জ্ঞাপন করছি।

অংশগ্রহণকারীর

সাক্ষর: _____ তারিখ: _____

গবেষকের

সাক্ষর: _____ তারিখ: _____

—

Annexure: IV

Consent Form (English)

The investigator Ezaz Ahmed is a 4th year student of B. Sc. In Speech and Language Therapy in Bangladesh Health Profession Institute (BHPI). This study is part of course curriculum. In this study participant has clearly been informed the purpose of the study as to find out mothers understanding about her Childs diagnosis in children with autism spectrum disorder.

In this study I am

a participant or sample and I have been clearly informed about the purpose of the study. I am willingly participant in this study. I will have the right to withdraw in taking part any time at any stage of the study and I am not bounded to answer to anyone to get me out of the study at any time. This study will not cause any benefit or impact on participant work at present and future.

I will also inform that, investigator will keep all information confidential and personal identity such as participant's name & address will not be published anywhere of the study. The research will be available to answer any study related question to the participant. I have been informed about the above- mentioned information and I agree participant willingly with giving my consent.

Signature of the study Participant:

Date:

Signature of the Researcher:

Date:

Annexure: V

Permission to conduct the study

Date: 14th September, 2014
To
Head (Acting),
Department of Speech & Language Therapy
Bangladesh Health Professions Institute (BHPI).
CRP, Chapain, Savar, Dhaka- 1343

Subject: Prayer for seeking permission to conduct the research project.

Sir,
With due respect I state that I am a 4th year student of B. Sc. in Speech and Language Therapy of BHPI, the academic institute of CRP. I am sincerely seeking permission to conduct my research project as a partial fulfillment of the requirements for the degree of B. Sc. in Speech and Language Therapy. The title of my project is "**Mothers' understanding of their child's diagnosis in children with Autism Spectrum Disorder.**". The main objective of this study is to explore mothers understanding about diagnosis of autism.

Now I am seeking your kindness to approve me to start research project and would like to guarantee that anything of my research project will not harmful for the participants and confidentiality will maintain for each participant.

So, I therefore pray and hope that you would be kind enough to grant me the permission of conduction the research and help me to conduct a successful study as a part of my course.

Yours obediently,

Ezaz Ahmed
4th year student of B. Sc. in Speech and Language Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka- 1343

Approved by	Comments and Signature
<p data-bbox="405 1290 820 1420">Head (Acting) Md. Jahangir Alam Department of Speech & Language Therapy Bangladesh Health Professions Institute (BHPI). CRP, Chapain, Savar, Dhaka- 1343</p>	<p data-bbox="906 1267 1347 1370">permitted to conduct the study.</p> <p data-bbox="1145 1317 1337 1370">Jahangir 14/9/14</p>

Annexure:VI

Permission for data collection

Date: 14th September, 2014
To
Head (Acting),
Department of Speech & Language Therapy
Bangladesh Health Professions Institute (BHPI).
CRP, Chapain, Savar, Dhaka- 1343

Subject: Prayer for permission to data collection for undergraduate dissertation.

Sir,
With due respect I state that I am a 4th year student of B. Sc. in Speech and Language Therapy of BHPI, the academic institute of CRP. In 4th year, I have to submit a research project to the University of Dhaka in partial fulfillment of the requirements for the degree of B. Sc. in Speech and Language Therapy. The title of my project is **“Mothers’ understanding of their child’s diagnosis in children with Autism Spectrum Disorder.”**. The main objective of this study is to explore mothers understanding about diagnosis of autism. I would like to collect data for my study from ‘Alokito Shishu’ and ‘Proyash’ in Dhaka city.

Now I am seeking your kindness to approve me to start data collection for research project and would like to guarantee that anything of my research project will not harmful for the participants and confidentiality will maintain for each participant.

So, I therefore pray and hope that your honor would be kind enough to grant me the permission of collecting data for my research project and will help me to conduct a successful study as a part of my course.

Yours obediently,

Ezaz Ahmed
4th year student of B. Sc. in Speech and Language Therapy
Bangladesh Health Professions Institute (BHPI)
CRP, Chapain, Savar, Dhaka- 1343

Approved by	Comments and Signature
<p data-bbox="363 1373 858 1518">Head (Acting) Md. Jahangir Alam Department of Speech & Language Therapy Bangladesh Health Professions Institute (BHPI). CRP, Chapain, Savar, Dhaka- 1343</p>	<p data-bbox="922 1361 1316 1451">you can proceed for your data collection.</p> <p data-bbox="1220 1444 1380 1512"><i>Jahangir</i> 4/9/14</p>

Annexure:VII

Permission letter from “Prayas”



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

(The Academic Institute of CRP)

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

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

তারিখ : ২১.০৯.২০১৪

প্রতি
অধ্যক্ষ
প্রয়াস
ঢাকা সেনানিবাস, ঢাকা।

Seen	
Principal	✓
Ops & Prog Offr	
Office Super	✓
Date	২১/৯/১৪

বিষয় : রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর প্রসঙ্গে।

জনাব,

আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন স্পীচ এন্ড ল্যান্ডুয়েজ থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামূলক।

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন স্পীচ এন্ড ল্যান্ডুয়েজ থেরাপি কোর্সের ছাত্র এজাজ আহমেদ তার রিসার্চ সংক্রান্ত কাজের জন্য আপনার সুবিধাজনক সময়ে আপনার প্রতিষ্ঠানে সফর করতে আগ্রহী।

তাই তাকে আপনার প্রতিষ্ঠান সফরে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

অধ্যাপক ডাঃ এম এ কাদের
অধ্যক্ষ
বিএইচপিআই।



Annexure: VIII

Permission letter from "Beautiful Mind"



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

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

তারিখ : ২১.০৯.২০১৪

প্রতি

সহকারী অধ্যক্ষ

বিউটিফুল মাইন্ড

রোড-৬এ, সেক্টর-৫, উত্তরা, ঢাকা।

বিষয় : রিসার্চ প্রজেক্ট (dissertation) এর জন্য আপনার প্রতিষ্ঠান সফর প্রসঙ্গে।

জনাব,

আপনার সদয় অবগতির জন্য জানাচ্ছি যে, পক্ষাঘাতগ্রস্তদের পুনর্বাসন কেন্দ্রে-সিআরপি'র শিক্ষা প্রতিষ্ঠান বাংলাদেশ হেল্থ প্রফেশনস ইনস্টিটিউট (বিএইচপিআই) ঢাকা বিশ্ববিদ্যালয় অনুমোদিত বিএসসি ইন স্পীচ এন্ড ল্যান্ডুয়েজ থেরাপি কোর্স পরিচালনা করে আসছে।

উক্ত কোর্সের ছাত্রছাত্রীদের কোর্স কারিকুলামের অংশ হিসাবে বিভিন্ন বিষয়ের উপর রিসার্চ ও কোর্সওয়ার্ক করা বাধ্যতামূলক।

বিএইচপিআই'র ৪র্থ বর্ষ বিএসসি ইন স্পীচ এন্ড ল্যান্ডুয়েজ থেরাপি কোর্সের ছাত্র এজাজ আহমেদ তার রিসার্চ সংক্রান্ত কাজের জন্য আপনার সুবিধাজনক সময়ে আপনার প্রতিষ্ঠানে সফর করতে আগ্রহী।

তাই তাকে আপনার প্রতিষ্ঠান সফরে সার্বিক সহযোগীতা প্রদানের জন্য অনুরোধ করছি।

ধন্যবাদান্তে

অধ্যাপক ডাঃ এম এ কাদের
অধ্যক্ষ
বিএইচপিআই।



Approved
21/10/2014
Vice-Principal
Beautiful Mind

