International Seminar on Autistic Personnel for Higher Education

Resource Person:

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Social Exclusion and Development of the Children with Autism

1. Introduction:

Autism Spectrum Disorder (ASD) is known as a complex developmental disability, a disorder of neural development characterised by impaired social interaction and verbal and non-verbal communication, and by restricted, repetitive or stereotyped behaviour. A person with an ASD typically has difficulty with social and communication skills and lives with social exclusion and disproportion. We do not accept an autistic child to be a normal child in the society. People with autism have social impairment and often lack the intuition about others. Autistic infants do not react to social interactions, smile or look at others, and respond less to their own name. Three-to-five year-old autistic children are less likely to exhibit social understanding, imitate and respond to emotions, communicate nonverbally, and take turns with others. Making and maintaining friendships often proves to be difficult for those with autism.

According to the National Research Council (2001), children with autism have major difficulties in both their social and emotional relationships in a number of areas: a) They have low rates of social initiation with and response to peers; b) They engage in little nonverbal communication; c) they pay less attention to others' emotional outbursts than to their typical peers; d) they show less empathy or shared emotion.

1.1 Possible "Red Flags"

A person with ASD might:

- Not respond to their name by 12 months of age
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play "pretend" games (pretend to "feed" a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel

1.2 Warning Signs of a Child with Autism

Babies develop at their own pace, some more quickly than others. However, you should consider an evaluation for autism if any of the following apply:

- does not babble or coo by 12 months of age
- does not gesture, such as point or wave, by 12 months of age
- does not say single words by 16 months
- does not say two-word phrases on his or her own (rather than just repeating what someone else says) by 24 months
- has lost any language or social skills (at any age)
- does not establish or maintain eye contact
- does not make facial expressions or respond to your facial expressions

2. Conceptual Clarification:

Children:

According to the **Article 1 of** Convention on the Rights of the Child (1989), the Convention defines a 'child' as a person below the age of 18, unless the laws of a particular country set the legal age for adulthood younger. The Committee on the Rights of the Child, the monitoring body for the Convention, has encouraged States to review the age of majority if it is set below 18 and to increase the level of protection for all children under 18.

Development:

Development refers the development of social abilities and passionate development that are required to build social interactions and communicate to others in the society. In order to develop socially, children require interacting with their peers and adults in a socially up to standard way. Parental communications are the building blocks for hale and hearty social development in children. By giving lots of love and attention to the baby, parents form a close attachment with the adolescents, allowing him or her to grow in a comfortable, secure and socially in good physical shape impression.

Social Development

Social development is about placing people at the centre of development. This means a commitment that development processes need to benefit people, particularly but not only the poor, but also a recognition that people, and the way they interact in groups and society, and that facilitates such interaction, shape development the norms processes. Social development means investing in people. It requires the removal of barriers so that all citizens can journey toward their dreams with confidence and dignity. It is about refusing to accept that people who live in poverty will always be poor. It is about helping people so they can move forward on their path to self-sufficiency.

Autistic Spectrum Disorder:

Autism is general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and non-verbal communication and repetitive behaviours. Some persons with ASD excel in visual skills, music, math and art. Autism appears to have its roots in very early brain development. However, the most obvious signs of autism and symptoms of autism tend to emerge between 2 and 3 years of age.

3. Social Exclusion of the Children with Autism:

Result and Discussion:

- i. Rearing a child with autism is not only stressful and difficult, but also expensive. Many people do not know the costs associated with raising a child with autism. All the demands of family members cannot be fulfilled with the family income.
- ii. In the context of a developing country, governmental and non-governmental assistance may be made available for people with autism spectrum disorders, which may include Medicaid Home and Community Based Waivers, Social Security Income, and Social Security Disability Insurance. This study has found that 17 per cent respondents are getting financial help from Government, 28 per cent from NGO, and 55 per cent respondents are yet to receive any assistance either from government or NGOs.
- iii. Having a child with developmental or psychological problems is always stressful for their parents who are taking care of them, even when the child is a grown up person, which would cause a constant incompatibility of parents with their child's disability in their social life. These parents, other than bearing financial pressures, are always facing emotional pressures such as feeling ashamed or guilty at the time of attending social functions with their children with ASD. 14 per cent of parents attended at social functions with the child with ASD, 46 per cent parents attended now and then at social functions with the child with ASD, but 40 per cent parents did not attend social functions with the child with ASD due to avoid unpleasant situation that may arise. Parents consider themselves sick, fight for services, sacrifice careers, sink into debt, and rage at the injustice of it all.
- iv. Child neglect is defined as a type of maltreatment related to the failure to provide needed, age-appropriate care. Unlike physical and sexual abuse, neglect is usually typified as an on-going pattern of inadequate care. Once children are in school, often child neglect is observed. Professionals have defined four types of neglect: physical, emotional, educational, and medical. These four types of negligence are all related to the child with ASD. Social exclusion and discrimination mounts from this family negligence.
- v. It is assessed from the study that most of the parents (91.03 per cent) demonstrating autism as the indicator of social exclusion and 08.97 per cent parents did not think so. 75.64per cent parents think their children are socially excluded from mainstream education, 93.59per cent think from special academic education and vocational training, 87.18 per cent from social dignity, esteem and honour, 91.03 per cent from family negligence, 96.15 per cent from proper Medicare facilities, 60.26 per cent from making social relationship. On the other hand, 89.74 per cent parents believe autism

as the indicator of social discrimination, while 10.26 per cent parents do not believe it. 88.46 per cent parents think their children are living with social discrimination because of family negligence, 65.38 per cent consider it absence of peer relationship with normal child, 60.26 per cent in lack of social dignity, esteem and honour, 85.90 per cent in special Medicare facilities, 93.59 per cent in special education & vocational training, and 98.72 per cent in playing games with normal child.

vi. It is exposed from the study that most of the family members avoid the child with ASD except only parents. 14.10% positively response to give nursing in case of illness of the child with ASD, but a massive number of people such as 53.85% do not give the so. 21.79% give nursing sometimes, 10.26% give it now & then.

Autism as the indicator of Social Exclusion			Autism as the indicator of Social Discrimination		
Address	Frequency	Percentage	Address	Frequency	Percentage (%)
	(n)	(%)		(n)	
Yes	71	91.03%	Yes	70	89.74%
No	07	08.97%	No	08	10.26%
Total	n=78	100 %	Total	n=78	100 %
If yes, mention the	he area of Socia	l Exclusion*	If yes, mention the	e area of Socia	l Discrimination*
Mainstream	59	75.64%	Family Negligence	69	88.46%
Education					
Special	73	93.59%	Hampered Peer	51	65.38%
Academic			Relationship with		
Education &			normal child		
Vocational					
Training					
Social Dignity,	68	87.18%	Be deficient in	47	60.26%
Esteem &			Social Dignity,		
Honour			Esteem & Honour		
Family	71	91.03%	Lack of Special	67	85.90%
Negligence			Medicare Facilities		
Proper	75	96.15%	Lack of Special	73	93.59%
Medicare			Education &		
Facilities			Vocational Training		
Social	47	60.26%	Negligence to give	77	98.72%
Relationship			opportunity in		
1			playing game with		
			normal child		

Table: Addressing Autism as the indicator of Social Exclusion & Discriminati
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More than one answer*

4. Social Development of the Children with Autism

4.1 TheoreticalPerspective &Social Development of Autism

Developmental Constructs and Theory: Kanner's (1943) original description of autism suggested that the basis for the social difficulties lay in a *child's inability to form emotional ties ("affective contact") with parent(s).*

Over arousal (encouragement) Theories of Autismhas been for focusing on <u>social</u> engagement.

4.2 Denver Model

In the Denver approach, social interactions with adults are taught in two ways. *Initiation and maintenance are taught through the use of "sensory social exchanges.*" These exchanges are naturalistic child-centered social activities in which a child makes choices, initiates pleasurable interactions with an adult, and continues them through several rounds, using whatever communicative behavior a child has available. Social responses are taught through adult-directed interactions, as are toy play skills. Imitation of peers' and adults' motor actions and object actions is taught through direct teaching and through prompting in typical social exchanges. Peer interactions are taught in inclusive preschool settings, in which both typical peers and children with autism are prompted to initiate object actions with each other (e.g., giving, taking, and passing objects); to imitate each other in play; and to engage in social routines like circle games, songs, and similar activities.

4.3 TEACCH

The TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) approach emphasizes individual functioning in a group setting, and its focus on <u>social interaction comes particularly through communication training</u>, *participating in group activities*, *following instructions and routines with others*, *and* <u>taking turns (Watson et al., 1989)</u>. In a TEACCH classroom, the staff teaches many toy play skills, games, and object skills, which can in turn be used to facilitate social interaction (Schopler et al., 1995).

4.4 Setting Goals for Social Development

1. The process of education involves assessment of existing skills, defining what skills has taught (setting goals and objectives), planning how the skills has taught (teaching strategies), implementing the teaching plan, assessing student progress, and adapting the teaching strategy so that a student acquires the target skill (Cipani and Spooner, 1994).

2. The developmental approach uses a model of typical development to guide the educational process involving assessment, goal setting, and teaching.

4.5 Developing Goals for Improving Social Interactions with Adults

For very young children with autism, goals for specific social behaviours or skills identified in interactions with adults may focus on early pre-linguistic behaviours, such as joint attention, turn taking, imitation, responding by gaze to adult initiations, and initiating social interactions with adults (Wetherby and Prizant, 1993). These interactions occur within a play context, so establishing and supporting toy play with an adult may be a goal for some children.

4.6 Developing Goals for Peer Interactions

Interaction with peers is another dimension of children's social development that becomes increasingly important for children beginning at the age of 3.

4.7 Assessment Strategies for Developing Social Goals

More detail about social development can be gathered with preschool curriculum assessments, most of which contain a social subscale. Some scales are standardized so that average levels are determined for children of different ages.

4.8 Interventions Used To Teach Social Behaviour

Since social development is an extremely important aspect of education for children with autistic spectrum disorders, a child's social behaviour with both adults and peers needs to be targeted for intervention, and intervention should take into account both specific evaluation of a child's current social skills and specific teaching goals and plans that address the social area.

4.9 Child-Parent Social Interactions

Dawson and Galpert (1990) described a pre-post study of 14 children aged 20 to 66 months and their mothers. The intervention involved teaching the parent to imitate a child in play with toys for 20 minutes each day for 2 weeks. Follow-up after 2 weeks demonstrated significant increases in the child's gaze to mother's face, increased number of toys played with, and increased number of play schemas used, as well as generalization to novel toys.

4.10 Child-Adult Interactions

Two approaches for increasing interactions with teachers or other therapists have been demonstrated using multiple baseline approaches. One approach comes from the work of Laura Schreibman, Robert Koegel, and colleagues, using pivotal response training (PRT; see Chapter 12). Stahmer (1995) compared two interventions, symbolic play training and language training. using pivotal response techniques with seven verbal preschool-aged children with autism. The children demonstrated increases in the targeted symbolic play skills and increased positive responses to adult initiations and in initiations to adults during the play training, but not during the language training, with maintenance for 3 months and generalization across settings and other adults.

4.11 Child-Child Interactions

Peer Mediated Techniques for Increasing Interaction and Responses toPeers. According to the peer-mediated approach, typical peers are taught to repeatedly initiate "play organizers" such as sharing, helping, giving affection, and praise. Peers learn the strategies through roleplay with adults and then are cued by adults to use those strategies with children with autism. Peers are reinforced by adults for their efforts, and the reinforcements are systematically and carefully reduced. The power of these strategies to increase social interactions of young children with autism, as well as generalization and maintenance, has been demonstrated in inclusive preschool classes, as reported in many published multiple baseline studies (Hoyson et al., 1984; Strain et al., 1979; Strain et al., 1977; Goldstein et al., 1992).

4.12 Result and Discussion:

Taking steps	Frequency (n=78)	Percentage (100%)	
Academic Education	33	42.31 %	
Vocational Education	42	53.85 %	
Proper Training	21	26.92 %	
Creating the facilities of playing game	11	14.10 %	
Mainstream Academic and Vocational Education	69	88.46 %	
Opportunities of giving Financial Assistance	67	85.90 %	
Give proper honour as like normal child	51	65.38 %	
Reduce family negligence	48	61.54 %	
Availing special facilities	71	91.03 %	
Giving first treatment instantly	75	96.15 %	
Others	04	05.13 %	

Table: Taking steps for the development of the child with ASD*

(More than one answer)*

Now it is high time to take steps for the welfare, education and development for the child with ASD by the society with the help of government organization, non- government organization, local administrative bodies, and religious leader. 42.31 % parents believe only academic education, 53.85 % vocational education, 26.92 % proper training, and 14.10% creating the facilities of playing game may help in this respect. But it is assessed that 88.46 % parents believe that mainstream academic and vocational education may perhaps support in this regard. 85.90 % parents have faith in creating opportunities of giving financial assistance to the comprehensive development of the children with ASD. 65.38 % parents expect to give proper honour as like normal child for the development of them. 61.54 % give emphasis on reducing family negligence to do the so. 91.03 % parents assessed for availing special facilities for special child. 96.15 % parents want to give first treatment instantly though it is though for them but they desire it from the society to create such opportunities for the development of them. 05.13 % parents keep on imperceptible to give answer of these questions.

20. What are your expectations to the Government to develop the children with ASD?	Percentages
	(100%)
Only Academic Education	61 %
Only Vocational Education	77 %
Proper Training	81 %
Creating the facilities of playing game may develop their conditions	66 %
Mainstream Academic and Vocational Education	59 %
Special Academic and Vocational Education for Autism	89 %
Opportunities of giving Financial Assistance	73 %
Implementing welfare law	72 %
Others	11 %

21. What is your expectations to society for the development the children with ASD?	Percentages
	(100%)
Special Social Service and Care	88 %
Social Honour & Dignity	81 %
Family Care & Support	79 %
Only Academic Education	43 %
Only Vocational Education	46 %
Proper Training	55 %
Creating the facilities of playing game may develop their conditions	47 %
Mainstream Academic and Vocational Education	33 %
Special Academic and Vocational Education for Autism	93 %
Opportunities of giving Financial Assistance	72 %
Implementing welfare law	42 %
Others	09 %

5. Conclusion and Recommendations

5.1 Conclusion:

GAPH- Bangladesh (2012) revealed some positive outcomes and suggests some future directions with the optimism that that the biggest gain has been in the creation of national awareness about Autism, triggering a chain of related and unrelated events and activities. The media, both print and electronic, has played a very significant role in creating awareness. Families have found new hope, and have come together in very large numbers, charting a journey from isolation and hopelessness to sharing a dream of inclusion. Civil society is coming forward to volunteer and governments are accepting their obligations and responsibilities with regard to Autism. Voluntary organizations are joining hands, recognizing the benefits of networking and sharing scarce resources. There is a whole new national level perspective and commitment to the cause of Autism, which can best be described as an awakening of a collective consciousness, unparalleled anywhere in the world. Policy development, policy adjustments and the ability to unite activities at the community level, is what the future tasks are all about. Given the enormous expectations of stakeholders, with matching government commitments, this can be achieved by the collaborative efforts of all governmental departments, non-profit organizations, tertiary institutions, parent bodies and professionals, civil society and the media in Bangladesh.

5.2 Recommendations:

Children with ASD also are the member of the society. It is real fact that parents of children only have deep feelings on their child than other people. Parents should play a significant role for the development of their child with ASD. The findings of the study might help us to do an objective judgment about the various social exclusion and discrimination related issues concerning the children with ASD. However, in the light of the various interesting facts it can be recommended to the parents and caregivers the following steps toward the welfare of the children with ASD.

- 1. Parents have to ensure that the children are in good health, free from pain and irritation, and in a safe, stimulating and pleasurable setting by giving clear guidlines.
- 2. Government should provide structure in the environment, with clear guidelines regarding expectations for appropriate and inappropriate behaviour.
- 3. Government should provide tools, such as written or picture schedules, to ensure that the flow of activities is understandable and predictable to eliminate the discrimination with believing that they are not socially excluded.
- 4. Focus on developing skills that will be of use in the children's current and future life in school, home, and community.
- 5. Encourage parents and other family members to participate in the process of assessment, curriculum planning, instruction, and monitoring.
- 6. The more the parents know about autism spectrum disorders, the better equipped they will be to make informed decisions for their child.
- 7. Parents have to educate themselves about the treatment options, ask questions, and participate in all treatment decisions.

- 8. Figure out what triggers the kid's "bad" or disruptive behaviors and what elicits a positive response. What does the autistic child find stressful? Calming? Uncomfortable? Enjoyable?
- 9. Enjoy your kid's special quirks, celebrate small successes, and stop comparing your child to others. Feeling unconditionally loved and accepted will help your child more than anything else.
- 10. It's impossible to predict the course of an autism spectrum disorder. Don't jump to conclusions about what life is going to be like for your child. Like everyone else, people with autism have an entire lifetime to grow and develop their abilities.
- 11. Positive reinforcement can go a long way with children with autism, so make an effort to "catch them doing something good." Praise them when they act appropriately or learn a new skill, being very specific about what behaviour they're being praised for. Also look for other ways to reward them for good behaviour, such as giving them a sticker or letting them play with a favourite toy.
- 12. Carve out a private space in your home where your child can relax, feel secure, and be safe.
- 13. A child coping with autism is still a kid. For both children with autism and their parents, there needs to be more to life than therapy. Schedule playtime when your child is most alert and awake. Figure out ways to have fun together by thinking about the things that make your child smile, laugh, and come out of their shell. Play is an essential part of learning and shouldn't feel like work.
- 14. Many children with autism are hypersensitive to light, sound, touch, taste, and smell. Other children with autism are "under-sensitive" to sensory stimuli.