



Bangladesh Development
Updates on

Autism Awareness





Centre for Research and Information

The Centre for Research and Information (CRI) is a not-for-profit policy research organization which aims to create a platform for public discussion on important matters of national policy in Bangladesh.

Analyzing key challenges facing the nation, CRI explores through people-centered debate the political ideas and the policy reforms that will define progressive politics and policies in a new, digital Bangladesh.

With a focus on youth engagement and democratized debate, CRI aims to bring politics closer to the people.

Aims we have

CRI believes in the active participation of citizens in matters of national policy. By bridging the gap between people and politics, CRI hopes to empower citizens and afford them a stake in their society. The organization aims to generate high quality research and data on the opinions and views of people, especially young people in Bangladesh through creative, revolutionary methods. By doing so, the views of the people are given an unfiltered platform which can influence policy decisions on both a local and national scale.

Things we do

CRI takes a strategic approach to achieving its goals. It combines its resources and expertise with ground-breaking market research and polling aimed at various groups, especially young and student groups, to produce the following:

- High quality research into the concerns and priorities of young voters and the youth demographic in Bangladesh;
- Unique platforms for voicing the opinions of young Bangladeshis, such as Let's Talk and Policy Café;
- Publications and blogs produced to the highest editorial, design and production standards, whether in print or digital form;
- Pioneering marketing and promotion efforts, through television, radio and social media outlets;
- Cutting-edge media and publicity efforts aimed at and, in some cases, created by and for, young people themselves

Our Central Theme

The central theme with which CRI goes about its tasks is youth engagement. With that underlying objective in mind, CRI has created a number of unique platforms like Let's Talk and Policy Cafe which provide youths an unprecedented opportunity to express their opinions, views, hopes and fears. CRI wants to hear what young people have to say about national policy, politics and society. When young people talk, CRI is there to listen and make the nation listen.

Youth Centred Approaches

CRI believes that the young people of Bangladesh have ideas; innovative, creative ideas which can help transform Bangladesh if they are afforded the right platform. There are

numerous examples of talented young people making an impact in Bangladesh, be it through social and political activities or volunteer work in the community. Yet there are many people whose voices are not yet heard. CRI sees youth participation as a vital component for the future development of the country, and believes that the young people of Bangladesh do not have to wait until later in adulthood to shape their nation. Keeping this overriding objective in mind, CRI has arranged for the following programmes specifically tailored for the youths of Bangladesh:

Let's Talk

Let's Talk provides a much-needed avenue for young people to constructively engage with Members of Parliament, ministers and other prominent politicians and debate topical issues which are of relevance to them. Through the Let's Talk events, CRI helps to facilitate opportunities for informal but in-depth political dialogue among the future leaders of Bangladesh – the youth and the politicians. No topic is off the cards, there are no formalities nor are there pre-screened questions. Everything is up for discussion, and everyone is invited to share their opinion.

Policy Café

Policy Café is a forum for the youth to voice their assessments on national policy frameworks. It is an avenue of democratic exercises where every young person is expected to share his/her thoughts, opinion and ideas regarding the formulation and functioning of policies. It is a forum for the young generation to be engaged in policy discourses; simultaneously it's a floor for them to be heard by the policy makers of the nation. It is a forum for the youth to garner their assessment on national policies, acts, ordinances and other important national instruments. It is not an implementing agency rather it recognizes itself as an avenue of democratic exercises where every young citizen is expected to share his/her thoughts, opinion and ideas regarding policies. It is a platform for the youth to be engaged in policy discourses; simultaneously it's a floor for them to be heard by the policy makers of the country.

CRI Junction

CRI Junction invites young poets, writers, artists, filmmakers, photographers, actors, performing artists and other cultural leaders to express their views on society and the world around them. The objective is to facilitate gatherings of young cultural groups, fuel intellectual debate and explore the various aspects of Bangali arts and culture which undoubtedly affect our nation today. Creative young minds are encouraged to share their ideas on Bangali heritage and culture and discuss how these feed into wider debates on national policy and current affairs. Topics discussed include the future profile of Bangladesh in a globalised world, Bangla language and literature, and the cross-cultural influences of the creative arts in modern Bangladesh.



Global Autism Movement and Bangladesh

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In contemporary epidemiological discourses, neurodevelopment disorder is now regarded as an issue of special concentration. It is because, studies are revealing that millions of children worldwide suffering in silence in the absence of adequate understanding of the problem.

Neurodevelopmental disorders extensively include autism, ADHD (Attention Deficit Hyperactivity Disorder), learning disabilities, developmental delays and intellectual retardation that extract an enormous emotional, mental and financial toll in terms of compromised quality of life and lifelong disability (Gupta 2008).

The Centers for Disease Control and Prevention, USA (CDC) recognizes ASD as a major public health challenge as it is currently estimated to occur in significantly higher rates than paediatric cancer, HIV and heart disease combined. Unfortunately among all the major mental health disorders, autism is

one of the least understood, and has the lowest amount of resources devoted to research and dissemination of best practices. The magnitude, complexity and overall burden of ASD deserve special and independent focus.

In Bangladesh, like in many other developing countries, neurodevelopmental disabilities such as autism are basically seen through the lens of misinformation and stigma. Dissemination within a community of a modern protocol of autism is a highly complex, multi-factorial challenge (Autism Speaks-Global Autism Public Health Bangladesh Report 2012). Bangladesh, despite these complexities and challenges, has successfully taken the base steps to deal autism. Distinguishing the issue as a national policy priority, Bangladesh is now trying to develop a rights-based paradigm for individuals with autism or other neurodevelopmental disorder.



Autism Spectrum Disorder (ASD)

Autism is the most commonly found neurodevelopmental disorder characterized by core deficits in three domains: social interaction, communication, and repetitive or stereotypic behaviour. There is no single specific form of autism rather various degrees of severity involved in this disorder. Therefore this condition is commonly referred to as autism spectrum disorder or ASD which include autism, Asperger's syndrome, pervasive developmental disorders not otherwise specified (PDD-NOS) and high-functioning autism (Gupta 2008).

The Centre for Autism & Neurodevelopmental Disorders, USA suggests that Symptoms of autism are always present before age three, but autism is often not diagnosed until a child is two to three years of age, or even later. Individuals with autism often remain undiagnosed or inaccurately diagnosed because many clinicians hesitate to discuss this possibility with parents of young children, even when some symptoms are present. These physicians are often concerned about family distress, the negative effects of labeling a child, the possibility of being wrong, or the hope that the symptoms will reverse or improve with time. However, researchers and physicians believe that the positive outcomes of an accurate diagnosis far outweigh the negative effects and families appreciate being informed as early as possible.

Boys are at higher risk for autism than girls. The ASD sex ratio averages 4.3:1 and is greatly modified by cognitive impairment: it may be close to 2:1 with mental retardation and more than 5.5:1 without. Modern studies have found no connection with socioeconomic status, and have reported inconsistent results about associations with race or ethnicity. ASDs are heritable, but the model of inheritance is very complex, probably involving multiple susceptibility genes. Newschaffer et al. (2007).

The Etiology of Autism

The etiology of autism is complex, and in most cases the underlying pathologic mechanisms are unknown. Autism is a heterogeneous disorder, diagnosed subjectively on the basis of a large number of criteria (Trottier G, Srivastava L, Walker CD 1999).

Many causes have been proposed towards autism, but its etiological theory is still incomplete. According to Newschaffer et al. (2007) there are a number of potential risk factors associated with etiology of autism:

- Hereditary factors
- Infection and immune dysfunction
- Neurotransmitters, peptides, and growth factors
- Endocrine factors
- Obstetric factors
- Neurotoxic environmental or other xenobiotic exposures
- Alcohol, smoking and illicit drug exposure

Global Prevalence

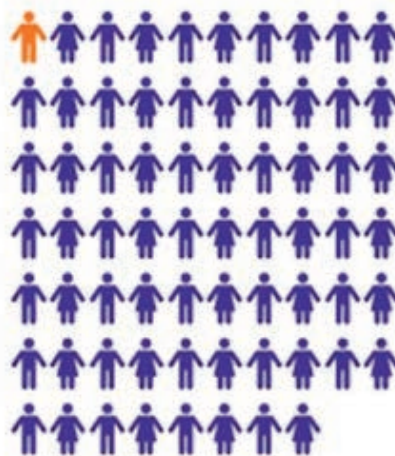
Scrutinizing the recent global trends of rising prevalence it can be asserted that on average, there is at least 1 person challenged by an ASD in any country.

The global prevalence of autism has increased twentyfold to thirtyfold since the earliest epidemiologic studies were conducted in the late 1960s and early 1970s. At that time, prevalence estimates from European studies were one in 2,500 children in the population and by the 2000s prevalence estimates from large surveys were 1%–2% of all children. Although the underlying reasons for the apparent prevalence changes are difficult to study empirically, select studies suggest that much of the recent prevalence increase is likely attributable to extrinsic factors such as improved awareness and recognition and changes in diagnostic practice or service availability (The CDC Surveillance Summaries 2014).

The USA: In 2014, the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network reported that approximately 1 in 68 children in the United States has an Autism Spectrum Disorder. This new estimate is roughly 30 percent higher than previous estimates reported in 2012 of 1 in 88 children. In the 1980's autism prevalence was reported as 1 in 10,000. In the nineties, prevalence was 1 in 2500 and later 1 in 1000.

The UK: The latest prevalence studies of autism indi-

NUMBER OF CHILDREN IDENTIFIED WITH ASD



1 in 68



U.S. Department of
Health and Human Services
Centers for Disease
Control and Prevention

cate that 1.1% of the population in the UK may have autism. This means that over 695,000 people in the UK may have autism, an estimate derived from the 1.1% prevalence rate applied to the 2011 UK census figures.

Why Bangladesh Scenario is Critical

It's been estimated that 1% of the world's population, suffer from an autism spectrum disorder. What does that mean when a country like Bangladesh has a population of over 160 million? Unfortunately, in many developing countries like Bangladesh we have no data for how many children or adults suffer from this lifelong debilitating developmental neurological condition. Needless to say this and many other scientific and medical questions need to be addressed urgently (Hossain, Saima 2011).

As one of the most populated countries in the world, it is of the utmost urgency that the needs of those with autism be immediately addressed in Bangladesh through proper epidemiological survey programs.

A recent 2013 pilot study in Bangladesh, utilizing community health workers, has found prevalence of all kinds of neurodevelopmental disability is 7.1%. Whereas, for ASD, the study indicates a prevalence of 0.15% (3% in Dhaka city and 0.07% in rural area).

Understanding the Rights of People with NDDs

Right Ensured in Bangladesh

The National Parliament of the Government of Bangladesh has promulgated two important acts to protect the rights and ensure safety of the differently able persons. One act is (i) The Disability Rights Law, 2013 and the other is (ii) Neuro Developmental Disability Protection Trust Act, 2013.

The Disability Rights Law, 2013

- Ensures rights & dignity of the persons with disabilities by stipulating 21 rights
- Rights to educational, physical and psychological improvement
- Rights to participation in social and state activities
- Rights to get the national identity cards and be listed in the voters roll
- Mandates enrolment in regular schools, reservation of seats on all forms of public transportation, accessibility provisions in all public places (including retrofitting), equal opportunities in employment, and protection of inherited property rights

Neuro Developmental Disability Protection Trust Act, 2013

- highlights the issues related to providing physical, psychological, and economic assistance to all persons with disabilities
- their nurture, security and rehabilitation
- ensures their social empowerment
- focuses to develop pertinent education system and knowledge paradigm

<p style="text-align: center;">UN Resolution (67/82) on Autism Spectrum Disorders, Developmental Disorders and Associated Disabilities Was passed on 12/12/2012 at 12:12 am</p> <p>Recognizes</p> <ul style="list-style-type: none"> <input type="checkbox"/> the need to promote and protect the human rights of all persons with disabilities <input type="checkbox"/> that the full enjoyment by persons with ASD, DDs and associated disabilities of their human rights and their full participation will result in significant advances in the social and economic development of societies and communities <p>Reaffirms</p> <ul style="list-style-type: none"> <input type="checkbox"/> the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms and the need for persons with disabilities to be guaranteed their full enjoyment without discrimination <p>Recalls</p> <ul style="list-style-type: none"> <input type="checkbox"/> that early diagnosis, appropriate research and effective interventions are vital to the growth and development of the individual, and emphasizing that early intervention is crucial 	<p style="text-align: center;">WHO Resolution (WHA 67.8) on Autism Was passed on 24th May, 2014</p> <p>Goal</p> <p>Making comprehensive and coordinated efforts for the management of autism spectrum disorders</p> <p>Purposes</p> <ul style="list-style-type: none"> <input type="checkbox"/> Increasing the capacity of health and social care systems <input type="checkbox"/> Mainstreaming into primary health care services the promotion and monitoring of child and adolescent development <input type="checkbox"/> Provide social and psychological support and care <input type="checkbox"/> Identifying and addressing disparities in access to services for persons with ASD
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Role Played by Bangladesh in Global Setting

Both within country as well as in the global context, Bangladesh is playing a commendable role in undertaking appropriate policies, and social awareness and intervention programs to mitigate the emerging and increasing problem of autism. The Honorable Prime Minister of Bangladesh Sheikh Hasina has taken a keen interest to take this issue forward both nationally and globally. Some of the pro-active roles of the Government of Bangladesh include the formation of South Asian Autism Network (SAAN) and preparation of its Charter.

In July 2012, Bangladesh hosted the largest regional conference on autism during which the Dhaka Declaration on Autism Spectrum Disorders was ratified by 7 regional countries. Bangladesh tabled “Resolution 67/82” Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities at the United General Assembly in 2013 which was unanimously adopted. Bangladesh was also the one to initiate the WHO resolution titled “Comprehensive and coordinated efforts for the management of autism spectrum disorders” proposed by the state of Qatar to the WHO Executive Board meeting held in May 2013, which was adopted unanimously. Saima Wazed Hossain, a school psychologist and global advocate for autism who is also the daughter of Prime Minister Sheikh Hasina has been actively engaged in global and domestic advocacy of mental health disabilities. She has been a significant champion for the cause of autism and assisted in mobilizing members on the Executive Board and the WHO Secretariat to support this resolution (Actions Speak Louder than Words: Bangladesh Unique Approach to Addressing the Public Health Challenge of ASD, 2014).

World Health Organization recently honoured Saima Hossain for her outstanding contributions to the area of Autism Spectrum Disorders. Saima Hossain is among the first two recipients of the newly instituted Award for Excellence in Public Health which were conferred by WHO Regional Director for South-East Asia Region, Dr Poonam Khetrpal Singh. Dr Khetrpal Singh commended Saima Hossain as the driving force behind Bangladesh’s leadership in advancing the cause of autism in the Region and worldwide. “Ms Hossain’s work has helped to build multidisciplinary/multi-stakeholder partnerships for ASDs and childhood development disorders which resulted in the adoption of resolutions at the United Nations and the World Health Organization” said Dr Khetrpal Singh.

Role in Enabling National Environments

All the relevant ministries of Bangladesh have undertaken programs to address the needs of the community based on each ministry’s jurisdiction but through a cooperative and collaborative multi-ministry committee and support from parents, experts and other relevant stakeholders.



Advisory Committee on Autism and Neuro-developmental Disorders

An 8-member “Advisory Committee on Autism and Neuro-developmental Disorders” headed by Saima Wazed Hossain helps the national steering committee develop priorities, design programs, devise implementation strategies, provide guidance on the appropriate use of resources, and identify necessary resources.

National Steering Committee on Autism and Neuro-developmental Disabilities

The MOHFW has a 15-member “National Steering Committee on Autism and Neuro-developmental Disabilities” headed by Secretary, MOHFW. It has a “National Advisory Committee (NAC)” headed by the daughter of the Honorable Prime Minister of Bangladesh Sheikh Hasina, Saima Wazed Hossain who serves as the Chairperson.

National Autism Technical Guidance Committee

There is a national level 17-member Autism Technical Guidance Committee whose responsibility it is to provide technical support to the advisory and steering committee. Working in specialized groups members are responsible for translating appropriate materials for use in Bangladesh, collating existing materials available in the country and region, identifying needs in the community and setting priorities.

Institutional Development Accomplished

- In 1999, Jatiyo Protibondhi Unnayan Foundation (JPUF) was founded to ensure that the persons with disabilities have adequate support to participate in the mainstream society
- Around 61 special needs schools are run by the NFDDP through different NGO's. 7 of these schools are based on an inclusion model
- In June of 2010 The Center for Neurodevelopment and Autism in Children (CNAC) was inaugurated. It is the first government initiative that is linked to a medical university
- 10 Shishu Bikash Kendra (Child Development Centers) in medical college hospitals has been established
- 73 Disability Service Centre is functioning in district & upazila level having an special Autism Corner. Another 60 is under process.
- The JPUF has been running a special school for the autistic children since 2011. 30 children with disabilities from 30 poor families are studying in this special school without any tuition fee

Approaches to Educating Children with NDDs

- Autism has been incorporated in the primary education curriculum
- Development of strategic action plan for children with special needs under umbrella of inclusive education
- Development of a module on autism sensitization by the National Academy for Education Management (NAEM)
- Inclusion of autism in national curriculum of Text Book Board "autism" as a subject in the "Physical Teaching, Health Science and Sports" book of Class IX and X and in "Economics" book of Class VIII
- Allowance of 20 minutes additional time in public examinations for all children with autism
- Allocation of 2% reserved seats for autistic children for admission in academic institutions not run by the public sector

Research Skill Development Initiated

Two national level survey projects have been conducted:

- first was a door to door survey for all form of disabilities conducted by MoSW
- second, a pilot screening project for developmental disorders in children through the community health clinics
- Arranged training of 3676 doctors, 480 nurses, 270 physiotherapist, and 186 special educator in Center for Neurodevelopment & Autism in Children, BSMMU and in National Institute of Mental Health;
- Arranged training of 2,575 health workers and social activists through 103 batches on autism and neurodevelopmental disabilities in 70 sub-districts of 64 districts of Bangladesh
- JPUF (Jatiyo Protibondhi Unnayan Foundation) has developed the capacity to conduct following training programs:
- Training for the mothers of mentally challenged children;

Institutional Development

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- Behavior modification and picture exchange communication system; and
- Autism and development disorder management training of parents' role in managing children with ASD

Bangladesh: Leading the Way in Autism Awareness

- In July 2012, organized a conference on autism and developmental disabilities in South Asia, where around 1000 participants from 11 countries were present
- The Conference also marked the official launching of Global Autism Public Health Initiative (GAPH).
- It also inaugurated the National Advisory Committee for Autism in Bangladesh and South Asian Autism Network (SAAN)
- The landmark Dhaka Declaration was unanimously ratified by 11 countries
- From 2011-2012 a comprehensive awareness campaign, parent and professional training and a situation analysis document was conducted by CNAC & MoHFW with the help of Autism Speaks and the WHO

Bangladesh in Public Awareness

- Every year, on 2nd April, the Ministry of Health and Family Welfare (MoHFW) observes the World Autism Awareness Day
- The Ministry of Primary and Mass Education (MoPME) has developed a short episode of 'Meena' cartoon to raise awareness of autism
- The MoPME staged an interactive popular theater in 158 sub-district level on autism
- Today, Bangladesh is a leading country championing the cause of autism at national, regional and global levels

Public Services Accomplished

- Protibondhi Sheba O Sahajya Kendro (organization for the assistance and services of the disabled) established in 2009
- It is providing physiotherapy, occupational therapy, counseling, assistive devices and other related services to nearly 30,000 individuals many of whom are diagnosed with autism
- A 'One Stop Mobile Service' program has also been introduced in order to reach families that live in villages that lack accessibility to medical services
- In the proposed budget of fiscal year 2014-15, special attention has been devoted to specially abled
- TK 200 million has been allocated to the trust established for people with neurodevelopment disorders and TK 50 million to the trust established for the physically disabled

Services Looking Ahead

- The Autism Resource Center is in process to be established to provide free therapeutic services, referral services and counseling
- Government allocated a total of 12.01 acres of land in Savar in favor of Jatiyo Protibondhi Unnayan Foundation (JPUF) to establish a Protibondhi Sport Complex as a center of excellence
- Expansion and development of PROYASH in Dhaka Cantonment Project to provide care to 400 children with autism and disability
- The construction of National Disability Complex has been inaugurated on 2nd April, 2014. Designed to provide care 360 special students including autistic children. There will also be a special education centre for 250 learners including autistic children and babies
- National Autism Academy under Ministry of Education to conduct substantial research to develop culturally sensitive, cost-effective and intervention based curriculum and contents

Efforts to be Sustained

Facts and figures clearly denote that a lot has been initiated by Bangladesh dealing autism. Bangladesh is regarded as a role model in autism awareness & the rehabilitation of people suffering from autism. The country was also being recognised globally as an exemplar for combating autism with measures to register child births, raising awareness at the national level on the role of family in the psychological and physical nourishment of the autistic children. Nevertheless, this is a critical period in the history of disability and neurodevelopmental disability in Bangladesh. The political will and pioneering initiatives of the present Government are really praiseworthy- but the legacy needs to be translated into sustainable strategies, multidisciplinary planning and evidence based actions.



It is equally important to customize the programs and planning based on the culture, social expectations, financial and professional resources, and existing infrastructure within Bangladesh.

Bangladesh like many developing Asian countries is poor, overpopulated and agrarian. We therefore need to work in partnership to assist and promote adequate measures for our families with autism.

We need more and more specialist physician, special educator, psychologist, therapist to confront the issue comprehensively. Conjointly, adequate screening for autism, culturally and linguistically appropriate interventions, scientifically based academic programs in inclusive settings, appropriate job trainings and sheltered accommodations for young adults with disabilities are the major future challenges for Bangladesh like any other country of the world.

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