

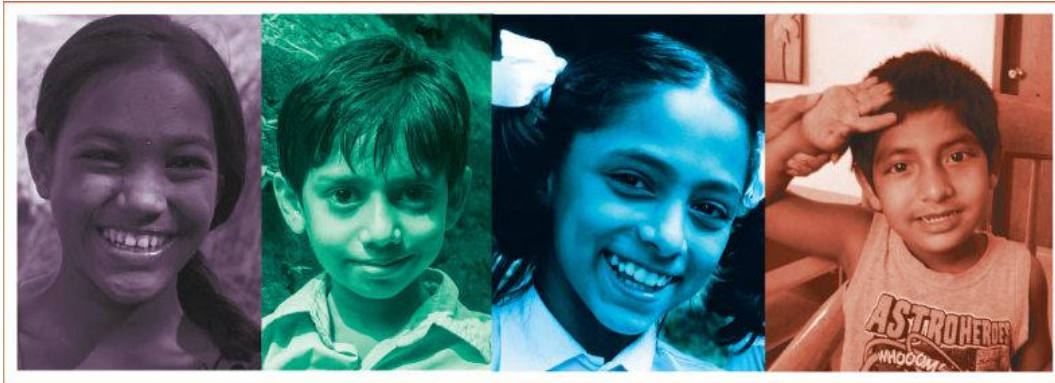
Soft Brick on Neurodevelopmental Disorders (NDDs)

What Neurodevelopmental Disorder is:

- impairments of the development of the central nervous system.
- refer to a disorder of brain function that affects **emotion, learning ability, self-control & memory**

Misnomer

Often, erroneously used as an exclusive synonym for **autism** and **autism spectrum disorders**



Red flags of Autism

If a child shows two or more of these signs, please ask your pediatric healthcare provider for an immediate evaluation.

Impairment in Social Interaction:

- Lack of appropriate eye gaze
- Lack of warm, joyful expressions
- Lack of sharing interest or enjoyment
- Lack of response to name

Impairment in Communication:

- Lack of showing gestures
- Lack of coordination of nonverbal communication
- Unusual prosody (little variation in pitch, odd intonation, irregular rhythm, unusual voice quality)

Repetitive Behaviors & Restricted Interests:

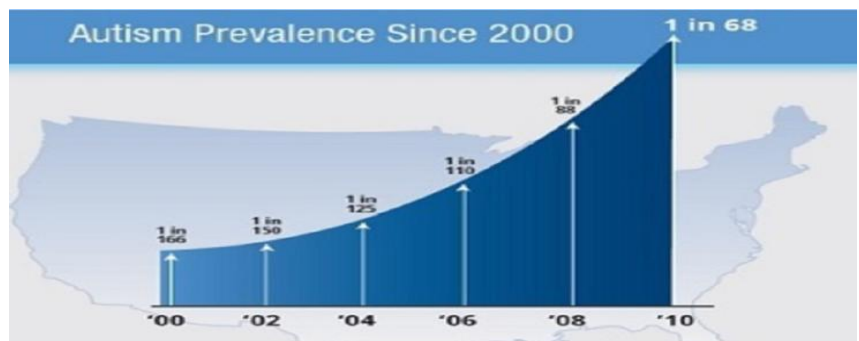
- Repetitive movements with objects
- Repetitive movements or posturing of body, arms, hands, or fingers

4 Things to Know About Autism Spectrum Disorder (ASD)

- one of the least understood public health problems
- No two people with autism look alike
- huge emotional and financial toll on families and communities
- its magnitude and complexity deserve special focus and resources

Prevalence: Global Context

- on average, there is at least 1 person challenged by an ASD in any country
- CDC, 2014 study finds one in every 68 children to be autistic in US - a rate 30 percent higher than what it was three years ago



CDC prevalence statistics for ASD

Prevalence: Bangladesh Context

- a 2013 pilot project in Bangladesh, utilizing community health workers, has found prevalence of all kinds of neurodevelopmental disability is 7.1%
- for ASD indicated a prevalence of 0.15% (3% in Dhaka city and 0.07% in rural area)

Initial Steps by the Govt. of Bangladesh

- From 2009 onwards the Honorable Prime Minister of Bangladesh Sheikh Hasina has taken a keen interest to take this issue forward both nationally and globally
- Centre for Neurodevelopment and Autism in Children (CNAC) was established at Bangabandhu Sheikh Mujib Medical University (BSMMU) under the direct patronization of Prime Minister Sheikh Hasina
- Development of National Strategic Plan on autism and neurodevelopmental disorders
- Orientation workshop and Training on Autism was held at NAEM(National Academy for Educational Management), DPE (Directorate of Primary Education) and Shishu Academy to develop Master Trainers for respective Ministries as follow-up activity of the GAPH BD(Global Autism Public Health Initiative) Bangladesh
- Teachers' Training on Autism was held on 6 September 2012
- Government of Bangladesh formed the South Asian Autism Network (SAAN) and prepared its Charter

Policy & Institutional Development

UN Resolution (67/82) on Autism Spectrum Disorders, Developmental Disorders and Associated Disabilities

Recognizes

- the need to promote and protect the human rights of all persons with disabilities
- 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

Reaffirms

- 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



Recalls

- 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

WHO Resolution (WHA 67.8) on Autism

Goal

Making comprehensive and coordinated efforts for the management of autism spectrum disorders

Purposes

- ✓ Increasing the capacity of health and social care systems
- ✓ Mainstreaming into primary health care services the promotion and monitoring of child and adolescent development
- ✓ Provide social and psychological support and care
- ✓ Identifying and addressing disparities in access to services for persons with ASD

Policy Guidelines

- Recognising the contribution of adults living with ASDs in the workforce
- Developing or updating and implementing relevant policies, legislation, and multi-sectoral plans in line with resolution WHA 65.4

Research & Development

- Organising research and public awareness-raising and stigma-removal
- Improving health information and surveillance systems that capture data
- Calling for evidence based early interventions



Rights Ensured in Bangladesh

- **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

- **NeuroDevelopmental 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

Bangladesh: Policy Actions

Advisory Committee on Autism and Neurodevelopmental Disorders

- an 8-member committee headed by Saima Wazed Hossain
- helps the national steering committee

National Steering Committee on Autism and Neuro-developmental Disabilities

- a 15-member committee headed by Secretary, Ministry of Health and Family Welfare (MoHFW)
- implements and co-ordinates the autism and neuro-development related action plan

National Autism Technical Guidance Committee

- a national level 17-member committee
- provides technical support to the advisory and steering committee

Institutional Development

- 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.

Research & Skill Development

Research

- 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



Training

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

Awareness Raising & Services

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 the Ministry of Health and Family Welfare (MoHFW) **observes the World Autism Awareness Day** with full participation of the Directorate General of Health Services, and all hospitals beginning from academic hospitals, tertiary care hospitals, and district hospitals to primary care hospitals
- The Ministry of Primary and Mass Education (MoPME) has developed a short episode of **'Meena' cartoon** to raise awareness of autism among children and mass people
- The MOPME also staged an interactive popular theater in **158 sub-district level on autism** which tells Apu's story to speak about autism.
- Today, Bangladesh is a **leading country** championing the cause of autism at national, regional and global levels

Accomplishment: Services

- During the 2010-2011 fiscal year eighty nine lakh forty five thousand takas (TK 89,45,000) have been distributed to provide loans, grants and other services free of cost to persons with disabilities
- Through the development program Protibondhi Sheba O Sahajya Kendro (organization for the assistance and services of the disabled) created in 2009, across the country are 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 ables
- **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



Education as Essential Public Services for the Specially Challenged Children

- 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

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



Sources Used

Action Speaks Louder than Words: Bangladesh's Unique Approach to Addressing the Public Health Challenge on Autism Spectrum Disorders, 2014, MoHFW

autismontario.com (<http://www.autismontario.com/>)

autismspeaks.org

Centre for Neurodevelopment & Autism in Children, Bangladesh

(<http://www.cnacbangladesh.org/>)

Centres for Disease Control & Prevention, USA (<http://www.cdc.gov/>)

firstsigns.org (<http://www.firstsigns.org/index.html>)

Official website Ministry of Social Welfare, Bangladesh (<http://www.msw.gov.bd/>)

Official website Ministry of Health & Family Welfare, Bangladesh (<http://www.mohfw.gov.bd/>)

UN Resolution (67/82) on Autism Spectrum Disorders, Developmental Disorders and Associated Disabilities

WHO Resolution (WHA 67.8) on Autism

wikipedia.org (http://en.wikipedia.org/wiki/Neurodevelopmental_disorder)



Centre for Research
and Information