

## Problems of Girls with Autism Spectrum Disorder and the Challenges faced by their Parents in Rearing

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**Abstract**—The paper aimed to understand the common and specific problems of girls with Autism Spectrum Disorder (ASD) and their parents' challenges in raising them. By using a qualitative research approach, the case study method was adopted, and a semi-structured interview schedule was used as a tool of data collection. The Sylhet city corporation was the subject of the study. As ASD girls were not fully cooperative for giving information, the parents of ASD children, medical service providers, and teachers were the respondents of the study. The thematic analysis was considered for data analysis and interpretation. The study reveals that children with ASD had multiple common and specific problems in their growing-up period. They had some specific problems compared with the same-aged girls. At the same time, parents faced so many challenges in their raising period. The common problems are looking after them, their education, fulfilling their basic needs, etc. There are some specific problems like looking after them during the menstruation period, taking them outside, etc. The parents had many challenges in their looking after. The common challenges are always remaining one of the parents with their girl, financial crises, fulfilling the medical treatment, and facing the bad comments from the outside people.

**Keywords:** Raising, Challenges, Looking after, Financial Crisis and Medical Treatment

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### I. INTRODUCTION AND REVIEW OF LITERATURE

Disability is an umbrella term, multifaceted and contentious and there is no universally approved definition (Nokrek, Alam and Ahmed, 2013). This phenomenon has come from Western societies (Coleridge, 2000) but it is important to measure and for policy formulation (Grech, 2009). Usually it is widely use to focus on individual functioning, including various types of impairment somewhat similar to the three-tier concepts of 'impairment', 'handicap' and 'disability' defined by World Health Organization (WHO). It has not only strong cultural relationship (Coleridge, 2000), but Metts (2004) focused on the different and multiple dimensions of the ASD. He argued that it is closely related to medial, social and environmental factors though it is necessary to understand it first. Disability has been getting international and national attention but failed to provide a unique definition of it. Generally it limits the person's full and effective access and participation in social arena which is rightly focused by United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) and WHO (2011). Disability is not only physical limitation, it could be mental and thus it invites similar obstacles as mentioned in Americans with Disabilities Act (ADA), 1990 (cited in Sultana, 2010).

Disability can be categories in different ways based on the impairment resulting disability. Physical, visual, hearing and more types of disabilities have been seen throughout the world. Even there are some special types of disabilities like Autism Spectrum Disorder (ASD) which have distinct features and lifelong consequences over one's life. Autism is a global



phenomenon with local implications (Ehsan, et. al., 2018). The word “spectrum” indicates those characteristics which often face by person having ASD (DSM-5; APA, 2013). ASD is considered as a neurodevelopmental condition where persons cannot make proper social interaction and communication, rather they show repetitive and control behavior (Tobing & Glenwick, 2002; Shu, 2009). Such deficits restrict them to communicate with others (Kanner, 1943). Contribution of genetic or environmental factors is not strongly examined and understood. Generally it occurs at early childhood but in most of cases parents could not understand at the initial stage. There are some wrong notions and understanding which often causes ASD before taking medical intervention. The accurate cause of ASD is still unidentified but may have connectivity with genetic tendency, or natural or even factors yet to be known. Despite having development of medical and biological science, genetic connectivity to ASD is still unrecognized (Chaste and Leboyer, 2012; Freitag, Staal and Klauck, 2010; Losh, Sullivan and Trembath, 2008).

ASD is a lifelong, usually constant condition that occupies regular impairments in language, social interactions and regular functions (Miranda, et. al., 2019). It was first mentioned by Leo Kanner in 1943. ASD could be diagnosed at early ages though there are no fixed markers to detect it (Anagnostou and Taylor, 2011). Initially it was viewed as person’s own problems as a result of social and environmental factors. After series of study, relation with neurological malfunction was established (Huq, Rahman and Mahbuba, 2017). Generally ASD child creates troubles in family environment and produces special needs which are essential for their development (Altiere, 2006; Baker et al., 2005; Shu, 2009; Smith, Hong et al., 2010). Thus it is difficult to identify their behavior but some common characteristics are seen among ASD child including problem in social interaction, proper response and both verbal and non-verbal communication (APA, 2013). Apart from such common behavior, they might have some special behavior patterns like aggressiveness, hyperactivity, sensory and intellectual disability which help to detect ASD (Novaes, Pondé and Freire, 2008).

Evidences show that the heterogeneous features are common in ASD (Anagnostou & Taylor, 2011) though variations may be seen in secondary characteristics (Aman et al., 2009; Baranek, 1999). Even in many cases poor attention may show some ASD characteristics in early childhood (Baranek, 1999) or may affect by a short attention span (Aman and colleagues, 2009). ASD can change communication and interaction pattern which forces them to show attacking behaviors including self-damage (Souders, Freeman, DePaul, & Levy, 2002). Not only verbal communication, they may have limitations in nonverbal communication and expressions etc (APA, 2013; Cowen, Harrison and Burns, 2012; Sadock, Sadock, and Ruiz, 2015). Majority of them have difficulty in talking to people (APA, 2013; Cowen, Harrison and Burns, 2012). Even they cannot use the right words or maintain the rhythm of words and sentences. Often they fail to understand the body language, tones or fail to interpret the meaning of symbolic interaction (Sadock, Sadock, and Ruiz, 2015).

Parents often showed negative reaction upon receiving an ASD diagnosis (Divan, et al., 2012). Although receiving a diagnosis allowed initial release, helps to aware them to understand greater needs and access to special services for their child (Calzada, Pistrang and Mandy, 2012). Current international and local research highlight resource limitations for healthcare and schooling, and foreseeable changes within the family unit (Fewster, 2014; Vassallo, 2016; Schlebusch, 2015; Bashir, Bashir, Lone, and Ahmad, 2014; Fletcher, Markoulakis and Bryden, 2012; . Matenge, 2013). Changes included, but were not limited to, catering to the ritualistic needs of the child (Dawson 2011; Johnson and Rodriguez, 2013), vocational changes of parents to accommodate the child (Dawson, 2011; Fletcher, Markoulakis and Bryden, 2012) and social isolation of the family (Divan, et. al., 2012). Children having ASD show similar behavior and curiosity (APA, 2013) and often do repetitive acts like inattentiveness, anxiety and troublesome behaviors (Hartley, Sikora, & McCoy, 2008; Simonoff et al., 2006). Different studies indicated that parents had little or no knowledge about it before diagnosis of their kids (Preity, et. al., 2017). The unusual behavior patterns cause significant difficulties (Cullen & Barlow, 2002). Having a child with ASD is a source of more stress for Parents and they are nearly three times vulnerable with compare to others to become psychologically ill (Brobst, Clopton, & Hendrick, 2009; Dillenburger, et. al., 2010; Gau et al., 2012;). It negatively impact parents’ mental health status but reduces

over time as their child's behavior improved (Gray, 2006; Hoffman, et. al., 2009). Such symptoms and behaviors are closely influence the mental condition of the parents (Abbeduto et al., 2004; Lecavalier et al., 2006).

Kiami and Goodgold (2017) showed that the majority of the cases, it produced stress among the parents. Even such parents face serious stress than the parents having disabled child (Barroso et al., 2018; Craig et al., 2016; Davis and Carter, 2008; Giovagnoli et al., 2015; Gupta, 2007; Hayes and Watson, 2013; Hoffman et al., 2009; Rao and Beidel, 2009; Watson et al., 2013;). Different studies have examined the marital satisfaction, conjugal crises and related issues among the parents having children with ASD. Gau, et. al. (2012) showed that such situation reduces marital pleasure and thus it can invite divorce (Hartley et al., 2010). But these are similar to all (Freedman, Kalb, Zablotzky, & Stuart, 2012) as opposite findings are also reported. In many cases it helped to produce additional satisfaction and sustainability of conjugal life (Gau et. al., 2012; Hartley, et. al., 2011). Karney & Bradbury (1995) explained parental problem using the vulnerability-stress-adaptation model. In one side, vulnerabilities decrease their capacity to hold positive couple interactions and stress obstructs partners to adapt. This model has wide range of use to explore parental stress (Cutrona et al., 2011; Doss, Rhoades, Stanley & Markman, 2009). Hartely, et. al. (2016) focused that this model has been using to get a valuable skeleton to explicate the interactions of parents who have such child.

Having a child ASD can create uncertainty among parents (Karst and Hecke, 2012) and form anxiety and depression (Almansour, et. al., 2013; Estes, et. al., 2013; Ou, Cha, and Wang, 2010). In this situation parents need social support may assist them to adjust with the reality and to concentrate to their children with ASD (Machado, 2016). Mothers are the vulnerable here as it produces stress and negative emotional, physical, economic or marital experiences (Cullen & Barlow, 2002; Dardas & Ahmad, 2014; Higgins, Bailey & Pearce, 2005; Kring, Greenberg, and Seltzer, 2010; Lecavalier, Leone, & Wiltz, 2006; Lee, 2009). Gradual increase of depression and parenting stress is revealed by Ingersoll and Hambrick (2011) and mothers are more vulnerable than fathers (Davis and Carter, 2008; Ekas, Lickenbrock & Whitman, 2010). Caring a child with ASD is very difficult and stressful. In many cases, parents faced stress, anxiety and depression which negatively influence their mental condition (Gau, et. al., 2010; Hoffman et. al., 2009). Negative mental condition invites negative mood and parenting stress (Pottie and colleagues, 2009). Moreover, parenting stress low emotional supports that lead marital difficulties (Pottie et al., 2009). Caring ASD child often disrupt daily activities that mostly hamper mothers (Larson, 2006). Though disruptive behaviors of such child determine parents' mental health, but become lower when their child's behavior improves over time (Gray, 2006; Hoffman, et. al., 2009). Caring and raring such child makes Parents vulnerable (Benjak, et. al., 2011; Olsson & Hwang, 2001).

There are many factors which produce parental stress. Studies of Bebko et al. (1987) and Moes (1995) showed that stress level is associated with the behavior pattern of child. Supporting their opinion, Baker-Ericzen et al. (2005) focused on the skill of social interaction is linked with such stress. If the ASD child fails to interact then it produces additional stress to parents. Different studies have explored the factors which invite sever stress for parents (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Pearlin, Aneshensel, & LeBlanc, 1997; Pearlin, 2000). Parents need more social and spousal support (Kersh, et. al., 2006; Saloviita, Itälinna, & Leinonen, 2003) to provide adequate support to their ASD child. In many cases, absence of necessary support and negative consequences reduces fathers' responsibility considering the negative consequences (Barbarin, Hughes and Chesler, 1985; Bristol, Gallagher and Schopler, 1988). Such situation seeks valuable time, resources and energy of parents (Seltzer et al., 2001) that result physical exhaustion and fatigue (North American Nursing Diagnosis Association, 2001; Ream & Richardson, 1996) and create gap between father and mother (Aylaz, Yilmaz, & Polat, 2012). It promotes bitterness between parents, especially among mothers (Gray, 2003; Luong, Yoder, & Canham, 2009) and encourages parents to blame each other for this situation (Fletcher, Markoulakis, & Bryden, 2012). But having a child with ASD has some positive influence and help to strong and improve relationships, family functioning, understanding and tolerance (Havens, 2005) and develop commitment to continue conjugal life (Bayat, 2007; Davis & Gavidia-Payne, 2009; Pakenham, Sofronoff, & Samios,

2011; Pelchat, Lefebvre & Perreault, 2003). Such cases help to strong family bondage, understand the positive meaning of life and develop their level of communication (Bayat, 2007; Zubrick, Williams, Silburn, & Vimpani, 2000).

Parents have to face unfavorable consequences and public comments in social arena (Farrugia, 2009; Gray, 2002; Lasser & Corley, 2008; Ludlow, Skelly, & Rohleder, 2011; Midence & O'Neill, 1999; Neely-Barnes, Hall, Roberts, & Graff, 2011; Safe, Joosten, & Molineux, 2012; Woodgate, Ateah, & Secco, 2008). It cans weaker marital happiness, produce disturbances (Higgins et al., 2005), increase anger, anxiety and depression (Gray and Holden, 1992), reduce social outings (Kraijer, 2000). Mothers often feel loneliness when make decision (Larson, 2006) and produce stress in families (Seltzer, et al., 2001; Smith et al., 2010) resulting high rate of divorce among parents having child with ASD (Hartley and colleagues, 2010). As ASD child often fail to obey social norms that bound the families to seek different ways to adjust their daily life (Bristol, 1984; Dunn, et al., 2001; Altieri & von Kluge, 2009), even parents like to withdraw their children with ASD from society to avoid unfamiliar situation (Glazzard and Overall, 2012). It affects family functioning, limits leisure activities (Myers et al., 2009). As a consequence, families may lose social support (Bromley et al., 2004; McConnell, Savage, & Breitkreuz, 2014) and socio-economic status (Georgiades, et al., 2008).

Parents have to play multiple roles and responsibilities, from care to education and struggle to ensure those essential needs (Klein & McCabe, 2007; Lutz, Patterson, and Klein, 2012; Woodgate and colleagues, 2008). Not only care, financial ability is also important here to arrange needs. Financial cost is higher, sometime three times (Järbrink et al., 2003) and may invites negative impact over their life (Järbrink et al., 2003; Sen & Yurtsever, 2007), or even change their financial status and face difficulties to manage expenditure (Altieri and von Kluge, 2009; Aylaz and colleagues, 2012; Fletcher and colleagues, 2012; Sharpe and Baker, 2011; Thomas et al., 2016; Vohra et al., 2014; Zablotzky et al., 2014). Not only that, parents had to change their employment or work place only manage the situation (Fletcher et al., 2012; Järbrink et al., 2003; Gray, 2003). Interestingly, parental commitment to secure their child with ASD encouraged them to extend their working our (Gray, 2003) to earn more but diverse thoughts and feeling were seen who had to stop working (McCabe, 2010).

Autism has been increasing rapidly since 2002, has become the global health issue (Action and Desmond, 2012) and approximately 1% of the global population affected by ASD (Pervasive, Disorders and Korea, 2012). But the prevalence rate of autism depends on many factors including age of children, investigation mechanisms and techniques, geographical area, etc. (Williams, Higgins and Brayne, 2006). However, it is assumed, in Bangladesh nearly 10.5 lakhs individuals may have autism. Statistical data is not adequate to understand the prevalence rate of ASD in Bangladesh though Haque (2015) claimed it 0.84%. Statistics of in the centre for Child Development and Autism at Bangabandhu Sheikh Mujib Medical University (BSMMU) clearly show the rapid growth rate of ASD cases (Faras, Ateeqi and Tidmarsh, 2010). Country wide study of 2013 showed that the prevalence rate is 1.5 per 1000 where the rate is much higher in urban areas. Generally it is estimated that one child among 500 has ASD and thus the total number is nearly 280,000. Different studies have showed that the general knowledge, awareness and parental attitude towards autism in Bangladesh is not positive. Over 95% of the parents had very little or even no knowledge of autism before diagnosis of their kids. Social stigma and barriers are also found as one of the key challenge in rural Bangladesh. Even parents felt hesitated and was social environment restricting them to go outside with their children, especially in the social gatherings (Preity, et. al., 2017). People often fail to understand it, ignore the needs of such child and thus try to focus it differently. Sometime people like to view it from religious ground, understand it as the punishment of God or devil related issue (Preity, et al., 2017; Zerin, 2015).

In Bangladesh, autism is still a concept to academicians. Studies on parenting challenges, stress and their coping are not adequate to focus it. Before diagnosis, parents have little or no idea about autism and this is the prime challenge for parents. In one side, parents often fail to give proper attention and care. In other side, it very difficult for them to tolerate their child's pain which produce depression among parents (Preity, et al., 2017). Their struggle starts from diagnosis and continues till throughout the life. Some studies have explored the parenting stress of Bangladeshi parents (Akter, et al., 2020; Preity, et al.,



2017) but their challenges are still hidden. Though stress is related to challenges but it has multiple implications which needed to be explored. Even how do parents cope with the challenges is also unexplored. Challenges are not only to manage their child, rather they face challenges to manage their own responsibilities, anger and depression. Even challenges could be different based on rural urban setting, family support, economic capacity to manage, family structure, etc. These areas are yet to be investigated to understand the issue properly. Such studies are not uncommon in other countries but rare in our country. Government has been trying to pay necessary attention to the needs of autistic children but we need to think it as an integrated way. As the parents have to manage everything, so their struggle, coping techniques are essential to explore.

Autism is a developmental disability which has multiple dimensions included impaired social interaction and communication. Early detection could be helpful to minimize its serious effects and consequences. But due to many factors including stigma, misconceptions, absence of proper medical facilities, economic condition of parents and poor understanding often create barrier to diagnosis at proper time suggested by different studies. Even after diagnosis, parents often fail to pay proper attention, necessary care and continue medical intervention. Moreover, it invites huge parental stress, couple conflict and break normal family functioning. This is one of the growing health issues for the world as well for Bangladesh but its consequences over family is still less focused. From proper diagnosis to management, parents of our country have been facing series of obstacles including hostile religious, social and cultural practices prevailing here. Government has been showing respect and care to this issue but absence of necessary support and services, vast majority has to meet the medical expenses and care without external support. But the most crucial aspect is the care and management of the autistic children by their parents. Evidences based on the different countries suggest that parents have to struggle to meet expense, to maintain their work and working hours, to keep peaceful conjugal life. Though some studies explored some positive impact on conjugal life but generally it has wide range of negative impact over parents. Stress, couple conflict, economic crises, social isolation and many negatives consequences often create vulnerable situation for families having children with autism. Bangladesh is a developing country where rate of autism has been increasing. Literally people are less or no aware about autism and in most of the cases they simply fail to understand the situation. Even people often face social and cultural pressure that makes their life more critical. Absence of necessary medical service also acts as a barrier to get proper treatment and therapy. All these events put more and more pressure on parents and its consequences are nearly unknown. How do parents cope with the situation and manage, is necessary to know to take necessary policy and to initiate service delivery system. Though there are some initiatives have been taken by the government but not adequate to meet the needs.

Studies on the issue are rare and parenting experience is nearly uncovered in Bangladesh. Parents not only struggle to ensure care, they have to cope with the existing social system. Even social stigma and misconceptions are strong here which often create additional crises for such parents. Existing literature and studies are not enough to understand parental struggle and coping. The propose study is designed to know the parenting experiences of parents including the difficulties, challenges usually face in inside and outside the family. It will also try to find out the consequences over their life and coping mechanisms. As a developing country, Bangladesh has to prepare itself to meet the growing up challenges of autism to achieve sustainable development goals. To obtain such goal, area of health and health education must be properly addressed to provide adequate service so that people could live with security. As autism is one of growing health issues of the world, as well as for Bangladesh, so we need to take preparation and to arrange necessary services. Findings of the study could be helpful for the policy makers to know the situation properly and to rethink about the issue and about the existing service delivery system. Even, academicians and researchers could get new inside to learn and to initiate new study to understand the issue in our context.

## II. METHODOLOGY

With the objective of understanding the problems of girls of ASD and their parents' challenges in their raising, a studying was conducted by using qualitative research approach. Sylhet City Corporation was the area of the study. It is one of the important

divisional cities of Bangladesh where people from different districts are living. There is no accurate or tentative statistics on ASD based on this city, so it is difficult to clarify the total population. Firstly, a list of girls living with ASD was collected from the District Social Services department. Information was also collected from some special schools studying the girls located in Sylhet city. Then a draft list of parents was made for drawing the sample. As parents having girl child with ASD were the population of the study, so the research team made a separate list of such parents. There are around 112 parents found who have girl child with ASD. Except parents, service providers like teachers of special schools, doctors, government officials and medical service providers were considered as the key informants of the study. Based on the lists, an initial contact with the parents was made but many parents did not show interest to participate. Even some parents found not reside in Sylhet city. Considering all the issues, purposive sampling technique was adopted to select the participants. Among the parents, 26 were interviewed and 6 persons were selected as key informants. The study used multiple data collection tools considering the nature of the study. Separate data collection tool was used for parent and key informants. A semi-structure schedule was developed and used to take in-depth interview of the parents. This schedule mainly focused on the problems of the girls living with AD and parents' challenges to look after them. A semi-structured interview protocol for the key informant interview was used for the service providers. This protocol mainly focused on the issues to understand the parenting challenges, social reality, their crises, future initiatives. The protocol also used some questions to cross-check the issues as raised by the parents. After successful data collection, necessary editing and furnishing were made by the researchers. Collected data was coded and analyzed for themes. Necessary statements were incorporated and interpretations were done. Thematic analysis has used to present the findings. Necessary interpretations have made carefully.

### III. FINDINGS AND ANALYSIS

#### III.I. DEMOGRAPHIC INFORMATION

The vast majority of the parents were Muslim except few parents from other religions. Among 26 participants, 18 was mother and 8 was father. Most of the cases, it was difficult to reach father as they usually stay outside during day time for their livelihood. Except 6 mothers, rest of them was housewife. One of them is teacher, another one is engaged in private job, and rest of the 4 is paid worker. Except few, most of the fathers (participant) were low paid worker. But participants also shared that, their partners have business or private job or other sources of income. Even in few families, there were multiple earners who helped to maintain family expenditure. In terms of their economic status, majority of them (two-third) belonged to lower income group but few of them found have better economic condition as they have multiple earner or multiple sources of income. Average monthly income of the lower income group was range between TK. 12000-18000. On the other hand, monthly income of the few participants was more than 30 thousands. They have business or multiple earners in the family. More than two-third of the participants lived in single family. Few of them lived in joint or extended family. It is also observed that they have migrated from rural area for better life and thus live in single family. Few of them lived in joint family with their parents or they are supposed to bind to live with them for their support. Participants were asked about their educational status. One-third of them completed primary education, where another one-third of them completed secondary level. Among others, number of graduates is very negligible portion. Even few of them can only read and write their name. Size of the family was also investigated under the study. Among the participants, nearly two-third of them family size is between 4-5 persons. On the hand, close to one-third of them family size is comparatively larger as they live in joint or extended family. They have 7-9 members including their older parents and siblings. Data also indicates that the ASD child is the first child of the nearly 40 per cent families. Only 20 per cent cases, more than one child found having disability but it is normal for the rest of the families. Even no parent was found having any form of disability.

## III.II. COMMON PROBLEMS OF GIRLS WITH ASD

The study focused on the major challenges usually face by the girls with ASD with in their daily life. Both the boys and girls face such difficulties but might have differences between them. Generally they are not able to do their daily activities though few of them can do it partially. Even through education and continuous counselling many of them develop their ability and can adjust with the socially accepted system though gaps are seen in many ways. Participants were asked about the issue and they shared their experiences. Most of the cases, inability to perform normal activities of daily living is the main problem in the life of autistic girls. They are also dependent on their parents for their daily needs. They have to face various problems starting from eating, bathing and using the toilet. As a result, they have to depend on their parents for these personal tasks. Vast majority of parents pointed out the major limitations or challenges are food taking, bathing, right selection, poor understanding about social action and interactions. These are the common among all the children but many of them gradually develop their ability by years. Several parents have expressed their experience of their daughter's reluctance and inability to do routine tasks. According to a parent,

*“She can't dress himself, and she can't tell if she's hungry, instead she chirps, and she chirps all the time. So it's hard to tell when she's hungry and when she's not. I have to ask her again and again. She can stay silent and keep silence for hours but her facial expression does not tell you anything.”*

Majority of the parents complained about their inability to do regular activities. They have been teaching about it but often they make mistake or forget to do. In some case, they try to do but in wrong way which invite additional pain for their mothers. One of the mothers expressed her pain like,

*“She can't do any work by herself, it causes more trouble. Can't go to the toilet alone, can eat with her own hands, and can't take a bath by herself. If for some reasons she doesn't like something, throws away the plate. Even she can't get dressed or doesn't want to get dressed.”*

Nearly similar opinion was shared by another mother. She told like,

*“She not only unable to do, but her intention is not positive. I have been trying to teach her to wear dress or how to use toilet but seems very reluctant. It seems to me that she enjoys my pain or she is totally unable to do her daily activities. If I show anger then she becomes rigid and does what she likes. For this reason, I do not like to warn her but has been producing stress.”*

In some cases, opposite experiences were shared by few parents. One-sixth of the parents shared that their daughters like to work without taking help of others. This is very positive as they have seriousness about their daily activities. Even they try to help their mothers in many ways. They show very soft attitude to their family members and try to give them relief by doing their tasks. Even parents have been trying to teach them the right way to do but they often try to do in different ways which produce work load for mothers and other family members, one of them shared her experiences like,

*“She is very active, always likes to help me and does her best to do her task. She always likes to prepare her bed, clean her reading table and room. Also she likes to help me in my household activities. But she fails to perform it properly and I have to do the same task again. But I am happy as she is cooperative and learning though very slowly. I hope she would be able to her daily activities in future. I always pray for that.”*



Few of them shared nearly similar experiences but their children's reactions are different. In some context, such children like to do their work but they have their own liking and disliking. A significant portion of parents informed that their children always try to do their activities seriously and do not like to take help of others. They often ignore suggestions or support of family members and do not accept cooperation. If someone wants to help them they react and become angry. One of them shared like,

*"Now she is 14 years and has been trying to manage her work alone. She is very serious and spends hours to complete her work. She always shows self-dependend attitude and never allow anybody to assist her. Problem is that, she takes more time to finish it and thus often fail to complete her work in time. Even she does not like to take help while doing her school work. She only accepts her house tutor but conditionally."*

But in some cases, girls show negative attitude to do their work and to receive support. Even they react if someone wants to help them as mentioned by few parents. One of them shared like,

*"She wants to do like a normal girl and we always appreciate her. But problem is that she does not like to ask or to get any support from us. Even we can't help as she becomes angry and show violent reactions."*

But their main problem is to manage and to adjust with the situation. Specially most of them often ignore gender difference and gender based demand. It is very hard for those who are in a certain age group which has distinct care and management demand but most of them are unable to understand it. Parents shared that, such girls need additional care and support whether they understand or not. For this reason, parents have to face additional challenges, even they need to force them to follow or maintain it. As a result, many girls explain it negatively and they become aggressive or violent. Girls often react to parents' advice and view it as a barrier to their freedom. One of the parents shared like,

*"My daughter is very emotional, and always likes to do independently. Even she does not like to hear any suggestion or support from us. It is a problem when she does not follow norms and values which are essential for a ten girl in our society."*

Forgetting is another common problem reported by the two-third of the parents. They put their own things in a place and after hours or day they search it in another place. By this time they invite tension for all and if not found they blame others for it. One of the parents shared like,

*"She always loses her necessary things like pen, pencil or books or even important things like money. She likes to hide those things in a hidden place so that nobody can find it. Problem is that she often forgets and then starts shouting. She blames her brother though he does not know anything. We have to find it and then she becomes silent."*

Language is one of the major problems for such girl and they often make mistake to make a meaningful complete sentence. Though many of them have been improving due to interventions but still now they face problem to express their opinions or emotion or even their needs and demands. One-third of the parents still facing such problem and one-fourth of them reported minor changes though problem is remaining. This is usual that they face difficulties to make a full sentence with meaning, but few of them have serious problem as they can't make a sentence. One of the parents shared like,

*“She is now 12 years but can’t express her needs or emotion in an understandable way. Now we are habituated but still we face difficulties to understand the meaning. Like, she frequently uses past tense to express her present need. Or she uses wrong words to tell us anything. Sometime we ask her again and again or try to understand it by showing objects.”*

Not only that, few of them do not use words or not able to express in words. So they use signs or show the things that they need. Parents often try to inspire them to express it in words but their limitations or less interest restrict them to do it. It needs continuous efforts and patience of parents and family members for their betterment as mentioned by teachers and doctors. They also complained that most the parents often make mistake to understand their language difficulty and thus they show negative reaction which is not good for their girls. One of them explained such limitations like,

*“Such child takes time to develop the vocabulary, in many cases it continues to their whole life. They like those words which they prefer and thus they use it. Parents need to repeat the words and try to make them familiar with new words. It will help them to know new words and thus they will able to make sentence with meaning.”*

Another key informant added like,

*“Usually autistic child often make mistakes to express his opinion, emotion and need. Parents need to know their expression and thus they could understand the meaning of their expression or incomplete sentence. In many cases, parents ignore it, rather they show negative expression which they should not do. Such reaction may make them more conservative and it will develop isolation and distance.”*

### **III.III. PROBLEMS OF GROWING UP WITH ASD**

#### **III.III.I. PROBLEMS DURING MENSTRUAL PERIOD**

In addition to the usual problems, a growing age autistic girl child has many other types of problems. There are some social and cultural demands, and natural changes with whom any growing up girl needs to adjust and follow it. It depends on the social and cultural setting but some changes are common to all over the world. A growing up girl needs to adjust with the physical changes, hormonal changes and also with ascribed and achieved situation which one can’t ignore. But when the girl has autism, it is more complex due to their mental ability and understands capacity. It is one of the major challenges for parents as well for the girls to manage such situation without facing embarrassing moments. Parents often face difficulties to teach their teen about menstruation, hiding physical changes, manage cleanliness and related issues. It is difficult for normal girls, so it is harder for autistic girls. Parents discussed about the challenges of teen girls with ASD and their experiences are not similar. Parents having teen girl with ASD, all most all of them have painful experiences including their sufferings and challenges. Except few, vast majority have been facing difficulties to teach their girls about monthly cycle. Many parents still facing difficulties as their daughters often make mistake to understand and to manage it. Nearly one-fourth of them have acute problem as they are literally unable to understand and manage their situation. One of them shared like,

*“She has no idea and still she is not aware about her monthly cycle. Though I have been informing her, even few of her friends have been motivating her but no change is seen. I have to remember date, change her sanitary napkin and keep her clean. Even she can’t wear it. If I forget her date, she can’t notice me.”*

Nearly similar problem was mentioned by another mother like,



*“There are so many problems every day. Besides I have to take care of my daughter during her period. She does not understand when to change the sanitary napkin. Sometimes she takes it off doesn't tell me. As a result, her dress and bed become dirty and create embarrassing moments for all.”*

Few of them found lucky as their daughters have better understanding than others but they have different forms of problems. In our society, it is secret health issue for women and generally we do not discuss it with others. But their daughters could not understand the social norms and they talk about it in open air as mentioned by those parents. One of them shared like,

*“My daughter can handle her monthly cycle, can change napkin and manage cleanliness. But she doesn't keep the confidentiality, rather share it with anyone. Even she asks many questions about it in front of other family members.”*

Management during menstruation is another challenge for parents as mentioned by many of them. Few parents informed that their daughters can understand it, even they are now able to change napkin, keep them clean but fail to understand the religious and social restrictions. They are not habituate to follow religious instructions as well as culturally ascribed restrictions and act without any difference. This is common to all as mentioned by parents and they have been trying to make them understand about it. One of them shared her experiences like,

*“She knows about it but does not understand religious and social restrictions. We have been teaching her about prayer but she wants to pray at that time. If I warn her she throws many questions about it. Even she is not prepared to maintain other restrictions. I know her limitations but trying to make her aware.”*

Physical problem or discomfort is common during menstruation and all most all of the girls have to face such issue. It is not similar to all, depends on their ability to adjust with the issues. Usually girls share it with their mother or sisters and thus they try to get solutions or support. But it is difficult for those who have ASD. Though many of them become habituated or develop understanding but not all of them are fortunate. Many girls with ASD have poor or no idea about it, even they can't express their problems or discomfort due to their limitations. Parents often face difficulties to know or to understand their problems. Thus many of them suffer but parents fail to know. One of the parents shared like,

*“Sometimes she complains about discomfort, sometimes not. I have to ask her every time but she often makes me confused. She can't express her problems properly but now I could understand her. Her facial expression tells me many things.”*

On the other hand, many of them show reactions not comfortable for parents as well for family members. In some cases, they show reactions more not only for pain, but also due to fear. Around 12 parents shared similar experiences as they have been facing. They have been trying to teach their girls but most of the time they fail to react properly. One of them shared like,

*“She often creates noise and unwanted situation which make us panic. Initially we took her to doctor but no problem found. Then we realize the fact, her reactions are not physical, rather mental. She becomes panic and often makes mistake to express it normally.”*

A significant portion of them often fail to maintain proper safety measures and invite unwanted situation for parents. Parents of them complained that they keep jumping, moving, playing and other activities which are not suitable at that time. Thus sometime they produce tense moments for parents. One of them shared like,



*“She always likes to jump and play. During monthly cycle she continues her such activities which is not accepted and, in some context, restricted. But she shows no respect as she is not unable to understand it. She made embarrassing moments for us but we have failed to change her. I don't know how I would have to face it.”*

It is a challenge for parents to send them to school during this time as many of them have problem to manage it. Some parents usually do not allow them to go to school due to fear. Moreover some parents informed about the food related problem as their daughters do not take proper food during that time. Some of them do not like to eat or drink or even keep silence as mentioned by their parents. Besides these problems, few of them face some other problems like mood swing, irritating behavior or keep distance from others. The main challenge is to make them aware and habituated about this natural event.

### **III.III.II. PROBLEMS RELATED TO HEALTH AND HYGIENE**

There are some related issues which also create problem for parents. Except few, majority of the parents indicated about issues like hygiene, mood swing, regular bathing, dress code, etc. these girls often make wrong attempts which are not comfortable and healthy for them. Even they take long time to understand and follow it regularly. In some cases, they try to follow the instructions given by parents but forget very quickly. So parents need to inform it every time as they shared. Parents also share their struggle to teach them about health and hygiene along with their negative experiences. All of the participants have to face such problem though their pain is not similar. Nearly one-third of them comparatively fortunate as their daughters have been able to manage it without their support. It does not mean that they did it very easily. But their daughters have been habituated and thus they can manage it. One of them shared like,

*“She is very serious about her health and hygiene though initially she did lots of mistake. We spent hours and days and now she is able to follow our instructions. Sometimes she makes minor mistake but we support her always. She takes bath regularly, cut her nails and change her dress properly.”*

Another parent shared like,

*“She took long time to learn but now she is almost fine and can manage herself. She can keep cleanliness and very careful about her dress. Problem is that she takes additional time to take her shower. We have been trying to change her habit but she shows less interest.”*

In many case, they can't follow basic health rules, rather they do unhealthy practices ignoring parents' instructions. As they have been informing but many of them fail to follow and they do what they like. If the parents force them, usually they react and show negative attitude. One of the parents shared like,

*“She likes to wear her favorite dresses, no matter dirty or clean. We can't change this habit as she shows aggressive reaction. Even she often makes mistake to wear dress considering the weather and temperature.”*

In some cases, problems are acute for those girls who have multiple disorders. These girls frequently make mistake, fail to follow basic health and hygiene rules and invite additional pressure for parents. Their level of understanding and inability often

create problem. Parents have to pay attention to ensure their health issues. In some cases, parents may not pay attention due to their business and thus these girls do unhealthy practices.

### III.IV. FOOD HABIT, DRESS AND SOCIAL VALUES RELATED PROBLEMS

In our society, there some norms and values regarding teen girls as they enter into new life with major changes. It is not easy for any girl to know and to follow without difficulty. Many girls face mental challenges as well as physical challenges and thus they make mistakes to perform properly. They need time to change their habit, develop understanding and to adjust with the socially ascribed demands. Considering all those factors, it is easy to understand that girls with ASD have to face serious troubles to perform like normal girls. Parents talked about their challenges as they have been facing and also shared their techniques to make them habituated. Problems related to food habit, dress code and social values found very common except few. Majority of the parents have to face it and even many of them are still facing it. One of them shared like,

*“Except few, most of them usually can’t understand social expectation and values; even it is very difficult to teach them. People often make mistake to understand their condition, rather they raise questions, or make negative comments by observing their dress, manner and behavior. I often face such moments though I have been trying to develop her awareness about dress and norms. Sometimes she does well, but most of the time she does what she desires.”*

Another parent shared different experiences like,

*“She likes to present her well-dressed but could not understand the social need. She behaves with anyone as she knows her but many people become puzzle. She doesn’t like say hello or say ‘salam’, rather she talks like a friend.”*

In some contexts, parents face negative social reactions and criticisms as people show different attitude towards their behavior. Specially they face it in social gathering or in public places. All most all of them have similar experiences though few of them have different opinions as their daughters have developed by the time. One of them shared like,

*“My daughter likes to eat and she eats continuously. But she can’t manage it, thus makes her dress dirty. We have been motivating her but changes are not satisfactory. Following doctor’s advice we try to ensure her social gathering but she often invites such moments which are not comfortable for us.”*

Opposite experiences are also noticed by some parents as their girls are very selective and eat only their favorite food items. If they get favorite food items, they keep eating, don’t allow other people to eat. It happens inside and outside the home. It’s a problem as they fail to ensure their nutrition and thus they face health issues. One of them shared like,

*“She loves some selected food items and I have to cook it regularly. On the other hand, she does not like many food items which are essential for her growth and development. We have been sharing it with her doctor but no change is seen.”*

### III.V. PROBLEMS RELATED TO THE SOCIALIZATION PROCESS

Socialization is a life-long process as we have to learn at every stage of life. It begins at the early stage of our life though depends on many factors. Family, peer group, educational institute, social groups, and many other factors often influence our life and learning. It is expected that people should learn and response according to the demand of our society. But people who



have certain mental, neurological and physical limitations or challenges, their socialization may face challenges. It is very difficult for those having disability or autism. Various studies have been focusing the issue. The present study also investigated the challenges related to socialization of such children and parents shared their opinions. Parents face many challenges in socializing autistic girls. Usually the first step in the socialization of any child is by the hands of the parents and this process continues throughout life. Parents give instructions on how the child should behave and interact with others at home and outside. But in the case of girls with autism, parents have to suffer more. It is not easy task to teach them about manner, rules, values and related elements which are essential in socialization process. As they have limitations to understand and to react accordingly, so they need continuous supervision and support to become habituated with social response. One of the parents shared like,

*“Not all children have same and similar problem but all of them face difficulties to understand normal social process. Some can learn easily but majority of them take time. My daughter has been trying to habituate but still she is not able to react accordingly. We try our best to assist her and we will continue it. All parents should do it.”*

Parents have to fight to manage their attention as they often ignore it. Parents have to spend hours and days just to develop their understanding. Sometime they pay serious attention but many times they do not. Two-third of the parents shared that their girls pay attention only when they desire. On the other hand, some parents informed that their girls only hear those things they like. So, it creates pressure for parents to make them aware about their behavior. In some cases, girls react positively but can't maintain it due to their limitations. They need repeated motivation and counseling. Few of them have opposite problem as they like to show expected behavior but fear and other factors bound them to do different reactions, as mentioned by their parents. Many parents' face problem to teach them manner and social behavior, even some of them do not try to learn as they have their own concept. They often ignore parents' instructions and do what they like. Parents of those children face serious problem to make them understand. One of the fathers shared like,

*“She does what she likes and understands. She hardly follows our advice, even she starts arguments when we tell her anything. Generally we do not force her but it depends on the situation.”*

Most of the parents have been facing to make them aware about social interaction though in many cases they often use wrong words, or show unexpected reactions or even do something not comfortable for others. Though some of them have been changing their behavior due to continuous interventions but parents need to keep an eye on them. One of the parents shared like,

*“She has been improving and now she could show positive manner to elder, friends and relatives. But we always pass tense moment if she does any mistake. When we go outside with her, we deeply observe her behavior and assist her to show expected manner.”*

Many of them informed that such children improve their social interaction but depend on their mood or environment. In some context, if they do not feel comfortable in a particular situation or they feel disturb, then they react and do different behavior. Nearly halve of them shared such experiences about their children. One of them shared like,

*“She is very keen about people and behave based on her mood. If she views someone not friendly or feels discomfort, then she starts unwanted behavior. She does it in any situation.”*



Parents struggle to control their aggressive behavior and explain how to dress in public. A parent said in this regard,

*“We have been teaching her about social norms, values, how to interact and how to behave. Even she has been getting guide from her teachers. It is positive as she has been improving but it is not fixed. We can’t assume how she would react in a particular situation. For this reason, usually we do not go anywhere with her considering her uncertain behavior. Sometimes she behaves politely but she can react at any moment.”*

In some cases, children with autism do not want to socialize or interact with relatives, friends or others; rather they like to live in their self-decorated world. Parents’ positive intention is a matter, but children’ willingness is more important as mentioned by one-third parents. Their children often show negative tendency to meet with people. This is a problem for parents to make them easy to interact. A parent said,

*“She is not really used to socialization. She feels alone when taken outside. I admitted her to a school but she didn't have any friends there. She used to sit quietly on a bench alone. When guests come to the house or cousins of her age, she sits quietly. She does not like to communicate to all. She can only mingle with me, her father, our family members. Even that depends on her mood. Does not always talk to us either.”*

Key informants discussed about the process and challenges of socialization of ASD child considering their ability and social environment. All of them focused on the process of socialization where many factors influence their learning and attention. As they mentioned, such children often seek comfortable environment and avoid negative words or reactions. As their ability is not like normal children, as they have repeated behavior and so it is the responsibility of parents not to force them. In many cases, parents wish to teach them quickly and when they fail to do it, they become angry or become hopeless. Parents must have clear understanding about their children, their liking and disliking and try to make them aware focusing their ability. Parents should not force them to perform like others, rather they should give them chance to modify their behavior. Majority of the key informants complained that parents often make mistake to know their interest, rather they become angry to them. It hampers their attention and thus they fail to show positive attitude. One of them said like,

*“Parents should not expect that their children can perform like normal children. As they have limitations, so parents must have to know it and do their best to assist them to overcome those limitations. But in many cases, parents lose their hope and force them to perform properly. They should give them positive motivation and friendly environment to learn.”*

Another key informant shared like,

*“I know how much straggle and stress parents have to face in terms of their child’s socialization. I have been observing the frustration of many parents as their children are not performing properly. But they should not lose their hope, attention and intention. Even they should not hope to see quick changes as such children have different learning ability and understanding capacity.”*

A teacher also shared her experience in term of socialization of such children. She explained like,

*“Being a teacher of special school, I have been dealing with such children who have multiple limitations, challenges and learning ability. In some cases, they can response but most of them need continuous nursing. Most of them often do what they*

*like and we can't force them to do what we like and expect. Many children take time to learn, but parents need to keep patience. Some parents often complain about their behavior, but do not try to understand their ability."*

### III.VI. CHALLENGES OF PARENTS

Raising a girl child with ASD is a challenging task for any parent. Parents have to face series of challenges and difficulties but depend on the child's condition. Parents of child with ASD have to go under personal, social, economic and cultural challenges and they need to cope with all the unfriendly circumstances. They have to face public reactions, criticisms, barriers and in some context, negative views of society. Both the ASD children and their parents have to face unfriendly social environment which hamper their life and activity. Even it invites mental and physical challenges for parents in many ways, make them disturb and produce frustration. Parents under the study shared their parenting challenges and consequences and their stories are painful. In some cases, they get positive responses, support, association and help but most of the cases opposite experiences are very common.

#### III.VI.I. CHALLENGES REGARDING TIME MANAGEMENT

Parents shared their challenges and majority of them indicated the daily routine management is one of the major challenges for them. It hampers parents' daily activities specifically for mothers who have to manage both their children and family activities. All most all the mothers viewed it their major challenge to make balance between regular activities and nursing their children. They have to spend additional hours though it is difficult for them. It is hard for working mothers who have to depend on external support to cope with the daily routine. Findings indicate that the significant numbers of parents depend on the family support, fully or partially to manage their daily routine. It is our traditional family system where family members always perform as a means of support system. Those who have adult family members like mother-in-law, sister-in-law or like other, they can seek their cooperation and thus they have been adjusting their daily activities. But all parents are not fortunate as they have to depend on other sources or adjust it differently. Some respondents seek voluntary help from relatives or neighbors to manage their daily routine. Not all have the opportunity to seek or get support, which bound them to depend on paid worker as mentioned by seven parents. Only rich families or those have sufficient amount of monthly income, they can use this technique. Even this mechanism is not always comfortable and safe, because paid workers may not able to manage such child.

Many parents have to use different or multiple mechanisms depend on the need and situation, as described during in-depth interviews. One of the working mothers shared like,

*"I have a paid worker just to give time to my child. I start my day early in the morning, cook food for all, and then feed them. Even I prepare food for launch and then go to my office. My husband tries to assist me but he is also busy. I come back at evening and then prepare dinner for them. My helping hand manage my child at day time and also do household works. This is my everyday routine. Honestly, I get only one day in a week to take normal breath."*

Those who have no paid worker or have additional support, they also explained their techniques to manage daily activities. One of them explained like,

*"My mother-in-law and elder sister have been providing support and cooperation to manage my activities. Most of the time mother-in-law manage my child, or my elder sister take her to their house. I know they have to face difficulties to manage my child, but I am fortunate as they show positive attitude."*

But not all have similar support or cooperation from family members, even they have no ability to recruit a paid worker. Respondents of that category also explained their experiences and techniques, like,

*“I have been struggling to manage my daily activities as I have no paid worker or adult family members. I have to work from dawn to dusk, but not possible in every day. Sometime I seek help from my neighbor just look after my child for hours. You know, it is not possible every day. Even when I need to go outside, I request my sister to come or I send my child to their house. Honestly I am trying to adjust but it has been creating pressure on me.”*

When the child becomes crazy and starts crying or anything else, this invites pressure and parents have to manage activities differently as mentioned by two-third of them. They also shared their strategies in that particular situation. One of them shared like,

*“If she becomes crazy, I have to manage her and it requires additional hours. I just try to do those tasks essential for us. Even I can't cook, arrange simple menu for all. My husband knows it and he does not react.”*

### III.VI.II. PHYSICAL HEALTH RELATED CHALLENGES

Raising an autistic girl is a daunting task for all parents. They pass busy time to complete their daily activities that force them to take additional work load. Besides household and professional responsibilities, parents have to pay attention and to serve their daughters. Most of the mothers usually pass restless days for long which impact on their physical condition. Additionally their age is also a factor. After a certain age, usually we face age related health issues. It becomes serious when they face continuous pressure, it hamper their physical condition. Among the participants, one-fourth of them have been facing physical problems and one-fifth of them have been taking medicine to get relief from physical problems. Even many of them often face some issues like headache, weakness, and other problems partially. One of them shared his situation like,

*“I work at a school, after coming home I help my wife take care of our daughter as much as I can. Now both of them are getting old. Some diseases become automatic with age. Often I feel tired and my physical activity has been declining. My wife does most of the household task but she has limit. She often complained about headache or body pain and we have visited to doctors. Doctor suggested avoiding the tension but it is not possible for her as well as for me.”*

Another parent described her experience. She said,

*“I have many physical ailments, ringing in my heart. I have lived to die or to serve my daughter and granddaughter. She has to be forcibly confined in the house, and after applying the force required, my chest hurts a lot. And all the time the thought works, sometimes she runs out of the house. I wake up sometimes.”*

Another parent said,

*Once food is given to her, she will sit for hours, sometimes very bored. Sometimes I beat and scold. I also say, “Why don't you die?” And when my mind is good, I caress her. What else can I do, I can't leave my daughter. She can do nothing by herself. I have to do everything. I am very old now. I have been sick since before. I can't walk well by myself. I don't see with my eyes, I hear less with my ears.”*

In many ways such children create workload for parents and thus they remain busy from dawn to dusk. Restless daily routine makes them tired and has been inviting physical problems. One of them explained her condition like,

*“You can’t imagine my daily routine as I have to work from morning to night. Even I can’t get free time for myself, visit to relatives or even go to market. It seems to me that I am a machine or moving like a fan. Sometime she is very cooperative but most of the time she creates additional task for me. I am tired, simply tired and now I need rest.”*

### III.VI.III. MENTAL HEALTH CHALLENGES

Like physical health, such situation often invites mental health issues for parents and different studies have explored it. As the parents have to face constant pressure, so it hampers their mental stability, blood pressure, creates anxiety, and future uncertainty also work as a barrier to lead normal life. All of them have been facing such mental health related challenges though some of them have acute problems. Having a child with ASD invites such pressure as mentioned by them. In one side, parents have to manage their children, on the other side they have to face all those obstacles which produce additional pressure on them. One of the mothers shared like,

*“It is very easy to understand that parents feel continuous pressure and face obstacles and no one is not free from it. If you have enough money, you can arrange various supports, but you can’t avoid tension. This is the natural reaction and we all have been facing it. It produces various mental reactions. Those who can cope with it they may live a better life than others.”*

Mental pressure or psychological impact depends on the economic condition, support, depth of child’s autism and some other factors. Those who have family support and economic strength they can avoid some unwanted problems which are not possible for others. Rich families can arrange proper treatment, get support and thus they have a better chance to ensure the care of their children. One of them explained like,

*“Think about my economic condition, we often face difficulty to provide medical expenditure, school fees and related expenditure. It has been increasing our stress and I have been suffering from some mental disorder like sleeplessness, headache and weakness. My husband is also facing the similar problems. But we have no alternative. When we think about our daughter’s future, it makes us weak. Those who are financially strong they are not facing such pressure.”*

Opposing the arguments few parents explained it differently. One of them shared like,

*“Yes, money is a factor but not a solution. We can arrange many things for our child but mentally we are not fit. Like others, we always think about her future and it has been disturbing us. I can’t go to market, visit my relatives and freedom is limited.”*

In some cases, parents have been under treatment due to a psychological problem. At least five of them reported that they have major psychological issues due to it. High blood pressure, anxiety, isolation and some other forms of psychological issues have been facing by them. One of them shared like,

*“I have been using sleeping pills but it is not the solution. When I wake up in the morning, my brain does not function properly. Often my blood pressure fluctuates, doctors warn me to avoid tension.”*

Isolation is another problem among few of them. They have been avoiding social gathering, visiting relatives and other social engagements as they have remain busy at home. One of them explained like,

*“In last 15 years, my life has been changing negatively. Due to my child I have been avoiding different social gathering, even I can't go to my relative house. People often view it negatively and thus many of them do not like to invite me. Now I do not like to participate any social gathering. Rather I keep me alone in my house.”*

Age of parents and their ability to face such pressure are important two factors here. Psychological impact is acute among aged parents than young couple. One of them shared like,

*“I am getting older and some physical problems are diagnosed. Now I can't tolerate any stress and thus my physical problems are increasing. I am passing a life without joy.”*

Another parent said helplessly,

*“We are so much stressed about our daughter. Today we are alive, if we die after two days then what will happen to our child? It has been destroying my mental ability. Now I am unable to hear any negative news.”*

Among autistic children, female parenting has more anxiety, which has a negative impact on mental health, as said by one parent. She expressed like,

*“Not only in the case of autistic children, have parents had two kinds of experience in raising normal boys and girls. In our society, parents of girls face more challenges than parents of boys. I know many people whose sons are autistic. They are also worried about security, now is not a good time. No boy or girl is safe. Still, their thinking is a little less than ours. We have to keep an eye on the girl all the time. I don't let you go out even for a while, there is no question of going anywhere alone. I spend time constantly worrying about these things.”*

Many parents regret not being able to take care of their children properly due to various obstacles. Due to their own limitations, additional worries pile up on them. Another parent said,

*“I got a little sick looking after her. I am running around with her a lot. There is always a tension working with her. There is a cost behind it. After all, thinking always works. I can't take care of myself like I used to, I'm sick. It also happened that I am much stressed; my body has become very bad. When I go to the doctor, the doctor always says that your body is getting worse because you are under too much tension.”*

### **III.VI.IV. EXPERIENCES OF HARASSMENT**

Many autistic children do not understand their safety like normal children. As they often fail understand social situation and negative intention of mass people, so their safety issue is one of the prime concerns of the parents. Parents always try to ensure their safety but many of them faced negative experiences as mentioned by some parents. All the parents showed keen attention and concern about the issue and shared their techniques which they have been using. Despite having their seriousness and keen attention, it is not possible by parents to avoid incidents. One of them shared like,



*“I can't go anywhere without my daughter, I always keep her at home, in front of my eyes. If I ever go out, her father looks after her. I can never leave her alone or hide from my eyes just for her safety. No such incident happened by the grace of Allah.”*

Though it is not widely happening or many parents might not interest to share it due to social stigma. But few of them shared such incidents and negative experiences. One of them shared like,

*“Years ago I went to my village home with her and stayed there few days. My daughter is introvert and usually she does not like to share her problems. One of my nephews took the chance and he molested her. She told me after few months though she was confused about such touch.”*

Another parent also shared her experiences like,

*“I keep a close eye on her now. Actually, there was an incident in her childhood when we used to live in the house a few years ago, there was a colony next door. There were many boys and girls her age or slightly older than her. As she played here, she used to play sports there. One day a boy there called her and took her near the shack on that side and held him in the mouth, and later somehow she came and told me about it. However, then a lot of trouble ensues. Finally we left that house because my daughter was very scared there. This has scarred her so much that she doesn't like boys anymore, she doesn't even go out to play.”*

In some cases, boys try to take chance to abuse such girls as they know their limitations. It happens in public places or social gathering as mentioned by few of them. Most of the cases, known persons do it or try to do it. In some cases, boys try to exploit them by using the girls' innocence thinking s mentioned by five of them. Even it is happen in combined school also. One of them shared like,

*“One day my daughter showed me a picture where my daughter and a boy of her class standing very closely. It increased my tension and I started to investigate it. What I came to know was not good and then I changed her school. Unfortunately my daughter could not understand the meaning of such behavior and the boy took the chance. I thought to take legal action but couldn't due to fear of losing social status.”*

Not only harassment, in many ways they face abusive behavior as mentioned by many parents. Their known persons take the chance and thus exploit them. Even they are not able to understand the meaning of many words or signs which are not positive in nature. In some cases, girls ask their parents but many of them do not want to know it. Thus they become the victim of exploitation or bullying unconsciously. One-fifth of the parents shared such experiences. Both the boys and girls, known or unknown try to catch their weakness and some of them have victimized in that way. One of the mothers shared like,

*“One of her friends (girl) took her some pictures and shared it on her social media account. It was simple matter but a boy started to send bad messages and images to her. Initially she had no idea about the meaning of these messages and images. She replied and then the boy got the access. One day my daughter shared me as she didn't understand it and then I could realize it. The boy was known to us and then I talked to the mother of the boy.”*



Using negative words and labelling are not uncommon in our society which often makes their life difficult. In some cases, known and close persons use it as fun but it has negative impact over their life. Many people often fail to differentiate between mental disorder and disability, thus they make mistake to show proper respect to girls with ASD, as mentioned by many parents. In many contexts, people use some negative words like ‘mad’, ‘abnormal’ and others words. Even many people evaluate them as negative and they have no right to get access as normal people. One of the parents explained like,

*“Some local boys often use negative terms when they see her, even they use some sings which are not comfortable. It hampers her normal life, she often feel discomfort and does not like to go out.”*

In some cases, friends and known people exploit them if they get chance as mentioned many parents. These people try to take their things like books, pen, pencil and even they take mobile of the girls at school. It happens at combined schools or when they meet their friends at social gathering. One of them informed us like,

*“She often losses her books, pen, pencil and other necessary things and can’t tell how it happens. In some cases, they exchange things with my daughter and give her broken things. Once, one of them took her mobile phone though we recovered it later. People often view them weak and thus they take the opportunity.”*

## IV. CONCLUSION

Rate of autism has been increasing in the world due to many reasons. This issue has been getting priority in the many countries. Parenting challenges are diverse and coping mechanisms of parents are depended on the many factors. The study explored the multidimensional challenges of the parents having girl child with ASD. But the most crucial challenge is to manage support for the child and their social security. Gender is a vital factor as female with ASD has to face acute problems, challenges and barriers in many ways. Not only financial limitations, parents have to face social challenges. Insecurity and exploitation are other forms of challenges as many parents have to face it. We have law, policy and services but gender based focus is not visible. We need to give special attention focusing the gender based challenges and limitations. Government should pay attention to gender based challenges and thus incorporate it in law, policy and services. Even we need to provide additional facilities to girls with ASD and to their parents. Gender based insecurity needs to be considered and need to take initiatives to reduce it. Parents should get support and services as they have to face challenges. Our policy should focus on the conjugal issues, family management and financial support properly. Even it is important to introduce counselling service for parents. Similarly our service providers may work as change makers by providing advice and mental support to parents. It is also important to broadcast information about existing services so that parents may inspire to get it. Parents like to get it easily, so special call number may be introduced to get necessary information. We need to focus on the parents who reside far from the city and in rural setting where services are absent or very limited. Government should take initiatives to incorporate different groups of people to provide wider services to them. Still now people are lees interested about autism, even it is unknown to many people including parents. This area need to get importance to make change. Service and quality life of girl child with ASD depends on the positive social and family environment, awareness of parents and support system. Our law, policy and service should focus on the issues properly. Thus, parents will get mental support and girl child with ASD will get desired services.

## REFERENCES

1. Abbeduto, L.; Seltzer, M.M.; Shattuck, P.; Krauss, M.W.; Orsmond, G. and Murphy, M.M. (2004). Psychological well-being and coping in mothers of youths with autism, Down Syndrome, or Fragile X Syndrome, *American Journal on Mental Retardation*, 2004; 109(3):237–254. [PubMed: 15072518]
2. Akter, Salma; Khatun, Shanzida and Biswas, Happy Bandana (2017). Parenting Stress of Mothers of Childs with Autism in Bangladesh, *Journal of Nursing and Health Science (IOSR-JNHS)* e-ISSN: 2320–1959.p- ISSN: 2320–1940 Volume 9, Issue 4 Ser. XII (Jul. – Aug. 2020), PP 06-14
3. Almansour, M.A.; Alateeq, M.A.; Alzahrani, M.K.; Algeffari, M.A. and Alhomaidan, H.T. (2013). Depression and anxiety among parents and caregivers of autistic spectral disorder children. *Neurosciences (Riyadh)*. 2013;18(1):58-63.
4. Altieri, M. J. & von Kluge, S. (2009). Searching for acceptance: Challenges encountered while raising a child with autism. *Journal of Intellectual & Developmental Disability*, 34(2), 142-152. doi:10.1080/13668250902845202
5. Altieri, M. J. (2006). *Family functioning and coping behaviours in parents of children with autism*. Unpublished doctoral dissertation, University of Eastern Michigan, EE. UU.
6. Aman, M. G.; McDougle, C. J.; Seahill, L.; Handen, B.; Arnold, E. L.; Johnson, C.,... Wagner, A. (2009). Research Units on Pediatric Psychopharmacology Autism Network. Medication and parent training in children with pervasive developmental disorders and serious behavior problems: Results from a randomized clinical trial. *Journal of the American Academy of Child and Adolescent Psychiatry*, 48(12), 1143-1154. doi: <http://dx.doi.org/10.1097/CHI.0b013e3181bfd669>
7. American Psychiatric Association (APA) (2013). *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition, Washington DC: American Psychiatric Association, 2013; pp-483.
8. Anagnostou, E. & Taylor, M. J. (2011). Review of neuroimaging in autism spectrum disorder: What have we learned and where we go from here. *Molecular Autism*, 2(4), 2-9. doi:10.1186/2040-2392-2-4
9. Aneshensel, C. S.; Pearlin, L. I.; Mullan, J. T.; Zarit, S. H. & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego: Academic Press.
10. Antony, P. J., & Banks-Joseph, S. R. (2010). Indian families in the U.S. who have children with disabilities: Implications for inclusive and culturally responsive practices. *Multiple*
11. Aylaz, R.; Yilmaz, U. & Polat, S. (2012). Effect of difficulties experienced by parents of autistic children on their sexual life: A qualitative study. *Sexuality and Disability*, 30(4), 395-406. doi:10.1007/s11195-011-9251-3
12. Baker, B. L.; Brookman L. & Stahmer, A. (2005). Stress level and adaptability in parents of
13. Baker-Ericzen, M. J.; Brookman-Fraze, L. & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, 30, 194–204. doi:10.2511/rpsd.30.4.194
14. Baranek, G. T. (1999). Autism during infancy: A retrospective video analysis of sensory-motor and social behaviors at 9-12 months of age. *Journal of Autism and Developmental Disorders*, 29(3), 213-224.
15. Barbarin, O. A.; Hughes, D. & Chesler, M. A. (1985). Stress, coping, and marital functioning among parents of children with cancer. *Journal of Marriage and the Family*, 41, 473-480.
16. Barroso, N. E.; Mendez, L.; Graziano, P. A. and Bagner, D. M. (2018). Parenting stress through the lens of different clinical groups: a systematic review & meta-analysis. *J. Abnorm. Child Psychol.* 46, 449–461. doi: 10.1007/s10802-017-0313-6
17. Bashir, A., Bashir, U., Lone, Z.A., & Ahmad, Z. (2014). Challenges faced by families of autistic children. *International Journal of Interdisciplinary Research and Innovations*. 2014; 2(1): 64–8. [https://doi.org/10.4103/AJOP.AJOP\\_4\\_18](https://doi.org/10.4103/AJOP.AJOP_4_18).
18. Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability*, 51, 702–714.

19. Bebko, J. M.; Konstantareas, M. M. & Springer, J. (1987). Parent and professional evaluations of family stress associated with characteristics of autism. *Journal of Autism and Developmental Disorders*, 17, 565–576 . doi:10.1007/BF01486971
20. Benjak, T., Vuletić Mavrinac, G., Pavić Šimetin, I., & Kolarić, B. (2011). *A comparative study on self-perceived health and quality of life of parents of children with autism spectrum disorders and parents of non-disabled children in Croatia*. A Comprehensive Book on Autism Spectrum Disorders. Dr. Mohammad-Reza Mohammadi (Ed.), InTech, doi: 10.5772/17368. Available from: <http://www.intechopen.com/books/a-comprehensive-book-on-autism-spectrum-disorders/a-comparative-study-on-self-perceived-health-and-quality-of-life-of-parents-of-children-with-autism->
21. Bristol, M. M. (1984). Family resources and successful adaption to autism children. In E. Schopler and G. B. Mesibov (Eds). *The Effects of Autism on the Family*. pp. 289–310. New York: Plenum Press.
22. Bristol, M. M.; Gallagher, J. J. & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology*, 24, 441–451.
23. Brobst, J. B.; Clopton, J. R. & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, 24(1), 38-49.
24. Bromley, J.; Hare, D. J.; Davison, K. & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8(4), 409-423. doi: 10.1177/1362361304047224
25. Calzada, L.R.; Pistrang, N. and Mandy, W.P.L. (2012). High-functioning autism and Asperger's disorder: utility and meaning for families. *Journal of Autism and Developmental Disorders*. 2012; 42(2): 230–3. <https://doi.org/10.1007/s10803-011-1238-5>.
26. Charles & Mertler, 2002 (Charles, C. M., & Mertler, C. A. (2002). *Introduction to educational research*. Boston: Allyn and Bacon.
27. Chaste, P. and Leboyer, M. (2012). Autism risk factors: genes, environment, and gene-environment interactions. *Dialogues Clin Neurosci*. 2012; 14(3):281–92.
28. Cowen, P.; Harrison, P. and Burns, T. (2012). *Shorter Oxford Textbook of Psychiatry*. 6th ed. Oxford University Press; 2012; 663
29. Craig, F.; Operto, F. F.; De Giacomo, A.; Margari, L.; Frolli, A.; Conson, M., et al. (2016). Parenting stress among parents of children with neurodevelopmental disorders. *Psych. Res.* 242, 121–129. doi: 10.1016/j.psychres.2016.05.016
30. Creswell et al., 2003 (Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, Calif: Sage Publications.)
31. Creswell, 1998 (CRESWELL, J. W. (1998). *Qualitative inquiry and research design: choosing among five traditions*. Thousand Oaks, Calif, Sage Publications.)
32. Creswell, 2002 (Creswell, J. (2002). *Educational research: Planning, conducting, and evaluating Quantitative and Qualitative research*. Upper Saddle River, NJ: Merrill Prentice Hall.)
33. Cullen, L. & Barlow, J. (2002). Kiss, cuddle, squeeze: The experience and meaning of touch among parents of children with autism attending a touch therapy programme. *Journal of Child Health Care*, 6, 171-181.
34. Cutrona, CE; Russell, DW; Burzette, RG; Wesner, KA and Bryant, CM. (2011). Predicting relationship stability among midlife African American couples. *Journal of Consulting and Clinical Psychology*. 2011; 79:814–825. doi: 10.1037/a0025874. [PubMed: 22004304]
35. Dardas, L. A. & Ahmad, M. M. (2014). Predictors of quality of life for fathers and mothers of children with autistic disorder. *Research in Developmental Disabilities*, 35(6), 1326-1333. <http://dx.doi.org/10.1016/j.ridd.2014.03.009>

36. Davis, K. & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual & Developmental Disability*, 34(2), 153-162.
37. Davis, N. O. and Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: associations with child characteristics. *J. Autism Dev. Disord.* 38, 1278–1291. doi: 10.1007/s10803-007-0512-z
38. Dawson, N. (2011). An ecological perspective on parents' experiences of having a child with autistic spectrum disorder (ASD) in the South African context. MA thesis. University of Witwatersrand. 2011.
39. Dillenburger, K.; Keenan, M.; Doherty, A.; Byrne, T. & Gallagher, S. (2010). Living with children diagnosed with autistic spectrum disorder: parental and professional views. *British Journal of Special Education*, 37(1), 13–23.
40. Divan, G; Vajaratkar, V.; Desai, M.U.; Strik-Lievers, L. and Patel, V. (2012). Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Research*. 2012; 5(3): 190–200. <https://doi.org/10.1002/aur.1225>.
41. DOI: 10.4108/eai.13-7-2018.155082
42. Doss, BD; Rhoades, GK; Stanley, SM and Markman, HJ (2009). The effect of the transition to parenthood on relationship quality: An 8-year prospective study. *Journal of Personality and Social Psychology*. 2009; 96:601–619. doi: 10.1037/a0013969. [PubMed: 19254107]
43. Dunn, M. E.; Burbine, T.; Bowers, C. & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 3, 39–52.
44. Ehsan, et. al. (2018). Confronting Autism in Urban Bangladesh: Unpacking Infrastructural and Cultural Challenges, *EAI Endorsed Transactions on Pervasive Health and Technology*,
45. Ekas, N.V. and Whitman, T.L. (2010). Autism symptom topography and maternal socio-emotional functioning. *American Journal of Intellectual and Developmental Disabilities*. 2010; 115:234–249.
46. Estes, A.; Olson, E.; Sullivan, K.; Greenson, J.; Winter, J.; Dawson, G. et, al. (2013). Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain Dev.* 2013;35(2):133-8.
47. Faras, H; Ateeqi, NA and Tidmarsh, L (2010). Autism Spectrum Disorders. *Ann Saudi Med*. 2010 Jul-Aug; 30(4): 295–300.
48. Farrugia, D. (2009). Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, 31(7), 1011-1027. doi:10.1111/j.1467-9566.2009.01174.x
49. Fewster, D.L. (2014). A qualitative study to understand the experiences and coping processes of primary caregivers of children with autism spectrum disorder. MA thesis. University of KwaZulu-Natal. 2014.
50. Fletcher, P. C.; Markoulakis, R. & Bryden, P. J. (2012). The costs of caring for a child with an autism spectrum disorder. *Issues in comprehensive Pediatric Nursing*, 35(1), 45-69. doi:10.3109/01460862.2012.645407
51. Freedman, BH; Kalb, LG; Zablotzky, B. and Stuart, EA. (2012). Relationship status among parents of children with autism spectrum disorders: A population-based study. *Journal of Autism and Developmental Disorders*. 2012; 42:539–548. doi: 10/1007/s10803-011-1269-y. [PubMed: 21590433]
52. Freitag, C.M.; Staal, W. and Klauck, S.M. (2010). Genetics of autistic disorders: review and clinical implications. *Eur Child Adolesc Psychiatry*. March 2010; 19(3):169–78.
53. Gau, S. S.-F.; Chou, M.-C.; Lee, J.-C.; Wong, C.-C.; Chou, W.-J.; Chen, M.-F.; Soong, W.-T. & Wu, Y.-Y. (2010). Behavioral problems and parenting style among Taiwanese children with autism and their siblings. *Psychiatry and Clinical Neurosciences*, 64, 70–78. doi:10.1111/j.1440-1819.2009.02034.x

54. Gau, SS-F; Chou, M-C; Chiang, H-L; Lee, J-C; Wong, C-C and Wu, Y-Y (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*. 2012; 6:263–270. doi 10.1016/j.rasd.2011.05.007.
55. Georgiades, K.; Boyle, M. H.; Jenkins, J.; Sanford, M. & Lipman, E. (2008). A multilevel analysis of whole family functioning using the McMaster family assessment device. *Journal of Family Psychology*, 22(3), 344–354. doi:10.1037/0893-3200.22.3.344
56. Giovagnoli, G.; Postorino, V.; Fatta, L. M.; Sanges, V.; De Peppo, L.; Vassena, L., et al. (2015). Behavioral and emotional profile and parental stress in preschool children with autism spectrum disorder. *Res. Dev. Disabil.* 45-46, 411–421. doi: 10.1016/j.ridd.2015.08.006
57. Glazzard, J. & Overall, K. (2012). Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD). *Support for Learning: British Journal of Learning Support*, 27(1), 38-45.
58. Gray, D. E. (2002). ‘Everybody just freezes. Everybody is just embarrassed’: Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, 24, 734–749.
59. Gray, D. E., & Holden, W. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18, 83–93.
60. Gray, D.E. (2003). Gender and coping: the parents of children with high functioning autism. *Social Science & Medicine*, 56, 631–642.
61. Gray, D.E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970–976.
62. Grech, 2009 (Shaun Grech (2009) Disability, poverty and development: critical reflections on the majority world debate, *Disability & Society*, 24:6, 771-784, DOI: [10.1080/09687590903160266](https://doi.org/10.1080/09687590903160266)
63. Gupta, V. B. (2007). Comparison of parenting stress in different developmental disabilities. *J. Dev. Phys. Disabil.* 19, 417–425. doi: 10.1007/s10882-007-9060-x
64. Hall, M.R. (2008). *The relationship among adaptive behaviors of children with Autism Spectrum Disorder, their family support networks, parental stress and parental coping*, Dissertation (PhD), University of Tennessee.
65. Haque, KR (2015). Addressing Autism and Disability: Making Progress in Bangladesh. 2015. Available from: [http://nhri.ohchr.org/EN/ICC/AnnualMeeting/28/Statementspresentations/Mr\\_Hoque%20-%20Bangladesh.pdf](http://nhri.ohchr.org/EN/ICC/AnnualMeeting/28/Statementspresentations/Mr_Hoque%20-%20Bangladesh.pdf), 2015.
66. Hartley, S. L.; Barker, E. T.; Mailick, M.; Floyd, F.; Greenberg, J.; Orsmond, G. & Bolt, D. M. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449-457. doi:10.1037/a0019847
67. Hartley, S.L.; Sikora, D.S. and McCoy, R. (2008). Maladaptive behaviors in young children with Autistic Disorder. *Journal of Intellectual Disability Research*. 2008; 52:819–829. [PubMed: 18444989]
68. Hartley, SL; Barker, ET; Seltzer, MM; Greenberg, JS. and Floyd, FJ. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal of Intellectual and Developmental Disabilities*. 2011; 116(1):81–95. doi:10.1352/1944-7558-116.1.81.
69. Havens, C. A. (2005). Becoming a resilient family: Child disability and the family system. *Monographs of the National Center on Accessibility*, 17. Retrieved January 10, 2012, from <http://www.indiana.edu/~nca/monographs/17family.shtml>
70. Hayes, A. F. (2013). Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach. New York, NY: The Guilford Press.
71. Higgins, D.J.; Bailey, S.R. & Pearce, J.C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9(2), 125–137.

72. Hoffman, C. D.; Sweeney, D. P.; Hodge, D.; Lopez-Wagner, M. and Looney, L. (2009). Parenting stress and closeness: mothers of typically developing children and mothers of children with autism. *Focus Autism Dev. Disabil.* 24, 178–187. doi: 10.1177/1088357609338715
73. Huq, Naznin; Rahman, Syka and Mahbuba, Suraiya (2017). Socio-Psychological Conditions of the Autistic Children in Bangladesh: A Psychological Study on Dhaka City. *IOSR Journal Of Humanities And Social Science (IOSR-JHSS)*, Volume 22, Issue 8, Ver. VI (August. 2017) PP 10-15 e-ISSN: 2279-0837, p-ISSN: 2279-0845.
74. Ilias, K., Cornish, K., Kummar, A.S., Park, M.S.A., & Golden, K.J. (2018). Parenting stress and resilience in parents of children with autism spectrum disorder (ASD) in Southeast Asia: A systematic review. *Frontiers in Psychology*, 9. <https://doi.org/10.3389/fpsyg.2018.00280>
75. Ingersoll, B. & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 337–344.
76. *interrelationships*. In C. S. Aneshensel & J. C. Phelan (Eds.), *Handbook of the sociology of mental health* (pp. 395–415). NY: Plenum.
77. Järbrink, K.; Fombonne, E. & Knapp, M. (2003). Measuring the parental, service and cost impacts of children with autistic spectrum disorder: A pilot study. *Journal of Autism and Developmental Disorders*, 33(4), 396–402.
78. Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: How
79. John, A. (2012). Stress among mothers of children with intellectual disabilities in urban India: Role of gender and maternal coping. *Journal of Applied Research in Intellectual Disabilities*. 25, 372–382. <https://doi.org/10.1111/j.1468-3148.2011.00672.x>
80. Johnson, L.N. and Rodriguez, D. (2013). Children with autism spectrum disorder at a pediatric hospital: a systematic review of the literature. *Pediatric Nursing*. 39(3): 131–41; 2013.
81. Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child: Journal of Psychopathology, Psychotherapy, Mental Hygiene, and Guidance of the Child*, 2, 217-250.
82. Karney, BR. and Bradbury, TN. (1995). The longitudinal course of marital quality and stability: A review of theory, methods, and research. *Psychological Bulletin*. 1995; 118:3–34. [PubMed: 7644604]
83. Karst, J.S. and Hecke, A.V.V. (2012). Parent and Family Impact of Autism Spectrum Disorders: A Review and Proposed Model for Intervention Evaluation. *Clin Child Fam Psychol Rev*. 2012;15(3):247-77.
84. Kersh, J. J.; Hedvat, T. T.; Hauser-Cram, P. P. & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, 50(12), 883–
85. Kiami, S. R. and Goodgold, S. (2017). Support needs and coping strategies as predictors of stress level among mothers of children with autism spectrum disorder. *Autism Res. Treat.* 2017:8685950. doi: 10.1155/2017/8685950
86. Klein, S. M. & McCabe, H. (2007). From mother to disability professional: Role change, resilience, and rewards. *Journal of Early Intervention*, 29, 306–319.
87. Kraijer, D. (2000). Review of the adaptive behavior studies in mentally retarded persons with autism/pervasive developmental disorder. *Journal of Autism and Developmental Disorders*, 30(1), 39-47. doi:10.1023/A:1005460027636
88. Kring, S. R.; Greenberg, J. S. & Seltzer, M. M. (2010). The impact of health problems on behavior problems in adolescents and adults with autism spectrum disorders: Implications for maternal burden. *Social Work in Mental Health*, 8(1), 54-71. doi: 10.1080/15332980902932441
89. Larson, E. (2006). Caregiving and autism: How does children's propensity of routinization influence participation in family activities? *Occupational Therapy Journal of Research*, 26(2), 69-79.



90. Lasser, J. & Corley, K. (2008). Constructing normalcy: A qualitative study of parenting children with Asperger's disorder. *Educational Psychology in Practice*, 24(4), 335-346. doi:10.1080/02667360802488773
91. Lecavalier, L.; Leone, S. & Wiltz, J. (2006). The impact of behaviour problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research*, 50, 172-183. doi:10.1111/j.1365-2788.2005.00732.x
92. Lee, G. K. (2009). Parents of children with high functioning Autism: How well do they cope and adjust? *Journal of Developmental and Physical Disabilities*, 21(2), 93-114. doi:10.1007/s10882-008-9128-2
93. Losh, M.; Sullivan, P.F. and Trembath, D. (2008). Current developments in the genetics of autism: from phenome to genome. *J. Neuropathol. Exp. Neurol.* 2008; 67(9):829-37.
94. Ludlow, A.; Skelly, C. & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology*, 17(5), 702-711. doi: 10.1177/1359105311422955
95. Luong, J.; Yoder, M. K. & Canham, D. (2009). Southeast Asian parents raising a child with Autism: A qualitative investigation of coping styles. *The Journal of School Nursing*, 25(3), 222-229. doi:10.1177/1059840509334365
96. Lutz, H. R.; Patterson, B. J. & Klein, J. (2012). Coping with autism: A journey toward adaptation. *Journal of Pediatric Nursing*, 27, 206-213. doi:10.1016/j.pedn.2011.03.013
97. Machado, Junior SB; Celestino, MI; Serra, JP; Caron, J. and Pondé, MP (2016). Risk and protective factors for symptoms of anxiety and depression in parents of children with autism spectrum disorder. *Dev Neurorehabil.* 2016;19(3):146-53.
98. Matenge, B. (2013). An exploration of the lived experiences of mothers raising children with autism. MA thesis. University of Cape Town, 2013.
99. McCabe, H. (2010). Employment experiences, perspectives, and wishes of mothers of children with autism in the People's Republic of China. *Journal of Applied Research in Intellectual Disabilities*, 23(2), 122-131. doi:10.1111/j.1468-3148.2009.00512.x
100. McConnell, D.; Savage, A. & Breitkreuz, R. (2014). Resilience in families raising children with disabilities and behaviour problems. *Research in Developmental Disabilities*, 35, 833-848. doi: 10.1016/j.ridd.2014.01.015
101. Metts (2004) (Metts, R. (2004). Disability and Development: Background Paper Prepared for the Disability and Development Research Agenda Meeting, November 16, World Bank: Washington, DC.
102. Midence, K. & O'Neill, M. (1999). The experience of parents in the diagnosis of autism. *Autism*, 3(3), 273-285. doi:10.1177/1362361399003003005
103. Miranda, A.; Mira, A.; Berenguer, C.; Rosello, B. and Baixauli, I. (2019). Parenting Stress in Mothers of Children With Autism Without Intellectual Disability. Mediation of Behavioral Problems and Coping Strategies. *Front. Psychol.* 10:464. doi: 10.3389/fpsyg.2019.00464
104. Moes, D. R. (1995). Parent education and parenting stress. In R. L. Koegel & L. K. Koegel (Eds.), *Teaching children with autism: Strategies for initiating positive interactions and improving learning opportunities* (pp. 79-93). Baltimore: Paul H. Brookes.
105. Myers, B. J.; Mackintosh, V. H. & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache:" Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, 3(3), 670-684.
106. Neely-Barnes, S. L.; Hall, H. R.; Roberts, R. J. & Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualizations. *Journal of Family and Social Work*, 14(3), 208-225. doi:10.1080/10522158.2011.571539
107. Nokrek, Alam and Ahmed, 2013 (Metts, R. (2004). Disability and Development: Background Paper Prepared for the Disability and Development Research Agenda Meeting, November 16, World Bank: Washington, DC.



108. North American Nursing Diagnosis Association (2001). *NANDA nursing diagnoses: Definitions and classification*, 2001–2002. Philadelphia: Nursecom.
109. Novaes, C.M.; Pondé, M.P. and Freire, A.C. (2008). Control of psychomotor agitation and aggressive behavior in patients with autistic disorder: a retrospective chart review. *Arq Neuropsiquiatr.* 2008;66(3b):646-51.
110. Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, 45, 535–543.
111. Ou, WX; Cha, CH and Wang, LH. (2010). Mental health state of parents of children with autism. *Zhongguo Dang Dai Er Ke Za Zhi.* 2010;12(12):947-49.
112. Pakenham, K. I.; Sofronoff, K., & Samios, C. (2011). Finding meaning in parenting a child with asperger syndrome. *Autism*, 9(2), 191-212.
113. Pearlin, L. I. (2000). *The stress process revisited: Reflections on concepts and their*
114. Pearlin, L. I.; Aneshensel, C. S. & LeBlanc, A. J. (1997). The forms and mechanisms of stress proliferation: The case of AIDS caregivers. *Journal of Health and Social Behavior*, 38, 223–236. doi:10.2307/2955368.
115. Pelchat, D.; Lefebvre, H. & Perreault, M. (2003). Differences and similarities between mothers' and fathers' experiences of parenting a child with a disability. *Journal of Child Health Care*, 7, 231–247.
116. Pervasive, O.; Disorders, D. and Korea, S. (2012). Global Perspectives on Autism. 2012. Available from:
117. Pottie, C. G.; Cohen, J. & Ingram, K. M. (2009). Parenting a child with autism: Contextual factors associated with enhanced daily parental mood. *Journal of Pediatric Psychology*, 34(4), 419-429. <https://doi.org/10.1093/jpepsy/jsn094>
118. Preity, Sumayia; Hawlader, Mohammad Delwer Hossain; Akther, Shaheen; Abdullah, Abu Sayeed Md. And Biswas, Animesh (2017). Views of the Parents of Autistic Children about Autism and Schools for Autistic Children: A Qualitative Study in Urban Bangladesh. *International Journal of Public Health Research*. Vol. 5, No. 5, 2017, pp. 56-xx.
119. Rao, P. A., and Beidel, D. L. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment and family functioning. *Behav. Modif.* 33, 437–451. doi: 10.1177/0145445509336427
120. Ream, E. & Richardson, A. (1996). Fatigue: a concept analysis. *International Journal of Nursing Studies*, 33(5), 519-529.
121. Richard, B. O. (2014). Families, well-being, and inclusion: Rethinking priorities for children with cognitive disabilities in Ladakh, India. *Intellectual and developmental disabilities.* 21(3): 308-323. <https://doi.org/10.1177/0907568214526264>
122. Sadock, B.J.; Sadock, V.A. and Ruiz, P. (2015). *Synopsis of psychiatry*, 11th edn, 2015. Philadelphia, USA: 1264.
123. Safe, A.; Joosten, A. & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual Developmental Disabilities*, 37(4), 294–302. doi:10.3109/13668250.2012.736614
124. Saloviita, T. T.; Itälina, M. M. & Leinonen, E. E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: A Double ABCX Model. *Journal of Intellectual Disability Research*, 47(4/5), 300–312.
125. Schlebusch, L. (2015). Families raising a child with autism spectrum disorder: determining the relationship between family routines and family quality of life. PhD thesis. University of Pretoria; 2015.
126. Seltzer, M. M.; Greenberg, J. S.; Floyd, F. J.; Pettee, Y. & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation*, 106, 265–286.
127. Sen, E. & Yurtsever, S. (2007). Difficulties experienced by families with disabled children. *Journal for Specialists in Pediatric Nursing*, 12(4), 238-252.

128. Sharpe, D. L. and Baker, D. L. (2011). "The financial side of autism: Private and public costs," in *A Comprehensive Book on Autism Spectrum Disorders*, ed M. Mohammadi (Rijeka: InTech), 275–296.
129. Shu, B. (2009). Quality of life of family caregivers of children with autism: A mother's perspective. *Autism*, 13, 81–92.
130. Souders, M.; Freeman, K.; DePaul, D. & Levy, S.E. (2002). Caring for children and adolescents with autism who require challenging procedures. *Pediatric Nursing*, 28(6), 555–562
131. South Asian Muslim immigrant families navigate autism. *Disability & Society*, 25(7),
132. Sultana, Z. (2010). Agony of Persons with Disability: A Comparative Study of Bangladesh, *Journal of Politics and Law*, 3(2), 212–221
133. Sumayia Preity, Mohammad Delwer Hossain Hawlader, Shaheen Akhter, Abu Sayeed Md. Abdullah, Animesh Biswas. Views of the Parents of Autistic Children about Autism and Schools for Autistic Children: A Qualitative Study in Urban Bangladesh. *International Journal of Public Health Research*. Vol. 5, No. 5, 2017, pp. 56–xx.
134. Taylor, S. & Stanton, A. L. (2007). Coping Resources, Coping Processes, and Mental Health. *Annual Review of Clinical Psychology*, 3, 377–401.
135. Thomas, K. C.; Williams, C. S. and Morrissey, J. P. (2016). Examination of parent insurance ratings, child expenditures, and financial burden among children with autism: a mismatch suggests new hypotheses to test. *Pediatrics* 137(Suppl.2), 86–195. doi: 10.1542/peds.2015-2851Q
136. Tobing, L. E. & Glenwick, D. S. (2002). Relation of the childhood autism rating scale-parent version to diagnosis, stress, and age. *Research in Developmental Disabilities*, 23(3), 211–223. doi: 10.1016/S0891-4222(02)00099-9
137. UNCRPD, 2006) UNCRPD (2006). Convention on the Rights of Persons with Disabilities, available at: [www.un.org-disabilities-default.asp?id=150](http://www.un.org-disabilities-default.asp?id=150), in 20.12.2014, retrieved 10 March 2014
138. Vassallo, T. (2016). "It's such a battle": a phenomenological account of raising a child on the autistic spectrum; a battle with bureaucracy and behaviour. *Plymouth Scientist*. 2016; 9(1): 229–51. <https://org/bcur.org/journals/index.php/TPSS/article/view/558>. (3 May 2017).
139. Vohra, R.; Madhavan, S.; Sambamoorthi, U. and St Peter, C. (2014). Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism* 18, 815–826. doi: 10.1177/1362361313512902
140. Voices for Ethnically Diverse Exceptional Learners, 12(2), 21–32.
141. Watson, S. L.; Coons, K. D. and Hayes, S. A. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part I: a comparison of parenting stress. *J. Intellect. Dev. Dis.* 38, 95–104. doi: 10.3109/13668250.2013.788136
142. Williams, JG; Higgins, JPT and Brayne, CEG (2006). Systematic review of prevalence studies of autism spectrum disorders. *Arch Dis Child*. 2006 Jan; 91(1):8–15.
143. Woodgate, R. L.; Ateah, C. & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research*, 18(8), 1075–1083.
144. World Health Organization (WHO). (2011). World Report on Disability
145. Young, H., Oreve, M. J., and Speranza, M. (2018). Clinical characteristics and problems diagnosing autism spectrum disorder in girls. *Archives de Pédiatrie*, <https://doi.org/10.1016/j.arcped.2018.06.008>
146. Zablotsky, B.; Anderson, C. and Law, P. (2013). The association between child autism symptomatology, maternal quality of life, and risk for depression. *J. Autism Dev. Disord.* 43, 1946–1955. doi: 10.1007/s10803-012-1745-z
147. Zerlin, SA. (2015). Fostering inclusive education. *The Daily Star* 2015. Available at: <https://www.thedailystar.net/fostering-inclusive-education-23813>



148. Zubrick, S. R.; Williams, A. A.; Silburn, S. R. & Vimpani, G. (2000). Indicators of social and family functioning (Department of Social Services, Report No. FaCS245.0008). Retrieved from <https://www.dss.gov.au/our-responsibilities/families-andchildren/publicationsarticles/indicators-of-social-and-family-functioning>