Collaborative framework for addressing Autism Spectrum Disorder in the South-East Asia Region

World Health Organization
REGIONAL OFFICE FOR South-East Asia

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Based on WHO South-East Asia Regional Strategy
on Autism Spectrum Disorder

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1. Introduction

In February 2016, technical experts, rights advocates and policy makers from the south-east Asia region gathered in New Delhi, India for a high-level consultation organized by WHO's South-East Asia Regional Office (WHO/SEARO) to develop a regional strategy for addressing the needs of persons with autism spectrum disorder (ASD). The purpose of the strategy is to define in succinct terms the objectives that WHO/SEARO Member States need to fulfill if persons with ASD (PwASD) are to enjoy the same human rights and opportunities for individual growth as everyone else in society.

This document has been developed for the explicit purpose of articulating to Member States:

a. the nature of autism spectrum disorder and the issues faced by PwASD and their caregivers;
b. the legal foundation upon which the Regional Strategy and associated framework has been based;
c. desired outcomes against each objective of the Regional Strategy;
d. recommended actions in order to fulfill each objective;
e. requisite parameters that should govern the recommended actions; and
f. suggested guidelines for monitoring, evaluating and reporting a Member State's progress towards fulfilling objectives.

2. Conceptual understanding of autism spectrum disorder (ASD)

Autism spectrum disorder is a lifelong condition that represents a category of neurodevelopmental disorders (NDDs) characterized by impairments in social reciprocity, communication and unusual or repetitive behavior. It is not a single disorder but rather a range of conditions grouped under a single spectrum as defined in the fifth edition of the Diagnostic & Statistical Manual of Mental Disorders (DSM-5). It occurs in all racial, ethnic and socioeconomic groups and is seen four times more in boys that in girls. The exact cause of ASD is yet to be identified

According to a 2012 review[a] of prevalence estimates from around the world, 1 in 161 people in the world have ASD (i.e. 0.62%), although that study lacked credible data from low and middle income countries, such as those in the South-East Asia region.

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[a] Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., & Yasamy, M. T. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, *5*(3), 160-179.

Table 1: Prevalence of ASD in some SEARO Member States

Member State	Prevalence (%)	Year of study	Age group	Researchers
Bangladesh	0.155	2013	0-9 years	Khan et al.
Bhutan	0.038	2012	0-22 years	JDWNR Hospital
India	0.233	2016	1-30 years	Poovathinal et al.
Indonesia	0.117	1992	4-7 years	Wignyo-sumarto et al.
Nepal	0.300	2016	10-13 years	Heys et al.
Sri Lanka	1.070	2009	1-2 years	Perera et al.
Thailand	0.270	2012	Children	Kopetz et al.

There are no prevalence figures available for Maldives, the Ministry of Health of Maldives highlighted that there is increasing observance of ASD among children in their *National Health Master Plan 2016-2025*[b].

2.1 Challenges faced by persons with ASD and their families and caregivers

No two individuals on the autism spectrum are alike but they all exhibit two common attributes:

- persistent difficulties with social communication and social interaction
- restrictive, repetitive behavior

While some PwASD possess exceptional cognitive skills, others struggle with some cognitive tasks that have nothing to do with intelligence, such as knowing when to cross the road. While some PwASD are able to concentrate on mundane, repetitive activities with extraordinary levels of attention and concentration, others are unable to maintain focus on any given activity. Most PwASD also lack the ability to understand the context of a given situation or statement. They are also unable to connect their past experiences with present situations, thus impairing their ability to recall relevant information, plan future actions and monitor those actions. They can also be highly impulsive and have difficulty with making and implementing plans (commonly known as executive functioning).

Around half of all PwASD have average or above average intelligence (i.e. IQ of 85 or above). Some PwASD have lower intellectual functioning (IQ below 70) which poses an additional challenge for them. Most often individuals with higher intellectual functioning, ability to verbally communicate and fewer disruptive behaviors are described as "high-functioning autistics". Those with significant challenges in verbal communication, intellectual functioning below the average range and significant disruptive behaviors are described as "low-functioning autistics". Highly verbal PwASD with significant skills in a specific area and intellectual functioning in the above average and gifted range are commonly known as Asperger's Syndrome[c].

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[b] Ministry of Health – Republic of Maldives. Available here: http://www.health.gov.mv/publications/

[c] The DSM-5 classifies Asperger's Syndrome under autism spectrum disorder, whereas in the previous version (DSM-IV-TR) it was distinctly classified under pervasive developmental disorders.

PwASD often also suffer from additional health concerns, such as epilepsy, gastrointestinal problems, impaired immunity, mental health issues (e.g. anxiety, catatonia, depression, schizophrenia, obsessive compulsiveness, and phobias), poor motor skills and heightened sensitivity to sounds, lights, textures and colors.

ASD significantly impacts immediate family members and others directly involved in their care. There are a whole set of issues that create emotional stress and strain, which include the day-to-day strain of providing care and assistance leading to exhaustion and fatigue, changes in the family life, such as abandoned career plans, especially for the females in the family, frustration with the availability and accessibility of services and supports, the financial burden of obtaining treatments, discontentment among family members regarding the disproportionate share of family's time, energy and money for the disabled member and suffering the negative attitudes projected towards them by friends, neighbors, people in the community and sometimes relatives.

2.2 Lifespan needs of persons with ASD

These needs are associated with one or more of the following stages in the individual's life: Pre-birth, Infancy (0 – 3 years), Early childhood (4 – 5 years), Childhood (6 – 10 years), Adolescence (11 – 18 years), Early adulthood (19 – 35 years), Midlife (36 – 50 years) and Late adulthood (51 years and above)

Five of the eight stages cover the first 18 years of life - which is only a third of an average PwASD's life[d]. This is significant because the best chance for PwASD to become functional and productive members of society is if their challenges are addressed at the earliest possible time i.e. during the first 18 years of their lives. There are nine general lifespan needs of PwASD that need to be addressed:

A. **Awareness, advocacy and sensitization:** Awareness about PwASD needs to be nurtured within the general community, particularly within influential members of society, such as elected representatives and religious leaders. An increase in awareness about PwASD is naturally followed by the need to advocate for their rights, as well as to develop the necessary services and supports to ease their challenges.

B. **Healthcare for parents, siblings and caregivers of PwASD:** Promoting safe pregnancy and safe delivery go a long way in ensuring healthy prenatal development and avoiding birth-related complications. Even though such precautionary efforts will not guarantee the prevention of ASD but they will greatly improve the chances of healthy births.

C. **Early identification:** As the cause of ASD is still being explored, the next best recourse is to identify children with developmental delays as early as possible. Addressing those issues early on gives those children the best chance of having a better quality of life in adulthood.

D. **Early intervention:** As there is no known cure for ASD, evidence-based interventions administered intensely as early as possible is required will help improve their overall well-being and possibly minimize the need for special support in schools, workplaces and other public places.

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[d] The average person with ASD lives 18 years less than a person without ASD. The life expectancy is even less for those who have comorbidities, such as those who have both ASD and intellectual disability. For more information, read: Autistica (2016). *Personal Tragedies, Public Crisis*. Available from: http://www.sciencemag.org/sites/default/files/documents/AUTISTICA%20REPORT%20-%20Personal%20Tragedies%2C%20Public%20Crisis.pdf

E. **Training of parents, siblings and caregivers of PwASD:** In addition to directly assisting PwASD, Member States should also invest in empowering the parents, siblings and other caregivers of PwASD by providing them training on early detection of developmental delays and home-based interventions.

F. **Special and inclusive education:** Member States should prioritize inclusive education if they are to successfully integrate PwASD into the socioeconomic network. Not only does inclusive education allow for PwD to avail the same opportunities as everyone else to acquire knowledge, skills and qualifications, it also encourages them to improve their social skills which is the toughest impediment for PwASD.

G. **Inclusive employment:** Getting PwASD to join the workforce would be a significant achievement for a Member State towards creating an inclusive society. To do so would require Member States to enable PwASD to acquire skills and vocational training for a variety of jobs, as well as to remove significant social barriers to inclusion that exist in a variety of industries.

H. **Protection of PwASD:** Protection of PwASD entails both response to all forms of abuse as well as financial support and preventive care. Social security is the foundation of economic security which is essential for those PwASD who cannot meet basic needs such as accommodation, sustenance, assistive devices that are too expensive for them, financial assistance for pursuing life-altering education opportunities and subsidized health insurance, to name a few. Safeguarding and promoting the welfare of PwASD is the process of protecting PwASD from abuse or neglect.

I. **Community support for PwASD:** PwASD need support from the community they live in in terms of educating general public about PwASD within the neighborhood promotes inclusion. Community support is vital for creating an inclusive environment for PwASD and involves enabling them to move about in public spaces, access public transportation, enjoy public recreational facilities and programs, and participate in social, community and cultural events.

3. International commitments for addressing ASD

Most disability legislation and policies are based on the assumption that PwD are not able to exercise the same rights as non-disabled persons, therefore legislation is aimed at addressing a need for rehabilitation and social support. However, the issues that need to be addressed calls for more comprehensive legislation to ensure that the rights of PwD in all aspects – political, civil, economic, social and cultural rights – are on an equal basis with persons without disabilities, with the explicit aim of overcoming existing discrimination and confer upon PwD equal opportunities in social life and economic development. Legislation at country level is vital for promoting the rights of PwD so long as they are based on international norms concerning disability.

3.1 Human rights based approach to disability

The United Nations outlined a "Common Understanding on a Human-Rights-Based Approach to Development Cooperation" in 2003 that articulates how human rights standards and principles should be incorporated in programmatic work at national and sub-national levels.

The human-rights-based approach (HRBA) particularly targets those who are most marginalized, excluded from society or discriminated against by more dominant factions of society. The HRBA is a shift from a "needs based approach" to action that has been dominant throughout the history of societies, to instead focus on fulfilling people's rights. This requires reinforcing the capacities of duty-bearers (namely the government) to respect, protect and guarantee those rights.

3.2 The Convention on the Rights of Persons with Disability (UNCRPD)

UNCRPD is an international treaty of the United Nations that promotes, defends and reinforce the human rights of all PwD. It seeks to make visible the rights of PwD which have been legally and politically ignored in most countries throughout the world for much of human history. UNCRPD consists of 50 articles that seek to uphold the rights of PwD in areas such as access to healthcare, education, work, employment and justice. It is considered to be a hybrid convention that combines civil, political, economic, social, and cultural rights.

3.3 UN Resolution No. 67/82

In 2012, the United Nations General Assembly unanimously adopted Resolution No. 67/82 *"Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities"*. Through it, the UN Member States recognize that:

1. PwASD have the right to full enjoyment of their human rights;
2. doing so would result in significant advances in a country's socioeconomic growth;
3. to achieve such inclusion would require the involvement of NGOs and other civil society actors;
4. there are barriers that prevent full participation of PwASD as equal members of society which need to be overcome;
5. failure to do so would be a violation of the dignity and worth of a PwASD as a human being

The resolution encourages Member States to:

- Combat stigma and discrimination by increasing awareness of ASD in all sectors of society;
- Increase local expertise among researchers and service providers;
- Improve service delivery through international collaboration;
- Ensure inclusive education;

- Develop life, social and professional skills within PwASD;
- Enhance access to social services and supports for PwASD and their caregivers in the community in which they reside.

3.4 World Health Assembly Resolution WHA67.8

In May 2014, as a direct consequence of UN Resolution 67/82, the Resolution WHA67.8, entitled "Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorder", was adopted by the World Health Assembly, which articulates specific actions, such as:

1. Capacity building of healthcare providers;
2. Shifting away from institutionalized healthcare to community-based services;
3. Sharing of best practices and technology to improve early identification and early intervention;
4. Providing psychosocial support and care to families affected by ASD;
5. Improving health information and surveillance systems to capture data on ASD;
6. Increasing research on the public health and service delivery aspects of ASD.

3.5 Linkage with Sustainable Development Goals

In September 2015, the UN Member States adopted the 2030 Agenda for Sustainable Development which defines 17 Sustainable Development Goals (SDGs) and 169 targets. The 193 Member States were all reminded that achieving success with SDGs will require, among other things, disability-inclusive planning and monitoring.

Disability is specifically addressed in four of the 17 goals:

- **Goal #4** is on inclusive and equitable quality of education and promotion of lifelong learning opportunities for all including PwD;
- **Goal #8** is on achieving full and productive employment and decent work, for all women and men including for PwD as well as equal pay for work of equal value;
- **Goal #11** makes provision for safe, affordable, accessible and sustainable transport systems for all persons including PwD;
- **Goal #17** aims to increase the availability of high-quality, timely and reliable data that is also disaggregated by disability in terms of the collection of data and monitoring and accountability.

4. WHO South-East Asia's Regional Strategy on ASD

The WHO/SEARO Regional Strategy on ASD (and this collaborative framework) has been developed based on the four strategic areas defined in WHO's *Mental Health Action Plan 2013-2020*. The Regional Strategy offers 31 objectives, based on both the aims highlighted in declarations and resolutions on autism and NDD as well as the four overarching strategic areas. Its purpose is to provide Member States with clear working targets to holistically address the lifespan needs of PwASD keeping in mind the needs of the stakeholders.

5. Framework for action in the four strategic areas

This document presents a framework of activities recommended for each of the 31 objectives of the Regional Strategy. The purpose of these activities is to fulfill those objectives by delivering the expected outcomes for Member States. The recommended activities, governing parameters and expected outcomes are based on the opinions of ASD stakeholders, such as researchers, experts, service providers, policy makers and parents of PwASD. The activities recommended in this document are by no means exhaustive of all possible activities that can be done to address the needs of PwASD. Member States are encouraged to participate in multilateral planning workshops to share their experiences in programmatic work addressing the lifespan needs of PwASD at regional, national and sub-national levels.

5.1 Strategy 1: Strengthening advocacy, effective leadership and governance for ASD

In order for PwASD to enjoy the same benefits and receive the same opportunities for personal growth as all other members of society, that society must first recognize the existence of barriers that are impeding PwASD. Recognition of those barriers must be followed by a sincere, collective effort by the whole nation to remove those barriers permanently. At state level, this change begins with establishing a legal framework that guarantees the rights of PwASD and their families and caregivers. This legal framework serves as a shield that protects PwASD from further denial of their rights within that society.

International agreements such as UNCRPD and ASD resolutions at the UN and WHO provide the guidelines that nations need in order to develop their domestic legal framework

In addition to strengthening a country's legal framework, the 1st strategy also emphasizes on the need to establish personnel with the authority to influence policy development, planning and program design. This would involve empowering PwASD, their parents and caregivers, as well as involving researchers and experts on autism to ensure that the human rights of PwASD and their caregivers are upheld and that services and supports address stakeholders' needs, are based on scientific evidence, easily accessible and affordable.

Table 1 in Annex 2 details the activities and indicators

5.2 Strategy 2: Providing comprehensive, integrated and responsive mental health and social care services in community-based settings for persons with ASD and their caregivers

The complex nature of ASD requires a wide range of specialized services and supports throughout their life. Invariably, such services and supports tend to be developed and based in large urban areas where professionals and specialized institutions are located. Hence, there is a need for services and supports designed for low-resource settings, which are supported by and linked to larger institutions.

Establishing clinics or special schools at each village is generally cost-prohibitive and not feasible due to a shortage of professionals. Therefore, a solution to this dilemma is to establish community-based services that provide a range of non-technical, low-cost services and supports not just for PwASD but for a larger target group, such as PwD in general. Community-based rehabilitation (CBR) is strongly advocated for by WHO.

The community-based services will ensure that people in grassroots communities have easy access to some basic services, such as primary level screening, emotional and social support, and information about proper actions to take to improve quality of life and avail benefits. CBR initiatives need to be developed in consultation with all stakeholders in order to develop services and supports that are effective and sustainable.

Table 2 in Annex 2 details the activities and indicators.

5.3 Strategy 3: Implementing strategies to minimize disabilities associated with ASD and promotion of mental, social and physical health and wellbeing in persons with ASD

The 3rd strategy emphasizes on the need to minimize the burdens experienced by PwASD, their families and their caregivers, which impact their livelihoods, income potential and in turn cause severe physical and emotional health problems. As stated in Chapter 2.3, ASD, like all disabilities, places a large economic cost on a society, which is due to the fact that ASD services are expensive[e] and the large of amount of time that caregivers need to spend in the care of PwASD.

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[e] Luengo-Fernandez, R., Leal, J., & Gray, A. M. (2012). UK research expenditure on dementia, heart disease, stroke and cancer: are levels of spending related to disease burden?. *European journal of Neurology*, *19*(1), 149-154.

Minimizing the physical burden of ASD will require detecting all associated developmental delays and comorbidities at the earliest possible stage in order to administer the necessary interventions at younger ages when the effect of intervention is longer lasting.

In addition to dealing with the communication and behavioral aspects of ASD, healthcare provision for PwASD requires an understanding that these individuals are at greater risk of secondary health conditions, age related conditions, health conditions as the result of violence and unintentional injury, as well as premature death. Other burdens suffered by PwASD and their families and caregivers that are generally overlooked include (but not limited to) the mental health of parents and siblings of PwASD and the emotional stress of being isolated from society. Policy-makers and service providers need to keep in mind that these mental health issues can aggravate physical health, whilst the physical stress of providing round-the-clock, daily care to PwASD can lead to other physical and mental health issues, as discussed in Chapter 2.1.

Table 3 in Annex 2 details the activities and indicators

5.4 Strategy 4: Strengthening information systems, evidence and research for ASD

Research plays a pivotal role in defining and achieving the national goals to improve the wellbeing of PwASD, their families and their caregivers. Sound research is needed at both pre-service and post-service stages. At the pre-service stage, researchers need to provide to policy-makers and government program developers scientifically valid solutions that are based on practical situations and needs. At the post-service stage, researchers need to monitor service delivery to determine efficacy of the service and identify reasons for any consumer dissatisfaction. It is therefore obvious that to conduct good research will require accurate surveillance systems to monitor service delivery and measure their output based on realistic and relevant performance indicators.

Up-to-date research on service delivery should also be made public so that policy-makers, primary stakeholders, civic and corporate leaders are able to make connections between public investment and public and private outcomes. In order to strengthen the evidence and research available for ASD, it is necessary to create, expand and improve the current health information and surveillance systems.

Table 4 in Annex 2 details the activities and indicators

6. Monitoring, evaluation and reporting

Monitoring and evaluation together provide the necessary data to guide strategic planning, to design and implement programs and projects, and to allocate, and re-allocate resources in better ways[f].

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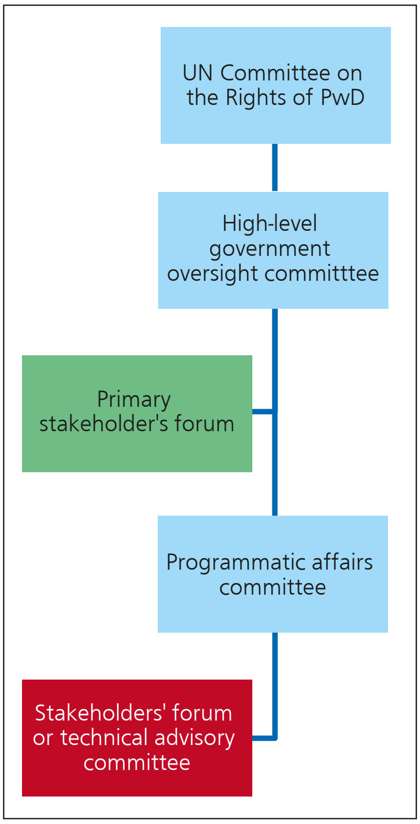
[f] Frankel, N., & Gage, A. (2007). M&E fundamentals: a self-guided minicourse.

6.1 Multi-sectoral oversight



Successful implementation of the Regional Strategy will require oversight of government initiatives at multiple levels. Oversight is needed to ensure that the planning of programmatic activities are committed to the HRBA as well as adequate adherence to technical standards. Oversight is also needed to ensure continuous surveillance of service delivery and consumer feedback, as well as periodic reporting to stakeholders.

It is proposed that Member States establish, where necessary, the following national-level committees:

High-level government oversight committee

UNCRPD requires the formation of a Committee on the Rights of Persons with Disabilities whose purpose is to monitor periodic State reports and to issue general recommendations. Three is also a requirement of UNCRPD to establish national focal points to facilitate and monitor steps taken by national and sub-national agencies to fulfill the Convention, thus ensuring oversight of UNCRPD compliance[g]. This committee would also be responsible for ensuring that the programmatic affairs committee is maintaining the HRBA in strategic and program planning.

Programmatic affairs committee

The programmatic affairs committee would be responsible for coordinating the development of national-level programs and projects to deliver services and supports to PwASD and their families and caregivers. This committee would be responsible for national strategic planning, encouraging inter-agency collaboration on multi-sectoral activities and providing financial guidance. This committee should be comprised of representatives from the various government bodies whose mandates include serving any of the lifespan needs of PwASD, as mentioned in Chapter 2.2. Examples of such government bodies include departments that deal with healthcare, education, social welfare, labor, etc.

Technical advisory committee

The technical advisory committee would be responsible for ensuring that all government programs and projects are designed in accordance to internationally acceptable technical and programmatic standards. This committee should be comprised of a wide spectrum of local autism experts (diagnosticians, therapists, special educators) as well as disability experts, self-advocates and caregivers. This committee would ensure that government activities are technically diligent and feasible prior to project implementation.

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[g] See Article 33 of UNCRPD. Available here: http://www.un.org/disabilities/convention/conventionfull.shtml

Primary stakeholders' forum

The primary stakeholders' forum would be a lobbying group that is comprised of self-advocates and parents of PwASD. This forum would be responsible for lobbying the government oversight committee for better services and supports for PwASD. They would meet the government oversight committee ideally two to four times a year to discuss progress reports submitted by the programmatic affairs committee. Another important function of this forum is to ensure that the government continues to address the needs of PwASD in a consistent manner after a change of government occurs.

This is different from the stakeholders' forum which provides a platform for sharing ideas and opinions about services and supports for PwASD and their families and caregivers. It is imperative that these two bodies be kept separate so as to avoid any potential conflicts of interest.

6.2 Analysis of service delivery

Service providers and others involved in the implementation of government programs must perform periodic and detailed analysis of activities, which is necessary for quality control and program modification. The Regional Strategy defines several general indicators that Member States are encouraged to utilize in order to monitor and evaluate their implementation of the strategy. These indicators have been further elaborated with specific indicators to measure the recommended activities stated in Chapter 5. These specific indicators have been listed in Annex 3.

6.3 Periodic reporting

One of the obligations that States commit to upon signing CRPD is periodic reporting to the Committee on the Rights of Persons with Disabilities. Additionally, the Optional Protocol affords the Committee the authority to examine individual complaints of treaty violations by a Member State. The guidelines for this reporting mechanism is exhaustive and therefore requires that States establish multi-sectoral reporting channels for a wide variety of indicators.

The first level of reporting must happen at grassroots level where service providers such as doctors, teachers and social workers interact with the recipients of government services and supports – namely, PwASD and their caregivers. These reports are usually very technical and numerical in nature but may also include qualitative feedback from the consumers, such reports should occur quarterly with adequate disaggregation of data in order to deliver a clear picture to the governing agencies.

The governing agencies are responsible for analyzing the field data in order to develop executive reports for the high-level government oversight committee. These reports should be according to the guidelines under Article 35 of UNCRPD. Additional guidelines may be offered by WHO for monitoring of the implementation of this framework to simplify the reporting.

7. Bibliography

(1) Durkin, M. S., Maenner, M. J., Meaney, F. J., Levy, S. E., DiGuiseppi, C., Nicholas, J. S., ... & Schieve, L. A. (2010). Socioeconomic inequality in the prevalence of autism spectrum disorder: evidence from a US cross-sectional study. *PLoS One*, *5*(7), e11551.

(2) Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., ... & Yasamy, M. T. (2012). Global prevalence of autism and other pervasive developmental disorders. Autism Research, 5(3), 160-179.

(3) Christensen, D. L. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR. Surveillance Summaries*, *65*.

(4) Kim, Y. S., Leventhal, B. L., Koh, Y. J., Fombonne, E., Laska, E., Lim, E. C., ... & Song, D. H. (2011). Prevalence of autism spectrum disorders in a total population sample. *American Journal of Psychiatry*.

(5) Lauritsen, M. B., Pedersen, C. B., & Mortensen, P. B. (2005). Effects of familial risk factors and place of birth on the risk of autism: a nationwide register-based study. *Journal of Child Psychology and Psychiatry*, *46*(9), 963-971.

(6) Autistica (2016). *Personal Tragedies, Public Crisis*. Available from: http://www.sciencemag.org/sites/default/files/documents/AUTISTICA%20REPORT%20-%20Personal%20Tragedies%2C%20Public%20Crisis.pdf

(7) Sigafoos, J., & Waddington, H. (2016). 6 year follow-up supports early autism intervention. *The Lancet*, *388*(10059), 2454-2455.

(8) Metts, R. (2004, November). Disability and development. In *Background Paper Prepared for the Disability and Development Meeting, World Bank*.

(9) Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA pediatrics, 168(8), 721-728.

(10) The Human Rights Based Approach to Development Cooperation: Towards a Common Understanding Among UN Agencies. Retrieved from: http://hrbaportal.org/the-human-rights-based-approach-to-development-cooperation-towards-a-common-understanding-among-un-agencies

(11) Fox, J. H., Burkle, F. M., Bass, J., Pia, F. A., Epstein, J. L., & Markenson, D. (2012). The effectiveness of psychological first aid as a disaster intervention tool: research analysis of peer-reviewed literature from 1990-2010. *Disaster medicine and public health preparedness*, *6*(03), 247-252.

(12) Luengo-Fernandez, R., Leal, J., & Gray, A. M. (2012). UK research expenditure on dementia, heart disease, stroke and cancer: are levels of spending related to disease burden?. European journal of Neurology, 19(1), 149-154.

(13) Tager-Flusberg, H. (2007). Evaluating the theory-of-mind hypothesis of autism. *Current Directions in Psychological Science*, *16*(6), 311-315.

(14) Gertler, P. J., Martinez, S., Premand, P., Rawlings, L. B., & Vermeersch, C. M. (2011). Impact evaluation in practice. World Bank Publications.

(15) Institute for Community Inclusion and Shuchona Foundation, *National Strategic Plan for Neurodevelopmental Disorders* (2016).

(16) Frankel, N., & Gage, A. (2007). M&E fundamentals: a self-guided minicourse.

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Annex-1

Summary of WHO/SEARO's Regional Strategy on ASD

Ref. No.	Objective
Strategy #1 – Strengthening advocacy, effective leadership and governance for Autism Spectrum Disorder	
OBJ 1-01	Develop, strengthen, update and implement national policies, legislation, strategies, plans and programs to address the needs of persons with ASD and their caregivers, in line with evidence, best practices, the Convention on the Rights of Persons with Disabilities and other international and regional human rights conventions.
OBJ 1-02	Establish a Rights-Based approach for helping those with ASD and their caregivers which should include appropriate institutional, legal, financial and service arrangements (human resource, technological, logistic), including an institutional focal point.
OBJ 1-03	Involve caregivers and their organizations, civil society/ non-government organizations involved in this subject area to help to create and implement more effective and accountable policies, legislations, and services for ASD in a manner consistent with UN Conventions (e.g. Convention on the Rights of Persons with Disabilities, United Nations Convention on the Rights of the Child) and other international and regional human rights instruments.
OBJ 1-04	Promote advocacy for equity dignity and human rights of people with ASD through leadership and commitment by governments and nongovernmental organizations and by persons with ASD, and their caregivers.
OBJ 1-05	Integrate ASD as an agenda in the existing national legislations, policies, plans and programs.
OBJ 1-06	Develop and implement, sensitization programs through media and other means on issues relating to ASD, in consultation with all stakeholders.
OBJ 1-07	Allocate appropriate budgets, across all relevant sectors, required to implement plans and actions to address ASD.
OBJ 1-08	Include issues related to ASD within all priority policies, laws, programs and partnerships. Some of the key areas include health (e.g. child health, early childhood programs, maternal health), education, employment, disability, the judicial system, human rights protection, social security , poverty reduction and development
OBJ 1-09	Establish legal and regulatory mechanisms to promote the rights and access to all services for persons with ASD.
OBJ 1-10	Establish and maintain provisions to ensure that all persons with ASD have access to supported decision making in accordance with UN Convention on the Rights of Persons with Disabilities (UNCRPD).
OBJ 1-11	Establish, promote and support parent/caregiver organizations and groups.
Strategy #2 – Providing comprehensive, integrated and responsive mental health and social care services in community-based settings for persons with ASD and their caregivers	
OBJ 2-01	Develop comprehensive community-based health and social care services for persons with ASD, their families and caregivers preferably through integration with primary care and hospital care, enabling such care to be available within and across health and social services.
OBJ 2-02	Ensure continuity of care between different providers and levels of the care system, effective collaboration between formal and informal care providers and the promotion of self-care.

Ref. No.	Objective
OBJ 2-03	Establish community-based service delivery that puts the emphasis on health promotion, rehabilitation, care and support including promotion of self-care that aims at meeting social, mental and physical health care needs of those with ASD to achieve optimal functioning, quality of life and their own aspirations and goals.
OBJ 2-04	Develop and mainstream monitoring and promotion of early detection and intervention programs into health, child development and social care services for ASD.
OBJ 2-05	Develop or adapt protocols and practices, for persons with ASD across the lifespan.
OBJ 2-06	Provide services to support individuals at different stages of the life course and, as appropriate, facilitate their access to housing and educational opportunities and employment, participation in community activities, programs and meaningful activities and recognize the contribution of adults living with ASD in the workforce, continuing to support workforce participation in partnership with the non-government and private sector.
OBJ 2-07	Ensure services and support for families and caregivers through the health and social services sector by provision of social support, respite care and promotion of caregiver support groups.
OBJ 2-08	Establish greater collaboration between "informal" health care providers, traditional or indigenous practitioners, as well as religious leaders, school teachers etc. and nongovernmental and caregiver organizations.
OBJ 2-09	Ensure the appropriate number and equitable distribution of competent, sensitive and appropriately skilled professionals and workers who can offer culturally appropriate services for persons with ASD. Improving capacity of care workers in the field to promote early detection and management of ASD, and deliver evidence-based psychosocial interventions and referral as appropriate to other levels of care and services.
OBJ 2-10	Actively involve persons affected by ASD, their families, caregiver and organizations that provide services on ASD at all levels of the system of care.
OBJ 2-11	Remove barriers to adequate social protection, regulated insurance coverage, accessible health, education and social care facilities, services and information for persons with ASD and proactively identifying and redressing disparities in access to services.
OBJ 2-12	Provide appropriate and age/ ability based services for all round education for persons with ASD across the lifespan.
OBJ 2-13	Provide adequate services for all mental health needs and psycho-social wellbeing for persons with ASD and their caregivers.
Strategy #3 – Implementing strategies to minimize disabilities associated with ASD and promotion of mental, social and physical health and well-being in persons with ASD	
OBJ 3-01	Develop and implement multi-sectoral strategies for promotion of physical, and psychosocial well-being of persons with ASD and their families.
OBJ 3-02	Establish interventions to minimize disabilities and comorbidities associated with ASD and ensure provision of responsive services for the specific needs across the lifespan are integrated into the broad array of national policies and programs (e.g. national health, health promotion and mental health policies and programs).
OBJ 3-03	Provide mental health promotion and support services to persons with ASD, their families and caregivers that include issues such as social inclusion, participation and de-stigmatization.
OBJ 3-04	Ensure early detection of persons with ASD along with provision of early intervention through evidence-based interventions based in the community.

Ref. No.	**Objective**
Strategy #4 – Strengthening information systems, evidence and research for ASD	
OBJ 4-01	Create, expand and improve health information and surveillance systems to gather appropriate sex- and age-disaggregated data, as well as other relevant information on ASD, collate and routinely report findings. The data could also include: a) Epidemiological data, b) Coverage of policy and legislations, programs that have been implemented and programs that are continuing, needs and unmet needs, direct and indirect costs, barriers and quality of life, programs to promote health and functioning including other systems of health and care and provide support to families of those with ASD and utilization of rate and pattern of services available for ASD using the ICF and the ICD. c) Effective programs and best practices developed in other countries in order to ensure that data are nationally relevant and internationally comparable.
OBJ 4-02	Promote research on ASD through improving research capacity and academic collaboration and establish centers of excellence.
OBJ 4-03	Provide priority for social and public health aspects and operational research with direct relevance to development and implementation of community-based models of early detection and early interventions. This requires engagement of all relevant stakeholders, including persons with ASD, their caregivers and service providers of both government and non-government sectors.

Annex-2

Outcomes, Activities and Parameters for implementing Regional Stately

Table 1: Strategy 1: Strengthening advocacy, effective leadership and governance for Autism Spectrum Disorder

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 1-01	Member States should have the necessary legal framework and policy guidelines that ensure a human rights based approach to serving the needs of PwASD and their families.	**ACT 1-01-01** Review all existing laws and policies[1] pertaining to disability affairs and mental health	Addressing ASD issues should be stated clearly OR covered under disability-specific clauses OR evident in the general language of any given law or policy. The laws and policies should also be reflective of the current scientific understanding of ASD.
		ACT 1-01-02 Amend existing laws and policies or replace them with new ones that are reflective of the needs of PwASD and their families.	The laws and policies should: 1) incorporate UNCRPD as a direct source of rights of PwD and government's obligations towards them; 2) directly articulate the unique lifespan needs of PwASD and the evidence-based practices to address them.
OBJ 1-02	PwASD and their families should benefit from living in a society that is attentive of their human rights and is steadfast in upholding them.	**ACT 1-02-01** Establish a high-level government oversight committee for disability affairs	This oversight committee should be empowered to hold any government agency accountable for failing to uphold the human rights of all PwD.[2]
OBJ 1-03	DPOs, parents' organizations and other ASD-focused organizations should be consulted on any policy and service development initiative.	**ACT 1-03-01** Establish a forum of disability-focused NGOs to assist the government in disability-sensitive development planning	The high-level government oversight committee should meet with the forum of disability-focused NGOs at least four times a year.
		ACT 1-03-02 Establish a technical advisory committee to provide technical guidance on government programs and projects	Government should have regulations in its planning and financing processes that requires clearance from the technical advisory committee for approval of any government program or project.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 1-04	Society should eradicate any discriminatory or disabling attitude that prevents PwASD from enjoying the same basic rights and dignity in their lives as they do.	**ACT 1-04-01** Conduct Public Service Campaigns to express positive messages about PwASD	Positive messages should encourage family members to seek professional assistance, as well as help de-stigmatize the condition and enable greater social inclusion.
		ACT 1-04-02 Mobilize local government officials and grassroots community leaders[3] to incorporate ASD awareness drives in local programs	Examples of local programs include school programs, community programs, healthcare programs, rural economic development programs, etc.
OBJ 1-05	Disability-inclusive national and ministerial planning must become regular practice.	**ACT 1-05-01** Establish a programmatic affairs committee[4] comprised of officials from relevant ministries[5] to ensure ASD concerns are part of disability-inclusive ministerial planning	The programmatic affairs committee should be conferred with the necessary authority to guide disability-inclusive planning within all member ministries.
		ACT 1-05-02 Develop a long-term national strategic plan for addressing the lifespan needs of PwASD and an associated action plan for implementing it	The national strategic plan should promote collaboration between member ministries in order to achieve convergence on cross-cutting lifespan needs, such as: 1) healthcare-and-education 2) education-and-employment 3) employment-and-social support, etc.
OBJ 1-06	Society should be made aware of and sensitized to the daily challenges faced by PwASD, their parents and caregivers.	**ACT 1-06-01** Produce mass-media programs and live performances to educate the public about the lives of PwASD	Examples include TV shows, short films, full-feature films, documentaries, radio discussions, theatrical plays, street skits, puppet shows, etc. These should be produced in local languages or dialects and utilize high standards in artistry and writing to evoke positive changes in social attitudes towards this condition.
		ACT 1-06-02 Produce sensitization messages that are scientifically accurate using local celebrities to educate the public about ASD	The objective re-education of the public is to reduce stigma and change the attitude from an "us versus them" attitude to one of communal support. Messages should be broadcast on TV, radio, YouTube, Facebook and other social media outlets.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 1-07	Budgets for ASD-focused government projects should be distinguishable in ministerial budgets.	**ACT 1-07-01** Establish a sub-committee under the aforementioned programmatic affairs committee to review ASD-focused budgetary plans and project proposals from member ministries	ASD-focused project proposals and budgetary plans should be cleared by the programmatic affairs committee as well as by the technical advisory committee before clearance is given for implementation.
OBJ 1-08	Government should be acutely aware of the lifespan needs of PwASD, including general issues as well newly emerging issues	**ACT 1-08-01** Build up the knowledge of key mid-to-high level government officials about ASD, as well as appoint technocrats to strategic government positions, if and where necessary	Key government sectors such as healthcare and education should have personnel who are sufficiently knowledgeable about ASD in order to guide ministerial planning for services and supports. Such officials need to remain in those positions long enough to establish sustainable mainstream services and supports for PwASD and their families.
		ACT 1-08-02 Organize or participate in periodic discussions with both local and international experts on ASD to ensure emerging issues are addressed	These discussions should be guided by the technical advisory committee.
OBJ 1-09	PwASD and their families should have the mechanisms at their disposal to pursue legal action against those who violate their rights to services, supports and opportunities.	**ACT 1-09-01** Establish a complaints mechanism for receiving, documenting and redirecting complaints and suggestions of PwASD or their caregivers to the relevant authorities for resolution	The mechanism should utilize modern facilities for mass communication such as social media, websites and call-centers.
		ACT 1-09-02 Establish a national legal aid call-center for PwASD and their families and caregivers	The scope of this call-center could be expanded to provide the same service to all PwD.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 1-10	PwASD and their families and caregivers should have easy access to evidence-based advice before making decisions that are in their best interest.	**ACT 1-10-01** Establish a consultative body comprised of lawyers, local leaders, teachers, experts, representatives from civil society, self-advocates, parents and caregivers to provide supported decision-making services to PwASD	This body should ensure that PwASD or their families and caregivers are able to access their services easily and that they are affordable (if such services are not offered freely).
		ACT 1-10-02 Set up an online forum for information that directly addresses existing myths and beliefs that are scientifically incorrect	The information posted in this forum should be easily distinguishable from hearsay and marketing ploys for services and treatment that claim to cure autism.
OBJ 1-11	PwASD and their families should have an empowered platform to lobby their country's policy makers for fulfillment of their rights in all sectors of life.	**ACT 1-11-01** Establish a lobbying group comprised only of self-advocates and parents of PwASD[6]	This group should have direct access to their leaders and local representatives on a regular basis.

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[1] Suggested legal and policy areas for review are healthcare, education, labor, social security, women's rights, children's rights, property rights, criminal justice, etc.

[2] See Chapter 6.1 of this document for more information about this suggested committee.

[3] In India, government awareness and sensitization initiatives are often channeled through village *panchayats* whose leaders have tremendous influence over their constituents and have proven to be highly effective in bringing about changes to social attitudes and implementing new policies and initiatives.

[4] See Chapter 6.1 of this document for more information about this suggested committee.

[5] Examples of relevant ministries include healthcare, education, social welfare, labor, commerce, sports, etc.

[6] This lobbying group would essentially be a forum of primary stakeholders, which has been more thoroughly described in Chapter 6.1. There is one such group in Bangladesh called the "Parents' Forum for the Differently Able".

Table 2: Strategy 2: Providing comprehensive, integrated and responsive mental health and social care services in community-based settings for persons with ASD and their caregivers

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 2-01	Community-based services should be sustainable, holistic and linked to various support programs that may be medical and non-medical in nature, depending on the needs of an individual or his/her family.	**ACT 2-01-01** Establish community-based primary healthcare services	These should be limited to non-technical services such as: • guidance for expecting mothers on safe pregnancy and safe delivery • guidance for monitoring child development • providing emotional support and assurance to parents • explaining treatment and other service/support options to the parents in a positive manner • referring caregivers to the appropriate services and supports
		ACT 2-01-02 Establish community-based social services	These services could be combined with the community-based primary healthcare service and focus on: • documentation of cases • notification and referral to relevant service providers • providing social and emotional support and arranging peer support for parents • guidance for registration with the relevant authorities in order to get welfare assistance • providing daycare and respite care services to working caregivers
OBJ 2-02	Disability-focused Government agencies should provide proxy services to coordinate the care of PwASD throughout their lives.	**ACT 2-02-01** Establish "rehabilitation coordinators"[1] as a social service for PwASD for grassroots communities	Rehabilitation coordinators could be medical or non-medical professionals with thorough knowledge about the needs of PwASD and how and where to avail the right services and supports to ease their burdens and augment their lives.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 2-03	Member States should try to utilize whatever resources they have at grassroots level to help PwASD overcome the challenges posed by their condition.	**ACT 2-03-01** Ensure that PwASD receive training at community-level on a variety of vital life skills, such as: • Daily living skills at pre-primary and primary schools • Social and communication skills through peer-bonding opportunities at youth clubs • Physical fitness at sports clubs	Member States should instruct government agencies with grassroots level resources to develop at least one service that addresses a need of PwASD and deliver them through those resources.
OBJ 2-04	Parents should be aware of the expected milestones (physical and behavioral) in a child's development. Member States should have a mechanism in place to detect developmental delays in children from all over the country as early as 18 months. Parents of newly identified PwASD should be instilled with hope and a positive attitude about the future of their children.	**ACT 2-04-01** Train expecting mothers within the vicinity of community primary healthcare service providers on safe pregnancy	Expecting mothers should be taught about nutritional intake, how to monitor their weight gain, how to deal with persistent illnesses such as colds and coughs, how to monitor fetal movements, how to avoid trauma, and identifying the signs of preeclampsia.
		ACT 2-04-02 Develop a standard guide[2] for parents to monitor their children's development	Guide should be non-technical and easy to understand without the need for any formal training, such as in the form of a self-help pictorial. Guide should be immediately made available to new mothers.
		ACT 2-04-03 Ensure liaison with local influential persons to provide emotional support to parents of newly identified PwASD	Examples of influential persons include community leaders, religious leaders and school-teachers. This service should be a component of community social services.
OBJ 2-05	Caregivers of PwASD should be well-informed about the proper actions that need to be taken at critical stages in the life of an individual with ASD in order to improve his/her quality of life.	**ACT 2-05-01** Develop clear, simple protocols for caregivers of PwASD, to be disseminated through community social services	Examples of key protocols should include: • Early identification protocol • Child development protocol • Education protocol • Transitioning to mainstream school • Skill development protocol • Employment and workplace protocol • Social participation and inclusion protocol

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 2-06	Member States should ensure the availability of qualified service providers who can facilitate PwASD and their caregivers at critical stages in their lives.	**ACT 2-06-01** Ensure the availability of qualified special educators to guide the educational development and mainstreaming of PwASD into the regular education system	Professional qualifications in special education should be offered at a sufficient number of tertiary level institutes. Primary and secondary schools throughout the country should each have at least one special educator.
		ACT 2-06-02 Ensure the availability of employment specialists to assist PwASD in acquiring jobs	These specialists should be able to advise PwASD in developing marketable skills, finding employment suitable to them, negotiate their employment contracts, assist them in managing their workplace behavior, and advise employers on workplace modifications.
OBJ 2-07	Member States should strive to minimize as much as possible the financial and physical stress on caregivers.	**ACT 2-07-01** Provide income support and/or welfare support to families and caregivers of PwASD	The support should be sufficient to offset the loss of income typically incurred by the families and caregivers of PwASD as a result of the time spent in caring for them.
		ACT 2-07-02 Ensure the availability of daycare and respite care services for caregivers of PwASD at a subsidized cost	These services could be center-based within the community or home-based available through a referral system coordinated by community social services.
		ACT 2-07-03 Establish caregiver support groups at community level to educate and support new caregivers	Trainings provided by these caregiver support groups should involve the use of standardized resource materials on topics such as daily living skills, social and communication skills, etc.
OBJ 2-08	Member States should utilize to the fullest extent possible the benefits offered by informal healthcare providers, as well as non-healthcare and non-governmental service providers.	**ACT 2-08-01** Establish a regulatory body for the practice of alternative medicine	This body's regulations should explicitly cover the use of alternative medicine to treat the symptoms and health conditions associated with ASD.
		ACT 2-08-02 Conduct awareness and sensitization drives to combat myths and beliefs about ASD	These drives should be designed and executed in collaboration with traditional healers and religious leaders.
		ACT 2-08-03 Conduct a resource mapping of all NGOs specializing in ASD and the services they provide to PwASD, their families and their caregivers	This information should be incorporated in the national directory of service providers suggested in ACT 3-02-04.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 2-09	Member States should ensure that there are sufficient community primary healthcare providers to effectively and efficiently serve the PwASD and their caregivers within their vicinity.	**ACT 2-09-01** Develop training module for community primary healthcare providers, covering services suggested in ACT 2-01-01, as well as how to deliver community-based interventions and to teach caregivers about home-based interventions	Module should ideally include culturally appropriate resources, a self-help manual and instructional videos.
		ACT 2-09-02 Train existing primary healthcare providers and incorporate training module into their pre-service training	Primary healthcare providers should be randomly tested to determine efficacy of the training module and, if necessary, be sent for supplementary trainings.
OBJ 2-10	Parents and caregivers of PwASD, DPOs and ASD-focused NGOs should be utilized to the fullest extent possible to train other parents and caregivers of PwASD.	**ACT 2-10-01** Develop a training module for TOTs for parents of PwASD, covering topics such as monitoring child development, home-based interventions and managing socially unacceptable behavior	Module should ideally include culturally appropriate resources, a self-help manual and instructional videos
		ACT 2-10-02 Conduct TOTs for parents of PwASD	Member States should develop a sufficient number of master-trainers to have a nationwide impact within five years' time. Master-trainers should undergo structured and well-monitored supervision to determine the efficacy of the training module and be required to attend supplementary trainings on an annual basis.
		ACT 2-10-03 Organize peer training sessions for new parents and caregivers of PwASD	Peer training sessions should be organized by community social service providers. Master-trainers should receive a stipend and have their travel, accommodation and daily expenses covered.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 2-11	Member States should strive to minimize the economic cost on society caused by ASD through the use of both direct and indirect initiatives that empower PwASD and their caregivers.	**ACT 2-11-01** Develop government-subsidized health insurance policies that cover regular health checkups and key interventions	These policies should allow for PwASD to avail the treatments necessary to quickly improve their quality of life.
		ACT 2-11-02 Establish outreach healthcare services for PwASD living in remote areas	These services should be affordable and effective, but used as a last resort after clinic, community and home-based interventions.
		ACT 2-11-03 Ensure that academically qualified PwASD are not barred from admission to mainstream schools due to lack of support or prejudice[3]	School principals, administrators, teachers and support staff need to be sensitized about PwASD and to respect their right to education. School teachers need to be trained on classroom management, dealing with structured and unstructured transition times, curriculum modification and behavior management techniques for working with PwASD in their classrooms.
		ACT 2-11-04 Develop ASD-compatible information and communications technology, such as apps, software, brain development games, websites and mobile devices.	Such technology ideally should be free-to-use, culturally appropriate and scientifically proven to be beneficial for PwASD, while also ensuring that the use of such technology does not prevent PwASD from engaging in appropriate social interaction with those around them.
		ACT 2-11-05 Provide allowances and, if feasible, food rations to PwASD who are unable to get jobs to sustain themselves	These allowances and rations need to be sufficient enough to cover basic living needs of PwASD.
OBJ 2-12	Member States should strive to ensure that PwASD receive learning opportunities that will give them the skills, knowledge and qualifications they need to pursue a livelihood.	**ACT 2-12-01** Ensure the availability of a wide variety of educational opportunities for PwASD within their community and within short commutes from their homes	Educational opportunities should include but not be limited to: ☐ Guaranteed placement in mainstream schools ☐ Scholarships to private schools ☐ Online courses ☐ Non-formal learning modules

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 2-13	Member States should strive to ensure that PwASD, their parents and their caregivers receive some form of psychosocial care to mitigate mental health issues such as anxiety, stress, depression, etc.	**ACT 2-13-01** Develop a training module for TOTs for community primary healthcare and social service providers on providing, among other things, psychological first aid to PwASD, their parents, their siblings, members of their household and other caregivers[4]	Module should ideally include culturally appropriate resources, a self-help manual and instructional videos.
		ACT 2-13-02 Conduct TOTs for community primary healthcare and social service providers	Member States should develop a sufficient number of master-trainers to have a nationwide impact within five years' time. Master-trainers should undergo random supervision to determine the efficacy of the training module and, if necessary, be sent for supplementary trainings.

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[1] The Government of Bangladesh trains individuals in each village (or cluster of villages) to become *krishi bondhu* or "farming friends" to provide advice to local farmers on agricultural issues. Similarly, BRAC operates an Internet-based info-service called *"Maya Apa"* to advise expecting mothers on safe pregnancy, safe delivery and healthy child development. Member States could establish similar services to either address the specific concerns pertaining to ASD or to expand the scope of the service to include all neurodevelopmental disorders or even all disabilities.

[2] An example of such a guide is the *Pink Book* used in Thailand.

[3] Every effort should also be made to ensure that ASD students with below average intellectual functioning and or learning disabilities are also given maximum opportunity to engage in regular classrooms with special education support in the classroom.

[4] The use of non-professionals (i.e. those who are neither psychologists nor psychiatrists) to provide psychosocial care has been known to be doable and effective as evidenced by their use during post-disaster situations to help survivors deal with trauma. Sufficient evidence for psychological first aid is widely supported by available objective observations and expert opinion. For more information, read: Fox, J. H., Burkle, F. M., Bass, J., Pia, F. A., Epstein, J. L., & Markenson, D. (2012). The effectiveness of psychological first aid as a disaster intervention tool: research analysis of peer-reviewed literature from 1990-2010. *Disaster medicine and public health preparedness*, *6*(03), 247-252.

Table 3: Strategy 3: Implementing strategies to minimize disabilities associated with ASD and promotion of mental, social and physical health and well-being in persons with ASD

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 3-01	Member States should develop cost-effective and sustainable strategies to promote social participation and inclusion of PwASD and their families.	**ACT 3-01-01** Establish one-stop service centers for PwASD and their caregivers, such as: • Disability service centers • Care centers for girls and mothers • Community-based primary healthcare centers[1] • Community-based social service centers[2]	Such centers should ideally be set up by building up the capacities of existing facilities to provide some diagnostic and rehabilitative services to PwASD, counselling, social support, respite care, as well as information about available services, supports and benefits for PwASD and their families and caregivers.
		ACT 3-01-02 Ensure the participation and inclusion of PwASD in different types of social clubs, such as: • Daycare and preschool centers • Youth clubs • Sports clubs and camps • Educational camps	The main objectives of these social clubs should be to provide peer bonding opportunities to PwASD and to sensitize the community.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 3-02	Member States should ensure availability of services that will minimize the burdens experienced by PwASD, their families and their caregivers. These services should be mainstreamed so that they are regularly funded and easy to access throughout the country.	**ACT 3-02-01** Ensure availability of qualified professionals who can offer evidence-based interventions[3] that focus on enhancing social communication skills, reduce challenging behaviors and increase self-care skills, incorporating components from these models of treatment : • Applied Behavioral Analysis (ABA) Therapy • Early Start Denver Model (ESDM) Therapy • Pivotal Response Treatment (PRT) • Verbal Behavior Treatment (VBT) • Relationship Development Intervention (RDI) • Floortime • Training and Education of Autistic and Related Communication Handicapped Children (TEACHH) • Picture Exchange Communication System (PECS)	This could be achieved either by building up the capacity of existing professionals (e.g. psychologists, psychiatrists, behavior specialists, special educators, occupational therapists and speech-and-language therapists) or by developing new human resources through scholarships, study-and-work programs and incentivized employment programs. These professionals should also receive continued professional development so that they are up-to-date with the latest therapeutic procedures, tools and equipment.
		ACT 3-02-02 Ensure the availability of qualified allied health professionals, such as: • Physiotherapists • Occupational therapists • Speech-and-language therapists • Dietitians/nutritionists • Prosthetists • Audiologists • Recreational therapists	These professionals provide a variety of sensory, motor, communication or biomedical interventions that can reduce more than 50% of the physiological challenges faced by PwASD. This could be achieved either by building up the capacity of existing professionals or by developing new human resources through scholarships, study-and-work programs and incentivized employment programs. These professionals should also receive continued professional development so that they are up-to-date with the latest therapeutic procedures, tools and equipment.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
		ACT 3-02-03 Establish a regulatory body for standardization of professionals, including setting up procedures for certifying professional courses and licensing service providers, all which meet international training standards	This body should regulate the professions of psychologists, special educators and allied health professionals for the country. Institutions in the region should create a recommended list and also provide special scholarships and training opportunities to said institutions.
		ACT 3-02-04 Create a comprehensive directory of intervention service providers	Directory should state exactly the types of interventions offered by each service provider as well as their credentials.
		ACT 3-02-05 Ensure availability of common medications to address typical comorbidities and other health issues associated with ASD, as well as ensure that physicians prescribing them are equipped with a medication management checklist[4] to guide them.	Typical conditions include ADHD, epilepsy, anxiety, insomnia, bipolar disorder and gastrointestinal issues – all of which can be managed with reliable and safe medication.
		ACT 3-02-06 Ensure that PwASD receive regular comprehensive health checkups throughout their lives in order to identify and treat any comorbidities that may manifest at different stages in their lives	Health checkups should be done at least annually and cover physical, psychological and behavioral assessment.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 3-03	PwASD should be assisted in managing psychological difficulties[5] including any socially challenging behavior that may manifest at different stages in their lives[6]. Caregivers of PwASD as well as service providers should understand the full range of socially challenging behaviors so that they understand the purpose of those behaviors and can learn skills on how to teach their dependents in social situations. Member States should be attentive towards the psychological, emotional and social needs of parents and caregivers of PwASD, the neglect of which will have devastating consequences on the wellbeing of PwASD and the integrity of their families.	**ACT 3-03-01** Ensure availability of qualified psychologists, psychiatrists and counselors to provide psychosocial support to PwASD, their parents and caregivers, as well as to help PwASD manage and modify socially unacceptable behavior	This could be achieved either by building up the capacity of existing professionals or by developing new human resources through scholarships, study-and-work programs and incentivized employment programs. These professionals should also receive continued professional development so that they are up-to-date with the latest counseling techniques and protocols.
		ACT 3-03-02 Produce resource materials on adolescent and young adult behavior for caregivers, service providers and employers	Emphasis should be on the causes/triggers of challenging behavior and techniques to manage such behavior.
		ACT 3-03-03 Develop and implement targeted sensitization drives for specific groups of people in order to destigmatize ASD in their minds	Groups to be targeted should include religious leaders, local leaders, school teachers, students, journalists, and industrial and professional associations.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 3-04	Member States should strive to identify PwASD as early as 24 months. Member States should ensure that children with any detected developmental delays are placed in early intervention programs without any delays.	**ACT 3-04-01** Develop standardized screening tools[7] to be used by mid-level healthcare providers[8]	Screening tools need to be validated and tested for reliability. Tiered screening helps to minimize the workload on tertiary-level institutes[9] where the final diagnosis and assessment of ASD would generally take place.
		ACT 3-04-02 Ensure the availability of qualified healthcare professionals capable of performing diagnosis and assessment of ASD	Health professionals that typically deal with ASD include child psychologists, child psychiatrists, developmental pediatrician and pediatric neurologists.
		ACT 3-04-03 Develop resource materials designed for caregivers and community-based service providers on home and community-based interventions	The resource materials should focus only on those interventions that are easy to learn for laymen and require easy-to-acquire, affordable tools and equipment[10].

[1] See ACT 2-01-01 for more information.

[2] See ACT 2-01-02 for more information.

[3] The interventions listed here are scientifically proven to be the most effective in minimizing many of the behavioral and communication challenges faced by PwASD.

[4] In South Korea, the physicians who prescribe medication for PwASD utilize the Aberrant Behavior Checklist.

[5] High-functioning PwASD tend to have difficulties processing the way people behave with them or understanding the way people normally act in everyday scenarios. PwASD may react negatively to normal human conduct and behavior, which ultimately leads to sadness, depression or anger. The ability to discern other's intentions, desires and beliefs is called "theory of mind" and typically develops at about age four or five but this development is deficient in PwASD. For more information, read: Tager-Flusberg, H. (2007). Evaluating the theory-of-mind hypothesis of autism. *Current Directions in Psychological Science*, *16*(6), 311-315.

[6] PwASD typically exhibit rage and violent behavior during adolescence and young adulthood.

[7] Some well-known screening tools are the Modified Checklist for Autism in Toddlers (M-CHAT), the Social Communication Questionnaire (SCQ), the Autism Spectrum Screening Questionnaire (ASSQ) and the Screening Tool for Autism in Toddlers and Young Children (STAT).

[8] In South Korea, pediatricians at mid-level (i.e. district and sub-district levels) hospitals and clinics perform screening for ASD using the Social Communication Questionnaire (SCQ).

[9] The Institute for Pediatric Neurodisorder & Autism (IPNA) in Bangladesh asserts that nearly 50% of the patients they receive thinking that they have neurodevelopmental issues are mild, temporary conditions brought on by other physiological factors such as metabolic problems.

[10] Examples of home-based interventions include structured home routines, use of visual cues as communication, creating a calm and quiet zone in the home, creating a learning zone in the home with minimal distractions and sensory stimulation, etc.

Table 4: Strategy 4: Strengthening information systems, evidence and research for ASD

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 4-01	Member States should have up-to-date data (no older than 6 months) on ASD prevalence, service delivery and feedback.	**ACT 4-01-01** Develop a list of indicators for each government service/support pertaining to the needs of PwASD and their families	Every service, support or activity devised to address a particular need of PwASD and/or their families should be monitored and evaluated on the basis of a quantifiable and measurable indicators.
		ACT 4-01-02 Develop standardized reporting procedures for service providers to submit data on the aforementioned ASD indicators	Reporting procedures should include standard documentation, timetables and verification protocols.
		ACT 4-01-03 Set measures in place to ensure that service providers deliver timely reports	Measures need to be fair, effective and firmly enforced in order to establish routine timely reporting from service providers across all sectors of the government. Government should ensure that service providers are reporting data truthfully by conducting random spot checks and third-party verification.
		ACT 4-02-04 Establish a centralized database for service providers to feed their data on ASD service delivery	The centralized database should ideally be IT-based and maintained by a high-level government authority responsible for the affairs of PwASD[1].
OBJ 4-02	Academics should engage in and publish viable research on ASD, particularly in their respective countries. Research on ASD should be conducted in collaboration with service providers in order to collect data on prevalence, service efficacy and consumer feedback.	**ACT 4-02-01** Offer scholarships for postgraduate studies (i.e. masters and doctoral degrees) and/or study-and-work programs in ASD and associated subjects from renowned institutes abroad	The scholarships should only be offered with the condition that the recipients return back to their country to work in the field of autism spectrum disorder for a reasonable length of time. Scholarships should prioritize learning in ASD diagnosis and management.
		ACT 4-02-02 Create partnerships with renowned institutes for ASD-related scholarship and training[2] to develop professional and vocational programs for local service providers	Partnerships should include training of instructors, development of culturally sensitive resource materials and periodic evaluation and improvement of program delivery.
		ACT 4-02-03 Establish one or more centers of excellence to specialize in research on ASD	ASD centers could be established within existing academic institutes or as stand-alone facilities. ASD centers of excellence will require guaranteed funding for the first few years until they can sustain themselves financially.

Objective	Expected outcomes for Member States	Recommended activities	Parameters to govern recommended activities
OBJ 4-03	The knowledge, experience and insight of all stakeholders of ASD should be accessed and shared with each other in order to develop community-based models for early identification and early intervention.	**ACT 4-03-01** Establish a stakeholders' forum that is facilitated by the government and consists of PwASD, their parents and caregivers, and service providers to meet, discuss and develop community-based models for early identification and early intervention.	This forum would be most effective with a web-based meeting place where they can rapidly share ideas and opinions, as well as with a few face-to-face congregations per year to decide on key issues. Forum should be administered by a convening president, a general secretary and a program manager[3].
		ACT 4-03-02 Sponsor the piloting of community-based models developed by the stakeholders' forum	Small-scale pilots are vital for determining the efficacy and feasibility of community-based models before nationwide replication. Stakeholders' forum should modify the models based on data acquired from monitoring and evaluating them.

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[1] In most countries, such an authority would usually be the government official/agency responsible for disability affairs.

[2] See Appendix 3 for a list of ASD-focused institutes and organizations in the South-East Asia Region.

[3] The program manager needs to be someone experienced in devising socioeconomic development programs at national level.

Annex-3

List of indicators for evaluation ASD-focused activities

Recommended actions	Responsible sectors of government	Indicators	Frequency of data collection
ACT 1-01-02	Disability affairs Legislature	• List of amended/new laws and policies that address the needs of PwASD and their families	Annually
ACT 1-02-01	Legislature Disability affairs	• Number of meetings with the governmental and non-governmental committees that deal with ASD affairs • Number of reports on disability affairs submitted to the UN and other international organizations	Annually Annually
ACT 1-03-01	Disability affairs Legislature	• Number of meeting between the parliamentary committee on disability affairs and the forum for disability-focused NGOs	Annually
ACT 1-04-01	Information & media Disability affairs	• Number of Public Service Campaigns	Annually
ACT 1-05-01	Disability affairs	• List of members of the programmatic affairs committee	Annually
ACT 1-05-02	Disability affairs	• List of government projects in line with the national strategic plan • List of government projects not in line with the national strategic plan	Biannually Biannually
ACT 1-06-01	Information	• List of media programs about PwASD and their families	Annually
ACT 1-06-02	Information	• Number of sensitization messages for the public	Annually
ACT 1-07-01	Finance	• Number of ASD-focused programs and projects, disaggregated by ministry • Total value of ASD-focused programs and projects, disaggregated by ministry and lifespan need	Annually Annually
ACT 1-08-01	Disability affairs	• List of trained/qualified focal points in the government for ASD affairs, disaggregated by ministry	Annually
ACT 1-08-02	Disability affairs	• Number of ASD-focused seminars held with government focal points for ASD affairs	Annually
ACT 1-09-01	Disability affairs	• Number of calls received for legal aid	Quarterly
ACT 1-09-02	Disability affairs	• Number of documented complaints from PwASD or their families • Number of resolved complaints	Quarterly Quarterly
ACT 1-10-01	Disability affairs	• List of members of the supported decision making trust	Annually
ACT 1-11-01	Disability affairs Legislature	• Number of meetings with leaders, local representatives and policy-makers	Biannually

Recommended actions	Responsible sectors of government	Indicators	Frequency of data collection
ACT 2-01-01	Healthcare Local government	• Number of community primary healthcare centers, disaggregated by location, number of people served and services offered	Annually
ACT 2-01-02	Social welfare Local government	• Number of community social service centers, disaggregated by location, number of people served and services offered	Annually
ACT 2-02-01	Social welfare	• Number of rehabilitation coordinators, disaggregated by location	Annually
ACT 2-03-01	Disability affairs Healthcare Social welfare Education	• List of schools at grassroots level teaching daily living skills, disaggregated by location and number served • List of youth clubs with activities that include PwASD, disaggregated by location and number served • List of sports clubs with activities that include PwASD, disaggregated by location and number of PwASD served	Biannually Biannually Biannually
ACT 2-04-01	Healthcare	• Number of expecting mothers trained on safe pregnancy, disaggregated by location	Quarterly
ACT 2-04-02	Healthcare	• Number of disseminated guides for monitoring child development, disaggregated by location	Quarterly
ACT 2-04-03	Social welfare Local government Religious affairs Education	• Number of meetings between parents of PwASD and local influential persons, disaggregated by location and type of person	Quarterly
ACT 2-05-01	Social welfare Healthcare	• Number of protocols disseminated through community social services, disaggregated by location and type	Quarterly
ACT 2-06-01	Disability affairs Education	• Number of licensed special educators working in schools, disaggregated by location and type of school	Biannually
ACT 2-06-02	Disability affairs Labor affairs	• Number of employment specialists, disaggregated by number of PwASD served	Biannually
ACT 2-07-01	Social welfare Disability affairs	• Number of families/caregivers of PwASD who have received financial support, disaggregated by location and amount	Quarterly
ACT 2-07-02	Social welfare	• Number of community social service providers offering daycare, respite care or referral to these services in the community, disaggregated by location	Biannually
ACT 2-07-03	Healthcare Social welfare	• Number of caregiver support groups at community level, disaggregated by location	Annually
ACT 2-08-01	Healthcare	• Number of licensed practitioners of alternative medicine, disaggregated by those who claim to offer treatments for ASD-related health conditions	Annually
ACT 2-08-02	Disability affairs Religious affairs	• Number of awareness and sensitization drives conducted at community level, disaggregated by location	Annually

Recommended actions	Responsible sectors of government	Indicators	Frequency of data collection
ACT 2-08-03	Disability affairs	- Number of NGOs specializing in ASD, disaggregated by location, type and range of services offered	Annually
ACT 2-09-02	Healthcare	- Number of community primary healthcare providers that have received training on ASD-focused services, disaggregated by location - Number of community primary healthcare providers that have received supplementary training	Biannually
ACT 2-10-02	Healthcare	- Number of trained parent master trainers	Biannually
ACT 2-10-03	Healthcare	- Number of peer training sessions for new parents and caregivers of PwASD, disaggregated by location	Biannually
ACT 2-11-01	Disability affairs Healthcare	- Number of PwASD who have health insurance, disaggregated by location	Biannually
ACT 2-11-02	Healthcare	- Number of PwASD that have received outreach healthcare services, disaggregated by location	Biannually
ACT 2-11-03	Education	- Number of PwASD currently enrolled in mainstream schools, disaggregated by location and type of school - Number of PwASD that drop out of mainstream schools, disaggregated by location and type of school	Biannually Biannually
ACT 2-11-04	Disability affairs	- Number of PwASD currently using ASD-compatible ICT	Annually
ACT 2-11-05	Social welfare	- Number of PwASD who have received allowances and other types of welfare support, disaggregated by location and type of support	Quarterly
ACT 2-12-01	Education	- Number of PwASD who have received scholarships - Number of online courses available for PwASD, disaggregated by subject - Number of PwASD who have registered to online courses - Number of non-formal learning options available for PwASD, disaggregated by location and subject - Number of PwASD engaged in non-formal learning, disaggregated by location and subject	Biannually Annually Biannually Annually Biannually
ACT 2-13-01	Healthcare Social welfare	- Number of trained master trainers on psychosocial care	Biannually
ACT 2-13-02	Healthcare Social welfare	- Number of PwASD, their parents and their caregivers who have received psychological first aid, disaggregated by location, recipient and deliverer	Biannually
ACT 3-01-01	Disability affairs	- List of one-stop service centers, disaggregated by type - List of services and information provided at each one-stop service center	Annually
ACT 3-01-02	Disability affairs Education Sports	- List of social clubs that have activities for and/or include PwASD, disaggregated by type	Annually
ACT 3-02-01	Healthcare	- List of intervention services available in the country	Annually

Recommended actions	Responsible sectors of government	Indicators	Frequency of data collection
ACT 3-02-01	Healthcare	- List of allied health professionals available in the country	
ACT 3-02-03	Healthcare	- Number of certified professionals under each category	Annually
ACT 3-02-04	Healthcare	- List of intervention service providers, disaggregated by location and type of service	Annually
ACT 3-02-05	Healthcare	- List of dispensaries that offer medications for PwASD, disaggregated by location and drug	Annually
ACT 3-02-06	Healthcare	- Number of PwASD who received annual health checkups, disaggregated by location, age and gender	Annually
ACT 3-03-01	Healthcare	- Number of psychologists, psychiatrists and counselors in the country, disaggregated by location and credentials	Annually
ACT 3-03-02	Healthcare Disability affairs	- Number of disseminated resource materials on managing adolescent and young adult behavior, disaggregated by location and type of recipient	Annually
ACT 3-03-03	Disability affairs	- Number of sensitization drives, disaggregated by target audience and location	Annually
ACT 3-04-01	Healthcare	- Number of mid-level healthcare providers trained on the screening tools, disaggregated by location and type of healthcare professional	Biannually
ACT 3-04-02	Healthcare	- Number of healthcare professionals qualified to diagnose and assess ASD, disaggregated by type of healthcare professional and location	Biannually
ACT 3-04-03	Healthcare	- Number of disseminated resource materials on home and community-based interventions, disaggregated by location and type of recipient	Annually
ACT 4-01-01	Planning Healthcare Education Social welfare Labor	- List of performance indicators for all services, supports and activities	Annually
ACT 4-01-02	Planning	- List of government department reporting ASD indicators	Annually
ACT 4-01-03	Planning	- Number of random spot checks and third-party verifications	Annually
ACT 4-01-04	Disability affairs	- Summary report on delivery of services and supports to PwASD and their families	Biannually
ACT 4-02-01	Education	- Number of scholarships and/or study-and-work programs - Total value of scholarships and/or study-and-work programs	Annually Annually
ACT 4-02-02	Education	- Number of partnerships with ASD-focused institutes	Annually
ACT 4-02-03	Education Healthcare Social welfare	- Number of centers of excellence for ASD - Total amount of funding for these centers of excellence	Annually Annually

Recommended actions	Responsible sectors of government	Indicators	Frequency of data collection
ACT 4-03-01	Disability affairs Healthcare Education Social welfare	• Number of members in the stakeholders' forum • Breakdown of members in the stakeholders' forum • Number of meetings of the stakeholders' forum	Annually Annually Annually
ACT 4-03-02	Disability affairs Healthcare Education Social welfare	• Number of pilot projects • Coverage size of pilot projects	Annually Annually

The collaborative framework for implementation of the “WHO South-East Asia Regional Strategy on Autism Spectrum Disorders” articulates to Member States: the nature of autism spectrum disorder and the issues faced by PwASD and their caregivers; the foundation on which the Regional Strategy and the collaborative framework is based; desired outcomes against each objective of the ASD Regional Strategy; recommended actions to fulfill each objective; requisite parameters that should govern the recommended actions; and suggested guidelines for monitoring, evaluating and reporting a Member State's progress towards fulfilling the objectives. It encourages Member States to share best practices and information for promoting cooperation and partnerships for development of effective and sustainable programmes.

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