

MEETING REPORT

Autism spectrum disorders & other developmental disorders

From raising awareness to building capacity

World Health Organization, Geneva, Switzerland
16 -18 September 2013



**World Health
Organization**

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1. Introduction

Developmental disorders

- Developmental disorders are a group of conditions with onset in infancy or childhood and characterized by impairment or delay in functions related to the central nervous system maturation.
- They may affect a single area of development (e.g. specific developmental disorders of speech and language, of scholastic skills, and/or motor function) or several (e.g. pervasive developmental disorders and intellectual disability).

Autism spectrum disorders

- The umbrella term 'autism spectrum disorders' (ASDs) covers conditions such as autism, childhood disintegrative disorder and Asperger syndrome.
- Core symptoms include a variable mixture of impaired capacity for reciprocal socio-communicative interaction and a restricted, stereotyped repetitive repertoire of interests and activities. Individuals with autism spectrum disorders may have decreased general intellectual ability.
- These conditions currently belong to the category in the International Classification of Diseases and Related

Epidemiological data estimate the global prevalence of ASDs to be one person in 160, accounting for more than 7.6 million disability-adjusted life years and 0.3% of the global burden of disease. This prevalence estimate represents an average figure, and reported prevalence varies substantially across studies. Some well-controlled studies have, however, reported rates that are substantially higher. The prevalence of ASDs in many low- and middle-income countries is as yet unknown.

Worldwide, people with ASDs and other developmental disorders represent a vulnerable group. They are often subject to stigma and discrimination, including unjust deprivation of health and education services, and opportunities to engage and participate in their communities. Globally, access to services and support for people with developmental disorders is inadequate, and families of those affected often carry substantial emotional, economic and care burdens.

Autism was brought to the attention of Member States and the United Nations General Assembly in January 2008, when the General Assembly adopted resolution A/RES/62/139 designating 2 April each year as World Autism Awareness Day. The subsequent observation of that day has substantially increased international awareness about ASDs.

In December 2012, the General Assembly unanimously adopted a resolution entitled *Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders (ASD) developmental disorders (DD) and associated disabilities (A/RES/67/82)*, which calls for greater attention to the problem by Member States and UN Agencies and recognizes the need for innovative, integrated approaches for implementation of feasible, effective and sustainable intervention programmes.

In May 2013, the 133rd WHO Executive Board adopted a resolution entitled *Comprehensive and coordinated efforts for the management of autism spectrum disorders (ASDs)*, which was supported by more than 60 countries. The resolution (EB133/4; Annex 3) urges the WHO Secretariat to collaborate with Member States and partner agencies

Health Problems (Tenth revision) of pervasive developmental disorders, within the broader category of mental and behavioural disorders.

- Neurodevelopmental impairments in communication, social interaction and unusual ways of perceiving and processing information can seriously hinder daily functioning of people with ASDs and severely impede their educational and social attainments. While some individuals with ASDs and other developmental disorders have varying degrees of abilities that could potentially lead to independent and productive lives with varying levels of support, others are severely affected and require life-long care and support.

in order to strengthen national capacities to address ASDs and other developmental disorders, as part of a well-balanced approach that strengthens systems to address mental health and disability, in line with existing, related action plans and initiatives.

This recent focus on ASDs and other developmental disorders should be viewed within the larger context of international advocacy for mental health in general, and child mental health in particular. *The Comprehensive mental health action plan 2013–2020* that was developed by WHO in consultation with Member States and adopted by the World Health Assembly in May 2013 articulates the urgent need to strengthen efforts to address the treatment gap for mental and neurological disorders and outlines strategies and targets for actions in countries.

This international attention, and successful advocacy by the community of stakeholders in this field, provides promising opportunities for transforming commitment from the global community into action. The health sector has a critical role to play in making this happen. Cooperation on a global platform can help to bridge both knowledge and treatment gaps and lead to

improvements in the lives of those affected. Essential to this aim is dialogue and coordinated efforts by governments, experts, United Nations agencies, civil society, including nongovernmental organizations, to identify sustainable strategies for provision of comprehensive and integrated support services.

In response to this call for action, WHO convened a consultation on *Autism spectrum disorders and other developmental disorders: From awareness raising to capacity building* on 16 -18 September 2013 with support from Autism Speaks, a nongovernmental organization based in the United States of America.

The purpose of the consultation was to develop a common agenda for action.

Three key objectives for the meeting were to:

- promote sharing of best practices and innovative solutions for strengthening capacities in countries;
- identify priorities for research and action;
- promote the establishment of a global network.

The consultation agenda and the list of participants of the consultation are given in Annexes 1 and 2.

2. State of the evidence on ASDs and other developmental disorders and research priorities

Recent reviews estimate a global median prevalence of 62/10 000: one child in 160 has an ASD and subsequent disability. This estimate represents an average figure, and reported prevalence varies substantially across studies. Some well-controlled studies have, however, reported rates that are substantially higher.

Based on epidemiological studies conducted over the past fifty years, the prevalence of ASDs appears to be increasing around the world. There are many possible explanations for this apparent increase in prevalence, including improved awareness, expansion of diagnostic criteria, better diagnostic tools and improved reporting. Other likely contributors comprise changes in diagnostic practices, including expansion of developmental screening, increased diagnosis and diagnostic substitution, whereby children who in the past would have been identified as having an intellectual disability are now being diagnosed with ASDs. Some of the increase in prevalence may also be the result of diagnostic accretion, whereby some people are given more than one diagnosis, and hence the prevalence appears higher, even though the same number of people is affected.

It is not absolutely clear if the above mentioned factors account fully for the recent changes in ASDs prevalence.

Developmental disorders, including ASDs, are disorders of early brain development, and although the cause of ASDs remains unknown, some specific prenatal, perinatal and environmental risk factors, such as high maternal and paternal age and specific gene mutations, have been identified. It is unclear what role these risk factors may play in the reported increase in prevalence.

Most people with ASDs and other developmental disorders live in low- and middle-income countries (LMICs); however, most of the knowledge about these conditions is based on research done in high-income countries. Good-quality prevalence estimates on ASDs are not available for any low-income country. The

financial inaccessibility and need for validation and adaptation across different contexts of varied diagnostic tools, the scarcity of skilled health professionals, and the lack of service development, make epidemiological studies both financially and ethically difficult in resource-poor settings.

Information on ASD-related needs and services are rarely collected at a country level, hampering efforts to describe the quality and equity of available care; monitor changes in the health status of populations and groups; evaluate the impact of social policies; and establish approaches to quality improvement. Without such information it is all too easy for the health needs of people with developmental disorders and their families to be ignored. The WHO Executive Board resolution on *Comprehensive and coordinated efforts for the management of ASD*, the WHO World Health Assembly Resolution on *The global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level*, and the WHO European Declaration and Action Plan on *the Health of children and young people with intellectual disabilities and their families* all urge countries to improve surveillance frameworks and information systems to better capture data on ASDs, intellectual disability (ID) and other developmental disorders.

Psycho-educational, developmental and behavioural interventions are the primary interventions used to address the core deficits in communication, social behaviour and behavioural flexibility in ASDs, and while they have demonstrated efficacy, they are very resource and labour intensive. However, emerging evidence shows that non-specialist providers in school and community settings can effectively deliver psychosocial interventions, including behaviour modification approaches and parent-mediated interventions, to children with ASDs and intellectual disability. Research that enables a better understanding of the effective elements of interventions may allow for the development of

evidence-based, lower-cost treatments for people with ASDs. Innovative intervention processes are beginning to emerge in this field that focus on making changes to the person's environment, including schools, (rather than changing the person's abilities) to enable functional or participation-based outcomes.

Available evidence on effective service delivery models for ASDs and developmental disorders is often grounded in high-resourced research settings, and it is challenging to generalize these models to 'real-world' settings and contexts. Much of the research into autism intervention strategies is hindered by the lack of both high-quality evidence from randomized controlled trials and health system research from low- and middle-income countries. Guidance on key indicators and instruments for assessing the impact of interventions at individual, family and community levels (including functioning, participation and financial cost) would be instrumental in facilitating the development of new models of affordable care.

Inadequate availability and/or inequity in distribution of mental health and child health specialists and their insufficient knowledge and skills to manage ASDs and developmental disorders in general, are recognized among the major barriers to improving access to care in high-income as well as low- and middle-income countries. However, evaluation of training approaches and e-health and m-health approaches have received little attention in autism research. Furthermore, much of the research on ASDs and developmental disorders focuses on children and it will be important to adopt a research agenda that takes a full life-course perspective and is inclusive of both adults with developmental disorders and caregivers/families.

Increasing efforts are being made to facilitate the production of policy-relevant evidence and its uptake by policy-makers and advocates. With the expansion of research in low-resource settings, it is crucial that such research is locally relevant, and that local communities are actively engaged, including people with ASDs and their families. Models of co-research now exist that enable the active participation of people with autism and other mental disorders in the research process and dissemination of findings.

Key messages

- Much of the knowledge on ASDs and other developmental disorders is based on research conducted in high-income countries. There is a need to increase evidence grounded in low-resource settings.
- An important source of information in countries is represented by surveillance systems and information systems. They should capture data on ASDs, IDs and other developmental disorders.
- Psychosocial interventions that are effective in reducing core symptoms and improving adaptive skills and functioning are available, but they are very resource intensive. Increased evidence on affordable service delivery models and effective and scalable capacity building approaches are required.
- Interventions mediated by parents and other non-specialist providers have the potential to significantly increase access to care.
- There is a need to strengthen research efforts addressing the needs of people with developmental disorders across the entire life course.
- Local communities, including people with developmental disorders and their families, should take active roles in the research process and dissemination of findings.

3. Advocacy, leadership and governance

Strong leadership and commitment by governments are among the key factors for developing and implementing evidence-based policies and plans addressing the needs of people with ASDs and other developmental disorders.

Planning, organizing and financing health systems is a complex undertaking involving multiple stakeholders. As the ultimate guardian of a population's health, governments have the lead responsibility to put in place appropriate institutional, legal, financing and service arrangements to ensure that needs are met and the well-being of people with ASDs and other developmental disorders is promoted.

Nonetheless, a strong civil society, particularly organizations of people living with ASDs, IDs or other developmental disorders, and families' or parents' associations, can help to create more effective and accountable policies, laws and services for mental health in a manner consistent with international and regional human rights instruments. This community has a strong presence in many countries.

A number of successful advocacy initiatives focused on autism have been undertaken in the past decade by both governments and civil society. UN General Assembly resolution A/RES/62/139 on World Autism Awareness Day; resolution A/RES/67/82 on *Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders (ASD), developmental disorders (DD) and associated disabilities*; WHO Executive Board resolution EB133/4 *Comprehensive and coordinated efforts for the management of autism spectrum disorders (ASDs)*; and at regional level, resolution SEA/RC65/R8 adopted by the WHO Regional Committee for South-East Asia on *Comprehensive and coordinated efforts for the management of autism spectrum disorders (ASDs) and developmental disabilities*, all represent landmark achievements and can be used as advocacy tools for mobilizing financial resources and stakeholders' commitment at all levels.

However, several challenges have been reported by advocates and patients' organizations, especially in

low- and middle-income countries. A general lack of public awareness, as well as prevalent stigma and discrimination act as significant barriers to the engagement of families and communities in advocacy efforts. Governments in many countries have very limited resources and face a lack of affordable strategies to implement programmes, even when there is commitment to take action. The inadequacy of human and financial resources to match the increased demands for services resulting from awareness-raising initiatives poses distinct ethical concerns. Furthermore, long-term monitoring of the outcomes of advocacy programmes is rarely performed, leading to missed learning opportunities and inefficient use of resources.

A few strategies have been proposed to influence decision-making with the goals of developing, establishing or changing policies, programmes and services, and gaining commitment from governments and partners. Scaling up efforts in countries requires concerted and coordinated actions by multiple stakeholders and cooperation across sectors, including health, education, labour and justice. Central to this multisectoral approach is the orientation and sensitization of stakeholders on opportunities for improving the well-being and broadening societal opportunities for people with ASDs and other developmental disorders, informed by global and region-specific data on the burden of the conditions and financial implications. Public education has been highlighted as a key focus area. Engaging institutions of higher-specialist training and employers can aid the dissemination of important advocacy messages. At the community level, education is needed to ensure individuals and families understand their rights and that user involvement is an integral aspect of advocacy programmes. The importance of facilitating communication among parents, local communities, professionals, governments and researchers is recognized as an important ingredient for developing evidence-informed policies and programmes.

Finally, it is also recommended that efforts to improve

services for autism are implemented in the broader context of service improvement for developmental disorders, child and family health, and mental health. There are various reasons for this. First, the increased international awareness of autism is an opportunity to persuade governments and other partners to increase allocation of resources for mental health in general. Second, it is inefficient (and unethical) to identify and provide services for only one narrowly defined group in a context of broader needs, particularly when these priorities are defined externally rather than according to rational, local needs assessment.

Key messages

- Strong leadership and commitment by governments, and civil society participation, are key factors for effective implementation of policies and plans on ASDs and other developmental disorders.
- WHO Executive Board resolution EB133/4 on comprehensive and coordinated efforts for the management of ASD represents a powerful advocacy tool for mobilizing financial resources and stakeholders' buy-in.
- Advocacy efforts in countries require multisectoral approaches and multi-pronged strategies. Public education as to the needs of people with ASDs and other developmental disorders – and the extent of the burden of these conditions on individuals, families and societies, along with orientation of stakeholders – are important elements.
- Advocacy for greater resource allocation should be based on assessment of local needs, and investment should not focus on narrow diagnostic categories where broader needs are identified.

4. Strategies for comprehensive and integrated services

According to the WHO definition, health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. A wide range of factors determine health status, including living and working conditions, socioeconomic, cultural and environmental conditions, social inclusion and access to health care services and education.

The goal of universal health coverage, currently being pursued by WHO and governments, is to ensure that all people obtain the health services they need without suffering financial hardship when accessing them. It requires recognition of the critical role played by all sectors in assuring human health, including education and employment.

People with ASDs and other developmental disorders have the right to attain their optimal health, well-being and functioning, and attain the highest standard of health care, without discrimination, in line with Article 25 of the *United Nations Convention on the Rights of Persons with Disabilities* (CPRD).

They typically have complex needs that require the provision of a range of health and social services, including support to carers and families. People with ASDs and other developmental disorders and their families are in need for increased access to evidence-based psychosocial interventions that have shown to be effective in improving developmental and behavioural outcomes and functional adaptive skills, such as behaviour modification interventions, parent-training interventions, and cognitive rehabilitation, training and support. Historically, there are many examples of non-evidence-based treatments, and by making more information available to parents and people with ASDs, they can make informed decisions about what will be effective to meet their needs. It is important that they are offered support in developing life skills and accessing community services, including developing skills to engage socially in their communities, access public transport, employment and leisure facilities.

Individualized management plans should be the norm, based on assessment and monitoring of evolving needs and functioning, with involvement of people

with ASDs and their carers, as appropriate, following procedures of informed decision-making.

Primary health care services have an important role to play as they are often the first point of contact for carers with concerns about achievement of developmental milestones or behavioural problems, and are best placed to provide support to people with developmental disorders, and their families, throughout childhood, adolescence and beyond. They can be the gateway to other community-based resources (including community-based rehabilitation programmes) and specialized health services for both the primary conditions and other co-morbid disorders. At present, the level of knowledge about mental health in general at this level is very low, particularly in LMIC, and people must often seek support through other routes.

People with ASDs and other developmental disorders seek more collaborative relationships with primary care providers in facilitating coordinated care and support. Care coordination promotes a cooperative, interdisciplinary team approach to health care service delivery, linking people with developmental disorders to appropriate services and resources. While initial investment of resources is required, coordination of health and community initiatives has the potential to improve quality and cost-effectiveness of health care service delivery in the longer term. Experiences from both high-income and low- and middle-income countries support the creation of collaborative, multidisciplinary, community-based teams or networks that assume and share tasks related to child development monitoring, screening, assessment, management and follow up for ASDs and other developmental disorders, including supporting access to education, housing and employment services, and leisure activities. Protocols for information sharing and collaborative working among health care, education and social services are instrumental. There remains much work to be done to understand how practical interventions that facilitate such care can be implemented.

There is consensus on the urgent need to strengthen

health systems to deliver integrated services for comprehensive management of ASDs in the context of management of other developmental and mental disorders and disabilities, and other chronic conditions, and in line with the *WHO Comprehensive mental health action plan 2013–2020*.

A holistic approach to health promotion, care, rehabilitation and support that aims at meeting both mental and physical health care needs, and facilitates optimal functioning and quality of life of people of all ages with ASDs is recommended. Improving the health and lives of people with ASDs and other developmental disorders cannot rely on interventions targeting individuals affected by these conditions only. Making the environment more accessible and making accommodations for improved functioning and participation of people with developmental disorders is equally important. This requires an intersectoral approach and the establishment of partnerships with multiple public sectors such as health, education, labour, criminal justice, housing, social, finance and other relevant sectors as well as the private sector, as appropriate to the country situation. The specific needs of most hard-to-reach, marginalized or neglected populations, including adults and the elderly with ASDs, orphans and abandoned children, need to be taken into consideration.

WHO Executive Board resolution EB133/4 emphasizes the importance of shifting the focus away from long-stay health facilities towards community-based non-residential services, and addressing disparities in access to care.

When services for developmental disorders are integrated into primary care and community-based services, people can access care closer to their homes, thus keeping their families together and promoting their autonomy and participation in community initiatives. Services delivered in primary care minimize stigma and discrimination and the risk of human rights violations that can occur in residential institutes. They are less expensive than long-stay facilities, for patients, communities and governments alike.

Innovative affordable strategies to increase coverage of services for developmental disorders at community level are needed.

The Mental Health Gap Action Programme (mhGAP) provides a clear set of actions to strengthen capacities in countries to deliver integrated evidence-based care packages for priority mental and neurological conditions, including ASDs and other developmental disorders. It facilitates the scale up of key interventions by mainstreaming them within existing health services, and adopting task-sharing approaches. Evidence-based guidelines for non-specialists in primary and secondary care services are available and are being used in high-income as well as low- and middle-income countries.

Key messages

- There is an urgent need to strengthen health systems capacities to deliver integrated services for ASDs in the context of management of other developmental and mental disorders and disabilities.
- Holistic and intersectoral approaches to health promotion, care and rehabilitation that facilitate optimal functioning and psychosocial well-being of people with ASDs, with the involvement of multiple public sectors, including health, education, social welfare and labour, are recommended.
- Primary health care services have an important role to play in early detection and facilitation of coordinated care and support.
- Collaborative models of care and task-sharing approaches are recommended, with multidisciplinary community-based teams assuming tasks related to assessment, management and follow up in consultation with specialists at secondary care levels.

5. Human capacity building

The need to develop human capacity, especially in LMICs, has been raised as a priority issue in the development of services for ASDs and other developmental disorders. An increasing number of capacity-building projects are being implemented, although mostly at a small scale, in LMICs. They provide lessons learnt and insights on principles of capacity-building that may be applicable across different regions. Emphasis has been placed on a multi-level and multidisciplinary framework that includes organizational and workforce development, resource allocation, partnership and leadership as core concepts.

At the organizational level, involvement of policy-makers and training institutions – especially universities, governments and professional associations – has proven to be a key element for sustained training initiatives. These should be supported by resource allocation strategies, changes in curricula of the professionals involved, and sound infrastructure for monitoring and evaluation of capacity-building outcomes.

At the workforce level, the development of training materials and training programmes for a variety of care providers, including mental health and child health specialists, general practitioners, nurses, teachers and other community-based resources (including parents), is being viewed as essential to strengthening human resource capacities in countries. They need to be based on adult-learning principals, evidence-based content, and competency-based approaches. Available evidence on feasible and scalable capacity-building models supports mixed-method approaches whereby distance learning and e-learning training sessions are supplemented by face-to-face training sessions and clinical supervision. E-learning has been used in a variety of other priority areas and is likely to serve the needs for human capacity building for developmental disorders well, when used in addition to the traditional learning methods. Continuous learning opportunities, motivation schemes, and regular supportive supervision are critical ingredients for capacity-building programmes that lead to sustained changes in clinical practice.

Caregivers play important roles in the delivery of care, in advocacy and community sensitization and need to

be empowered with knowledge and skills. Innovative models for engaging caregivers and people with developmental disorders, in the development and delivery of training are available. As caregivers face substantial economic, personal and social burdens, they require societal supports and the help of other community resources.

As specialists face the challenge of serving millions of people in many low-resource settings, it is advisable that they are equipped with managerial and leadership skills for them to be employed as trainers, supervisors and mentors of non-specialists, and lead multidisciplinary teams at primary and secondary care levels.

A number of training packages are currently available as open-access resources for care providers dealing with ASDs and/or other developmental disorders. They include training focusing on stigma reduction, sensitization on human rights of people with these conditions, child development monitoring and community-based rehabilitation. Training materials on assessment and management of ASDs and other developmental disorders, in line with the WHO mhGAP evidence-based guidelines, are available for field testing.

Key messages

- The development of human resources is critical for improving access to services and addressing health care disparities.
- Evidence-based and competency-based training materials for a range of care providers including parents, teachers and other community resources should be available to countries.
- E-learning approaches have the potential to significantly reduce treatment gap in low-resource settings.

6. Tools and strategies for early detection, assessment and follow-up

Early interventions have proven to produce the best returns in investment and better results in terms of developmental outcomes and improvement in daily functioning. However, early detection (for example, before two years of age) remains a global challenge in both HIC and LMIC. The detection of ASDs and other developmental disorders in the adult population also poses challenges and requires increased allocation of resources, to allow the recognition of undetected cases and enable access to services.

A variety of instruments are available for developmental monitoring, screening and diagnosis of ASDs, and for functional assessment to inform management plans and follow up. More recently, tools are being developed to examine level of participation within various community environments to identify outcomes meaningful to a child and their families. Most measures have been developed for use in high-resource settings and sometimes in research contexts; hence, their utilization by care providers in low-income countries poses a number of challenges and ethical concerns, including the need for validation and cultural adaptation. The fact that many of them are financially inaccessible for professionals in LMIC and only available in English compounds the problem. Both researchers and clinicians expressed the need for increased exchange of information on available assessment instruments and dialogue regarding adaptation, possibly facilitated by online platforms.

While increased screening for developmental disorders is, in principle, desirable, it is important that children and families who are identified through screening are offered relevant information, services and/or referrals, and practical support. There is consensus on the need for developmental monitoring to be integrated in routine maternal and child health care, in the context of growth monitoring, early childhood development and parents' counselling, and provision of comprehensive care for children with specific needs and their families. The adoption

of strengths-based assessment and bio-psychosocial approaches whereby assets and risks in the family and broader environment are considered, and families are empowered with appropriate knowledge, skills and support, are recommended.

Key messages

- Early detection of ASDs and other developmental disorders requires the mainstreaming of child development monitoring into routine child health care services.
- It is important that developmental monitoring and screening are conducted in the context of early childhood development programmes along with family psycho-education and the provision of comprehensive care for children with ASDs and other developmental disorders and their families.
- A variety of assessment instruments is available. Guidance on their use, if necessary with adaptation, for early detection, assessment and follow up during routine care practice is needed.

7. Promotion of health in persons with ASDs and other developmental disorders

People with developmental disorders present the same health problems that affect the general population. Furthermore, they often present co-morbid conditions, including epilepsy, depression, anxiety and attention deficit hyperactivity disorder (ADHD). They may be more vulnerable to developing chronic noncommunicable conditions because of the influence of behavioural risk factors such as physical inactivity and poor dietary preferences, and are at greater risk of violence, injury and abuse.

People with ASDs and other developmental disorders, and associated disabilities, require accessible health services for general health care needs like the rest of the population. General health needs include health promotion, preventive care, and treatment of acute and chronic illness. These needs should be met through primary health care in addition to secondary and tertiary facilities, as relevant. Nevertheless, people with developmental disorders have higher rates of unmet health care needs compared with the general population. Insensitivity to pain, difficulty in self-monitoring and problems of communication contribute to increased risk of receiving inappropriate or inadequate treatment in the event of medical emergency or acute illness. People with ASDs and other developmental disorders are also more vulnerable to experiencing inadequate access to support, education and health care during humanitarian emergencies.

A common barrier is represented by health care providers' misconceptions about the comprehensive health needs of people with ASDs and other developmental disorders. As a consequence, people with ASDs and other developmental disorders are not considered as a target for health promotion interventions and they face challenges in accessing health education messages, including parental education, and sexual and reproductive health education. Communication difficulties between people with developmental disorders and care providers are often mentioned as an area of concern. Recommended strategies for addressing inequalities in health include making

available information materials in formats that are easily accessible to people with developmental disorders.

Individuals with developmental disorders and their families should be given the opportunity to advocate for their rights and help ensure that health care services are appropriate, sensitive, comprehensive and accessible. Developing co-produced understandable health information – for example, easy-read booklets or videos on relevant health topics – and engaging people with developmental disorders in training of care providers and monitoring of quality of care are all viable approaches.

International and regional policies and legislations can support national efforts towards removing barriers and making existing health and education care systems more inclusive and accessible to people with ASDs and other developmental disorders, and associated disabilities. The CRPD is a useful advocacy tool. The rights of people with developmental disorders to access health information and services is covered under Article 25 of the CRPD, which states that “persons with disabilities have the right to equal access to the same standard of health care and health care services as others”. This article also requires governments to “provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons”.

Furthermore, according to the International Covenant on Economic, Social and Cultural Rights (ICESCR), the right to health includes the right to seek, receive and impart information on health. In relation to this specific area, Article 9 of the CRPD emphasizes the need for communication and information services to be designed so that they can be used and reached by people with disabilities by “providing information intended for the general public to persons with disabilities in accessible formats and technologies

appropriate to different kinds of disabilities in a timely manner and without additional cost”.

Other legal instruments available at the regional level include the *Charter of rights for persons with autism* adopted as a written declaration by the European Parliament (1996); the Council of Europe Recommendation CM/Rec(2009) to Member States on the education and social inclusion of children and young people with ASDs; and the WHO *European Declaration on the Health of children and young people with intellectual disabilities and their families* (EUR/51298/17/6) and related *Action plan* (EUR/RC61/R5).

The WHO *International classification of functioning, disability and health* (ICF) provides a universal framework for measuring functioning, disability and health, whereby functioning is not considered as the consequence of a disease, but the result of the interaction between a health condition and both personal attributes and environmental influences. The ICF enables reliable and valid disability statistics and can be used as an operative instrument to monitor policies and support planning.

Key messages

- People with ASDs and other developmental disorders have higher rates of unmet health care needs compared to the general population.
- Recommended strategies to addressing inequalities in health for people with ASDs and other developmental disorders, include:
 - making available health education materials in formats that are easily accessible to people with developmental disorders;
 - empowering people with developmental disorders and their families;
 - improving knowledge and change attitude of care providers.
- The CRPD can be used as useful advocacy tool.
- The WHO International classification of functioning, disability and health can be used to monitor policies and support planning.

8. Key messages and the way forward

The purpose of this consultation was to bring together experts and representatives from governments, UN agencies, and civil society to identify research needs and current challenges in providing comprehensive care programmes at scale for people with ASDs and other developmental disorders, and to establish a collaborative commitment to strengthening capacities in countries.

Worldwide, people with ASDs and other developmental disorders represent a vulnerable group. They are often subject to stigma, discrimination and human rights violations, including unjust deprivation of health, education and social opportunities. Globally, access to services and support for people with developmental disorders is inadequate, and families of those affected often carry substantial emotional and economic burdens.

Related resolutions of the UN General Assembly and the WHO Executive Board represent powerful advocacy tools. This international attention to ASDs and other developmental disorders can be viewed within the larger context of international advocacy for mental health in general. The *Comprehensive mental health action plan 2013–2020* that was adopted by the World Health Assembly in May 2013 outlines strategies to address the treatment gap for mental and neurological disorders and targets for actions in countries.

Sustained advocacy efforts at country level supported by policy-relevant evidence on the economic burden of ASDs and other developmental disorders are needed in order for this increased awareness to translate into changes in policies and practices.

There is consensus on the urgent need to strengthen health systems to deliver comprehensive and coordinated services for ASDs in the context of management of other developmental and mental disorders and disabilities, and other chronic conditions. A holistic approach to health promotion, care, rehabilitation and support that aims at meeting both mental and physical health care needs and facilitates optimal functioning and quality of life of people of all ages with ASDs is recommended. The

health sector must assume responsibility for ensuring the mainstreaming of evidence-based interventions for ASDs and other developmental disorders in existing health services through service user-driven treatment plans and, where appropriate, with the active engagement of families and caregivers. Intersectoral collaboration across health, education and social sectors is crucial to ensure a holistic package of care and continuity of support for the people affected by these conditions and their families.

Psycho-educational, developmental and behavioural interventions are the primary treatment to address the core deficits in communication, social behaviour and behavioural flexibility in ASDs, and while they have established efficacy, they are very resource and labour intensive. Task-shifting and task-sharing approaches – whereby non-specialists in school, family and community settings deliver psychosocial interventions – can significantly contribute to increasing access to care in low-resource settings. Interventions targeting individuals with ASDs and other developmental disorders need to be accompanied by broader actions for making physical, social, and attitudinal environments more accessible, inclusive and enabling.

Inadequate availability and/or inequity in distribution of mental health and child health specialists and their insufficient knowledge and skills to manage ASDs and developmental disorders in general, are recognized among the major barriers to improving access to care in countries of all income categories. E-learning approaches, competency-based approaches, and innovative models for engaging caregivers and, when appropriate, people with developmental disorders, in the development and delivery of training are promising directions.

Early interventions have proven to produce the best returns in investment and better results in terms of developmental outcomes and improvement in daily functioning. However, early detection remains a global challenge. There is consensus on the need for developmental monitoring to be integrated into routine maternal and child health care, in the context of growth

monitoring, parental counselling on child development and provision of comprehensive care for children with specific needs and their families. Assessment tools can be important aids, but there are often challenges related to financial cost and use of assessment instruments in different cultural contexts. A variety of assessment instruments for early detection of ASDs and other developmental disorders, assessment and follow up are available. Guidance on their use, and adaptation for use, during routine care practice is needed.

Information on needs and services are rarely collected at the country level, hampering efforts to describe the quality and equity of care provided; monitor changes in the health status of populations and groups; evaluate the impact of social policies; and establish approaches to quality improvement.

Much of the research into autism intervention strategies is hindered by the lack of both high-quality evidence from randomized controlled trials and health system research from low- and middle-income countries. Furthermore, much of the research on ASDs and developmental disorders focuses on children and it will be important to adopt a research agenda that takes a life-course perspective and is inclusive of both adults with developmental disorders and their caregivers/families. Guidance on key indicators and instruments for assessing the impact of interventions at individual, family and community levels (including functioning, participation and financial cost) would be instrumental to facilitate the development of new models of affordable care.

The meeting discussed possible roles of WHO, along with the role of other stakeholders. It was recommended that WHO contribute to assessing needs and resources in countries, providing guidance on services, improving epidemiological information and the evidence-base for policies and services, as well as methods and tools for the delivery, scale up and evaluation of interventions throughout the life course.

During the past five years, WHO's efforts in this field focused on developing evidence-based guidelines for management of developmental disorders by non-specialist providers (*mhGAP Intervention guide for mental, neurological and substance use disorders in non-specialized health settings*) and other tools to support the mainstreaming and scale up of

interventions for developmental disorders in countries, and particularly in low-resource settings. A set of training materials for a range of care providers at the primary health care level, in community and school settings are currently being pilot tested to assess their acceptability, feasibility and effectiveness.

Strategic partnerships with international developmental organizations, academic institutes and civil society organizations, along with sustainable global mechanisms for financing, will be instrumental to sustained efforts for strengthening capacities in countries.

Key actions by stakeholders

Key actions for research and academic institutes to support capacity building in countries

- Contribute to improved evidence on effective and feasible care packages and service delivery models for meeting the needs of people with ASDs and other developmental disorders in low-resource settings and across the life course.
- Contribute to evidence generation on effective and scalable capacity-building approaches for care providers and parents and early detection strategies.
- Facilitate the engagement of local communities, including local academic institutes, and the uptake of research findings.
- Contribute to resource mobilization for research on public health aspects of ASDs and other developmental disorders.

Key actions for civil society to support capacity building in countries

- Contribute to enhancing commitment of governments and raising international awareness.
- Contribute to creating and sustaining global network of civil society organizations and advocates.
- Contribute to public education and sensitization on the needs and rights of people with ASDs and other developmental disorders.
- Contribute to monitoring the implementation of laws, policies and plans related to ASDs and other developmental disorders, and the quality of care services.
- Contribute to and support evidence generation, by informing and participating in research, in partnership with research institutes and international organizations.
- Contribute to resource mobilization for sustainable efforts.

Key actions for governments to support capacity building in countries

- Contribute to international advocacy efforts on autism.
- Contribute to improved country-specific data on ASDs and other developmental disorders, by enhancing health surveillance and information systems.
- Develop policies and plans for meeting the needs of people with ASDs and other developmental disorders, based on international legal and policy frameworks i.e. CRPD, and UN/WHO resolutions, with involvement of multiple public sectors.
- Strengthen health systems, including human resource capacities, to detect and deliver integrated care for ASDs and other developmental disorders.
- Contribute to and support generation of evidence.
- Contribute to resource mobilization for sustainable efforts.

Key actions for WHO in collaboration with partners to support capacity building in countries

- Contribute to enhancing commitment of governments.
- Establish and sustain a global network of experts, UN agencies and civil society organizations.
- Contribute to generation of evidence to inform interventions and programmes for ASDs and other developmental disorders.
- Contribute to assessment of needs and resources in countries and provide guidance on services.
- Provide guidance on the use of instruments for detection, assessment and follow up of people with ASDs and other developmental disorders.
- Provide guidance on outcome indicators for evaluation of programmes and services.
- Make cost-effective training materials available for assessment and management of ASDs and other developmental disorders across the life course.
- Provide country support, especially in building capacity to implement multisectoral response to ASDs and other developmental disorders.
- Contribute to resource mobilization for sustainable efforts.

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Annex 1 Agenda

Consultation on Autism Spectrum Disorders and other developmental disorders

From raising awareness to building capacity

WHO Executive Board Room

PROVISIONAL AGENDA

Monday, 16 September 2013

08:45 - 09:00	Registration	
09:00 - 09:30	Welcome and introduction	Oleg Chestnov
09:30 - 09:35	Objectives of the meeting	Chiara Servili
09:35 - 10:20	Session 1: Current state, opportunities and challenges	WHO EB Resolution on Comprehensive and coordinated efforts for the management of ASD <i>Shekhar Saxena</i> Civil society response <i>Andy Shih</i> Current evidence and knowledge gaps <i>Maureen Durkin</i>
10:20 - 10:40	Coffee	
10:40 - 12:10	Session 2: Advocacy, leadership and governance	Facilitators: – <i>Michael Rosanoff and Andy Shih</i> Initial comments by: – <i>Merry Barua</i> – <i>Vladimir Kasatkin</i> – <i>Teruko Ujita</i> – <i>Saima Hossain</i>
12:10 - 13:30	Lunch	

This consultation is being organized by WHO with support from Autism Speaks

13:30 - 15:00

Session 3:
**Strategies for comprehensive
and integrated health, education
and social services**

Facilitator:
– *Myron Belfer*
Initial comments by:
– *Julian Eaton*
– *Lynne Jones*
– *Connie Kasari*
– *Chiara Servili*
– *Shoba Srinath*

15:00 - 15:15

Coffee

15:15 - 16:45

Session 4:
**Information systems, evidence
and research**

Facilitator:
– *Francesca Happe*
Initial comments by:
– *Tony Charman*
– *Rajae El Aouad*
– *Mayada Elsabbagh*
– *Matilde Leonardi*
– *Brian Reichow*
– *Vianne Timmons*

16:45 - 17:45

Session 5:
**Health promotion and impact
on long term functioning**

Facilitator:
– *Petrus De Vries*
Initial comments by:
– *Philipa Bragman*
– *Facundo Chavez Penillas*
– *Samanmali Sumanasena*
– *Zsuzsanna Szilvasy*

18:00

Reception

Tuesday, 17 September 2013

09:00 - 10:30

Session 6:
Tools and strategies for early detection, assessment and follow up

Facilitator:
– *Maureen Durkin*
Initial comments by:
– *Petrus De Vries*
– *Melissa Gladstone*
– *Naila Khan*
– *Vibha Krishnamurthy*
– *Catherine Rice*

10:30 - 10:45

Coffee

10:45 -12:15

Group work:
Challenges, opportunities and priorities for action and research

Group 1:
Advocacy, leadership and governance
Group 2:
Comprehensive and integrated care services
Group 3:
Tools and strategies for early detection, assessment and follow up
Group 4:
Health promotion and impact on long term functioning
Group 5:
Information system, evidence and research

12:30 - 13:30

Lunchtime seminar:
Disabled or specially abled? Why business companies want to hire people with autism

Moderator:
– *Shekhar Saxena*
Panelists:
– *Liliana Mayo, Thorkil Sonne and Anka Wittenberg*

13:45 - 15:15

Feedback from groups and discussion

15:30 - 17:00

Session 7:
Human capacity building

Facilitator:
– *Eileen Hopkins and Norbert Skokauskas*
Initial comments by:
– *Samira Al-Saad*
– *Gauri Divan*
– *Rosa Hoekstra*
– *Yong-hui Jiang*
– *Olayinka Omigbodun*
– *Hemamali Perera*

Wednesday, 18 September 2013**09:00 - 10:15**Session 8:
The perspective of familiesFacilitator:
– *Merry Barua*
Initial comments by:
– *Souad Al-Eryani*
– *Erlinda Borromeo*
– *Philipa Bragman*
– *Hon Mike Lake MP*
– *Isabelle Steffen***10:15 - 10:30**

Coffee

10:30 - 12:00**Round table
on the role of partners**Facilitators:
– *John Peabody and Andy Shih*
Initial comments by:
– *HE Ms Alya Ahmed Saif Al-Thani*
Mohamed Al-Jalahma
– *Liri Berisha*
– *Sergio Gulbenkian*
– *HE Mr Abdul Hannan*
– *Rain Henderson*
– *Eileen Hopkins*
– *Saima Hossain*
– *Hon Mike Lake MP*
– *Dominique McMahon*
– *Frank Witney***12:00 - 12:45****Plenary discussion
on outcomes and next steps**Facilitators:
– *Shekhar Saxena and Andy Shih***12:45 - 13:00**

Conclusion

Annex 2 List of participants

ABA, Swiss Early Intervention Project in Autism (Swiss EIPA)

Ghadeer Barghouthy, Research Coordinator

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Frank Witney, President and CEO

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Liri Berisha, President

Lauresha Basha

Autism Hearts Foundation, USA

Erlinda P. Borromeo, President

Betty Buccat, Director

Joyce Diloy, Director

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Merry Barua

Autism-Europe and Autistak Országos Szovetsege, Hungary

Zsuzsanna Szilvassy, President

Autism Speaks, USA

Suzanne and Bob Wright, Co-founders (Unable to attend)

Andy Shih

Michael Rosanoff

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Isabelle Steffen

Mandy Barker

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Olayinka Omigbodun, President

**International Association for the Scientific Study of Intellectual
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Eileen Hopkins, Director of Global Initiatives, ICare4Autism
Autism Consultant, Shirley Foundation

International Society for Autism Research (INSAR), USA/

King's College London, UK
Francesca Happé, President and Director

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Teruko Ujita, Member, Committee Board of Experts
Masako Suzuki

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Tony Charman

Kuwait Awqaf Public Foundation, Kuwait

Mohammed Al-Jalahma, Deputy Secretary General

Kuwait Centre for Autism, Kuwait

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McGill University, Canada

Mayada Elsabbagh

McMaster University, Canada

Briano Di Rezze

Ministry of Health and Family Welfare, Bangladesh/GAPH Initiative Bangladesh, Bangladesh

Saima Hossain, Chair, National Advisory Committee
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Ministry of Health Lesotho

Michael Lebina, Director, Mental Services

Member of Parliament for Edmonton, Canada

Hon. Mike Lake, Member of Parliament for Edmonton-Mill Woods-Beaumont
and Parliamentary Secretary to the Minister of Industry

National Institute of Mental Health and NeuroSciences (NIMHANS), India

Shoba Srinath, Dean

Office of the United Nations High Commissioner for Human Rights

Facundo Chavez Penillas

Open University, UK

Rosa Hoekstra
Ilona Roth

Permanent Mission of Bangladesh to the United Nations, Geneva

H.E. Mr Abdul Hannan, Ambassador, Permanent Representative

Permanent Mission of Bhutan to the United Nations, Geneva

Pema Tshomo, Second Secretary

Permanent Mission of Sovereign Order of Malta to the United Nations, Geneva

Jean-François Kammer, Counsellor

Permanent Mission of the State of Qatar to the United Nations, Geneva

H.E. Ms Alya Ahmed Saif Al-Thani, Ambassador, Permanent Representative

Pro Aid Autisme and Pro Aid Autism France

Pascal A. Diethelm, Geneva Representative

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Anka Wittenberg, Senior Vice President

Specialist People Foundation (Specialisterne), Denmark

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Connie Kasari

Ummeed Child Development Center, India

Vibha Krishnamurthy, Medical Director

University Mohamed V Souissi, Morocco

Rajae El Aouad

University of Cape Town, South Africa

Petrus de Vries

University of Colombo, Sri Lanka

Hemamali Perera

University of Kelaniya, Sri Lanka

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Trinity College, Ireland
Norbert Skokauskas

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Brian Reichow

Yemen Foundation for Special Education and Autism/ Yemen Center for Autism, Yemen

Souad Al-Eryani, Chairman
Ibrahim Al-doofi

Observers:

Laura Pacione, former intern, postgraduate trainees in psychiatry, McGill University, Canada

Rachel Lacrampe, Executive Assistant to Hon. Mike Lake, Parliamentary Secretary to the Minister of Industry

WHO Secretariat:

Claudina Cayetano, Mental Health, Substance Use and Human Security, Pan American Health Organization, Panama

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For any further information please contact Dr Chiara Servili (servilic@who.int)

Annex 3 WHO Resolution EB133/4

133rd session
Agenda item 6.1

EB133.R1
30 May 2013

Comprehensive and coordinated efforts for the management of autism spectrum disorders

The Executive Board,

Having considered the report on the comprehensive and coordinated efforts for the management of autism spectrum disorders,¹

RECOMMENDS to the Sixty-seventh World Health Assembly the adoption of the following resolution:

The Sixty-seventh World Health Assembly,

Recalling the Universal Declaration of Human Rights 1948; the Convention on the Rights of the Child 1989; the Convention on the Rights of Persons with Disabilities 2007; United Nations General Assembly resolution 62/139 declaring 2 April as World Autism Awareness Day; and United Nations General Assembly resolution 67/82 on addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities;

Further recalling, as appropriate, resolution WHA65.4 on the global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level and resolution WHA66.9 on disability; resolution SEA/RC65/R7 adopted by the Regional Committee for South-East Asia on comprehensive and coordinated efforts for the management of Autism Spectrum Disorders (ASDs) and developmental disabilities; resolution EUR/RC61/R5 adopted by the Regional Committee for Europe on the WHO European Declaration and Action Plan on the Health of Children and Young People with Intellectual Disabilities and their Families; resolution EM/RC57/R.3 adopted by the Regional Committee for the Eastern Mediterranean on maternal, child and adolescent mental health: challenges and strategic directions 2010–2015 all of which emphasize a strong response to the needs of persons with developmental disorders including autism spectrum disorders and other developmental disorders;

Reiterating commitments to safeguard citizens from discrimination and social exclusion on the grounds of disability irrespective of the underlying impairment whether physical, mental, intellectual or sensory according to the Convention on the Rights of Persons with Disabilities, and promoting all persons' basic necessities of life, education, healthcare and social security; and attention to vulnerable persons;

Noting that globally, an increasing number of children are being diagnosed with autism spectrum disorders and other developmental disorders and that it is likely that still more remain unidentified or incorrectly identified in society and in health facilities;

Highlighting that there is no valid scientific evidence that childhood vaccination leads to autism spectrum disorders;

Understanding that autism spectrum disorders are life-long developmental disorders and are marked by the

presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interest; manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual;

Further noting that persons with autism spectrum disorders continue to face barriers in their participation as equal members of the society, and reaffirming that discrimination against any person on the basis of disability is inconsistent with human dignity;

Deeply concerned about the rising number of identified individuals with autism spectrum disorders and other developmental disorders and that individuals with autism spectrum disorders and their families face major challenges including social stigma, isolation and discrimination, and children and families in need, especially in low resource contexts, often have poor access to appropriate supports and services;

Acknowledging the comprehensive mental health action plan 2013–2020 and, as appropriate, the policy measures that are recommended in resolution WHA66.9 on disability, which can be particularly instrumental for developing countries in the scaling up of care for autism spectrum disorders and other developmental disorders;

Recognizing the need to create or strengthen, as appropriate, health systems that support all persons with disabilities, mental health and developmental disorders, without discrimination;

1. URGES Member States:

- (1) to give appropriate recognition to the special needs of the individuals affected by autism spectrum disorders and other developmental disorders in policies and programmes related to early childhood and adolescent development, as part of a comprehensive approach to address child and adolescent mental health and developmental disorders;
- (2) to develop or update, and implement relevant policies, legislation, and multisectoral plans as appropriate, in line with resolution WHA65.4, supported by sufficient human, financial and technical resources to address issues related to autism spectrum disorders and other developmental disorders; as part of a comprehensive approach to supporting all persons living with mental health issues or disabilities;
- (3) to support research and public awareness raising and stigma removal campaigns consistent with the Convention on the Rights of Persons with Disabilities;
- (4) to increase the capacity of health and social care systems, as appropriate, to provide services for individuals and families with autism spectrum disorders and other developmental disorders;
- (5) to mainstream into primary health care services the promotion and monitoring of child and adolescent development in order to ensure timely detection and management of autism spectrum disorders and other developmental disorders according to national circumstances;
- (6) to shift systematically the focus of care away from long-stay health facilities towards community-based, non-residential services;
- (7) to strengthen different levels of infrastructure for comprehensive management of autism spectrum disorders and other developmental disorders, as appropriate, including care, education, support, intervention, services and rehabilitation;
- (8) to promote sharing of best practices and knowledge about autism spectrum disorders and other developmental disorders;
- (9) to promote sharing of technology to assist developing countries in the diagnosis and treatment of autism spectrum disorders and other developmental disorders;

(10) to provide social and psychological support and care to families affected by autism spectrum disorders and to include persons with autism spectrum disorders and developmental disorders and their families within disability benefit schemes where available and as appropriate;

(11) to recognize the contribution of adults living with autism spectrum disorders in the workforce, continuing to support workforce participation in partnership with the private sector;

(12) to identify and address disparities in access to services for persons with autism spectrum disorders and other developmental disorders;

(13) to improve health information and surveillance systems that capture data on autism spectrum disorders and other developmental disorders, conducting national level needs assessment as part of the process;

(14) to promote context-specific research on the public health and service delivery aspects of autism spectrum disorders and other developmental disorders; strengthening international research collaboration to identify causes and treatments;

2. REQUESTS the Director General:

(1) to collaborate with Member States and partner agencies in order to provide support and to strengthen national capacities to address autism spectrum disorders and other developmental disorders, as part of a well-balanced approach, which strengthens systems, to addressing mental health and disability, and in line with existing, related action plans and initiatives;

(2) to engage with autism-related networks, and other regional initiatives, as appropriate, supporting networking with other international stakeholders for autism spectrum disorders and other developmental disorders;

(3) to work with Member States, facilitating resource mobilization in different regions and particularly in resource-poor countries, in line with the approved programme budget, which addresses autism spectrum disorders and other developmental disorders;

(4) to implement resolution WHA66.8 on the comprehensive mental health action plan

2013–2020, as well as resolution WHA66.9 on disability, in order to scale up care for individuals with autism spectrum disorders and other developmental disorders, as applicable, and as an integrated component of the scale-up of care for all mental health needs;

(5) to monitor the global situation of autism spectrum disorders and other developmental disorders, evaluating the progress made in different initiatives and programmes in collaboration with international partners as part of the existing monitoring efforts embedded in related action plans and initiatives;

(6) to report on progress made with regard to autism spectrum disorders, in a manner that is synchronized with the reporting cycle on the comprehensive mental health action plan 2013–2020, to the Sixty-eighth, Seventy-first and Seventy-fourth World Health Assemblies.

(Third meeting, 30 May 2013)



There is No Health Without Mental Health

For more information, go to www.who.int/mental_health

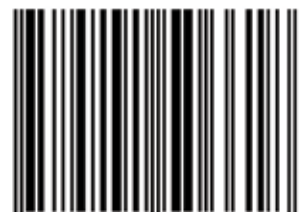


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