



Executive Summary

Report: International Conference on Autism & Neurodevelopmental Disorders, 19-21 April 2017

Introduction

The International Conference on Autism & Neurodevelopmental Disorders 19th-21st April 2017 (www.ANDD2017.org) held in Thimphu, Bhutan was co-hosted by the [Ministry of Health, Royal Government of Bhutan](#) and [Ministry of Health & Family Welfare, People's Republic of Bangladesh](#), with the technical support of [Shuchona Foundation](#), [WHO Regional Office for South-East Asia](#) and [Ability Bhutan Society](#).

Theme: *Developing effective and sustainable multi-sectoral programs for individuals, families, and communities living with autism spectrum disorder (ASD) and other neurodevelopmental disorders (NDDs)*

The **objectives** of the Conference were:

- 1) To provide a platform for policy-makers to engage with all stakeholders
 - a. Discourse among policy-makers, multi-sectoral experts and direct stakeholders
 - b. Soliciting commitment for the implementation of international resolutions on autism and other neurodevelopmental disorders
- 2) Sharing and learning best practices for national-level development and deployment of programs
- 3) Promoting cooperation and partnerships for development of effective and sustainable programs

The 3-day Conference comprised of panel discussions, professional workshops, high level discussions and special interest groups and poster displays. Each panel consisted of researchers, practitioners, academics, self-advocates and parents.

Conference proceedings

DAY 1

The inaugural ceremony on 19th April at the Royal Banquet Hall, Thimphu was graced by the presence of HM the Druk Gyaltsuen, Jetsun Pema Wangchuk, HE Sheikh Hasina, Honorable Prime Minister, People's Republic of Bangladesh, HE Dasho Tshering Tobgay, Honorable Prime Minister, Royal Government of Bhutan, and Dr. Poonam Khetrapal Singh, Regional Director, WHO-SEARO, along with Ministers of Health from the region and other distinguished guests and participants. The tone of the conference was set with the special presentation of [Dr. Yolanda Liliana Mayo Ortega](#), on *'The power of two: families and*



professionals working as partners for children with autism to become independent, productive and happy'.

The High-Level Discussion that followed, ***Enabling countries to successfully address autism and other neurodevelopmental disorders as part of their Sustainable Development Goals*** featured interventions by regional directors and representatives of various UN bodies, ambassadors, country representatives and experts. The session was chaired by HE, Sheikh Hasina, co-chaired by Dr. Poonam Khetrpal Singh, and moderated by Saima Hossain, then WHO Champion for Autism in South-East Asia. The discussion began with a presentation on the use of telemedicine and telehealth by [Evelyn Cherow](#) and focused on commonality between autism and other disabilities and the urgent need for ensuring their inclusion, for countries to achieve the SDGs. *(see pg. 16 in main report)*

The first panel was focused on **early identification** of autism and other neurodevelopmental disorders through community-based programs. Split into two sessions, the first focused on *Screening vs. Diagnostic Evaluation* methods and the second session on *Screening and Diagnosis* within the health system. Speakers through pre-prepared open ended questions, discussed matters around research, development of universal diagnostic tools, definition of early identification, and markers for ASD, and challenges faced in screening and assessment. The necessity of a multi-disciplinary team was emphasized along with the need for screening for disability as part of regular child development care. *(see pg. 19)*

DAY 2

Day 2 panel discussion on **interventions** discussed *Models for Intervention Services* from around the world and the benefits and challenges of implementing *Evidence-based Intervention Programs* in varying cultural and economic contexts. Experiences and opinions on how to reach marginalized and low resourced populations, barriers to inter-professional collaboration, policy recommendations, and strategies for reducing the burden of ASD and NDDs on the communities, as well as inclusive education were explored. *(see pg. 23)*

The **Education Panel** discussed the variation of needs particularly for children with ASD, the need for maximum time with same age typically functioning peers, the challenges and resources required for inclusive education and the urgent need for employable skills development within educational programs. *(see pg. 25)*

A **Special Session**, featured the experiences of three self-advocates, [Dr. Stephen Shore](#) from USA, [Daniel Giles](#) from Australia, and [Qazi Fazli Azeem](#) from Pakistan. Each shared their unique journeys to becoming self-advocates and emphasized the importance of self-advocacy, crediting their success to their supportive family and community. The session was chaired by Shri Faggan Singh Kulaste, State Minister, Ministry of Health and Family Welfare of India, and co-chaired by Beda Giri, Executive Director, Ability Bhutan Society. The Honourable Prime Minister of Bhutan Dasho Tshering Tobgay attended the session as a special guest. *(see pg. 43)*

DAY 3

The final day featured panel discussions on **employment** and **supported independent living**. Panelists discussed the challenges faced by persons with ASD and NDDs, both with seeking and holding down jobs. The need for supportive policy, open-minded employers and supportive family and schools was emphasized. Success stories from around the world were also shared, where employment of persons with ASD and NDDs was a financial benefit to not just the family but also the employing company. *(see*



pg. 32) The discussion on *supported independent living* showcased successful models from around the world, barriers to effective institutions, culture-specific influences and the need for innovation and individuality. (see pg. 35)

A **Round-Table Discussion** on the WHO-SEARO regional collaborative framework for addressing autism focused on developing a cost-effective systematic response that is structured, coordinated and feasible for low-resource countries through partnerships. The panelists included representatives from the government, non-governmental organizations, civil society, and international organizations, as well as professional bodies. A short overview of the collaborative framework highlighted the challenges in the South-East Asia region, e.g. the treatment gap, lack of awareness and policies, stigma, paucity of financial, institutional and human resources, and the need for a coordinated response for inclusive development. Collaboration between and within agencies, sharing of technical resources, would ensure information systems and develop effective cross-sectoral networks. (see pg. 39)

The 11 professional workshops held concurrently, provided the participants the opportunity to learn about recent developments in research and other effective programs implemented in various countries. Topics included diagnostic and intervention tools such as, [Social Attention and Communication Study \(SACS\)](#), the [Jasper Model](#) for inclusive learning, the [Early Start Denver Model](#), and [WHO-Autism Speaks' Parent Skills Training](#) program. Other workshops showcased the different ways that ASD and NDDs are being addressed in different countries and regions.

The [Early Childhood Development Task Force](#) (ECD TF) of UNICEF's Global Partnership on Children with Disabilities (GPCWD), conducted an informal discussion on Day 2, enabling an important opportunity for networking and developing collaborative efforts.

The content of the **Thimphu Declaration** was finalized in a closed group meeting comprised of relevant government officials from Bangladesh and Bhutan, WHO-SEARO and international autism experts. (see pg. 51) The document was then formally adopted at the Closing Ceremony of ANDD2017, which was attended by 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, the current [WHO Goodwill Ambassador for Autism](#) in the South-East Asia Region.

Cross-cutting issues highlighted by attendees:

i. Funding

- Need for Government funding for effective projects and including NDDs in the development of all disability projects
- Corporate funding for NDD projects that correspond to their mission, and gives them an opportunity to give back to the community

ii. Political will

- Political will is a necessity for any advancement of services

iii. Multi-sectoral approach

- Collaborative partnerships that are cross-sectoral between relevant stakeholders is key to the cause of NDDs



Recommendations for stakeholders

The following is a summary of the recommendations made by the practitioners, parent-experts, self-advocates, academics, and others present at ANDD2017:

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, considering the life-course needs of individuals including employment opportunities
- Benefit programs 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 can get into mainstream schools
- Form 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 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 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 diverse group of stakeholders from various professions in attendance at ANDD2017 totaled more than 300 participants and represented 31 countries. Along with the Thimphu Declaration and Regional Collaborative Framework, the Conference resulted in the compilation of essential recommendations necessary for the effective implementation of international resolutions on ASD, NDDs and disability, in a manner that will not only help countries achieve their SDGs but also enable persons with disabilities to live with dignity and success.

