

Problems of Autistic Children and Their Families: A Study in the Urban Areas of Bangladesh.

Advanced Research Monograph



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LIST OF ACRONYMS

ABC	=	Autism Behaviour Checklist
AS	=	Asperger's Syndrome
ASD	=	Autism Spectrum Disorder
CDD	=	Childhood Disintegrative Disorder
DCC	=	Dhaka City Corporation
FGD	=	Focus Group Discussion
HFA	=	High Functioning Disorder
IQ	=	Intelligence Quotient
NSAC	=	National Society for Autistic Children
PDD	=	Pervasive Developmental Disorder
PDD-NOS	=	Pervasive Developmental Disorders Not Otherwise Specified
SBRS	=	Social Behaviour Rating Scale
SPSS	=	Social Performance Survey Schedule
WCC	=	Weak Central Coherence
WHO	=	World Health Organization

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Abstract

Autism is now firmly established as a disorder of the developing mind and brain functions. Autism prima fascia a problem of enological maturation which becomes apparent in three years from birth and the very problem leads to inability of a child in normal and expected social interaction. Literature shows that it has a gender dimension that boys are more vulnerable to develop autism reveals in impediment of oral communication, observation and 'abnormal' behavior. Now autism is still full of mystery. Most people have accepted that autism is a lifelong condition and that it is inappropriate to expect a cure. People with autism often find social interaction difficult, have problems with verbal and non-verbal communication; demonstrate restrictive and repetitive behavior; have a limited set of interests and activities. ASDs include Asperger syndrome, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified. Experts estimate that three to six children out of every 1,000 will have autism. Males are four times more likely to have autism than females. Autism is a developmental disorder where language disorder is the most common characteristic in it, the sort of problems that children with ASD may have include as- not being able to express themselves well, not being able to understand gestures, facial expressions, or tone of voice, saying odd things, echolalia, pronoun reversal, sometimes using many words when one would do, using odd phrases and odd choices of words, making up their own words, not being able to understand difficult orders. Very few individuals who fail to achieve spoken language by this age later develop complex speech. For the majority **of** individuals with language impairments, the comprehension of language is generally at a higher level than their expressive abilities.

Social relatedness includes marked impairment in non-verbal communication, peer relationships and social-emotional reciprocity. Restricted interests and activities includes encompassing preoccupations, adherence to non-functional routines or rituals, stereotypes and motor mannerisms. Communication/play includes either a delay or total lack of spoken language and lack of developmentally-appropriate make-believe or social play. A significantly greater number of PDD children displayed the problems:

inaccessibility, strange behavior, and sleeping problems. The specific problems more or less in here in autism. Developmental deviance and retardation in the domains of cognition, language and socialization; rigid, stereotyped and inflexible style of functioning. The non-specific type of problems is additional to and not necessarily bound up with autism among these overactive behavior, temper tantrums, aggression, self-destructive behaviors, fears and phobias, sleeping problems and problems with toilet-training. In infancy non-specific symptoms are recognized, such as the lack of initiative, hyperactivity and sleeping and feeding problems. Children may develop normal speech until the age of two and then stop. Fifteen percent of children with autism develop seizures in the first few years of life and these spasms or seizures are thought, in some case, to cause autistic withdrawal. Some of autistic children are unable to make peer relation. They play only in themselves have very eccentric introvertness. They don't understand the social norms. As they are unaware of basic social norms, they cannot maintain the interactional reciprocity in a given social context. For example to wear heavy weight dress during summer is odd for interaction but they are unaware of it. Children with autism would not or could not perform the tasks possibly due to severe mental retardation or the deficits in comprehension of language, impaired perception of rewards for cooperation, or severe impaired attention. Early onset of autism is widely accepted as before two and a half to three years of age. Learning difficulties are reported in 70% of children with autism (Taylor, 2006: 511). The majority of children with autism are mentally retarded and, therefore, a minority of children with autism function in the normal to near-normal IQ range. Children with autism can have impaired hearing, but most do not. Some have impaired vision, but again, most do not. One of the earliest attempts to explain the cognitive problems of children with autism tend to touch, taste, and smell objects and people, often in a socially embarrassing way. Experimental evidence, however, soon showed that the excessive use of taste, touch and smell was not specifically associated with autism, but was associated with low mental age. This study asserts that the parents of autistic children undergo a high degree of stigmatization and public negligence in social interaction which makes them prone to stress regarding their children's future.

1.1 Introduction

Autism can be a difficult disorder to understand due to the diverse ranges of abilities for each individual but is generally characterized by a triad of impairments in socialization, communication and ritualistic behaviours. Szatmari (2004) describes autism as the invisible disability. There are no facial anomalies or outward evident signs that a child is affected by this distressing neurological disorder. Autism is a neuro developmental condition which is usually diagnosed in the first 3 years of life by a deficit in social reciprocity, language and communication and behaviour. It has been estimated that there is 1 in 1000 children who is diagnosed as having autism. The causes can be separated into psychological, neurological, genetic and environmental. The number of people diagnosed with autism has been increasing dramatically since the 1980s, partly due to changes in diagnostic practice and government-subsidized financial incentives for named diagnoses; generally parents become concerned when their child has delays in speech development, limited social relatedness, and restricted interests and activities. The child may avoid direct eye contact and exhibit odd behaviors. There may be unusual motor movements such as hand flapping, self stimulation or walking on toes. Although the cause of autism is unknown, it is generally believed that etiology may be due to multiple factors. Many genetic, environmental, metabolic and neurological conditions that affect the normal functioning of the brain are being researched. Bromley, Hare, Davison and Emerson (2004) explain that parents of children with autism are more likely to experience serious psychological distress than parents of children with other developmental disabilities. The possible cause of autistic regression is thought to be sub-clinical epilepsy. However, in the study carried out by Baird et al.(2006: 607), no evidence was found that epileptiform discharges in the sleep of autistic children is the cause of autism or autistic regression. They do, however, state the importance of awareness of epilepsy complicating autism and vice versa. However, despite the many difficulties associated with autism, families can maintain a solid familial life style. Parents of autistic children have been found to experience more stress than parents of other children and this stress may lead to difficulties in assisting with their child's treatment and may cause more maladaptive behaviour in the child. The current prevalence of autism spectrum disorders is estimated at 6 per 1000, with a male and female ratio of 3–4:1. Autism presents with a triad of core symptoms which include: A qualitative impairment of social interaction (an inability to relate to others

often with lack of eye contact); Stereotypical, ritualistic, repetitive, restrictive patterns of interests, behaviours and activities and; Major defects in language development and in other communication skills. These rather distinctive set of symptoms additionally form the basis of the diagnosis for autism. Affected children also manifest with other non-specific symptoms including: unusual sensory perception skills and experiences, motor clumsiness and insomnia. The majority of autistic children also have limited intelligence (IQ 100 in 5%). Strongly considered differentials for the diagnosis include childhood schizophrenia, learning disability and deafness. The common characteristics among autistic children are physical or learning disabilities, developmental disabilities and parenting stress, include scattered intellectual abilities or isolated skills and pervasive problem behavior such as self-stimulatory behaviors. Parents with autistic children have felt stigmatized in public situations such as supermarket or a shopping mall(Gray DE. 1993). Parents of autistic children to be at a higher risk for depression, social isolation and marital discord. Some parents go through periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt.

Autism affects girls and boys of all races and in all geographic regions and has a large impact on children, their families, communities and societies. The prevalence is currently rising in many countries around the world. Caring for and educating children and young people with this condition places challenges on health care, education and training programmers. The government is going to count the number of autistic children in Bangladesh. About 10% of Bangladesh's people are challenged of those, 1% is estimated to be autistic, amounting to around 1.5 lakh people. Social stigma poses a major challenge in the early diagnosis of autistic children. Due to lack of understanding of autism, people are negligent about treating autistic children until it is too late. Bangladesh needs to train community healthcare providers on how to understand signs and symptoms of autism. Many parents don't want to face the reality that their children are autistic. They often feel shame to disclose it to others in the early stages. Relatives and family members should show respect to the suffering of such parents. In Bangladesh, treatment and schooling for autistic children are expensive, which is a burden for a family that has to take care of other children. If our government can take initiatives for a cost-effective programme for autistic children, thousands of families will be grateful. Sometimes autistic girls are in more vulnerable situation than boys.

1.2 Statement of the Problem

The problematic foundation of autism in the family centers on autism and its biological and behavioral manifestations. Childhood is a demanding and challenging period for all parents, and when a child has a problem, the demands and challenges are magnified. When the problem is autism, one of the most devastating and least understood mental disorders of childhood, it is hard to imagine how parents and siblings cope. This study is about autism as problems of autistic children and their family members. Autism is a pervasive developmental disability that is rapidly growing in our world today. Leo Kanner, a former child psychologist at Johns Hopkins University, first introduced autism to medical literature in 1943 (Elisabeth Hill and Uta Frith, 2003). Presently an exact cause or cure for autism remains unknown. However, early diagnosis and active interventions in life can lead to positive outcomes. Medical research is currently investigating possible causes such as immunizations, environmental factors, genetic mutations, and viral illness. Fortunately, autism is now understood as a neurological syndrome and autistic symptoms are recognized as the final pathway with which the brain expresses a great variety of lesions and malfunctions of the infant central nervous system. The parents of autistic children are particularly vulnerable to stress. High levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children (Sloper P, Turner S., 1993). The parental distress and family functioning impacts children in numerous ways, affecting their cognitive, behavioural and social development. Developmental disorders are mental retardation, deafness, blindness, and aphasia. Social interaction problems are forming attachments and showing affection, parents of autistic children denied fundamental rewards of parenthood. Parents of children with autism face greater challenges than other parents. The research problem is the foundation of the research study and in this study the research problem is centered on autism and the particular needs parents have in raising children with autism. In The United States of America autism is diagnosed in one in every 166 births (Autism Society of America, 2007). In the 1990s, in the United States of America, the autism increase was 172% (Autism Society of America, 2007). In the United Kingdom 38.9 in every 10 000 children are diagnosed with autism. Simplified, this is a ratio of 1 in 257. Autism is still a mysterious and a complex disorder. Researchers do not find a specific cause of it; however, they find out its various symptoms and characteristics. Studying each symptom or characteristic thoroughly will help

us deal with this puzzle to solve it. One of the most essential symptoms in Autism is language deficit; studying this problem may help in improving the language of autistics, so that their communication skills could be improved. The literature suggests that one challenge faced by these parents is social isolation. It is often more challenging for families with a special needs child to go out into the community for shopping, meals, or other typical family outings. A second challenge frequently reported in the literature is that parents of children with mental retardation are subject to stigma. ASD is lifelong disability that affects not only the individual but the family as well. Although society has gained knowledge related to ASD in the last 20 years, the behaviors exhibited by individuals with ASD may appear odd, threatening, and unacceptable in social situations. ASD is not diagnosed at birth leaving parents, family members and friends to believe the child will develop normally. Many parents developed concerns when their child was 18 to 24 months of age and failed to develop language skills. The study will probe into these parents' extraordinarily difficult odyssey of learning and transformation, the present problem has been considered as research problem.

1.3 Rationale of the Study

The term of autism means a developmental disorder which is characterized by impaired social interaction and communication. At the age of three years, repetitive and restricted behaviour may also be seen. Although autism has a strong genetic basis but in some cases it is associated with different agents which cause birth defects. The number of people diagnosed with autism has increased dramatically since the 1980s in developed countries but some later in developing countries. The symptoms include lack of social or emotional behavior, disturbance in person relation, disturbance in communication, disturbance in sensory processing, parrot like repetitive use of language or idiosyncratic language and persistent preoccupation with parts of objects and overall developmental delay. Onset must be prior to age three years, with delays or abnormal functioning in either social interaction, language as used in social communication or symbolic or imaginative play. Autistic infants are usually content to sit quietly in their playpens, completely self-absorbed, never noticing the comings, goings, and doings of other people. These children are so unresponsive that their parents may believe that they are deaf. By age two or three many autistic children do form some emotional attachment to their parents or to other caregivers, though it is still considerably

weaker than that of normal toddlers. Autistic children may be compliant and engage in the selected activity for a period of time. Physical play, such as tickling and wrestling, may appear to be enjoyable to autistic children. Observations of their spontaneous play in an unstructured setting reveal that children with autism spend much less of their time engaged in symbolic play, such as making a doll drive to the store or pretending that a block is a car, than do either mentally retarded or normal children of comparable mental age. In Bangladesh, there is no correct statistical information about autism. Most of the time, the children with autism spectrum disorder are detected by general paediatrician. But the management needs multidisciplinary approach including occupational therapy, sensory integration treatment, cognitive therapy, behavioural modification techniques, speech therapy, treatment based school, psychotherapy, dietary management etc. Current prevalence rates of Autism are 1 in 160 children in Australia, 1 in 100 in United Kingdom and 1 in 91 in the United States. In India the estimated prevalence rate is 1 in 250. We do not know the prevalence rate for Bangladesh. There will be around 76,000 children with ASD under the age of five in Bangladesh if we consider prevalence rate of India. The number is quite large. In our country, delay in typical language development is usually the first concern of the parents that leads to seeking help from health care professionals. There are some children who develop their language at an early age but when it is time to socialize, there are difficulties in doing so. Parents of these children, who are diagnosed with Aspergers Syndrome, notice the difficulty and seek professional help usually when the children can't cope in school environment. These concepts of late language development and lack of socialization vary in different families under different circumstances.

1.4 Objectives of the Study

The purpose of this study is to identify challenges faced by parents when their child is diagnosed with ASD. I will specifically examine research related to the difficulties parents may experience related to the diagnostic process, how parents respond and react to the diagnosis, what are the positive and negative coping strategies used by parents, and identify specific challenges parents face related to raising a child with ASD. The aim of the research is to conduct a needs assessment of parents of children with autism in order to provide professionals with information that will assist in improving service delivery to parents of children with autism.

Generally:

The general objective of the present study is to know the problems of autistic children and challenges of family members living in society.

Specially:

More specifically the objectives of this study are as follows:

1. To identify some problems of autistic children.
2. To study the parental stress and coping with autistic children.
3. To know the impact of autism on family members.

1.5 Operational Definition of the Concepts

There are some concepts which are used in the research. The following definitions have been provided to assist the reader with clarification.

Autism: The term ‘Autism Spectrum Disorders’ (ASD) refers to a cluster of developmental disorders that present from birth or very early in development, with usually life-long effects on essential human behaviours such as social interaction, communication, imagination, and relationships with others (National Research Council, 2003). It is a neurological, pervasive developmental disorder, which is characterized by impairments in communication, and social interaction and repetitive and stereotypic patterns of behavior.

Disability: A physical or mental impairment that limits one or more of the major life activities of an individual.

Etiology: Refers to the specific cause or origin of a disease, syndrome or abnormal condition.

Pervasive Developmental Disorder: A group of conditions that involve delays in the development of many necessary skills which frequently involve communication and socialization. An umbrella category for a range of conditions that include symptoms such as difficulties with communication and social skills, unusual interests or habits and insistence on sameness.

Asperger’s Syndrome (AS). A pervasive developmental disorder characterized by deficits in social adaptation.

Autism Spectrum Disorder (ASD). A group of developmental disabilities characterized by atypical development in socialization, communication, and behavior. It includes autism, Asperger’s syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified.

High Functioning Autism (HFA). Term used to describe children who had classic signs of autism in early childhood but as they developed, where shown to have a greater degree of intellectual ability, socialization, adaptive behavior, and communication skills than is usual in children with autism.

Abnormal activity levels:

The child with autism is most often either hyperactive or hypoactive with only a few children having normal activity levels. In the preschool years hyperactivity is common, early school years are characterized by normal active behaviour and then hypo activity is common in adolescence (Gillberg & Coleman, 2000: 20).

Aggression and self-injury;

Aggression presents particularly in adolescents and young adults. Self-injury, however, is present in children with a combination of autism and mental retardation and is in the form of head-banging, wrist or knuckle biting, chin-knocking, cheek-smacking, eye-poking, hair-tearing and clawing (Gillberg & Coleman, 2000: 21).

1.6 Significance of the Study

Autism is one of the pervasive developmental disorders (or autism spectrum disorders) and a commonly diagnosed condition in child and adolescent psychiatry, which was initially described by the psychiatrist Leo Kanner in 1943 (Kanner, 1943). Childhood autism is broadly defined by the presence of abnormal and impaired development, which manifests into a series of clinically relevant areas (or symptoms). Citing Rutter defines Autism as "a disorder evident before 30 months of age, in which there is a profound and general failure to develop normal social relationships, together with delayed and deviant language development and the presence of ritualistic or compulsive phenomena ". Whatever the causes may be, the effects of autism on the cognitive and behavioral processes of children are devastating. Autism is a severe disruption of the normal developmental processes that occur in the first two years of life. Autism leads to impaired language, cognitive, social, and adaptive functioning causing the children to fall farther and farther behind peers, as they grow older. Autistic individuals seem not to understand simple verbal communications, are confused by sensory input, and withdraw in varying degrees from people and the world around them. They become preoccupied with seemingly meaningless activities, objects, and repetitive behaviors. Their problems seem to be related to perception. Autistic individuals

seem lost in their own inner world. Robinson describes Autism as "a medical disorder with neurobiological basis, most likely due to unusual connections within a child's brain". She remarks that in the United States, 1 out of 110 children are autistic and argues that early recognition of Autism and intense interventions may help in the improvement of autistic child's developmental delays. She states that this disorder can be easily detected at age 3; this is probably so because most normal children are able to talk at this age. She adds that it can be detected earlier for the reason that at age 12 to 18 months almost all autistic children show a delay in eye contact, responsiveness and social smiling compared to normal children. Children with autism often are unsuccessful at building developmentally appropriate relationships with their peers. This results in part from a perceived indifference to the interests of others which is often demonstrated. Children with autism will often respond to communication attempts by their peers by talking about something of interest to themselves rather than engaging in a reciprocal interaction. Children with autism cannot carry on a conversational interchange of thoughts and information about the same topic with another person (National Institute on Deafness and Other Communication Disorders, 2010). Problems of socialization, communication and imagination are sufficient and necessary to capture much of the behaviour found to be specific and universal to autism. A person with autism may have no speech or gesture, whatever they may be echolalic only, or they may have fluent but oddly used language; but all these variations can be seen as manifestations of a communication handicap. The person with autism may run away from social approaches, may seem cut off and passive or may pester people with questions and monologues; but these behaviours all demonstrate a fundamental lack of social understanding (Wing 1988). The task faced by cognitive theories of autism is to explain the specific pattern of deficits and preserved abilities across these three areas in autism as problems in socialization, communication and imagination. Family problem were the autistic family member's difficult personality characteristics including their management problems, their degree of dependency and their need for assistance in self-help skills; and on the other hand a lack of activities, services, and prospects for independent living. Autism has been reported to be associated with prenatal stress both with retrospective studies that examined stressors as job loss and family discord and with natural experiments involving prenatal exposure to storms; animal studies have reported that prenatal stress can disrupt brain development and produce behaviours resembling symptoms

of autism. The lack of support and assistance given to parents of children with autism may lead to poor parenting of the child with autism, poor education of the child, little or no social, emotional and cognitive development of the child, parental stress, emotional and psychological distress, strain on the marital relationship and strain on relationships within the family. The problems ensuing from the lack of support for the parents of children with autism are significant and indicate the necessity for a needs assessment in order to establish what these needs are and to gain a better understanding of them. Parents of children with ASD have higher levels of stress. Siblings of children with ASD report greater admiration of and less conflict with the affected sibling than siblings of unaffected children and were similar to siblings of children with Down syndrome in these aspects of the sibling relationship. However, they reported lower levels of closeness and intimacy than siblings of children with Down syndrome; siblings of individuals with ASD have greater risk of negative well-being and poorer sibling relationships as adults. Although the evidence does not implicate any single pregnancy-related risk factor as a cause of autism, the risk of autism is associated with advanced age in either parent, and with diabetes, bleeding, and use of psychiatric drugs in the mother during pregnancy. The risk is greater with older fathers than with older mothers; two potential explanations are the known increase in mutation burden in older sperm, and the hypothesis that men marry later if they carry genetic liability and show some signs of autism. Most professionals believe that race, ethnicity, and socioeconomic background do not affect the occurrence of autism. Though we have many organisations in Bangladesh working with various fields of disability, there is hardly any quality institute developed exclusively for the autistic children. The problem further is aggravated with the unavailability of centres to train trainers or teachers to work with autistic children. Similarly, there is no facility available for the training or motivation of parents or caregivers of autistic children. Parents, relatives and teachers of autistic children should be more patient in raising such special child. We have to develop a strong programme through government and NGO collaboration to ensure a useful methodology to help these autistic children and their families.

1.7 Literature Review

The appropriate point in the planning process at which to concentrate on the literature is something which may well vary in different styles of research. In the traditional model of research, the literature is reviewed as part of the

research planning and question development stage. The literature itself becomes an input to the analysis and planning during this stage. This is the recommended way to precede in many research situations, and it has been the model typically followed in quantitative research and in some types of qualitative research. The literature is dealt with are matters for judgment in the light of the overall logic of the study (Punch Keith F.,1998:43). Here discuss the review of current literature available on autism and resilience for the purpose of exploring the affects of autism and the positive attributes and characteristics that foster resilience in families. Often, families of a child with autism seem consistently distressed and anxious about aspects of everyday life. Other families with a child with autism have managed to overcome the constant challenges and trials of autism.

Study- 01

Ashum Gupta and Nidhi Singhal (2005) conducted a study on ‘Psychosocial support for families of children with Autism’, address the levels of stress and adjusting strategies used, in the families of children with autism. Here writers focus on different ways of providing effective support services for parents and in coping strategies adopted by the father, mother and siblings of a child with autism. This paper basically draws attention to the prevailing scenario of autism in India. There may be as many as 2 million people in India with autism. Yet, autism as an area of research is still emerging in the Indian sub-continent. Writers try to show in this research that the parents of autistic children are particularly vulnerable to stress. High levels of distress have been found in up to 70% of mothers and 40% of fathers of severely disabled children (Sloper P, Turner S., 1993). Research indicates that siblings of children with autism are also at risk of bearing the psychological and emotional brunt of growing up alongside a child with behavioural difficulties. There have rumoured that the siblings of autistic children have high levels of loneliness and problems with peers. Kaminsky and Dewey (2002), found loneliness related to a lack of social support from friends. Social support from classmates was also importantly correlated with academic problems. Siblings of autistic children are importantly more likely to experience depression than the general population. Additionally, many children are receiving diagnosis at earlier ages. While in the past, children typically were diagnosed around the age of 5 years when they entered school. According to this study, psychological literature reveal the parental distress and family functioning

impacts children in numerous ways, affecting their cognitive, behavioural and social development. Developmental disorders are mental retardation, deafness, blindness, and aphasia. Social interaction problems are forming attachments and showing affection, parents of autistic children denied fundamental rewards of parenthood. As a result, autism has been marked as complex and intractable developmental disorders with which families may have to cope. In this study writers revealed the common characteristics among autistic children are physical or learning disabilities, developmental disabilities and parenting stress, include scattered intellectual abilities or isolated skills and pervasive problem behavior such as self-stimulatory behaviors. Parents with autistic children have felt stigmatised in public situations, such as supermarket or a shopping mall. Stigma was exacerbated among those with children who were more severely disabled or children under the age of 12 (Gray DE. 1993). Parents of autistic children to be at a higher risk for depression, social isolation and marital discord. Some parents go through periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt. The process of increasing autistic children, presents unique challenges to families. Getting a diagnosis of autism and accepting a lifelong responsibility of bringing up a child with autism is a traumatic experience for the parents. So fulfill the lacking of this study and to create something new, we have conducted the present study.

Study- 02

Lynn Koegel, Rosy Matos-Fredeeen, Russell Lang, and Robert Koegel, (2011) in their article named “Interventions for Children With Autism Spectrum Disorders in Inclusive School Settings” explained that ASD Students face challenges to school systems. The purpose of this article is to provide a summary of research-based interventions for students with ASD. This article execute in inclusive school settings by teachers and classroom support personnel. They provide a general overview of interventions designed to reduce challenging behavior, teach communication skills, and improve social relationships which is followed by a depiction of the impediments to intervention implementation that may be present in school environment. At laset government schools provide an ideal system for delivering interventions for autism, as children are in school for many hours a day and for the majority of their chronological years. It facilitates to deliver an intensive,

comprehensive intervention focusing on improving communication and socialization, and expanding the autistic child's interests. Notwithstanding, delivering these services through the school system is challenging, research findings related to addressing these challenges are described in detail in this article.

Their highly evaluated work mentions that, the number of public school children in the United States found with an autism spectrum disorder has increased and may now be as high as 1 case per 110 students (Center for Disease Control, 2010). However, California now have legislation requiring that teachers working with children with severe disabilities have some specialized autism-specific training. Most of the cases, Students with ASD often fail to develop meaningful social relationships with teachers and classmates, may struggle to communicate (lacking spoken language), the mentioned communication skill is plagued with challenging behavior, ranging from tantrums to self-injury, aggression, and property destruction. Finally, they conclude by offering an index of intervention guidelines. Challenging behaviors may hinder academic instruction, limit opportunities for social interaction, and cause physical harms (Sigafoos et al., 2003).

Study- 03

In this article (‘Coping over time: the parents of children with autism’) writer by D. E. Gray (2006) mentioned that longitudinal study of parents coping with autistic children over nearly a period of ten years. This research emphasized indepth interviews and participant observation. Here focus on the child’s medical history and referral experience, the effects of the autistic children problems on the well-being of parents, the upshot of autism on the social life of family members, parental coping strategies, illness ideas and the parents’ anticipations for the future life. Coping strategies changed from the time of the initial study, as fewer parents coped within reliance on service providers, family support, social withdrawal, individualism, religious faith and other emotion-focused strategies. According to this study, the vital challenge for autistic family members is autistic spectrum disorders to cope with society that stressful of childhood developmental disabilities. Problems with communication, emotional expression and antisocial behaviours, all combined to place tremendous stress on the families of autistic children. Despite these problems, families do cope with autism and often cope successfully (Bristol 1984; Marcus et al.1997). This research indicates that parents often use

technical coping strategies to deal with their child's autism involving support from family and friends (Marcus 1977; Gray 1994). Previous research has provided valuable information and it indicates that the coping activities of individuals change over time (Lazarus 1996).

According to this study, most of the parents emphasizing religion as a coping strategy remained the same over time, its share of the proportion of all coping activities increased. In one case where the parents reported religion as their main coping strategy in the follow-up study, the parents had previously focused the use of treatment services as their main means of coping. Here reflects both the declining importance of treatment services and an acceptance by the parents that their earlier expectations about their child's improvement will not be fulfilled. Under the circumstance, the parents may have found it more important to acknowledge the permanence of their child's disability and find a way of thinking about it that will put it into a meaningful perspective. The final coping strategy was a residual category of different activities that were described as 'other'.

For the families in this study, the problems of parenting a child with autism, and their means of coping with it, have changed over time. The total number of coping strategies reported by parents declined and there was a general shift away from problem-focused towards emotion focused means of coping. The reasons for these changes may reflect both the changing problems of the children and the services currently available for their treatment. In one case, most of the children have improved over time as they have become less disrupted .

Study- 04

Pilar Pozo, Encarnación Sarriá and Ángeles Brioso (2011) in his article(“Psychological Adaptation in Parents of Children with Autism Spectrum Disorders”) described that autism and Autism Spectrum Disorders (ASD) are the most cryptic and embarrassing disorders that affected individuals demonstrate preferences in three basic areas of development, such as correlative social interaction, verbal and non-verbal communication, and flexibility in their selection of fascinate and behaviours. ASD create major problems in the family dynamics and generate needs in all sectors and contexts of development (Altiere, 2006; Baker et al.,2005). Other problems are related with the nuclear characteristics of autism. These include Mental retardation and behaviour problems related with stereotyped, self-injurious or aggressive conduct that exists in the long duration. These problems affect the

development of individuals with autism and the well-being and adaptation of their parents to a greater or lesser extent. Most of the studies suggest that the synchronous behaviour problems in ASD, compared to the severity of the disorder itself are frequently associated with stress, anxiety and depression. However, many families related with ASD children have continued successful psychological adaptation. From this autistic children may not be the only factors that influence adaptation but also involved, including social support, perception of problems and coping strategies.

In the last section of this book described the adaptation of families of children with ASD. Until the late 1980s, family and disability studies focused on the negative effects of a child's disorder and its consequences in the family. Empirical research on the positive contributions of a disabled child to the family was very rare. However, parents with their disabled children have always included positive aspects. Two major aspects stand out as possible points for intervention: the importance of the perception of positive contributions and the protective role of the SOC and its resilience to chronic stress. When the adjustment of families of children with ASD is studied, the focus is often on negative effects, while the positive effects are ignored. This system must solve the problems, but it will not influence the development of positive perceptions among parents. Social support from family, friends, institutions, associations or support groups can make life more durable and understandable. Here at last emphasize the families of children with ASD can be helped to meet the child's needs in appropriate ways. Moreover, this process of adaptation influence to parents have an experience of growth and maturity that empowers them. Research on adaptation processes can help to identify dangerous and protective factors. In this sense, the multidimensional perspective has proven not only of the weights of the various factors but also of the relationship dynamics that explain the psychological adjustment of parents. Research in this area is only beginning and much future.

Study- 05

David E Gray in his article (æTen years on: a longitudinal study of families children with autism”) described that parents have repeated observation of psychological well-being, the social experiences of their immediate family members and their relations with members of other family. The parents in these families undergo high levels of stress and had few

opportunities in terms of care or residential placement to deal with their condition. Longitudinal research on the social experiences of the families of autistic children is relatively rare. Most of the problems related with schools, treatment providers and their other children are common, most families experience a relatively good period. In particular, improvements in the child's sociability, emotional control and attention span mean that their behavior becomes more orderly and their family's life more settled (DeMeyer, 1977). In this study, writers presented the interviews included questions about autistic children, these are the child's medical history and referral experience, the child's present symptomatology, the effects of the situation on the parent's health and career, the various effects of autism on the family's social life, parental coping techniques, illness conceptualizations, and parents' expectations for their child's future development. The results from the previous research indicated a high level of emotional distress for many of the parents including depression, anxiety and anger (Gray, 1994). Career problems were common with some parents reporting moderate to serious limitations on their careers and mothers avoid any opportunity for outside employment due to their child's disability. According to this study, the most difficult problems that parents mentioned were poor language skills, inappropriate and embarrassing public behavior, disruption and destruction in the home, violence and aggression, inappropriate sexual expression and obsessions with eating or toileting. In particular, communication was less frequently cited as a major coping problem, parents considered this to be the most painful aspect of their child's autism.

1.8 Limitation of the Study

In the beginning, this study was meant to only include autistic children. However, after several visits to autistic people's care centers, the researcher found that the sample of the study should be extended to include autistic people from different ages, i.e. children and adults. Having enough sincerity, activeness and willingness, there are some limitations created massive problem for the research too. This is by no means an extensive study of the problems of autistic children and their family members of our country. Moreover, the insufficiency of books, journals and previous research work related to this area may make it unsuccessful-

1. The first constraint for my study is time. Within this short sphere of time this research could not analyze elaborately some of its important factors.

2. The study was limited to geographic location and the specific sample in urban areas of Bangladesh. But it would not represent properly different urban areas of Bangladesh without Dhaka city.
3. Identifying the residence of autistic children is quite impossible. For this reason I would go different institution, foundation and school of autistic children to collect data. Besides, some cases, most of the guardian of does not stay with their children. So data collection from guardian was very tough.
4. No question was asked directly to autistic children about their problems because they cannot answer the question properly for their different problems. In this context, question was asked directly to the parents of autistic children.
5. Parents of autistic children often decline to be interviewed because of social superstition. They are not helpful to provide the problematic information faced by autistic children and their family members.
6. The low response rate of respondent viewed the motive of interview with suspicion which creates new problems to collect data.
7. Related literature is so much important for any research. But there have not available research on autism in Bangladesh. So, there is a lack of background information.
8. It was not possible to select to a large number of respondents for data collection. Because most of the time I had to engage in academic activities like regular classes and exams had to face some problems.
9. Many of the respondents haven't enough time to give information because of their prestigious fact. As a result the interview had to shorten the interview session.
10. As the terms founded in the outcome of the research related with medical science, sometimes it was hard to understand.
11. After all, the lack of financial support has created vital problem for me. Because I had to bear all the expenses of the study. Which sometimes hampered the continuous flow of the work.

2.1 Methodology of the study

The present study is compiled with various methods considering its objectives. The following methods were conducted to achieve the exact and keen measures for this study. Methodology is considered to be the æheart of the research”. The present chapter describes the entire methodology and data collection procedure underlying this research. It also explains the rationale behind each of the research strategy chosen for the study. Furthermore a detailed exposition of research design, research instrument, participants, methods of data collection, the procedure of data gathering and analyzing enriches the chapter to justify the study.

2.2 Types of the study

This study is a data exploratory research. So this study is sample survey based research. Basically, by using sample survey technique, this study has been conducted. This particular study was conducted to address the concern that problems of autistic children and their families in Dhaka city may not be receiving the assistance and support that they require. This is true for this study as I have little knowledge on parenting problem a child with autism. In this study, I explored the problems of autistic children and their family members.

2.3 Location of the study

All area of Dhaka city corporation (DCC) has been considered as the area of the study. But, because of popularity and familiarity of Shymoli, Mohammadpur and Lalmatia as the areas of autistic institutions, foundation and school , the study has been conducted on the basis of only those areas for exploring the real data of the research. I had selected some autistic institutions in Dhaka city such as:

1. Society for Welfare of Autism Children (Pisiculture, Shymoli)
2. Autistic welfare Foundation (Pisiculture housing society, Mohammadpur)
3. Alokito Shishu (Shakertake, Mohammadpur)
4. School for Gifted Children (Lalmatia)

2.4 Research Design

The research design is the way in which the researcher will go about collecting the data. Neuman (2003: 121) refers to research designs both within qualitative and quantitative research. For this research study the researcher will

use terminology of research design. The present study follows a mixed method research design. According to Creswell and Plano Clark (2007) a mixed method research design is a procedure for collecting, analyzing and æmixing” both research approaches, namely, quantitative and qualitative. These two approaches can also be conducted as combined research and methods in a single study to understand to research problem. ‘Mixed method research is not simply collecting two district æstrands” of research- qualitative and quantitative, it consists of merging, integrating, linking or embedding the two ‘strands’ in short, the data is æmixed” in a mixed methods study’ (Creswell, 2008, P. 552). The qualitative approach is interpretive and holistic; it aims to understand meaning, perception, seek illumination and extrapolation to similar situations, uses an inductive approach, which has an emphasis on developing insights and generalizations from the collected data, while quantitative research uses a deductive approach, which emphasizes detailed planning, scientific explanation and aims to measure, test, generalization of findings and predict phenomena. The researches incorporated a number of qualitative and quantitative instruments such as document analysis, structured questionnaire, in depth-interview and focus group discussion (FGD) on parents and teachers. Both quantitative & qualitative information were analyzed separately by using descriptive statistical analysis. The following table summarizes the different process involved in conducting the study.

2.5 Mixed Methods Research

There are important strengths and advantages to the qualitative approach. Qualitative methods are flexible, more so than quantitative methods. Therefore they can be used in a wider range of situations and for a wider range of purposes. The important thing is the matching of question with method- using quantitative methods for quantitative questions and qualitative methods for qualitative questions. (Punch Keith F., 1998:244). Creswell and Clark (2007) define mixed methods research as ‘the combination of quantitative and qualitative approaches that provides a better understanding of research problems than either approach alone’ (pp. 8-9). Mixed methods research can therefore embrace both qualitative and quantitative approaches. Philosophically, the mixed methods research paradigm is associated with pragmatism, as its primary concern is whatever method gives a workable solution to a given research question. Practically, mixed methods research is characterised by the use of triangulation and multiplism. Triangulation

strengthens the validity of research results by using multiple methods to investigate the same phenomenon, thus offsetting biases, and multiplism supports triangulation by recruiting as many data sources as possible.

2.5.1 Mixed Methods Design

Greene et al. speak of five mixed methods research designs – triangulation, development, expansion, complementarity and initiation – of which the first three are relevant to this study because they strengthen the validity of the results gained. Triangulation seeks a convergence from different methods, while development refers to the use of the results gained from one method to guide the use of another method. Lastly, expansion refers to the use of appropriate methods in order to increase the range and depth of the inquiry. Embedded design incorporates different forms of data into a study to increase the number of workable solutions that are available for different questions. Explanatory and exploratory designs use both quantitative and qualitative data, supplementing one with the other to develop or build upon the initial results. This study draws upon the triangulation and exploratory designs in particular. Triangulation is used to strengthen the validity of research findings, and exploratory design, which is particularly oriented to a qualitative study.

2.5.2 Rational for mixed methods

Problems of Autistic Children and their Families. For this purpose mixed method study design was used in this study for the following reasons: (i) By using quantitative method, it is not possible to measure the problem only through a questionnaire, (ii) Structured qualitative method may not be adequate to collect all the related information, (iii) in a qualitative study assessment and measurement of treatment outcome take a long time.

2.5.3 Strategy of Inquiry: Sequential Explanatory Mixed Methods

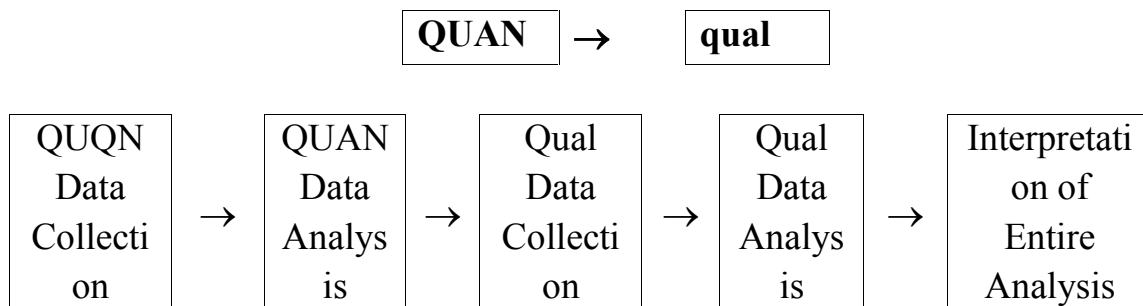
This study followed a mixed methods research design specifically an explanatory sequential mixed method research strategy was used to collect and analyze both quantitative as well as qualitative data. The sequential explanatory strategy consists of two phases, first collecting quantitative data and then collecting qualitative data to help explain or elaborate the quantitative results (Creswell, 2008). The visual model of the mixed method strategy of inquiry is shown below.

Table-01: The visual model of Mixed Methods Strategy of Inquiry.

Implementation	Priority	Integration	Theoretical perspective
Sequential Quantitative first	Quantitative	At data interpretation	Implicit

(Source: Creswell, 2009: P. 209)

Implementation means either the researchers collection both the qualitative data in phases (Sequentially) or they gather it at the same time. Here the implementation indicates that the study has collected both the quantitative & qualitative data in phases but the quantitative data has been collect first. In first phase the statistical problems of Autistic children and thus families have been determined then in the second phase qualitative data through FGDs and interviews were collected to describe the quantitative findings of the first phase. Priority refers whether greater priority or weight is given to the quantitative data or qualitative data. For the present study priority has been given to the quantitative data. This is done by introducing it first in the study and having it represent a major aspect of data collection and a small qualitative component follows in the second phase. (Creswell, 2008; P. 556). Integration states show two types of data have been mixed up. For the present study at the interpretation level data has been integrated to understand the findings of the study. And the theoretical perspective is limited to implicit only in data interpretation level. As pre this model the present study was conducted by an initial phase of quantitative data collection and analysis followed by a phase of qualitative data collection and analysis. The findings of there two phases were then integrated during the interpretation level.

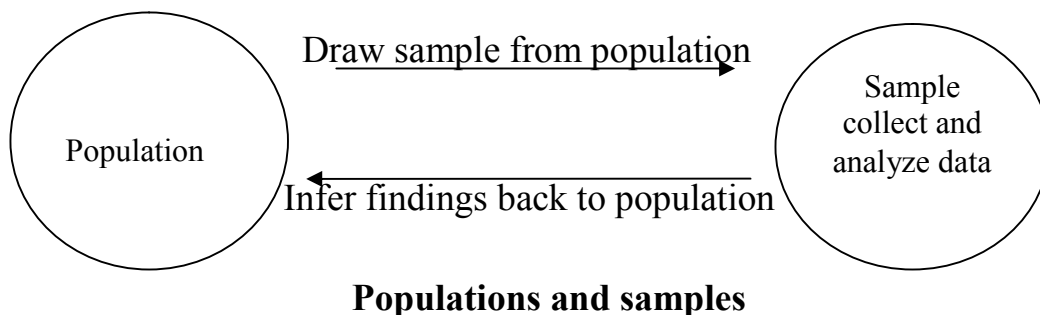
Table-02: Study Design: Sequential Explanatory Strategy.

(Source: Creswell 2009, P. 209).

The ‘QUAN’ refers to more weight placed on the quantitative data and ‘qual’ refers to minor emphasis given to qualitative data. This also implies that an initial phase of quantitative data (questionnaire) was collected and analysis then a qualitative data (FGD and interviews) collection has taken place. Then at the interpretation level quantitative results were explained in details with the assistance of the qualitative findings.

2. 6 Sample and sampling

Sampling has been, historically, an important topic in the research methodology, with well developed and mathematically sophisticated sampling plans. All research, including qualitative research, involves sampling. This is because no study, whether quantitative, qualitative or both, can include everything. Sampling in quantitative research usually means ‘people sampling’. The logic of quantitative sampling is that the researcher analyses data collected from the sample, that logic is shown in the following figure.



Sampling strategies are equally important in qualitative research. Whatever sampling strategy is used, the research proposal needs to address three questions:

- How big will the sample be, and why?
- How will it be chosen, and why?
- What claims will be made for its representativeness? (Punch Keith F.,1998:106).

A sample is the part of the population that is considered for the study. The sample came from parents who had children of school-going age with autism. Parents may or may not have more than one child with autism and may have a typical child not diagnosed with autism. The parents must have at least one school (includes play/nursery school) age child with autism. The sample was originally going to come from parents of children who attend the different

autistic institutions of Dhaka city. I have been collected data from parents until saturation of data took place.

2.6.1 Sample unit

All the families having autistic children in upper and middle class in Dhaka city have been considered as the unit of the study.

2.6.2 Sample size

Purposive and snowball sampling technique have been used for the present study. On the basis of purposive and snowball sampling techniques, two categories of subjects have been included in the present study- parents of autistic children and teachers of different autistic institutions. A total of 85 subjects have represented the pilot study taking 65 from parents of autistic children and 20 from teachers of different autistic institutions who are teaching and caring autistic children.

2.6.3 Selection of School:

In this study only four schools were selected as the representative school of Dhaka city for accessibility and financial constraints.

2.7 Data collection

“Interviewing is the predominant mode of data or information collection in qualitative research”. Semi-structured interviews were conducted with parents of children with autism. These interviews were tape recorded and the researcher wrote notes on areas of particular importance or interest whilst conducting the interview. These notes and tape recordings were used in the data analysis process. As the researcher generates data from a range of sources different steps were taken to collect data from different sources.

2.7.1 Context and purpose of the data collection

The purpose of the data collection was to explore and describe the needs of the parents of children with autism in Bangladesh, in order to provide information to professionals such as social workers, psychologists, child therapists and teachers, as well as to other parents of children with autism. This information might enable these professionals to form a helping partnership with the parents to improve service delivery, assistance and the support provided to the parents. This information provided to parents of

children with autism may enable them to feel less isolated in their experience of raising a child with autism and they may be able to use recommendations from other parents who have or are experiencing similar difficulties.

2.7.2 Techniques of data collection

As a research technique data and substantiation have been generated from various sources by using different instruments such as- questionnaires, in-depth interviews and focus group discussion. At the beginning of the study a structured questionnaire schedule was prepared in English for the purpose of collecting required data through direct interview. Both open and close ended questions were included in the schedule. However, I have been maintained the responsibilities of data collection.

2.7.2.1 Questionnaire

One sets of questionnaire were prepared to conduct a detail perception study of the people who attend the different autistic institutions of Dhaka city. The questionnaires pretested before the survey. Finally the questionnaires were printed for actual survey. Once the subject relevance was determined, I had been determined the focus of the study on the structured questions. The questionnaires are attached in the appendix.

2.7.2.2 Interview

The interview is one of the main data collection tools in qualitative research. Interviewing has a wide variety of forms and a multiplicity of uses. The most common type of interviewing is individual, face-to-face verbal interchange, but it can also take the form of face-to-face group interviewing, mailed or self-administered questionnaires, and telephone surveys. Interviewing can be structured, semi structured, or unstructured. (Punch Keith F.,1998:175).

Table-03: The continuum model for interviews

Structured interviews	Focused or semi-structured interviews	Unstructured interviews
Standardized interviews Survey interviews Clinical history taking	In-depth interviews Survey interviews Group interviews	In-depth interviews Clinical interviews Group interviews Oral or life history interviews

(Source: Minichiello et al., 1990:89, Quated from Punch)

In structured interviews the respondent is asked a series of pre-established questions, with pre-set response categories. The data from group interviews are the transcripts (or other records) of the group's interaction. They might be used as the only data gathering technique in a study, or frequently, in conjunction with other quantitative or qualitative techniques. There is a wide range indeed when it comes to unstructured interviewing. The traditional type of unstructured interview is the non-standardized, open-ended, in-depth interview, sometimes called the ethnographic interviews (Punch Keith F.,1998:178). In this study, in-depth interview used for data collection methods.

2.7.2.3 Focus Group discussion

The present research used focus group Discussion (FGD) to collect qualitative data from the parents and teachers. A focus group typically consists of six to twelve individuals who are asked to discuss topics suggested by a facilitator. As FGD aims to draw upon respondent's attitudes, opinions, feeling, experiences and reactions in a way in which it would not be feasible using other methods, for example observations, one to one interviewing or questionnaires survey.

2.7.3 Source of data collection

2.7.3.1 Primary sources

Actually the data of the study has been collected from primary sources. In this regard, the primary data has been collected from parents and teachers of autistic children through social survey. To collect primary data, I have gone to different autistic institutions many times.

2.7.3.2 Secondary sources

Secondary sources were also used here. Literature, text book, document journal, brochure, previously published papers on autistic children and their families have been used as secondary sources. I have got valuable information from the archive of daily newspaper. I have gone through numerous articles and journals from online resource centre and taken expert opinions to make my understanding clear.

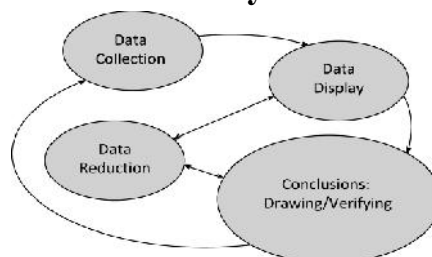
2.8 Data analysis and publishing

Data analysis involves collecting and recording data, managing data, reading, generating categories, themes and patterns and finally coding the data. The collected data were written down (see Appendix). The obtained data were analyzed in terms of word classes as used by the autistic children of the subjects of the study. After adequate collection of information data have been finally checked and edited, and responses of the structured and unstructured questions have been carefully coded. Data has been processed mainly in the computer and necessary statistics have been showed in graphical presentation. After processing the data has been analyzed and interpreted according to the objective. Finally completing the all task carefully it has been published as research report. Mixed method research has a number of different ways to analysis data depending on its research design. As a sequential research design has been adopted for the present study, first the quantitative analysis has been produces following by a qualitative analysis. At the discussion chapter the analysis is integrated on the basis of the main research questions both the quantitative and qualitative data analysis procedure has been discussed below. Data analysis itself has different meanings among qualitative researcher and these interpretations lead to different methods of analysis. Qualitative research concentrates on the study of social life in natural settings. (Punch Keith F.,1998:199). Miles and Huberman, in a comprehensive sourcebook, describing analysis which is directed at tracing out lawful and stable relationships among social phenomena, based on the regularities and sequences that link these phenomena. They lable their approach ‘transcendental realism’ and their analysis has three main complements:

- data reduction
- data display
- drawing and verifying conclusions.

They see these as three concurrent streams or activities, interacting throughout the analysis of a figure.

Components of data analysis: interactive model



(Source: Miles and Huberman, 1994:12, Quated from Punch)

2.8.1 Quantitative Data

The analysis of quantitative data is usually called statistics. Quantitative data obtained from the questionnaire was analyzed through descriptive (SPSS) statistics. Data gathered through closed ended questions for two types of semi-structured questions were analyzed statistically using descriptive analysis approach, collected quantitative data were given codes and entered in computer software named SPSS.

2.8.2 Qualitative Data

For the analysis of qualitative data obtained from FGD and in-depth interview with parents of autistic children and teachers to follow up the quantitative findings of the study. A qualitative strategy was used and analyzed it in narrative form. Recorded narrative data was transcribed and analyzed using the mode of content analysis.

2.9 Ethical Consideration

This study did not use any unethical means to collect information. Participant information sheets and consent forms were prepared in English. The participant information sheets cover the nature of the research, including its purpose, benefits and methods. The interview consent form explains that consent is made on the basis of the information provided in the participant information sheet. It adds that participation is voluntary and withdrawal from the study is available at any time. It also clarifies the obligations of the researcher to maintain the confidentiality of participants, and to monitor any potential risks associated with participation in the study. The data collection process commenced at the completion of the ethics approval process.

3.1 Sick role: Parsons view

Talcott Parsons' sick role is one of the most fun elementary concepts in medical sociology, was first illustrated in a 1948 journal article but broadly depicted in his 1951 book, *The Social System*. Parsons emphasized the relation of illness with society which is not simply a biological or psychological condition, and it is not simply an unstructured state free of social norms and regulation. While talking about the thesis, Giddens remarks æ Sick role in order to describe the patterns of behavior which the sick person adopt in order to minimize the disruptive impact of illness.” .When one is ill, one does not simply exit normal social roles to enter a type of social vacuum; rather, one substitutes a new role—the sick role—for the relinquished, normal roles. The sick role is, æalso a social role, characterized by certain exemptions, rights, and obligations, and shaped by the society, groups, and cultural tradition to which the sick person belongs.” Parsons viewed sickness as a type of deviant behavior in that it is a violation of role expectations. Functionalist theorists (Parsons) are concerned about the impact of deviant behavior upon society and parts of society. Sickness is assessed as being dysfunctional for the family because when one member is sick and relinquishes normal responsibilities, other members are required to pick up the slack and may become overburdened in so doing. In addition, sickness is dysfunctional for society. The equilibrium that society holds can be disrupted when individual members, due mainly to sickness, fail to fulfill routine responsibilities.

The sick person, in accordance with the view, is *prima facie* excluded from normal roles attributed by the society. Depending on the nature and severity of the illness, a physician can legitimize the sick role status and permit the patient to forgo normal responsibilities. The physician's endorsement is required so that society can maintain some control and prevent people from lingering in the sick role. The æsick person” is not considered as sick for a subjective judgment which is devoid of clear objectivity. Society accepts that cure will require more than the best efforts of the patient and permits the patient to be ætaken care of” by health care professionals and others.

The concept leads an erudite gaze to the social regulation of illness: to the mechanisms that guarantee the compliance of sick persons, help to revitalize the normal and expected conditions of health, and ensure that only the genuinely sick are exempt from normal responsibilities. It also provides a means of scrutinizing the motivational factors which are concomitants of

illness. Parsons, notwithstanding, suggested that because of these motivational components illness could be considered a special form of deviance, functional to the social system in directing deviant propensity away from group formation, solidarity, and successful claims to legitimacy. Since the arguments readily plague the validity of the theory with the consideration of degrees of subjectivity for illness, none the less, the concept of the sick role has been central to sociological thinking about health and illness, and its importance would be hard to overestimate.

3.2 Social Stigma: Erving Goffman view

Canadian sociologist Erving Goffman, remarks the term ‘stigma’, to purvey his highly celebrated work, as ‘situation of the individual who is disqualified from full social acceptance’. Although, witnessing the recent decades it may be argued that there have been some remarkable shifts in relation to some of the areas of stigma discussed by Goffman. While challenging stigma in areas where it is no longer a social force, the medical profession plays a leading role in promoting stigma where it continues to sanction discrimination and social exclusion. Social stigma is the extreme disapproval of (or discontent with) a person or group on socially characteristic grounds that are perceived, and serve to distinguish them, from other members of a society. Social stigma can result from the perception of mental illness or mental disorder, physical disabilities, diseases, illegitimacy, obesity, skin tone and education. They feel different and devalued by others. This can happen in the workplace, educational settings, health care, and even in their own family. Stigma may affect the life of those who are stigmatized. Those who are stereotyped often start to act in ways that their stigmatizers expect of them. It not only changes their behavior, but it also shapes their emotions and beliefs. In Erving Goffman's theory of social stigma, it is provided that a stigma is an attribute, behavior, or reputation which may and indeed contributes discrediting in a particular way in a given social setting. Empirical research on stigma compatibly inclined with mental disorders, stress, pointed to a deviant, paranormal attitude of the collective conscience. Those who were told that mental disorders had a genetic basis were more prone to increase their social distance from the mentally ill, and also to assume that the ill were dangerous individuals, in contrast with those members of the general public who were told that the illnesses could be explained by social and environment factors. Furthermore, those informed of the genetic basis were also more likely to

stigmatize the entire family of the ill. Although the specific social categories that become stigmatized can vary over time and place, the three basic forms of stigma (physical deformity, poor personal traits, and tribal out group status) are found in most cultures and eras, leading some researchers to hypothesize that the tendency to stigmatize may have evolutionary roots.

Most importantly, stigma relations of shame, has a long ancestry and has from the earliest times been associated with deviations from the 'normal', including, in various times and places, deviations from normative prescriptions of acceptable states of being for self and others. It starts with an appreciation and critique of Goffman's benchmark sensitisation and traces his influence on the personal tragedy or deviance paradigm dominant in the medical sociology from the 1970s. The advocacy of a rival oppression paradigm by disability theorists from the 1980s, notably through re-workings of the social model of disability, is addressed. There is a cultural stereotype of mental illness, blunted by sins of omission and commission. Stigmatization can be overt. It can manifest as aver-sion to interaction, avoidance, social rejection, discount-ing, discrediting, dehumanization, and depersonalization of others into stereotypic caricatures. Accordingly, a study was conducted to explore the attitudes of the general population towards patients with mental disorders.

3.3 The Labelling Theory

Labeling theory was first proposed during the late 1950's in opposition to normative theorists. Several people who contributed to it's development were Howard Becker (1963), Tannenbaum (1951), and Lemert (1938). Lemert is considered to have been the first to really introduce the ideal and Becker is the one who became the leader of the movement. Lemert did not consider himself to be a labeling theorist however he introduced primary and secondary deviance. Primary deviance is the behavior that causes the initial labeling of a person as a deviant. Once that label has been established deviant behaviors afterward are called secondary deviance.

Labeling theory is based on the idea that behaviors are deviant only when society labels them as deviant. As such, conforming members of society, who interpret certain behaviors as deviant and then attach this label to individuals, determine the distinction between deviance and non-deviance. Social research indicates that those who have negative labels usually have lower self-images, are more likely to reject themselves, and may even act more defiantly as a result of the label. Unfortunately, people who accept the labeling of othersÍbe

it correct or incorrect. I have a difficult time changing their opinions of the labeled person, even in light of evidence to the contrary.

Nevertheless, children and adults with significant interpersonal deficits are being lumped together with children and adults with language acquisition problems. Currently, with the loosening of the diagnosis of Asperger, children and adults who are shy and timid, who have quirky interests like train schedules and baseball statistics, and who have trouble relating to their peers but who have no language-acquisition problems are placed on the autism spectrum. According to the diagnostic manual, Asperger syndrome is "a continuous and lifelong disorder,"

But many experts believe these unsociable behaviors were just about as common 30 or 40 years ago. The recent explosion of cases appears to be mostly caused by a surge in special education services for autistic children, and by a corresponding shift in what doctors call autism. Autism has always been diagnosed by making judgments about a child's behavior; there are no bloods or biologic tests. For decades, the diagnosis was given only to kids with severe language and social impairments and unusual, repetitious behaviors. Many children with severe autism hit themselves or others, don't speak and don't make eye contact. In the 1990s, the autism umbrella expanded, and autism is now shorthand for a group of milder, related conditions, known as "autism spectrum disorders." The spectrum includes Asperger's syndrome and something called PDD-NOS. Some support groups report more than half of their families fall into these categories, but there is no commonly accepted scientific breakdown.

3.4 Social exchange theory of Autism

Social exchange theory as it applies to autism states that: "The behavior of each party in an exchange, e.g., the autistic child's behavior in an exchange with his parents, is determined by the consequences for him in terms of reinforcement and punishment of the behavioral response he emits." Social exchange theory, then, is based upon the principles of operant conditioning. An exchange is any interaction between two or more persons in which each party gives and receives something. The exchange begins with an initiation (a behavior, a word or statement, a question, a request, a demand, a noise, etc.), which is then responded to in some way, and then the response is responded to (or reciprocated) by the actions, words, or inaction of the person who initiated the exchange.

Parents of children with autism seem to be more conditioned by the social exchanges than the children. Over time, the parent's behavior is mostly shaped by the negative reinforcement of escaping the child's disruptive behavior. The parent knows that "giving in" to the child's demands is not the best thing to do, but on a 24/7 schedule this knowledge becomes secondary to the fact that "giving in" provides relief from the child's tantrums, screaming, or head banging. No one can cause autism through his or her actions. Parents (especially mothers) were once blamed for causing autism by parental neglect or rejection. That is absolutely false. Research has shown that autism is more than likely a biochemical and/or neurological disorder. While we are not the cause of someone's autism, we may unknowingly interact with the person with autism in ways that maintain the patterns of interaction we dislike. The parent's "giving in" and other inadvertently reinforcing behavior is a function of the child's behavior and is, in fact, an escape reaction to it. The autism is the source of the original behaviors; both parent and child maintain each other's inappropriate behaviors thereafter. Social exchange theory provides an answer to this dilemma.

3.5 The Social Motivation Theory of Autism

The idea that social motivation deficits play a central role in Autism Spectrum Disorders (ASD) has recently gained increased interest. This review delineates the concept of social motivation and capitalizes on recent findings in several research areas to provide an integrated picture of social motivation at the behavioral, biological and evolutionary levels. They conclude that ASD can be construed as an extreme case of diminished social motivation and, as such, provides a powerful model to understand humans' intrinsic drive to seek acceptance and avoid rejection.

Concomitantly, the impact of motivational factors on the development of social skills and social cognition has received little attention. Recently however, social motivation has emerged as a promising research domain at the intersection of social psychology, behavioral economics, social neuroscience and evolutionary biology. Social motivation is a powerful force guiding human behavior and that disruption of social motivational mechanisms may constitute a primary deficit in autism. Social motivation is subserved by a network of brain regions including the amygdala, the ventral striatum, and orbital and ventromedial regions of the prefrontal cortex. Each region plays a greater role in specific aspects of motivation, but no region operates in isolation.

Subcortical structures are most involved in the generation of reward utilities, but require cortical involvement for conscious hedonic representations. Social motivation models of ASD posit that early-onset impairments in social attention set in motion developmental processes that ultimately deprive the child of adequate social learning experiences and that the resulting imbalance in attending to social and non-social stimuli further disrupts social skill and social cognition development. The adverse effects of social isolation on well-being are a natural consequence of the strength of social motivation. Economists and social psychologists have long emphasized that social bonds are indispensable for achieving happiness and epidemiologists have confirmed that lack of social support constitutes a major health risk, comparable in magnitude to well-established risk factors such as smoking and alcohol consumption.

3.6 Executive Dysfunction Theory: Elisabeth L. Hill

In an article ‘Executive dysfunction in autism’ written by Elisabeth L. Hill, it has been mentioned that studies on autism have not sufficiently conducted and needed more research on executive function of individuals across the lifespan. For her, ‘Executive function’ conceptualized as the wide array of planning, working memory, impulse control, inhibition and mental flexibility, as well as for the initiation and monitoring of action. These functions corroborates the need to untie from the immediate environment to guide actions. Executive functions are typically impeded in patients with acquired harmful complexity to the frontal lobes as well as in a range of neurodevelopment disorders that are seemingly to incorporate congenital deficits in the frontal lobes. Such clinical disorders include attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder, Tourette syndrome, phenylketonuria, schizophrenia and autism spectrum disorder. She further goes on to remark these should be noted that executive dysfunction can be observed in those with acquired damage to non-frontal brain areas. Autism spectrum disorder is a developmental disorder with impaired social contact and communication and repetitive behaviours and restricted interests.

She emphasized that ‘Over the past twenty years several executive functions have been studied in autism. In this review, I focus on three of these: planning, flexibility and inhibition for detailed reviews of these and other aspects of executive function in autism’. She argued that planning is such a complex, dynamic operation which comprises a sequence of planned actions and should

be subject to monitoring in continuum, re-evaluation and update. In terms of mental flexibility, she holds that poor mental flexibility is revealed by preservative, stereotyped behaviour and complications in the regulation. And inhibition is considered by her somewhat different in the arena of executive functions of individuals with autism.

Autistic performance might be united to dysfunctional integration of the frontal lobes with the rest of the brain, abnormal developments in neuronal sophistication and abnormal myelinisation. But the executive dysfunction account of autism to be valid as a cognitive account of the primary symptoms, these difficulties must be a universal feature of autism. This theory not only help to clarify the universality of executive dysfunction to autism but also the impact of social aspects of tasks that could cause enlarged complexity in autism and it lead to important improvements in the implementation to ameliorate the consequences of executive dysfunction in the daily lives of individuals with autism spectrum disorder.

Link with Executive Dysfunction Theory

In our society autistic children cannot function most of the perspectives in their life. Actually we mean executive function in people with autism as working memory, ability to inhibit, plan, shifting attention, generating goal-directed behaviour, strategic problem-solving and inhibiting impulses. But when we can not see above functions in our society in autistic children, at that time executive dysfunction create in neurodevelopment disorders, lack of consensus, problems of normal IQ levels with autistic children. The Executive Dysfunction theory of autism was first proposed in our society when researchers observed that some symptoms of autism were similar to those related to specific brain injury. In this context, this theory attempts to explain the repetitive behaviour and need for routine and sameness of people with autism.

3.7 Central Coherence Theory

Central coherence refers to global processing, in other words, processing whole systems. The theory essentially proposes that, while typically developing individuals process information by extracting an overall meaning, individuals with autism lack this drive for coherence and thus process things in a detail-focused or piecemeal way. One positive feature of WCC theory is that it can be used to explain higher level conceptual abilities such as language.

López and Leekham (2003) proposed that ability to detect WCC in autistic individuals was dependant on whether the task used was verbal and/or visual. Autism is characterized by a series of strengths as well as weaknesses. People with autism demonstrate weak central coherence as there is a superior attention to detail. Tests that tap factual knowledge and focused attention on detail can lead to peak performances, whereas tests tapping common sense comprehension can be surprisingly poor. Some of these features are explained by the theory of ‘central coherence’. The Central Coherence Theory differs from the Empathizing-Systemizing Theory when it comes to the whole. The Empathizing-Systemizing Theory predicts that the autistic person will display a strong desire to understand the whole system, while the Central Coherence Theory predicts that the person with autism will fail to grasp the whole system or the relationships between parts of the system (Baron-Cohen, 2005). However, research using visual illusions has produced inconsistent results with some studies showing autistic individuals as susceptible to illusions while other studies indicate the opposite. It was subsequently suggested that this disparity might be related to higher-order processing in some way, while the influence of question wording on task performance has also been raised. According to the theory, the concepts of autistic individuals are narrower, sharper and have more clearly defined boundaries. Thus, this theory can potentially explain why people with autism often have difficulty generalising newly learned behaviour to a novel environment Rajendran & Mitchell (2007).

3.8 Theory of Mind Deficit

The theory of mind account of autism has been remarkably successful in making specific predictions about the impairments in socialization, imagination and communication shown by people with autism. In 1985 Cognition published an article by Baron-Cohen, Leslie, and Frith, entitled: Does the autistic child have a ‘theory of mind’? The perceptive reader would have recognized this as a reference to Premack and Woodruff’s (1978) question: Does the chimpanzee have a theory of mind? The connection between these two was, however, an indirect one -the immediate precursor of the paper was Wimmer and Perner’s (1983) article on the understanding of false beliefs by normally developing pre-school children. Each of these three papers has, in its way, triggered an explosion of research interest; in the social impairments of autism, the mind-reading capacities of non-human primates, and the development of social understanding in normal children.

This theory essentially proposes that individuals with autism lack ‘the ability to attribute mental states to oneself and others, and to make sense of and predict behaviour on the basis of mental states’ (Baron-Cohen, 1999). Theory of mind is the notion that explain autism as individuals do not understand that other people have their own plans, thoughts, and points of view. Furthermore, it appears that they have difficulty understanding other people's beliefs, attitudes, and emotions which has impact on the behavior of individuals with AS. Theory of mind difficulties can provide a possible explanation for the communication and social challenges that define autism spectrum disorders. Theory of Mind can be summed up as a person’s inability to understand and identify the thoughts, feelings and intentions of others.

4.1 Autism

Autism is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs). Autism is a developmental delay that includes symptoms such as speech difficulties, lack of eye contact, isolation and no fear of danger. Autistic children act and sound like much younger children. The label had already been introduced by the eminent psychiatrist Eugen Bleuler near the beginning of the twentieth century and was well known in psychiatry. Hence the words ‘autistic’ and ‘autism’ from the Greek word *autos* meaning ‘self’. Today they are applied almost exclusively to the developmental disorder that we now call autism. Above all the children seemed to be unable to establish normal relationships with their peers (Frith Uta, 1989:05)..

Autism is a life-long, often devastating, disorder that profoundly affects almost every aspect of an individual's functioning. Impairments in communication limit the ability to understand what is happening or why, and make it almost impossible effectively to control events, people or the environment. Difficulties in social understanding mean that even the simplest interactions are fraught with problems. Inability to cope with change and the need to adhere to fixed routines and patterns of behaviour can make every-day life threatening and disturbing (Howlin Patricia, 1991:01).

4.2 Autism as a Developmental Disability:

Historically autism was considered a form of social withdrawal by vulnerable children from emotionally cold, rejecting, "refrigerator mothers". This conception brought autistic children under the exclusive jurisdiction of mental health, with several important negative consequences for such children and their families. First, the children were frequently seen in inappropriate verbally oriented play therapy while their parents were seen in therapy aimed at correcting their "destructive attitudes." Second, the children were excluded from public schools. Autistic children frequently appear emotionally disturbed, but when they do it is in reaction to the frustration caused by their deficits rather than that the emotional difficulties cause their learning deficits. In recent years autism is increasingly accepted as a developmental disability (Schopler, Rutter, & Chess, 1979). This conception has been incorporated in the definition of autism used by the National Society for Autistic Children (NSAC). Autism is included under the Developmental Disabilities Act of 1975

and the U.S. Office of Education has also initiated reclassification by removing autism from the emotionally disturbed category (Schopler E. & Mesibov G.B., 1985:413).

4.3 Developmental disorder

The typical image of the child with autism is surprising. Those familiar with images of children who suffer from other serious developmental disorders know that these children usually look handicapped. Autism is a disorder of childhood. In fact, autism starts to be noticed in childhood, but it is not a disorder of childhood. Instead it is a disorder of development. Since it is a disorder that affects all of mental development, symptoms will necessarily look different at different ages. Autism affects development and in turn, development affects autism (Frith Uta, 1989).

4.4 Autism and Mental Retardation

Approximately 80 percent of autistic children score below 70 on standardized intelligence tests. Because of the significant number of autistic children who are also mentally retarded, it is sometimes difficult to differentiate the two disabilities. There are important differences, however. Although retarded children usually score consistently poorly on all parts of an intelligence test, the scores of autistic children may have a differentiated pattern. In general, autistic children do worse on tasks requiring abstract thought, symbolism, or sequential logic, all of which may be associated with their language deficits. They usually obtain better scores on items requiring visual-spatial skills, such as matching designs in block design tests and putting together disassembled objects

4.5 Types of Autism

The American Psychiatric Association lists five subtypes of ASD under the umbrella term of Pervasive Developmental Disorders:

4.5.1 Autistic disorder

Autistic Disorder is a impairment in social interaction, as manifested by at least two of the following: marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction, failure to develop peer relationships appropriate to developmental level, markedly impaired

expression of pleasure in other people's happiness, lack of social or emotional reciprocity, delay in or total lack of the development of spoken language, stereotyped and repetitive use of language or idiosyncratic language, lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level.

4.5.2 Asperger Syndrome (AS)

In 1944, Hans Asperger, a Viennese medical student unaware of Kanner's earlier report, suggested the concept of autistic psychopathy or what is now usually termed Asperger's syndrome. Asperger's description resembled that of Kanner in some ways, e.g. in the use of the word autism to describe marked problems in social interaction. Asperger suggested that the condition he described was seen only in males, was observed in the face of relatively strong language and cognitive skills, and tended to run in families (Volkmar F.R,1998). The term "Asperger's syndrome" was first used by Lorna Wing , who introduced the diagnosis in an attempt to gain recognition for those very able autistic people who do not fit the Kanner stereotype of being silent and aloof. She listed six diagnostic criteria based on Asperger:

1. speech Í no delay, but content odd, pedantic, stereotyped;
2. non-verbal communication Í little facial expression, monotone voice, inappropriate gesture;
3. social interactions - not reciprocal, lacking empathy;
4. resistance to change - enjoy repetitive activities;
5. motor coordination - gait and posture odd, gross movements clumsy, sometimes stereotypies;
6. skills and interests - good rote memory, circumscribed special interests.

In addition to these, she reports Asperger's claim that this disorder is more frequent in males than females and rarely recognized before the third year of life (Happe F.1994:83).

Wing modified these criteria, according to her own clinical experience, making three changes:

- (i) Language delay - only half of the group Wing would label as having "Asperger's syndrome" developed language at the normal age.
- (ii) Early development - before the age of 3 years the child may be odd, e.g. no joint attention.

- (iii) Creativity - Wing claims these children are not creative, and for example do not show true pretend play. Rather than being "original", their thought is inappropriate.

Table-4: Diagnostic criteria for Asperger's syndrome suggested by Szatmari et al. (1989a)

1. Solitary - two of: •no close friends •avoids others •no interest in making friends •a loner	2. Impaired social interaction - one of: •approaches others only to have own needs met •clumsy social approach •one-sided responses to peers •difficulty sensing the feelings of others •detached from feelings of others
3. Impaired nonverbal communication — one of: •limited facial expression •unable to read emotion from facial expression •unable to give message with eyes •does not look at others •does not use hands to express self •gestures large and clumsy •comes too close to others	4. Odd speech — two of: •abnormal inflection •talks too much or too little •lack of cohesion in conversation •idiosyncratic use of words •repetitive patterns of speech
5. Does not meet DSM-III-R criteria for autistic disorder.	

(Source: Happe F. *Autism*;1994: 86)

4.5.3 Rett's Syndrome

Rett (1966) reported an unusual syndrome, observed only in girls, where a very brief period of normal development is followed by decelerated head growth, loss of purposeful hand movements and development of severe psychomotor retardation (Volkmar F.R, 1998).

4.5.4 Childhood disintegrative disorder

Childhood Disintegrative Disorder is apparently normal up to the age of at least 2 years. The presence of normal age-appropriate skills in communication, social relationships, play and adaptive behaviour at age 2 years or later is required for diagnosis. There is a definite loss of previously acquired skills at about the time of onset of the disorder. The diagnosis

requires a clinically significant loss of skills in at least two of the following areas: social skills or adaptive behavior, expressive or receptive language, motor skills, bowel or bladder control, play.

4.5.5 Pervasive Developmental Disorder

The term pervasive developmental disorder-not otherwise specified (PDD-NOS) was included in DSM-IV to encompass 'sub-threshold' cases. It is intended to describe individuals who have a marked impairment of social interaction, communication or stereotyped behaviour patterns or interest suggestive of a pervasive developmental disorder but who do not meet the criteria for any of the formally defined disorders in that class (Volkmar F.R, 1998). It also called Atypical Autism. Pervasive developmental disorders emphasized that autism involves a serious abnormality in the developmental process itself and thus differs from the mental disorders that originate in adulthood.

4.6 Causes of Autism

What causes autism specifically is not known. Some experts believe there are bio-chemical reasons for autism; others suspect that it is a psychiatric disorder. The cause of autism is unknown. It has long been presumed that there is a common cause at the genetic, cognitive, and neural levels for autism's characteristic triad of symptoms. Medical research is currently investigating possible causes such as immunizations, toxic chemicals, genetic mutations, and viruses. There are strong genetic factors as well as prenatal biological determinants. Recently, vaccines have been incriminated as a cause of autism, however, Taylor states that no definite post-natal environmental causes have been identified. The researcher discusses all the possible causes of autism.

4.6.1. Genetic causes

As convincing evidence for the genetic causes of autism has now emerged, a new twist has been added to the story. Kanner's and Asperger's clinical intuitions about the often intellectual and detached parents of the children they saw were not mistaken. Well-controlled studies have shown that fathers as well as mothers may have some of the same traits as their children, often in very mild form (Frith Uta, 1989:30). Genetic factors are the most significant cause for autism spectrum disorders. Early studies of twins estimated heritability to be over 90%, in other words, the genetics explains

over 90% of whether a child will develop autism. Though autism's genetic factors explain most of autism risk, they do not explain all of it. A common hypothesis is that autism is caused by the interaction of a genetic predisposition and an early environmental insult.

4.6.2 Environmental causes

It has been found that prenatal exposure to particular teratogens an environmental agent that can cause abnormalities in a developing organism, e.g., the rubella virus) is a risk factor associated with autism and indicates that fetus mal-development is a likely path to autism. Wier et al. describes a study of Swedish patients where prenatal exposure to a teratogen occurred which resulted in a greater proportion of autism. They suggest that first-trimester injury may impair brain development, which potentially leads to autism. Insults occurring during gestation in the foetus lead to neuro-developmental disorders, particularly autism spectrum disorders.

Environmental causes are attractive to consider because it might be possible to avoid them and prevent the disorder. A famous example is phenylketonuria, a metabolic disease with a genetic cause and an environmental trigger, phenylalanine, which the body in this case cannot metabolize. This is critical, as phenylalanine is in much of the food we normally eat. If unchecked, the consequence of the disease is subtle damage to the brain and intellectual impairment (Frith Uta, 1989:72). Essentially, any environmental risk factor that can lead to brain damage early in development may be considered a potential nongenetic cause of autism. Prenatal factors and birth complications are risk factors that might result in brain damage. A number of studies have shown that significantly more hazards of pregnancy and birth are present in autistic than in normal children.

4.6.3 Psychological causes

Gillberg and Coleman (2000: 102) state that there are three psychological concepts involved in autism. These are metalizing, central coherence and executive function. People with autism have been found to fail tests for metalizing and central coherence. Not all people with autism are impaired in all three areas; however, it is generally accepted that there are many neuropsychological impairments in people with autism.

4.6.4 Neurological causes

According to Brothers, social intelligence is a function of three regions of the brain: the amygdala, the orbitofrontal cortex and superior temporal sulcus and gyrus, together called the social brain. The amygdala is activated when decoding signals of social importance, such as gaze, expression-recognition, and body movements” (Baron-Cohen, 2005:400). Patients with lesions in the amygdala have impairments to social judgement similar to autism. Abnormalities of the amygdala have been found in people with autism. Such abnormalities are: increased cell density in the amygdala, reduced amygdala volume and less amygdala activation during an empathizing task. As the amygdala is linked to autism, it is likely that there are other areas of neural abnormality possibly linked to autism. Cerebellar dysfunction is indicated by difficulty walking in a straight line, reduced stride regularity with increased variability in velocity and the coexistence of variable stride lengths and duration. Children with autism have been found to be less coordinated and more variable and inconsistent than other children.

4.6.5 Parental age

A child’s risk of developing autism is associated with the age of its mother and father at birth (Gardener H, 2009). The biological reasons for this are unknown: possible explanations include increased risk of pregnancy complications; maternal autoimmunity; increased risk of chromosomal abnormalities or unstable trinucleotide repeats in the egg, imprinted genes, spontaneous mutations and confounding socio-cultural factors in the sperm since ages of the father and mother are correlated, it is possible that only the mother’s age, or only the father’s age or both, contribute to the risk (Ruiz & Avant, 2005).

Although it is rare for families to have more than one child with autistic disorder, the risk of a second child being affected by a form of autistic disorder has been estimated as 3-6 percent. This must be compared with a normal population risk of 0.6 percent, making it 5-10 times as high.

In early research of autism there was said to be no genetic link. Today, autism is thought to be one of the most heritable psychiatric conditions, however, there is no consensus on the mode of transmission of autism”. According to Gillberg and Coleman (2000: 232), there is a consensus that the autism spectrum is mainly composed of underlying genetic diseases. This consensus

is not proven and cannot be proven until each person diagnosed with autism has a specific diagnosis. They have said that twin studies have shown that there is a hereditary factor to autism and that the genetic element has been found to be unusually strong. Badawi et al. state that the best supported hypothesis in the cause of autism is a genetic predisposition. However, they state that there are multiple interacting genes that contribute to autism. This may indicate that there is a shared gene and/or an environmental insult that occurred during pregnancy that led to the congenital anomaly and autism. They also suggest that congenital anomalies are on the causal pathway to autism spectrum disorders.

4.6.7 Pregnancy Cause

Two new studies add to a growing body of evidence pointing to pregnancy as a critical period in the brain changes that lead to autism. But studies have found that children are at higher risk for autism if they are born early or very small; if they are in medical distress during delivery; if they have older mothers or fathers; or if they are born less than a year after an older sibling. Autism risk also goes up if a mother has diabetes or high blood pressure; is obese; is infected with rubella, or German measles; is exposed to significant air pollution during pregnancy; had low levels of folic acid; takes medications such as an anti-seizure drug called valproic acid; or makes antibodies toxic to the fetal brain. Science has ruled out vaccines as a cause of autism, says Gregory, who notes that the original myth about autism and immunizations arose from bogus research that has since been retracted.

4.6.8 Autism caused by poor nutrition

It seems unlikely that malnutrition can cause autism. But megavitamin therapies have been used for many years to treat autistic symptoms. Certain supplements, particularly omega fish oils, do seem to be helpful for treating some aspects of autism.

4.7 How is autism diagnosed?

ASD can sometimes be diagnosed by age 14 months, although diagnosis becomes increasingly stable over the first three years of life: for example, a one-year-old who meets diagnostic criteria for ASD is less likely than a three-year-old to continue to do so a few years later. Autism is a complex disorder. A comprehensive evaluation requires a multidisciplinary team including a

psychologist, neurologist, psychiatrist, speech therapist, and other professionals who diagnose children with ASDs. It is particularly hard to diagnose autism among the visually impaired, partly because some of its diagnostic criteria depend on vision, and partly because autistic symptoms overlap with those of common blindness syndromes or blindness. A differential diagnosis for ASD at this stage might also consider mental retardation, hearing impairment, and a specific language impairment. The presence of autism can make it harder to diagnose coexisting psychiatric disorders such as depression. Doctors rely on a core group of behaviors to alert them to the possibility of a diagnosis of autism. These behaviors are:

- no babbling or pointing by age 1
- no single words by 16 months or two-word phrases by age 2
- no response to name
- Delayed and deviant language development
- excessive lining up of toys or objects
- poor eye contact
- normal physical appearance

Children with some symptoms of an ASD but not enough to be diagnosed with classical autism are often diagnosed with PDD-NOS. Children with autistic behaviors but well-developed language skills are often diagnosed with Asperger syndrome. Much rarer are children who may be diagnosed with childhood disintegrative disorder, in which they develop normally and then suddenly deteriorate between the ages of 3 to 10 years and show marked autistic behaviors.

4.8 Common Signs and Symptoms of Autism Children

The hallmark feature of autism is impaired social interaction. Parents are usually the first to notice symptoms of autism in their child. As early as infancy, a baby with autism may be unresponsive to people or focus intently on one item to the exclusion of others for long periods of time. A child with autism may appear to develop normally and then withdraw and become indifferent to social engagement. Children with autism may fail to respond to their name and often avoid eye contact with other people. They have difficulty interpreting what others are thinking or feeling because they can't understand social cues, such as tone of voice or facial expressions, and don't watch other people's faces for clues about appropriate behavior. They lack empathy. Many children with autism engage in repetitive movements such as rocking and

twirling, or in self-abusive behavior such as biting or head-banging. They also tend to start speaking later than other children and may refer to themselves by name instead of "I" or "me." Children with autism don't know how to play interactively with other children. People with AD may display a number of behavioral symptoms, including hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors, and temper tantrums.

Parents and relatives should be concerned about their infant or toddler if they notice any of the following developmental delays or behavioral problems and discuss concerns with their child's pediatrician to obtain appropriate referrals for evaluation:

- ❖ Lack of or delay in development of spoken language
- ❖ Repetitive use of language or motor mannerisms
- ❖ Impairments of social interaction
- ❖ Impaired social development
- ❖ Fascination for objects Repetitive stereotyped behaviours
- ❖ Inflexible adherence to specific routines or rituals.
- ❖ Lack of interest in peer relationships
- ❖ Repeating words or phrases in place of normal, responsive language
- ❖ Laughing for no apparent reason; showing distress for reasons not apparent to others
- ❖ Little or no eye contact even when spoken to directly
- ❖ Prefers to be alone; aloof manner evident to strangers and family members
- ❖ Impaired ability to initiate or sustain a conversation with others
- ❖ No real fears of danger despite obvious risks of harm.

4.9 Epidemiology

The recorded incidence of autism in the population depends crucially upon how it is diagnosed and defined. The incidence in most studies appears to be around 4-10 autistic children in every 10,000 live births. However, Wing & Gould (1979) reported an incidence of 21 per 10,000 for "the triad of social, language and behavioural impairments" in the Camberwell study. Gillberg et al. (1986) found similarly high rates of the triad and mental handicap in Swedish teenagers. Other studies report an incidence of around 10 per 10,000 (Bryson et al. 1988, Tanoue et al. 1988, Ciadella & Mamelie 1989). These recent studies (from America, Japan and France, respectively) suggest that autism is found throughout the world, and is not more common in any one society than in others. While the reported incidence of autism has increased in

recent years, this is probably due to better information and a wider conception of autism. All the epidemiological studies show a significantly greater number of boys than girls with autism. Male to female ratios vary from 2:1 (Ciadella & Mamelie, 1989) to almost 3:1. The sex ratio seems to vary with ability: most girls with autism are at the lower end of the ability range, while at the more able end boys may out-number girls 5:1. Szatmari & Jones (1991) have suggested some possible reasons for the lower IQ of females with autism; for example, females may be more strongly affected by the autism gene or there may be genetic heterogeneity, with more "mild" forms of disorder being X linked and hence more common in boys. Both Kanner and Asperger remarked on the intelligence and high social standing of the families of children with autism, and this has given rise to the idea that autism is more prevalent among the higher socio-economic classes. There is little support for such an idea - of the many epidemiological and population-based studies of autism, only one to date has shown any evidence of a social class bias (Happé F., 1994).

4.10 Autism in Bangladesh

‘An issue that is hidden inside the closet’ is perhaps the best way one could describe the fate people suffering from autism in Bangladesh. With no means or hope of leading a decent life and with a public system that lacks the basic facilities; usually concentrated within the four walls of their rooms. It is shown that 1 in every 100 individuals in the world suffer from an autism spectrum disorder. Large number population of Bangladesh suffering from ASD is therefore not a surprise. There are many problems in the field that needs to be addressed in the upcoming years. Researchers in Bangladesh often term Autism more of a human rights problem rather than a medical problem. The reason behind that is the social conundrum that many have to face due to the neurological disorder. Children can’t go to school, families prefer locking the member suffering from ASD within the corners of the house and at one point of time there were rarely any quotas in the public sector for them. Since the independence of Bangladesh in 1971, the constitution mandates the equality, non discrimination and creation of equitable measures for all those who are underprivileged under the auspices of the Ministry of Social Welfare. Therefore all programs and services for autism and other disabilities are currently under its jurisdiction. According to reports, the government has been taking initiatives to work on the issue through various development projects. One such report states that during the 2010-2011 fiscal year eighty nine lakh

forty five thousand takas (TK 89,45,000) was distributed through the development program called: Protibondhi Sheba O Sahajya Kendro (organization for the assistance and services of the disabled) created in 2009, 5 main districts across Bangladesh are providing physiotherapy, occupational therapy, counselling, assistive devices and other related services to nearly 15,000 individuals many of whom are diagnosed with autism. It is scheduled to be expanded to 10 more districts by the end of 2011. Reports further state the initiation of a 'One Stop Mobile Service' program introduced in order to reach families that live in villages that lack accessibility to medical services. In April of 2010, 2 hostels were opened in Dhaka in order to help families' access medical services in Dhaka. At least special needs schools are run through NGOs. In June of 2010 The Centre for Neurodevelopment and Autism in Children (CNAC) was started, the first government initiative that is linked to a medical university. These developments have lead to certain progress that is required for the need of progress of individuals suffering from autism in the country. However, these need to be deep-rooted into society and there needs to be a huge change in the thought-processes of a number of individuals in the country.

The South Asian Autism Network is the outgrowth of an international conference on autism held in Bangladesh in July 2011. Attendees from countries including India, Bangladesh, Sri Lanka, and the Republic of Maldives adopted the 'Dhaka Declaration', which urged international organizations such as the UN and WHO to encourage and support the efforts of governments around the world in helping those affected by ASD and other developmental disabilities. Its seven-point agenda included an emphasis on improving the capacities of healthcare professionals and increasing awareness so that those affected would receive the services and support they need within their home countries. While the Dhaka Declaration was crucial in bringing to light the ever-increasing need for such services, which in many countries did not exist at all, its call to arms has not yielded observable results. Raising awareness is critically important, but as we've learned through our partnerships around the world, the work needs to extend beyond discourse and into the realm of on-the-ground action. The United Nations General Assembly unanimously declared April 2 as World Autism Awareness Day to highlight the need to help improve the lives of children and adults who suffer from the disorder so they can lead full and meaningful lives. Autism can bring significant economic hardships to families, given the lack of health resources

often found in developing countries. The stigmatization and discrimination associated with these illnesses also remain substantial obstacles to diagnosis and treatment. The absence of autism spectrum disorders and other mental disorders among children from lists of the leading causes of death has contributed to their long-term neglect by both public policy-makers in developing countries, as well as donors.

5.1 Data Presentation and Analysis

It is mentioned prior that the present study follows an explanatory mixed method research design. Here the researcher pursues a sequential strategy in collecting and analyzing the data. Quantitative data is collected first in the sequence followed by the qualitative data. Qualitative data has been used to explain and understand the result of the quantitative data. Hence in the first phase quantitative data is analyzed using the descriptive and inferential statistics technique of data analysis and presented through tables and graphs. In the next phase for analyzing the qualitative data content analysis technique is used. An effort is made to identify the patterns, themes and trends emerging from the data. All the qualitative data are presented in a narrative form under separate themes follows the research question of the study.

5.2 Presentation of Quantitative Data

Research is based on data. The research which is more enriched in data that is more scientific and acceptable. Data were collected from 60 respondents. Among them 45 respondents are parents of autistic children and 15 other respondents are teachers of different autistic institution. Respondents were selected by following purposive and snowball sampling procedure and using a standard pre-tested questionnaire composed of close ended questions. Draft instruments were pre-tested and finalized. After finalization of the instruments in consultation with the guide, with the help of data collection instruments bulk of information on personal, family challenges, social, treatment and rehabilitation were collected. The data, which I found from the study of ‘Problems of Autistic children and their families’. I tried to study the problems of difficulties in the family having autistic children and I focus on the teachers who are training those autistic children although their numbers are few considering the number of these types of children.

5.2.1 Data collection from parents of autistic children.

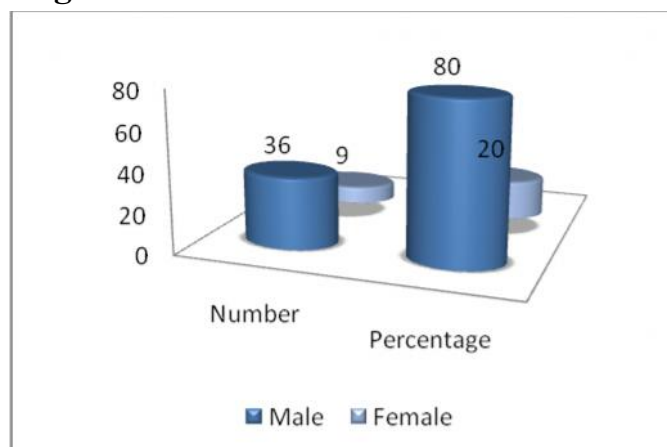
I have taken 45 parents of autistic children as respondents of this research. I have collected different types of data from them relating to this research. Now I am presenting below the data collecting from parents of autistic children in different institution, foundation and school of some urban areas especially in Dhaka city.

Table-5: Percentage of Sex distribution of autistic children.

Sex	Number	Percentage
Male	36	80
Female	9	20
Total	45	100

[Source: Field Level Survey- 2013]

In this study I collected information from the parents of autistic children. In this study maximum number of autistic children (80%) is male, while minimum number (20%) is female. So the percentage of male autistic children is 60% more than female autistic children.

Figure-1: Percentage of Sex distribution of autistic children.**Table-6: Percentage distribution of first diagnosis age on the Autism spectrum.**

Age	Number	Percentage
0-2	15	33.33
3-5	24	53.33
6-8	3	6.67
9-11	1	2.22
12-14	1	2.22
15+	1	2.22
Total	45	100

[Source: Field Level Survey- 2013]

This data gathered on the above table indicates that 33.33% of autistic spectrum diagnosis at aged 0-2 years, 53.33% of autistic spectrum diagnosis at aged 3-5 years, 6.67% at aged 6-8, 2.22% at aged 9-11 years, 2.22% at aged 12-14 years, 2.22% at aged 15⁺ years. It indicates that in our country the parents feel that their child seems to be a autistic at the aged 3-5 years.

Figure-2: Percentage distribution of first diagnosis age on the autism spectrum.

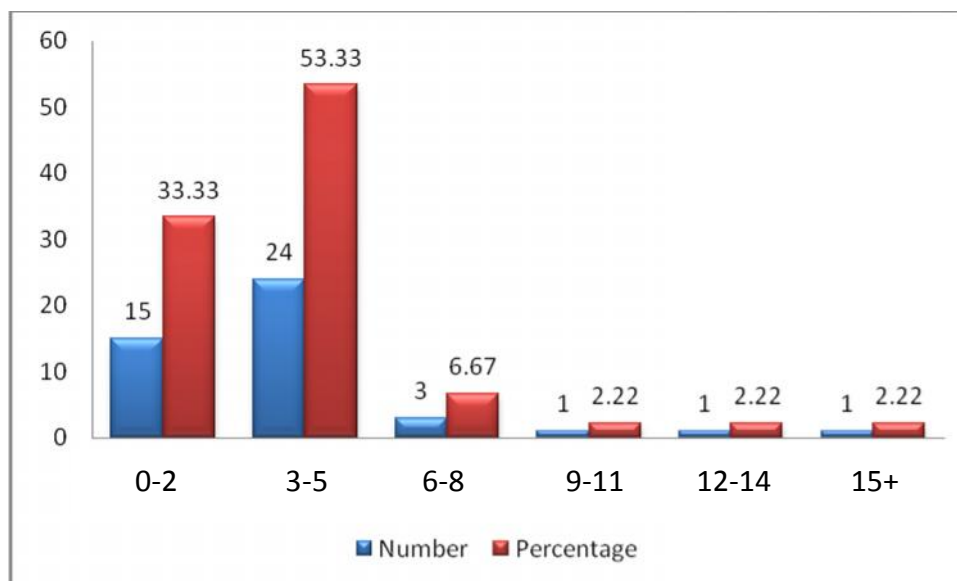


Table-7: Percentage distribution of the possible causes of Autistic Spectrum Disorder of autistic children.

Cause	Number	Percentage
Unknown	22	48.89
Environmental	5	11.11
Neurological	2	4.44
Genetical	9	20.00
Malnutrition	5	11.11
Pregnancy	2	4.44
Total	45	100

[Source: Field Level Survey- 2013]

In this study, the possible cause of autistic spectrum disorder 48.89% is unknown to the parents of autistic children, 11.11% is environmental that can cause abnormalities in a developing organism, 4.44% is neurological, 20.00% parents view is genetical, 11.11% is poor nutrition and 4.44% is pregnancy

cause of autistic spectrum disorder. Most of the families have a little consciousness about the exact cause of the autism of their children. In case of educated family at least they try to mention the cause of autism of their children.

Figure-3: Percentage distribution of the possible causes of Autistic Spectrum Disorder of autistic children.

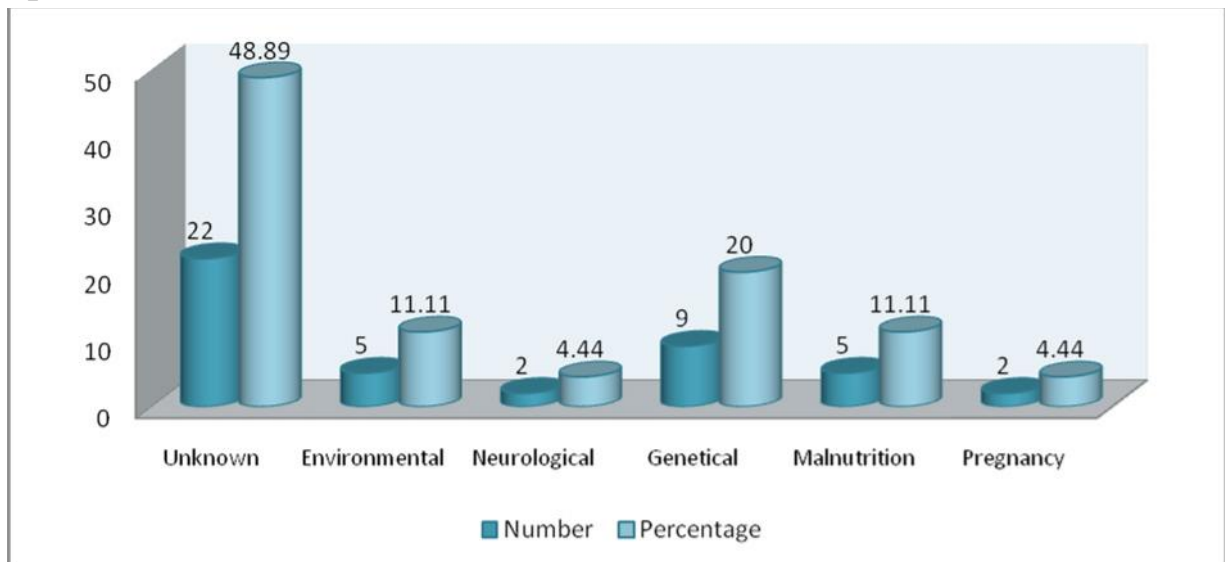
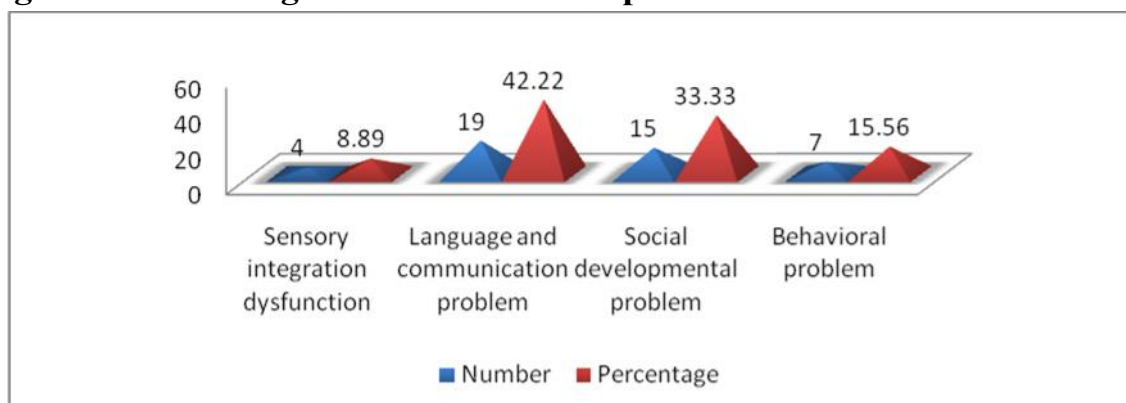


Table-8: Percentage distribution of the problems of autistic children.

Problems	Number	Percentage
Sensory integration dysfunction	4	8.89
Language and communication problem	19	42.22
Social developmental problem	15	33.33
Behavioral problem	7	15.56
Total	45	100

[Source: Field Level Survey- 2013]

Here I asked to the parents of autistic children or their family member's to know the particular problem of their autistic children that overlook in the life of autistic children. This data set shows me 8.89% autistic children face sensory integration problem, 42.22% face language and communication problem, 33.33% face social developmental problem, 15.56% behavioral problem. It indicates that most of the autistic children face language and communication problem in my study.

Figure-4: Percentage distribution of the problems of autistic children**Table-9: Percentage distribution of respondents about types of language and communication problem of autistic children.**

Language & Communication Problem	Number	Percentage
Stereotyped and repetitive use of language	13	28.89
Delay or lock of spoken language	14	31.11
Inability to sustain a conversation	10	22.22
Facial expression	4	8.89
Pronoun reversal	4	8.89
Total	45	100

From my study it is seen that 28.89% autistic children use stereotyped and repetitive language, 31.11% have delay or lock of spoken language, 22.22% autistic children is not able to sustain a conversation with others, 8.89% fail to facial expression, 8.89% use pronoun reversal. In this study, it is clear that every autistic child face language and communication problem, it will be in different kind of communication.

Figure-5: Percentage distribution of respondents about types of language and communication problem of autistic children.

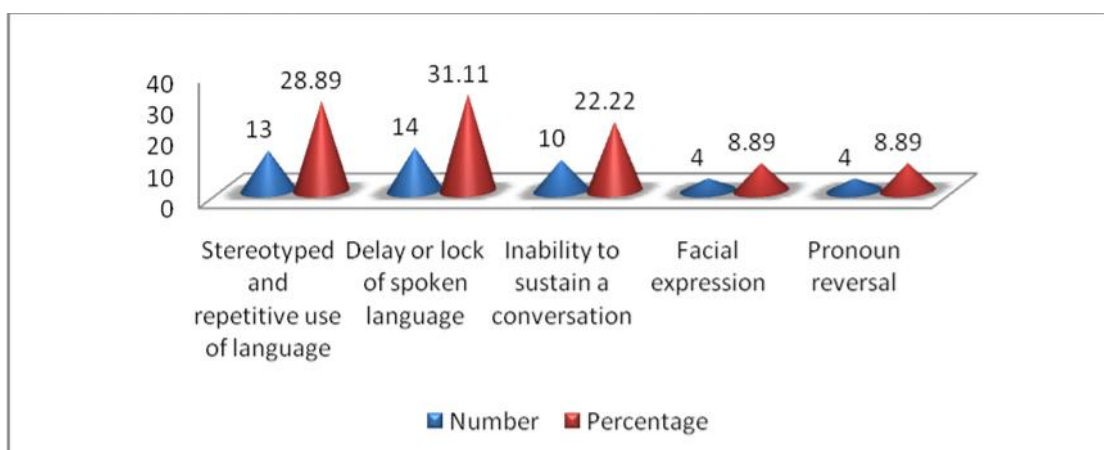


Table-10: Percentage distribution of behavioral problems of autistic children.

Behavioral problem of autistic children	Number	Percentage
Self-injuries behavior	5	11.11
Unusual obsessions	7	15.56
Stereotyped and repetitive motor mannerisms	25	55.56
Destructive behavior	5	11.11
Compulsive behavior	2	4.44
Other	1	2.22
Total	45	100

[Source: Field Level Survey- 2013]

In this table it is seen that 11.11% of respondent in our country feel that their child co-exist with behavioral problem in their daily life, 15.56% is unusual obsessions, 55.56% show their stereotyped and repetitive motor mannerisms behavior, 11.11% have destructive behavior, 4.44% compulsive behavior & others is 2.22%. Most of the autistic children face behavioral problem in their life.

Figure-6: Percentage distribution of behavioral problems of autistic children.

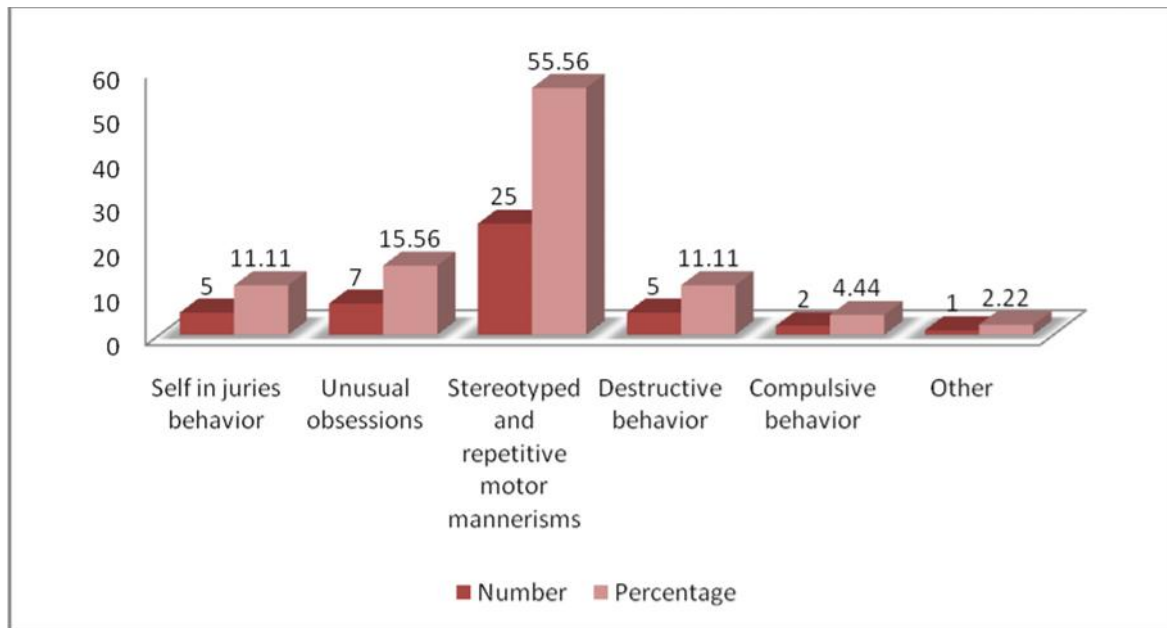


Table-11: Percentage distribution of social developmental problem of autistic children.

Social developmental problem	Number	Percentage
Social cues	10	22.22
sharing	8	17.78
Responsiveness	5	11.11
Failure to develop peer relationship	14	31.11
Lack of social or emotional reciprocity	8	17.78
Total	45	100

[Source: Field Level Survey- 2013]

In my study 22.22% of parents deliver the information about social cues problem of their autistic children, 17.78% autistic children cannot share with other, 11.11% cannot response when anyone call him/her, 31.11% fail to develop peer relationship, 17.78% have lack of social or emotional reciprocity. Here I seen that most of the autistic child have peer relation problem because they interested in loneliness.

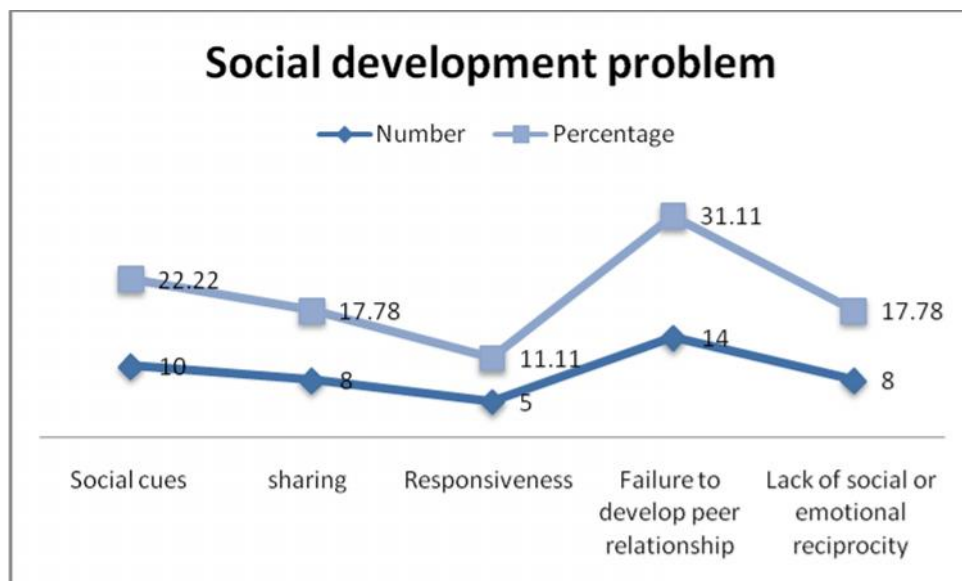
Figure-7: Percentage distribution of social developmental problem of autistic children.

Table-12: Percentage distribution about daily life problems of autistic children.

Daily life problem	Number	Percentage
Sleeping problem	13	28.89
Toileting problem	9	20
Playing problem	9	20
Eating problem	14	31.11
Total	45	100

[Source: Field Level Survey- 2013]

In the above figure seen that (28.89%) autistic children face sleeping problem in their daily life. (20%) children have toileting problem. (20%) children have playing problem. (31.11%) children have eating problem.

Figure-8: Percentage distribution about daily life problems of autistic children.**Table-13: Percentage distribution about sensory integration problem of autistic children.**

Sensory integration problem	Number	Percentage
Fail to share emotional experiences	8	17.78
Poor imagination	9	20.00
Doesn't seem to feel pain	7	15.56
Unusual sensory experience	6	13.33
Hearing problem	15	33.33
Total	45	100

[Source: Field Level Survey- 2013]

Sensory integration problem is basic problem of autistic child, (17.78%) autistic children fail to share emotion. On experience with other, (20.00%) autistic children have poor imagination (15.56%) children doesn't seem to feel pain, (13.33%) children have unusual sensory experiences, (33.33%) autistic children face hearing problem. They can't easily understand other speaking.

Table-14: Percentage distribution about the parents of autistic children who faced different problem.

Problem face	Number	Percentage
Yes	45	100
No	0	0.00
Total	45	100

[Source: Field Level Survey- 2013]

In the above table, (100%) parents face the different kind of problem. There have no parents who do not face problem because every autistic child has different problem as like behavioral problem, sleeping problem, community problem, eating, socialization, etc. For this reason parents face different problem. But it is rare that parents of autistic children do not face any problem.

Figure-9: Percentage distribution about the parents of autistic children who faced different problem.

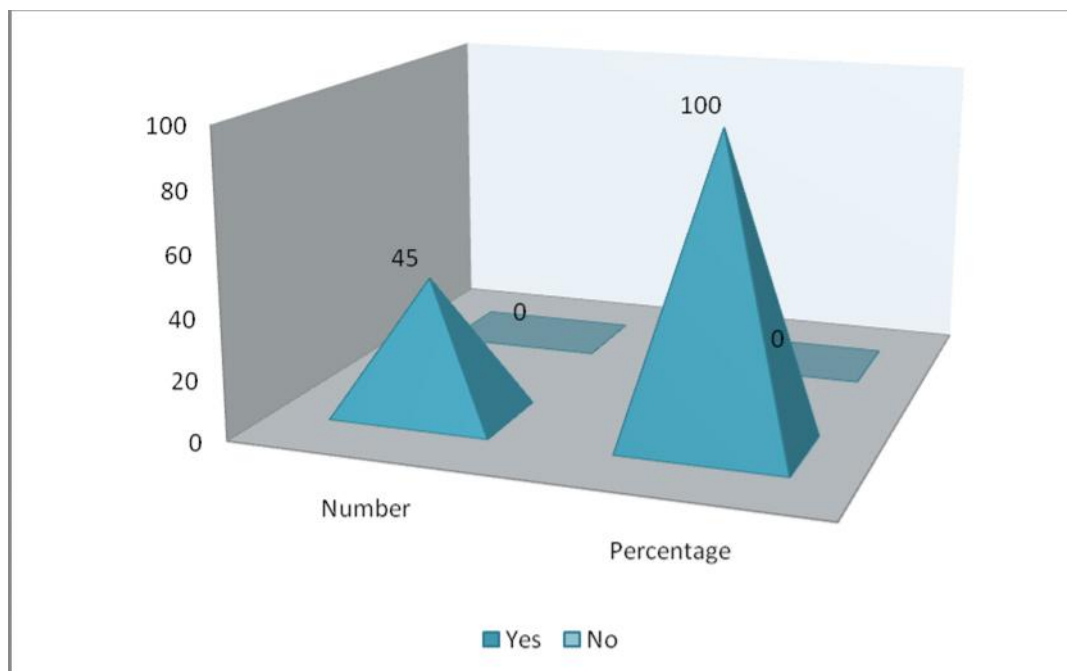


Table-15: Percentage distribution of parental problems of autistic children.

Parental Problem	Number	Percentage
Financial	4	8.89
Stress	20	44.44
Social Stigma	13	28.89
Divorce Problem	3	6.67
Sleeping Problem	5	11.11
Total	45	100

[Source: Field Level Survey- 2013]

From the above table it is seen that (8.89%) parents of autistic children face financial problem, (44.44%) parents suffer stress problem, (28.89%) parents discriminated for social sigma from different facilities of society, (6.67%) husband divorce their wife for autistic child and 11.11% face sleeping problem. I seen that most of the parents of autistic children cannot free from tension because all time they should look at their autistic child and they feel tension about future life of autistic child.

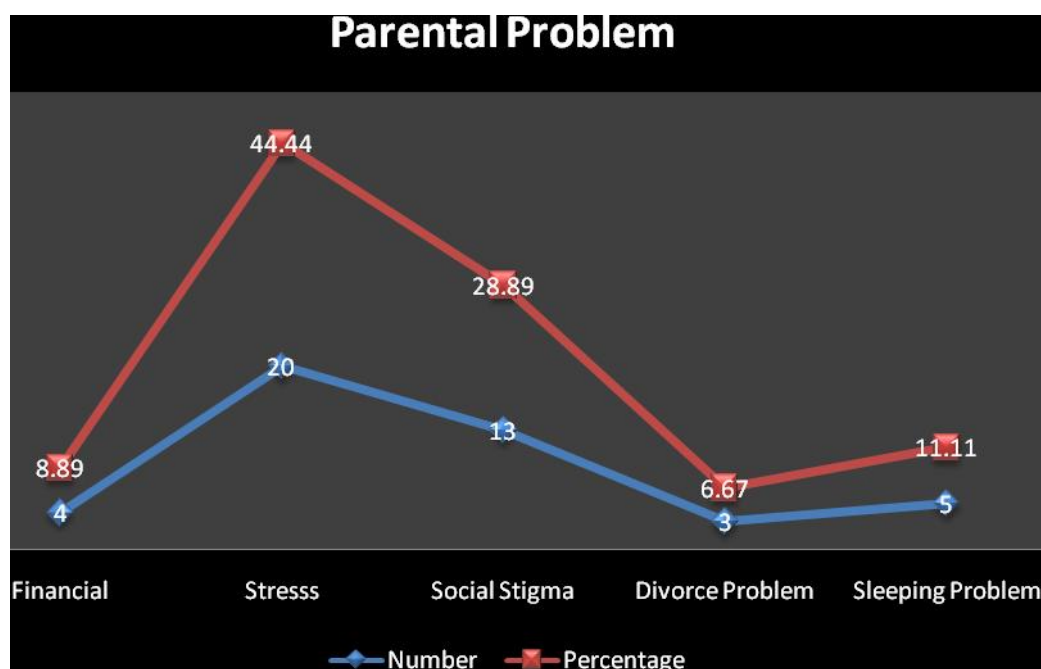
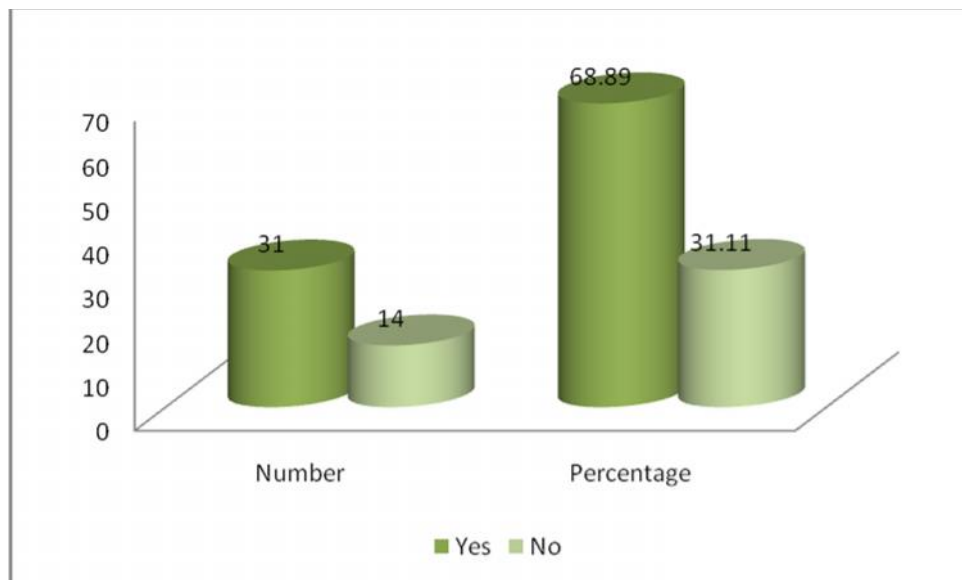
Figure-10: Percentage distribution of parental problems of autistic children.

Table-16: Distribution about imitation of autistic children.

Imitation	Number	Percentage
Yes	31	68.89
No	14	31.11
Total	45	100

[Source: Field Level Survey- 2013]

In the above table, (68.89%) autistic child imitate other talking or expression, they can not easily express their language and communication with other, repetition and imitation is the basic problem of autistic child. (31.11%) Autistic child do not imitate other. They have high functioning power, for this reason they do not express their imitation by talking, behavior etc.

Figure-11: Distribution about imitation of autistic children.**Table-17: Percentage distribution of interaction with other children.**

Interact	Number	Percentage
Yes	5	11.11
No	40	88.89
Total	45	100

[Source: Field Level Survey- 2013]

Autistic children cannot interact with other children. In my study, it is clear that (88.89%) autistic children cannot interact with other child. Most of the time they express interesting alone from build correlation with other, loneliness is one kind of problem of autistic children. (11.11%) autistic

children able to interact and communicate with other children. Hyperactivity exist in some autistic children, who have hyperactivity, they able to interact with other.

Figure-12: Percentage distribution of interaction with other children.

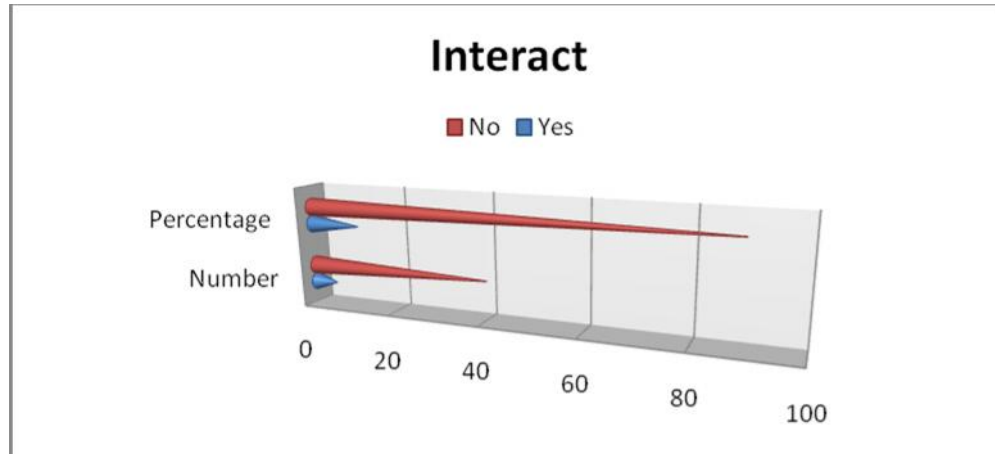


Table-18: Percentage distribution of normal Eye-contact of autistic children.

Eye-contact	Number	Percentage
Yes	35	77.78
No	10	22.20
Total	45	100

[Source: Field Level Survey- 2013]

Autistic children have a major problem that is eye-contact, In my study (77.78%) autistic children are not able to contact by their eye. When one person call his/her than they can not response and when someone talk with his/her that time autistic child can not eye-contact. (22.22%) autistic children can eye-contact for their hyperactivity. Only those children can normal eye-contact who have higher hyperactivity, they are exceptional and their memory is sharp and high functioning.

Figure-13: Percentage distribution of normal Eye-contact of autistic children.

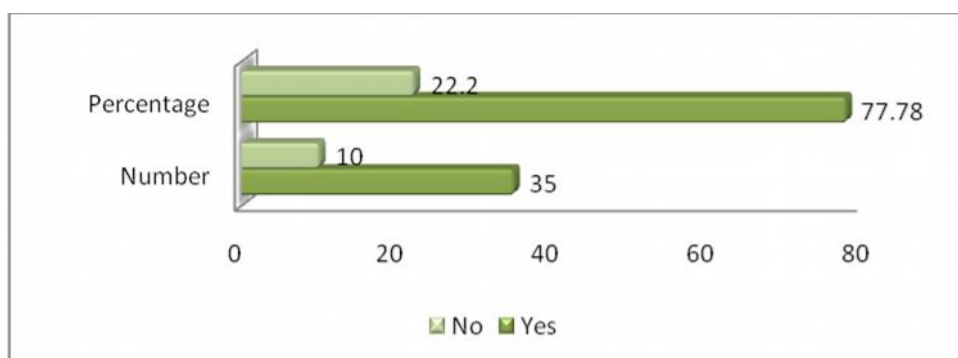


Table-19: Distribution about nature of treatment of autistic children.

Nature of treatment	Number	Percentage
Therapy	9	20.00
Autistic institution	30	66.67
Autistic hospital	2	4.44
Child specialists	2	4.44
In abroad for higher treatment	1	2.22
Other	1	2.22
Total	45	100

[Source: Field Level Survey- 2013]

The table about the nature of treatment of autistic children show that (20.00%) autistic children depend on therapy for their improvement, (66.67%) go autistic institution for improvement their problem, because there give treatment and training for improvement. (4.44%) go autistic hospital with autistic institution. Beside (4.44%) children need to go children specialists. In some cases (2.22%) children go abroad for higher treatment (2.22%) children give different treatment for the improvement their problems.

Table-20: Distribution about the improvement after treatment or admitting to the institution.

Improvement	Number	Percentage
Detoriate	3	6.67
An Usual	5	11.11
Few changes	32	71.11
Remarkable	5	11.11
Total	45	100

[Source: Field Level Survey- 2013]

For the above table, it is clear that (71.11%) children improve (few changes) after treatment or admitting to the institution, by the training and therapy they improve. (11.11%) autistic children remarkable improve after treatment (11.11%) children can not improve, they result after treatment is as usual. (6.66%) children is detoriate. So, it obviously say that autism problem cannot solve, but by the treatment it can few change.

Figure-14: Distribution about the improvement after treatment or admitting to the institution.

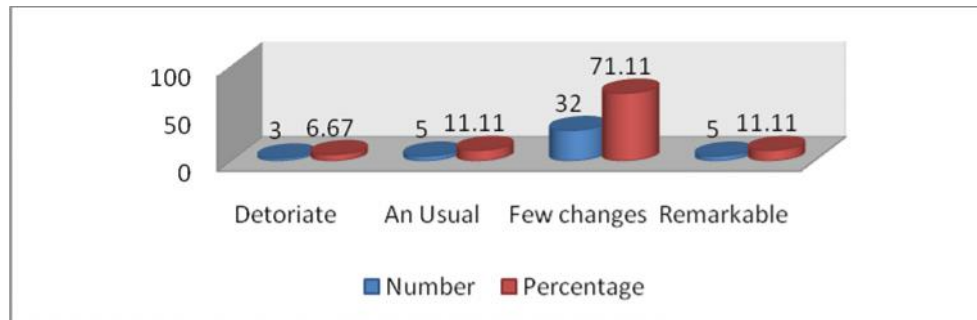


Table-21: Distribution about obstacle to achieve education faced by autistic children who going to school.

Obstacle	Number	Percentage
Obstacle to move	30	66.67
Helpless of classmate	6	13.33
Lack of care by teacher	1	2.22
NO obstacle	0	0.00
Other	8	17.78
Total	45	100

[Source: Field Level Survey- 2013]

In the above table, (66.67%) autistic children face obstacle to move, they cannot go to school without the help of others parents cannot rely on them to move alone only (13.33%) children cannot help from their classmate, most of the teacher is cordial to the child, it may be (2.22%) rude behaviors. Every autistic child obstacle to achieve education. (17.78%) autistic children face different obstacle to achieve education.

Figure-15: Distribution about obstacle to achieve education faced by autistic children who going to school.

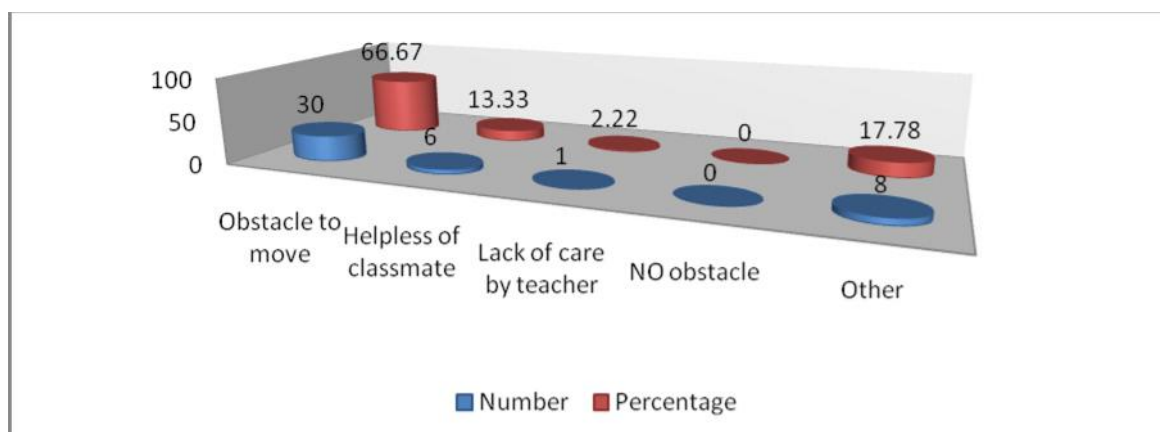


Table-22: Distribution about participating in various social & religious ceremonies of autistic children.

Participation in ceremonies	Number	Percentage
Yes	15	33.33
No	30	66.67
Total	45	100

[Source: Field Level Survey- 2013]

In my study (66.67%) parents of autistic children can not join in various social or religious ceremonies for their autistic child. Because most of the autistic child can not cope with need environment, they can not take any food, they should gradually etc. (33.33%) parents easily join in different ceremonies because the coping ability of their child is medium, but all time parents table anxiety for showing unusual behavior in any time. Those parents look to their child all time in the ceremonies.

Figure-16: Distribution about participating in various social & religious ceremonies of autistic children.

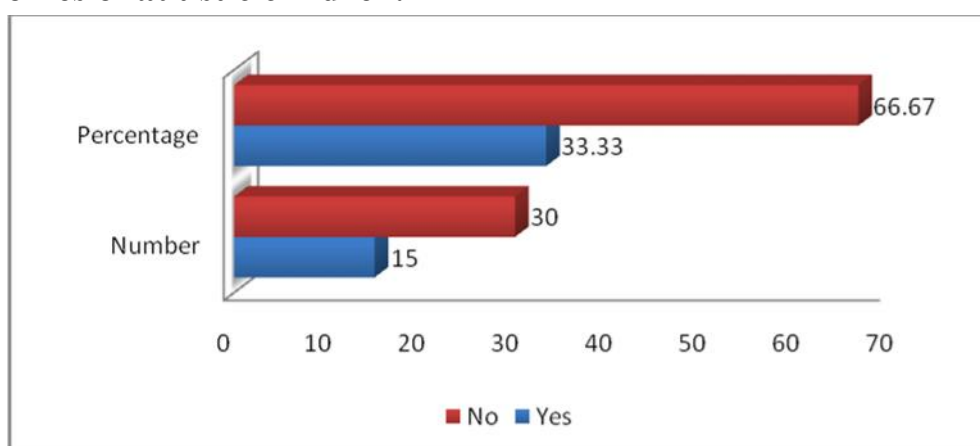
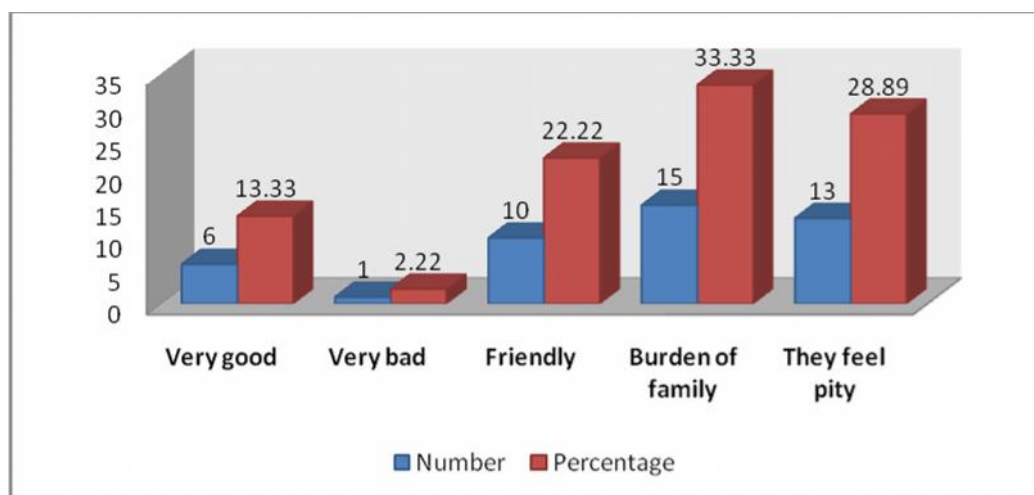


Table-23: Distribution about the attitude of other household members towards autistic children.

Attitude	Number	Percentage
Very good	6	13.33
Very bad	1	2.22
Friendly	10	22.22
Burden of family	15	33.33
They feel pity	13	28.89
Total	45	100

[Source: Field Level Survey- 2013]

The attitude towards autistic child from the other household members is not so good. Because (13.33%) members feels very good with autistic child, (2.22%) feels very bad, (22.22%) members show friendly behavior with autistic child, (33.33%) household members feel burden or family and they can not do any action against autistic child, (28.89%) members feel pity with autistic child. So, we can say that the other household members expressed the negative attitude towards the autistic children that bough a serious harmful influence upon the mental condition of the autistic children.

Figure-17: Distribution about the attitude of other household members towards autistic children.**Table-24: Percentage distribution about the attitude of neighbors towards the autistic children.**

Attitude	Number	Percentage
Disgrace to the family in the eye of society	5	11.11
They find something interesting	10	22.22

Nothing to do with them	0	0.00
Very good	22	48.89
They feel pity towards them	6	13.33
Other	2	4.44
Total	45	100

[Source: Field Survey- 2013]

In response to the question, 11.11% regarding in attitude of neighbors feel disgrace their family in the eye of society, (22.22%) neighbors find something interesting to autistic family for autistic child and they fun with our members include autistic child. Respondents do not find way without interacting with them, (48.89%) neighbors show the good attitude with autistic children, neighbors take part in the rearing and take part in helping. (13.33%) Parents feel pity towards them by neighbors. Only (4.44%) neighbors express negative attitude towards autistic family members above criteria.

Figure-18: Percentage distribution about the attitude of neighbors towards the autistic children.

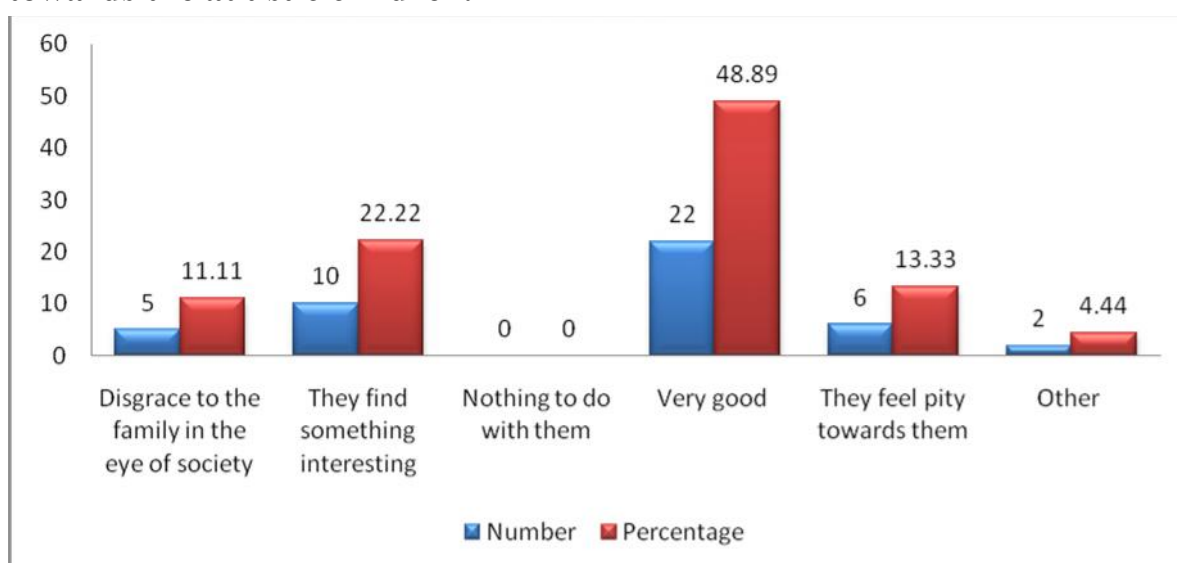


Table-25: Percentage distribution of the respondents of willingly introduce of autistic child with relatives.

willingly introduce with relatives	Number	Percentage
Yes	17	37.78
No	28	62.22
Total	45	100

[Source: Field Level Survey- 2013]

In my study (62.22%) respondents are not agree willingly introduce their autistic children with relatives when unknown person or promote relatives come their house. Because of shameness or prestigious, respondents are not agree to introduce willingly and they hide their child. In constant (37.78%) respondents introduce willingly their autistic child with relatives. They seem that this problem is from Allah, there have no hand from them. Respondents want to help for future life of those child from relatives.

Figure-19: Percentage distribution of the respondents of willingly introduce of autistic children with relatives.

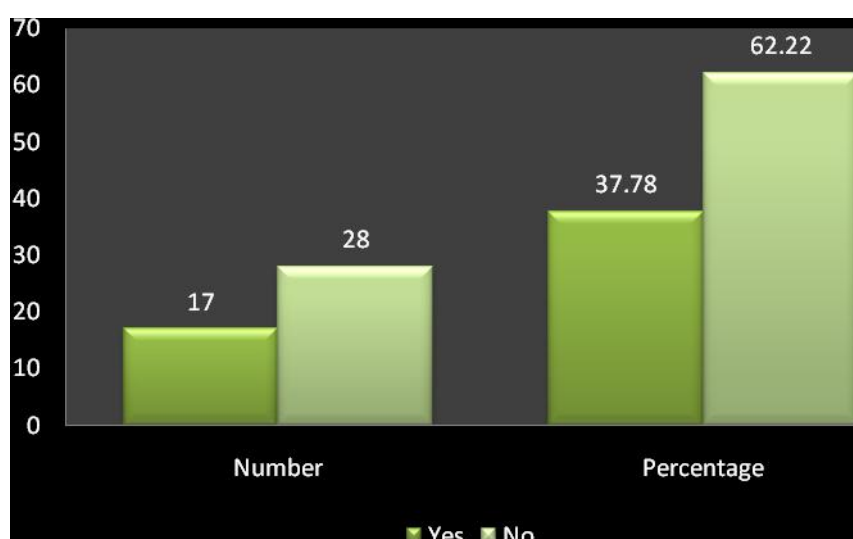


Table-26: Distribution of respondents of the rearing of autistic children is more expensive than normal one?

Rearing cost more expensive	Number	Percentage
Yes	15	33.33
No	30	66.67
Total	45	100

[Source: Field Level Survey- 2013]

From the above table it is seen that (66.67%) respondents seen that rearing cost of their child is not more expensive or burden because they are upper class family, the daily cost of their normal child is similar to their autistic child. But (33.33%) respondent seem that the rearing cost of their autistic child is more

expensive, they are middle class family members, they say that annual and monthly fee of those institution is high than other educational institution. They claim that Govt. institution is not sufficient for education or treatment of those children. There have few private institutions in Dhaka city and the cost of training or education system of those institutions is high so, the rearing cost of autistic child is more expensive to middle class family than the higher class family.

Figure-20: Distribution of respondents of the rearing of autistic child is more expensive than normal one?

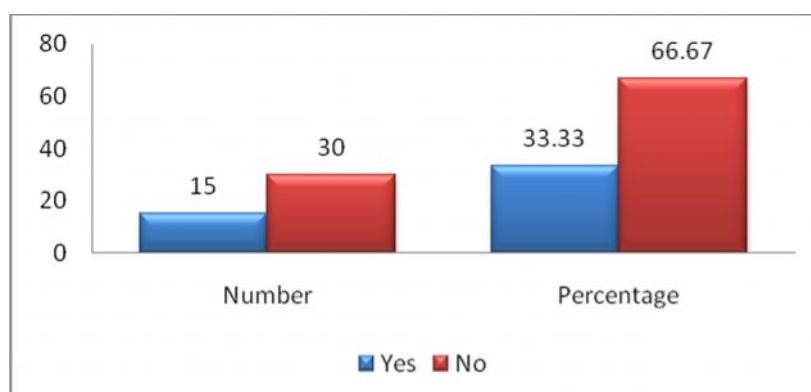


Table-27: Percentage distribution of respondents according their view regarding need to borrow money from other in monthly basis?

Need to borrow money	Number	Percentage
Yes	2	4.44
No	43	95.56
Total	45	100

[Source: Field Level Survey- 2013]

Above data show that (95.56%) respondents need not to borrow money from other or outside because most of the respondent basically rich according to their opinion. For this reason they don't need to borrow money from other in monthly basis. (4.44%) respondents say that they need to borrow money from other because they are poor, but the monthly cost of those institutions is highly expensive they are not able to pay monthly fee of those institution for this reason they borrow money from other.

Figure-21: Percentage distribution of respondents according their view regarding need to borrow money from other in monthly basis?

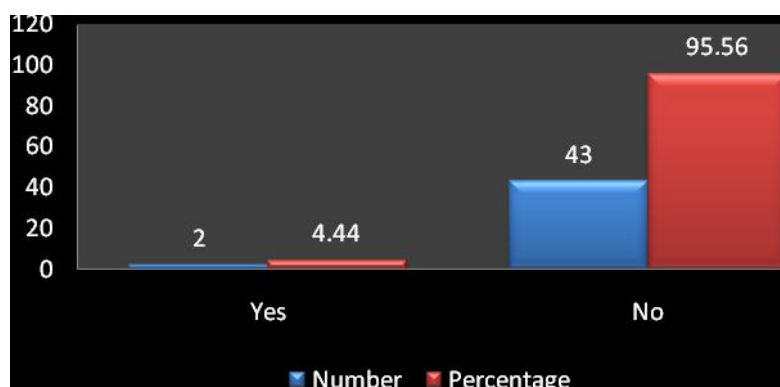


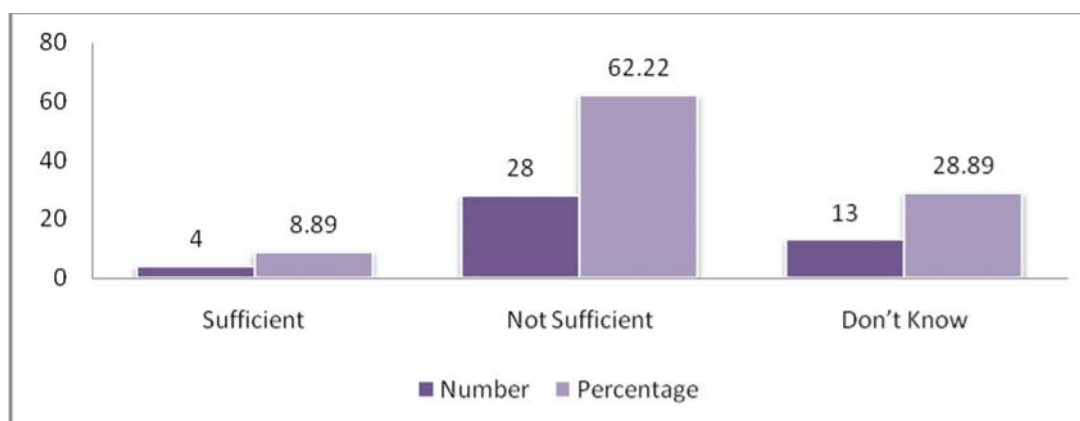
Table-28: Percentage distribution of opinion about the activities of the GOs and NGOs regarding autistic children.

Activities of GOs & NGOs	Number	Percentage
Sufficient	4	8.89
Not Sufficient	28	62.22
Don't Know	13	28.89
Total	45	100

[Source: Field Level Survey- 2013]

In response to the question regarding the activities of the GOs and NGOs about autistic children those (8.89%) respondents feel that the role of GOs and NGOs in regarding to activities is not sufficient. Most of respondent (66.22%) talk about the activities of GOs and NGOs is not sufficient. They comment that GOs should take more activities that is needed for every autistic child. It is clear that (28.89%) respondent don't known about the activities of GOs and NGOs about that treatment, training or improvement of autistic children.

Figure-22: Percentage distribution of opinion about the activities of the GOs and NGOs regarding autistic children.



5.2.2 Data collection from teachers of autistic children.

I have taken 15 teachers of autistic children who teach them as respondents of this research. I have collected different types of data from them relating to this research. Now I am presenting below the data collecting from teachers of autistic children in different institution, foundation and school of some urban areas especially in Dhaka city.

Table-29: Percentage distribution of current diagnosis on the autism spectrum.

Current diagnosis types	Number	Percentage
Autistic disorder	3	20
Asperser's syndrome	3	20
Rett's syndrome	1	6.67
pervasive developmental disorder	4	26.67
Childhood disintegrative disorder	4	26.67
Total	15	100

[Source: Field Level Survey- 2013]

From the above table it is seen that current diagnosis types of autism spectrum terms are new and hard, when I asked respondent about types of autism, at first they did not the answer but after describing detail about the identity of their diagnosis types then given me the answer frequently. This data set shows me 20% autistic children diagnosed by autistic disorder type, 20% diagnosed by asperser's syndrome, 6.67% include with Rett's syndrome, 26.67% face pervasive developmental disorder, 26.67% face childhood disintegrative disorder. Above diagnosis types is something related with problems of autistic children.

Figure-23: Percentage distribution of current diagnosis on the autism spectrum.

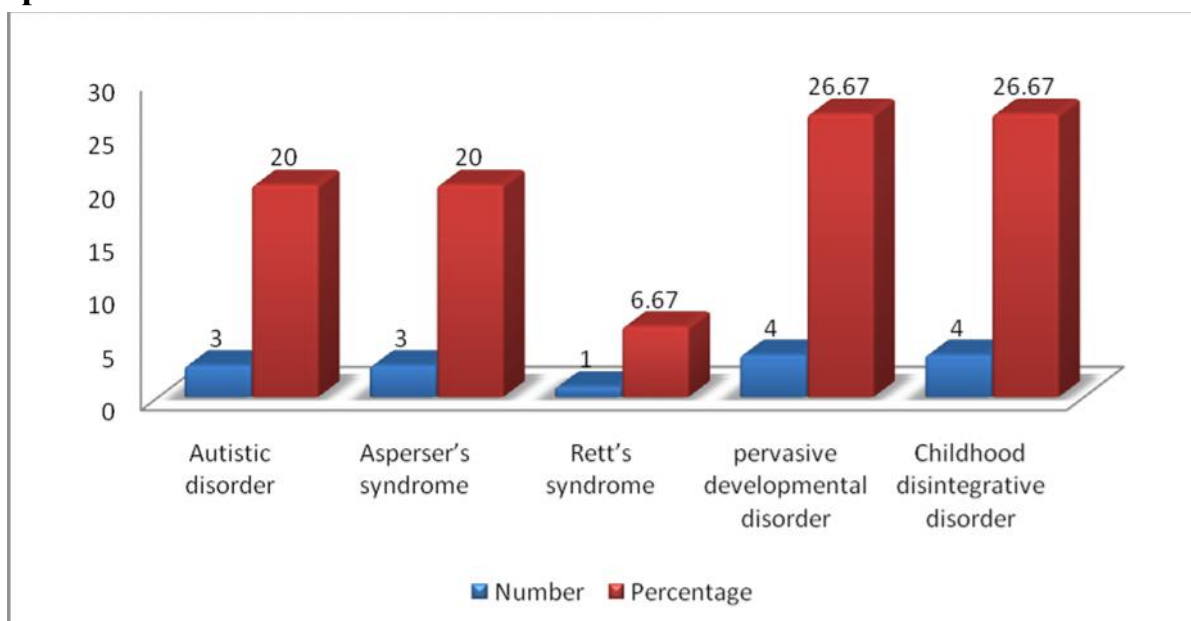


Table-30: Distribution of the monthly expenditure for the autistic child.

Cost	Number	Percentage
2500-3000	2	13.33
3000-3500	7	46.67
3500-4000	6	40.00
Total	15	100

[Source: Field Level Survey- 2013]

Generally in Bangladesh the children go to school normal schools, there expenditure is not high, but the cost of autistic child in the especial institution is high. In my study (13.33%) teachers say that the monthly expenditure for autistic child from 2500-3000, (46.67%) teachers view that this cost is from 3000-3500 and (40.00%) say that the monthly costing in 3500-4000. Here it is clear that monthly costing is not same for different institution.

Figure-24: Distribution of the monthly expenditure for the autistic child

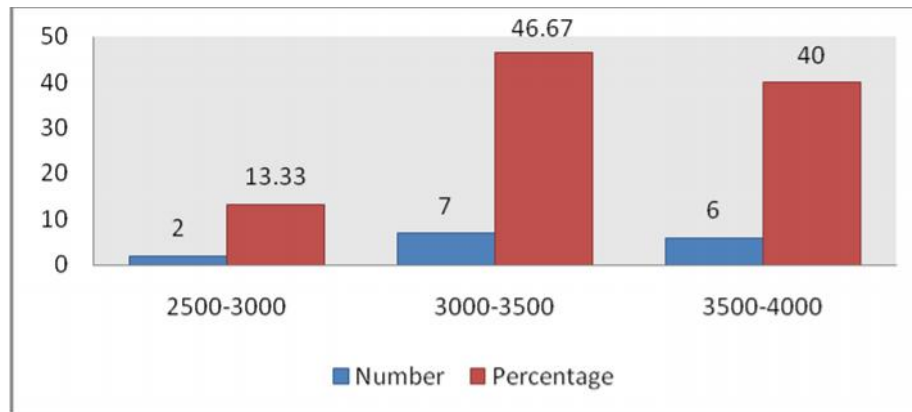


Table-31: Distribution about bearing cost for middle class family.

Possible cost	Number	Percentage
Yes	3	20.00
No	12	80.00
Total	15	100.00

[Source: Field Level Survey- 2013]

In the above table, it is clear that (80.00%) teachers say that the bearing cost for a middle class family is not possible in our institution. Because the monthly cost in our institution is high. For this reason middle class family member can not admit their children in those institutions. (20.00%) teachers say that the cost of their institutions is not high, middle class family can do admit their children in this institution. Teachers say that for the middle on low class family members, government and institutions provide help or free costing teaching system.

Figure-25: Distribution about bearing cost for middle class family.

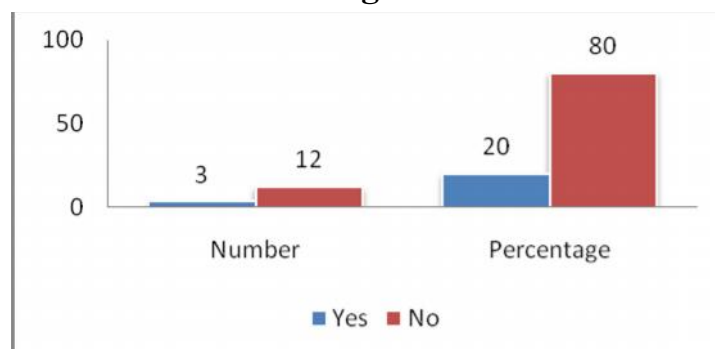


Table-32: Percentage about autistic child's problems and weakness.

Child's problems & weakness	Number	Percentage
Lack of understanding	5	33.33
Speaking problem	5	33.33
Communication problems	3	20.00
Problems of achieving education	2	13.33

Total	15	100.00
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[Source: Field Level Survey- 2013]

(33.33%) teachers say that autistic children have lack of understating (33.33%) is teacher say about speaking problem of autistic children (20.00%) teachers say that autistic children cannot communicate with other but they can do anything (13.33%) respondents say that education achieving problem for autistic children is high. They, try to give training in their institution and try to teach different technique or education to autistic children.

Figure-26: Percentage about autistic child's problems and weakness.

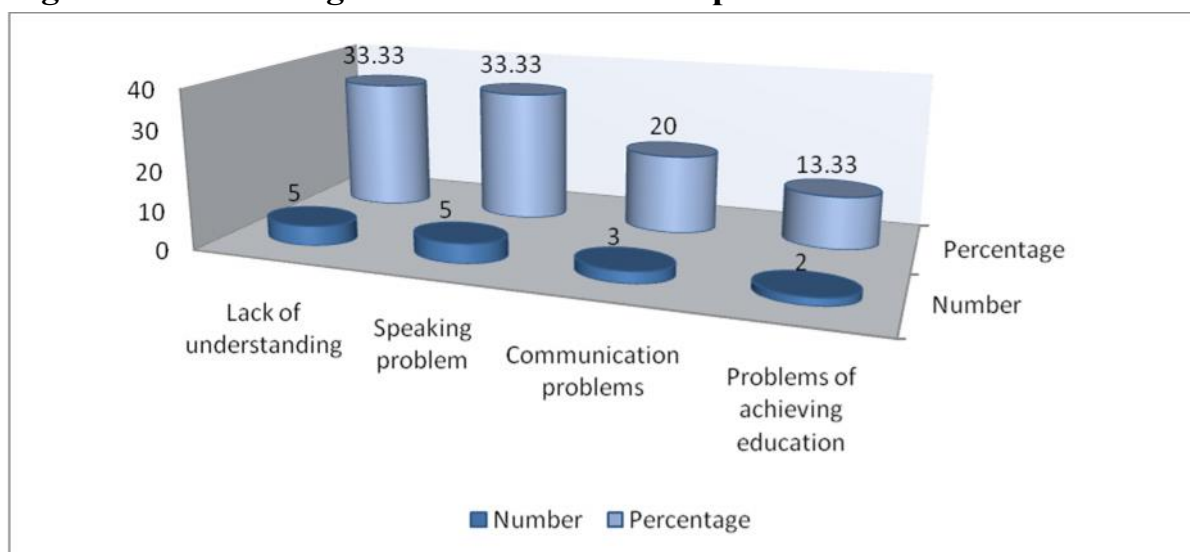


Table-33: Percentage distribution about challenges autistic children.

Challenges	Number	Percentage
Face unusual behavior	8	53.33
Cannot cope with children	3	20.00
Disturbance	2	13.33
Sadness	2	13.33
Total	15	100.00

[Source: Field Survey- 2013]

(53.33%) teachers face unusual behavior of autistic children in their institutions. Autistic children express abnormal behavior with other. (20.00%) teacher can not cope with autistic children. (13.33%) teachers feel disturbance during teaching period. (13.33%) teachers feel sadness for the problems of autistic children. At the period of giving teach to autistic children, teachers face different challenges.

Figure-27: Percentage distribution about challenges autistic children.

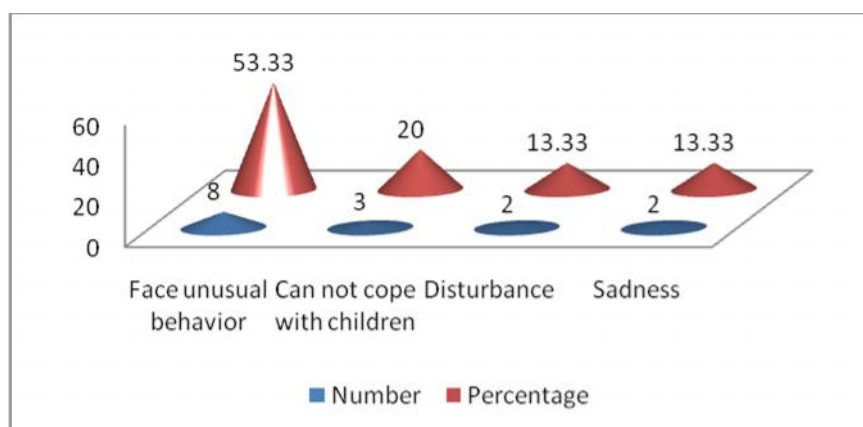


Table-34: Percentage about the improvement of the problems of autistic children in educational institutions.

Problems Improvement	Number	Percentage
Yes	12	80.00
No	3	20.00
Total	15	100.00

[Source: Field Level Survey- 2013]

In my study, it is shown that (80.00%) teachers say about the effective role of educational institutions. They say that autism can not remove but it can change the severity by training or therapy. 20% educational institutions is not effective for solving problems of autistic children. They say that parents should take care their child in their home and they go to child specialist and give different treatment in different places. For this reason parents face problem to treat their children.

Figure-28: Percentage about the improvement of the problems of autistic children in educational institutions.

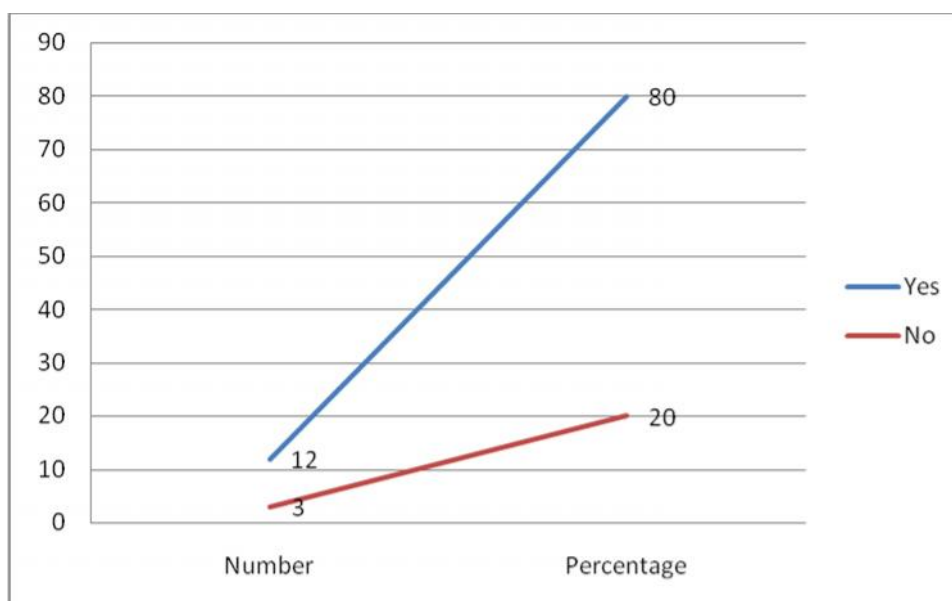


Table-35: Percentage distribution about the limitations autistic institutions.

Limitations	Number	Percentage
No enough space	6	40.00
No sufficient teacher	2	13.33
No fund	4	26.67
No help from govt.	3	20.00
Total	15	100.00

[Source: Field Level Survey- 2013]

In my study, (40.00%) teachers say that there have no enough space in their institution for this reason parents face waiting problem for admitting their child in their institution. (13.33%) teacher says that the amount of teacher is not enough. (26.67%) teachers view that they cannot give fund from different place (20.00%) teachers say that government do not give enough help for those institutions.

Figure-29: Percentage distribution about the limitations autistic institutions.

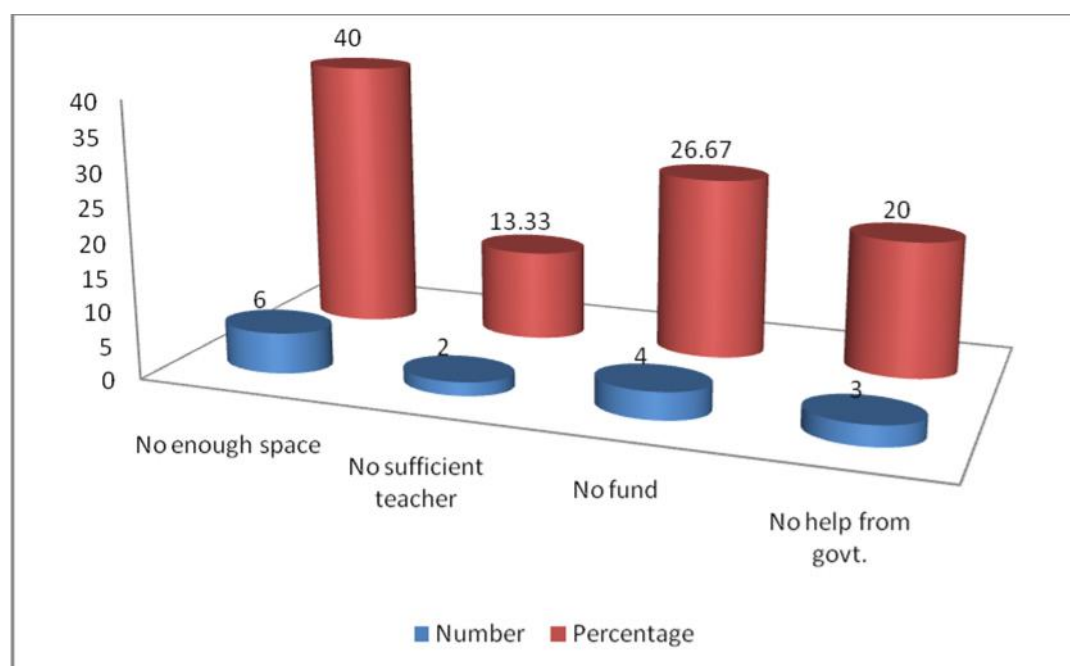


Table-36: Percentage distribution about activities of autistic children is as good as normal.

As good as normal child	Number	Percentage
Yes	4	26.67
No	11	73.33
Total	15	100.00

[Source: Field Level Survey- 2013]

(73.33%) teachers say that autistic children are not same as good as normal children. Autistic children have different problem in their life as language, communication, socialization, behavioral problem. For this reason they are not as like as normal children. (26.67%) teachers seem that autistic children are like normal children who have hyperactivity and at a glance; no one can identify the problems of autistic children. But when they communicate with other then people identify about the problems of autistic children.

Figure-30: Percentage distribution about activities of autistic children be as good as normal.

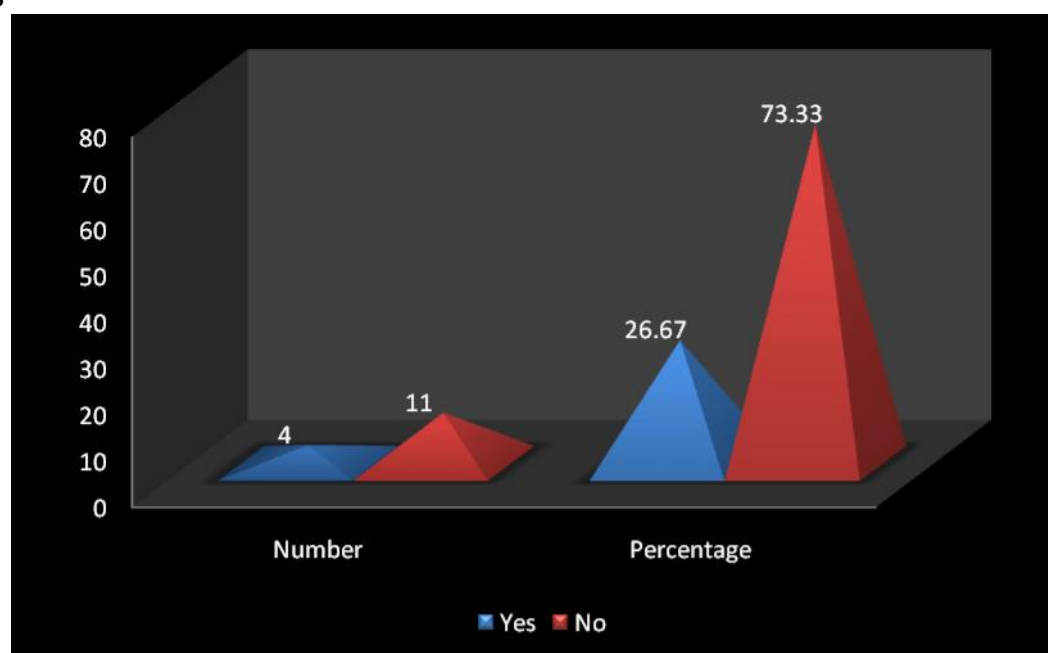


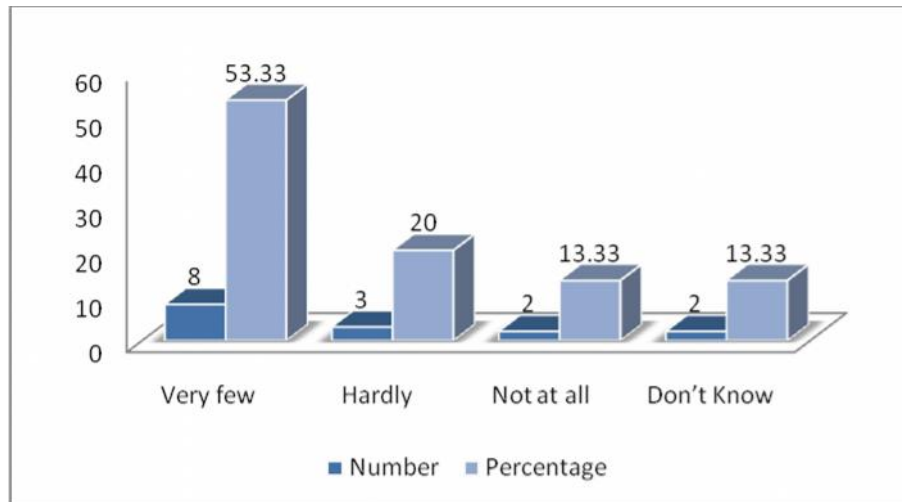
Table-37: Distribution of the teachers according to the knowledge of proper implementation of law and rights in Bangladesh.

Implementation of Laws & Right	Number	Percentage
Very few	8	53.33
Hardly	3	20.00
Not at all	2	13.33
Don't Know	2	13.33
Total	15	100.00

[Source: Field Level Survey- 2013]

Though autistic children cannot perform perfectly they can not get sufficient opportunity in our country 53.33% teachers believed that the implementation of laws and rights in Bangladesh is very few, (20.00%) teachers say that the implementation is hardly, (13.33%) views that the implementation is not at all and (13.33%) teachers do not know about the implementation of law. Most of the teachers say that government should take the step for create and implementing the laws and rights for autistic children.

Figure-31: Distribution of the teachers according to the knowledge of proper implementation of law and rights in Bangladesh.



5.3 Presentation of Qualitative Data

In this section presents the qualitative data. The data for qualitative part are collected through FGDs with parents and teachers, interviews with parents and teachers. In this section 20 respondents as parents and 5 respondents as teacher for interview and 4 FGDs with parents and teachers. Here I study some problems, challenges of autistic children and some parental problem for their children faced in society.

5.3.1 Problems of Autistic Children

Autism spectrum disorder (ASD) is a range of complex neurodevelopment disorders, characterized by a triad of impairments. The triad of impairments is: social impairments, verbal and nonverbal communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. Parents of autistic children say that their children face different problems. By answering the question of parents and teachers, here describe the problems of autistic children.

5.3.1.1 Delay in language acquisition

There is often language delay in children with autism and the language that does develop is deficient in conversational use, especially non-verbal

language. The child with autism fails to grasp the meaning of communication and has difficulty comprehending gestures and speech. The child makes little social use of communication skills and has a deficit in the use of social imitation. Coupled with this difficulty, is the child's misinterpretation of facial expressions. The child with autism usually has a delayed development of speech, or normal development until the age of two years when it ceases. The speech that the child with autism does develop tends to have an oddity in vocal volume and pitch. 15 out of 20 parents say that their children with ASDs show delays in nonverbal communication and spoken language. They may have words that they use to label things but never request things. They may have unusual words for their overall language level, such as saying letters or numbers when they do not yet have names they use for family members. Most young children go through a phase where they repeat what they hear. Children with ASDs may repeat for a longer period and repeat movies or conversations with the tone of voice in which they heard them. 4 out of 5 teachers say that the pivotal problem of Autistic children is problem of speech. Maximum children are devoid of clear speech capability. Some repeat, some babble or some may experience abnormal sound or unwanted gesture. Some come into view totally mute.

5.3.1.2 Repetitive and stereotyped play

Repetitive actions are one of the main diagnostic criteria of autism. However, they are not uniquely associated with autism. 11 out of 20 parents say that repetitive actions have long been recognized as a common component of mental disturbance. Stereotypes are involuntary movements that are rhythmic, repetitive and purposeless. These may include rocking, head nodding or Self-injurious behaviours are also stereotyped and repetitive behaviours but differ in that they have the potential to cause harm to the child. These may include: hitting, biting, scratching etc; Compulsions are purposeful behaviours that are repetitive and performed according to rules. These include ordering, checking, hoarding and so forth.

5.3.1.3 Conversational problem

Children with autism cannot carry on a conversational interchange of thoughts and information about the same topic with another person. 5 out of 5 teachers say that 90% autistic children cannot continue conversation with other

when they start talking, they can talk with single word and normally they are unable to make a question to other.

5.3.1.4 Little eye-contact

Few autistic children initiate play with other children, and they are usually unresponsive to any who may approach them. Autistic infants may avert their gaze if parents try to communicate with them, and they are described as engaging in less eye contact than do their peers. The sheer amount of gazing may sometimes be relatively normal, but not the way in which it is used. Normal children gaze to gain someone's attention or to direct the other person's attention to an object; the autistic child generally does not.

5.3.1.5 Rigid behaviours

There are categories of rigid behaviours displayed by people with autism. These categories are: stereotypy, self-injury, compulsion, ritual, sameness and restriction. 50% parents face rigid behaviours of their child in home and outside and 60% teachers say that they face rigid behavior of autistic children when they teach them.

5.3.1.6 Loss of social skills

Sometimes a child may seem to lose social skills that they once had. This may be skills such as waving goodbye. In this study it is found in about 1 out of 4 cases.

5.3.1.7 Imitative action

The autistic children gave an unexpected tendency to imitate others. For instance when some chant in front of them, they start of recite. Parents and teachers say that autistic children try to imitate other gesture, language activities etc.

5.3.1.8 Loneliness

Autistic children like to be isolated from others. They are unable to move alone or themselves. 8 out of 20 parents say that their children like to be alone from autistic people. They feel happy loneliness in home. Teachers say that they all-time try to communicate with children. So they cannot identify the loneliness of autistic children, then they presume 25% children interested in their institution.

5.3.1.9 Hearing problem

20% parents say that their children have hearing problem and teachers say that 10% autistic children face hearing problem. But they are not deafness.

5.3.1.10 Sleeping Problem

Children with ASD tend to have problems falling asleep or staying asleep, or have other sleep problems. During the first few months of life, babies ease into a normal cycle of sleep and wakefulness. They gradually reduce the number of daytime naps they need and start sleeping for longer periods of time at night. 7 out of 20 parents say that their children continue to have difficulty falling asleep or sleeping through the night, and the problem can persist long after children start school.

5.3.1.11 Eating problem

All children are not habituated same food habit. Many of them are incompetent chewing. Some suffering from dental complicacy which is a potable impediment of eating. Some vomit when the meat piece is bigger than normal size in which they are used to. Unusual eating behavior occurs in about 30% of children with ASD, to the extent that it was formerly a diagnostic indicator. Selectivity is the most common problem, although eating rituals and food refusal also occur

5.3.1.12 Marriage problem

Maximum autistic children in their mature age cannot comply with expected social roles like marriage. Although those have hyperactive are able to marry, but statistically they are little number only one in ten.

5.3.1.13 Toileting problem

The serious challenge among family members emerges when autistic children are incompetent with some expected behavior like shutting down. Some autistic children can manage themselves but most of them cannot.

5.3.1.14 Lack of understanding

It's not easy to understand their demand or design, when children express outside their language 8 out of 20 parents face understanding problem by their children.

5.3.1.15 Epilepsy disease

Many suffer from the epilepsy disease which internal physiological disorder which in its motion, they feel sleepy or get slept but 10 % parents say about the their child epilepsy.

5.3.1.16 Educational problem in schools for autistic children

The majority of children with autism will, of course, never reach a high level of attainment. Around half of all children with autism have severe to moderate learning problems and because of this many education authorities argue against placement in highly specialized autistic provision, when places are readily available in schools for children with more general learning disabilities.

5.3.1.17 Autism and mental retardation

The terms mental retardation and learning disability imply slow development and poor learning. But even individuals with limited intelligence have the capacity to learn. Mental retardation is a classification that is based largely on IQ scores. Yet even though these children cannot pass many academic exams, they may learn to read, write, and be numerate. It has been widely reported that 75 percent of children with autism have mental retardation, an estimate that was based on clinic populations and did not include the full range of the autism spectrum.

5.3.1.18 Deficits in responding to environmental stimuli

An additional characteristic was initially identified through studies that indicated that autistic children fail to respond to environmental stimuli. Experimental studies supported the finding that the autistic child has difficulty integrating sensory data from different modalities. The majority of autistic children tend to respond to only a limited portion of cues when presented with a stimulus complex.

5.3.2 Problems faced by parents

Parents face humiliating, dishonor which may cause continuous streets disorder with the future concerns for their Children. The Children can't go to school alone. He/she requires a continuous guide with him which is financially traumatic for a middle class family. For this reasons, the parents always are in

uncertainty. Parents of autistic children face some exclusive problems when they are at outside with them. For instance, the child freedoms unruly inside of public transport. Thus the parents must have a private arrangement like CNG, private car.

5.3.2.1 Feelings of social isolation

Parents of autistic children feel hesitation to communicate, social festivals etc. Parents cannot join willingly for their child. 6 out of 20 parents seem that they feel isolation from social activities and feel sadness for this curse. Neighbors seem, autism is cursed from God, so they do not interact with the family members of autistic child.

5.3.2.2 Mental disorder

80% parents feel mental disorder in their daily life. Parents think that what will be in future of their child and how they improve and co-operate with others. Parents feel mental stress for coping with society, communication, interaction of their child.

5.3.2.3 Stress for Autistic child

The stress of caring for an autistic child is both real and acute. Parents are more stressful for their children than other types of handicaps. However, fathers of children with disabilities, in comparison to mothers, have higher levels of stress associated with the child's communication abilities and in their feelings of attachment to the child. In this study 44.44 percent of mothers of children with autism reported some symptoms of physical and psychological tension. Fathers seem to have some of the same troubles as mothers, but they are unable to express it. Most of the fathers in the study expressed concern about the well-being of their wives due to the excessive burden.

5.3.3 Parents experiences of challenges or sadness for autistic child

This challenge often leads others to believe that the individual with autistic child does not show empathy or understand them, which can create great difficulty in social situations. There may be special problems in mobilizing support and services from spouses, siblings, and grandparents during the child's early period, and community services may have to be developed to provide badly needed respite care. Other parents of handicapped children may be needed not only for

emotional support, but as a norm group which communicates to the family that their efforts on behalf of their child are worthwhile.

5.3.4 Participation in social activities

For autistic child parents cannot participate in various social activities. 35 percent parents claim that they face problem to participate in activities for the basic problems of their children.

5.3.5 Impact of having a child with autism on inter family relationship

In a society where there is a stigma attached to autistic children, the parents have to fight a war to rear them, they added. Autism has been termed an epidemic. It's actually a family epidemic. Parents, siblings, grandparents, and extended family members are all affected by autism in my study parents say that in five main areas of family functioning they commonly affected. The degree of challenge may vary depending on the severity of the autism, but the autism-related issues that families have to deal with are similar, whether a child is severely affected or has high-functioning autism.

5.3.6 Autistic child's relationship with his peers within and outside of school

The child with autism has a reduced capacity for shared attention and fails to develop skills to attract other people's attention. This is presented in the failure to develop normal peer-relationships, the avoidance of visual or physical contact and the behaviour of the child with autism towards people as if they were objects. Children with autism often are unsuccessful at building developmentally appropriate relationships with their peers. This results in part from a perceived indifference to the interests of others which is often demonstrated. Children with autism will often respond to communication attempts by their peers by talking about something of interest to themselves rather than engaging in a reciprocal interaction.

5.3.7 Problems of social interaction with neighbors faced by family members

Most of the parents are want to interact with the neighbor but sometimes they cannot interact. 5 out of 20 parents says, they are not able to interact with neighbour willingly. Sometimes neighbours do not agree to interact with the autistic family members.

5.3.8 Parents hope and dream for autistic children

Most of the parents and teachers hope that they will improve and communicate with other as normal child. If they improve, they feel proud and happy.

5.3.9 The future plan for equipping autistic child

Mothers and fathers of autistic children both showed pessimism about the future of their children, especially about problems that may arise when their children reach adulthood. This source of despair for the parent is often present throughout the life of the child, but may intensify as parents reflect on their own mortality and the effects that their deaths may have on the autistic child. Family planning regarding who will take care of the child after the deaths of the parents can be a stressful activity and, potentially, may cause family conflict.

5.3.10 Existing laws or rights of Autistic Child

Parents and teachers claim that the existing law of our country is not sufficient. For weakness of law, parents cannot implement child's rights. For this reason they face deferent problems in society or community. So, it is necessary to construct strong laws and rights of autistic children to help their future life.

5.4 FGD from parents and teachers

FGD- 1**Multi dimensional challenges of Autistic children**

Autistic disorder followed by the incompetent blood circulation in Brain. Although they are not mentally sick. The pivotal problem of Autistic children is problem of speech. Maximum children are devoid of clear speech capability. Some repeat, some babble or some may experience abnormal sound or unwanted gesture. Some come into view totally mute. Most of the Autistic child talks in a single word which is broken sometimes. Thus the speech is very vague for understanding of others. They are unable to move alone or themselves. It's not easy to understand their demand or design. Many suffer from the epilepsy disease which internal physiological disorder which in its motion, they feel sleepy or get slept. Some of autistic children are unable to make peer relation. They don't understand the social norms. As they are unaware of basic social norms, they cannot maintain the interactional reciprocity in a given social context. For example to wear heavy weight dress during summer is odd for interaction but they are unaware of it. Autistic children have different impairments in social functioning, and social deficits are at the core of all diagnostic systems. Amongst the specific deficits noted is the failure to understand or respond appropriate to others' feelings or emotions, the lack of ability to share emotions or experiences, and poor mixing of social, emotional and communicative behaviors within an interpersonal context. Echolalia is also more likely to occur when individuals are stressed, anxious, or in highly constraining situations. In many cases, too, echolalia is an important precursor to more creative and rule-governed language. As with any other 'autistic' behaviour, therefore, it is crucial to assess the role that the echolalia plays for the individual concerned before any attempts are made to modify it. All children are not habituated same food habit. Many of them are incompetent A chewing. Some suffering from dental complicacy which is a potable impediment of eating. Some vomit when the meat piece is bigger than normal size in which they are used to. Maximum autistic children in their mature age cannot comply with expected social roles like marriage. Although those have hyper action are able to

marry, but statistically they are little number only one in ten. Most of the cases, gestures and facial expressions are not used in the place of speech, and communication is severely limited. This is different from hearing-impaired children, who find ways to communicate their desires and emotions even without speech. In fact, even when speech develops, communication is impaired. The child who echoes words and phrases but does not spontaneously generate them should give rise to worry just as much as the child who does not produce any words.

FGD – 2**Divergent problems faced in family sphere stemmed from having autistic children.**

Parents of autistic children face some exclusive problems when they are at outside with them. For instance, the child freedoms unruly inside of public transport. Thus the parents must have a private arrangement like CNG, private car. Parents face humiliating, dishonor which may cause continuous streets disorder with the future concerns for their Children. In new place they create problem of adopting. They are waiting to eat before new faces. Thus parents are required to take meal with them. The Children can't go to school alone. He/she requires a continuous guide with him which is financially traumatic for a middle class family. For this reasons, the parents always are in uncertainty. Although bad comment doesn't take place in truant of parents. But neighbors often comment bed in absence. They can't move anywhere along leave alone the school. The monthly fee is of school is 3200-3500. Some institution requires 2000 to 25000 taka in advance. Apart from this, some parents manage home tutor and home maid. The whole arrangement is very cost which is not possible for many of parents. In public place, people comment with unacceptable lice, abnormal 'deaf' this indicates that ordinary people even don't know anything about autism. More many people call the autistic children as 'mad'. When they visit to a park, they sometimes behave 'abnormally'. This time people may misbehave with them by labeling 'mad' or 'Psycho' such humiliation, rejection makes parent feel worst. Those families have autistic children are humiliated, stigmatized and become isolated in social interaction. People don't communicate, cooperate with them. In such progression, family finds the autistic children as burden. Lack of medical knowledge and prevalence of folk explanation that mother is responsible for autistic child. Sometimes women undergo battering and violence. Family members specially the aged one blames the wife. Even they adopt divorce to tract the mother of autistic child. Parents often get humiliated, stigmatized when they are in public place like office, market.

FGD – 3

Coping and adaptation strategies of family members for the autistic children

Autism has at its core a basis in the brain, and this view is now widely accepted. Autism is not caused by psychodynamic conflicts between mother and child. With blatant disregard for the biological evidence, the erroneous belief that autism can be cured by resolving deep-seated conflicts lingers on. It lingers on together with the belief that one can die of a "broken heart," or be made ill by the "evil eye." Autism occurs in all kinds of families and cultures, and not particularly in problem families with unresolved emotional conflicts. Problem families may well produce problem children, but there is a world of difference between an emotionally disturbed child and a child with autism. There is no reason to think that parents of children with autism love their children less, or try less hard to nurture and educate them. The visible evidence is that many try harder, and are more selfless in their efforts. Evidence for social impairment becomes much easier to obtain in the second and third year of life. Lack of normally expected social responses toward other children is often the key observation. Visits to pre-school playgroups may expose the difficulties for the first time. Sometimes it is the lack of appropriate response toward a newborn sibling that sets alarm bells ringing, but this may be explained away by jealousy. The normally developing child tends to be intensely interested in other children and is not prevented by jealousy from expressing this interest. In contrast, the child with autism tends to be intensely interested in the world of objects. Keeping up outside friendships as a couple and as a family is healthy. But getting through picnics and parties can be difficult with an autistic child. Many children with autism have trouble with social interactions and changes in routine. Still, parents find a way to cope. With more awareness about autism and what it is, parents may expect friends and acquaintances to be accommodating to their autistic child's needs.

FGD – 4

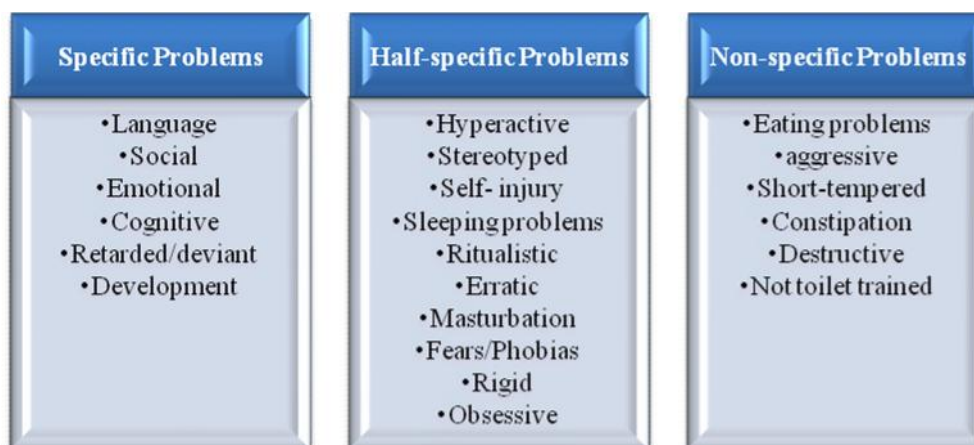
Role of teachers in the challenges of autistic children

Autism spectrum disorder (ASD) covers a set of developmental disabilities that can cause significant social, communication, and behavioral challenges. People with ASD process information in their brain differently than other people. ASD affects people in different ways and can range from mild to severe there are, and whether other problems are present. In school, the teacher student ration is 1:2. In a single room, 6 children are accommodated for training. Every single room has attached toilet. Teacher always take care them. For abrupt behavior of autistic children, sometimes teachers are hurt. To teach them peer-relation, students are consulted by teachers. Teachers always try to interact with them, as they can be more social. The teachers of autistic institutions are more helpful for reducing the problem, they provide training, therapy (speech therapy, occupational therapy), and different methods to improve of autistic children. They arrange a seminar, workshop on autism in various places for creating awareness among the general people and in their institutions to concern the parents & other family members of autistic children. By providing teaching to children, parents can reduce their stress for his/her child. Teachers can role nationally and internationally, where autistic children are discriminated, neglected. So the role of teachers is very important.

6.1 Problems of Autistic Children

Autism is a highly variable neurodevelopment disorder that first appears during infancy or childhood, and generally follows a steady course without remission (World Health Organization, 2007). Overt symptoms gradually begin after the age of six months, become established by age two or three years and tend to continue through adulthood, although often in more muted form. It is distinguished not by a single symptom, but by a characteristic triad of symptoms: impairments in social interaction; impairments in communication; and restricted interests and repetitive behavior. Other aspects, such as atypical eating, are also common but are not essential for diagnosis. Autism is a diagnosis classified under the broad term of pervasive developmental disorders. It is the most severe pervasive developmental disorder in which there is language and social impairments and pattern of restrictive and stereotyped behaviors, interests and activities. Autism is a developmental delay that includes symptoms such as speech difficulties, lack of eye contact, isolation and no fear of danger. Autistic children act and sound like much younger children. What causes autism specifically is not known. Some experts believe there are bio-chemical reasons for autism; others suspect that it is a psychiatric disorder. Some believe that a combination of the wrong foods and too many antibiotics and environmental toxins can damage the colon and lead to physical and behavioral problems, including autism. Children on the autistic spectrum display significant social deficits that negatively impact daily functioning and may lead to serious mental health problems. Autism's individual symptoms occur in the general population and appear not to associate highly, without a sharp line separating pathologically severe from common traits.

Figure-32: Specificity of problem behavior in Autistic Children



(Source: Kraijer Dirk, *Autism and autistic-like condition in mental retardation*;1997:94)

6.1.1 Language and Communication Problems

Communication was also difficult for individuals with ASD. Autistic children often doesn't seem to want to communicate and lose language or other social milestones, usually between the ages of 15 and 24 months to say words or sentences. Vincelette said he began to speak only at year five and was diagnosed as having intellectual disabilities, until his first IQ test when he scored above 140. O'Neill, in contrast, began speaking earlier and then stopped, and commented that 'to judge someone by the fact that she speaks or does not speak and to escalate that into a huge deal is petty.

Autistic children are unable to successfully communicate and interact with others. Children with ASD may have difficulty developing language skills and understanding what others say to them. They also may have difficulty communicating nonverbally, such as through hand gestures, eye contact, and facial expressions. Not every child with ASD will have a language problem. Some children with ASD may be unable to speak. Most children with ASD have little or no problem pronouncing words. The majority, however, have difficulty using language effectively, especially when they talk to other people. Many have problems with the meaning and rhythm of words and sentences. They also may be unable to understand body language and the nuances of vocal tones. Their problems have been linked to a language disorder known as 'semantic-pragmatic disorder'. (National Institute on Deafness and Other Communication Disorders (NIDCD). The range of communication handicaps in the autistic spectrum is very striking - from the totally mute autistic child who does not use even gesture to communicate, through the echolalic child who may parrot whole sentences which appear to have no relation to the context. Some of the language problems which emerge as specific to autism and not due merely to developmental delay, or to superimposed additional specific language impairment include the following:

6.1.1.1 Delay or lack of development of speech

Autistic children start talking later than other children. Almost all children with ASDs show delays in nonverbal communication and spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime). They may have words that they use to label things but never request things. They may have unusual words for their overall language level, such as saying letters or numbers when

they do not yet have names they use for family members. Most young children go through a phase where they repeat what they hear. Children with ASDs may repeat for a longer period and repeat movies or conversations with the tone of voice in which they heard them.

6.1.1.2 Natural speech problems

About a third to a half of individuals with autism does not develop enough natural speech to meet their daily communication needs. No single words by 16 months or two-word phrases by age 2, no response to name, speaks with an abnormal tone or rhythm (singsong voice or robot-like speech). Differences in communication may be present from the first year of life, and may include delayed onset of babbling(no babbling or pointing by age 1), unusual gestures, diminished responsiveness, and vocal patterns that are not synchronized with the caregiver. There have articulation and phonological problems.

6.1.1.3 Impediments of language expression or Expression language problem:

Autistic children may have difficulty with imaginative play and with developing symbols into language. In a pair of studies, high-functioning autistic children aged 8–15 performed equally well as, and adults better than, individually matched controls at basic language tasks involving vocabulary and spelling. Both autistic groups performed worse than controls at complex language tasks such as figurative language, comprehension and inference. As people are often sized up initially from their basic language skills, these studies suggest that people speaking to autistic individuals are more likely to overestimate what their audience comprehends.

6.1.1.4 Problems of facial expression

Doesn't often have appropriate facial expressions. Unable to perceive what others might be thinking or feeling by looking at their facial expressions.

6.1.1.5 Echolalia or Stereotyped and Repetitive use of language

A child may repeat words he or she has heard over and over, a condition called echolalia. Children with ASD are often echolalia when the child repeats words someone has just said. For example, the child may respond to a question by asking the same question. In delayed echolalia, the child will repeat words

heard at an earlier time. The child may say "Do you want something to drink?" whenever he or she asks for a drink. Some children with ASD speak in a high-pitched or singsong voice or use robot-like speech. In which the child echoes, usually with remarkable fidelity and in a high-pitched monotone, what he/she has heard another person say. The teacher may ask an autistic child, "Do you want a cookie?" The child's response may be "Do you want a cookie?" This is immediate echolalia. In delayed echolalia the child may be in a room with the television on and with others conversing and appear to be completely uninterested. Several hours later or even the next day, the child may echo a word or phrase from the conversation or television program. Mute autistic children who later acquire some functional speech through training usually first pass through a stage of echolalia. Bogdashina (2004:174-76, 195) defines echolalia as a "parrot-like repetition of another person's spoken words". She argues that there are two familiar types of echolalia; the first one is immediate echolalia and defines it as a "repetition of words and phrases just heard", and the second one that is delayed echolalia which is defined as "repetitions of words and phrases heard in the past".

6.1.1.6 Affirmation by Repetition

Bogdashina (2004:186) points out that Kanner (1943) is the first one who observed the feature affirmation by repetition. She defines it as a characteristic in autistic language where the children confirm a question by repeating it, instead of saying 'yes'. She explains this by describing the word 'yes' as a difficult one for autistic children to understand and use.

6.1.1.7 Repetitive Questioning

Bogdashina (2004:186) defines repetitive questioning as the persistence of the autistic child to ask the same question, in spite of knowing the answer. Moreover, the answer of the repeated question must always be the same (regarding the word order, intonation and so on), and if it is not, a tantrum will occur. The child does this behavior not to get information, but to be assured that everything is going well.

6.1.1.8 Uneven language development

Many children with ASD develop some speech and language skills, but not to a normal level of ability, and their progress is usually uneven. For example, they may develop a strong vocabulary in a particular area of interest

very quickly. Many children have good memories for information just heard or seen. Some children may be able to read words before 5 years of age, but they may not comprehend what they have read. They often do not respond to the speech of others and may not respond to their own names. As a result, these children sometimes are mistakenly thought to have a hearing problem.

6.1.1.9 Abnormal non-verbal communication

Children with ASD often are unable to use gestures such as pointing to an object to give meaning to their speech. They often avoid eye contact, which can make them seem rude, uninterested, or inattentive. Without meaningful gestures or the language to communicate, many children with ASD become frustrated in their attempts to make their feelings and needs known. They may act out their frustrations through vocal outbursts or other inappropriate behaviors. These include striking discrepancies on intelligence test batteries, where non-verbal ability often far exceeds verbal skills. Around 1 in 10 people with autism show so-called savant abilities, much in advance of their overall IQ, in music, drawing or calculation (Rimland 1978, Rimland & Hill 1984).

6.1.1.10 Eye contact

When having a conversation, children may not look directly into the eyes of the person speaking; this is thought to be a self-regulating strategy to compensate for visual input difficulties. Nevertheless, it is true that autistic children seek help and comfort less often than do normal and intellectually disabled children; they show less mutual eye contact, less attention to people and show more avoidant behavior (Volkmar F.R.,1998:82).

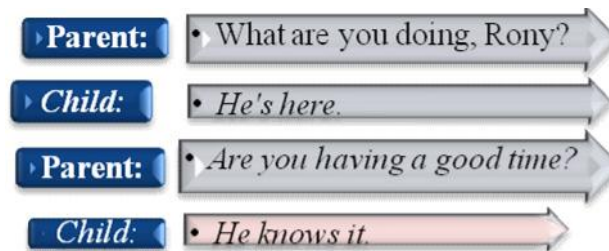
6.1.1.11 Verbal language

Forty to forty-five percent of students with ASD are nonverbal.

6.1.1.12 Pronoun reversal

Refers to self as "you" and others as "I," and may mix up pronouns. In the second and third years, autistic children have less frequent and less diverse babbling, consonants, words, and word combinations; their gestures are less often integrated with words. Autistic children are less likely to make requests or share experiences, and are more likely to simply repeat others' words reverse pronouns (Kanner L. 1943).The children refer to themselves as "he," or "you," or by their own proper names. Pronoun reversal is closely linked to

echolalia. Since autistic children often use echolalia speech, they will refer to themselves as they have heard others speak of them and misapply pronouns (Davison G.C. & Neale J.M., 1998). For example-



6.1.1.13 Steriotyped phrase

Autistic children use stereotyped and repetitive use of language or idiosyncratic language. Many individuals with autism show motor stereotypies such as rocking, walking on tip-toes, hand-flapping or flicking their fingers rapidly in front of their eyes (Happe F.,1994).

6.1.1.14 Metaphorical Language

Bogdashina (2004:184) points out that Kanner is the one who coins the concept 'metaphorical language'. This concept refers to a characteristic of autistic language where autistic individuals create their own private meanings of words that can be only understood by them. These words carry completely different definitions from their common ones and it can only be interpretable if their origin be revealed.

6.1.1.15 Deficient prosodic patterns:

Bogdashina (2004:187) states that many autistic people have a speech with a strange prosody; such as a tedious voice and a peculiar intonation. Furthermore, they are unable to use intonation or understand it as a communication tool. They cannot interpret the speaker's intention behind it and tend to explain the utterance literally.

6.1.1.16 Impaired understanding of spoken language

Impairment in communication due to autism is evident if an individual has at least two problems as delay in or total lack of the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication, such as gesture or mime) and In individuals with adequate speech, marked impairment in the ability to initiate or sustain conversation with others (APA, 1994, pp. 67-68).

6.1.1.17 Failure to respond to others' speech

Autistic child doesn't orient to his own name.

6.1.1.18 Lack of conversation

Autistic children can't start a conversation in the natural as give and take in a talking with other and may talk only of their obsessions. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others. The semantic pragmatic language impairments which are shared with high functioning autistic cases include comprehension deficits, literal interpretations of messages, perseveration, deficits in turn taking and problems with maintaining conversational topics (Volkmar F.R.,1998:89).

6.1.2 Personal and Social developmental Problems

The development of social interaction skills in the autistic student become critical if one considers the relationship of early social interactions and communication development. Howlin (1978) points out that the poor social interaction and poor communication skills evidenced by the autistic child may be a result of the child's inability to comprehend what is expected in the social situation rather than an unwillingness to do so (Schopler E. & Mesibov G.B.,1985).The available evidence does not rule out the possibility that autism's true prevalence has increased, a real increase would suggest directing more attention and funding toward changing environmental factors instead of continuing to focus on genetics. Boys are at higher risk for ASD than girls. The sex ratio averages 4.3:1 and is greatly modified by cognitive impairment: it may be close to 2:1 with mental retardation and more than 5.5:1 without. Several other conditions are common in children with autism.

6.1.2.1 Personal problems

Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.

6.1.2.2 Lack of social understanding

In autism, the complex skills required for developing and maintaining social, emotional or sexual relationships are often lacking. Because of this

failure of understanding, attempts to acquire a partner are often extremely primitive and can sometimes lead to serious problems (Howlin Patricia, 1991:246).

6.1.2.3 Failure to interpret cues

These problems in emotional and social expression are paralleled by difficulties in recognizing or responding appropriately to the emotional expressions of others. Although many able people with autism are aware that smiles, gesture, touch, facial expression and eye-contact play a crucial role in social interactions it may still prove very difficult for them to interpret these correctly (Howlin Patricia, 1991:72).

6.1.2.4 Social impairment

It also included all children with any one of three behaviors typical of autism, regardless of retardation. These three features were severe social impairment, defined as inability to engage in reciprocal two way interaction, especially with peers; severe communication impairment, defined as inability to communicate by both verbal and nonverbal means; and severe impairment in the pursuit of imaginative activities with the substitution of repetitive behavior. This was defined as an inability to engage in ordinary symbolic play with dolls (Frith Uta, 1989:61).

6.1.2.5 Socialization Problem

Teaching social skills to students with ASD is extremely important, and is beneficial not only for the student but for classmates as well. Parents of children with ASD report restrictions on socializing and not being able to take the child shopping (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008). However, although some families may feel overwhelmed by their child's disability and may therefore perceive many unmet needs, others may not view their child's disability as a burden and may report few unmet needs. This appraisal may affect the direction or strength of the association between the child's functional independence and the parent's perceptions of unmet need and so is hypothesized to modify this relationship. Autistic children are not globally impaired in social functioning. For example, autistic children seem to show attachment behaviours which are no different from those of other (non-autistic) children with severe learning difficulties (Shapiro et al. 1987). Autistic people are able to respond differentially to different people and to

different types of approach (Clarke & Rutter 1981). Many-autistic children are not pervasively aloof, and do show proximity-seeking behaviours and vocalizations for social attention. Autistic children cannot engage in different activities, some of these described below:

- (a) **Inability to share and direct attention:** Autistic children do not point to things in order to share their locus of interest so-called "protodeclarative". By contrast, normal children from around 9-12 months will follow an adult's point or eye gaze, to share their focus of attention.
- (b) **Problem with imitation:** There is some evidence that even newborn normal infants show imitation - they will stick out their tongues to an adult making this face, and open their mouths to an open-mouthed adult (Meltzoff & Moore 1977).
- (c) **Impaired recognition of affect:** A number of studies have suggested deficits in the recognition of emotion by autistic children, although, again, subjects tend to be aged 5 years or older. However, there has been some suggestion that autistic subjects do not show specific problems if compared to controls of the same language level (Happé F., 1994).

6.1.2.6 Impediments of response

Doesn't respond to name being called but does respond to other sounds (like a car horn or a cat's meow). Doesn't point at things to indicate needs or share things with others. Doesn't respond to a parent's smile or other facial expressions.

6.1.2.7 Problems with peer relationships

Failure to develop peer relationships appropriate to developmental level and unable to make friends or uninterested in making friends. The inability of young autistic children to engage in social play, to join in with the activities of their peer group, or to form close friendships is well documented. Indeed, many autistic children may avoid contact with others of their own age, preferring adult company or if they play at all, will tend to try to join in the games of much younger children.

6.1.2.8 Lack of share enjoyment

Autistic children have a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest).

6.1.2.9 Lack of emotional expression

Lack of social or emotional reciprocity. No emotion when it is warranted.

6.1.2.10 Social cues

Children may have difficulty understanding social cues and reading others' nonverbal gestures.

6.1.2.11 Sharing

Children may display problems with sharing or waiting for a turn during a game.

6.1.2.12 Impairment in social interaction

Autism is a developmental disorder of the brain, it affects many parts of the brain. It is characterized by a problem with social interaction, impairment in verbal and nonverbal communication and a pattern of repetitive behavior with narrow, restricted interests. One of the most important developmental differences between children with ASDs and other children is a delay or lack of joint attention. It is a building block for later social and communication skills. Engaging in many back-and-forth social interactions, such as exchanging a lot of emotional expressions, sounds, and other gestures, is called reciprocal social interaction. Delays in joint attention skills are found in most children with ASDs and rarely seen in children with other types of developmental problems. Thus, joint attention deficits are thought to be among the most characteristic deficits of ASDs.

Children may lack the skills, ability, or understanding to make friends, initiate contact, and maintain social interactions.

6.1.2.13 Responsiveness

Children may be more interested in "things" than in people, and may lack interest in responding to other children.

6.1.2.14 Lack of feeling

Appears unaware of others feelings

6.1.2.15 Loneliness

Seems to prefer playing alone, confined to his or her 'own world'. The major symptoms are extreme autistic aloneness, a failure to relate to other people; communication problems, consisting of either a failure to learn any language or speech irregularities, such as echolalia and pronoun reversal; and preservation of sameness, an obsessive desire to keep daily routines and surroundings exactly the same. Although no certain biological basis of autism has been found, a biological cause is suspected for a number of reasons: its onset is very early; family and twin studies give evidence of a genetic predisposition; abnormalities have been found in the brains of autistic children; a syndrome similar to autism can develop following meningitis and encephalitis; and many autistic children have the low intelligence associated with brain dysfunctions (Davison G.C. & Neale J.M.,1998:448).

6.1.2.16 Failure to Generalize and Maintain Trained Skills

Browning and Lovaas, Koegel, Simmons, and Stevens-Long demonstrated that behavioural change in a one-to-one treatment situation did not adequately generalize to other situations. Rutter and Bartek evaluated different educational approaches and found that the behavioral movements observed in specific educational settings did not generalize to the home and other settings. Lovaas et al. collected generalization and follow-up measures on 20 autistic children. Follow-up results that were recorded 1-4 years after treatment depended largely on the type of post treatment in the environment. Generalization does not take place without special intervention in the nontraining environment.

6.1.3 Behavioural problems

Behavioural problems caused difficulty in the lives of people with ASD. These included disruptive and compulsive behaviour and tantrums, rocking, banging, scratching, and kicking. Such problems tended to decline with age. Problem behaviours includes property destruction, physical aggression, self-injury, and tantrums are major barriers to effective social and educational development. Such behaviors put young children at risk for exclusion and isolation from social, educational, family, and community activities.

6.1.3.1 Repetitive behavior

Autistic individuals display many forms of repetitive or restricted behavior, which the Repetitive Behavior Scale-Revised (RBS-R). The behavioral syndrome of autism includes abnormalities of language and thinking skills. Stereotypy is repetitive movement, such as hand flapping, head rolling, or body rocking, abnormal responses to sensations, spinning, sways, twirls fingers, walks on toes for a long time etc. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

6.1.3.2 Self-injuries behaviour

This is common in more severe forms of autism. Children may, for example, bite themselves. Self-injury includes movements that injure or can injure the person, such as eye poking, skin picking, hand or wrist biting, and head banging. Self-stimulatory behaviours such as these, which occasionally involve self-injury through hand-biting or head-banging, can also be found in non-autistic people with severe mental handicap. A 2007 study reported that self-injury at some point affected about 30% of children with ASD.

6.1.3.3 Compulsive behaviour

Unusual obsessions and compulsions is intended and appears to follow rules, such as arranging objects in stacks or lines. Children may become preoccupied with a single television program.

6.1.3.4 Ritualistic behaviour

It involves an unvarying pattern of daily activities, such as an unchanging menu or a dressing ritual. This is closely associated with sameness and an independent validation has suggested combining the two factors.

6.1.3.5 Restricted behavior

Restricted behavior is limited in focus, interest, or activity, such as preoccupation with a single television program, toy, or game.

6.1.3.6 Stereotyped movements

Stereotyped movements, such as rocking, flicking or flapping are often less in evidence as individuals grow older and if they do occur may be an

important indicator of distress or anxiety (Howlin Patricia,1991:105). Although problems related to stereotyped behaviours may lessen in adulthood or be important indicator of other, hidden anxieties, the main difficulty is that they appear much more out of place as individuals grow older. Whilst flapping and rocking may go almost unnoticed in a very young child, they will rapidly draw attention to an adult with autism, often exacerbating their social difficulties and reducing their chances of integration and acceptance.

6.1.3.7 Unusual behaviours

These are typical and include one or more of the following:

- ✓ Odd mannerisms such as hand-flapping or other odd pointless movements.
- ✓ Anger or aggression if routines are changed. Children with ASD may hurt themselves when they are angry by banging their head or hitting their face. Sometimes they do this to get attention.
- ✓ Actions may be repeated over and over again (like rocking backwards and forwards).
- ✓ Obsessions may develop in older children and adolescents. For example, they may have interests in unusual things like train timetables and lists.

Parents often find these problems very confusing and may become frustrated. Epilepsy (seizures) occur in around 3 in 10 cases. This usually happens for the first time around puberty. Seizures usually happen in children who are severely affected by ASD.

6.1.3.8 Inappropriate Behaviour

The educational progress of the autistic child is often further hampered by the frequent occurrence of inappropriate behaviors. These behaviors may include stereotypic or repetitive behaviors that interfere with teaching appropriate social, language, self-help, or vocational skills. Wing (1978) suggests that the social deficits, the repetitive stereotyped behavior, the abnormalities affecting comprehension, the use of all forms of communication and the development of symbolic functioning are facets of the same underlying impairment in autistic children (Schopler E. & Mesibov G.B.,1985).

6.1.3.9 Sleeping problem

Sleeping problems are associated with difficult behaviors and family stress, and are often a focus of clinical attention over and above the primary

ASD diagnosis. Studies have shown that some children with autism don't release melatonin at the correct times of day. Instead, they have high levels of melatonin during the daytime and lower levels at night. Another reason children with autism may have trouble falling asleep or awaken in the middle of the night could be an increased sensitivity to outside stimuli, such as touch or sound. While most kids continue to sleep soundly while their mother opens the bedroom door or tucks in the covers, a child with autism might wake up abruptly. Anxiety is another possible condition that could adversely affect sleep. Children with autism tend to test higher than other children for anxiety.

The term sleep disturbance is applicable when for at least three months in succession a child has trouble going to sleep or is regularly awake at night, and after bedtime forces his parents-through calling, crying, screaming, hurting himself, getting out of bed, making noises, etc to give him attention. In all likelihood, sleep disturbances occur comparatively frequently in mentally retarded children and even more frequently in children with a PDD. Just as with SIB, sleep disturbances can roughly be subdivided into four types on the basis of their background or organ:

- a. **Instrumental sleep disturbances:** Typically a child with this type of sleep disturbance demands through crying, calling, hammering on the door or SIB-the attention or nearby presence of his parents or other persons who are taking care of him.
- b. **Reactive sleep disturbances:** With this type of sleep disturbance, tensions or unpleasant experiences gained during the course of the day undermine the child's ability to sleep, notably to fall asleep. It may take hours before the tensions have subsided sufficiently for the child to be ready to be overcome by sleep.
- c. **Self-stimulatory sleep disturbances:** This type of sleep disturbance is clearly the result of boredom. It was in fact very rarely found in the present sample of children.
- d. **Structural sleep disturbances:** Unlike structural SIB, this type of sleep disturbance is the least common one. Two subtypes may be distinguished: (1) a sheer habit which has grown out of an instrumental, reactive or self-stimulatory sleep disturbance; (2) a manifestation of a fundamental and almost autonomous restlessness stemming from severe brain dysfunction which in a small number of cases is suggestive of a

fundamentally disturbed periodicity of sleep and wakefulness (Kraijer Dirk,1997:141).

6.1.3.10 Effects of sleeping problems

Not getting a good night's sleep can have a serious impact on a child's life and overall health. Research has shown that, in children with autism, there is a connection between lack of sleep and the following characteristics:

- Aggression
- Depression
- Hyperactivity
- Increased behavioral problems
- Irritability
- Poor learning and cognitive performance

One study showed that the parents of autistic children sleep less, have poorer sleep quality, and wake up earlier than parents of non-autistic children.

6.1.3.11 Repetitive use of objects

Stacking or lining up objects, for example, may become a fixation. Doesn't look at objects or events a parent is looking at or pointing to, doesn't point to objects or events to get a parent to look at them, doesn't bring objects of personal interest to show to a parent.

6.1.3.12 Eating Problem

In the present context, however, the term eating disorder applies to children who for at least three months have eaten insufficient food or an insufficient variety of foods in the absence of clear organic reasons, such as a motor disturbance of the muscles of the mouth which would prevent a child from chewing or swallowing food (Kraijer Dirk,1997:151).

6.1.4 Sensory Integration Problem

Many children with autism have sensory integration problems, which according to Piek and Dyck, provides insights into the social difficulties experienced by children with autism. Children with autism experience problems with multi-modality sensory integration and sensory processing failure (Frith, 2003: 149-166).

From the behavioural characteristics listed above, it can be deduced that parents of a child with autism commonly experience stress. At the time of diagnosis, parents are faced with assessing their child's health problems as

well as sensory, educational and behavioural needs. This is an extremely stressful time. These parents may not be receiving any form of support in raising their child with autism and, therefore, may have many needs unmet.

6.1.4.1 Lack of emotional understanding

For other individuals it is not so much their lack of social understanding that is the primary problem but their inability to cope with the emotional demands of a close relationship (Howlin Patricia, 1991:247).

6.1.4.2 Unusual sensory experiences

Children with ASD may be hypersensitive at all to smells, sounds, lights, textures, and touch.

6.1.4.3 Feel pain

Doesn't seem to feel pain

6.1.4.4 The failure to share emotions or experiences

A lack of 'shared attention', or the failure to participate in the activities or enjoyment of others, has been highlighted as a particular deficit of children with autism and is a problem that tends clearly to distinguish them from children with other developmental or communication disorders. Few children with autism try to share their own enjoyment with others; nor do they seem able to share in other people's feelings of pleasure or happiness. Just as they are often unable to share pleasurable experiences, many people with autism are unable to share pain and distress in the normal way. Examples of inappropriate responses to other people's distress are described above but people with autism are just as likely to have problems talking about their own feelings or experiences (Howlin Patricia, 1991:70).

6.1.4.5 Poor imagination

Pretend play is usually limited in children with ASD. They tend to do the games and activities that they learn over and over again. Games may remain exactly the same every day. Games are usually those that a younger child would play.

6.1.4.6 Hearing problems

Sometimes hearing problems can make it difficult for a child to be sociable. If they are concerned about an ASD they may ask a special team to observe your child. This team will normally be made of several different types of health professional. They will observe your child over a period of time before making a decision about the diagnosis. Their observations decide whether your child has an ASD. Blood tests may be taken. These do not test for an ASD, but help to look for and rule out other conditions that may seem similar. Because hearing problems can cause behaviors that could be mistaken for autism, children with delayed speech development should also have their hearing tested. After a thorough evaluation, the team usually meets with parents to explain the results of the evaluation and present the diagnosis.

6.1.5 Psychological problems

6.1.5.1 Mental retardation

The percentage of autistic individuals who also meet criteria for mental retardation has been reported as anywhere from 25% to 70%, a wide variation illustrating the difficulty of assessing autistic intelligence. In comparison, for PDD-NOS the association with mental retardation is much weaker and by definition, the diagnosis of Asperger's excludes mental retardation. Stereotyped behaviours also occur in mentally retarded persons without a PDD, albeit more frequently in mentally retarded persons with a PDD (Kraijer Dirk, 1997:93).

6.1.5.2 Anxiety disorders

Anxiety disorders are common among children with ASD; there are no firm data, but studies have reported prevalences ranging from 11% to 84%. Many anxiety disorders have symptoms that are better explained by ASD itself, or are hard to distinguish from ASD's symptoms.

6.1.5.3 Anxiety, fears and phobias

Another major problem related to obsessions in older people is the high anxiety levels that these behaviours may produce, often for a variety of different reasons. Obsessions and fears often become inextricably linked, so that children who have an obsession with a particular object at one stage can develop a great fear of it later (Howlin Patricia, 1991:106).

6.1.5.4 Epilepsy

Epilepsy, with variations in risk of epilepsy due to age, cognitive level, and type of language disorder (APA. 2000. p. 80).

6.1.6 Educational problem

Some major characteristics of autistic children that impact on acquiring education in whole life time as puzzle have been described in the following:

The researcher speculated that, as the child with autism has developmental difficulties, education of the child may be a challenge and may differ from the education received by a typical child. The researcher narrowed the focus to the parents' perceptions of the school experience of their child with autism. Bloch, Weinstein and Seitz affirm that there needs to be collaboration between the responsibilities at home and at school.

Problem behaviors of children with autistic spectrum disorders and other children are among the most challenging and stressful issues faced by schools and parents in their efforts to provide appropriate educational programs. In addition, problem behaviors may place an onerous burden on families, particularly as children grow from preschool into school age (Bristol et al., 1993). Concerns about school behavior problems led to new standards and procedures for discipline, student suspension, and expulsion in the 1997 amendments to the Individuals with Disabilities Education Act. Specifically, the regulations include provisions for the use of functional behavioral assessments and positive behavioral interventions and support. There are many reasons that a child diagnosed with autism spectrum disorders is not able to learn in a regular classroom setting.

These include but are not limited to the following reasons:

- ⇒ Coexisting learning disabilities.
- ⇒ Coexisting intellectual disability.
- ⇒ Speech and communication delays.
- ⇒ Aggression to self or others.
- ⇒ Affective Instability.
- ⇒ Require individual supervision to participate in the classroom.
- ⇒ Social reciprocity problems.

Students with ASD often have difficulty with generalizing a newly learned skill to another environment, so if skills taught at school are not reinforced at home (and vice-versa), the student may be unable to generalize the skills he or

she acquires in the classroom. Offering parents a chance to observe a portion of the class can help them visualize strategies explained by the teacher.

Children with autism often are not engaged with academic or social tasks when exposed to uninteresting tasks, these children can often have mild to moderate disruptive behaviors in order to avoid or escape the task. When the avoidance or escape happens, the children miss key learning opportunities. Active participation is as essential a skill to children with autism as it is for children without autism, as children are expected to engage in these skills both in and outside the classroom. Without participation skills, children are at a disadvantage when it comes to school and other settings, such as extracurricular activities and the workforce.

6.2 Family Problems: Problems Faced by Parents and Family Members

Having a family member with autism presents emotional, social, and financial challenges. The stress placed on parents and other family members of people with autism can be influenced by a number of factors. Siblings of children and teens (13-19 years) with autism seem to fare better in their understanding and acceptance of the family member with autism when provided with education about their loved one's condition. A child's autism diagnosis affects every member of the family in different ways. Parents/caregivers must now place their primary focus on helping their child with ASD, which may put stress on their marriage, other children, work, finances, and personal relationships and responsibilities. The parents of a child with autism usually begin to recognize some developmental delays or problems during their child's first three years of life. Autism is congenital, therefore present at birth, but the signs are difficult to identify in infancy. Parenting a child with ASD is associated with maternal psychological distress, reduced marital happiness, and reduced family adaptability and cohesion. These outcomes are thought to be due to the physical and emotional demands of dealing with the challenging behaviours and poor social and communication skills associated with ASD. Research suggests that the stress experienced by parents of a child with ASD is more extreme than that experienced by parents of a child with another developmental disability or special healthcare need autism affects families in many ways.

6.2.1 Impact on family life

The child with autism has an impact on the family. Faux and Nehring (2007: 91) state that "there is a long-held popular belief that having a child with an IDD [Intellectual and developmental disabilities] is a universally negative event, leading to long-term parental suffering (i.e., chronic sorrow) and negative emotional and psychological sequelae for other family members". Cosser found that the family's daily routine needs to be adapted, as a child with a disability takes up more time than a child without a disability. "Raising a child with ASD can impose a great deal of stress on the entire family" (American Academy of Pediatrics, 2001: 1224). Parents of children with autism reported high levels of stress and aggravation, markedly higher than parents of children without special needs. Parents of children with autism face unique stressors and may benefit from family-centred treatment. Mothers of children with an intellectual disability experience psychological distress and social disruption due to social deprivation and the child's emotional and behavioural difficulties. Mothers experience many demands, including time demands and lack of time for social and recreational activities. Working mothers raising a child with a disability have less time for personal care and leisure than mothers raising a typical child. When mother was no longer able to attend yoga classes due to the needs of her child with autism. Potential health consequences caused by the lack of time for recreation and physical activities are hypertension, coronary heart disease and depression. Decrease in personal care time and time for socializing and leisure directly affects the mother's sense of control over her life. The child with autism sometimes splits the families up; the child acts as another wedge separating these families from normal family life".

6.2.2 Special Problems in Families of Autistic Children

Mothers

Some studies in fact indicate that in families of mentally retarded children the divorce rate may be triple the national average and the suicide rate may be twice the national average. The prevalence of depression among mothers of autistic children has been documented. However, a third of mothers in autistic children face depression in response to stress associated with the birth of autistic child in the family.

Father

Price-Bonham & Addison (1978) reveal that significant emotional and financial strains are experienced by fathers, who often lack outlets to deal with such stress or to contribute to the child's progress.

Siblings

Studies of siblings of autistic children also reveal mixed outcomes. Some siblings suffer from emotional and behavioral disorders. The pervasive nature of this stress is highlighted by studies which indicate that the negative effects on siblings may continue into adult life (Cleveland & Miller, 1977; Grossman, 1972)

6.2.3 Impact on Family Members of Autistic Children

From the moment they begin to suspect that their child isn't developing in a neuro-typical way, families of children with autism spectrum disorders begin to face challenges that set them apart from other family groups. This disorder can be emotionally devastating for parents, especially just before and after the child is diagnosed. Additionally, there's the stress of navigating complicated therapy schedules, following through on treatment at home, juggling family commitments with job responsibilities, and many other issues. While these difficulties may feel insurmountable, most families learn to cope and adjust with time.

6.2.4 Emotional and Psychological Problem

The stress of living with an autistic individual can affect the psychological well being of a family as well as generate conflicts among them. The difficulties produced by autism, however, go beyond the family, in that families with autistic children have to interact with the outside world.

Autism is an emotional roller coaster ride that begins before diagnosis and continues throughout life. According to a study published in the journal *Pediatrics*, mothers of children on the autism spectrum frequently rated their mental health status as "poor" or "fair." They had a much higher stress level than the general population. In addition to the higher stress level, many parents of children with autism experience the following emotions:

- ⇒ Feelings of being overwhelmed
- ⇒ Relief at having a name for the challenges their child faces
- ⇒ Anger at their spouse, the doctors, or themselves
- ⇒ Resentment of the child and guilt for that resentment

- ⇒ Despair at the incurable nature of the disorder
- ⇒ Guilt that something they did may have caused their child's challenges
- ⇒ Frustration that the parenting experience they have is not what they envisioned
- ⇒ Feelings of social isolation
- ⇒ Embarrassment at child's behavior in public

6.2.5 Mental Disorder

Furthermore, results from a study by Bouma and Schweitzer provide empirical support for the suggestion that chronic mental disorders such as autism contribute more to family stress than chronic physical disorders such as cystic fibrosis, even though the latter is usually fatal. In addition, Sanders, and Morgan also found perception of family problems by parents of autistic children to be significantly more severe than the other groups.

6.2.6 Psychological distress

Parents of children with developmental disabilities face challenges placing them at risk for high levels of stress and other negative psychological outcomes. Parenting a child with autism may pose additional stressors related to the child's challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding. Several studies reported increased psychological distress, including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic complaints and burnout, among parents of children with autism and related autism spectrum disorders (ASDs) in comparison to parents of typically developing children or parents of nonautistic children with mental retardation or other developmental disabilities. Studies by Bristol and Schopler (1983), reports that parenting stress is significantly higher in parents of autistic children when compared to parents of children who have Down syndrome, mental retardation, or are normally developing.

6.2.7 Physical Impact

Autism also has an indirect impact on the physical health of family members. Anxiety, depression, and exhaustion all take a toll on the physical health of families with children on the autism spectrum. Stress can lead to lowered immunity, and sleep deprivation may result in difficulty concentrating, memory impairment, and other health complications.

6.2.8 Financial Impact

Parents may also modify their family planning, worrying about having more children with disabilities, and adding to the financial burden of caring for an autistic child. Studies by Rodrigue, and Plenis, Robbins, & Dunlap report concerns about the availability and adequacy of financial resources. Parents in this study reported concerns about the financial costs incurred secondary to raising an autistic child and whether family income was sufficient to cover the child's current and future expenses (e.g., special schooling, therapy, medical services). Unlike developmentally normal children, who usually achieve financial independence, most children with autism require long-term financial resources. Most autistic children will remain dependent all their lives. Mothers of autistic children report that the caretaker burden is theirs, thus creating one-income households, adding further financial strain.

The financial impact on families of autistic children is enormous. Most private health insurance plans do not cover all expenses related to therapy and treatment for autistic children, and the co-pays for office visits and medications often results in huge financial debt. In addition to therapy and medical expenses, there are added financial burdens like specialized educational toys, equipment like weighted blankets and vests, and much more. According to a study in Pediatrics, having a child with autism resulted in an average of a 14% loss in total family income. It is often extremely difficult for both parents to continue working full-time, which means a reduction in household income to go along with the increased expenses. Since many parents need a full-time job in order to provide health insurance, loss of full-time employment can have a dramatic and negative impact on the family's finances.

6.2.9 Impact on Marriages

One of the biggest ways that autism impacts families is by placing additional stress on the parents' marriage. According to a study published in the Journal of Family Psychology, parents of children with autism were 9.7% more likely to get divorced than their peers. There are several ways that autism stresses the marriage:

- Often, parents accept the child's diagnosis in different ways and at different rates, leading to conflict.
- Inconsistent schedules and numerous commitments make it difficult for parents to spend time together.

- It can be challenging to find child care for children with autism, which also makes it hard for parents to go out as a couple.
- Financial stresses can cause additional conflict between parents.

6.2.9.1 Increasing Divorce Rate

It has been estimated that the divorce rate is in the 80% range in families with children who have autism (Bolman, 2006). Despite high rates of marital conflict, many couples do not reach out for couples therapy. Detrimental effects on marital relations could range from divorce, with one spouse completely separating themselves from the family, to arguments on who gets up with the child on sleepless nights. Also left out may be the pileup, and escalation of stressors that can result in separation (mentally or physically), or divorce.

6.2.10 Societal Problem

Gray (1993) reports that as a consequence of the behaviors of autism, many parents tend to isolate themselves and their families from social contact with the outside world, and furthermore, the social life that families do manage to maintain are restricted to their extended family, a few friends who can deal with their child's condition, or other families with autistic children. Rodrigue reports patterns of social withdrawal, less contact with extended family, changes in friends, fewer husband-wife activities, decreased church attendance, and fewer visits with neighbors. As a result of a study done by Sanders and Morgan, they conclude that the strong feelings the parents of autistic children have about their children's negative characteristics place them at higher risk for withdrawing into the family, and making less use of social supports and outside activities that may alleviate stress.

6.2.10.1 Social Stigma

In the case of autism, because there are no physical differences, social stigma comes from ignorance; it ranges from stares and hostile glances to social service agencies reporting physical abuse of a child who will not stop crying or has bruises from self-injurious behavior.

6.2.10.2 Feeling of Isolation

Also, the couple eventually feels isolated because they feel it is hard to take an autistic child to people's homes and are uncomfortable inviting people

over. Sometimes the couple becomes closer than ever, bonded in their shared circumstances.

6.2.11 Parental Sleeping Problem

The most important thing to realize is that autistic behaviors do not happen in a vacuum. They happen in a family system and therefore, they affect family life. For example, if a child with autism does not sleep through most of the night the parents will be affected. We have all heard the stories of parents of normal newborns, who, during the first few weeks or months, do not sleep through the night. Imagine having a child with autism, who, for the first twelve or more years of life not only does not sleep during much of the night, but also spends that time yelling, singing, repeating conversations, roaming around the house or trying to leave the house. The domestic problems may well extend beyond the home to strained relations with neighbours and to problems at work.

6.2.12 Family Stress

There is conflicting evidence on whether parents of children with autism endure more stress than parents of children without autism. Koegel, Schreibman, O'Neill, and Burke (1983) found that parents of children with autism did not differ significantly on measures of stress when compared to a normative group of happily married couples. However, McKinney and Peterson (1987) discovered that parents who have a child with autism endure more stress than parents of children without autism. It seems that the stressors of raising a child with autism that accumulate over time and the absence of adequate resources and support lead to depression and burnout.

The increased level of stress can take its toll on families with a child with a chronic disability. Crnic, Friedrich, and Greenberg completed a literature review of studies that assessed parental attitudes, personality, emotional difficulties, marital satisfaction and psychosocial problems related to raising a child with mental retardation. This study suggested that such families are at greater risk for numerous difficulties (e.g., marital, emotional, and physical problems) than families with nonretarded children. Studies of parents of children with autism report greater levels of stress and depression, and lower levels of marital intimacy than do parents of normally developing children. Mothers of children with chronic disabilities are more at risk for psychological disorders such as anxiety and depression. There is evidence that the very

nature of autism causes this condition to be more stressful for families than other childhood disabilities. The higher level of burden on the mother may explain the increased marital distress among families of children with disabilities. If the mother takes on the majority of the caregiving duties related to the child with autism, then the other children may receive less attention. In addition, the mother may have little time for herself or her husband because of the increased amount of caregiving time that a child with autism requires. The family may struggle to achieve a balance within the disrupted system and to acquire effective coping strategies.

6.2.12.1 Stress in families of autistic children

When families of autistic children with different types of handicaps are compared, families of autistic children report more coping problems and stress than families of children with other types of handicaps such as Down's syndrome or psychiatric disorders. Mothers of both Down's syndrome and autistic children reported similar problems of poor health, depressed moods, excessive time demands, and excessive reliance of their children on them, pessimism about the child's future, and limits on family opportunity (jobs, education, etc.) because of the autistic child. Mothers of autistic children, however, reported more problems and tension in areas such as taking their children to public places and more embarrassment and disappointment than parents of Down's syndrome children. Autistic children depend on care of others.

6.2.12.2 Family coping with stress

For some time now sociologists have been attempting to determine what factors in families precipitate family crises in the face of stress and what factors provide families with the resiliency which makes them "crisis-proof." Although many questions remain unanswered, there are some conclusions that can be drawn about family coping after more than three decades of research. It is clear that not every stressor, no matter how serious, causes a family crisis. Hill (1958) has proposed a classic, interactive model of family stress:



In this model the family's crisis-meeting resources and definition of the

problem mediate the family's ability to prevent a stressor event from creating some crisis in the family system. Although the severity of the stressor is important (Hill, 1958; McCubbin, 1979), what is equally important are the resources the family has to deal with that stress and the subjective definition the family makes of that stress. Single parents of handicapped children experience greater stress than parents with spouses. Mothers alone with adult-size autistic children may be physically unable to cope with them as they reach adolescence. The lack of an adult male in the home may precipitate residential placement of a child who might otherwise be able to continue living at home (Schopler E. & Mesibov G.B., 1985:269).

Siblings of autistic children may be the only persons besides the parents and teacher who can handle the management of their autistic brother or sister. This may present an enormous source of support for parents and give them precious opportunities to shop and do other things without worrying about the autistic child. On the other hand as siblings themselves enter adolescence they may be more self-conscious about having an autistic sibling and less willing to be seen in public with the family. Siblings may be dealing with fears of having handicapped children themselves. Many parents expressed concern that siblings were now at an age to leave home themselves and that soon one of the parents' best sources of support would be gone.

6.3 Impact on Siblings

Autism also affects neuro-typical siblings. These children face many of the same pressures as the rest of the family, and they may not have the full support of parents who are overwhelmed with the needs of their child with autism. Sibling rivalry can become more intense in a family with a mixture of typically developing siblings and children with autism. If the ASD child's need for extra time and attention becomes a permanent issue, as often happens with autism, siblings can feel left out, and resentment can build. However, many families are able to sort out these challenges as long as they can control other stress factors. A study in the *Journal of Autism and Developmental Disorders* found that the biggest predictor of sibling emotional adjustment was the presence or absence of other risk factors like low socio-economic status. If these factors were controlled, the experience of being a sibling to a child with autism actually enhanced the emotional and psychosocial health of the sibling. The challenges of having a brother or sister on the spectrum can have both positive and a negative effects on a sibling. The factors that affect how a

sibling adjusts include: family size, severity of the brother or sister's impairment, age of the sibling at the time of the diagnosis, gender and age of sibling, and their place in the birth order. The parents' attitudes and expectations have a strong bearing on how a sibling adjusts. Many siblings develop a maturity and sense of responsibility greater than that of their peers, take pride in the accomplishments of their brother and sister and develop a strong sense of loyalty. Siblings of ASD children are usually more tolerant of differences in people and show compassion of others with special needs. However, many siblings feel resentment at the extra attention the child with autism receives, and some feel guilt over their good health. When little, they may think they can 'catch' autism from their sibling. They may also feel saddled with what they perceive as parental expectations for them to be high achievers. Many feel anxiety about how to interact with their brother or sister, and feel rejected by the lack of reciprocity. Often there is a feeling of resentment at having to take on extra household chores, coupled with restrictions in social activities. When one of the parents has AS, this creates another set of challenges.

6.3.1 Sibling stress and implications

There appear to be both positive and negative effects on siblings of living with a child with autism. A recent study by Gold of MacMaster University compared the siblings of autistic boys to those of a control group and found that brothers and sisters of boys with autism scored significantly higher on depression than the comparison group, but not on problems of social adjustment. Children with a sibling with autism appeared to be more embarrassed in the presence of other children and peers than children in other groups, such as mentally retarded or Downs syndrome children, most likely because of the bizarre behaviors. In one of the few comparative investigations of autistic children, DeMyer (1979) studied 59 brothers and sisters of autistic children and 67 siblings of normal controls. She found more children in the autistic group (30%) reported feelings of being neglected; 18% reported worries and anxieties associated with the condition; and 15% of parents reported problems of toileting and eating.

Rates of language-related problems, such as early speech delays, or later reading and spelling problems, are significantly higher in the siblings of autistic children than in other families. Amongst other types of difficulties reported in normal siblings are feelings of guilt and fears that they may

somehow be responsible for the condition. Identity problems have also been noted, with the normal child having secret fears that he or she, too, might be affected in some way. Psychological stress is reported frequently. Siblings may feel the need to over-achieve or make up for the limitations of the autistic child. They may feel under pressure to provide for the needs of their autistic sibling, as the parents grow older and eventually deceased (Howlin, 1988). Bolton et al. (1994) found that 3% of the siblings of the children with autism had been diagnosed with autism as well, while 6% was diagnosed with a pervasive developmental disorder (PDD). Excluding the siblings with PDD, between 12% and 20% of the siblings exhibited milder forms of social and communication deficits.

6.3.2 Worrying About the Siblings of Autistic Children

Whether the child with autism is the first-born, in the middle, or the baby, parents often worry about the effect that dealing with the autism -- and the time commitment it involves -- will have on the other children. "I think most parents bend over backward so it doesn't affect the other children," says McCarton. In a recent study published in the *Journal of Autism and Developmental Disorders*, researchers compared siblings of autistic children with siblings of non-disabled children and found those with the autistic sibling were actually better adjusted psychosocially and emotionally. They did find, however, that it's more difficult for the non-disabled child to cope with the autistic sibling if multiple risk factors such as low income are present.

Susan Senator, the Boston-based author of *Making Peace with Autism*, says that siblings may also form a very close bond with each other, helping one another cope with the fact that their brother or sister has autism. Senator's son Nat, now 18, has autism. Her sons Max, 16, and Ben, 10, have a close bond. "They seem to really support each other," she says, even though there is the six-year age difference. "The kids have to figure out how they are going to relate to their sibling with autism," Senator says, "and that changes over the years." The siblings may have different reactions, as Senator knows. "My middle son is mellow and accepting. The little one said Nat ruined his life," she says. "I have to have hope it will change."

6.4 Problems of Grandparents

Unlike the parents who are totally focused on the autistic child's needs, grandparents are concerned about the effects of autism on their adult children

(the parents), other grandchildren and future generations. They also suffer stress similar to that of parents and siblings. Grandparents are concerned about the difficult situations they see their own children experiencing. They may provide the autistic child's parents (who may be depressed, single, or divorced) with necessary support in the way of childcare, financial support and advocacy. But, they may also contribute to stress because of conflict regarding behavioral symptoms and treatment (Hillman, J. 2007). Sometimes grandparents get involved in the blame-game about the possible causes of the child's autism, which can be particularly terrible if the couple splits up and there are disputes over custody. Grandparents may want to help by babysitting, but most do not have the training in behavior management or may not have the physical strength required to handle behavioral episodes. They may just want to play with the child and spoil him/her, and end up feeling rejected by the lack of 'typical' exchange.

7.1 Summary

1. Autism is found to be associated with several other conditions like genetic disorders, mental retardation, epilepsy and metabolic defects, is one group of developmental disorders that has lifelong consequences. Autism is the particular social impairments and thought disorder in some of his patients for whom he introduce the label æschizophrenic.”
2. The diagnosis of autism is based on the criteria developed by Creak and revised by Rutter and the NSAC (Schopler & Rutter, 1978). The features of the disorder are- the child is impaired in his interpersonal and social relationships; speech and language are absent, delayed, or peculiar; the child shows repetitive and ritualistic behaviours and becomes upset when these are interfered with; and the onset of the disorder is early in life, before 3 years of age. 53.33% parents diagnose autistic problem 3-5 years of their children and 33.33% parents diagnose autistic problem 0-2 years of their children.
3. The causes of autism is unknown. Medical sciences did not discover the real causes of autism. For this reason in my study it is clear that 48.88% parents don't know about the causes of their child Autistic Spectrum Disorders (ASD).
4. Autistic children have different problem. In my study I describe the basic problem of autistic children. Among them 42.22% parents say that their children have language and communication problem. 15 out of 20 parents say, their children have delay or lack of spoken language. 22.22% parents say about inability to sustain conversation with other. 11 out of 20 parents say about stereotyped and repetitive use of language of their children. They may have delayed or a total lack of spoken language. They may exhibit social impairments that can be seen in the lack of spontaneous make-believe play or imitative play that is appropriate to their developmental level. Most of the Autistic child talks in a single word which is broken sometimes. Thus the speech is very vague for understanding of others. Repetitive speech can also disrupt attempts to foster more normal conversation. Even before they acquire language autistic children show deficits in communication.

5. 15.56% parents say, their children face behavioural problem. 10 out of 20 parents observe the rigid behaviour of their children. 11.11% parents observe the self-injuries behaviour of their children. 55.56% parents say about their child's stereotyped motor mannerisms problem. Autistic children are given to stereotypical behavior, peculiar ritualistic hand movements, and other rhythmic movements, such as endless body rocking, hand flapping, and walking on tiptoe. They spin and twirl string, crayons, sticks, and plates, twiddle their fingers in front of their eyes, and stare at fans and spinning things. These are often described as self-stimulatory activities. These behaviors may not have any significance in young babies, but they are strongly associated with autism if they persist in childhood.
6. 33.33% parents say, about the lack of social developmental problem of their children. 17.78% children cannot share with other. 31.11% cannot develop peer relationship.
7. Children with high-functioning autism suffer from more intense and frequent loneliness compared to non-autistic peers, despite the common belief that children with autism prefer to be alone. Making and maintaining friendships often proves to be difficult for those with autism. 8 out of 20 parents say about loneliness of their children and 25% teachers say that autistic children normally cannot interact with other.
8. Sleeping problems can have far-reaching repercussions on family life. Some parents may struggle for hours in the evening or at night to calm their child down and to get him to sleep. Some parents decide to take the child to their own room, or to sleep in his room. Sooner or later they will become moody and overtired, and some will eventually be completely exhausted. Sleep disorders may be even more common in children with autism. The biggest sleep problems among these children include: Difficulty falling asleep, Inconsistent sleep routines, Restlessness or poor sleep quality, waking early and waking frequently. A lack of a good night's sleep can affect not only the child but everyone in his or her family. 28.89% autistic children face sleeping problem.

9. Handing play equipment to low-functioning autistic children usually results in its misuse or inappropriate use and in no increase in socialization of the children. Socialization and play must be taught, and can be taught, to varying degrees. Autistic children cannot continue the role of socialization, they have no awareness about socialization.
10. Most of the autistic child cannot eat as like normal child. 31.11% face eating problem, 20% children face toileting problem, 20% face playing problem according to quantitative data in my study.
11. Sensory integration problem is the major problem of autistic children. 20% children fail to share emotional expression. 33% children have hearing problem and 15% children do not feel pain in their body.
12. Most of the parents face different problem of their autistic children. 8.89% parents face financial, 44% face stress, 28% face social stigma, 6% face divorce problem.
13. Autistic children cannot go alone. All time they depend on other, autistic children cannot interact with other and sometimes neighbors, relatives do not help them.
14. The rearing cost of autistic children is high. Middle class family can not admit their autistic children in especial institution.
15. After admitting in autistic institutions, most of the autistic child get improvement. Because, the teacher of those institutions is helpful to the children, they teach them different training, provide therapy etc.
16. Routine is essential for almost everyone if they are to organize their lives in an effective way: leaving the house at a certain time, eating at regular intervals, developing regular patterns for washing, dressing, going to work or even pursuing leisure activities can be crucial if life is to run smoothly. It is only when such habits become so fixed that they disrupt other activities, or when a behaviour that was once acceptable can no longer be tolerated because of changing circumstances or expectations that problems occur.

17. The key difference between social motivation and social cognition accounts is one of causality. In the social motivation framework, diminished social interest is thought to deprive the developing child of social inputs and learning opportunities, which, ultimately, leads to diminished expertise in social cognition. Social cognition deficits, which constitute a downstream consequence of diminished exposure to the social world, might only appear in a subgroup of individuals, while social motivation deficits, which are primary, ought to appear in all or nearly all with ASD. Social motivation deficits should precede social cognition deficits in ontogeny.
18. Theory of mind difficulties can provide a possible explanation for the communication and social challenges that define autism spectrum disorders. Howlin, Baron-Cohen, and Hadwin (1999) further identified deception, empathy, self-consciousness, and the use of persuasion as being dependent on theory of mind understanding. Theory of mind, the ability to attribute mental states to self and others in order to understand and predict behavior, is an area of weakness for individuals across the autism spectrum.
19. The excess of boys over girls with autism, at a ratio of 4:1 on average, is now well established, and the excess in Asperger syndrome is even likely to be in the region of 15:1. Boys predominate much less at lower levels of ability. One early study by Cathy Lord (1982) and colleagues that addressed gender differences reported results from 384 boys and 91 girls, aged three to eight years. All children were seen between 1975 and 1980 and were thoroughly investigated by psychological tests and interviews taking into account each child's development. The ratio of boys to girls was 5:1 at the higher end of the ability range and only 3:1 at the lower end. A 2009 US study found the average age of formal ASD diagnosis was 5.7 years, far above recommendations, and that 27% of children remained undiagnosed at age 8 years. Experts estimate that 1 out of 88 children age 8 will have an ASD (Centers for Disease Control and Prevention: Morbidity and Mortality Weekly Report, March 30, 2012). Males are four times more likely to have an ASD than females.

20. May have a good rote memory, especially for numbers, letters, songs, TV jingles, or a specific topic. Children may be highly skilled in one area, such as painting. Hypersensitivity can lead to unexpected outbursts of fear or rage. It can also contribute to a severely restricted behavioral repertoire, for instance wearing only certain clothes, and eating certain foods. These sensory peculiarities often persist and can be found at all ages.
21. During the interview, every family described feelings of sadness, loss, anger, and desperation when their child was diagnosed with autism. It seems that the mothers were more likely than the fathers to quickly “overcome” these feelings and mobilize their resources to find aid for their child. Many fathers seemed to withdraw for a period after the family received the diagnosis. For the majority of families in this sample, both parents spent much of their time researching causes of autism and possible treatments for their child.
22. There have not sufficient role of government in Bangladesh. Lack of autistic specialized school, training centre, treating institution, rearing facility create problems for autistic children. Parents face social stigma. For this reason, parents claim to government for proving the facilities of autistic children like development countries.

7.2 Conclusion

The syndrome was first identified in 1943 by a psychiatrist at Harvard, Leo Kanner, who noticed that eleven disturbed children behaved in ways that were not common in children with mental retardation or schizophrenia. He named the syndrome early infantile autism; because he observed that there is from the start an extreme autistic aloneness that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside. Autism spectrum disorders are a group of related brain-based disorders that affect a child's behavior, communication, and social skills. These disorders include autistic disorder, Asperger syndrome, and pervasive developmental disorder, not otherwise specified. They are defined by the number and severity of the symptoms. Because most children with ASDs will master early motor skills such as sitting, crawling, and walking on time, parents may not initially notice delays in social and communication skills. Looking back, many parents can recall early differences in interaction and communication. From the time it was first distinguished, autistic disorder has had a somewhat mystical aura. Kanner considered autistic aloneness the most fundamental symptom, and he also found that these eleven children had been unable from the beginning of life to relate to people in the ordinary way. They were also severely limited in language and had a strong obsessive desire for everything about them to remain exactly the same. Although the social withdrawal and inappropriate affect seen in autistic children may appear similar to the negative symptoms of schizophrenia, autistic children do not exhibit hallucinations and delusions and do not grow up to become schizophrenic adults. Autistic disorder begins in early childhood and can be evident in the first weeks of life. Studies show that about four times more boys than girls have autism. Autism is found in all socioeconomic classes and in all ethnic and racial groups. Autism is likely the result of multiple factors. These factors can be genetic, infectious, neurologic, metabolic, immunologic, and environmental. Early theories of the causes of autism centered on the concept of emotional deprivation. It was believed that autism was caused by a lack of maternal warmth. Characteristics of autism include poor or non-existent toilet skills, refusing food, aimless wandering with no fear of getting lost, climbing on dangerous and inappropriate objects such as kitchen counters, roofs, railings, and little or no communication. Echolalia, the repeating of sounds and words, is quite common. Autistic individuals repeat words, sentences, and

sometimes whole songs and movies. They may excel on the computer, yet cannot ask for a glass of milk, and in some cases cannot chew food. There is no comprehension of hygiene, or respect for others or their property. Bizarre body movements and stiffening of the body are often present. Biting, pinching, and hitting, themselves and others, is usually accompanied by tantrums.

7.3 Recommendation

- ✓ Parents of autistic children say that for the future life of their children, Govt. should construct a centre for autistic children.
- ✓ Govt. should create the awareness among the people about autism.
- ✓ Parents want to good behaviours from relatives and neighbours for interacting with their children.
- ✓ There have not enough especial school for autistic children, parents claim a especial school for their children.
- ✓ We need various treatment centres for autistic children in every places of Bangladesh.
- ✓ Govt. should provide the facility for the middle and lower class autistic child family.
- ✓ General people should good behave with autistic children and their family members.
- ✓ In home, there is a need to have some playing tools. In school they follow a well defined routine and the home environment should contain such a routine to discipline them. Such discipline has been proved too good for the autistic children.
- ✓ Autism erodes family happiness and health. Parents as well as their other children need training, respite, and counseling. Parents need to be helped to see that residential placement is the logical aftermath of the early home years, to be sought without guilt. It is not the white flag of poor parenting; it can be the supreme act of good parenting, and can result in the rescue and rehabilitation of an entire family.
- ✓ Neighbours should not ignore the autistic child's family members.
- ✓ There have need strong laws for the future of autistic children in Bangladesh.

- ✓ All the people of the Bangladesh should express good behaviours about autistic children and their family members.

REFERENCES

- ✚ Altieri, M. J. (2006). *Family functioning and coping behaviours in parents of children with autism. Unpublished doctoral dissertation*, University of Eastern Michigan, EE. UU.
- ✚ American Psychiatric Association (2000). *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision*. Washington, DC: American Psychiatric Publishing, Inc.
- ✚ Ashum Gupta and Nidhi Singhal(2005) Asia Pacific Disability Rehabilitation Journal, Vol. 16 No. 2.
- ✚ Autism Society of America, 2008. æFamily Life.” <http://www.autism-society.org>
- ✚ Baird G., Charman , T., Baron-Cohen, S., et al.(2000) A screening instrument for autism at 18 months of age : A 6-year follow-up study , *Journal of The American Academy of Child and Adolescent Psychiatry* ,39,694-702.
- ✚ Baker, B. L., Brookman L., & Stahmer, A. (2005). Stress level and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, 30 (4), (194-204).
- ✚ Baron-Cohen, S. (2005), Autism, in Hopkins, B. *The Cambridge Encyclopedia of Child Development*. Cambridge: Cambridge University Press. 398 – 401.
- ✚ Bogdashina, Olga. (2004). *Communication issues in Autism and Asperger syndrome: Do we speak the same language?*. London: Jessica Kingsley Publishers.
- ✚ Bolman, W. (2006). æThe Autistic Family Life Cycle: Family Stress and Divorce.” asa.confex.com/asa/2006/techprogram/s1940.htm.
- ✚ Bryson, S.E., B.S. Clark, I.M. Smith (1988). First report of a Canadian epidemiological study of Autistic Syndromes. *Journal of Child Psychology and Psychiatry* 29, 433-45.

- ✚ Bristol, M. (1987). Mothers of children with autism or communication disorders: Adaptation and the Double ABCX. *Journal of Autism and Developmental Disorders*, 17(4), 469-484.
- ✚ Bristol, M.M. (1985). Designing programs for young developmentally delayed children: *A family systems approach to autism*. Remedial and Special Education, 4(6), 46-53.
- ✚ Bristol, M.M., & Schopler, E. (1983). Stress and coping in families of autistic adolescents. In M.E. Schopler & G.B. Mesibov (Eds.), *Autism in adolescents and adults* (pp. 251-278). New York: Plenum Press.
- ✚ Bromley J, Hare DJ, Davison K, Emerson E (2004). Mothers supporting children with autistic spectrum disorders: *social support, mental health status and satisfaction with services*. 409– 423
- ✚ Cassidy, A., McConkey, R., Truesdale-Kennedy, M., & Slevin, E. (2008). Preschoolers with autism spectrum disorders: The impact on families and the supports available to them. *Early Childhood Development and Care*, 178(2), 115-128.
- ✚ Centers for Disease Control and Prevention. (2009). *Prevalence of autism spectrum disorders - ADDMN, United States, 2006*. MMWR 58(SS-10).
- ✚ Ciadella, P. & N. Mamelie (1989). An epidemiologica study of infantile autism in a French Department (Rhône): a research note. *Journal of Child Psychology and Psychiatry* 30, 165-75 .
- ✚ Cleveland, D.W., and Miller , N. B. (1977), *Attitudes and Life commitmentds of Older siblings of Mentally retearded Adults : An exploratory study . Mental Retardation*, 15,38-41.
- ✚ Clarke, P & M Rutter (1981), Autistic Children's Responses to structure and Interpersonal demands. *Journal of Autism and Developmetnt Dosorders*, 11,201-17
- ✚ Creswell, J. W. (2008) *Educational Research: Planning, conducting and Evaluating Quantitative & Qualitative Research*, (3rd ed). New Jersey: Pearson Education, Inc.
- ✚ Creswell, J. W. (2009), *Research Design: Qualitative, Quantitative and Mixed Method Approaches* (3rd ed.) Thousand Oaks, CA: Sage Publication.
- ✚ DeMeyer, M. K. (1979). *Parents and children in autism*. Washington, DC: V. H. Winston.

- ✚ Davison Gerald C. & Neale John M., (1998) *Abnormal Psychology*, John Wiley & Sons, Inc.
- ✚ Elisabeth L. Hill (2004), *Trends in Cognitive Sciences* Vol.8 No.1, pp.26-32
- ✚ Firth, Uta. (1989). *Autism: Explaining The Enigma*, Blackwell Publishing.
- ✚ Frith, U., & Happé, F. (1994). Autism: Beyond 'theory of mind'. *Cognition*, 50 , 115-132.
- ✚ Gerdener, H. Spiegelman, D. & Buka, SL. (2009), *Parental risk factors for autism. Comprehensive meta-analysis. P 7-14.*
- ✚ Gillberg,C. & Coleman, M. (2000). *The Biology of the Autistic Syndromes*. 3 Rd Ed. London: Mac Keith Press.
- ✚ Gray D. E.(2006), *Journal of Intellectual Disability Research* .Volume-50, Part.12, PP 970-976.
- ✚ Gray D. E. (1994) Coping with autism: Stresses and strategies. *Sociology of Health and Illness* 16, 275–300.
- ✚ Gray, D. E. (1993b). Perceptions of stigma: the parents of autistic children. *Sociology of Health & Illness*, 15, 102–120.
- ✚ Happé, F., (1994). *Autism: An introduction to psychological theory*. Cambridge, MA:Harvard University Press.
- ✚ Hill, R. (1958), *Sociology of Marriage and Family Behavior* , 1945-1956: A rend report and bibliography. *Current Sociology*.
- ✚ Howlin, Patricia. 1991, *Autism: Preparing for adulthood*, Routledge, London and New York.
- ✚ Kanner, L.(1943) Autistic disturbances of affective contact, *Nervous Child* , 2,217-50. Reprinted in L. Kanner , *Childhood Psychosis*; Initial studies and *New Insights* (Wanshington, DC : V.H. Winston, pp -247)
- ✚ Kaminsky L, Dewey D. (2002), *Psychosocial adjustment in siblings of children with autism*. *Journal of Child Psychology and Psychiatry and Allied Disciplines* 2002; 43: 225-232.
- ✚ Kraijer, Dirk. (1997), *Autism and Autistic- like conditions mental retardation*, Swets & Zeitlnger Publishers.
- ✚ Lazarus R. S. (1996) The role of coping in the emotions and how coping changes over the life course. In: *Handbook of Emotion, Adult*

- Development, and Aging* (eds C. Magai & S. H. McFadden), pp. 289–306.
- ✚ Lynn Koegel, Rosy Matos-Fredeeen, Russell Lang, and Robert Koegel, (2011), *Cognitive and Behavioral Practice*, PP.1-12 Available online at www.sciencedirect.com
 - ✚ Marcus L. (1977) Patterns of coping in families of psychotic children. *American Journal of Orthopsychiatry* 47, 383–99.
 - ✚ Meltzoff, A. N. & M. K. Moore 1977. Imitation of facial and manual gestures by human neonates. *Science* 198, 75-8.
 - ✚ Neuman W. Lawrence, (1997). *Social Research Methods: Qualitative & Quantitative Approach*, Allyn and Bacon.
 - ✚ Pilar Pozo, Encarnación Sarriá and Ángeles Brioso (2011) "Psychological Adaptation in Parents of Children with Autism Spectrum Disorders" Available online at www.sciencedirect.com
 - ✚ Punch Keith F. (1998), *Introduction to Social Research: Qualitative & Quantitative Approaches*. Sage Publications, London.
 - ✚ Rett , A. (1966). Ube rein eigenartiges hirntophisches Syndrome bei Hyperammonie im kindersalter . *Wein Medizinische Wochenschrift* ,118, 723-6
 - ✚ Rimland, B. & A. L. Hill (1984), Idiot savants. In *Mental retardation and developmental disabilities*, Vol. 13, Wortis, J.(ed), 155-69.New York: Plenum Press.
 - ✚ Rogers S. J. & DiLalla , D. L.(1990). Age of sympom onset in young children with pervasive development disorder . *Journal of The American Academy of Child and Adolescent Psychiatry* , 29, 863-72.
 - ✚ Rutter, M. (1983) Cognitive deficitsin the pathogenesis of autism, *Journal of Child Psychology and Psychiatry*, 24, 513-31, p-526
 - ✚ Rutter , M. (1985). The treatment of autistic children . *J. Child Psychol. Psychiatr.*, 26, 193-214.
 - ✚
 - ✚ Rutter ,M., & Scholper , E. (1978), Autism : *A reappraisal of concepts and treatment* . New York : Plenum Press.
 - ✚ Rutter ,M., & E. Scholper , E. (1987), Autism and pervasive development disorders: conceptual and diagnostic issues. *Journal of Autism and Developmental Disorders* 17, 159-86.

- ✚ Ruiz, R.J. & Avant, K.C. (2003). *Effects of Maternal parental stress on infant outcomes. A Synthesis of the literature*. ANS Advances in Nursing Science, (345-355).
- ✚ Schopler , E., Ruuter , M., & Chess , S. Editorial: (1979), Change of journal scope and title . *Journal of Autism and Developmental Disorders*, 9, 1-10.
- ✚ Schopler, E., Meisbov , G., DeVellis , R., & Short , A. (1981), Treatment outcomes for autistic children and their families . In *Frontiers of Knowledge in mental retardation* , Vol. I (P. Mittler , ed.) , Baltimore : University Park Press.
- ✚ Schopler, Eric. And Mesibov B Gray. (1985) *Autism In Adolesnts and Adults*, Plenum Press, New York and London.
- ✚ Shapiro, T.D., M. Sherman, G. Calamari, D. Koch (1987). Attachment in autism and other development disorders. *Journal of the Academy of Child and Adoloscent Psychiatry* 26, 480-84.
- ✚ Sigafos, J., Arthur, M., & O'Reilly, M. (2003). *Challenging behavior and developmental disability*. London: Whurr.
- ✚ Sigman M., Mundy P., Sherman T . and Ungerer J. (1987) . *Social interactions of autistic Mentally retarded and normal children and their care- givers* . *Journal of Child Psychology and Psychiatry* , 27, 647-656.
- ✚ Sloper P, Turner S (1993). *Risk and resistance factors in the adaptation of children with severe physical disability*. *Journal of Child Psychology and Psychiatry*; 34: 167-188.
- ✚ Steffenbrg, S & G. Gillberg (1986), Autism and autistic-like conditions in Swedish rural and urban areas: a population study. *British Journal of Psychiatry* 147, 81-7.
- ✚ Szatmari, P. & M. B. Jones (1991). IQ and the genetics of autism. *Journal of Child Psychology and Psychiatry* 32, 897-908.
- ✚ Taylor, J., & Seltzer, M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 40, 1431-1446.
- ✚ Volkmar, Fred. R. (1998), *Autism and Pervasive Developmental Disorders*, Cambridge University Press.
- ✚ Wing, L. (1988), The continuum of autistic characteristics. In *Diagnosis and assessment in autism*, E. Schopler & G. B. Messibov (eds), 91-110. New York: Plenum Press.

- ✚ Wing, L. & J. Could (1979). Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders* 9, 11-29.

APPENDIX -1
Questionnaire
Department of Sociology
University of Dhaka

Research Title: - Problems of Autistic Children and their Families: A study in the Urban Areas of Bangladesh

Consent: I am a student of M.S.S (2nd Semester) in Department of Sociology in University of Dhaka. I have a thesis on the title mentioned above, assigned by the Department of Sociology as a partial fulfillment of the Masters degree of Social Sciences final examination. You are selected as a respondent for giving related research information. It is assumed you that all of your information will be used only for research and will be kept absolutely confidential as well.

Respondent No.

Information Collector's

Signature & date

Part 1: Personal and family Information of respondent

1. Age of Autistic child:
2. Sex : ☐ Male ☐ Female
3. Religion : ☐ Islam ☐ Hindu ☐ Christian ☐ Buddhist
4. Present Address :
5. Father or Guardian name of Autistic Child :
6. Information about the family :

Sl no.	Relation	Age	Sex	Marital Status	Relationship with Autistic Child	Education	Occupation	Income	Comment

Part 2: Questions to the family members (Parents, siblings, etc)

7. When your child was first diagnosed with an Autism Spectrum Disorder?

☐ 0- ☐ 3- ☐ 6-8
☐ 9- ☐ 12-14 ☐ 15+
8. What is the possible cause of Autism Spectrum Disorder of your child?

☐ Unknown
☐ Environmental
☐ Neurological
☐ Genetically

- ☐ Malnutrition ☐ Pregnancy cause
9. What kind of problem does your child have in particular?
☐ Sensory integration dysfunction ☐ Language and communication problem
☐ Social developmental problem ☐ Behavioural problem
10. What kind of language and communication problem
☐ Stereotyped and repetitive use of language ☐ Delay or lack of spoken language
☐ Inability to sustain a conversation ☐ Facial expression
☐ Pronoun reversal
11. Which behavioural problem do you overlook in your autistic child?
☐ Self-injuries behaviour ☐ Unusual obsessions
☐ Stereotyped and repetitive motor ☐ Destructive behaviour
☐ Compulsive behaviour ☐ Other
12. What kind of social developmental problem survives in your child?
☐ Social cues ☐ Sharing
☐ Fail to develop peer relationship ☐ Responsiveness
☐ Lack of social or emotional reciprocity
13. What kind of daily life problem does your child have in particular?
☐ Sleeping problem ☐ Toileting problem
☐ Plying problem ☐ Eating problem
14. What kind of sensory integration problem persists in your child?
☐ Fail to share emotions or experiences ☐ Poor imagination
☐ Doesn't seem to feel pain ☐ Hearing problem
☐ Unusual sensory experiences
15. Do you face any problem for your autistic child?
☐ Yes ☐ No
 (If the reply is positive, what type of problem do you face?)
☐ Financial ☐ Stress ☐ Social stigma ☐ Divorce ☐ Sleeping
16. Does your child imitate you?
☐ Yes ☐ No
17. Does your child respond to his/her name when you call?
☐ Yes ☐ No
18. Does she/he find it easy to interact with other children?
☐ Yes ☐ No
19. Does she/he make normal eye-contact?
☐ Yes ☐ No

20. Has your child been treated even for Autism?

☐ Yes ☐ No

(If the reply is positive, what was the nature of treatment?)

☐ Therapy ☐ Autistic institution ☐ Autistic hospital
☐ Child specialists ☐ In abroad for higher ☐ Other

(If the reply is negative, then what is the cause?)

☐ Fear of public disgrace ☐ Ignorance ☐ Economic hardship ☐ Other

21. Do you find any improvement after treatment or admitting his / her to the institution?

☐ Deteriorate ☐ As ☐ Few changes ☐ No ☐ Remarkable

22. What kind of obstacle to achieve education faced by Autistic children who go to school?

☐ Obstacle to move ☐ Helpless of class- ☐ No obstacle
☐ Lack of care by teacher ☐ Other

23. Does your child take part in various social and religious ceremonies?

☐ Yes ☐ No

24. What is the attitude of the other household members towards Autistic Child?

☐ Very good ☐ Very bad ☐ Friendly
☐ Burden on family ☐ They feel pity

25. What types of attitude is chosen by the neighbors to the person with Autistic?

☐ Disgrace to the family in the eye of ☐ Very good
☐ They find something interesting ☐ They feel pity towards of
☐ Nothing to do with ☐ Other

26. Do you willingly introduce Autistic Child with relatives, when they come your house?

☐ Yes ☐ No

27. Do you think the rearing of autistic child is more expensive than normal one?

☐ Yes ☐ No

28. In rearing your autistic child, do you need to borrow money from others on a monthly basis?

☐ Yes ☐ No

29. What is your opinion about the activities of GOs and NGOs regarding this issue?

☐ Sufficient ☐ Not sufficient ☐ Don't know

Part 3: Question to the teachers (school, band directors, etc)

30. What is your child's current diagnosis on the Autism Spectrum?

☐ Autistic disorder ☐ Asperger's ☐ Rett's syndrome
☐ Pervasive developmental ☐ Childhood disintegrative

31. How much cost for a single Autistic Child in your institution?
☐ 2500-3000 ☐ 3000-3500 ☐ 3500-4000
32. Is it possible for middle class family to bear the cost of your institution?
☐ Yes ☐ No
33. What are the autistic student's problems and weaknesses?
☐ Lack of understanding ☐ Communication problem
☐ Speaking problem ☐ Problem of education achieving
34. Please share some challenges you experienced to teach autistic children.
☐ Face unusual behaviour ☐ Cannot cope with children
☐ Disturbance ☐ Sadness
35. Do you agree that Educational Institutions are effective to improve the problems of Autistic Children?
☐ Yes ☐ No
36. What kind of limitation do you face in your institution?
☐ Not enough ☐ No sufficient ^{teacher} ☐ No fund ☐ No help from govt.
37. Do you agree that teaching methods are helpful for autistic children?
☐ Yes ☐ No
38. Can any autistic child be as good as normal child?
☐ Yes ☐ No
39. Do you know about any existing law or rights on autism?
☐ Not at all ☐ Very few ☐ Hardly ☐ Don't know

'Thanks for your endurance interview'

Appendix-2

Interview Schedule for Parents

This interview is assigned by the Department of Sociology, University of Dhaka as a Master's Theses on the title **æ Problems of Autistic Children and their Families: A Study in the Urban Areas of Bangladesh.** The interview will be used for research purpose only and your information and answer will be treated strictly confidentially.

Please, give me the answers of the following questions.

1. What is your name?
2. How old are you?
3. What kind of problem does your child face?
4. What kind of problem do you face in your daily life for your autistic child?
5. How do you feel stress for your child?
6. Please share some challenges you experienced for your autistic child.
7. Does your child participate in social activities?
8. Please share some experiences of sadness in your child. Stories of challenges?
9. Can you illustrate the impact of having a child with autism on inter family relationship? For example how do you, as a parent, ensure that the needs of the individual family members are met?
10. Can you describe your child's relationship with his peers within and outside of school?
11. Is there any kind of disturbance in the family for the person with Autism?
12. How the family members face the problems of social interaction with neighbors?
13. How parents face socially disapproval with Autism?
14. What are your hopes and dreams for your child?
15. What are your plans for equipping your child for the future?
16. Do you know about any existing laws or rights of Autistic Child?
17. Is there anything else you would like to tell me about your Autistic Child?

Appendix-3

Interview Schedule for Teachers

This interview is assigned by the Department of Sociology, University of Dhaka as a Master's Theses on the title **æ Problems of Autistic Children and their Families: A Study in the Urban Areas of Bangladesh.** The interview will be used for research purpose only and your information and answer will be treated strictly confidentially.

Please, give me the answers of the following questions.

1. What is your name?
2. How old are you?
3. What kind of problem do you look in autistic child?
4. What kind of problem do you look in family members of your autistic child?
5. Please share some challenges you experienced about autistic child at teaching period?
6. Does autistic child participate in social activities?
7. Can you describe autistic child's relationship with his peers within and outside of school?
8. How the family members face the problems of social interaction with neighbors?
9. How parents face socially disapproval with Autism?
10. What are your hopes and dreams for autistic children?
11. What are your plans for equipping autistic children for the future?
12. Do you know about any existing laws or rights of Autistic Children?
13. Is there anything else you would like to tell me about your Autistic Children?

Appendix-4

FGD with Parents and Teachers

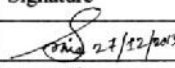
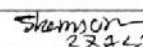
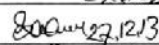
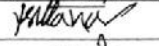
- FGD 1: Multi dimensional challenges of Autistic children.
- FGD 2: Divergent problems faced in family sphere stemmed from having autistic children.
- FGD 3: Coping and adaptation strategies of family members for the autistic children.
- FGD 4: Role of teachers in the challenges of autistic children.

Signature of FGD Respondents

FGD No-01					
S.L	Name	Age	Occupation	Education	Signature
1	Shamimun Noor	30	Housewife	M.M.S.	
2	Sabina Yasmin	38		M.M.S.	
3	AFSANA AKTER	54	Home-Maker	H. Com (WU) M.B.A	
4	Roshan Jahan	30	House wife	M.A. (Eco)	
5	Asma Hassan	32	House wife	B.SS	
6	Sayedur Rahman	29	P. Service	M.S.C	

FGD No-02					
S.L	Name	Age	Occupation	Education	Signature
1	AYESHA	38	Housewife	M.S.S.	
2	Gumfira	61	Student	W.D.W.D	
3	জিয়াবী	60	শ্রমিক	H.S.C.	
4	Rabeya	32 year	Student	H.S.C.	
5	জিয়াবী	30	শ্রমিক	H.S.C	
6	FARZANA HOSSEN	35	Private Service	M.S.C	

FGD No-03					
S.L	Name	Age	Occupation	Education	Signature
1	Sharifa Begum	33	House wife	S.S.C	
2	DR. BAZI HENA FERDUS	35 year	Medical Doctor	M.B.B.S, M.P.H.	
3	জিয়াবী	34	House wife	M.A.	
4	SHARMIN AKTER	37 year	House wife	M.S.C	
5	HASINA AKTER	38 year	House wife	M.A	
6	Rabia Sultana	43	House wife	S.S.C	

FGD No-04					
S.L	Name	Age	Occupation	Education	Signature
1	Sonia Sabirin	27	Psychologist	MS	
2	Mr. Abul Bashir	28	Teacher	M.M.S	
3	Shamsunahar	29	Teacher		
4	Shahana Islam	24	Assistant teacher	B.O.S	
5	Yuliana	28	Assistant teacher	M.S	
6	Md. Bayezid Rostami	28	"	H.S.C	

Appendix-5

Case Study- 01

Before her son was 15 months old, Serwah Quaynor suspected that something was wrong. After going from doctor to doctor in the United States searching for answers, Quaynor's son was labeled "mildly autistic" at the age of 8. It took four more years and a two-week home-visit with a psychologist before he was finally diagnosed with full-fledged autism. "For him to get the proper treatment, he had to have a proper diagnosis," Quaynor said. But the diagnosis was just the beginning. As puberty and hormones hit, her son became aggressive. He required more attention and care than Quaynor could offer him alone, especially considering her own health problems. Despite her reservations about the lack of resources available to autistic children and their families in Ghana, Quaynor decided to join her husband who had moved to Accra a few years earlier to start a business. "Ghana was the only place I could get the support I needed," Quaynor said. The idea of starting a support group for families with autistic children had been in the back of her mind for years, but never did it occur to Quaynor that she would one day be the recipient of the Ayekoo Excellence Foundation Award for her success in establishing a non-profit organisation that provides care to autistic children, trains parents, educators, and caregivers about dealing with autism, and spreads awareness throughout Africa.

AACT (Autism: Awareness, Care, and Training) had only 8 members when it was formally established in 1999. Today, the center provides care to more than 30 children and their families. "Children with any kind of handicap are marginalised all over the world," Quaynor said, "but especially in Ghana. It is the fastest growing developmental disease in the world, and it is here." Despite the ignorance about the condition and the negative connotations associated with the term, Quaynor found it surprisingly easy to find people

who, like herself, needed support. Although she said she is not naturally comfortable with public speaking, Quaynor went to church prayer meetings and spoke up about autism. "When God says yes, no one can say no," she said. "I'm in your face with autism." Quaynor's sister referred her to an acquaintance whose daughter had signs of autism. When describing her child, the woman simply said that she did not speak. Quaynor called her and asked if she had ever heard of the word autism. She had. "The tears started coming," Quaynor said. Like her, the woman had lived in the U.S. where her daughter, Linda, was diagnosed with autism. She immediately drove to Quaynor's house, relieved to finally find someone who understood, said Quaynor. After a few months, Quaynor had connected with a small group of families. They met at her house, went on outings together, and received group training through Mawusi Adiku, who earned a masters degree in special education and speech therapy in St. Petersburg. The group registered as a non-profit organisation with just 2 girls and 3 boys, but word soon spread. They eventually moved from Quaynor's home to a larger space so more families were able to join the group. "When parents would come to me, I would tell them 'If you want to work with me, you have to be involved. This is not a dumping ground,'" Quaynor said.

Although Quaynor had done volunteer work with her son's schools in the states and had done a significant amount of reading about autism independently, she needed help just like everyone else. With the help of parents, teachers, and volunteers, Mawusi now designs tailor-made programs for each individual child, encompassing academic skills, social development, language skills, and behaviour intervention. "The bottom line is autism, but each case is unique," he said. Mawusi implements activities that involve art therapy, music, rhythm, and number skills to help each child progress at their own pace. "The future is bright," he said, "because from the way things are moving, most kids are no longer here."

AACT actively lobbies private schools in Ghana to absorb the children once they have reached a certain point of development. Despite the accomplishments of the center, autism still has no known cure. Mawusi is also actively involved in training caregivers, parents, and educators about how to best approach autism's unique challenges. He spent six weeks in February training a group of teachers from Nigeria. It was curiosity combined with his desire to help children that drove Mawusi to study special education. He

remembers sitting in lecture theaters listening to professors talk about developmental disorders, and casting his mind back to Ghanaian society.

"I could see that we have this in Ghana," he said.

Quaynor said cultural beliefs about children with disabilities being possessed by evil spirits, and parents disheartened by the idea that their children will not be capable of taking care of them in their old age, are causing autistic children, and those with similar disabilities to be beaten, locked in rooms, and worse. "I get choked (up) even thinking about these kids," she said. "It's ignorance."

AACT is taking action to eliminate ignorance about autism. On April 2, 2008, AACT joined the United Nations in celebrating Autism Awareness Day. The children from the center had a parade and passed out fliers in shops and offices around the center, said Quaynor, hoping that at least one person would read and learn something. Among AACT's success stories is Quaynor's son. He now enjoys a basic level of reading and has his own laptop on which he makes pictures. Linda, now back in America, has a job folding clothes at a department store. "It shows the possibilities," Quaynor said. But the center still faces challenges. They are now at capacity and in need of a bigger location. Quaynor urges people to donate time, money, prayers, and understanding to the cause. "In Ghana, we don't have the spirit of volunteerism," Quaynor said. "There are a lot of Ghanaians who have the where-with-all to give their heart." Despite their need for more support, Quaynor says the AACT staff are determined to keep going. She says they have a "just do it" attitude. "Nike should be paying me for this," she said with a smile. "It's all about the children. If we can make a difference in the life of one single child, then we have achieved something."

Case Study- 02

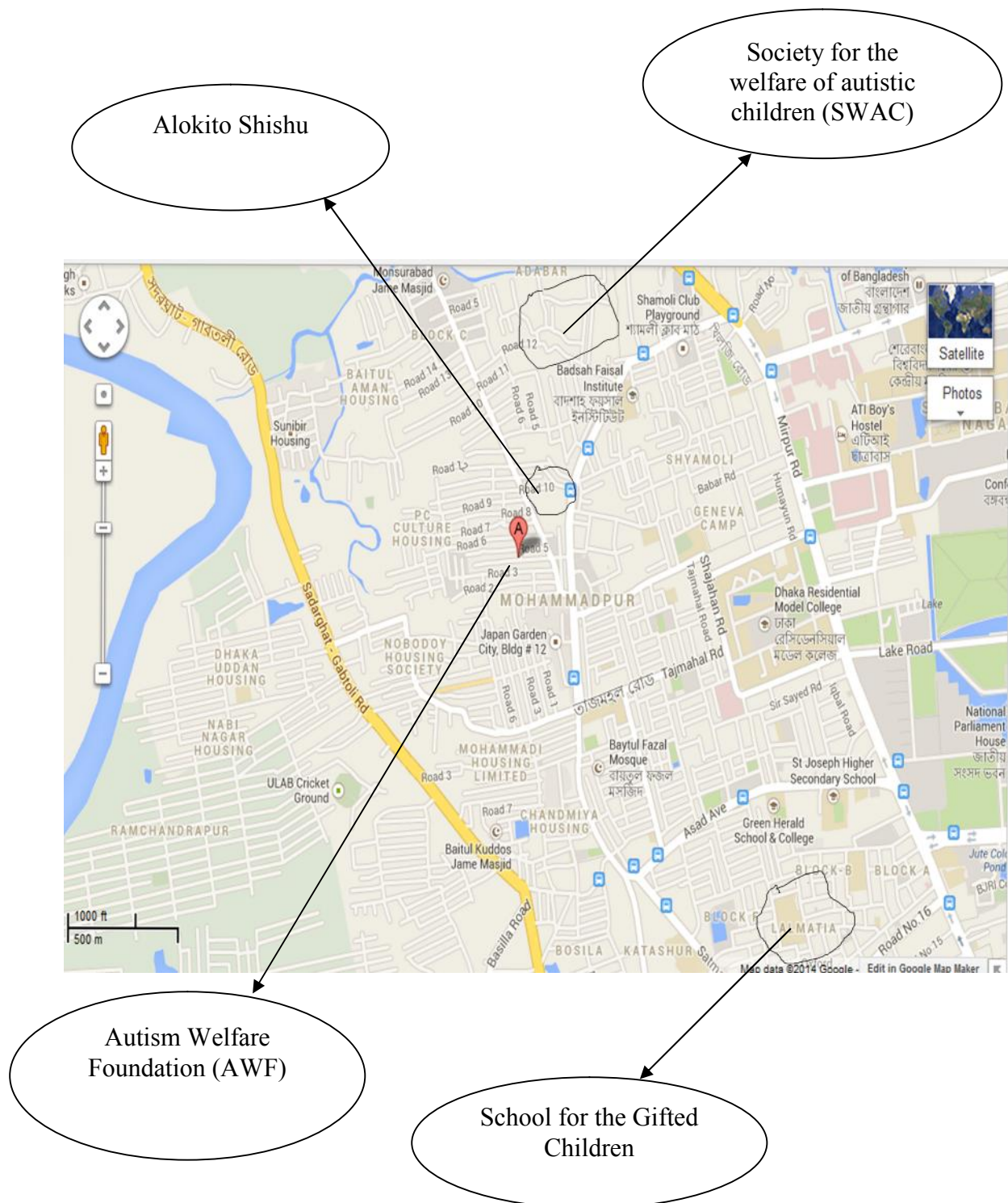
Family rituals such as vacations, taken for granted before, can become challenging or seemingly impossible for families with an autistic child. Many people deal with those challenges by opting out, according to McCarton, which, she says, is a mistake. She says it's important to think through what can be done to make the child with autism -- who can become extremely upset by changes in routine that come with vacations -- more comfortable on a trip. A loving extended family, for instance, may rent a big beach house together, where everyone is free to pursue their interests. Senator and her husband take their three boys to Cape Cod every year, an easy drive from their home. "They became familiar with it," she says. "You only have a few choices of what to

do, and a routine was established. My parents have a house near where we rent, and they can babysit." They've returned year after year. Gradually, they figured out what activities make Nat happy and content. "He likes to fill up a bucket and pour it out," she says. "He likes the ocean side, not the bay side, because he likes the waves crashing. He boogie boarded, and his brothers could do it with him."

Other trips, especially those involving airplanes, have not been as easy, Senator tells WebMD. "When we went to Colorado, we went on the Internet, and got lots of pictures about security [showing] how he would have to take off his shoes so he would know what to expect." How to have a restful vacation? Senator says, "The key is to get down on paper what the issues are, the hardest things, and then try to think of a solution for each." For Nat on the Cape Cod vacations, she says, it was boredom on the beach -- until they observed what activities interested him and focused on those. Going to big family parties can be stressful, says Kathleen Patrick. "When we go to a family event, we go early so he can get his bearings," she says. "It's easier for him to settle in when the crowd is not already there." Patrick and her husband Steve often decide to take two cars in case the event becomes too overwhelming for Adam. When making restaurant reservations for her husband Dan and two daughters, Singer will ask for a booth, knowing that her daughter Jodie "bounces around" when sitting in a restaurant. "I ask for the booth against the wall," she says. That helps Jodie be free to bounce without disturbing other diners.

Appendix-6

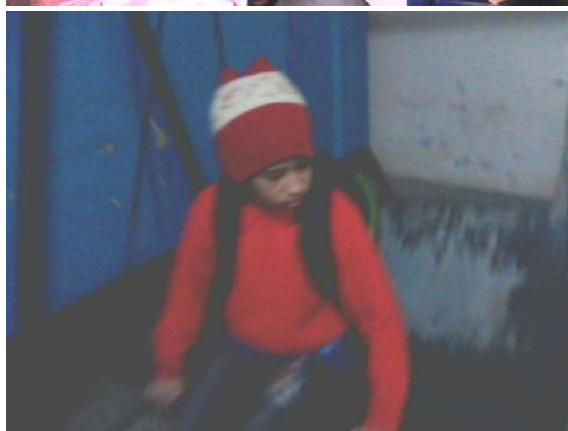
Map: Study Areas



Appendix-7

PHOTOS







Appendix-8

Explanation of Autism Term in Bangla

Autism: অটিজম হচ্ছে শিশুদের মস্তিষ্কের বিন্যাসগত বা পারিবারিক বিকাশগত সমস্যা। যার লক্ষণ শিশুর জন্মের ৩ বছরের ভিতর প্রকাশ পায়। অটিজম বৈশিষ্ট্য শিশুদের ভিতর সামাজিক আচার-আচরণ, যোগাযোগ ব্যবহারে প্রচণ্ড সমস্যা লক্ষ্য করা যায়। বর্তমানে অটিজমকে বিশেষজ্ঞরা ‘অটিজম স্পেকট্রাম’ (ASD) বলে আখ্যায়িত করেছেন যার ফলে সামান্য থেকে শুরু করে অধিক সমস্যাগ্রস্থ শিশুরা এর আওতায় চলে আসছে। আমেরিকান সাইকিয়াট্রিস্ট লিও ক্যানার (Leo Kanner) ১৯৪৩ সালে প্রথম অটিজম আবিষ্কার করেন। বিভিন্ন গবেষণায় দেখা গেছে মেয়েদের তুলনায় ছেলেদের অটিজম হবার প্রবণতা বেশী রয়েছে, যার অনুপাত ১:৪।

চিরায়ত অটিজম (Autistic Disorder): চিরায়ত অটিজম হল গুরুতর বৈকল্যের অটিজম। এসব শিশুরা বুদ্ধির বিকাশের দিক থেকে অনেক পিছিয়ে থাকে। তারা মনোজগত ও বাইরের জগতের সঙ্গে সমতা বজায় রেখে চলতে পারে না। বাইরের উদ্দীপনায় সাড়া দিতে ব্যর্থ হয় এবং শারীরিক বিকাশের সঙ্গে সঙ্গে মনের বিকাশের অনেক পার্থক্য দেখা দেয়। ভাষাগত বিকাশ ও সামাজিক সংজ্ঞাপনের ক্ষেত্রে গুরুতর মাত্রায় বৈকল্য দেখিয়ে থাকে। অনেক অটিজম বলতে শুধু এই শ্রেণির অটিজমকেই বুঝে থাকেন।

পিডিডিএনওএস (Pervasive Developmental Disorder): উল্লিখিত বৈশিষ্ট্যগুলো এসব শিশুদের মধ্যে বিদ্যমান নেই। এই সমস্যাটি অত্যন্ত জটিল এবং সহজেই চিহ্নিত করা যায় না তাতে সমস্যাগুলো স্বাভাবিক অটিজমের মতো নয়। সামাজিক উন্নয়নের ক্ষেত্রে তাদের সমস্যাগুলো বেশি হয়, যেমন- বাচনিক ও অবাচনিক ভাষিক দক্ষতার সমস্যা, সামাজিক যোগাযোগের সমস্যা, স্টোরিওটাইপড আচরণ এবং কার্যকলাপ বর্তমান থাকে।

বিশিষ্ট শিক্ষাবিদ মাইকেল রাটার (১৯৭৮) অটিজমের চারটি প্রধান মনদণ্ডের উল্লেখ করেছেন-

১. বিলম্বিত ও ভিন্নধারার ভাষার বিকাশ, অর্থাৎ কথা বলতে সক্ষম হলে ভাষার অনুপোয়ুক্ত প্রয়োগ, অদ্ভুত ধরনের ভাষা (অন্যের কথার পুনরাবৃত্তি)।
২. সামাজিক বিকাশের ক্ষতি অর্থাৎ পিতামাতা, পরিবারের অন্য সদস্য বা সমাজের অন্যদের সাথে সম্পর্ক স্থাপনের গুরুতর ক্রটি।
৩. বিশেষ ধারা আচরণ করার প্রবণতা, পুনরাবৃত্তিমূলক শরীর সঞ্চালন (আঙ্গুলের বিভিন্ন ভঙ্গিমা, আকস্মিক ঘোরপাক খাওয়া) বা অভ্যাসগত আচরণের প্রবণতা (যেমন- খেলনা বা আসবাবত্র একটি নির্দিষ্ট ধারায় সাজানো)।
৪. শৈশবকালীন প্রকাশ অর্থাৎ সাধারণত তিন বছর বয়সের মধ্যে এ সকল লক্ষণ দেখা দেয়।

এসপার্জার’স সিনড্রোম (Asperger’s Syndrome): লিও কেনারের প্রায় সমসাময়িক সময়ে ১৯৪৪ সালে হ্যাস এসপার্জার এ সমস্যা চিহ্নিত করেন। এসপার্জার’স সিনড্রোম- এ সাথে অটিজমের মূল পার্থক্য হল শিশুর বিকাশ পর্যায়ে ভাষা ও কাল্পনিক খেলার ক্ষেত্রে কোন বিলম্ব থাকে না। এদের বুদ্ধি গড় বা গড়ের বেশি থাকতে পারে।

রেট'স সিনড্রোম (Rett's syndrome): রেট'স সিনড্রোম ক্ষয়মূলক রোগ। ৬-মাস থেকে ১৮ মাস বয়সের মধ্যে কিছু লক্ষণ প্রকাশ পায়। যথা কথা বন্ধ হওয়া, হাতের কাঁপুনি, শরীর দোলানো, মাথা ঠুকা এবং সামাজিক উদাসীনতা এ ধরনের শিশুরা বুদ্ধি প্রতিবন্ধী হতে পারে। কদাচিৎ এ রোগ দেখা যায়।

চাইল্ডহুড ডিসইন্টিগ্রেশন ডিসঅর্ডার (Childhood Disintegration Disorder): দুই বা তদুর্ধ্ব বয়স অবধি স্বাভাবিক বিকাশ হওয়ার পর আচরণগত ক্ষমতা অবলুপ্ত হতে থাকে। যেমন ভাষার দক্ষতা সামাজিক দক্ষতা বা অন্যান্য আচরণগত দক্ষতা। যেমন- পেশাব-পায়খানা নিয়ন্ত্রণ, খেলা বা সঞ্চালনমূলক দক্ষতা লোপ পায়।

Hyperactivity অতি চাঞ্চল্য হল জেদি বা আক্রমণাকর্মকাণ্ড, ধ্বংসাত্মক বা আত্মঘাতী আচরণ করে থাকে, যেমন- টেলিভিশনের চ্যানেল পরিবর্তন করা হলে সে রাগ করে টিভিটি ভেঙ্গে ফেলতে চায়। যদি তাকে বাধ দেয়া হয় সেক্ষেত্রে সে আরো বেশি ধ্বংসাত্মক আচরণ করতে শুরু করে।

Eye contact: মা-বাবা বা অন্য কারো সঙ্গে সংযোগ (eye contact) করতে না পারা। চোখে রেখে না তাকানো এবং চোখে রেখে কথা না বলা। দৃষ্টি সংযোগের অভাবে কে কী করেছে, কেন করেছে সেগুলোর প্রতি মনোযোগ দিতে পারে না। কাছে গিয়ে চোখে রেখে রেখে কথা বললেও অটিস্টিক শিশুরা অন্য দিকে তাকিয়ে থাকে অর্থাৎ দৃষ্টি সংযোগ পরিবর্তন করতে পারে না।

কথা-প্রতিধ্বনি (Echolalia): শিশুকে যা বলা হয় প্রশ্ন করা হয় সে তার উত্তর না দিয়ে বরং বক্তা বা প্রশ্নকর্তার কথার পুনরাবৃত্তি করে।

সর্বনাম বিব্রাট (Pronoun reversal): এটাও সম্ভবত কথা প্রতিধ্বনি স্বভাবের ফল। এক্ষেত্রে শিশু সাধারণত 'আমি' শব্দ বলতে চায় না। তাকে যদি বলা হয় 'তুমি কি খেতে চাও?' উত্তরে সে 'আমি খাব' না বলে বরং বলবে 'তুমি খাবে'। অনেক সময় নিজের নাম ধরে বলবে 'অমুক খাবে'।

বিশেষ ধারার কথা (Stereotyped phrase): অনেকে ভাববিনিময়ের জন্য উপযোগী নয় এমন সব শব্দ বা কথা বলে থাকে। যেমন- কোন গানের কথা, বিজ্ঞাপনের শ্লোগান, গালি বা অন্য কোন অর্থহীন শব্দ।

বিশেষ অর্থবোধক বাক্য (Jargonlike language): প্রায়ই কোন শিশু বাক্যাংশ বা বাক্য বলে যা অর্থপূর্ণ, কিন্তু ঐ পরিস্থিতির জন্য উপযোগী নয়। যেমন- গণনা শেখার সময় বললো আকাশে পাখি উড়ে যাচ্ছে, সেগুলি খুব সুন্দর।

উপমাধর্মী কথা (Metaphorical language): অনেকে সরাসরি কোন একটি বক্তব্য প্রকাশ না করে বরং উপমাধর্মী শব্দ বা বাক্য ব্যবহার করে। যেমন- খিদে পেলে বলে 'ভাত নাই'।

হ্রস্ব কথ্য (Deficient prosodic patterns): কথার মধ্যে বিরতি, উচ্চস্বর, নিম্নস্বর ইত্যাদির মাধ্যমে একটা হ্রস্ব প্রকাশ হয়, কিন্তু অনেক অটিস্টিক শিশুর কথায় এরূপ হ্রস্ব অনুপস্থিত থাকে। ফলে তারা একঘেয়েভাবে কথা বলে যায়।

কথ্যভাষা বুঝার ক্ষেত্রে সমস্যা (Impaired understanding of spoken language): প্রায় সকল অটিস্টিক শিশুর কথ্যভাষা বুঝার ক্ষেত্রে সমস্যা দেখা যায়। সাধারণ সরল নির্দেশ কোন সমস্যা ছাড়াই তারা বুঝতে পারে বিশেষ করে যদি কোন শারীরিক ইঙ্গিত দেয়া হয়। কিন্তু জটিল নির্দেশ প্রদান করা হলে ভুলভাবে বুঝে থাকে যেমন- 'ছোট চেয়ারে রাখা লাল বলটি আন এবং তারপর দরজা বন্ধ কর'।

উপযুক্ত অঙ্গভঙ্গীর অভাব (Lack of appropriate): অনেক অটিস্টিক শিশু ভাবপ্রকাশের জন্য কেন অঙ্গভঙ্গী ব্যবহার করে না; বরং শিক্ষক বা পিতামাতার কজি (হাত নয়) ধরে উদ্ভিষ্ট বস্তুর দিকে নিয়ে যাওয়ায় তাদের একমাত্র অঙ্গভঙ্গী রাটার (১৯৭৮)।

Sensory integration Dysfunction: Sensory integration Dysfunction বলতে আমরা বুঝি যে, অনুভূতির সামঞ্জ্যতা। এটা একটা নির্দিষ্ট প্রক্রিয়া যার মাধ্যমে বিভিন্ন ধরনের অনুভূতিগুলো আমাদের আশ-পাশের তথ্যগুলি সংগ্রহ করে এবং সেগুলো মস্তিষ্কে পৌঁছে দেয়। অনুভূতিগুলোর বিকাশ ঠিকভাবে না হওয়ার কারণে দৈনন্দিন কাজে ব্যাঘাত ঘটা। নিম্নে কিছু সম্ভাব্য লক্ষণ দেয়া হল যার মাধ্যমে আমরা বুঝবো যে শিশুর Sensory integration - এ সমস্যা থাকতে পারে-

স্পর্শকাতরতা, অস্থিরতা, বেশী আলো, গন্ধ, শব্দ সহ্য করতে না পারা, অতিরিক্ত শব্দ, গন্ধ, স্পর্শে কোন সমস্যা না হওয়া, চুল, নখ কাটতে না দেওয়া, খুব বেশী কাজ করার স্পৃহা বা কাজের প্রতি বেশী অনিহা থাকা, কথা বলা শিখতে দেরি হওয়া, সুক্ষ্ম কাজ শিখতে দেরি হওয়া। যেমন- কলম ধরা, জামার বোতাম লাগানো লেখাপড়ায় পিছিয়ে পড়া, কাজ সম্পন্ন করার অক্ষমতা, আচরণগত সমস্যা ইত্যাদি।

ব্যক্তিগত ও সামাজিক বিকাশ (Personal and Social Development): শৈশব থেকে যে সামাজিক উদাসীনতা দেখা যায় তার ফলে অন্যের সঙ্গে সম্পর্ক স্থাপন ক্ষীণ হয়। প্রথম কয়েক মাসের মধ্যেই লক্ষ্য করা যায়, অধিকাংশ অটিস্টিক শিশু মানুষের মুখের দিকে তাকাতে আগ্রহবোধ করে না, চোখের দিকে তাকায় না বা মেলামেশায় আগ্রহী নয়। অনেককে শান্ত প্রকৃতির মনে হয়। কারণ, তারা পিতামাতার সান্নিধ্য প্রত্যাশা করে না। তারা সহযোগিতামূলক বা অভিনয়মূলক খেলা খেলতে পারে না কারো সঙ্গে তাদের বন্ধুত্বও গড়ে উঠে না এবং একা থাকতে চায়। বাধ্যবোধকতামূলক প্রবণতার জন্য সীমিত ধরনের পুনরাবৃত্তিমূলক খেলা করে, বিশেষ কোন জিনিষের প্রতি অতিরিক্ত আসক্তি দেখা যায় এবং অনেক ক্ষেত্রে পরিবেশ পরিবর্তনে বাধা দেয়। অনেক শিশুর প্রাথমিক বিকাশ স্বাভাবিক হলেও ১৮ মাস থেকে দু'বছরের মধ্যে ক্রমান্বয়ে অর্জিত দক্ষতা লোপ পেতে থাকে। লোভাস ও নিউসম (১৯৭৬) অটিস্টিক শিশুদের সামাজিক আচরণের কয়েকটি বৈশিষ্ট্য উল্লেখ করেছেন। যথা-

- (১) ইন্দ্রিয় ক্ষমতার আপাত ঘাটতি লক্ষ্য করা যায় অর্থাৎ শিশুর আশেপাশের ঘটনার প্রতি কোন প্রতিক্রিয়া করে না, দেখে মনে হয় সে কোন কিছু শুনছে না বা দেখছে না।
- (২) তারা আবেগীয়ভাবে নিস্পৃহ থাকে অর্থাৎ আদর-ভালবাসার প্রতি কোর প্রকার আগ্রহ প্রকাশ করে না। কেউ আদর করলে মনে হয় তাকে চেনে না বা তার প্রতি কোন প্রকার গুরুত্ব প্রদান করে না।
- (৩) তারা নিজেকে উদ্দীপিত করার মত নানা আচরণ করে অর্থাৎ অনেকে দোলাতে থাকে, কোন জিনিস ঘোরাতে পছন্দ করে, বারবার হাততালি দেয়, আঙ্গুল পর্যবেক্ষণ করে, অথবা একই নিয়ম মেনে চলার প্রবণতা থাকে।
- (৪) অনেকের মেজাজ খিটখিটে প্রকৃতির হয়। চিৎকার, কান্নাকাটি করে, হাত-পা ছোড়াছুড়ি করে, জিনিস ছুঁড়ে ফেলে কিংবা অস্থিরতা, প্রদর্শন করে। নিজের ক্ষতিকার আচরণ করে। যেমন- মাথা ঠুঁকে, শরীর কামড়ায়, শরীর আচড়ায়, চোখে আঙ্গুল দিয়ে খোঁচায়। কিন্তু এসব করে কোন ব্যথা অনুভব করে না।
- (৫) তারা বয়স অনুপাতিক আচরণও করতে পারে না।

সমাজবিজ্ঞান বিভাগ
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December 12, 2013

Honorable Chairperson
Autism Welfare Foundation
Mohammadpur, Dhaka-1207.

Subject: Application for Collecting Information for Academic Research.

This is to certify that Md. Abdur Rakib is a student of 2nd semester MSS-2012, Department of Sociology, University of Dhaka. He is conducting a research in partial fulfillment of his course requirement. His research topic is "Problems of Autistic Children and their families: A study in the urban areas of Bangladesh". For his research requirement he has to need collect information and interview from your foundation.

I request to extend all support to the concerned student for this research.

Sincerely,
Research Supervisor


(Rasheda Irshad Nasir)
Professor
Department of Sociology
University of Dhaka
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Mrs. Rasheda Irshad Nasir
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27/12/13

