

## A Study on Autism in Bangladesh: Current Scenario and Future Prospects and Challenges

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### Abstract

### Original Research Article

**Background:** Addressing the inclusion of persons with autism is an integral part of government-implemented strategies for sustainable development. Inclusion is predicted on principles of universal human rights on the Rights of Persons with Disabilities and upheld by the social and human rights models of disability. **Objective:** The main objective of this study is to evaluate the current scenario and visualize the future prospects and challenges of autism in Bangladesh. **Method:** This was a cross sectional study to identify the prevalence of autism, the situation of autism, association of factors with autism, and prevalence in different local (urban, rural, community/hospital based) and demographic contexts (age, sex) throughout Bangladesh. For this study data were taken from children aged 2 to 9 years. **Results:** Persons with disabilities are more likely to live in poverty due to the adverse economic impacts of disability. Affordable community-based services allow for persons with disabilities to remain with their family and local community and participate fully in community life. All efforts should ensure local community-based supports to ensure community independence. National, regional and local initiatives should be coordinated to ensure facilities and employment for persons with disabilities. Implementation of effective monitoring and evaluation plans, which include consumer feedback loops, are key to ensuring accountable and successful interventions. The situation assessment covers the following areas: a review of the scale and prevalence of autism with trends of the disorder in the recent past in Bangladesh; estimation of likely disease burden in the near future; assessment of the social response to autism in Bangladesh; recommendations for monitoring, supervision and reporting mechanisms for autism services at the national level. **Conclusion:** The knowledge about the general condition of disabled children is shamefully inadequate. Autism data is scarcer, further compounded by the complexity of layperson identifying the disorder. But investigators have summarized key strategic recommendations for consideration.

**Keywords:** Autism, Disability, Challenges, Neurodevelopment.

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## INTRODUCTION

There is sufficient evidence researched all over that indicates that persons with disabilities are often more prone to suffering economic and social difficulties and at a great risk of poverty [1]. In addition to constraining their lives, exclusion of a debilitating effect on their societies as well. Aside from being a major issue of human rights abuse, studies have been conducted to gauge the severity of the impact of this exclusion on economies. In comparison to non-disabled persons, it is extremely challenging for persons with disabilities to secure full-time employment. The International Labour Organization estimated based on a study of ten low- and middle-income countries that 3-

7% of GDP is lost each year because of exclusion of persons with disorders from the workforce, partly due to a lack of educational opportunities for them in those countries [2]. Within the disability group, this is even truer for persons with Autism, because of the complexity and significant variations in the manifestation of the disorders. The result is that in most countries, disabled people are among the poorest of the poor. Adults with disabilities typically live in poorer than average households. In July of 2011 in Dhaka, the Government of Bangladesh hosted the largest and most high-profile international conference that has ever been held for a single psychological disability. The experts suggested that disability related programs must be

based on culture, social expectations, financial and professional resources, and existing infrastructure within Bangladesh [3]. This includes monitoring and regulation of services currently being provided in country, the training of professionals and family members for service delivery, and the development of higher education programs to serve as centres for professional development. This has led to a gap in services for those with autism and their families in Bangladesh. Currently, families have little to no access to high-quality health or educational services for their children. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic or occupational functioning. These brain function deficits can affect a person's emotions and memory, as well as his or her ability to learn, socialize, and maintain self-control. The range of developmental deficits varies from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence. It's not unusual for these disorders to co-exist. While there are no known cures for neurodevelopmental disorders, medication and therapy treatments do exist that can help a child or adult. The deficits are present in early childhood, typically before age three, and lead to clinically significant functional impairment. Sample symptoms include lack of social or emotional reciprocity, stereotyped and repetitive use of language or idiosyncratic language, and persistent preoccupation with unusual objects. The world's knowledge of the general status of children living with disabilities is shamefully scant. It is impossible to generate global estimates based on national data that is outdated, inconsistent or unreliable, thus resulting in an unclear picture internationally due to the difficulty of sourcing globally comparable data. A situation analysis is a key foundation for any sound intervention. It helps to ensure a program's relevance and to find out the best course of action by learning about community attitudes and practices regarding autism, and identifying what has already been done to address autism and what results and lessons were obtained, as well as who the main actors have been and who might be key to engage. This present situation assessment would serve as a supplement to update and expand upon the previous situation analysis report completed and will guide the policy makers in developing a national-level strategy and action plan. The lack of a professional body mandated to develop service providers in country has significantly hindered the training of competent services providers [4]. In addition to ensuring the appropriateness of the intervention to the local context,

carrying out a situational analysis will help avoid duplication of efforts, something that is needed in Bangladesh. Autism and neurodevelopmental disabilities are commonly recognized in developed countries, this is comparatively new concept in Bangladesh. There is a need to explore the epidemiology of autism in Bangladesh to find out the exact statistics to help facilitate an appropriate program and intervention plan to rehabilitate those with autism.

## OBJECTIVE

To evaluate the current scenario and visualize the future prospects and challenges of autism in Bangladesh.

## MATERIAL AND METHODS

The research terms included each of the following terms: "autism", "neurodevelopmental disorder (NDD)", "neurodevelopment impairment", "prevalence of autism", "Autism disorder", "Situation Assessment of Autism" etc. Most of the studies in Bangladesh were community-based. Nine studies were conducted in urban areas, five studies included both urban and rural areas, and four studies focused on the rural context in Bangladesh. Reported diagnoses of the following were included: attention deficit hyperactivity disorder; intellectual disability; autism; learning disorders; communication disorder; speech disorder.

### Study Design and Diagnostic Tool

Studies reviewed sought to identify the prevalence of autism, the situation of autism and NDD, association of factors with autism and NDD, and prevalence in different local (urban, rural, community/hospital based) and demographic contexts (age, sex) throughout Bangladesh. Most of these studies were executed through cross-sectional design followed by retrospective study and cohort study. For autism identification the most common diagnostic tool was the Autism Diagnostic Observation Schedule (ADOS).

### Data Collection Method

Data were collected from secondary sources like journals, books and different websites.

## RESULTS

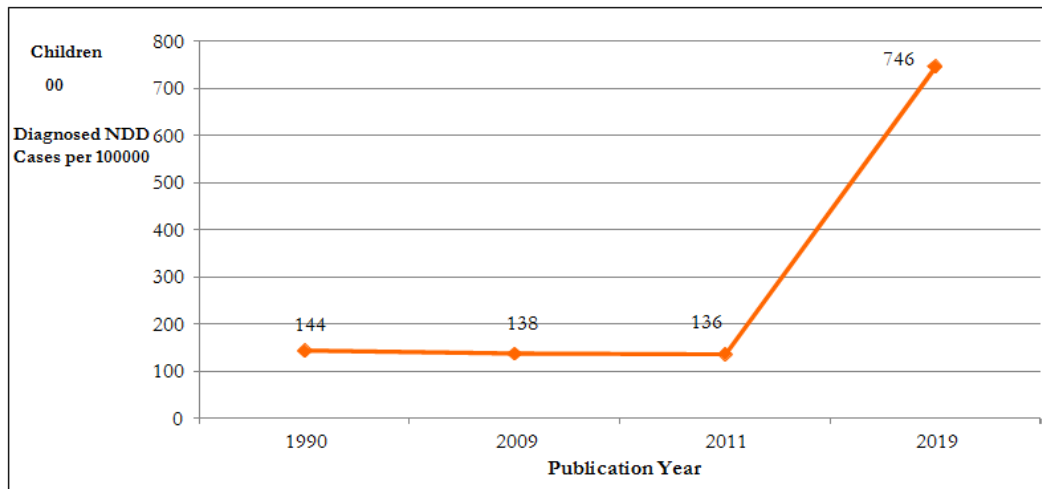
The disorders listed in Table-1 below are some of the more frequently cited neurodevelopmental disabilities. If the prevalence figures for these disorders are added together, it results in an estimate of 3.5% for NDDs.

**Table-1: Global prevalence figures for common NDDs**

DISORDER	YEAR	SOURCE	PREVALENCE
Autism spectrum disorders	2019	WHO	0.625%
Down syndrome	2018	WHO	0.095%
Intellectual disorders	1980-2017	Maulik et al	1.037%

In Figure-1, the results do not show any trends. To make numerical evaluations, Mann-Kendall trend statistics were applied to test the null hypothesis and the result was statistically insignificant ( $p > 0.05$ ). Since

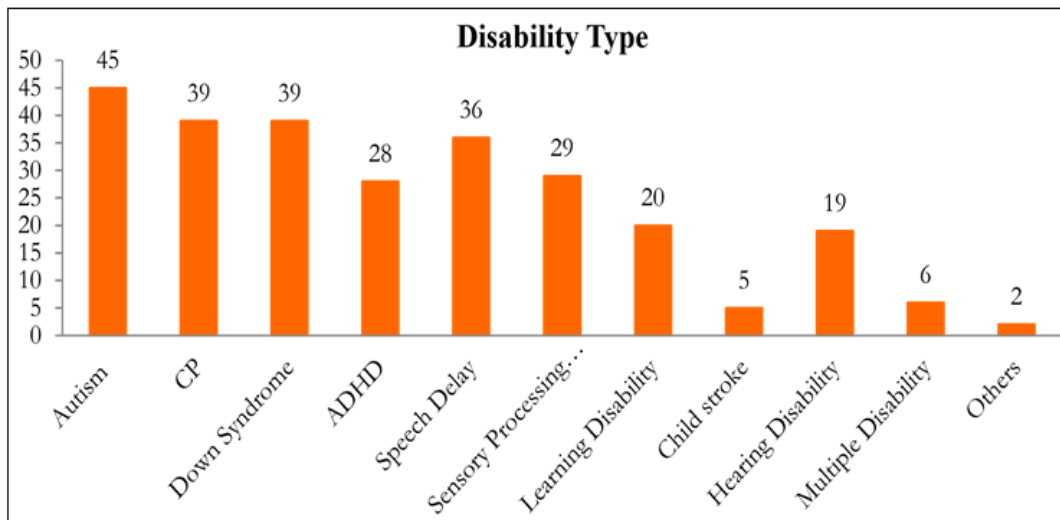
there are very few previous records of data and insignificant trends of available datasets, an estimate of the likely disease burden of NDD cases is not possible.



**Fig-1: Number of neurodevelopmental disorder cases per 100,000 children**

Icddrb has collected an inventory of 46 entities, both government and nongovernmental organizations. Among them, 45 organizations provide

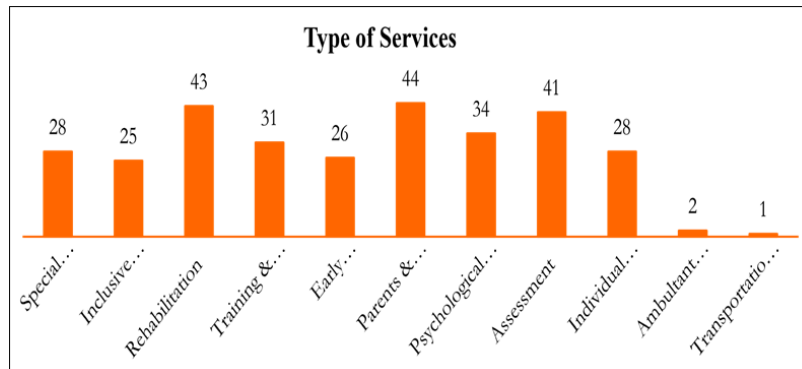
autism services. When looking at organizations at the government level, mainly services for ASD, CP, Down syndrome and ADHD were found. See Figure-2.



**Fig-2: Number of Organizations by disability type**

The graph in Figure-3 shows that, among the 46 organizations in Bangladesh that provide services for autism and NDDs, 28 organizations provide special

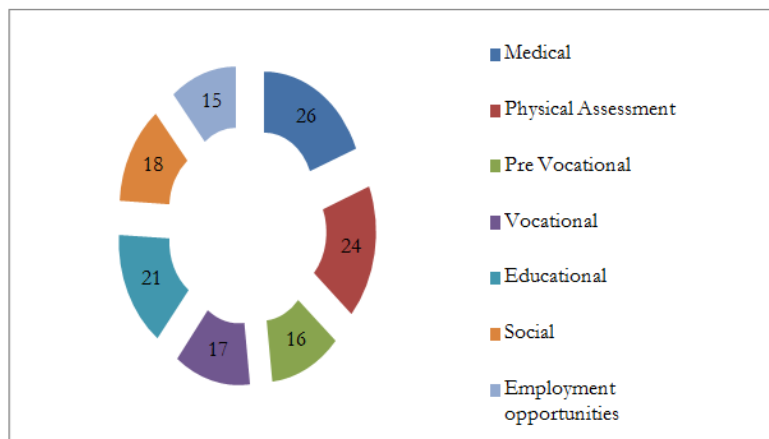
education, 25 provide inclusive education, but only 31 organizations provide training for capacity building.



**Fig-3: Number of organizations by type of services**

Of the 46 organizations, three don't offer any type of rehabilitation services. Among the 43 organizations that support rehabilitation, 16

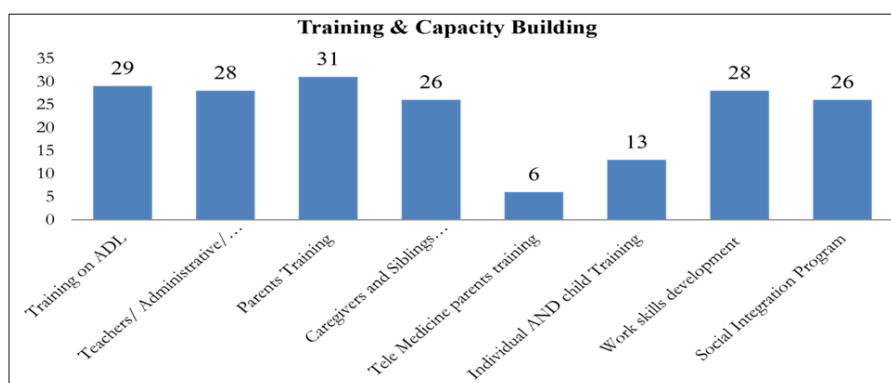
organizations provide vocational services, which are very important for people on the autism spectrum and those with NDDs. See Figure-4.



**Fig-4: Number of organizations by type of rehabilitation**

Among the 46 organizations in Bangladesh, only 31 provide different types of training for capacity building of parents, teachers, family members, or school staff. As the chart below shows, 31 organizations

provide parents' training, but only six provide telemedicine, which is very important for people on the autism spectrum and those with NDDs. See Figure-5.



**Fig-5: Number of organizations by type of training**

## DISCUSSION

In order for a society to be truly inclusive, it is vital to improve understanding and respect for persons with autism at both the government and community level. Social marketing campaigns, educational

awareness campaigns, and the media should be utilized to reduce stigma, improve attitudes, and present positive stories of persons with neurodevelopmental disorders and their families. Most of the organizations are using multiple types of therapy, but mainly speech & language therapy comparative to other types of

therapy. Rehabilitation and vocational training centers should be creating more therapies and creating job postings. Telemedicine and well-baby clinics at clinics or hospitals, as well as their referral systems, should be maintained properly. Home visit services should be included. Teacher/parent training and counseling/psychological support must be offered and implemented properly. It was found that most of the literature was on disability in general, but very little of it focused on autism and NDDs in Bangladesh. Some studies were conducted in solely in specific areas due to lack of resources which does not represent the entire population of Bangladesh. It is difficult to analyze the trend of prevalence of autism and NDDs in Bangladesh. The most common challenges came out from parents meeting in Dhaka, Sylhet, and Chittagong. Barriers mentioned at these meetings included inefficient tools to screen autistic and NDD children; lack of knowledge among parents, family members, relatives, social communities, and even clinicians, as well as unskilled care givers. Also, meeting attendees agreed that treatment, medication, transport, and education are too expensive, so that it is difficult for parents to bear all these costs. Another issue was duplication in services provision due to lack of coordination among different government and nongovernment sectors.

### Future Prospects

Here are some future prospects of autism:

#### Development of screening tools followed by early intervention

The development of a universal screening tool for early detection of autism in every hospital, accompanied by early intervention after early detection. In addition screening and diagnostic tools should be available in schools and community health centres. This would not only assist on an individual basis, but would allow for accurate collection of data so that there is full understanding of the extent of autism among the population. The Guide for Monitoring Child Development [5] is a monitoring tool to gauge the development of children who are at risk for developmental disabilities or delays. This is a simple tool designed for low-and-middle-income countries for use by field-level non-professional workers.

#### Clear and accurate information from doctors

If autism is diagnosed, it is critical that the doctor be explicit without hesitating with parents regarding the diagnosis, so that parents understand the specifics of the situation and how to manage, and how to ensure their child's needs should be taken care of.

#### Establishment of Strong Referral System

An improved referral system is highly recommended, that would include a call centres to answer questions about services and disabilities.

### Establishment of Service Centres for Autism

The establishment of service centers throughout the country with core standards, the availability of early screening and detection services, and where children with autism can get services for less cost is needed. This would include access both financially and logistically to therapy services.

### Use of ID cards to enhance access to services

It is recommended to use systems, such as ID cards, to enable children with autism to more efficiently access services.

### Professional Training

There is a need for extensive training of staff providing supports, including medical staff, community services staff, and educators, to ensure consistent quality. This also includes training to improve both teacher knowledge and attitudes towards students with autism.

### Training Centres

A group recommended the creation of autism training centres for professional development, and where knowledge is developed, and information can be accessed.

### Parental Awareness

It is recommended that all couples be informed about the signals and symptoms of autism during pregnancy, so that they look for potential signs of NDD after the child is born.

### Parental and Family Support

Training for parents, siblings, and relatives of individuals with autism is highly recommended, to ensure they have the necessary information to provide care for their family member and manage the various challenges involved within the home and community. Parental support recommendations also include establishment of parent-to-parent peer groups, which may help to socialize a baby and child with autism and reduce the potential psychological effects on families, such as depression, of parents. Counselling, training, and guidance to parents on an ongoing basis using a common platform is also recommended.

### Education

Creating and expanding opportunities for children with autism to attend mainstream schools is recommended as well as establishing additional specialized schools offering services. Specialized schools must also ensure they are using qualified trained personnel, and that students are able to access and use the services provided. Improving monitoring and quality assurance of existing schools is also recommended. Also, current research indicates that autistic patients have significantly lower rates of internet use than non-disabled people; in some cases,

they may be unable to access even basic products and services [6].

### Day Care for Children with Autism

There is a need for a day care system for children with autism whose mothers are employed.

### Increase Public Awareness and Understanding of Disability

In order for a society to be truly inclusive, it is vital to improve understanding and respect for persons with NDDs at both the government and community level. Social marketing campaigns, educational awareness campaigns, and the media should be utilized to reduce stigma, improve attitudes, and present positive stories of persons with NDDs and their families.

### Challenges

The World Report on Disability makes nine recommendations for Governments to address the disability issue with seriousness and urgency [7]. Within the country, there are challenges that hinder service provision and the rehabilitation of those with autism. Primarily among these are a delays or absence in detecting the disability and providing an accurate diagnosis early in the child's life. A contributing factor is the lack of awareness and knowledge about autism by family members and the community at large. Services exist in some areas but not in others. When they do exist, the services are sporadic and not comprehensive. For example, there may be a community health clinic but the community does not have access to a speech and language therapist and rehabilitation only includes daily activities and does not include providing specific therapies according to what a child or adult actually needs. Lack of awareness is a contributing factor to services being underutilized. Conversely, when the benefits of services are realized, the demand for them exceeds the capacity to provide them, as there are not enough professionals or para-professionals available to deliver services. Low pay scales are one reason why there is a personnel shortage and if the pay scales are not adjusted for experience and competence, there will be continuing problems in attracting individuals to pursue occupations in the autism field. Contributing to the service delivery challenges are funding shortfalls or a comprehensive and coordinated mechanism for establishing costs and funding services across ministries. Currently, many services are very expensive which may be due to the scarcity of service providers and when services are delivered, there is a premium for receiving them. Disparities exist between services in rural and urban areas, with the urban areas benefitting more from the available services. Finally, practices for referring individuals for services are not uniform across the country. Studies varied by population and population size, culture, and context, which led to inconsistent results. Some studies are conducted in

limited areas due to lack of resources not allowing for an adequate representation of the population of Bangladesh. Some factors made it difficult to analyze the trends and prevalence of autism in Bangladesh. There is not uniformity among these in the types of curriculum or services being offered. Some schools offer training to staff and parents and others do not. Many teachers are not properly trained about autism. The cost of services is high. Private schools rely upon private fund raising in addition to charging a tuition fee.

## CONCLUSION

The burden of childhood disability like autism as a public health problem in developing countries remains unrecognized and it is not uncommon in Bangladesh as well. The child survival rate in Bangladesh has improved a lot now. The knowledge about the general condition of disabled children is shamefully inadequate. Autism data is scarcer, further compounded by the complexity of layperson identifying the disorder. The main reasons behind such a lack of data on disability are a combination of social, technical and practical factors, making it very difficult to collect accurate, usable national data. Practical problems include a lack of trained staff to perform surveys of disability identification in rural areas, which eventually leads to lower awareness of the prevalence of disability.

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