

Meeting of experts on community-based approaches to Autism

Bangkok, Thailand, 15-17 September, 2010

A Report



**World Health
Organization**

Regional Office for South-East Asia

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Executive summary

The WHO Regional Office for South-East Asia organized a meeting of Experts on Community-based Approaches to Autism in Bangkok from 15-17 September 2010. The meeting was inaugurated by Dr. Chatri Banchuin, Director General of Mental Health, Ministry of Public Health, Thailand. The meeting was chaired by Dr. R.K. Shrivastava, Director-General of Health Services, Ministry of Health and Family Welfare, Government of India.

Experts from seven Member States in the Region participated. The background of the participants included psychiatrists, developmental pediatricians, therapists, psychologists, psychiatric nurses, special educators, sociologists, academicians and three parents of children with autism.

The objective of the Meeting was to review the situation of autism in the Region, and to develop community-based approaches to the management of autism in the SEA Region from a public health perspective.

On day one, the participants were taken on a field visit, first to a rehabilitation special school, to a school with a policy of inclusive education, to a tertiary care psychiatric hospital caring mainly for autistic children, and finally to a district-level hospital where services are provided for autistic children from the surrounding areas. Participants were impressed with the quality and the range of services provided in every centre and the strong bi-directional linkages between them.

The second day's proceedings started with a review of the situation of autism in the Region followed by seven presentations on epidemiology, current research, on-going community-based projects, NGO activities, assessment tools developed, human resources development as a strategy, and public health challenges in autism.

The third day's proceedings consisted of group discussions on strategies for interventions and the development of an action plan for the development of community-based approaches to autism. Two pilot projects, one in India (multi-centric, funded by the Government of India) and the second one in Sri Lanka (funded by WRO, Sri Lanka) will be

developed/strengthened over the next one year with the objective of testing the efficacy of a community-based approach to identify children with developmental delay, followed by determination of the domain of delay. The second step in the community-based approach will be the development of a screening instrument for identification of autism in the primary health care setting, in Bangladesh, Maldives, Nepal and possibly in Indonesia. The specific interventions for children with autism include: primary prevention, early identification, early intervention, transition and adult care services.

Recommendations for governments include developing policy framework/legislation for early detection and community-based intervention strategies for autism; integrating advocacy/awareness campaigns and early detection of autism through the overall maternal and child care system; building capacity of all stakeholders, forging partnerships and promoting multi-sectoral linkages within the country.

Recommendations for WHO include establishing centres of excellence in the South-East Asia Region for training and capacity building in autism; developing technical guidelines for identification, interventions and best practices for autism; undertaking advocacy with governments and partner agencies for prioritizing autism within the public health agenda and promoting legislation and policy frameworks; and promoting applied operational research on the development of community-based approaches for the management of autism.

1. Background

There is increasing awareness among policy makers in Member States of the South-East Asia Region that the burden of disease from learning and behavioural disorders, including autism, is substantial and leads to suffering and morbidity among affected children and families. Thus, governments of Member States have requested technical support from the Regional Office for South-East Asia (SEARO) to develop programmes related to autism. This meeting was organized in response to these requests.

Traditionally, information used for development of public health programmes is mainly statistical data on prevalence, morbidity and mortality. In the context autism, quantitative information is limited in most countries of the South-East Asia Region and relevant qualitative information is even less. Even if such data were available, it would be quite insufficient to develop and implement public health problems. At this time, programme development should consider the reported increase in prevalence over time, paucity of services at the community level, primary and tertiary health care levels, the perceptions of communities, the diverse agencies involved, the initiatives already in place, and the current capacities and gaps that need to be filled. Autism-related programmes should not only be developed, strengthened and expedited, but also made contextual to the environments in which they will be implemented.

A situation review was undertaken first of the global situation of autism, as well as that of Member States in the South-East Asia Region. Analysis of the information received from focal points in governments through the WHO Country Offices in response to a questionnaire from the MHS Unit, has provided valuable inputs to the situation review. The review revealed that most extensive services in the Region were available in Thailand. Thus, it was decided to have the meeting in Bangkok to provide an opportunity to delegates to visit the training and service delivery services for autism.

In the South-East Asia Region, many languages, religions, ethnicities, cultural norms, geographic diversity, political ideologies and forms of government co-exist. This diversity leads to many variations in perceptions and programmes related to autism, not only between countries, but also

within countries. Traditional western models of urban, informed, health-seeking behaviour have not been commonly-observed in countries of this Region, due perhaps to the many exclusionary factors associated with the stigma related to autism and the lack of awareness among professionals, policy makers, families and civil society.

Moreover, large populations in this Region are rural-based. It has been observed from country reports at UNESCAP/JICA meetings on disability in 2003, that there is significantly higher prevalence of disability in general (3-5 times more) among the rural population in the Region as compared to the urban. When this factor is added to the scarcity of trained rehabilitation professionals in almost all Member States, then there is a strong case for the adoption of management approaches to autism which are community-based, and family-centred.

Therefore, initiatives to control and manage autism in this Region have to take into account all the above factors. A “one-size-fits-all” solution to this problem does not exist in the context of this Region, or in the context of a complex disorder like autism. Hence, care should be taken to ensure that interventions are tailored to the countries and communities being addressed. If this does not happen, the effectiveness and the efficiency of interventions are bound to suffer. It is imperative that policy makers, programme planners in government and other agencies responsible for dealing with autism at the country level have relevant information to design and implement programmes that are effective at the community level.

2. Proceedings

Day one was devoted to field visits.

Sataban Saeng Sawang Foundation Training Centre

The first visit was to a rehabilitation centre, the Sataban Saeng Sawang Foundation Training Centre for special education services, established in 1979. This centre is run by an NGO. Funds are obtained entirely from voluntary donations. The centre has a comprehensive range of rehabilitation services for children with diverse special needs (including mental retardation, cerebral palsy, Attention Deficit Hyperactivity Disorder,

autism and other learning and behavioural disorders). Sixty per cent of the students are those with autism, 20% are with Down syndrome, and 20% are with mixed diagnoses. The aim of the school is to prepare students for mainstream life. The higher-functioning students devoted their time to school-readiness programmes, the others towards improvements in functional outcomes including prevocational and vocational activities. Twenty students with autism from this centre have completed high school, some have entered university level courses and a few had found jobs in the open market. The school depends on Yuwaprasat Hospital, for professional support/guidance on technical matters. It is an outstanding facility for delivering comprehensive rehabilitative services to children with special needs. Delegates greatly appreciated the services being provided.

Implications for the Region

The model of strong linkages with a tertiary care hospital lends itself well to the development of high quality services. This bi-directional link between a government hospital and an NGO is an example of optimal utilization of limited resources in low-resourced settings.

Kasem Phittaya School

The second visit was to Kasem Phittaya School, Bangkok, a private school linked to (and mentored by) the Sataban Foundation and Yuwaprasat Hospital. Of a total of 1600 students, there are currently 88 children with special needs, integrated into curricular and co-curricular activities of the school. The school is an excellent example of inclusionary practices for mainstreaming of children with special needs into the regular educational system. The owners accept the additional cost of inclusive education as a part of their social responsibility and in keeping with their philosophy that all children need to be educated. The inclusive spirit of the school, almost palpably felt in the classrooms, and the parent-teacher partnerships, was a lesson for every participant. It was near-impossible to distinguish the special children from the others, so cohesive was the group.

Implications for the Region

- The school's philosophy of total inclusion in both curricular and co-curricular activities and their strategy for interactive learning processes is a model to be studied and adapted.
- The forward-backward linkages with the special school and the hospital help to support each other in their own areas of expertise.

Yuwaprasart Waithayopathum Child Psychiatric Hospital

The third visit was the Yuwaprasart Waithayopathum Child Psychiatric Hospital, which is one of the foremost tertiary care hospitals in Thailand, under the Department of Mental Health, Ministry of Public Health, devoted to providing comprehensive management to children identified as having autism. This hospital is under Royal patronage. The centre provides tertiary care clinical services for children with autism, consultation to other facilities, rehabilitation, treatment as well as training centre for psychiatrists and pediatricians. Highly advanced clinical and research work is conducted here. A wide range of multidisciplinary services are available including psychological testing, nursing services, gross and fine motor training, sensory stimulation, language and communication training, special education services, as well as art and rehabilitation therapy. There are inpatient and outpatient facilities for different age-groups and severity levels. There is also provision for home-based training through the empowerment of families/parents. The centre has developed a screening tool, Pervasive Development Disorders Social Quotient (PDDSQ), which is used as a screening tool for cases to be referred from all over Thailand. This hospital could serve as a centre of excellence for training delegates from other Member States in the South-East Asia Region where such facilities are not available.

Implications for the Region

This is a model of holistic care, medical and rehabilitative services which may be considered as an ideal model for SEAR:

- The quality, range, nature and scope of services in this hospital are outstanding.

- There is a commitment to, and respect for, a multidisciplinary approach.
- Understanding the need for early detection, and catering to holistic early intervention is the recommended approach to autism.
- The concept of pre-diagnosis intervention is particularly relevant to autism, where a diagnosis can be confirmed only at age 2-3 years, when the most critical period for development and learning-readiness for all children, is almost over.
- The parent-mediated model of intervention is also particularly relevant in countries where there is both a paucity of rehabilitation staff as well as availability/access to hospital-cum rehabilitation centres.

Bangplee District Hospital

The fourth visit was to Bangplee District Hospital, where basic diagnostic and treatment services for children with autism are available. The advantage is that it is located in the community so families do not have to travel far. This hospital is closely linked to the community-based primary health units (PHU) and provides regular mobile outreach programmes. They also screen for developmental delays in their well-baby clinics using the “pink book” which is a pictorial child development monitor. All parents in Thailand have this book, enabling them to suspect any variation from the norm. This encourages early and self-referrals of suspected cases of developmental delay.

Implications for the Region

- The concept of mobile technical units although desirable is resource intensive.
- A practical solution in low resource countries is the utilization of nursing staff in stimulation/intervention for developmentally delayed children.
- The practice of handing out pictorial IEC material to **all parents** through Maternal and Child Health programmes enables early

identification of children with any form of developmental delay, ensuring improved outcomes particularly for children with autism.

An important component of the diverse range of services in Thailand is the strong bi-directional linkage between the educational, rehabilitation and medical sectors which facilitates easy transitions for parents of children with autism.

Day Two: Opening session

The Chief Guest for the Inauguration was Dr. Chatri Banchuin, Director-General of Mental Health, Ministry of Public Health, Thailand. He stressed the importance of taking urgent action in addressing issues relating to the management of autism and appreciated SEARO's initiative to provide a forum for intra-regional sharing of experiences on autism. He highlighted the need of addressing autism as a public health issue in child psychiatry. He also stated that Thailand has recognized the problem for many years and established facilities to address the needs of autistic children.

Dr Vijay Chandra, Regional Adviser, Mental Health and Substance Abuse WHO SEARO welcomed the participants on behalf of WHO and appreciated the commitment of the Royal Thai Government on this issue and thanked them for hosting this meeting. He emphasized that there was a need for a public health and community-based approach to address this issue reaching out to all segments of the population.

Election of chair, co-chair and rapporteur

The Director-General of Health Services, Government of India, Dr. R.K. Shrivastava, was elected as Chairperson, Dr. Panpimol Wipulakorn, Director of Rajanukul Institute for Intellectual Disabilities, the Co-chairperson and Dr. Anoma Jayathillake, NPO, WHO Sri Lanka, was nominated as the Rapporteur.

Objectives of the meeting

Dr Vijay Chandra introduced the background and objectives of the meeting. The objective of this meeting was to review the situation of autism in the Region, and to develop community-based approaches to the management of autism in the Region from a public health perspective. It was a new and challenging subject and this meeting was therefore extremely important in suggesting the way forward in terms of integrating autism-specific services into the existing primary health care system.

In his opening remarks, Dr. Shrivastava stressed the need for developing models that can incorporate a public health approach with customized care which children with autism respond to best. Thus partnerships between government programmes, NGOs and family groups will be needed. He mentioned that although there was a vast amount of data from developed countries, data specific to the SEA Region is lacking. There was a belief that the prevalence of autism was as much, if not higher than in developed countries. The lack of data may explain the near-absence of awareness of the nature and burden of the disease. Therefore, there is a need for commitment from WHO to bring into focus the public health aspects of autism.

Dr. Panpimol Wipulakorn, spoke about the importance of this meeting in the context of the increasing burden due to autism and thanked SEARO for taking the initiative and the lead to assist Member States in Region to develop autism-related services.

The participants introduced themselves. They were from different fields including public health, psychiatry, developmental and neurological paediatrics, sociology, special and general education, psychology, nursing, academics and three parents of autistic children.

Presentations

Situation of autism in the SEA Region

In her presentation, Ms. Aloka Guha referred to the reported increase in global prevalence of autism, as per data available from the CDC, which showed that between 1960 and 1980 the prevalence was 1 in 2000 children, whereas since the availability of Diagnostic and Statistical Manual

of Mental Disorder (DSM IV) and International Classification of Diseases (ICD 10) in the 1990s, there has been a steady increase and currently the prevalence in the USA is 1 in 110, or approximately 1% among children.

In the SEA Region, a WHO-sponsored community survey conducted in 2009 by the Department of Mental Health, Government of Bangladesh in Dhaka Division, using DSM IV criteria, found prevalence of Autism to be 0.84% in the 0 - 18 year age group population. In Thailand, a MOH study using DSM IV criteria in 2004, found the prevalence of autism to be 1 in 1,000 children. This finding led to the initiation of services in autism in 29 provinces.

Although prevalence of autism is reported to be increasing in developed and developing countries, there is no convincing evidence of an increase in the incidence rates of autism, although the currently available epidemiological studies cannot conclusively exclude this. Some of the reasons attributed to the reported increase could be changes in the diagnostic criteria in the DSM-III-R published in 1987, increase in the awareness of doctors and the general public, availability of more effective interventions specific to autism which require early diagnosis, diagnostic substitution between autism and intellectual disability, and the perception of autism as being a *less* stigmatizing condition than intellectual disability in many societies.

In a situation review of autism in the SEA Region, conducted by the MHS unit, it was found that:

- There was lack of recognition of the nature as well as the public health burden of the disorder, due perhaps to the lack of reliable data. This resulted in autism not been as a public health priority, but as a rare occurrence among the urban, educated elite.
- There was a paucity of trained professionals and lack of adequate services/facilities across the Region except perhaps in Thailand. In this vacuum, it was NGOs and parent initiatives that had helped to address needs, but these were small scale and with limited coverage.
- One Member State had legislation (India)

- One country had a large-scale public health programme (Thailand)
- One country had a pilot project (Sri Lanka) and
- Four countries had their own screening tools (Indonesia, India, Sri Lanka and Thailand).

Implications for the Region

It is evident that while there is scope for intra-regional sharing of knowledge and experiences there is also the need to develop comprehensive and country-specific plans for awareness campaigns, promotion of legislation/policy framework, reliable data, advocacy for allocation of financial, infrastructural and human resources, development and delivery of an accessible service delivery continuum within each Member State, as well as development of research priorities and funding for the same, as well as networking and partnerships within the Region.

Government of India tool for assessment of autism

In her presentation, Dr. S. Aneja explained that the need for the development of this tool was to provide a measurable basis for the issuance of disability certificates for the purpose of facilitating entitlements by persons with autism. Researchers in India found that currently available tools for assessment of autism were time consuming required keen observation by trained personnel, were expensive to buy and use, and developed in western countries without being culture-specific.

The methodology for the development of this tool involved three stages comprising of Stage I for test construction, Stage II for selection of field centres and training to research staff and Stage III for validation and standardization of the tool. The tool is called the Indian Scale for Assessment of Autism (ISAA). The ISAA is a rating scale comprising of 40 test items grouped under six domains. The scoring system, test materials, psychometric properties and the 10 sites in India where this tool was field-tested were described.

The tool can differentiate persons with autism from persons with mental retardation and from the normal population. Thus the ISAA is a

standardized tool with good psychometric properties. It is a reliable and valid tool for assessment of persons with autism. High concordance between ISAA and the gold standard Childhood Autism Rating Scale was also observed. She reiterated that it is available and inexpensive and can be easily administered after a three-day training. The simple tool kit and training manual can be used in similar cultures e.g. in SAARC countries.

Implications for the Region

This tool is validated across many centres in India. It is inexpensive, easy to administer, easy to train health workers in and is culture-sensitive. It has enormous potential for using in the Region, after country-specific modifications.

Current research on autism:

In her presentation, Dr Vibha Krishnamurthy said that a review of current research from South-East Asian countries suggests that most research from this area focuses on genetics, medical etiologies and epidemiology. Little has been written about early identification, health care provider knowledge, interventions or advocacy.

This presentation was divided into four sections. The first gave a brief overview of current global research in epidemiology, the second focused on etiology/causes, the third reviewed studies on early identification and diagnosis, and the last on intervention.

- Epidemiology – current data from CDC suggests a prevalence of 1 in 110. Data from South-East Asian countries is inconsistent in terms of prevalence estimates due to variable methods of case finding and diagnosis. The challenges in many South-East Asian countries caused by the absence of registries and records were discussed, as were currently on-going prevalence studies.
- The section on causes/etiology focused first on the genetics of autism. There is sufficient data now to suggest that autism is a biological and heritable condition. Less than 10% of cases are due to a clearly identified medical condition. Nonetheless, this has practice implications for the identification of medical conditions associated with a higher risk of autism such as Fragile

X syndrome. For most cases of autism, the exact genetic etiology is not easily identifiable. Review of environmental factors implicated in autism suggests that autism may be associated with other disabilities linked to antenatal and perinatal risk factors. Therefore public health measures that impact these risk factors will improve outcomes for autism linked with these causes.

- Although most global research points to the fact that autism can be diagnosed by 12 to 24 months, the average age of diagnosis continues to be approximately four years even in high income countries. Current research also suggests that deficits in social responsiveness are far more specific early signs of autism in infants and toddlers. There is a need to increase awareness of these signs among professionals and parents.

Several studies have looked at screening instruments in the general population (e.g. Checklist for Autism in Toddlers-Modified). While some of these seem promising, there does not seem to be a single ideal screening instrument. Also, preliminary studies from South-East Asian countries suggest that some of these instruments may need to be adapted to be culturally appropriate. In the absence of an ideal screening instrument the key to early diagnosis appears to be ongoing monitoring/surveillance of child development by those with access to infants and toddlers.

- Research on early intervention shows a shift towards more naturalistic behavioral models of intervention such as Pivotal Response training, Incidental learning etc. There is now emerging data on the efficacy of developmental models as well as models combining behavioral and developmental approaches (e.g. Early Start Denver Model, Social Communication Emotional Regulation and Support). Lastly, there is now data to support the efficacy of parent-mediated interventions.

Implications for the Region

This presentation has given a clear understanding of the nature of autism, the situation of research, the way forward and the priority areas for research in the context of this Region.

Public health aspects of autism in Thailand

In her presentation, Dr. Amporn Benjaponpitak presented the situation of autism in Thailand. She explained about the health care delivery system, from village health volunteers to the specialist psychiatric hospital. She also explained how other sectors such as Ministry of Education, Ministry of Social services, the Thai police, temples etc link into the medical services.

Since 2001, the Department of Mental Health under the Ministry of Public Health has sharpened its focus on autism. Research funding was granted to discover more practical knowledge and feasible technological support in addition to the development of an autism registry and training initiatives on early detection targeting parents, educators and physicians. In addition, the Royal Thai Government's commitment to persons with disabilities was reinforced with the passage of the Rehabilitation Act 1991, the Education Act 1999, the National Autistic Awareness Campaign in 2003, and recently, the Persons with Disabilities' Quality of Life Promotion Act in 2007 according to which, autism is classified as a developmental disability thereby providing access for autistic persons to all facilities that people with other disabilities have.

The prevalence of autism among the general population in Thailand was not well established until 2002-2005, when at least two studies were reported. The prevalence of pervasive developmental disorders was estimated to be in the range of 1.0 - 3.2 per 1000 children which was rather high when compared to previous reports, but it was consistent with recent studies in the United States and Europe.

In 2003, the Department of Mental Health, together with the Local Public Health Bureau launched the National Autistic Awareness Campaign as a major action to promote early detection and early intervention. The campaign motto: "No eye contact, no speech and no pointing" in Thai language was delivered nationwide. The Department of Mental Health also carried out other relevant information dissemination on a wide scale through telephone, television, publications, radio and through their own websites.

After the National Autistic Awareness Campaign, an epidemiological study was conducted to determine the prevalence of persons with autistic disorders. The results indicated that the prevalence for children diagnosed with autism was approximately 1 per 1000 in Thailand. Data from the

national statistical office and office of the higher education commission demonstrates that, in 2010, the prevalence of autism in the Thai population was estimated to be 6 per 1000 or 372,000 cases.

In 2005, under supervision of the Department of Mental Health, Yuwaprasart Hospital established a holistic care programme for children with autism. The hospital's objectives were to set up autism care units in 26 provinces (expanded in 2009 to 38 provinces) through cooperation of centre-hospitals and provincial public health offices, to organize autistic screening networks, and to set up primary care providers in the areas participating in the programme.

As a consequence of the campaign, Thai society now understands better the concerns and needs of individuals with autism. The Ministry of Education plays a significant role in including autistic children in mainstream schools and in teacher training; parents associations have been formed, like the Association of Personal Autism Parents (Thailand) and Autistic Foundation of Thailand.

Implications for the Region

- This model of care delivered through the Department of Mental Health, Ministry of Public Health, is an excellent example of government commitment to a cause.
- The development of the awareness campaign and the helpline are important for this Region.
- The integration of autism into the other relevant sectors in the community could be adapted in the Region.

Community-based pilot project for children with autism in Sri Lanka

In his presentation, Dr Neil Thalagala explained that the Ministry of Health, Sri Lanka is in the process of piloting a community-based model for children with special needs and it includes care for children with autism as a component.

The pilot project includes a component for assessing the overall development of all children; those found to have potential developmental delays or deviations will be referred to a primary child guidance clinic for

specific assessments. The specific assessments will include screening and diagnostic measures for autism. All diagnosed children will be referred to secondary child guidance centres to further supplement the diagnostic process, especially the search for co-morbidities.

The children diagnosed with autism will be referred to early intervention centres (EIC) which will be set up at the community level. The interventions will be primarily parent mediated. At the EICs, a group of therapists (PHC workers/pre-school teachers) will initiate autism interventions with the participation of parent/caregiver. After they have been found to have acquired satisfactory levels of skills to provide interventions independently, home-based interventions will be the main strategy for service-delivery. Reassessment of skills will be done periodically by the EIC therapists.

A periodic follow up of these children will be carried out on a weekly or fortnightly basis by specially trained physicians (MOH/MOMHs). The whole process will be formally monitored and evaluated by a central team of experts. The IEC materials for relevant training have already been developed.

The Family Health Bureau of the Ministry of Health, Sri Lanka will be the focal point for the programme. The Child Development and Special Needs Unit of the Bureau will design the interventions and coordinate field-level implementation. The WHO country office will provide financial and technical assistance.

Implications for the Region

- This is an extremely important model for the Region because it seeks to integrate issues of developmental delays within the context of normal child development, through the maternal and child health sector, which is the most logical location for such interventions.
- This model should be studied and followed more closely. If successful, it can be adapted in other countries of the Region.

NGO-directed Activity in Indonesia

Dr Melly Budhiman talked of how a NGO can become a powerful tool in starting a movement for advocacy in the country on behalf of autistic individuals.

She highlighted the activities conducted by the Autism Foundation of Indonesia. This include starting awareness campaign for autism by doing radio and TV shows, writing articles in news- papers/magazines, distributing brochures about autism in the streets, and putting billboards in several locations, awareness/education for the community, parents, teachers and professionals through conducting regular seminars, workshops and conferences. Similarly, seminars were conducted across the country for young doctors and paramedics. Collaboration with the Ministry of Health and the Ministry of Education are a strong foundation for their work.

Implications for the Region

- Autism is a low priority in the public health agenda in the Region; NGOs play a crucial role in awareness, training and in service delivery in most countries of the Region. Partnerships between governments and nongovernmental organizations is the most important aspect of the way forward as each sector has it's discrete set of strengths and limitations, and no one sector can ensure both quality and coverage.
- The presentation also pointed out the limitations of individual NGOs, working without financial and other support.

Parent-directed Programme in Bangladesh

In his presentation, Mr Mohammed Mofijul Islam said that in Bangladesh, there is widespread ignorance, prejudice and superstition about disability in the society, especially among the illiterate, and the poor. The term 'autism' is unknown to most people in Bangladesh. Even doctors and professionals do not have a clear idea about this disorder.

In rural areas and urban slums, children with autism and other disabilities are taken to priests for prayers and treatment as it is believed that the children are possessed by evil spirits. In some cases they are left

unidentified. These children are rarely taken to the doctor for a diagnosis. Many autistic children who are taken to a doctor often get misdiagnosed or referred to psychiatrists who put them on antipsychotic medications. Parents are in a state of anguish and frustration when they do not get proper guidance to help their child.

In the absence of government facilities, a group of very enthusiastic and devoted parents of children with autism started the Society for the Welfare of Autistic Children (SWAC) on February 3, 2000. The aim of SWAC is educating and training children with autism to develop to their fullest potential. Awareness about autism has increased but there is no government facility to rehabilitate them through training, perhaps due to lack of resources, as well as shortage of professional experts like speech and language therapists, and others.

Implications for the Region

Like several other speakers before him, Mr Islam reiterated the need for convergence at the community level, awareness-raising, and the involvement of the local government.

- Parents of children with autism are a rich resource in the community and are the child's best and first teacher. Their concerns regarding delays /deviations in development have usually proved to be right. It is therefore logical and cost-effective to involve them at every step of the planning and implementation process and treat them as co-therapists.
- For advocacy with policy makers also, their voice needs to be heard as they are the most directly affected.

Human resource development for autism in India

In her presentation on the subject, Mrs Merry Barua explained that in India, there was recognition over the last 20 years, that the quality and relevance of services for persons with disabilities is heavily dependent on a regular supply of well-trained service providers and that investments in the development of human resources is the best strategy for the sustainability of rehabilitation services in the long run. This understanding led to the establishment of a statutory autonomous body called the Rehabilitation

Council of India (RCI-1992), for the standardization, administration and regulation of training for rehabilitation professionals. The RCI has nearly 400 institutions recognized under it, which, along with a number of universities, run 63 types of courses (direct and distance) to produce a wide range of rehabilitation professionals and personnel for all categories of disability.

Currently there are over 50,000 registered personnel with the RCI. Though it took some effort to convince the RCI of the large numbers of persons with autism who need specialized support, it has been receptive and supportive. It recognizes an undergraduate course, (a one-year Diploma in Special Education, Autism Spectrum Disorders). The course started in four metro-based centers in India in 2003, and expanded to 14 centres across India by 2009. So far nearly 1200 teachers have been trained under this programme. This year the RCI has also given permission to start a degree course on autism.

In addition, through the Continuing Rehabilitation Education (CRE) programmes of the RCI, there are numerous small and medium sized recognized training programme on autism that upgrade knowledge of other professionals working in the disability sector as well as for parents; this is done both through distance training as well as through satellite training which is beamed live to 500 training institutions across the country, every day. There is an University-based distance learning certificate course for parents, and a first of its kind Child Development Aides course with autism embedded in it. So far, over 40,000 teachers in regular schools have also been trained in inclusive education in RCI recognized courses.

There is a four-tier strategy adopted by the RCI.

- (1) The first is to train a level of Master Trainers through one-year courses;
- (2) The second tier is where autism is part of other long-term courses, as in intellectual disability, speech therapy etc;
- (3) The third is where autism is part of 3-4 modules in a one-year caregivers' training course; and
- (4) The fourth is where autism is part of in-service training modules, either through direct contact classes or through distance learning.

Implications for the Region

- This investment by the government of India, in human resources for autism has paid rich dividends, and has very wide implications across the Region, which is marked by the absence/shortage of skilled rehabilitation professionals. This four-tier strategy for addressing huge gaps in human resources,(common to this Region) could be a model for other Member States, and exchange/placement of staff could be considered.
- In the light of the large numbers of children with autism diagnosed and the difficulty in accessing professional advice for each child, it is also important to empower/train parents to become effective teachers for their children. All this necessitates urgent action in the area of human resources development in all other Member States.

Development, discussion on the materials developed by the participants

Each participant presented the material on autism produced by their organization which included simple leaflets, posters, early detection checklists, newsletters, journals, training curricula and manuals for different types of partners, including teachers in general schools, special educators, and paediatricians.

Implications for the Region

- This discussion has highlighted the need for more networking and for intra-regional sharing of materials developed, which has the potential of cutting down on costs, time and effort in the future.

DAY 2

Group discussions and development of action plan

Two groups were formed to discuss “Community-based Approaches to Autism”.

The first group concluded that the future plan of action should be based on the following:

- (1) Incorporation of autism-related plans into existing facilities of the health sector.
- (2) Promotion of a grassroots level approach (population coverage is important) in recognition of the higher prevalence of disabilities in rural areas in the SEA Region.
- (3) Adoption of a multidisciplinary approach (with education/health/social welfare and other sectors involved), given the complex nature of autism.
- (4) Recognition of the importance of early identification as a secondary preventive measure, and facilitation of linkages with early childhood development for routine developmental screening.
- (5) Given the chronic shortage of service-facilities, promotion of family-centred care.
- (6) Ensuring capacity building at all levels, given the low levels of awareness about autism, and paucity of trained staff.
- (7) Adoption of a rights-based approach in the context of contemporary understanding of the human rights of persons with autism.
- (8) Addressing issues through an evidence-based approach, in the context of developing models of care for other low-resourced countries.
- (9) A multi-sectoral approach should be followed. Key partners could be:
 - Family / community
 - Health care System
 - Education system
 - Other systems like social welfare, women's empowerment and child protection etc
 - Private sector – health, schools, NGOs

- (10) The framework for action should be:
- Primary prevention
 - Secondary prevention
 - Early detection
 - Early intervention
 - Transition and adult care / services

The second group presented the on-going pilot project in Sri Lanka on first identifying children with developmental delay, and then, from this group, determining the domain of disability.

Action plan for community-based services for children with autism

The proposed action plan has two components:

- Community-based approaches
- Specific interventions

Community-based approaches

Rationale for community-based approaches applicable to all children:

If one needs to ensure satisfactory care for a child with autism, the best strategy would be to include several generic interventions at points along the child's life span. These include:

- (1) The child should get routine general developmental screening at fixed points during infancy so that early signs of developmental concern or delay (red flags) could be spotted as early as possible. These developmental screeners should be integrated into existing PHC contact points for infants (such as immunization visits/well baby visits). The screening should be started early in life (6m/ 9m/ 12 m) and should cover every child. Self referrals by parents will be used as a supplementary screening strategy.
- (2) If the child is found to have any signs of developmental delay (red flags), the child should be offered intensive interventions at the PHC level to facilitate development. These interventions should be principally parent mediated and supervised by the

PHC worker. Parent mediated interventions have to be pilot tested to suit local contexts. Two types of interventions, one for pre-diagnostic early intervention and one for post-diagnostic autism interventions have to be developed and pilot tested.

- (3) At the optimal developmental age (e.g. 18 -24 months), the child should be administered definitive assessments for autism. *Early signs can precede definitive signs of autism by months or may be years.*
- (4) If the child is found to have autism, specific behavioural interventions should be initiated as early as possible. Considering the resource constraints of most Member States in the SEA Region, these interventions also have to be adapted for use by parents and PHC / social service providers. Simple, easy to use screening tools for developmental screening and Autism assessments have to be adapted and PHC staff have to be trained on their usage.

Developing pilot projects to test the community-based approach:

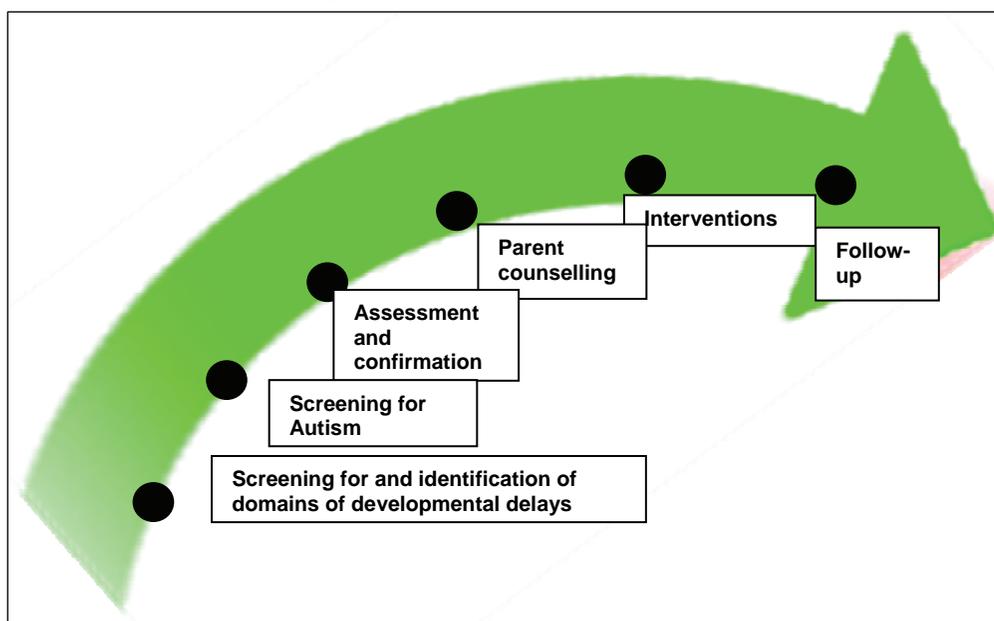
(A and B) At present a one year project is being planned.

A. Two pilot projects of MOH, one in India (multi-centric, funded by the Government of India) and the second one in Sri Lanka (funded by WHO country office in Sri Lanka) would be developed/strengthened over the next one year with the following tasks:

- Identify a community with approximately 5,000 children under five years of age (all sites combined in India)
- All children would be screened for developmental delay using two instruments:
 - "A Guide for Monitoring Child Development in Low and Middle Income Countries" Ref Dr Ilgi Ertem's questionnaire, validated in several countries.
 - Sri Lanka Family Health Bureau (Child Development and Special Needs unit) of the Ministry of Health scale for early child development (under development).
- Those identified as having developmental delay will be examined by a primary health care based physician, to determine the domain of developmental delay. From this

information, an estimate of the proportion of children with possible autism in the community will be obtained. This will be a preliminary estimate as a validated instrument for identification of autism in the primary health care setting is yet to be tested.

Fig.1: **Proposed model for work**



The timeframe will be till October 2011 to achieve up to the second bullet.(seen in Fig. 1 above)

B. In clinical settings over the next one year, two instruments mentioned below will be tested in Bangladesh, Maldives, Nepal and perhaps Indonesia, through the experts who participated in the meeting. Funds need to be identified to support these projects.

There are two screening instruments:

- The Indian Scale for Assessment of Autism (ISAA). This has been validated at multiple sites in India.
- The Pervasive Development Disorders Social Quotient (PDDSQ) developed in Thailand and used all over Thailand.

Specific interventions

Primary prevention

- Strengthening existing services to improve perinatal and early childhood outcomes; universal immunization for rubella, genetic counseling and early stimulation for children.

Early identification

- Monitoring and surveillance of developmental status of children should be incorporated into well-child care services or routine immunization visits. Deviation from normal development could follow the following steps:
 - Administration of screening instruments for developmental delays
 - Screening for autism among children who have developmental delays
 - Confirmatory diagnosis of autism
- Awareness of early signs in families, communities, healthcare professionals, educationists, etc.

Early intervention

- Family-centred care
- Evidence-based interventions

Education

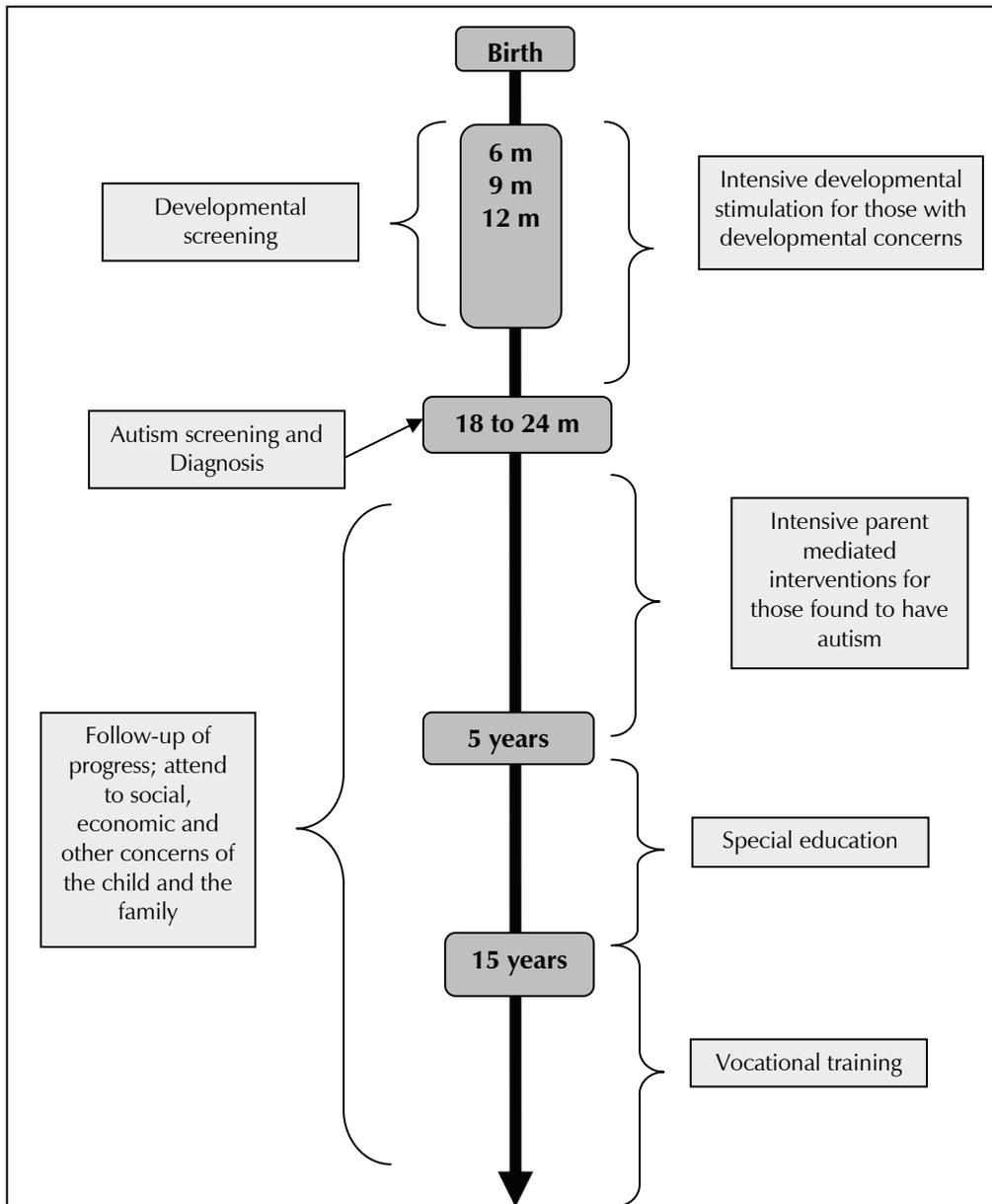
- Range of options relevant to each country: special schools, open schools, inclusive schools
- Capacity building for each type of educational institution

Transition and adult care services

- Strengthen and improve quality of existing services for adults across sectors (e.g employers, vocational training institutes, etc)
- Introduce planning for transition as part of educational curriculum

- Build capacity of families for transition of a person with autism from adolescence to adulthood.

Fig. 2: **Presents the essential action points during the major milestones in the life of a person with autism.**



Recommendations

Recommendations for governments

- To develop a policy framework / legislation for early detection and community-based intervention strategies for autism.
- To integrate advocacy/awareness campaigns and early detection of autism in the overall maternal and child care system.
- To build capacity of all stakeholders, forge partnerships and promote multi-sectoral linkages within the country.

Recommendations for WHO

- To establish centres of excellence in the South-East Asia Region for training and capacity building in autism.
- To develop technical guidelines for identification, interventions and best practices for autism.
- To undertake advocacy with governments and partner agencies for prioritizing autism within the public health agenda.
- To promote applied operational research on the development of community-based approaches for the management of autism

Concluding session

The Chairperson Dr. R.K. Shrivastava conveyed his appreciation to the Regional Director for approving the organization of this first-ever initiative on autism in the Region. He felt that it had been a very fruitful and intensive meeting and that every participant had learned from the intra-regional experiences shared. He said that he was committed to taking forward the steps outlined at this meeting and looked forward to SEARO's technical support and networking in bringing together ideas and best practices on autism in the Region. He thanked the Ministry of Public Health, Thailand, for providing excellent opportunities for learning from their autism work, and for their warm hospitality.

The Co-chair Dr. Panpimol Wipulakorn thanked SEARO for bringing into focus the issues related to autism. She said that although Thailand has undertaken work on autism for 2-3 decades, even then she felt that she

had learned a lot from the other experts and from the discussions. She looked forward to the fructification of the plan of action developed by the experts.

Dr. Vijay Chandra thanked the Chair, the Co-chair and Rapporteur for their leadership in guiding the discussions and in making the meeting a successful platform for the development of an action plan for community-based approaches to autism in the SEAR. He thanked the Ministry of Public Health, Thailand, for their excellent arrangements for the conduct of this Meeting and Dr. Amporn Benjaponpitak for her untiring efforts over the last several weeks. He also thanked every member of her team for their coordinated efforts in making this Meeting a success. Finally he thanked all the participants for their valuable contributions and taking the time to come to the Meeting and assisting SEARO develop a plan of action.

Annex 1

List of participants

BANGLADESH

Md Mofijul Islam
Program Manager
Society for the Welfare of Autistic Children
(SWAC), Dhaka.

INDIA

Dr R. K. Shrivastava
Director-General
Health Services, MOHFW, Government of
India

Mrs Merry Barua
Parent
Special Educator and Founder, Action for
Autism, New Delhi

Dr (Mrs.)Vibha Krishnamurthy
Developmental Pediatrician
Founder of Ummeed Centre for Autism,
Mumbai

Dr (Mrs.) S. Aneja
Head
Department of Pediatrics, Lady Hardinge
Medical College, New Delhi

INDONESIA

Dr(Ms) Melly Budhiman
Child Psychiatrist
Activist and President of Yayasan Autisme,
Jakarta

MALDIVES

Ms Fathimath Shaneez
Maldives Autism Association, Male

NEPAL

Dr (Ms)Sunita Maleku Amatya
Vice-Chair person
Autism Care Nepal, Kathmandu

SRI LANKA

Dr Neil Thalagala
Pilot Project on Autism
Ministry of Health, Government of Sri Lanka,
Colombo

THAILAND

Dr(Ms) Amporn Benjaponpitak
Director
Bureau of Mental Health Technical
Development
Department of Mental Health, Ministry of
Public Health, Bangkok

Dr(Ms) Panpimol Wipulakorn
Director
Rajanukul Institute for Intellectual Disabilities,
Bangkok

Person with Autism
(name to be identified by Rajanukkul
Hospital, Bangkok)]

Dr Dusit Liknapichitkul
Director
Yuwaprasat Hospital, Muang District,
Samutprakarn

Dr Samai Sirithongthaworn
Director
Rajanagarindra Institute of Child
Development
Mae-Rim District, Chiang-Mai

Dr Duangkamol Tangviriyapaiboon
Pediatrician
Rajanagarindra Institute of Child
Development District, Chiang-Mai

Dr Nattawat Ngamsamut
Child and adolescent psychiatrist
Yuwaprasat Hospital, Muang District,
Samutprakarn

Dr Wiranpat Kittisaraphan
Child and adolescent psychiatrist
Yuwaprasat Hospital, Muang District,
Samutprakarn

Dr Tawee Mekvilai
Clinical Psychologist
Bureau of Mental Health Technical
Development
Department of Mental Health, Ministry of
Public Health, Bangkok

OBSERVERS

Dr(Ms) Chandhita Pruksananonda
Developmental Pediatrician
Division of Growth and Development
Pediatrics Department, Faculty of Medicine
King Chulalongkorn Memorial Hospital,
Bangkok

Ms Pattama Permpoon
Teen Center, Samitivej Srinakarin Hospital,
Bangkok

Ms Saengabha Srisopaporn
Disability projects assistant, ILO
Bangkok

Ms Paojjan Chuaykool
Speech-Language Pathologist
Yuwaprasat Hospital, Muang District,
Samutprakarn

Ms Usa Puangthum
Psychiatric Nurse
Bureau of Mental Health Technical
Development
Department of Mental Health, Ministry of
Public Health, Bangkok

Ms Weena Boonsaeng
Psychiatric Nurse
Bureau of Mental Health Technical
Development
Department of Mental Health, Ministry of
Public Health, Bangkok

Ms Thanyalak Kaewmuang
Occupational Therapist
Bureau of Mental Health Technical
Development
Department of Mental Health, Ministry of
Public Health, Bangkok

Dr Taweesak Siriratrea
Child and Adolescent Psychiatrist
Rajanukul Institute for Intellectual Disabilities,
Bangkok

Dr Woranart Raksakulthai
Director,
Kindergarten Division,
Kasemphittaya School, Klong-Tun, Wattana,
Bangkok

Chintara Taechatugkiyapan
Director, Sataban Saengsawang Foundation
Klong-Tun, Wattana, Bangkok

Dr Verapon Nitipong,
Medical Chief Officer
Muang District, Samutprakarn

Dr Wonchai Paisalsin,
Bangplee Hospital
Bangplee District, Samutprakarn

Dr Munchit Prasithirun
Bangplee Hospital
Bangplee District, Samutprakarn

WHO:

Dr Vijay Chandra
Regional Adviser, MHS/SEARO

Ms Aloka Guha,
TIP (MHS) SEARO

Dr (Ms) Anoma Jayathillake
Parent and Focal Point for Maternal and Child
Health, WRO, Sri Lanka

Annex 2

Objectives

General Objective:

- Development of community-based approaches to the management of Autism in the SEA Region

Specific Objectives:

- Review the situation of Autism in Member States of the South-East Asia Region
- Discuss community-based approaches to the management of Autism
- Develop key components of a strategy for community-based approaches for the management of Autism from a public health perspective

Annex 3

Agenda

- (1) Field visit to outreach programmes on Autism.
- (2) Welcome address by Dr Chatri Banchuin, Director-General, Department of Mental Health, Ministry of Public Health, Thailand
- (3) Remarks by Regional Adviser, Mental Health and Substance Abuse, WHO
- (4) Introduction of participants and election of office bearers.
- (5) Presentations by experts on community-based approaches to Autism
- (6) Group discussions on components of community-based approaches to Autism
- (7) Development of an action plan for addressing the gaps in Autism-related programmes
- (8) Way forward and conclusion

Annex 4

Tentative Programme

Day 1: 15 September Wednesday	
07.00	Registration
07.30	Departure from Asia Hotel Lobby for Field Visit
10.30	Kasempittaya School
14.00	Yuwaprasat Hospital (Child Psychiatry Hospital)
16.00	Bangplee District Hospital
17.00	Departure for Asia Hotel
19.00	Welcome Reception
Day 2: 16 September Thursday	
09.00 – 10.00	<ul style="list-style-type: none">• Welcome address by Dr Chatri Banchuin, Director-General Department of Mental Health, Ministry of Public Health, Thailand• Address by Dr. Vijay Chandra, Regional Advisor, Mental Health And Substance Abuse Unit, WHO, SEARO• Introduction of participants and election of office-bearers
10.00 – 13.00	Paper presentations
14.00 – 16.00	Paper presentations (contd)
16.00 – 18.00	Discussions of material developed by experts/organizations
Day 3: 17 September Friday	
09.00 – 12.00	Group discussions on components of community-based approaches to Autism
12.00 – 13.00	Presentation of group discussions
14.00 – 16.00	Development of action plan for addressing the gaps in Autism-related programmes
16.00 – 17.00	The way forward and conclusion

Annex 5

The terminology of autism

People with any form of autism share three broad characteristics:

- Impaired social interactions with limited desire for social involvement:
- Impaired verbal and non-verbal communication, ranging from inability to produce any words to subtle difficulties in the correct social use of language; impairments in thinking and behaving including lack of imagination or the ability to know what other people are experiencing,
- A very limited range of interests and intolerance of new experiences or change, and repetitive, stereotypical (mechanical and unchanging) movements.

Many autistic people have difficulty modulating their sensory input and may react in unusual ways to touch, smell, noise, or light; and many autistic people are clumsy and poorly co-ordinated. Most autistic people have some degree of cognitive impairment (mental retardation) but some are of normal or even superior intelligence. Because of this great range of possible manifestations of the disorder, and the equally wide range in severity, the term “autism or autism spectrum disorder (ASD)” is often used. Within the spectrum, the various diagnostic manuals and professional organizations select specific criteria to delineate particular autistic syndromes, such as Kanner syndrome (early infantile autism) and Asperger syndrome (in which the communication impairment is more subtle and does not cause delayed speech). Some experts recognize different types of social impairment, such as the aloof group, the passive group, the “active but odd” group and the group with over-formal, stilted people with little social spontaneity. The diagnostic criteria used by different professional groups change over time, reflecting research findings and changes in professional attitudes. The number and severity of symptom-behaviors may change over time, especially in the early years, so that a child thought at two years of age to have a mild form may prove four or five years later to

have a more severe condition with more symptoms, or, more commonly, a child thought to have the most severe form of autism may by the age of seven be showing much milder impairments. It is important to realize that all autistic people share, to some degree of severity, the same three broad characteristics (known as “Wing’s triad) and that because of these behavioral characteristics the individual’s participation in society is limited. In documents emanating from the USA, the term ASD is more commonly used.

The term autism is subsumed under the term Pervasive Developmental Disorders (PDD), first used in the 1980s to describe a class of disorders that include (1) Autistic disorder, (2) Rett’s disorder or syndrome, (3) Childhood disintegrative disorder, (4) Asperger’s disorder or syndrome, and (5) Pervasive Developmental Disorder Not Otherwise Specified, or PDDNOS.

Clinically, as in DSM IV, they are often still referred to as pervasive developmental disorders (PDDs). Classic autism, the form with behavioral features closest to those described by Leo Kanner in 1943, is called autistic disorder or nuclear autism. Over time, the diagnostic criteria for autistic disorder have been modified, new criteria have been added for other ASDs (pervasive developmental disorders not otherwise specified [PDD NOS], and Asperger Syndrome), and the way these criteria have been applied in practice has also changed.

This report uniformly uses the term autism.

Annex 6

Why focus on autism?

Autism should receive some priority in public health for the following reasons:-

- The steady rise in reported prevalence of Autism is reaching a level of public health concern.
- There is difficulty in identification of Autism in the absence of external signs. This issue needs to be addressed because, where there is no primary preventive measure, then early identification becomes even more crucial as a public health measure.
- There is sufficient evidence to suggest that early identification impacts early intervention and later functional outcomes.
- There is also evidence to support the fact that the cost of caring for adults with autism who have received little or no intervention is much more than the investments in early identification and intervention.
- It may be reiterated that the focus on autism is not to the exclusion of other disabilities – it is in the context of promoting early childhood development and identification of all disabilities
- Recognition that addressing Autism through public health systems could be a model for community- based care of other developmental disabilities as well.

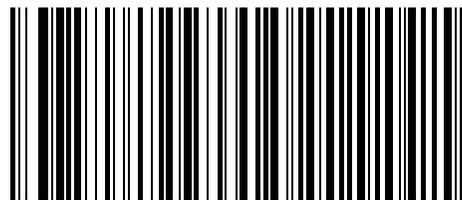
There is now increasing awareness among policy makers in Member States of the South-East Asia Region that the burden of disease from learning and behavioural disorders, including autism, is substantial and leads to suffering and morbidity among affected children and families. Both quantitative information and relevant qualitative information is limited. Strengthening programme development, reporting increase in prevalence over time, augmenting services at the community level, primary and tertiary health care levels, the perceptions of communities, the diverse agencies involved, and increasing the current capacities and gaps needs to be filled. Autism related programmes should not only be developed, strengthened and expedited, but also made contextual to the environments in which they will be implemented.

With scarcity of trained rehabilitation professionals in Member States, and with the overall general objective of development of community-based approaches to the management of autism in the South-East Asia Region, a meeting of experts on community-based approaches to autism, was organized in Bangkok from 15-17 September 2010. This report covers the proceedings and recommendations made by the Experts at the meeting.



**World Health
Organization**

Regional Office for South-East Asia
World Health House
Indraprastha Estate
Mahatma Gandhi Marg,
New Delhi-110002, India



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