

State Responses to Demands for Rights of Autistic (specially gifted) Children in Bangladesh

Sharmin Akter¹ and Mahfuz Ashraf²

¹Research Scholar, Dhaka, Bangladesh

²Research Director, Brainstorm Bangladesh, Dhaka, Bangladesh

Corresponding author's E-mail: Sharmin.ir22@gmail.com

Abstract

In Bangladesh just a few years back, people were merely aware about disability with Autism. So lack of knowledge in Autism is common in Bangladesh. Most of the times they are considered as disable children although they are completely different. This has added with the lack of public-private supports. However autistic children in Bangladesh will not be looked down upon anymore. Bangladesh is now being recognised as a role-model for combating autism. Despite some challenges, the Government of Bangladesh is actively considered autism issues with measures to register child births, raising awareness at the national level, the role of family in the psychological and physical nourishment of the autistic children, holding international conference on autism (held on 25-26 July, 2011 in Bangladesh) and many more. The aim of the paper is to appraise the initiatives taken by Bangladesh government and highlights policies targeting. We argue that, awareness with the appropriate policy formulation is very much necessary. The cooperation of social awareness and Governmental, Non Governmental initiatives at the society level can bring a dramatic change about the condition and development of autistic children in our society.

Keywords: Autism, Policy, Rights, Children, Bangladesh.

1. INTRODUCTION

Autistic children are not like other disabled children. Autistic children face lifelong developmental disability that affects their communication with other people (Rapin & Tuchman, 2008). It is a neurological disorder that also affects how they make sense of the world around them (Mythili & Shanavas, 2014). Most of the autistic children have natural intelligence. According to the doctors, children with Autism Spectrum Disorders (ASDs) develop motor, language, cognitive and social skills at different rates from other children at their age. For instance, they may be very good at solving math problems or fine art but have great difficulty making friends or talking. Thus, socially very often they are termed as “Specially gifted Children”. According to World Health Organisation (WHO), autism has defined as “ASD refers to a range of conditions characterised by some degree of impaired social behaviour, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively”.

Due to lack of awareness of parents and government's assistance, autistic children suffer most from inhospitable attitudes of the society. Families with autistic children often feel unable to attend social and cultural programs as a fear that their child may get negative or even aggressive reactions from surrounding peoples (Kempe 2015). In spite of constitutional obligation and number of initiatives taken by government and private sector, parents with autistic children face problem. In Bangladesh just a few years back, people were merely aware about disability with Autism. An international conference on autism held in Bangladesh on 25-26 July, 2011 got everyone's attention. Unfortunately, our country did not have any policy regarding autistic children. They are considered as disable children although they are completely different. So normally the concern arises, despite of having

difference between other disability and autistic children why there is no specific policy in national children policy and law to meet the demand of the rights of autistic children?

However it is a matter of great prospect that recently Bangladesh has come to the forefront in this regard. The state is positively responses to the rights of the gifted children. Some initiatives done by Bangladesh government are adoption of Rights of Persons with Disabilities Act2013(amended), Final Approval of the Neuro Developmental Disabled Persons Protection Trust Act 2013, setting up National Advisory Committee on Autism and Neurodevelopment Disabilities, running a pilot program, embracing Dhaka declaration. And On December 12, 2012 the United Nations General Assembly (UNGA) passed a new resolution. The resolution was drafted and tabled by the Mission of Bangladesh with the support of Autism Speaks.

2. DISCRIMINATIONS AGAINST AUTISTIC CHILDREN IN BANGLADESH

According to the ministry of social welfare of Bangladesh, it was estimated that the number of autistic children in Bangladesh is 14 lakh and 86 thousand (Hossain 2009). But exact figure is yet to be known as survey is started to conduct. Symptoms of autism in the children are usually first noticed by their parents. Parents try to protect their child from hostile attitudes of the society. Many parents don't want to face the reality that their children are autistic. This attitude comes due to lack of knowledge, appropriate support from state policy regarding the autism and lack of education.

Our society treated them as social curse. They are invisible in marketplace, station, work place and social programs. The lacking of social awareness is accountable for this condition. Socio-economic status play significant role in terms of development of the special children. Social stigma poses a major challenge in the early diagnosis of autistic children. Due to lack of understanding of autism, people remain negligent about treating autistic children. Inappropriate education system is another obstacle for their development. Autistic children face discrimination at the mainstream education system. As there is no specific policy guideline, mainstream schools reject the application of autistic children. Even after the admission sometimes school authority exclude them in response to the objection of regular students. In Bangladesh, treatment and schooling for autistic children are expensive, which is a burden for a family that has to take care of other children. Sometimes autistic girls are in more vulnerable situation than boys. These especially needy children face obstacles in every basic rights of life in our country. They are even deprived of the property inherited rights. These circumstances are happening for short of proper policy implication, lack of awareness and negative psyche of the society. In these circumstances it is well understood why such deliberation from state is vital for the welfare of the gifted children.

3. AN APPRAISAL OF STATE'S RESPONSE

For the last five years autism has been an important focus in Bangladesh's development policy. Rights of autism and disable persons have played a significant role in national budget and development plan. On this endeavor 2013 and 2014 was remarkable years for autism circumstances in Bangladesh. Government approved a law: "National Trust for Rights and Protection of Persons with Neuro Developmental Disabilities Act 2013."

3.1. Adoption of Rights of Persons with Disabilities Act 2013(amended)

It has been long demanded by the parents and various organizations who working on autistic children to revise the disable child welfare act 2001. Governmnet of Bangladesh has responded positively in this regard. The process to amend the act, which started about two years ago, finally came into light in this year. At the very first, on July 15, 2013, the Cabinet approved the draft of the Disabled Persons Protection and Rights Bill 2013.

Then lastly Parliament on 3rd October passed the revised law of the Rights and Protection of People with Disabilities 2013 (Bangladesh Sangbad Sangstha 2013). The existing Bangladesh Disabled

Persons Welfare Act, 2001 has been scrapped with the passage of the bill. Although the bill is known as “Protection and Preservation of the Rights of the Disabled Persons Bill-2013”, it addresses all kinds of disabilities including autism. Therefore it can be taken as landmark to fulfil the demands for rights of autistic (specially gifted) children in Bangladesh.

Amended law includes separate section for defining different disability. Here autism entails a details explanation that implies autism mentioned at section 4 of revised law. According to the law the people with disability will get all facilities and opportunities such as legal recognition, individual freedom, access to justice and information, health, education, voting rights and others like any other citizen.

Moreover many other prerequisite like Upazila committee, unified education, special education, clarification of discrimination, inclusive education in mainstream school, societal rehabilitation, equal recognition before the law has been recognized in section 2-(1), (2), (19), (20), (25), (26) and (28). Many autistic children face discrimination during the study at normal school. Sometimes school authority deny to admit them and sometime although accept but after some days they are rejected by complain from the parents of normal children. Section 15 of the revised law will be fruitful to remove this type discrimination as it clearly mentioned in 15(h) that, it is the rights of disable children to take part in every education level in institution.

There is a penalty section also. According to section 36(1), anyone standing in the way of the legal rights of the people with disabilities will face three years in jail and a financial punishment of Tk 500, 000. A 28-member high-powered national committee will have to be formed with the social welfare minister to oversee the implementation of the law. Similarly, each of the upazilas will have separate committees to protect the rights of the people with disabilities.

3.2. Final Approval of the Neurodevelopmental Disabled Persons Protection Trust Act 2013

Beside the amendment of the Rights and Protection of People with Disabilities Act 2013, government finally approved Neurodevelopmental Disabled Persons Protection Trust Act 2013. It is a great responsive acceptance by the government to ensure the rights and welfare of autistic children. The law involved the issues related to providing assistance to autistic people, their nurture, security and rehabilitation. According to this law an advisory council will be set up headed by the prime minister and overall 13 ministers and state ministers will be the members of the council. Further, a trustee board comprising experts and other stakeholders will be created to look after the enforcement of the law and will provide registrations to organizations interested to work on autism. The Act offers to develop a national institute for education and training of the people with special needs and a separate unit at every hospital for them. It also emphasize on initiatives to ensure their employment and right to inherit property.

3.3. National Advisory Committee on Autism and Neurodevelopment Disabilities

This committee is doing great for extending support for the rights and welfare of the autistic children. It is the rights of the autistic children to get priority in terms of obtaining ticket to visit doctor and also priority on doctors’ chamber to meet doctor. Because of the advocacy and support of this committee Bongabondhu Sheikh Mujib Medical University has extended another step of their support toward the children/persons with special needs. Now parents will get priority with their autistic children to obtain ticket or see doctor.

3.4. A pilot Program

The government has so far built more than 13,000 community clinics, pledging to build a facility for every 6,000 population (Hasib 2013). Under the pilot program, training has been given to the community health worker to monitor development disabilities using tailor-made tools. The Ministry of Health had already trained about 8,000 community health workers from seven districts to screen development disabilities.

3.5. Dhaka Declaration

In 2011, Autism Speaks, WHO and the government of Bangladesh organized an international conference on autism. Here “Dhaka Declaration,” was adopted to bring attention to the unmet needs of millions of individuals with developmental disabilities including autism. The Dhaka Declaration endorsed the priority actions to meet the healthcare needs of the children with developmental disorders. The declaration also approved a plan to increase the awareness about the rights of autistic children, strengthen healthcare capacity, increase the capacity of professionals and mobilize and allocate human and financial resources for the healthcare of those children. It also urged governments to strengthen their mental health services and attend to the needs of people with developmental disorders.

3.6. Bangladesh Proposal on Autism

Bangladesh is pioneer to propose resolution on autism in United Nations and that resolution was adopted unanimously. Dhaka Conference on Autism Spectrum Diseases in July 2011 has contributed significantly to the UN resolution. It is a great contribution of Bangladesh regarding autism because it will act as the basis for high level discussion on autism at the United Nations in 2013. This resolution will assist UN agencies and organizations and member states to collect disintegrated data on ASD and DD. It will help rehabilitation and treatment of autistic children and end discrimination to them. It will also influence governments to prepare a database for the autistic children and take necessary steps for their rehabilitation. Beside this, WHO accepted the resolution namely “Comprehensive and Coordination Efforts for the Management of Autism Spectrum Disorders (ASDs)” in response to Bangladesh’s request.

4. A LONG TRAIL

No doubt Bangladesh has taken such initiative indicating positive response to the rights of autistic children .Government is giving proper attention towards them. But a long trail is still ahead to pursue. The approved acts need to be implemented effectively to ensure the benefits to the autistic children. There is still some deficient in the disabilities act 2013, regarding the demand of autistic children. For illustration, section 32 mentions that, any educational institution would not reject the admission of such person who have capability only by the excuse of being disabled according to description mentioned in section 5(physical disability), section 7(b, c--partial blindness, low vision), section 8 (b, c, d-speech disability) and section 10, subsection 2(b, c-hearing disability).Therefore it leave out the instruction about the education of autistic children.

In addition most special education center and organizations are Dhaka centric. Even in Dhaka city all ward don’t have special education or supporting center. Although some organizations are taking some initiative for workshop on awareness building lying on outside the Dhaka city but the numbers and initiatives are not satisfactory enough.

Logistic and Financial constrain is a big issue. In Bangladesh trained health worker and specialist are not enough in number compare to autistic children’s number. Furthermore, the organizations are running their program with the help of foreign assistance, some private bank and private sources and also by receiving certain fees from parents of autistic children. In this case government involvement is very unsatisfactory. Those nongovernmental organizations who are currently working on the special education are enough enthusiastic for giving special care and education to autistic children but the reality is that they are facing financial and logistic support. They are opted for government participation.

There is no specific action policy for special education based program. Most of the special education center don’t have fully developed program. As a result during certain age they have to leave that center, even though they are needy. Hence Bangladesh government must add the special education

program under the education ministry and there must have definite allowance for the education and welfare of autistic children.

Parents demand that there should be some reliable center and specific action policy so that after passing away their children do not face any problem. For example, autistic children don't have rights in hierarchical resources of their parents. So there must have government sources where parents can deposit money which will take the responsibility after their parents' death. Section 6.9 of national children policy deals with special education program of autistic children. So measures shall be taken to mainstream them in society with ensuring their active participation. It is appreciable as government give concern and includes section on autism in national children policy. But this policy fell short since it do not specifically stated about the measures to mainstream them in society. There is no segment about their property right and employment also. Therefore national children policy should be reshuffled.

Besides Autistic girls are more susceptible than any other children. But autistic girls do not get any special assistance from "women and child abuse law". There should have precise segment for them. Therefore the implementation of the National Neurodevelopmental Trust act 2013 is very much required. Only high level governmental policy is not enough, there must have community based program. Monitoring sell under the community should look after the various incentives. Table 1 summarises the key policy and legislatives issues dealing with autism and disable persons in Bangladesh.

Table 1: Key Policy and Legislative issues Dealing with Autism and Disable Persons in Bangladesh

Key Policy and Legislative issues	Descriptions
Section-4 and 6 (Definition of Autism and Disability)	This section entails a details explanation that implies autism
Section -1 (Upazila Committee)	Refers to a committee established for every Upazila (sub-district) to promotes the rights of persons with disabilities. Here logistic and financial constrain is a big issue
Section-2 ,32 (Equal Unified Education)	Refers that no institution can omit the admission of any student with disabilities for any reason. But it leaves out the specific instruction about the education of autistic children.
Section -6 and 17 (Inclusive Education)	Refers that general schools will arrange inclusive special education for persons with any type of disability. There is no specific action policy for special education based program. Most of the special education center don't have fully developed program.
Section -19 (Equal Lawful Acceptance)	Refers to persons with disabilities having the right to act independently without depending on others
Section -20 (Social Rehabilitation)	Refers that disable person can participate in all branches of society. Yet they need special treatment. In Bangladesh trained health worker and specialist are not enough in number compare to autistic children's number
No section on hierarchical rights of parents resources	There must have government sources where parents can deposit money which will take the responsibility after their parents' death

5. CONCLUSION

Autistic children normally suffer lifelong developmental disabilities despite having some intelligence. They are different than other disabled children. However, there was no specific policy available in Bangladesh to protect their rights and benefits in few years back. They were considered as like other disabled children. They are being discriminated from their basic rights, education and even from property rights. These situations are happening due to the lack of proper policy/law, lack of social awareness and negative attitude of the society. Previously only the urban parents were mainly concerned about their children with Autism .But at present, the situation is improving gradually throughout the country. Government has responded positively to demands for rights of autistic children in Bangladesh. They have taken some good initiatives to protect the rights of the autistic children such as, adoption of Rights of Persons with Disabilities Act 2013(amended), final approval of the Neurodevelopmental Disabled Persons Protection Trust Act 2013, setting up National Advisory Committee on Autism and Neurodevelopment Disabilities for extending support to the rights and welfare of the autistic children, running a pilot program to give training to the community health worker to monitor development disabilities using tailor-made tools, embracing Dhaka declaration to increase the awareness about the rights of autistic children and contribution to the development of new resolution on Autism in United Nations.

Not only government, both electronic and print Media plays an important role to build up awareness on this issue. Non-government organisations and foreign agencies are also working for awareness building in this regard. Organisations like SWAC (Society for the Welfare of Autistic children), ASSC (Advanced School For Special Children) are working enthusiastically with the aim of educating, training and rehabilitating children, adolescents and adults with autism. Enabling them to develop and perform to their fullest potential, making them independent and active members of the society, facilitating them to integrate and contribute to the mainstream of national development and establishing their rights as citizens of this country. Some other organizations like YPSA (Young Power in social action) is working to facilitate ICT based capacity of youths with disabilities. So that they can exercise equal employment and business opportunities from the society& state by using their ICT skills. Since different acts have been passed by the government, now the new challenges are to implement those policies correctly and effectively. If implementation can be done in a proper way, then the rights of the autistic children can be ensured in Bangladesh.

REFERENCES

- Bangladesh Sangbad Sangstha. (2013). JS passes Disabled Persons Protection and Rights Bill-2013, Accessed via <http://www1.bssnews.net/newsDetails.php?cat=7&id=362148&date=2013-10-03&dateCurrent=2013-10-09>, on 10 October, 2016.
- Hasib, N.I. (2013). Putul thrust on early autism detection, Accessed via <http://bdnews24.com/bangladesh/2013/05/21/putul-for-thrust-on-early-autism-detection> , on 22 October, 2016.
- Hossain, A.B.M.A. (2009). Country paper on the current situation and issues of education for children with Autism - Promoting Autism education with perspectives toward a cohesive society. 29th Asia-Pacific International Seminar on Education for Individuals with Special Needs, December 1-5, 2009, Yokohama Symposia, Japan.

Kempe, A.J. (2015). Widening participation in theatre through ‘relaxed performances’, *New Theatre Quarterly*, 31(1), 59–69.

Mythili, M.S. & Shanavas, A.R.M. (2014). A novel approach to predict the learning skills of autistic children using SVM and Decision Tree, *International Journal of Computer Science and Information Technologies*, 5(6), 7288-7291.

Rapin, I. & Tuchman, R.F. (2008). Autism: definition, neurobiology, screening, diagnosis. *Pediatric Clinics of North America*, 55, 1129–1146.