

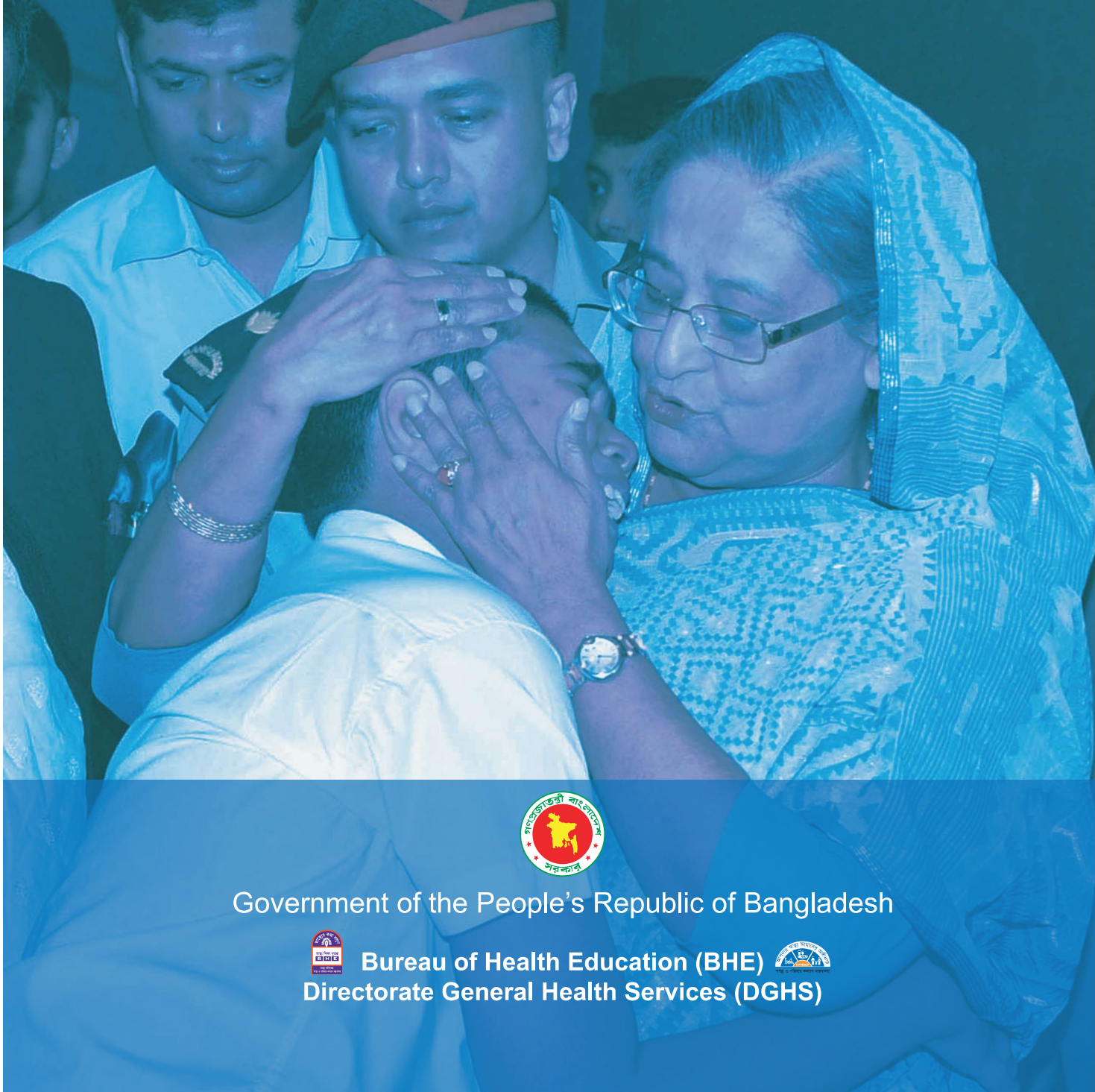
ACTIONS SPEAK LOUDER THAN WORDS

May 2014

**Bangladesh's Unique Approach
to Addressing the Public Health Challenge of
Autism Spectrum Disorders**



Government of the People's Republic of Bangladesh
Ministry of Health & Family Welfare



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Bureau of Health Education (BHE)



Directorate General Health Services (DGHS)

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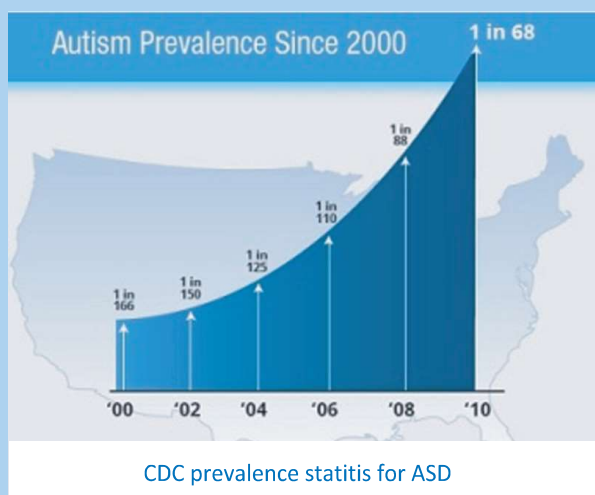
What is autism?

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterized by delay in developing age appropriate verbal, physical and social skills, as well as limited communication skills, varying sensory sensitivities and self-stimulating behaviors. It affects not only the individual but also their family's physical and mental health as well as their social interaction and economic productivity.

Autism is a multi-dimensional problem

From a human perspective, the effect of ASD is multi-dimensional. It is a developmental disorder, a mental health problem, a disability, and a social and economic problem.

It is estimated that on average, there is at least one person challenged by an ASD in any country. The prevalence is increasing exponentially, with rates as high 1.5% to 2.6% in the few countries like the USA and South Korea, which have the financial and technical expertise to conduct well planned prevalence studies (<http://www.cdc.gov/ncbddd/autism/data.html>). New Research estimates that autism's costs to the American Nation have reached to \$137 billion per year (<http://www.autismspeaks.org/science/science-news/autism%E2%80%99s-costs-nation-reach-137-billion-year>). The research also finds that autism's life time costs for one individual to



be more than \$2.3 million for a person with ASD and intellectual disability and \$1.4 million for a person with ASD and no intellectual disability. Intellectual disabilities affect around 40% of those with autism. Most countries around the world do not have estimates of the prevalence of ASD and the social and economic costs of the disorder.

About 1% Bangladeshi children may have ASD

A 2013 pilot project in Bangladesh utilizing community health workers to screen for neuro-developmental disorders indicated a prevalence of 0.15% for ASD (3% in Dhaka city and 0.07% in rural area). However, prevalence of all kinds of neuro-developmental disability was 7.1% (MOHFW. Survey of autism and neurodevelopmental disorders in Bangladesh, August 2013).

Autism is one of the least understood public health problems

The CDC recognizes ASD as a major public health challenge as it is currently estimated to occur in significantly higher rates than pediatric 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.

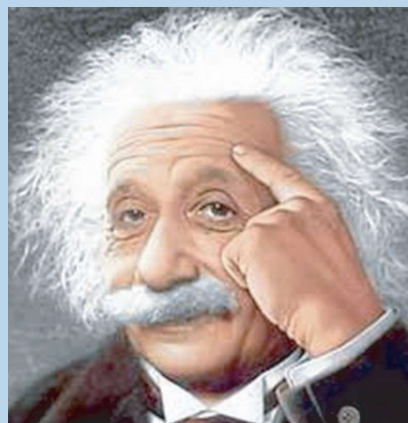
The CDC estimates 23% and 78% increase in prevalence of autism in the USA between 2009 and 2010 and between 2007 and 2010 respectively. In all countries, many families are living with ASD

(<http://www.cdc.gov/ncbddd/autism/data.html>).

The situation is a great public health concern, particularly in developing countries with huge population and a demographically large proportion of children. In addition, limited number of skilled professionals, and lack of education and standardized training on diagnosis and intervention for ASD poses as a significant barrier to garnering a better understanding of this health challenge.

Autism has unique characteristics and significant diversity

It is said that no two persons with autism look alike. This is the most unique aspect of the syndrome as each person with autism will differ greatly in symptom presentation and level of functionality. It therefore takes a thorough



Albert Einstein was claimed having autism

understanding of what autism is along with what autism is not in order for a professional to conduct an accurate diagnosis and develop a suitable intervention plan. Most children with autism have average to above average intellectual functioning with a small percentage in the gifted range. Each person will also differ in the capacity to communicate using language and have sensitivities to sensory stimulations. Recent studies have also indicated that although with average IQ levels many persons with autism have unique interests and skills and if given the appropriate education, training and opportunity can excel in their area of interest.



Burden of autism on families and country is huge

According to the CDC, the emotional and financial toll of autism on families and communities is staggering. Therapy costs are beyond the reach of many families and are most often required to be one-on-one. The cost for treatment and care of a child with autism (inclusive of health care, education, ASD-related therapy, family-coordinated services, and caregiver time) in the United States is estimated to be at least US\$17,000 more per year compared to a child without ASD (<http://www.cdc.gov/ncbddd/autism/data.html>). For a child with more severe ASD, costs per year increase to over US\$21,000. Taken together, it is estimated that total societal costs of caring for children with ASD were over US\$9 billion in 2011. The average medical expenditures for each autistic child is higher by US\$4,110 to \$6,200 per year than a non-autistic child, which is 4 to 6 times higher. In addition to medical costs, intensive behavioral interventions for children with ASD cost US\$40,000 to US\$60,000 per child per year. If this is the case in the United States, we can imagine the health care burden among developing nations.

Importance of early diagnosis must not be forgotten – but requires policy support

Research in brain plasticity reveals that with intense evidence based intervention, the brain can form new neural pathways which help the individual increase their functionality. However for maximum effectiveness, it is necessary to diagnose the child at the earliest age possible and provide the appropriate intervention. Although there is no cure for autism, the reduction in symptomology would decrease the burden on families and help the individual live a more productive life. However, the opportunity of early diagnosis using the current system of health services is far from the reach of developing countries. Therefore, innovative community based screening, diagnostics and an intervention protocol which engages parents and caregivers as partners in the process will help overcome many of the barriers.



Recognition of autism in global forums & helping countries

The significance of ASD is being particularly recognized globally as an issue requiring policy priorities, attention and sensitization. Such reflections are revealed in the observance of Global Autism Awareness Day on the 2nd of April. On 18 December 2007, the United Nations adopted a resolution to celebrate 2nd April each year as the World Autism Awareness Day. Given the huge burden of ASD as a medico-social problem requiring independent attention, the WHO, being an important UN organ responsible for providing global leadership for health, has decided in its Executive Board held in May 2013 to propose a resolution to the 2014 World Health Assembly on “Comprehensive and coordinated efforts for the management of autism spectrum disorders” with a view to undertaking specific visible and strong roles and interventions about this particular condition.



Saima Wajed Hossain, a well-known global autism activist speaking at World Health Organization



(continued..)

Different WHO regions, viz., SEARO, EURO, EMRO, AFRO, etc. have adopted resolutions and undertaken mentionable actions. In South-East Asia, WHO has also supported constitution of a South Asian Autism Network (SAAN) engaging the commitments of the highest level political leaders from each of the WHO's Regional Member States. It is true that a resolution or some interventions will not necessarily solve the entire problem of ASD. However, to bring meaningful and positive changes in the lives of those millions who have been affected by autism, the united global steps will place a framework and mechanism to act together.

Bangladesh remains in the fore-front of global autism movement & also is pro-active in domestic autism actions

Bangladesh is a small country in Asia. The land area is only 147,570 sq. km. But, the population is huge; of about 160 million. This makes Bangladesh the world's densest country with 1,100 people living per square kilometer of land area. The country is the world's worst climate victim, with natural calamities like floods, cyclones, tornados, land slides, etc. being almost yearly phenomenon claiming many valuable human lives, live stocks, homes, assets and infrastructures. Substantial development resources go for rehabilitating and rebuilding the infrastructures. Seventy percent of the people live in rural areas and 17.6% of the people are extremely poor living on <US\$1.25 a day. There are competing development priorities such as social safety net, education, food, health, rehabilitation-

building- rebuilding of infrastructure, etc. Despite all these constraints, Bangladesh has made impressive progress in all the parameters of sustainable development including the MDGs and Human Development Index. 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. This resolution will now be placed in the 67th World Health Assembly to be held in May 2014 for final adoption. 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 she assisted in mobilizing members on the Executive Board and the WHO Secretariat to support this resolution.



Bangladesh domestic autism actions

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 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.



Honorable Prime Minister of Bangladesh Sheikh Hasina speaking at the national event organized on the occasion of World Autism Awareness Day



Late Honorable President of Bangladesh Mohammed Zillur Rahman was always very supportive to autism and neuro-developmental disability related activities. Ms. Saima Wajed Hossain is seen speaking to him in Bangabhavan, the presidential house



Honorable Prime Minister of Bangladesh Sheikh Hasina never missed the opportunity to encourage the autistic and other disabled individuals



Highlights of the activities carried out by different line ministries of the government

Ministry of Health & Family Welfare (MOHFW)

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.

The Steering Committee has following terms of reference:

- Effective implementation and co-ordination of the autism and neuro-development related action plan;
- Ensuring engagement and participation of the civil society, non-state organizations, guardians' forums, higher education and research organizations;

- Motivation of the print and electronic media personnel to help positive social attitude and awareness about autism;
- Consideration for adoption of appropriate actions for implementation of the action plan and for updating it as and when required;
- Coordination of autism related activities of different ministries; and
- Holding discussions on issues related to activities related to implementation and convergence of autism and developmental disabilities and to undertake measures if there is problem.

Highlights of progress by MOHFW

- Developed short and long term action plans for mitigation of autism and related problems;
- Nearly completed development of a national strategic plan on the above issue;



- Mainstreamed autism and neuro-developmental related disorders in the Health, Population and Nutrition Sector Development Program (HPNSDP 2011-2016) through inclusion of mitigation activities in the related operational plans, viz., non-communicable disease control; in-service training; improved hospital service management, etc.;
- Established child development centers in 10 medical college hospitals;
- Established "Institute of Neuro-development & Autism" at the Bangabandhu Sheikh Mujib Medical University (BSMMU). A budget worth US\$3.2 million was allocated for this purpose.
- Conducting national level training programs for doctors and nurses on autism by the "Center for



Autistic children are given care and treatment by medical doctors and social service rehabilitators in the autism health center

Activities included in operational plans of HPNSDP 2011-2016 of MOHFW

Non-Communicable Disease Control (NCDC)

- Development of National Strategic Plan on autism and neuro-developmental disorders;
- Training of 540 doctors and 480 nurses in Center for Neuro-development & Autism in Children, BSMMU and in National Institute of Mental Health;
- Inclusion of topics on autism and neuro-developmental disorders in undergraduate medical curriculum; and
- Piloting of home based screening on autism and neuro-developmental disorders of children aged 0 to 9 years in selected upazilas of 7 divisions of Bangladesh.

Improved Hospital Services Management (IHSM)

- Establishment of child development centers in 10 medical college hospitals.

In-Service Training (IST)

- Training of 2,575 health workers and social activists through



Neuro-development and Autism in Children" and by the "National Institute of Mental Health" and also at the sub-district levels for paramedics and parents with use of effective IEC materials;

- Completed pilot in 2012-13 fiscal in 7 sub-districts of 7 divisions of Bangladesh on home based screening of autism and neuro-developmental disorders among children aged 0 to 9 years. The experience of the pilot is awaiting scaling all over the country; and
- Continuing effort to include programs on autism and neuro-developmental disorders in the biennium program of WHO.

Observance of World Autism Awareness Day

The MOHFW of Bangladesh observes the World Autism Awareness Day every year 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. All kinds of measures like rallies, discussion meetings, blue lighting, etc. are undertaken to draw attention and create social awareness.

Catalytic role to promote the cause of ASD in global perspective

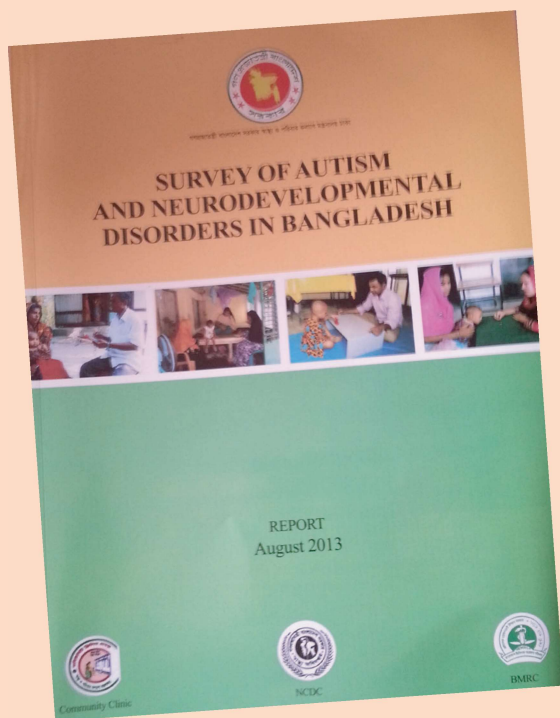
The MOHFW of Bangladesh played an instrumental role in the formation of the South Asian Autism Network (SAAN) and in preparation

of SAAN's Charter. Under this ministry's initiative, the WHO resolution titled "Comprehensive and coordinated efforts for the management of autism spectrum disorders" was adopted by the WHO Executive Board meeting held in May 2013. This resolution is expected to be finally adopted in the forthcoming 67th World Health Assembly (May 2014). The MOHFW also floated the autism resolution which was adopted by the 65th Regional Committee meeting of the WHO South-East Asia Region.

Pilot study on neuro-developmental development

The MOHFW through its three subordinate or allied organizations, viz. Community Clinic Project, Non-communicable Disease Control Program and Bangladesh Medical Research Council supported the conduction of a survey on autism and neuro-developmental disorders in Bangladesh with the objectives of understanding (a) whether frontline community health workers can be used for screening of neuro-developmental impairments and disorders (NDIs/NDDs); (b) the prevalence of NDIs/NDDs among children identified by para-professionals who used validated tools for assessment of such conditions; (c) the prevalence of underlying medical, psychological, mental and other health and related problems among the children diagnosed as having NDIs/NDDs; (d) the feasibility of instituting a surveillance and referral system from home to community clinic





to upper tier hospitals for early detection and intervention of NDIs/NDDs; and (e) the major risk factors that are preventable. The survey carried out from January to June 2013 included 7,280 children aged 0 to 9 years in selected rural communities of 7 sub-districts (one sub-district in each of 7 divisions of Bangladesh) and 5 urban localities of Dhaka city. The results show prevalence of ASD of 0.15% which varies from 3% in Dhaka city to 0.07% in the rural areas of Bangladesh. Prevalence of NDIs/NDDs combined and NDDs was 18.5% and 7.1% respectively. The

survey reveals that with proper training, the frontline community health workers can be used for screening of NDIs/NDDs followed by further assessment by para-professionals and professionals and they can also be used as a bridge for an NDIs/NDDs surveillance system between homes and clinics/hospitals.

Training of community health workers

Without integration of detection and care of autism and NDIs/NDDs with primary health care, it would not be possible to ensure a national scale inclusive program to cater this one of the most difficult and least understood public health problems. The MOHFW understood this fact and engaged its frontline health workers, like community health care providers (CHCPs about 13,500) of the community clinics, health assistants (about 24,000) under the health services, family welfare assistants (about 50,000) under the family planning service and community support groups (health volunteers for community clinics about 780,000) through giving them orientation on ASD and on other NDIs/NDDs so that they can make primary suspicion and refer the cases for assessment and follow up if any one is detected to have ASD or other NDI/NDD. A manual has been developed, printed and distributed among the frontline community health workers to use it as a ready field handbook. The manual uses pictorials and easy to understand descriptions on how to suspect, screen, refer, care and follow-up an individual

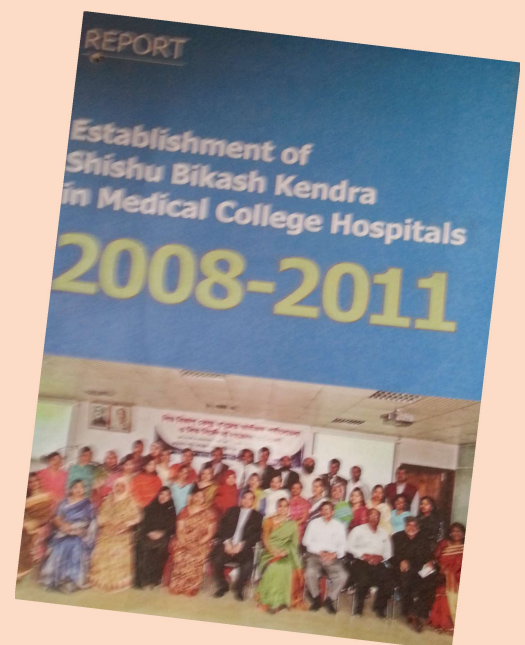


with neuro-developmental disability and help parents ensuring best environment and behavior for their affected child.

Shishu Bikash Kendra

The “Shishu Bikash Kendra” is the synonym of “Child Development Center”. The MOHFW established 10 such centers, one in each of 10 key government-owned medical college hospitals of the country. The vision of this project is to prevent disability, optimize development and improve quality of survival of all children in Bangladesh. These are the model child- and family-friendly centers. There are a number of objectives, viz. (a) to engage and train multi-disciplinary professionals including physicians, psychologists, development therapists, etc. all for children’s domain; (b) to make application of standard tools, methodologies and strategies for early screening, assessment, intervention, treatment and management of entire range of developmental

delays, disorders, impairments and disabilities; (c) to conduct epidemiological surveys and clinical research with aim to providing an evidence based health service delivery system, and identify causal risk factors to help towards prevention of major childhood disabilities; (d) to provide mental health services to children with pervasive developmental disorders through home based and family supported programs; (e) to provide outreach services by conducting child development camps by linking the Shishu Bikash Kendras with primary health care at sub-district hospitals; (f) to establish a digital database of information related to child development and disability across Bangladesh; (g) to provide continuing training and supervision of services through various strategies including internet-based technologies. The clinical services provided from Shishu Bikash Kendras include walk in clinic; general development assessment;



seating and feeding clinic; epilepsy clinic; low vision clinic; speech; language and communication clinic; psychological assessment clinic; psychological counseling; more than word clinic for improved socialization and communication; well-baby clinic for high risk infants, etc.



Ministry of Social Welfare (MOSW)

The Ministry of Social Welfare (MOSW) is one of the important development ministries of the Government of the People's Republic of Bangladesh working for the human resources development. It has several multidimensional programs like socio-economic development and protection of rights for the destitute, poor, orphans, senior citizens, widows, vulnerable children, persons with disabilities and marginalized people of the country.

The National Parliament of the Government of Bangladesh has promulgated two important acts to protect the rights and ensure safety of the disabled persons. One act is (i) Neuro-developmental disabled persons' protection Act 2013; and the other is (ii) Disabled persons' protection of rights and safety Act 2013.

Neuro-developmental disabled persons' protection Trust Act 2013

Neuro-developmental Disabled Persons Protection Trust Act 2013 was legislated for enforcement from 10 November 2013 to create a Trust with a view to support creation of a fund and a sustainable organizational system for ensuring rights and safety of the neuro-developmental disabled persons through providing them physical, mental and financial help. The Trust keeps provision for the

Honorable Prime Minister of Bangladesh to serve as ex-officio chair and 13 Honorable cabinet Ministers from the line ministries to serve as the ex-officio members and the Secretary to the Ministry of Social Welfare to serve as the ex-officio member secretary. The Trust will soon be realized to create an institutional system for providing appropriate training, comprehensive development, social empowerment and other ways to enabling the disabled from neuro-developmental causes to live independently in society. Moreover, the Trust will identify the persons with neuro-developmental disabilities, help him/her to live in her/his family, live long and receive care at his/her parents' death; provide special education, employment opportunities, and ensure his/her inheritance. Under this act, volunteer organizations working for above purpose will be financially subsidized. Currently work is underway to make rules under this Act.

Disabled persons' protection of rights and safety Act 2013

This Act was also endorsed by the National Parliament of the Government of Bangladesh in 2013, which went to enforcement from 9 October 2013. The purpose of the Act is to make legal bindings on state and citizens to safeguard the rights and safety of the disabled persons



irrespective of the kind of disability. The Act creates legal binding on the state and society to not create any discrimination between an otherwise healthy person and a disabled person and establish similar and equal rights in all matters, such as, enjoyment of all civil rights, such as, inheritance; expression of opinion; right to information; living with family and society, marital relationship; entering places where all others can go; appropriate education; employment; protection from torture or oppression; safe, healthy and appropriate environment and infrastructure; highest quality

healthcare within the available limit, accommodation; rehabilitation and dependency allowance if applicable; participating in cultural and sporting events; travel; privilege to use indicative communication language; voting; national identity card; creating and joining any organization, etc. Headed by the Minister for Social Welfare, this Act keeps provision of a national coordination committee with members from national parliament, several secretaries from different line ministries and representatives from organizations working for the disabled persons.



The Department of Social Service and Jatiyo Protibondhi Unnayan Foundation under Ministry of Social Welfare have a significant role in implementing different programs to foster the cause of autism and other neuro-developmental disabilities inclusive of all other disabilities.

Jatiyo Protibondhi Unnayan Foundation (JPUF)

The basic human rights of a citizen of Bangladesh has been protected by its constitution regardless of gender, class, religion, race, etc. not discriminating between persons with or without disabilities guaranteed through the “National Policy for Persons with Disabilities” and relevant constitutional provisions on the rights of the people with disability. In accordance of this National Policy and the international commitments on United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, the Government of Bangladesh enacted the Disability Welfare Act 2001 to protect and promote the rights of the persons with disabilities. In order to address the disability issues including autism, the Jatiyo Protibondhi Unnayan Foundation under the Ministry of Social Welfare was established in 1999. The JPUF provide following services through organizations:

Autism resource center

The JPUF established an autism resource center in 2010 in its own campus. From this center, special education therapy and referral services and counseling are being given to the autistic children and their guardians. A group of experts consisting

of psychologist, clinical occupational therapist, clinical speech and language therapist, and clinical physiotherapist is working in this center. So far 500 persons with developmental disabilities have been given services. The center also registers children with ASD and provides to them home based intervention services.

Free school for children with autism

Under the patronization of Ministry of Social Welfare, the JPUF has been running a special school for the autistic children since 2011. Thirty children with disabilities from 30 poor families are studying in this special school without any tuition fee.

Disability Service Centre (Protibondhi Sheba O Sahajya Kendra)

JPUF has been implementing a program titled 'Protibondhi Sheba O Sahajya Kendra' since 2009. under the program there are currently 68 centers in different areas of the country. From these centers physiotherapy, hearing test, visual tests, counseling, referral services, etc. are being provided to persons with disabilities free of cost. Besides, assistive devices like wheel chairs, standing frames, crutches, elbow crutches, tricycles, artificial hearing aids, etc. are also being distributed free of cost among the disabled persons. So far as many as 350,000 disabled persons have been given such free of cost services. Gradually this program will be extended up to the upazila level of the country. Honorable



Prime Minister Sheikh Hasina formally inaugurated this program on 2 April 2010.

Autism corner

An autism corner was established in all 64 Protibondhi Sheba O Sahajya Kendra. Under this program, 68 centers were established in 64 districts. Another 5 centers will be established soon. From these centers, necessary therapeutic services are being provided to the children with autism free of cost.

One stop mobile therapy service

Another important program called one stop mobile therapy service has also been inaugurated by the Honorable Prime Minister Sheikh Hasina on 2 April 2010 for bringing therapy services to the door step of the autistic people.

Autism Training Program

- JPUF is conducting 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.

Protibondhi Complex

Government of Bangladesh has taken up an elaborate plan to construct a Protibondhi Complex in the capital city. This Complex will have a beautiful complex for 360 special students including autistic children. There will also be a special education centre for 250 learners including autistic children and babies. The complex will also have a rehabilitation center, shelter home, day care center, etc. for all kinds of disabled persons including persons with autism,

Protibondhi Sports Complex

The government has taken a program to establish a protibondhi sport complex as a center of excellence. For this purpose, government allocated a total of 12.01 acres of land in Savar upazila of Dhaka district in favor of Jatiyo Protibondhi Unnayan Foundation (JPUF). Preparation of DPP of this project is underway. It is estimated that the cost of construction of the said complex will be about \$12.82 million.

The Department of Social Services (DSS)

The Department of Social Services (DSS), the executive agency of the Ministry of Social Welfare (MOSW), is implementing multidimensional programs for protection of rights and development of the autistic children especially for those who are with ASD. The programs / projects are described below:



Sheikh Fazilatunnessa Mujib Memorial Specialized Hospital & Nursing College

The project is located near the capital city of Dhaka in Kashimpur, Gazipur. Started in January 2010 and completed successfully in June 2013, this 250-bed specialized hospital provides treatment and care among others to persons with neurodevelopmental disabilities. The institute's activity also includes social and clinical research on children with autism.

Institute for Autistic Children and Blind Old Home & TN Mother Child Hospital

The work of this institute and hospital, which is located in Hemayetpur, Savar, Dhaka was started

in January 2009 and completed successfully in June 2012. The aim of this institute and hospital is to improve health conditions of the people in the neighboring communities especially with respect to maternal, neonatal, and child health care, as well as children with autism.

Expansion and development of PROYASH in Dhaka Cantonment

"Proyash" means "Effort". The project located in Dhaka Cantonment was started in October 2011 and is going to be completed by June 2014. This specially designed center will provide care to 400 children with autism and disability. The main objective of the project is to provide education



Honorable Prime Minister Sheikh Hasina with the autistic and disabled children in the national event on World Autism Awareness Day 2014 (Dhaka, 2 April 2014)



and training to the children and youths with autism and disability to ensure their optimum development.

Disability detection survey

The Department of Social Service, with technical assistance from UNICEF, is conducting a survey to understand the prevalence of disability in the country and also to electronically register and track the registered disabled persons. Meanwhile, data collection has been finished in all districts of the country. More than 16 million people are targeted for inclusion in the survey. A major part of data collection has been completed and so far 743,961 disabled persons have been identified. Data entry will begin after completion of data collection. This survey will make it possible to estimate the number of disabled persons in the country and then to make need based planning and support programs for each of the disabled persons. Autism related displays were made in 64 districts and 564 upazilas and UCDs in the country during dissemination and orientation meetings for the purpose. Measures were also undertaken to create awareness by a national level workshop and dissemination and orientation meetings in 8 venues of all 7 divisions of Bangladesh.



Ministry of Primary & Mass Education (MOPME)

The Directorate of Primary Education (DPE) is responsible for ensuring enrollment of every child of schooling age into basic education facilities. In doing so, the department gives equal importance to the enrollment of children with special needs and continuation of their primary education in the main stream. Under the leadership of Saima Wazed Hossain, Chair of GAPH (Global Autism Public Health Initiative)-Bangladesh, a special plan of actions has been formulated. The achievements out of the program are as follows:

Curriculum

Autism has been incorporated in the primary education curriculum. The focus theme is "autism is a psychological problem -- not a disease and affected children can get rid of the problem if managed properly". Autism has been incorporated in the inclusive education curriculum. A teachers' training manual will be developed and concerned education officers and teachers will be given training.

Popular tele-cartoon film "Meena" to enhance social awareness and responsibility to the autistic children and persons

In Bangladesh, a popular tele-cartoon film titled "Meena" after the name of an imaginary village girl created enormous social awareness for child

education and health. The popularity of the cartoon film made "Meena" a popular character whom every viewer loves. The young children in Bangladesh are fans of "Meena". The MOPME has developed a short episode of "Meena" to raise awareness of autism among children and mass people. The script was developed through a series of workshops held in May 2012. On successful completion, the "Meena" cartoon film was broadcasted in different electronic media.

Interactive popular theater (IPT)

The MOPME also staged an interactive popular



"Meena" seen in pink upper and red colored lower is the central character of "Meena" cartoon



theater on autism which tells Apu's story to speak about autism. "Apu" is a friend of "Meena". The interactive popular theater was staged in the sub-district level and so far 158 shows have been staged.

Autism as a theme of Meena Day (24 September each year)

The MOPME has declared 24 September as the "Meena Day" to raise awareness among children and families about child education and prevent school dropouts. The 2012 "Meena Day" had the theme of "autism is not the barrier for education of school children if they become friend".

Poster

The MOPME has developed, printed and distributed a poster on autism.

Training

- One orientation workshop on Autism was held at DPE on 16 October 2012 as follow-up activity of the GAPH Bangladesh;
- Teachers' Training on Autism was held on 6 September 2012;
- With aim to development of master trainers to train the teachers of inclusive education on autism, 32 field level DPE officials received five days TOT as part of the GAPH Bangladesh; another group will soon receive training to become master trainers; it is planned to train in 2013-2014 one teacher from each primary

school on inclusive education on autism.

Other programs

Different programs have been planned and implemented in partnership with UNICEF to create social awareness on autism. The social motivation and awareness programs cover different creative productions and events on autism like drama serial, TV spot, Meena cartoon, TV scroll, communication strategy document, message, mother/parent meeting, SMC meeting, etc. Furthermore, series of orientations, seminars, workshops and different motivational programs on autism have been conducted with participation of senior policy makers, officials, civil society members, parents, public representatives and community people to raise awareness about the issue.

Autism actions under Primary Education Development Program (PEDP-2)

There is a development program named "Primary Education Development Program, Phase-2 under the Directorate of Primary Education for improvement of primary education in the country. Supported by World Bank, this program although does not include autism as direct program, several autism related activities have been carried out as in-built component, which are as follows:

- Development of strategic action plan for children with special needs under umbrella of inclusive education;



- Development of tool-kit for identifying mental and intellectual problems;
- Development of information brochure on inclusive education along with four action plans;
- Identification of teachers and assistant directors of primary education as focal persons for coordination of local autism activities;
- Development of training manuals (three in number) for trainers, field officials and teachers;

Training held

- One day orientation program for all primary education personnel all over the country (PTI field officials);
- 5-day TOT to 270 officials for implementation

of inclusive education;

- 3-day training of one teacher from each government primary school on inclusive education;
- 3-day training to all field officials (2,694 participants) of the Department of Primary Education on inclusive education;
- 5-day training to assistant directors of primary education of all 64 districts of Bangladesh on inclusive education; they have been designated as district focal persons for autism as well; and
- Training of two instructors / assistant superintendents from each primary teachers' training institutions on inclusive education.



Ministry of Education (MOE)

The Ministry of Education adopted an action plan on autism in June 2012. Following adoption of this action plan, activities are being carried out as per the action plan.

Following activities have been done so far:

- Training on awareness building on autism to the senior officers of the ministry through internal policy;
- Undertaking a project worth US\$ 9.5 million approved by the Executive Committee of the National Economic Council headed by Honorable Prime Minister Sheikh Hasina for construction of academic cum administrative buildings inclusive of accommodation, dining, furniture and other user friendly equipment for autistic children and for recruitment of manpower for smooth running of the academy. This project keeps provision of creation of 161 posts in revenue budget to end up in an autistic academy after completion of the project;
- Development of a module on autism sensitization by the National Academy for Education Management (NAEM);
- Training on "Training of Master Trainers on Inclusive Education for all Disabilities with emphasis to ASD and other neuro-developmental disabilities" to 27 faculty members of NAEM to develop them as master trainers; the training was jointly organized by Global Autism and Public Health (GAPH) Initiative in Bangladesh and NAEM;
- Development, printing and distribution of posters and leaflets and also campaign in mass media for awareness building;
- 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; and
- Allocation of 2% reserved seats for autistic children for admission in academic institutions not run by the public sector, which include primary and secondary schools and colleges for higher secondary or above level education. However students should fulfill minimum requirements.



Ministry of Woman & Child Affairs (MOWCA)

The Ministry of Woman & Child Affairs conducts the following activities to mitigate autism and related conditions:

- Development of friendly facilities for all children including children with disability and autism through all policies, projects, programs and activities of the ministry;
- Organization of courtyard and community meetings through active engagement of registered women's associations under the Directorate of Women Affairs (DWA) with a view to create awareness among their members on how to deal with children with autism;
- Sensitization and creation of awareness on autism among the officers, teachers and health instructors of 42 day-care-centers run by the DWA;
- Creation of awareness on autism among different categories of the officers of DWA in head office and at district and sub-district levels;
- Building awareness on disability with special attention to autism among the members of adolescent and youth clubs along with their mothers, family members and close society.

Activities carried out by Bangladesh Shishu (children) Academy, which is an affiliated organization of the ministry:

- Free training on painting to special needs children being given each year;
- Various kinds of awareness building programs inclusive of competitions such as, art, recitation, dance, song, etc. for the special needs children in district level offices of Bangladesh Shishu Academy;
- Training to 30 officers of head office of Bangladesh Shishu Academy on autism and neuro-developmental disabilities;
- Mainstreaming children with autism into regular early childhood centers run by the Bangladesh Shishu Academy under "Early Learning for Children Development Program".

Future plan of Bangladesh Shishu Academy

- Finalization of training manual for special needs children through sharing workshops and piloting;
- Creation of awareness among pre-school teachers of disabilities and autism for engaging them in awareness building of the parents and guardians of the pupils in



monthly parents' meetings and inclusion of autism in parenting activities;

- Preparation of classroom materials for children with autism spectrum disorders; and
- Undertaking training, workshops and other awareness building activities on autism and neuro-developmental disabilities.



An easy to guide poster is used as a tool for autism detection

Information & Communication Technology (MOICT) Division

The Information & Communication Technology Division is playing the pioneering role in materializing the government's dream of implementing Digital Bangladesh Vision 2021. Two programs of the division, such as, "Text to Speech" and "Talking Book" are for helping the blind people. Bangladesh Computer Council (BCC), an organization of this division. It held 21 training courses on development of computer skills beginning from 2009 and continuing as of

April 2014. The number of participants was 291 which included 69 physically disabled persons, 136 blind persons and 86 persons having other kind of disabilities; males were 188 (35%) and females were 103 (65%). The current year's (2014) computer training will include 160 disabled persons through 8 batches with 20 participants in each batch; the training will range from basic computer course to advanced training on hardware and graphic design to ICAP and DICP.



Ministry of Labor & Employment (MOLE)

The Ministry of Labor & Employment amended the existing labor and employment law to focus on the rights and opportunities of the persons with disabilities. Following changes have been incorporated in the law:

- The word "labor" has been rephrased as "labor and disabled labor" everywhere when the word "labor" appears;
- Bar has been imposed against engagement of disabled persons in use of machines and works that can cause physical risks to them;
- Preference has been given to disabled persons when nominated for providing internship training; and
- The phrase "male and female" has been replaced by "male, female and disabled", everywhere when the same appears in the law.

Initiatives and activities of the ministry

- To develop an action plan on autism; To take appropriate actions for raising awareness among the officers and staffs of the ministry in collaboration and coordination with other ministries;
- To create appropriate environment for the autistic person through creating physical facilities in different office and industrial buildings;
- To organize workshops;
- To develop, print and distribute posters and leaflets; and
- To motivate the owners of the industries to create an appropriate environment in the work place for recruitment and work of the autistic persons.

Local Government Division of the Ministry of Local Government, Rural Development & Cooperatives (MOLGRDC)

The Local Government Division of the Ministry of Local Government, Rural Development & Cooperatives (MOLGRDC) has undertaken a program called "Planning and development of a strategic and convergent action plan for autism and neuro-developmental disabilities in Bangladesh". Under this program, following office orders have been issued:

- To include autism as a regular discussion agenda in the meetings of Union Parishad permanent committee on "Education, Health & Family Planning";
- To include autism as a regular discussion agenda in the meetings of "health related committee" of Upazila Parishad;



- To constitute health related committee in each municipality under clause 55(2) of Municipality Act and include autism as a regular discussion agenda in the committee meetings;
- To constitute health related committee in each city corporation under clause 41 and 1(1.1) of 3rd Tafshil of City Corporation Act and include autism as a regular discussion agenda in the committee meetings.

Ministry of Finance

The Ministry of Finance responded to generously allocate funds to implement various projects and/or programs on autism and disability. Whereas all ministries received financial allocations for this purpose, notable allocations that require mention are those for special projects/programs under Ministry of Health & Family Welfare (MOHFW) and Ministry of Social Welfare (MOCW). The cumulative utilization of fund by MOHFW from fiscals 2009-10 to 2012-13 was \$1.19 million and that by MOSW from fiscals 2009-10 to 2013-14 was \$68.10 million.



Honorable Prime Minister Sheikh Hasina is witnessing the replica model of one of the several autism and neuro-developmental disability infrastructures built by the Ministry of Social Welfare

Challenge: Translating Promises to Action

Bangladesh, through its limited ability, participated with the regional and global community to raise awareness and draft international policy to enable prioritizing the public health challenge of autism spectrum disorders. In July 2011, Bangladesh with leadership provided by the Ministry of Health & Family Welfare organized an International Conference in Dhaka. WHO-SEARO, Autism Speaks and the Bangabandhu Sheikh Mujib Memorial Hospital's Center for Neurodevelopmental Disorders in Children provided technical support. Mrs. Sonia Gandhi



Bangladesh organized the first South East Asian Conference on Autism Spectrum Disorders (Dhaka, 2011)



Ms. Saima Wajed Hossain with Dr. Margaret Chan, the Director General of World Health Organization (May 2013)

from India and First Ladies from Sri Lanka and Maldives were present at the conference and expressed their common solidarity. We saw remarkable changes in the regional initiatives afterwards in each country ranging from autism programs to national action plans to address this socio-medical problem. In Bangladesh, the Global Autism Public Health Initiative, Bangladesh and National Advisory Committee (NAC) on Autism chaired by Saima Wazed Hossain were constituted. The NAC constituted four task forces to conduct situation analysis study in the country. The Strategic and Convergent Action



Plan on Autism and Neuro-Developmental Disabilities (SCAPAND) is the response to the study. The SCAPAND is a multi-ministerial effort engaging 8 ministries of Bangladesh backed by an inter-ministerial coordination committee (IMCC) comprising of experts and an NGO working group. This accomplishment ensures coordination in interventions, efficient use of resources and avoidance of duplication.

Mainstreaming autism in primary health care

Mainstreaming autism screening programs in the primary health care program is the only answer for early diagnosis and subsequent interventions of the disorder. In Bangladesh, the Ministry of Health and Family Welfare has undertaken an appropriate program in its ongoing Health, Population & Nutrition Sector Development Program 2011-16. One of the activities is to engage the grassroots level 18,000 community clinics, one for every 6,000 population, as well as the community based domiciliary health workers to interface autism screening programs with the families and primary health care centers. However, international collaboration would be required as Bangladesh is a country of 160 million people, and the country has resource constraints. International assistance will help Bangladesh to serve its citizens affected with ASD and other neuro-developmental disorders more effectively.



A community clinic, which has become the unique symbol for delivering primary healthcare to the people living in the grass-roots level of Bangladesh



Intensification of international efforts and alliance is crucial

Many facts about ASD and related neuro-developmental disorders are still unknown and undiscovered. The conditions together confront us with one of the most difficult social and public health challenges the world has ever seen. Through effective collaboration between international institutions, INGO's, NGO's and government bodies, countries can hope to devise cost effective, feasible and sustainable methods to combat this public health challenge. Bangladesh calls to the global community to collaborate and jointly strengthen such initiatives.

