

Social Acceptance of Special Children with Autism Challenges of Parents in Bangladesh

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Abstract

Autism is a complicated developmental disability. It is a neuro-developmental disorder that is characterized by impaired social interaction, verbal and non-verbal communication, and restricted and repetitive behavior as well as by unique strengths and differences. We know that there are many types of autism, each caused by different combinations of genetic and environmental influences. Though there is not any specific statistic on the cases of special children but the number is not negligible. It's an increasing fact for Bangladesh. Our society, alternatively fails to accept children who are suffering from autism. A majority of parents, left with no choice locks up their kids at home and do not allow them to socialize. Experts in the medical field point out that social acceptance about autism can go a long way in making children who suffer from autism comfortable and this can help them live a better life. Lots of initiative has been taken as well is continuing to mitigate disability and autism issue but social awareness and parents' sufferings are not in consideration yet. Aim of this research is to increase awareness of the society about autism and to rise participation of the family and the community to overcome the challenges. To fulfill the aim, situation analysis was undertaken through open end questionnaire survey on various respondents like Parents, family members, neighbors, relatives and therapists from Dhaka, Bogra & Jessor district. Questionnaire has been designed after intensive investigation of existing literature from home and abroad as well as from practical situation. Response was explanatory and analysis has done on summary. Observed that, social negligence and lack of understanding has a greater impact on development of autistic children as well increase suffering and insecurity of parents. Ideas have been provided based on result of analysis.

Key words: *Autism, Acceptance, Challenges, Social Awareness*

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Introduction

One specific disability in children that has received quite a bit of attention in recent years is autism. The word autism originated from the Greek word *autos*, - meaning self, implying narrowing of relationships to the world (Janzen, 1996). Leo Kanner first coined the term autism in a clinical paper in 1943 describing eleven children with “autistic disturbances of affective contact.” Kanner's work described the difficulties with socialization, communication difficulties, repetitious behaviors, and ineffective use of language (Kanner, 1943). Autism is a developmental disorder that appears in early childhood, usually before age three. While cases range from mild to severe, all autism spectrum disorders affect a child's ability to communicate and interact with others. Even though the struggles facing parents of children with autism can seem insurmountable, the good news is that for every challenge, experts say there are solutions to ease the stress and worry that can accompany this very difficult role (Daley, 2002).

There is no specific medical test for Autism and a diagnosis is made after a thorough evaluation. The evaluation might include clinical observations, parent interviews, developmental histories, psychological testing, speech and language assessments, and possibly the use of one or more autism diagnostic tests (CDC, 2007). This disorder has no clear biological marker, unlike many other developmental disabilities such as mental retardation, deafness, and blindness. Without a definitive test, the diagnosis of and prognosis for autism is fraught with uncertainty. This ambiguity makes it extremely difficult for parents to accept the child's condition and second, because it is characterized by problems of social interaction, such as forming attachments and showing affection, parents of children with autism are often denied some of the fundamental rewards of parenthood. As a result, autism has been considered as one of the most complex and intractable developmental disorders with which families may have to cope. In fact, research has shown that autism can create greater parental anxiety and tension than parents of non-disabled children, parents of children with other physical or learning disabilities or parents with children with other developmental disabilities (Budzienski, 2014). Families with autistic children face a multitude of challenges because of the behavioral problems associated with the disorder. Having a child with autism in the family may have adverse effects on various domains of family life including marital relationships, sibling relationships and adjustment, family socialization practices as well as normal family routines (Greeff and Walt 2010).

In Bangladesh, autism has already been identified as burden of diseases and it has been assumed that the magnitude is high and majority cases, is undetermined. Especially in the rural settings, Autism has been found as neglected disease. A recent 2013 pilot study in Bangladesh, utilizing community health workers, has found prevalence of all kinds of

neurodevelopment disability is 7.1% Whereas, for Autism, the study indicates a prevalence of 0.15% (3% in Dhaka city and 0.07% in rural area) (Report MH&FW 2014). It is learned that out of every 94 boys, one is affected by Autism. For girls, it is one in every 150. In Bangladesh, no research has been carried out but it is assumed that about 3, 00,000 children are affected (Autistic Children's Welfare Foundation, Bangladesh, 2011). General attitude towards autism is mostly negative and it is seen as a social barrier. Even today, autism is considered a God-given curse and children with Autism are taken as possessed by the Devil. Also, bad parenting is accused. As such demands of living with a person with autism are great and families frequently experience high levels of stress. The uniqueness of each individual with autism makes the experience of living with autism different for each family. There is no alternative but to live with autism for such families; but the concern is how better this living can be made. Recognizing and preparing for the challenges that are in store will make a tremendous difference to all involved, including parents, siblings, grandparents, extended family, friends and society.

The Objectives of the Study

Main objective of this study is to identify the need of proper guidance and support from the society for autistic children in order to overcome their problem. Emphasize will be given on Government and policy makers to introduce new practices in special schools and social awareness, which are meant for these children. So that it could help them to bring improvement in their day to day life. Specific objective is:

1. To study various challenges faced by parents of children with Autism.
2. To assess the awareness of people in society regarding Autism.

Literature Review

Globally and in Bangladesh particularly, autism remains a challenging condition for the children and their families. To date, much of the literature on Autism has been conducted from country and world perspective. Several relevant literatures like articles, books, researches etc. on autism have been reviewed. Ozdemir, S. (2008) conducted a study on “The effectiveness of social stories on decreasing disruptive behaviors of children with autism: Three case studies” in the Journal of Autism and Developmental Disorders. The study reflected significant decrease in the target behavior of each participant when the social story was implemented. Properly constructed and visually presented social stories may decrease the disruptive behaviors of children with autism.

D. E. Gray (2006) conducted a study entitled “Coping over Time: The Parents of Children with Autism”. The paper reports the results of a longitudinal study of parents coping with autism over a period of approximately a decade. Parents raising a child with autism face extreme

difficulties in dealing with challenging behaviors, teaching their child to communicate, teaching basic life skills, guarding their child from danger, and preparing their child for adult life (Dyches et al 2004). There are high-risk factors that might induce acute or chronic stress and trauma to the parents of autistic children and, in turn, lead to dysfunctional parenting. These include: a) the ambiguity of diagnosis; b) the severity and duration of the child's disorder; c) a very low I.Q.; d) lack of congruity with the community norms, bizarre forms of communication and behavior; and, e) enduring disruptive or disorganized behaviors (Kourkoutas, et al 2012). Families with autistic children have been perceived by their societies in different ways causing the families to be shaped by the beliefs systems of autism specific to their society. Because of social stigma, there is a lot of discrimination not only of the autistic child but also of the family as a whole because the family is seen to be a part of the illness. Fear of discrimination and the stigmas surrounding disabilities lead many families to refuse to go to professionals and receive a diagnosis for their children. By refusing to be diagnosed, families can avoid having disability identities (Ecker, 2010). The troublesome symptoms such as tantrums, self-destructive acts and other inappropriate public behaviors associated with the disorder are difficult to cope with. Consequently, the parents with autistic children frequently encounter hostile or insensitive reactions from public, mostly because of the inappropriate behavior shown by their children. The public reaction to such families is often stereotypical and negative (Gray 1993). Because of delayed communication in autistic children, parents may experience positive and negative changes as the children grows and enters school system. The school system initiates a new involvement concerning the needs of the child and the parent. Parents and school personnel are closely related in pursuing the most appropriate education for the child (Hoppe 2005). Caregivers of autistic children may perceive their children as more difficult temperamentally than other children and therefore, use greater control strategies with their children. Thus, caregiver perceptions of their children's characteristics may influence the ways in which they interact with their children (Kesari et al 1997). Families with autistic children need social support for coping with stress and attunement due to having a child with developmental disabilities (Meral et al 2012). Family members of children with autism are often perceived to experience negative psychological effects which may include higher risk for depression, social isolation and marital discord. Many parents also experience periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt (Gupta and Singhal 2005). Specific stressors that contribute to parental distress include concerns over the permanency of their child's condition, poor acceptance of autistic behaviors by society and, other family members and low levels of social support received by other parents (Prince 2007).

The above literature showed different perspective of autism and the family with autism. However, little research has been conducted in this current study area. The current study is based on the experiences and challenges of parents of children with autism and societal view. This research will make a number of contributions to the understanding of the challenges of parents raising a child diagnosed on the spectrum to the field. Few researches examining the experiences of parents and families but the current study highlighted the experiences and challenges of families in particular parents of children with autism in Urban Area.

Methodology

Qualitative research approach is used to conduct the study. This study is based on case study and focus group discussion (FGD) method. All area of Dhaka, Bogra & Jessor has been considered as the area of the study. But here, autistic institutions were selected for the convenient of collecting data such as Proyash. Parents, relatives, neighbor, care giver & Therapist considered for the population of the study and each of Childs of the study area is considered as a unit of analysis. Systematic random sampling technique was used to select the respondents. Self-devised interview schedule was applied on parents and others in order to collect requisite information from them. Three FGDs are conducted with the intention of capturing a diversity of voices from the respective areas. Interview and observation technique are applied to collect data. A guideline with semi-structure question is used in conducting case studies and focus group discussions (FGDs). These interviews were tape recorded and noted down on areas of particular importance or interest whilst conducting the study. Relevant information was also gathered from secondary sources reviewing available literature on the existence on autism. After the completion of Case study and FGDs, the recorded narrative data was transcribed and efforts are also made to edit the collected qualitative data to ensure accuracy of information. The edited data is then furnished using a qualitative strategy and analyzed it in narrative form. The data collection process commenced at the completion of the ethics approval process.

Analysis & Discussion

The purpose of this study was to understand parents' sufferings and challenges, and build social awareness. Two specific objectives were posed during conducting questionnaire survey and FGDs. Autism is considered to be a severe disability because of the intense lifelong effects it has on the individual and his or her family. Parents face humiliating, dishonor which may cause continuous stress and 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 reason, the parents always are in uncertainty. Parents of autistic children face some exclusive problems when they are at outside with

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them. Parents of autistic children feel hesitation to communicate, social festivals etc. Parents cannot join willingly for their child. They feel isolation from social activities and feel sadness for this curse. Parents feel mental disorder in their daily life. Parents think that what will be the future of their children and how they improve and co-operate with others.

The stress of caring for an autistic child is both real and acute. 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. The mothers of children with autism have some symptoms of physical and psychological tension.

Parents experience the 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. Parents of autistic child cannot participate in various social activities. Parents face problem to participate in activities for the basic problems of their children.

Impact of having a child with autism on inter family relationship is high. In a society where there is a stigma attached to autistic children, the parents have to fight a war to back them. Autism has been termed an epidemic. It is actually a family epidemic where Parents, siblings, grandparents, and extended family members are all affected by autism.

Problems of social interaction with neighbors are faced by family members. Most of the parents want to interact with the neighbor but sometimes they cannot interact. They are not able to interact with neighbor willingly. Sometimes neighbors do not agree to interact with the autistic family members. Sometimes people do not want to invite the family in any social gathering.

The autistic children live in such a condition with their mental position in adverse situation for which it is not possible for them to live a normal life. Considering major findings of the study some Ideas can be constructed as follows:

- Concretization and awareness building activities should be intensified which will remove misconception of the people about autism and inject a sense of hope in minds of children with autism. This will help in changing the social outlook towards the children with autism.
- Measures should be taken for ensuring suitable recreational facilities for the children with autism.

- The government and the non-government organizations should take social consciousness, raise efforts and take proper measure to spread knowledge of autism.
- Political leader and the government should take steps to build up awareness and reduce autism.
- Government should build up Autistic Centre with all support for the children with autism.
- Social worker should work to campaign of awareness rising about autism both urban and rural area.
- Properly designed programs having components like education, campaign and training as means of awareness rising may help possible victims to face all the odds from a realistic point of view.
- It is imperative to develop a training program for workers in the educational system to learn skills on how to work with children with Autism. This will help to ensure that the children with Autism are taught the right behaviors and will receive the most benefit from their education.
- Development of administrative structures and Community Based Rehabilitation (CBR) to support autism affected child and families.

Conclusions

This research provides a preliminary look at what the experience and challenges of raising a child on the spectrum may be like for parents including the process of evaluation and diagnosis; the experience of accessing supports and services; and the impact on parents and other family members. Although parents clearly identified areas where systemic improvements would be helpful to their families, including greater awareness of Autism in the community and especially on the part of school staff, as well as greater government-subsidized supports and services among many things. These life-enhancements include redefining priorities in life, increased tolerance, patience, and self-advocacy or assertiveness. Although raising a child on this spectrum appears to be a long and possibly stressful journey for many Parents. This research serves to inform existing literature in this area from around the world, but also provides greater insight into the needs of children on the spectrum and their parents of Bangladesh.

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