

2013-2020; and that it was designed for low resource settings. She emphasized that the following needs to be done on an urgent basis: advocacy for policy and financing, awareness building, development of structural and human resources, multi-sectoral involvement, early detection and surveillance, and research on burden.

Following Dr. Anwar's presentation, the panelists from international organizations: Aiko Akiyama, Dr. Shekhar Saxena, Dr. Khalid Saeed and Jean Lieby of UNESCAP, WHO, and UNICEF, recounted the progress that has been made in the last two decades. They emphasized that there was considerable political will to take forward the agenda of autism spectrum disorder and other neurodevelopmental disorders. The panelists highlighted the fact that there was a need for systematic inter-ministerial and inter-organizational collaboration at the international level, and inter-institutional and inter-sectoral collaboration within countries to coordinate various efforts.



Minister of Health, Bhutan & Deputy Minister of Health, Nutrition & Indigenous Medicine, Sri Lanka at the Round Table Discussion

They emphasized the importance of collaboration on generating financial and human resources, and networks for sharing information and good practices. Additionally, Ms. Akiyama stressed on the need for cross-disability collaboration and Dr. Saxena focused on the need for collaboration to increase capacity in the health, educational, social and disability sector of families, and mentioned that WHO could assist in this process by making information and capacity building tools like the Parent Skills Training Manual and the WHO Mental Health Intervention Guide readily available. Jean Lieby stated that

the UN Committee of Rights of the Child had issued 6 recommendations which were fully in line with the proposed WHO collaborative framework and could provide a basis for intergovernmental agencies, like UNICEF and WHO to work together with governments.

Panelists representing government organizations in the region, Dr. Swarna Wijetunge, and Dr. Muhammad Waqar Azeem; apprised the audience about developments in their nations; e.g. the National Plan for Children with Special Needs in Sri Lanka and the National Autism Plan in Qatar. They also emphasized that nations could learn from each other to take the agenda forward. Specifically, Dr. Swarna Wijetunge mentioned that child and adolescent mental health had been included in the Mental Health policy document in Sri Lanka, and challenges to collaboration were being overcome through development of multidisciplinary professional bodies, utilization of media and hotlines for awareness building, use of primary care for early detection and intervention, use of maternal and child health services to provide primary mental health care to children and adolescents, and work with education department to develop an "Education for All" policy and with the Social Empowerment Ministry towards a Disability Act. While speaking about the National Autism Plan for Qatar, Dr. Muhammad Waqar Azeem elaborated on the process

pillars (awareness, screening and early detection, diagnosis, early intervention, education, and transition to adulthood and elder status), reasons for success, and international support towards development. He illustrated how stakeholders including political leaders and parents and people with disabilities had come together to make this possible.

Valerie Taylor, Founder and Coordinator, Centre for the Rehabilitation of the Paralysed in Bangladesh emphasized the need for collaboration in development and retention of human resources in Bangladesh; and networking for generating awareness and educational resources. Prof. Cui Yonghua, Prof. Lee Moon-soo, Dr. Samir Dalwai, and Aloka Guha, emphasized the need for seamless services in various sectors and empowerment of families to ensure services are optimally utilized. Prof. Yonghua particularly, stressed on the role of governments for ensuring appropriate care for people with autism spectrum and other developmental disorders. Prof. Moon-soo underlined the need for case managers and coordinators for individualized care planning and Dr. Dalwai, emphasized adherence to evidence based practices and provided examples of how the Indian Academy of Pediatrics is developing national guidelines for identification and intervention. He also stressed upon the need to regulate practices in the region. Ms. Guha highlighted the need for strong laws on disabilities, including penalties for non-adherence in order to ensure implementation; the need to shift to a rights-based approach and social model of care instead of the earlier medical model of care; the need to develop services hand-in-hand with awareness to lower the incidence of malpractices and the need for collaboration to ensure the sustainability of programs.

The Chair and Co-Chair, Dr. Thamarangsi and Dr. Sirithongthaworn summed up the session by stressing that there was in fact, considerable untapped potential, e.g. extensive experience and available tools in the field; however, these could be best utilized by collaborating on information systems and documents, developing networks within and across sectors, a comprehensive strategy to work together, and all-inclusive and collective capacity building.

Special Session: Let's Talk Self Advocacy

Chair: Shri Faggan Singh Kulaste, Honorable State Minister, Ministry of Health & Family Welfare, Government of India

Co-Chair: Beda Giri, Executive Director, Ability Bhutan Society

Moderators: Joanne Byron, Palm Beach County School District, USA
Dr. Nusrat Ahmed, Shuchona Foundation, Bangladesh

Speakers:

- Dr. Stephen Shore, *Assistant Professor, Special Education, Adelphi University, USA*
- Qazi Fazli Azeem, *Assistant Professor, Karachi Institute of Technology and Entrepreneurship, Pakistan*
- Daniel Giles, *Graphic Designer & Photographer, Australia*

Key Points:

1. One must have a strong sense of self and **self-determination**, in order to be an effective self-advocate
2. Decisions impact people in **different** ways, so the perspectives of those affected by the decisions need to be included in the decision-making process
3. A **strong supportive family** and partnership in the **community** are important factors in the journey of the self-advocates

The Special Session, held on the second day of the conference focused on the voices of self-advocates with presentations by Dr. Stephen Shore from USA, Daniel Giles from Australia, and Qazi Fazli Azeem from Pakistan. The session was Chaired by Shri Faggan Singh Kulaste, State Minister, MoHFW, Government of India, and Co-chaired by Beda Giri, Executive Director, Ability Bhutan Society. The Prime Minister of Bhutan, Dasho Tshering Tobgay took a keen interest in the subject matter and attended the session.

The Chair of the session in his opening remarks said while many initiatives are being taken, there is still much more to do. He stressed upon the need for advocacy in the political and policy level, experts' and practitioners' level, and family and societal level to bring awareness and address all aspects of NDDs; along with involving citizens and recognizing the role of family in addressing mental health issues. He concluded with the recommendation to create a roadmap, which would include policy advocacy, establishment of national taskforce, public-private partnership in training stakeholders, and research.

The speakers focused on the importance of self-advocacy and shared their respective journeys to becoming self-advocates. Individual experiences are unique, just as each person on the spectrum are different, thus, warranting customized intervention. Despite their differences in experiences and the interventions they received, they all had one thing in common: a strong supportive family and network of friends, which enabled them to feel a part of the community. The speakers emphasized on the importance of developing a sense of self, and having self-awareness, as part of the process of becoming effective self-advocates. The presentations were followed by Q&A with those in the audience.



Self-Advocates at the Special Session

Dr. Stephen Shore, who is Assistant Professor at Adelphi University, was diagnosed with Asperger's Syndrome / Autism as a child. He grew up in a household where the word "autism" was normalized and knew he was a person with autism from a young age. His parents played an instrumental role and were involved in home-based early intervention. From an early age he received a mainstream education and went on to become a university teacher. His talk focused on how to become a self-advocate, and what is necessary to become one. An important aspect is to have an awareness of the need for self-advocacy, along with environmental, cognitive, and socio-emotional needs. As autism is a spectrum disorder, and no two persons are alike, he feels that needs are also varied and may come up at different times for different people. He advised that in order to be an effective self-advocate, one must have self-determination, to attain which, one must have a sense of self. For instance, his parents supported his interests, and being able to pursue those interests helped to build a sense of self, thus self-determination. Additionally, it is important to find strength in a person for each challenge, as opposed to weakness. Knowing

strengths and challenges help understand self, after which comes disclosure. It is not easy telling someone that (s)he is on the spectrum, as it is an invisible disability. Making them understand is a challenge but effective interventions catered to individuals – “matching needs with individuals” - help this process. It is necessary to focus on ability too; to look at what people can do rather than what they cannot do.

Dr. Shore shared his personal experiences from childhood onwards to illustrate how self-determination was achieved making him a self-advocate. Throughout his talk he acknowledged the role his parents, and family played, in helping him to understand himself.

“It is not about independent living because reality is hermits live independently. Interdependent living is reality.” **Dr. Stephen Shore**

Daniel Giles, a graphic designer by profession who lives independently, spoke about his journey to becoming a self-advocate. He learned about his autism from his father around the age of 11 or 12, and was able to understand himself through meeting others with autism. Hearing about others’ journeys helped him in his. Daniel has had many speaking engagements in different forums including the Asia Pacific Autism Conference (APAC). He writes opinion pieces, and researches on improving quality of life in Australia.

His work as a self-advocate focuses on highlighting ability; what people with autism can do, along with disability access, and customer service for people with speech impediments. He mentors in schools, and works to educate communities and businesses. He is associated with Australia’s first social enterprise by persons with Autism called “I Can Network”. He said he does all this because self-advocacy is important. Decisions impact people in different ways, so perspectives of those affected by the decisions need to be included in the decision-making process.

Qazi Fazli Azeem echoed what the two speakers preceding him said: it is important to know one’s self before becoming a self-advocate. Although not officially diagnosed with autism until he was 25, Fazli Azeem learned at a young age, ways of addressing some of the characteristics of ASD. He shared that there were many members in his family on the spectrum who were accommodated within the family setting. In addition to intervention and learning coping mechanisms - headphones for loud noise, reading and play area activities for hyperactivity, etc. - he advised to turn interests into obsessions and hobbies, as they help define a person. It is important to know how to address the challenges one faces before going on to self-advocacy. He advised that to be a self-advocate, one must use methods that will get the message across; it may be through using local language, videos, social media, etc. One must also know that no one is alone; there are other self-advocates from whom to learn.

The session also had a question and answer section which brought out queries from parents, service providers, self-advocates, policy-makers, and high-level government delegates. In her closing statement, co-chair of the session Beda Giri of Ability Bhutan Society re-emphasized the importance of self-advocacy, and effective support mechanisms for self-advocates and others.

Closing Ceremony

The closing ceremony of ANDD2017 immediately followed the WHO Roundtable on *the Collaborative Framework for Addressing Autism Spectrum Disorder in the South-East Asia Region*. The speakers at the closing ceremony were: Mohamed Cassim Mohamed Faizal, Honorable Deputy Minister of Ministry of Health, Nutrition and Indigenous Medicine of Sri Lanka, Zahid Maleque, Honorable State Minister, Ministry of Health and Family Welfare, Bangladesh, Lyonpo Tandin Wangchuk, Honorable Minister, Ministry of Health, Royal Government of Bhutan, and Saima Hossain, Chair of the Scientific Committee of ANDD2017, and WHO's Goodwill Ambassador for Autism in the South-East Asia Region.

Dr. Kinzang P. Tshering, Chair of the Technical Committee and member of the Scientific Committee for the Conference read out the Thimphu Declaration (see Annex 1).

Deputy Minister of Sri Lanka, Mohamed Cassim Mohamed Faizal said that although Sri Lanka has a yearly budget of Rs. 10 million to address disability, autism has not been the priority. However, the discussions at the conference were useful and a decision has been made to address autism and other neurodevelopmental disorders in the country.

State Minister of Bangladesh, Zahid Maleque expressed Bangladesh's commitment to addressing autism and neurodevelopmental disorders. He acknowledged existing challenges which include political will, trained manpower, infrastructure, funding, and dignity.

Minister of Health of Bhutan, Lyonpo Tandin Wangchuk highlighted the need for advocacy to eliminate stigmatization, to institute a structured collaborative partnership, and to establish referral and intervention initiatives, saying that Bhutan will take initiatives to address these. He acknowledged the Prime Minister of Bangladesh, Sheikh Hasina's presence, saying it strengthened the bilateral relationship, and concluded by thanking the co-hosts.

Saima Hossain, Chair of the Scientific Committee of ANDD2017 in her speech said she hoped the 3 days of intense discussions, workshops and networking was educational, had resulted in those present to continue to work towards making a lasting change about how participants think about autism and NDDs, and be motivated to forge ahead to include those with disability in future planning. She hopes that by committing to the Thimphu Declaration, stakeholders are making a promise to ensure that people with Autism and other NDDs in our communities, societies, nations have the opportunities and resources necessary to experience their right to a meaningful and productive life. During her speech, Ms. Hossain read out part of a heartfelt message that she received from a parent a few days before the Conference:

"I and other parents, caregivers, ASD children and adults are counting on you to fill in for us and to safeguard, protect and defend our loved ones as not only their advocate but also as their interpreter and the loudest voice in the room in Bangladesh, Bhutan and all over the world. Let the world know that they are more than their diagnosis and more than their limits and disabilities and that above all they are people, with

emotions, likes and dislikes. Not because they have special needs and need more kindness and love but because they are people. And all people need more kindness and love. Just like you changed our vision, preconceptions and ideas, I know you will do the same with others along the way."

- Anonymous Parent

She concluded by thanking all the co-organizers, particularly Dasho Tshering Tobgay, Honorable Prime Minister of the Royal Bhutanese Government and the Royal family for their patronage. She thanked Lyonpo Tandin Wangchuk for his support, and WHO-SEARO, especially Dr. Poonam Khetrupal Singh and Dr. Thaksaphon for giving all the leverage, and support to organize the Conference.



ANDD2017 Participants at the Royal Banquet Hall

Cross-cutting issues

In summary, the three central cross-cutting issues that need to be addressed for people with ASD and NDDs, as per the discussions of the 3-day Conference are:

iv. Funding

- a. The need for Government funding for effective projects and to ensure that NDDs are included as a part of disability projects
- b. Corporations can also be sources for funding NDD projects that correspond to their mission, since they have a corporate responsibility to give back to the community

v. Political will

- a. In order for the proper execution and implementation of NDD-related initiatives, it is necessary for there to be strong political will behind it

vi. Multi-sectoral approach

- a. Panelists all emphasized the need for collaboration and partnerships between relevant stakeholders, in order to advance the cause of NDDs

Recommendations for stakeholders

In line with the objectives of the Conference, certain recommendations were made by the practitioners, parent-experts, self-advocates, academics, and others present at the conference. A consolidated list of the recommendations are as follows:

For Governments:

- There must be a systematic screening process for childhood development set up for the entire population to ensure early identification.
- The screening process should be integrated into the health system to maximize effectiveness
- Effective implementation of existing policies such as the NDD Protection Trust Act of Bangladesh
- Mobilize assistance for countries with low resources
- Develop education strategies focused on teaching problem-solving, modifying the curriculum in such a way to better prepare those with special needs to live independently
- Develop defined national policy to properly address the needs of persons with ASD and NDDs, taking into account the life-course needs of individuals including employment opportunities
- Benefits program in place for employers that hire persons with NDDs, so that they may see the financial benefit to employment beyond CSR and tax credit
- Ensure the legal rights of persons with ASD and NDDs

For Professionals:

- Develop comprehensive identification tools that are age-specific
- Continued evidence-based research and practice, possibly leading to the development of comprehensive tools and interventions for persons with ASD and NDDs
- Develop and continued capacity building of human resources through training of parents, teachers, healthcare professionals, and relevant stakeholders to successfully address the needs of persons with ASD and NDDs
- Host similar follow-up conferences for continued networking & relationship building, and sharing of work and good practices both regionally and globally
- Country-specific advocacy for inclusive education to ensure that persons with ASD and NDDs are able to get into mainstream schools
- Form a multidisciplinary team involved in the overall screening and diagnostic process
- With respect to interventions, shift from a clinical to a more community-based approach, considering the cultural context to ensure effectiveness
- Experts should seek out the opportunity to learn from families and parents of persons with NDDs

For Multi-sectoral Collaboration:

- Increasing awareness about disability among non-disability groups, sectors like hospitals, colleges, universities, schools, etc.
- Ensure that the family is a key component of the whole intervention process; empowering parents and forming more peer-support groups
- Formulating mechanisms to enable families to be linked to their community
- Documentation of services and service delivery in order to monitor and evaluate their effectiveness and generate knowledge for future learning
- Implement monitoring and evaluation plans for existing services run by governments and private service providers to ensure standardized practices and lower the rate of malpractice
- Human resource development through research and standardized training
- Creation of employment opportunities for persons with ASD and NDDs
- Creation of a web-based library where users can access different tools, information and latest research on ASD and NDDs for professionals, parents, and caregivers
- Coordination between resources and improved quality of standardized practices
- Effective networking and communication nationally and internationally

Conclusion

The International Conference on Autism & Neurodevelopmental Disorders, 2017, brought together a diverse group of stakeholders including researchers, academics, practitioners, self-advocates, caregivers, legislators and bureaucrats, heads of states, ministers, high-level government officials, and development partners, with nearly 300 participants from 31 countries.

In addition to the Thimphu Declaration, one of the main outcomes of the 3-day Conference was *WHO Collaborative Framework for addressing Autism Spectrum Disorder in the South-East Asia Region*. The framework outlines a list of recommended activities for each of the 31 objectives that are in the WHO South-East Asia Regional Strategy on ASD. The purpose of the activities is to fulfill the objectives by delivering the expected outcomes for Member States, which would thereby address the needs of the population with ASD and NDDs and positively impact all disabilities.

The need for inclusive policies and practices were highlighted by most speakers, in all sectors including education, employment, migrant issues, and the overall development agenda. Innovation and use of technology to develop ways to include all including those with autism and other neurodevelopmental disorders was stressed upon by the experts.

The panelists all highlighted the fact that there was a need for systematic inter-ministerial and inter-organizational collaboration at the international level, and inter-institutional and inter-sectoral collaboration within countries to coordinate various efforts. They emphasized the importance of collaboration on generating financial and human resources, and networks for sharing information and good practices.

It is clear that the challenges of ASD and NDDs need a global systematized response, which is coordinated, structured, well planned and feasible for low resource countries in order to be included as part of the SDG agenda. Through international collaboration and partnerships with governments, organizations, experts and families, a more inclusive global community can be achieved.

Annexures

Annex 1

Thimphu Declaration on Autism and Neurodevelopmental Disorders

We, as a group of leaders, policy makers, academics, professionals, practitioners, advocates, self-advocates, caregivers, families, civil society organizations, and other stakeholders participating in the International Conference on Autism and Neurodevelopmental Disorders, held in Thimphu, Bhutan, 19-21 April 2017:

Aware that autism and other neurodevelopmental disorders, a lifelong disability affecting brain function, may cause significant challenges in the enjoyment of their human rights and fundamental freedoms if adequate support is not provided;

Noting the increase in the number of individuals diagnosed with autism spectrum disorders and other neurodevelopmental disorders, and the likelihood that still more persons remain unidentified or incorrectly identified and cared for in society and in health facilities mainly due to lack of awareness, limited access to and capacity of health care systems, particularly in low and middle income countries;

Concerned over the vast impact of autism and other neurodevelopmental disorders on health and well-being, as well as the economic burden, on individuals, families, and the whole of society;

Deeply concerned that individuals with autism spectrum disorders and other neurodevelopmental disorders face major challenges including social stigma, isolation and discrimination, and that individuals and families in need, especially in low resource contexts, often have poor access to appropriate information, support and services;

Recognizing the important contributions of governments, international community and civil society organizations, that have led to increased public concerns and awareness and political commitment to address autism and other neurodevelopmental disorders;

Recalling the Universal Declaration of Human Rights; the Convention on the Rights of the Child; the Convention on the Rights of Persons with Disabilities; United Nations General Assembly resolution 62/139 declaring 2 April as World Autism Awareness Day; and United Nations General Assembly resolution 67/82 on "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities";

Recognizing that Sustainable Development Goals (SDGs) have addressed the needs of persons with autism and other developmental disorders, including through ensuring healthy lives and promote wellbeing for all at all ages (SDG3), inclusive and equitable quality education and promote lifelong learning opportunities for all (SDG4), promote sustained, inclusive and

sustainable economic growth, full and productive employment and decent work for all (SDG8), reduce inequalities (SDG10), make cities and human settlements inclusive, safe, resilient and sustainable (SDG11), and strengthen the means of implementation and revitalize the Global Partnership for Sustainable Development (SDG17).

Recalling the World Health Assembly Resolution 67.8 on Autism, and the WHO SEA Regional Committee Resolution SEA/RC65/R8 "Comprehensive and coordinated efforts for the management of autism spectrum disorders and development disabilities", adopted in 2014 and 2012 respectively;

Reaffirming the 2011 Dhaka Declaration on Autism Spectrum Disorders and Developmental Disabilities, and the 2013 Delhi Declaration of the South Asian Autism Network (SAAN) for Autism Spectrum Disorders Conference;

We hereby adopt this Declaration and undertake to:

1. Welcome the WHO South-East Asia Regional Strategy on Autism Spectrum Disorders;
2. Call upon governments to integrate the needs of those with autism and other neurodevelopmental disorders in health, education, social services and socioeconomic development policy, planning and implementation, as well as other national efforts in achieving Sustainable Development Goals;
3. Collectively enhance whole-of-society and whole-of-government efforts to strengthen national capacity; including health, education and social care systems; to provide services and cares for, as well as take measures to remove stigma and promote social inclusiveness for individuals and families with autism spectrum disorders and other neurodevelopmental disorders;
4. Strengthen information systems and research and promote knowledge and experience sharing, within and across countries, particularly on best practices with a focus on the lifespan needs of those with autism and other neurodevelopmental disorders;
5. Call upon governments at all levels to work together with civil society including academia, professionals, and non-governmental organizations, as well as private sector and the media, in addressing autism and other neurodevelopmental disorders, and effectively implement this Thimphu Declaration on Autism and Neurodevelopmental Disorders.
6. Invite United Nations agencies, development partners and international organizations to facilitate cooperation and collaboration and support countries in the implementation of this Thimphu Declaration, in accordance with the 2030 Agenda for Sustainable Development.

Annex 2

Poster of Self-Advocates

Singing at the "Victory Day" program

Dhrupad's depiction of a village hut

Portrayal of village walkway by Dhrupad

Loves singing while riding his cycle

Rainy season in Dhrupad's eyes

Finding comfort in nature

Having fun with his younger brother

Dhrupad's painting featured in Unilever Bangladesh calendar of 2015

Enjoys MCing different events

Dhrupad Asad, 14
Dhaka, Bangladesh

Dhrupad is the house warden, he knows where the napkins are and where the keys have been kept. He loves to cycle and often asks his mother to buy flowers from the shop on his cycling route. Dhrupad's artwork have been showcased in greeting cards sent by Sheikh Hasina, Hon'ble Prime Minister of Bangladesh, also in different calendars and book illustrations. Dhrupad spreads positive energy through his work.

INTERNATIONAL CONFERENCE ON AUTISM & NEURODEVELOPMENTAL DISORDERS BHUTAN 2017

World Health Organization
Regional Office for South-East Asia

PAN PACIFIC
SONARGAON DHAKA

MINISTRY OF HEALTH
GOVERNMENT OF BANGLADESH