

Technical workshops

ANDD2017 had eleven technical workshops conducted by experts from Bangladesh, India, South Korea, Malaysia, United States, Singapore and Australia on intervention models, regional adaptation of education and intervention models, and research opportunities and best practices. The technical workshops were held at the Faculty of Public Health and Nursing, National Institute of Traditional Medicine, Faculty of Traditional Medicine and the Royal Banquet Hall; these institutions provided the venues to the ANDD2017 Organizers out of courtesy. The participants had the opportunity to learn about recent developments in the field of ASD and NDDs as well as network and discuss plans for possible collaborations. Along with international delegates, the majority of the workshop participants were Bhutanese health workers and teachers from all parts of the country. The workshops were designed to give a brief overview of these programs and not to develop expertise.

Day 1 Workshops

The Indian Scale for Disability Assessment: the AIIMS Assessment Tool

by Professor Sheffali Gulati

Prof. Gulati provided an outline of the development and key features of the new All India Institute of Medical Sciences (AIIMS) assessment tool at this workshop. AIIMS modified the existing INDT-ASD (International Clinical Epidemiology Network [INCLEN] diagnostic tool for autism spectrum disorder), as per DSM-5 specifications. This new AIIMS Modified INDT-ASD tool has two sections (Section A and Section B). Section A has 28 questions to address 7 items (3 items in the domain of social interaction/communication along with 4 items in the domain of restrictive/repetitive behavior). Section B has analysis of items in Section A. In addition, Section B has two mandatory items of onset at early development and impairment in daily functioning that is a prerequisite for the diagnosis of “autism spectrum disorder”. The AIIMS Modified INDT-ASD Tool was validated in 225 children in the age group 1 to 14 years, and was noted to have a sensitivity of 98.4% and specificity of 91.8%.

Establishment of Child Development Centers across Bangladesh: sharing technology and experiences

by Professor Naila Zaman Khan

Prof. Khan provided participants with an overview of services which can be adapted in countries with limited expertise and low resources for children with neurodevelopmental disorders including autism, at all levels of health-care, by presenting the Bangladesh model of Child Development Centers (CDCs). During her workshop, Prof. Khan emphasized that the institutionalization of early childhood development services within Departments of Pediatrics was critical to sustainability. Establishing early childhood development services within the health sector enabled rapid and extensive reach, especially to poor children early in life. As services were

developed within CDCs, the focus shifted more to the quality of care being provided rather than the number of children being seen. Many children from privileged backgrounds, especially children with autism were failing to avail services in the public system. To achieve greater equity of service provision, it was necessary to also establish services within private health facilities where higher-income level families receive care. A tiered system of referral from home-based screening to community and clinic-based functional assessments to CDC-based diagnostic workups is in the process of being scaled up, and is necessary to extend the reach of the CDC network into the rural communities.

Current Clinical Practice of Autism Spectrum Disorder in South Korea

by Professor Lee Moon-Soo & Professor Yang Daniel Moonbong

During the workshop, Professor Lee and Professor Yang presented the current situation of clinical practice of autism spectrum disorder (ASD) in South Korea and shared their experience of building the network for ASD in their country. Previously, services for ASD was mainly provided by the non-government and private sector in South Korea but the situation has changed and it is now recognized as an important issue. This was reflected by the



Prof. Lee & Prof. Yang at the Workshop

change in the Government's health policies, strengthened laws and improved access to care for persons with ASD. These efforts included early detection, providing managed care and working towards creating an autism-friendly environment. The Government now provides nation-wide developmental screening in the clinics. However, the lack of skilled resources for the care of ASD is still one of the major problems in South Korea. The Korean Ministry of Health and Welfare now focuses on the lack of essential qualified professionals and works towards increasing public-sector investment to provide quality standardized care for persons with ASD.

Session 3

*Community-based models for delivering **interventions** to individuals with neurodevelopmental disorders and their families*

Chair: Mohamed Cassim Mohamed Faizal, Deputy Minister of Health and Nutrition and Indigenous Medicine, Sri Lanka

Co-Chair: Nasima Begum, Secretary, Ministry of Women and Children Affairs, Bangladesh

Moderator: Afsar Hossain, Barrister, A Hossain & Associates

Speakers:

- Prof. Hasnah Toran, Permata Kurnia Center, Malaysia
- Prof. Naila Zaman Khan, Dhaka Children's Hospital, Bangladesh
- Dr. Panpimol Wipulakorn, Ministry of Public Health, Thailand
- Dr. Sunita Maleku Amatya, AutismCare Nepal Society, Nepal
- Dr. Gauri Divan, Sangath, India
- Prof. Giacomo Vivanti, AJ Drexel Autism Institute, USA
- Indrani Basu, Autism Society West Bengal, India
- Karma Lhaki, JDWNRH, Bhutan
- Dr. Vibha Krishnamurthy, UMMEEED, India

Key Points:

1. There should be a shift from clinical to a more **community-based approach**
2. Interventions should be **transdisciplinary** and incorporated directly into the health-system
3. All children should have an assessment of their **development**; low-income families should receive a child-plan allowance to enable this

Session 3 focused on best practices in interventions that have been successfully implemented at the community level. The session was divided into two panels: the first half focused on **models for intervention services** and the second half on **evidence-based intervention programs**.

The questions to speakers at the guided discussion were about existing programs adapted to specific cultural contexts and also to marginalised populations, overcoming barriers to inter-professional collaboration for early intervention, policy recommendations, low-resource effective intervention, early interventions' positive impact on reducing the burden of autism and NDDs on LMIC economies, and implementation strategies for inclusive education.



ANDD2017 Panelists at Session 3

While it was agreed that in intervention, a shift from clinical to community based approach where parents / primary caregivers are involved, is preferred, the cultural context needs to be incorporated in order to make the intervention more effective. Speakers shared their experiences as practitioners and parents from different countries including Malaysia, Bangladesh, Nepal, and Thailand. They discussed that interventions can be transdisciplinary, and the mechanism by which they can be

incorporated into the health system, especially in low-resource settings. One effective country model Dr. Wipulakorn described is in Thailand, where health volunteers in the village level are trained to use developmental tools, and know when to refer a child to community hospitals. The basic idea is that all children should have development assessment, and low-income families receive a child plan allowance to enable their participation. Early identification needs to be connected to intervention services of the community as much as possible.

In order to adapt interventions in specific cultural contexts, the speakers discussed that what is now needed, is an evaluation of the effectiveness of innovative methods to ensure replicability. The panelists agreed that for interventions to be more effective, countries need trained professionals such as teachers, health care workers, allied health professionals, and for them to work closely with not only persons with NDDs, but their families, and communities. They emphasized the need to shed the top-down medical model and involve families and communities.

Session 4

Education for individuals with autism and other neurodevelopmental disorders

Chair: Dr. Kimihoto Harada, Research Director & Head, Center for Promoting Inclusive Education, National Institute of Special Education, Japan

Co-Chair: Dr. Somporn Warnset, Director, Center for Special Education, Ministry of Education, Thailand

Moderator: Aloka Guha, Former Chairperson, National Trust for Persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disability, Ministry of Social Justice & Empowerment, India

Speakers:

- Prof. Connie Kasari, UCLA, USA
- Eileen Chew, Lazarus Center, Singapore
- Erlinda Borromeo, Autism Hearts Foundation, Philippines
- Dr. Fahmida Chowdhury, FARE, Bangladesh
- Joanne Byron, School District of Palm Beach County, USA
- Merry Barua, Action for Autism, India
- Dr. Stephen Shore, Adelphi University, USA

Key Points:

1. **Learning strategies** for children with ASD need to be experiential, fun, and motivating
2. It is key to identify a child's **strengths** and **abilities** and foster that for the future
3. Intervention should not be in isolation, but **integrated** in different spaces such as schools, playgrounds, conducted through professionals, teachers, parents
4. Education for children with ASD extends **beyond school** and into homes

Individuals with autism and other NDDs have varying levels of skills and benefit from maximum time spent with same-age typically functioning peers. The experts featured in this session were asked questions about various models for appropriate education opportunities and the resources required for inclusion of individuals with NDDs in all settings.

During this discussion, the experts opined that learning strategies for children with ASD need to be made experiential and the learning environment should be fun and motivating. Additionally, parents need to help the teachers by feeding them regular information about behavioral changes and state of mind of their children. Conversely, children with ASD should not shy away from the label of their disability but rather embrace it so that they can self-advocate for their rights and needs as well as figure out how best they could learn in school.

Transitioning for children with ASD truly begins at around four years of age when one can begin to identify a child's strengths and abilities that could one day lead to a future hobby or area of study/employment. A successful choice of study/employment is one where the individual with ASD has found something he likes to do, is good at it and has enthusiasm for it. The ultimate objective is to go from awareness to acceptance and finally to appreciation; when people with ASD are truly valued for who they are and, more importantly, for what they are capable of contributing to society.

In addition to in-school learning, pairing a child with ASD with a typically-developing peer as a shadow friend who could support and accompany him/her at any time allows for more social imitation/modeling, which is a highly instrumental way for a child to learn. Interventions can be used to improve peer relationships for children



ANDD2017 Panelists at Session 4

with ASD by, for instance, engaging them in interest-based activities where they could work together. Moreover, although parents in this part of the world prefer for their children with ASD to get their therapy in privacy, it would be more beneficial for those children to have access to therapeutic equipment in places like playgrounds and modified schools/classrooms. Post-secondary educational institutes also need to have qualified support persons to assist students with ASD to answer questions, allay fears and confusion, and deal with difficulties like bullying.

Finally, education for children with ASD extends beyond school and into their homes where parents have the potential to make a huge improvement in their children by enhancing their social interaction and communication. They can do so, rather than over-focusing on the bad

behavior, by picking up on the good behavior and show children that they could get access to reinforcement and attention by doing the good things they want to do. It is also very important that parents positively empower their children first, by not outwardly projecting any embarrassment they have about them and secondly, by not imposing their own life expectations on them.

Day 2 Workshops

Promoting the Identification of Autism in Infants and Toddlers: Social Attention and Communication Study (SACS)

by Professor Cheryl Dissanayake

Research into the effect of early experiences particularly, socio-linguistic inputs on brain development in children has led the American Academy of Pediatrics to recommend that all children be monitored for brain development from 12 months onwards. Yet, despite being a developed nation, the average age at which ASD is diagnosed in Australia is 49 months, whereas only 3% of children with ASD are diagnosed before 24 months. Prof. Dissanayake's work is about bringing down the age of diagnosis to as low as possible in order to enable access to early interventions before the end of a child's developmental period. While researchers are convinced that there is indeed a strong genetic component to this disorder, they are still unclear about the exact underlying neuropathologies behind it, which also vary from person to person. This makes diagnosis difficult because there is no one single behaviour that definitively indicates that a person has ASD. Therefore, diagnosis of ASD still relies on behavioral presentation and developmental history, which can be difficult and lead to delayed diagnoses because behavioral expression varies from child to child. The research findings presented by Prof. Dissanayake during her workshop showed that early identification and diagnosis, in enabling access to early intervention, can alter the developmental trajectories of children with autism enhancing their developmental opportunities.

Early Intervention in Education based Settings: the Jasper Model

by Professor Connie Kasari

Prof. Kasari during her workshop introduced the JASPER model – Joint Attention, Symbolic Play, Engagement & Regulation. JASPER is a comprehensive social communication model that can be added into existing preschool programs for children with autism spectrum disorder. Multiple randomized trials have demonstrated that JASPER can improve



Prof. Kasari at her Workshop on Day 2

children's social communication, play and language abilities. Research has targeted parents, teachers and therapists for delivering JASPER. A focus of research has been on children who are preverbal (young children not yet talking) as well as older, school aged children who are still nonverbal or minimally verbal. For minimally verbal children, JASPER includes augmentation with a speech generating device. Prof. Kasari's talk focused on school-based interventions with teachers and assistants delivering the intervention in small groups or individually. The specific assessment of intervention targets were described by Prof. Kasari, using the Short Play and Communication Evaluation (SPACE), as well as the strategies that teachers can use to improve joint attention, joint engagement and play in their children. Strategies include environmental arrangement incorporating appropriate teaching targets and materials, development of play routines, expansion of play and language, behavior regulation, and techniques for improving gesture use. The workshop aimed to enable participants to identify intervention targets in their children using SPACE, while also providing them with an outline of two to three strategies that would help them to improve communication outcomes.

Service Development in Malaysia by PERMATA Kurnia

by Professor Hasnah Toran

Prof. Toran provided an overview of the current service development model in Malaysia during her workshop. In particular, she spoke about PERMATA Kurnia, a new initiative under the PERMATA program, Prime Minister's Department, that provides specifically designed comprehensive early intervention for children with autism and their families. The objectives of this center is to educate children with autism to become independent, contributing members of society, empower parents to enable them to provide appropriate care-giving to nurture their children's development, provide training and consultation to teachers and therapists on evidence-based strategies in educating children with autism, heighten public awareness on autism and the challenges faced by individuals with autism and their families, and to become the model demonstration centre for future centers throughout the country. Three services are offered in PERMATA Kurnia; Pre-School Program, Early Intervention, and Family Support Program and Community Education Program. Currently 300 children with autism are enrolled in this center; 120 in the Preschool Program and 180 in the Early Intervention & Family Support Program.

Empowering Families and Community Workers for Early Communication Intervention in Bhutan

by Jean Ho

A speech and language therapist by profession, Ms. Jean Ho's workshop provided an introduction to language development for young children. The practical strategies to meet the communication needs of both non-verbal and verbal children with autism spectrum disorder (ASD) was discussed in detail. She also provided information on the caregiver training program that was successfully conducted in Bhutan in 2016 for families living with ASD. Feedback from the 5 families of Ability Bhutan Society (ABS) living with children with ASD who attended the caregiver training program in April 2016 acknowledged the benefits of the skills they acquired. The training program was a research-based, family-centred intervention program called More Than Words, established by The Hanen Centre in Toronto, Canada. Most significantly, all the participants recognized how they had personally changed the way they interacted with their children, and how this had in turn positively impacted on their children's communication. Ideas on how to use everyday routines and play activities as ways to maximize the children's opportunities to develop communication skills were also shared by Ms. Ho.

Side event: Meeting of Early Childhood Development Task Force

The Early Childhood Development Task Force (ECD TF) of the Global Partnership on Children with Disabilities (GPCWD), whose Secretariat is at UNICEF, held a meeting as a side event at ANDD2017 on the 2nd day of the Conference. At the open-to-all meeting, ECD TF members, Evelyn Cherow, Dr. Andy Shih, Prof. Naila Zaman Khan, Dr. Sylvia Choo, and Dr. Vibha Krishnamurthy, provided an overview of the ECD TF mission and



ANDD2017 Participants at the ECD TF Meeting

activities; representatives of UNICEF from Bhutan and Bangladesh participated and shared materials about program priorities; and participants discussed the inclusive ECD programs they have developed with colleagues in their respective countries (Bangladesh, Bhutan, Singapore, India, Indonesia, France).

The ECD Task Force serves as a network hub for an integrated ECD-ECI voice, and “connect-the-dots” between the UN Convention on the Rights of the Child (CRC) and the Convention on the Rights of People with Disabilities (CRPD) with advocacy for inclusive early childhood development (IECD). Further details of the taskforce and its work can be found in <http://www.gpcwd.org/early-childhood-development.html>.

Thimphu Declaration

A working group meeting on the Thimphu Declaration was held during lunchtime on the second day of ANDD2017. The meeting was attended by both regional and international experts, as well as self-advocate, Dr. Stephen Shore. Representatives from the Ministry of Foreign Affairs in both Bangladesh and Bhutan also participated in the meeting. WHO Goodwill Ambassador for Autism in the South-East Asia Region, Ms. Saima Hossain, along with Dr. Thaksaphon Thamarangsi and Dr. Nazneen Anwar from the World Health Organization were also in attendance. The overall content of the Declaration was prepared with input from all the members of the working group.



Participants at the Working Group Meeting on the Thimphu Declaration

Session 5A

Creating employment opportunities for individuals with autism and other neurodevelopmental disorders

Chair: Lyonpo Ngeema Sangay Tshempo, Minister of Labour and Human Resources, Royal Government of Bhutan

Co-Chair: Irmgarda Kasinskaite-Buddeberg, Program Specialist (Knowledge Societies Division), UNESCO

Moderator: Dr. Vibha Krishnamurthy of UMMEED Child Development Center, India

Speakers:

- Daniel Giles, Self-advocate, Australia
- David Hoff, ICI, University of Massachusetts Boston, USA
- Farida Yesmin, DRRRA, Bangladesh
- Merry Barua, Action for Autism, India
- Dr. Wiranpat Kittitharaphan, Ministry of Public Health, Thailand
- Dr. Yolanda Liliana Mayo Ortega, CASP, Peru

Key Points:

1. Recognizing the **value** behind hiring people with autism and other NDDs will help improve the employment situation of persons with special needs
2. The education system should invest **more time** to help prepare those with disabilities to seek out and successfully gain employment
3. All stakeholders should work as a **team**, where professionals can act as middlemen, helping to match jobs with individuals
4. Families tend to invest in the more productive children, especially in low-income scenarios. Therefore, governments should help develop a strong program to enable persons with autism and other NDDs to become **productive citizens**

The fifth and last panel discussion of ANDD2017 was further divided into two sub-panels. The first half of the session focused on **employment** and the second half on **supported independent living**. The panelists consisted of self-advocate, practitioners and parent-experts, amongst others.

The questions asked to the panelists were about challenges they feel persons with ASD and NDDs face in obtaining and holding down jobs, and what type of support from governments, parents and siblings, schools, and employers encourage employers to employ those with ASD and NDDs. Additionally, various models of employment training were discussed with input from different perspectives including self-advocate and long-term service provider. Daniel Giles suggested that an understanding of autism and other special needs by employers, recognizing the value behind employing people with ASD, and preparing employees on how to interact with fellow colleagues in the workplace will all help improve the employment situation of people with special needs.



ANDD2017 Panelists at Session 5A

“It is important to be able to find a niche for skills and talents and work with that in a productive manner.”

Daniel Giles
Self-advocate

The importance of gainful employment was highlighted by panelists who said that to ensure PwNDDs’ ability to remain employed, along with skills development, employers need to be shown the financial

and social value of employing persons with ASD and NDDs. This discussion with the panelists highlighted some of the key points directed at governments, employers, service-providers, family, and other support structures.

Speakers emphasized on the need for government interventions, and having a national policy which address the needs of not only those who are physically disabled, but those with invisible disorders such as ASD.

Governments typically are the largest employers in most countries, so were urged to employ persons with NDDs, thus, leading by example and critically addressing the low employment rate in this group. Speakers from Australia and Thailand gave examples of existing regulations in their countries put in place by their governments, which encourage employers to employ special needs persons. It was acknowledged that inclusive employment policy, incentives, and highlighting to employers the value of employing PwNDDs may be more beneficial than punitive action, as punitive measures often lead to negative attitude towards PwNDDs.

It was discussed that in order to be successfully employed, what is needed is preparation for employment from an early age. Employment like any other life-course need cannot be addressed in isolation. Persons with ASD and NDDs require support to find jobs, and learn skills. Capacity based on one's strengths and abilities need to be built from early in life, much before the person is old enough to join the workforce. The main reasons that there are low employment rates among those with NDDs are poor practical skills, bad job matching, and poor social skills.

The support system for PwNDDs are their families, caregivers, teachers, and support service providers. Teachers and the education system should play a vital role to help them set a plan for life, education, and career path, including training and empowerment programmes. Experts suggested that in preparation for future employment, basic life skills such as self-care, manners, basic social skills, communication skills, ways to handle money, etc. should all be taught. The education system should also invest more time to help prepare those with disabilities to gain employment.

It was recommended that along with incentives and encouragement, employers need to be made aware of the value added by employing people with NDDs, and an effective way to do that is to have employers speak to each other. They should be made to understand that minor modifications can go a long way, and learn how to adapt, how to communicate and work with persons with ASD and other NDDs. All stakeholders should work as a team, where professionals can act as middlemen, helping to match jobs with individuals.

Session 5B

Facilitating supported independent living for individuals with autism and other neurodevelopmental disorders

Chair: Mahinda Senevirathna, Secretary, Ministry of Social Empowerment and Welfare, Sri Lanka

Co-Chair: Md. Zillar Rahman, Secretary, Ministry of Social Welfare, Bangladesh

Moderator: Dr. Muhammad Waqar Azeem, Chair, National Autism Plan Working Group, Qatar

Speakers:

- Aloka Guha, Expert, India
- Prof. M. Golam Rabbani, NDD Trust, Bangladesh
- Karen Purdie, IRODA, Tajikistan
- Michael Rosanoff, Columbia University, USA
- Qazi Fazli Azeem, KITE, Pakistan
- Sajida Rahman Danny, PFDA Vocational Training Center, Bangladesh
- Zsuzsanna Szilvasy, Autism-Europe, Hungary

Key Points:

1. Needs of individuals are **different** so no “one size fits all” definition for independent living will necessarily work, which brings up the need for thinking in innovative rather than traditional ways
2. **Community based** solutions need to be developed to accommodate the varied needs of people with ASD and NDDs, to enable them to have a fulfilling life
3. There are not enough **comprehensive** programs for adult PwNDDs, especially those who are not employed and live with aging parents or caregivers
4. Formal structures such as the **Neurodevelopmental Disability Protection Trust** in Bangladesh, help raise awareness, wider acceptance, inclusion in developmental schemes, in addition to ensuring basic services are provided on a priority basis
5. **Barriers** to comprehensive programs for adults include stigma, funding, human resource constraints, lack of trained professionals and knowledge, and truly effective support services

The second part of the fifth session of the Conference focused on the topic of *supported independent living for individuals with autism and other NDDs*. The questions for the panelists were focused on country-specific programs in Bangladesh, Pakistan, and Hungary, and their impact on PwNDDs. Experts were asked about what they felt the barriers to institutions functioning effectively are, and what the specific cultural influences in shaping opportunities for independent living are.

Independent living is intimately intertwined with quality of life. The speakers at the session explained country initiatives taken to improve the lives of persons with ASD and NDDs. Prof. Golam Rabbani and Sajida Rahman Danny spoke about the Neurodevelopmental Disability Protection Trust in Bangladesh and the NDD Protection Trust Act, and its impact on the lives of persons with ASD and other NDDs.



ANDD2017 Panelists at Session 5B

There has been greater awareness, wider acceptance, inclusion in developmental schemes, formation of health insurance, priority healthcare up till tertiary level, priority in receiving government services, and others.

The Act has expanded the horizon of services for PwNDDs, and addresses it from a rights-based perspective. In addition to services that can be availed, and greater awareness and increased acceptance, what the Act has truly done is legitimized PwNDDs as citizens who have rights. The NDD Protection Trust has ensured that professional healthcare providers receive training on NDDs in order to provide the services effectively, and have a call center to provide assistance to PwNDDs and their caregivers in the event of physical and psychological distress and emergencies. NDD Trust's work is in coordination with the Ministry of Health and Family Welfare in Bangladesh.

While services and awareness raising programs are in place in many areas helping a large number of people, panelists said that there are not enough comprehensive programs for adult PwNDDs, especially those who are not employed and live with aging parents or caregivers. This makes them a burden on their governments.

Generally, the difficulties adult PwNDDs face is that there are not enough support services for them. Needs of individuals are different so no one size definition for independent living will necessarily work, which brings up the need for thinking in innovative rather than traditional ways. Speakers suggested exploring community based solutions in this regard. It was stated that in terms of health, there is a need for public health policy that promotes knowledge based research and service delivery. Knowledge transfer, medical center establishment, diagnosis centers are all

required for bridging the gaps. Social media, and use of other technology can help, and speakers suggested to replicate models that are effectively in place in other countries.

It was stated that barriers to comprehensive programs for adults include stigma, funding, human resource constraints, lack of trained professionals and knowledge, support services that will truly help them to live independently and the belief that they may not need any assistance in daily living.

Day 3 Workshops

Clinical Identification of Neurodevelopmental Disorders in Bangladesh

by Professor Golam Rabbani, Professor Narayan Saha & Narsis Rahman

This workshop highlighted how neurodevelopmental disorders can be identified clinically in low resource settings. The speakers discussed the burden of neurodevelopmental disorders and the need for early and appropriate clinical identification. The discussion provided the participants with an idea about the role of the family, community and clinicians as potential contributors in the identification process of the disorders. The clinical features of common neurodevelopmental disorders based on the Diagnostic and Statistical Manual of Mental Disorders (DSM 5) was also discussed in detail. Moreover, the presenters showed a video demonstration of the common symptoms of these disorders in order for the better understanding of participants. There was also a live demonstration/role modeling on how early identification of a neurodevelopmental disorder can clinically be made. The workshop aimed to contribute in the clinical identification of neurodevelopmental disorders in the primary health care set up by increasing awareness regarding this issue.

Early Intervention using the Early Start Denver Model

by Professor Giacomo Vivanti

Prof. Vivanti's workshop focused on the principles, strategies and evidence base of the Early Start Denver Model (ESDM), an early intervention program designed to address symptoms of autism during infancy, toddlerhood and the preschool years. ESDM emphasizes the importance of providing intensive teaching, drawing from evidence-based educational strategies, individualizing the program, and addressing multiple developmental domains. The ESDM approach has a distinctive focus on early social-emotional engagement, social motivation and social learning as the framework for learning. Additionally, the ESDM includes specific procedures to individualize treatment goals so that the teaching program is built on each child's individual profile of strengths and weakness and ongoing monitoring of treatment response. The naturalistic framework of ESDM is based on the notion that teaching is more powerful when embedded in the context of the real-life daily routines, where the behaviors targeted by treatment would naturally take place. During the workshop, participants learnt about: (1) the principles and strategies of ESDM, (2) the different ways in which the ESDM can be delivered,

including group-based implementation and parent-implemented programs, (3) the differences and areas of overlap between ESDM and other early intervention approaches, and (4) recent research on the effectiveness and sustainability of ESDM.

Workshop on World Health Organization-Autism Speaks Parent Skills Training (PST) Program

by Dr. Shekhar Saxena & Dr. Andy Shih

Several evidence reviews suggest that parents can learn the skills needed to help their children improve behavior, social skills and communication, and that parent training programs lead to improved child development and family well-being (McConachie, 2007; Odom, 2010). Evidence further shows that non-specialists in community settings can effectively deliver parent training programs (Reichow et al, 2013). The WHO Mental Health Gap Action Programme (mhGAP) aims to expand services for mental, neurological, and substance use disorders in low- and middle-income countries. The programme recommends parent training for management of developmental disorders including autism, in the context of primary-health care and community-based services. For this reason, WHO, in collaboration with Autism Speaks, undertook a rigorous process to develop a parent skills training program. During the workshop, participants were provided with 1) a comprehensive overview of the context, rationale and process for program development and implementation, 2) an introduction to program structure, roles of stakeholders, adaptation process and monitoring and evaluation framework and 3) additional details and guidance to inform decisions to pilot and implement the program to enhance existing services.

Developing Practical Skills in Curriculum Adaptation for Inclusive Education

by Aloka Guha

Ms. Guha provided an introduction to Curriculum Adaptations for students with diverse needs; the What, the Why and the How of it. The Index for Inclusion by Tony Booth, 2011, was also discussed in detail. Participants were provided with an overview of Nine types of Adaptations, at school, classroom and individual levels, during the workshop. They were sensitized in making adaptations to actual lessons from primary classes, using Universal Design of Learning. The implications of some disabilities on particular learners, with specific reference to the teaching and learning of Mathematics, Science, Social Studies and English were also shared by Ms. Guha.

Session 6

Roundtable Discussion on *WHO's Collaborative Framework for Addressing Autism Spectrum Disorder in the South-East Asia Region*

Chair: Dr. Thaksaphon Thamarangsi, Director, Noncommunicable Diseases and Environmental Health, WHO-SEARO

Co-Chair: Dr. Samai Sirithongthaworn, Deputy Director General, Ministry of Public Health, Thailand

Moderator: Merry Barua, Action for Autism, India

Presentation by: Dr. Nazneen Anwar on *WHO-SEARO Collaborative Framework for addressing ASD in the South-East Asia Region*

Speakers:

- Ajmalul Hossain, QC, *A. Hossain & Associates, Bangladesh*
- Dr. Shekhar Saxena, *Director (Mental Health & Substance Abuse), WHO*
- Dr. Khalid Saeed, *Regional Advisor (Mental Health & Substance Abuse), WHO-EMRO*
- Jean Lieby, *Chief of Child Protection, UNICEF, Bangladesh*
- Prof. Cui Yonghua, *Director, Pediatrics, Beijing Anding Hospita, China*
- Dr. Muhammad Waqar Azeem, *Chair, National Autism Plan Working Group, Qatar*
- Prof. Lee Moon-soo, *Professor of Psychiatry, College of Medicine, Korea University*
- Dr. Swarna Wijetunge, *President, Sri Lanka Association of Child Development, Sri Lanka*
- Dr. Samir Dalwai, *National Chairperson, Indian Academy of Pediatrics, Chapter of Neurodevelopmental Disorders, India*
- Valerie Taylor, *Founder and Coordinator, Center for the Rehabilitation of the Paralysed, Bangladesh*
- Aloka Guha, *Former Chairperson, National Trust for Persons with Autism, Cerebral Palsy, Mental Retardation & Multiple Disability, Ministry of Social Justice & Empowerment, India*

Key Points:

1. **Collaboration** can happen in a number of ways; systematic inter-ministerial and inter-organizational collaboration at the international level, and inter-institutional and inter-sectoral collaboration within countries
2. There is extensive experience, and available tools in the field; these can be better utilized by collaboration on information systems and documents, developing networks within and across sectors, a **comprehensive strategy** to work together, and all-inclusive and collective capacity building
3. **Standardized**, evidence-based guidelines and practices, and strong laws supporting them and protecting the human rights of persons with ASD & NDD is necessary
4. Participants urged to focus on a shift to a **rights-based approach** and social model of care instead of the medical model of care

The objective of this discussion was to present a cost-effective systematic response that is structured, coordinated and feasible for low-resource countries. The discussion assisted in identifying partners and prioritizing goals for the South-East Asia region.

After the opening remarks by the Chair and Co-Chair, Dr. Nazneen Anwar presented a short overview of the WHO collaborative framework. She 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. She emphasized that WHO can help countries in collaborating with each other and international agencies; and provide technical support towards meeting a mutual agenda.



Dr. Nazneen Anwar presenting at the Round Table Discussion

Speaking on the WHO framework, Dr. Nazneen mentioned that it aims to: 1) strengthen advocacy, effective leadership and governance for Autism Spectrum Disorders (ASD); 2) provide comprehensive, integrated and responsive mental health and social care services in community-based settings for persons with ASD and their care-givers; 3) implement strategies to minimize disabilities associated with ASD and promotion of mental, social and physical health and well-being in persons with ASD; and 4) strengthen information systems, evidence and research for ASD. Dr. Anwar also stressed on the fact that it was in line with the Mental Health Action Plan