

Report

International Conference on Autism & Neurodevelopmental Disorders

Thimphu, Bhutan

19th – 21st April 2017

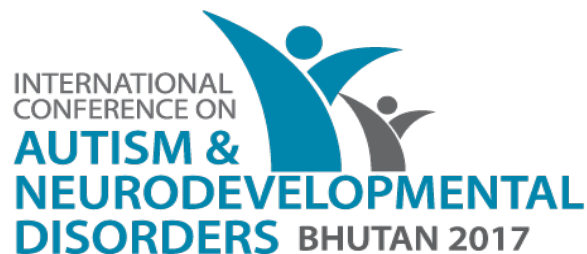


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Purpose of the Report

This report was prepared by Shuchona Foundation at the request of the World Health Organization, Office for the South-East Asia Region, in order to provide a comprehensive summary of the **International Conference on Autism & Neurodevelopmental Disorders (ANDD2017)**, held from the 18th – 21st April, 2017 in Thimphu, Bhutan.

It is hoped that the outcomes documented in this report will assist countries in prioritizing activities in planning programs for persons with Autism Spectrum Disorder and other neurodevelopmental disorders and their families.

Acknowledgements

Organizers

We would like to express our sincere gratitude to the organizers of ANDD2017:

The Royal Government of Bhutan
The Government of the People's Republic of Bangladesh
World Health Organization, Office of the South-East Asia Region

We are grateful to **Lyonpo Tandin Wangchuk**, Minister of Health, Royal Government of Bhutan, **Mohammed Nasim**, Minister of Health & Family Welfare, Government of the People's Republic of Bangladesh and **Dr. Poonam Khetrpal Singh**, Regional Director, WHO South-East Asia Regional Office, for their guidance and support.

Contributors

We would like to acknowledge the valuable contribution of *all* participants who attended the Conference.

Special thanks to the following individuals for documenting the thematic panel discussions and workshops (*in alphabetical order*):

Dr. Helaluddin Ahmed, National Institute of Mental Health, Bangladesh
Malka Shamrose, Shuchona Foundation, Bangladesh
Prof. Mimi Lhamu Mynak, Head, Department of Pediatrics, JDWNRH, Bhutan
Prof. Narayan Saha, National Institute of Neurosciences, Bangladesh
Dr. Nusrat Ahmed, Shuchona Foundation, Bangladesh
Dr. Pratap Sharan, All India Institute of Medical Sciences, India
Saad Mustafa Zaman, Shuchona Foundation, Bangladesh
Dr. Sajeeva Ranaweera, Sri Lanka Medical Association, Sri Lanka
Dr. Yatan Pal Singh Balhara, All India Institute of Medical Sciences, India

Session Coordinators *(in alphabetical order)*

Mr. Gaden Chopel, Draktsho, Bhutan
Mr. Jayendra Sharma, PPD, Ministry of Health, Bhutan
Karma Lhaki, Jigme Dorji Wangchuk National Referral Hospital, Bhutan
Mr. Karma Wangdi, VP, Mongar LS School, Bhutan
Dr. Mahrukh Getshen, Bhutan
Prof. Mimi Lhamu Mynak, Jigme Dorji Wangchuk National Referral Hospital, Bhutan
Dr. Neyzang Wangmo, Khesar Gyalpo University of Medical Sciences of Bhutan
Pema Norbu, Ministry of Education, Bhutan
Ms. Thuji, Ability Bhutan Society
Tshering Dhendhup, WCO, Bhutan
Tshering Norbu, Jigme Dorji Wangchuk National Referral Hospital, Bhutan

We would like to acknowledge all the volunteers from Bhutan, especially **Dr. Kinzhang P. Tshering** and his team for their hospitality and for tirelessly working to ensure that ANDD2017 was a success.

Photography

Rohit Vohra, Art Photo Feature
Ministry of Health, Royal Government of Bhutan

This report has been prepared by Aneeqa R. Ahmad and Nazish Arman from Shuchona Foundation.

Saima Wazed Hossain, *Chairperson, National Advisory Committee on Autism, Bangladesh and WHO Goodwill Ambassador for Autism in the South-East Asia Region* provided the overall direction and supervision of the report.

ANDD2017 Program

TUESDAY, 18TH APRIL 2017

16:00	Professional Workshops
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WEDNESDAY, 19TH APRIL 2017

09:00	Inaugural Ceremony
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11:15	Special Presentation
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14:00	High Level Discussion
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17:00	Panel Discussion on Early Identification
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THURSDAY, 20TH APRIL 2017

07:30	UNICEF ECD Task Force Meeting
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09:00	Panel Discussion on Intervention
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11:30	Special Session: Let's Talk Self Advocacy
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14:30	Panel Discussion on Education
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17:00	Professional Workshops
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FRIDAY, 21ST APRIL 2017

09:00	Panel Discussion on Employment
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11:30	Panel Discussion on Supported Independent Living
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14:30	WHO-SEARO Round Table Discussion
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16:00	Closing Ceremony
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17:00	Professional Workshops
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Executive Summary

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 posters displays. Each panel consisted of researchers, practitioners, academics, self-advocates and parents.

Conference proceedings

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 Khetrpal 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 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 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)

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 was 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

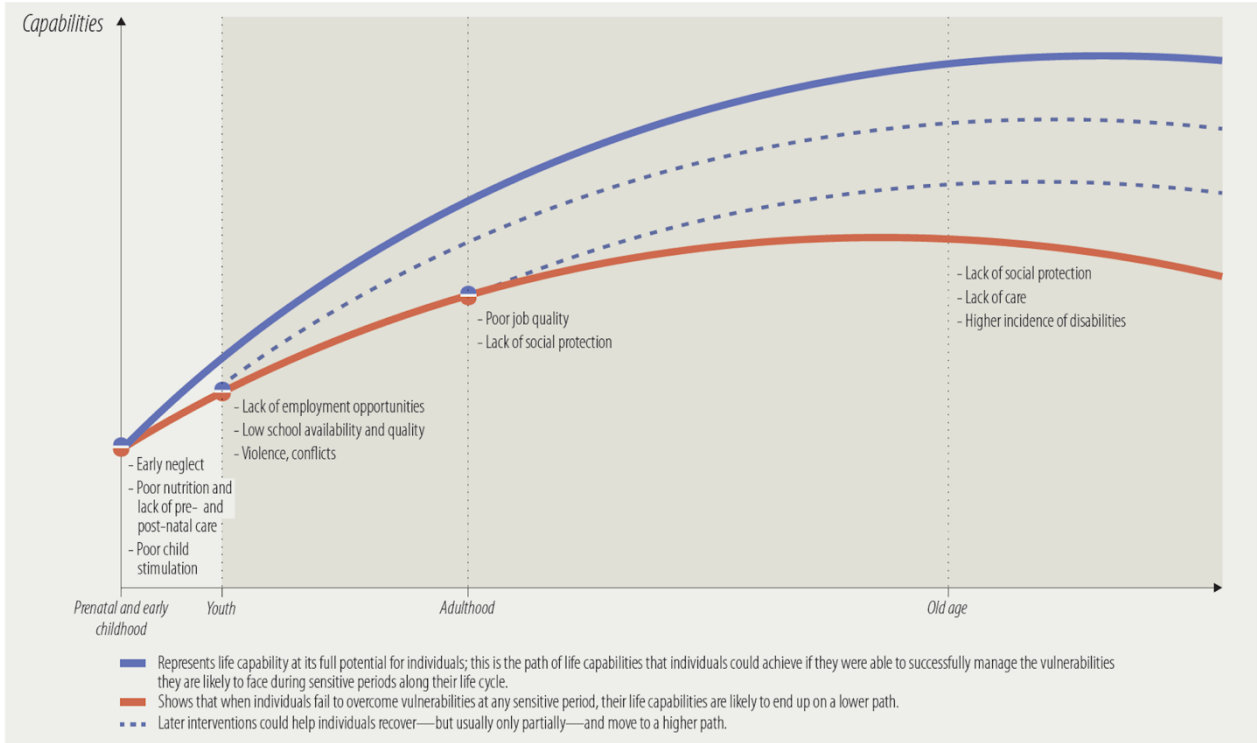
Conclusion

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.

Background

According to the DSM-V,^[1] neurodevelopmental disorders are a group of conditions with onset in the developmental period, continuing throughout an individual’s lifetime. The disorders typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. This can affect a person’s emotions and memory, as well as his or her ability to learn, socialize, and maintain self-control. The range of developmental deficits varies from very specific limitations of learning or control of executive functions to global impairments of social skills or intelligence. Autism Spectrum Disorder (ASD) and Neurodevelopmental Disorders (NDDs) not only challenge the life of the individual, but also significantly impacts the emotional, social and economic well-being of the family.

There is sufficient evidence researched all over the world that indicates that persons with disabilities (PWDs) are often more prone to suffering economic and social difficulties, and are at a greater risk of poverty. In developing countries, particularly for those living in poverty, the situation is further compounded by poor infrastructure, shortage of trained professionals, lack of reliable data, limited intervention programs, and research and training centers. Existing services often lack standardization in both management modalities and capacity of professionals, are limited to urban settings, and usually beyond the financial reach of most families.



Source: Human Development Report Office calculations.

Source: Human Development Report 2014, UNDP

In addition to constraining their lives, exclusion of PWDs has a debilitating effect on the society as a whole. Studies have been conducted to gauge the severity of the impact of this exclusion on economies. As seen in the figure above from the UNDP Human Development Report (2014), it is evident that when investments in life capabilities occur earlier, the future prospects are better. Moreover, the World Bank estimated in 2008 the annual cost of disability in Bangladesh, computed from the forgone income of PWDs and their caregivers as a result of missing out on educational and employment opportunities, to be USD 1.2 billion – about 1.7% of GDP.^[2]

The World Health Organization has reported a global prevalence of Autism as 1 in 160 while recent studies in the United States and other countries point to much higher rates of occurrence. It is also estimated that more than 80% of adults with autism are unemployed. Employment opportunities for PWDs are often very limited in number and restrictive in nature (such as informal jobs). Rather, they are more likely to be ‘underemployed’ – with low salaries, part-time jobs and a minimal scope for career advancement. Current approach for autism and other neurodevelopmental disabilities is gradually shifting from a welfare approach to a more right-based approach. A lack of coordinated action from governments, which address issues throughout the individual’s life, results in further marginalization and exclusion and increase their vulnerability. In order to ensure that the needs of persons with ASD and NDDs are being met, it is vital to ensure that their life-course needs are being properly addressed.

[1] American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5. Washington, D.C: American Psychiatric Association.

[2] The World Bank, Project Appraisal Document on a Proposed Credit to the People’s Republic of Bangladesh for a Disability and Children-at-Risk project (2008).

Introduction

The International Conference on Autism & Neurodevelopmental Disorders 2017 (ANDD2017), 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.

The overall theme of the Conference was **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:

- 4) 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
- 5) Sharing and learning best practices for national-level development and deployment of programs
- 6) Promoting cooperation and partnerships for development of effective and sustainable programs

The 3-day Conference consisted of thematic panel discussions on community based services for achieving **early identification**, delivering **interventions**, developing comprehensive and supportive **education** programs; **employment** opportunities and training; and ensuring rights and **supported independent living** for individuals with autism and other neurodevelopmental disorders in the community.

Each panel consisted of speakers who were researchers, practitioners, academics, self-advocates and parents. ANDD2017 also featured a high-level discussion, a special session highlighting self-advocates, a roundtable discussion on WHO-SEARO's Collaborative Framework for addressing Autism Spectrum Disorder in the South-East Asia Region, and adoption of the Thimphu Declaration. Additionally, there was a poster display showcasing the work of self-advocates, latest research and interventions, and the work of different organizations, amongst others. The posters of the self-advocates who did not have an opportunity to speak at ANDD2017 are attached in Annex 2.

Inaugural Ceremony



ANDD2017 Opening Ceremony

The inaugural ceremony of the Conference on 19th April 2017, began with the traditional Marchang Ceremony welcoming the distinguished guests from around the world to the Royal Banquet Hall in Thimphu, Bhutan. Her Majesty Gyaltsuen Jetsun Pema Wangchuck, Queen of the Kingdom of Bhutan, wife of the fifth King Jigme Khesar Namgyel Wangchuk, was present at the inaugural session along with Her Excellency, Sheikh Hasina, Honorable Prime Minister of the People's Republic of Bangladesh, His Excellency DASHO Tshering Tobgay, Honorable Prime Minister of the Royal Government of Bhutan, and Dr. Poonam Khetrpal Singh, Regional Director, WHO-SEARO along with other distinguished guests and participants. Following the Marchang Ceremony, the Honorable Minister of Health, Bhutan delivered the welcome address, Dr. Poonam Khetrpal Singh, Regional Director, WHO-SEARO, delivered a speech as Special Guest, and Ms. Chhimi Lhaden, a parent, provided insight into her life's story of triumphs and struggles while raising a child with autism in Bhutan.

The keynote presentation by Dr. Yolanda Liliana Mayo Ortega set the tone for the 3-day Conference of nearly 300 attendees from 31 countries. A renowned expert on autism research and intervention, with experience spanning almost four decades, Dr. Ortega from Peru is the Founder and Executive Director of Centro Ann Sullivan del Peru (CASP). Her presentation titled, *'The power of two: families and professionals working as partners for children with autism to become independent, productive and happy'* was about CASP's model, that of a partnership fostered between professionals and families in order to enable individuals to become self-dependent contributing members of their community. CASP addresses all life-course needs through their work, and as a result of many years of continuous training, CASP families are now creating a multiplicative effect by training other families across Peru through the Mother-to-Mother Program and internationally through Long Distance Education. Dr.



Keynote presentation by Dr. Mayo

Ortega's is a success story of a model that is replicable in all resource settings, and the presentation left the delegates feeling inspired.

Dr. Yolanda Liliana Mayo Ortega's presentation was followed by a speech from the Honorable Prime Minister of Bhutan and the address by the Guest of Honor, Sheikh Hasina, Honorable Prime Minister of Bangladesh. Additionally, Her Majesty, the Gyaltshen launched a book titled, "*Guideline for Differently Abled Friendly Construction*" published by the Ministry of Works and Human Settlement, Royal Government of Bhutan. The book aims to provide a comprehensive guideline in the design of new facilities, to remodel existing structures to enable use by differently abled people in Bhutan. The inaugural ceremony concluded with a vote of thanks to all the Conference participants, delivered by the Honorable Health Secretary of the People's Republic of Bangladesh, Md. Sirazul Islam.

Session 1: High Level Discussion

Enabling countries to successfully address autism and other neurodevelopmental disorders as part of their Sustainable Development Goals

Chair: Sheikh Hasina, Honorable Prime Minister, People's Republic of Bangladesh

Co-Chair: Dr. Poonam Khetrpal Singh, Regional Director, WHO Regional Office for South-East Asia

Moderator: Saima Hossain, Chairperson, National Advisory Committee for Autism & NDDs, Bangladesh

Keynote Speaker:

- Evelyn Cherow, *Founder & CEO, GlobalPartnersUnited, USA*

Speakers:

- Dr. Michael J. Klag, *Dean of the Bloomberg School of Public Health, Johns Hopkins University, USA*
- Prof. Atif Rahman, *Professor of Child Psychiatry, University of Liverpool, UK*

Remarks by:

- Nestor Fernando Santiago, *Assistant Secretary, Department of Health, Republic of the Philippines*
- Maria Nenett Motus, *Regional Director, IOM, Regional Office for the Asia & the Pacific*
- Miwa Kato, *Regional Director for Asia, UN Women*
- Valerie Cliff, *Deputy Regional Director for the Asia & the Pacific, UNDP*
- Dr. Gowher Rizvi, *Advisor to the Honorable Prime Minister of Bangladesh on International Affairs*
- H.E. Marcia Bernicat, *Ambassador, United States of America to Bangladesh*
- H.E. AHN Seong-doo, *Ambassador, Republic of Korea to Bangladesh*
- Rudolf Schwenk, *UNICEF Country Representative, Bhutan*
- Prof. Cui Yonghua, *Director, Pediatrics, Beijing An Ding Hospital*
- Dr. Kimihoto Harada, *Research Director & Head of Center, National Institute of Special Education, Japan*
- Irmgarda Kasinskaite-Buddeberg, *Programme Specialist (Knowledge Societies Division), UNESCO*
- Dr. Thaksaphon Thamarangsi, *Director (Non-communicable Diseases & Environmental Health), WHO-SEARO*

Key Points:

1. Inclusive, **cross-sectoral policies** need to be developed and implemented. The policies and subsequent plans should include education, health, labour, and other sectors, taking into account that ASD and other NDDs affect persons' whole lives, not just childhood.
2. **Innovative** approaches using new technologies can be used in developing effective plans for intervention.
3. **Barriers** include funding, political will and commitment, stigma attached to those who have ASD or other NDDs.

The high level discussion (HLD) focused on our common aspirations and provided a direction for the discussion of the three days. The powerful remarks by the speakers paved the path for an effective way forward so that children and adults with NDDs can be included in the global development agenda.

The HLD was chaired by Sheikh Hasina, Honorable Prime Minister of the People's Republic of Bangladesh, co-chaired by Dr. Poonam Khetrpal Singh, Regional Director, WHO Regional Office for South-East Asia, and moderated by Saima Hossain, Chairperson of National Advisory Committee for Autism and NDDs, Bangladesh and WHO Goodwill Ambassador for Autism in the South-East Asia Region.

In her opening remarks, Prime Minister Sheikh Hasina highlighted the importance of formulating an integrated approach for inclusive development. She stated that NDDs are a complex issue that affects social, educational, professional, human rights, and also the development of community and country. She suggested that attendees make recommendations in line with the 2030 SDGs.

The keynote speaker Ms. Evelyn Cherow, founder and CEO of GlobalPartnersUnited and former advisor to US federal agencies such as CDC, NIH and FDA on disability federal policies in education, health, early identification, and social security, presented on *health systems and the use of ICT (Early Intervention and Early Childhood Development for children and families)*. Speaking in the context of SDGs, the talk focused on the importance of cross-sectoral systems for inclusive development. Effective use of technology through e-health, m-health, and telehealth, can benefit children and adults with disabilities, positively impacting the global economy. Existing barriers to technology, namely, weak ICT infrastructure in rural areas, cultural and gender divide, and limited awareness, coupled with the lack of finances, enabling political environment,



ANDD2017 High Level Discussion

leadership, coordination, and standardized monitoring and evaluation practices, have prevented effective utilization of technology.

She stated that it is crucial to develop a societal inclusion model of development through the use of technology in a mass scale, along with disaggregated data, which can enable us to create effective partnerships between different sectors whose work addresses various aspects of autism and other NDDs.

Following Evelyn Cherow's presentation, there was a video message from Dr. Michael J. Klag, Dean of the Bloomberg School of Public Health, Johns Hopkins University, and a presentation by Prof. Atif Rahman, Professor of Child Psychiatry, University of Liverpool, on service provision for disability, focusing on over-burdened health-systems, highlighting the role of community, technology and practitioners.

While each high-level delegate spoke on the basis of their work contexts and constituencies, there were common threads running through their speeches. 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 promote inclusion for those with autism and other neurodevelopmental disorders was stressed upon. Speakers illustrated ways their respective countries or organizations were addressing autism and other neurodevelopmental disorders through policy advocacy and implementation in general and specific sectors. For example, Dr. Nestor Fernando Santiago, Assistant Secretary, Department of Health of the Philippines, spoke about the resolutions on e-health passed by the government to reach remote island populations through telemedicine, while Dr. Irmgarda Kasinskaite-Buddeberg spoke about UNESCO's model for combining policies in education and policies in ICT, accessible training for people with disabilities, and universal access to information, data, and research results. Dr. Kimihoto Harada of the National Institute of Special Education in Japan spoke about the institute which promotes the need for special education for development, while Korean Ambassador to Bangladesh AHN Seong-doo spoke about Korea's work at both home and abroad to address ASD and NDDs including the development of a unique intervention model and providing support to other countries to take forward their agenda in this sector.

The role of family members and communities in helping people with disabilities integrate into society as stated in Dr. Ortega's presentation, was echoed by a number of speakers at the HLD who stressed upon the need for partnerships between various stakeholders. Additionally, political commitment, the need to eradicate stigma, fostering of leadership, promoting diversity, the need to incorporate ASD and NDD component in organizational plans, and the need for funding, was discussed in detail during this session

Session 2

*Community-based services for achieving **early identification** of autism and other neurodevelopmental disorders*

Chair: Lyonpo Tandin Wangchuk, Minister of Health, Royal Government of Bhutan

Co-Chair: Dr. Kinley Tshering, Paediatrician, Military Hospital, Royal Bhutan Army

Moderator: Evelyn Cherow, GlobalPartnersUnited, USA

Speakers:

- Dr. Andy Shih, *Autism Speaks, USA*
- Prof. Cheryl Dissanayake, *Olga Tennison Autism Research Centre, La Trobe University, Australia*
- Prof. Sheffali Gulati, *All India Institute of Medical Sciences (AIIMS), India*
- Dr. Yoriko Nishizawa, *Jigme Dorji Wangchuck National Referral Hospital (JDWNRH), Bhutan*
- Dr. Lola Nasriddinova, *IRODA, Tajikistan*
- Dr. Nahid Chowdhury, *parent and medical doctor, UK*
- Prof S. C. Girimaji, *National Institute of Mental Health and Neuro Sciences (NIMHANS), India*
- Prof. Smita Deshpande, *Post Graduate Institute of Medical Education, India*

Key Points:

1. Screening for disability needs to be part of a regular **child development and monitoring** program
2. Early identification tools need to be **age-specific**
3. While it is important to take cultural aspects into account for intervention tools, **screening** can be universal since the presentation of ASD is same across cultures
4. It is very important to have a **multi-disciplinary team** involved in the overall screening and diagnostic process

The objective of the session was for experts on the panel to discuss how identification can be conducted in the community level at the earliest stages. This is on the premise that neurodevelopmental disorders are a group of conditions with onset in the early developmental period. Although ASD may not be diagnosable until later, developmental deficits can be recognized and adequate intense interventions can positively improve brain functioning.

The Chair illustrated the way health care in Bhutan is delivered through a three-tiered service delivery method encompassing Outreach Clinics to Basic Health Units at the primary level, district hospitals at secondary level, and the regional and national referral hospitals at the tertiary level. Teams of pediatricians and physiotherapists in district hospitals assess children.

The panel was split into two separate sessions, with the first focusing on **Screening vs Diagnostic Evaluation** and the second on **Screening and Diagnosis through the Health System**.

Questions during the guided discussion to speakers encompassed research, development of universal diagnostic tools and the universal definition of early identification, early markers for ASD, and challenges faced in screening and assessment.

While ongoing research has provided many answers, especially in relation to genes and environmental factors to ASD, there is still much left to know. Research



ANDD2017 Participants at Session 2

helps in screening and diagnostics as illustrated by Dr. Gulati who had been involved in developing two screening tools for neurodevelopmental disorders. While cultural aspects have to be incorporated in intervention tools, screening can be universal since presentation of ASD is same across cultures. This was stated by Dr. Dissanayake, who also said that early identification tools need to be age specific. Dr. Yoriko's response was Bhutan-specific, illustrating particularly the challenges faced in screening and evaluation, which include human resource constraints, geographical accessibility, ASD and NDDs being an invisible disorder, etc. The parent-experts on the panels spoke about early detection, navigating the support systems, and taking steps to address ASD and NDDs, from the parents' perspectives. Personal experiences recounted showed the different ways to reach out to parents, and that the steps parents took after their child was diagnosed were unique to their situation. Additionally, practitioners gave practical information on the relationship between seizures and autism and the importance of early screening.

The influence of cultural beliefs and attitudes play a role in how autism is perceived amongst people. South-East Asia region's "wait and see, the child will grow out of it with time" attitude often delay the early identification process.