

Comprehensive and coordinated efforts for the management of autism spectrum disorders

Report by the Secretariat

FEATURES OF AUTISM SPECTRUM DISORDERS

1. Autism spectrum disorders comprise a range of developmental disorders characterized by impairment in functions related to central nervous system maturation. This umbrella term covers conditions such as autism, childhood disintegrative disorder and Asperger syndrome. These disorders are characterized by a varied mixture of impaired capacity for reciprocal socio-communicative interaction and a restricted, stereotyped repetitive repertoire of interests and activities. These conditions currently belong to the category in the International Statistical Classification of Diseases and Related Health Problems (Tenth revision) of pervasive developmental disorders, within the broader category of mental and behavioural disorders.
2. Individuals with autism spectrum disorders may have decreased general intellectual ability and adolescent-onset epilepsy. The level of intellectual functioning is extremely variable, extending from profound impairment to superior non-verbal cognitive skills. Specific cognitive talents, most frequently associated with music or numbers, are common.
3. Autism spectrum disorders begin in childhood but tend to persist into adolescence and adulthood. In most cases development is abnormal from infancy and, with only a few exceptions, the conditions become manifest during the first five years of life.
4. The identification of an autism spectrum disorder is difficult before the age of about 12 months but diagnosis is ordinarily possible by the age of two years. Characteristic features of the onset include delay in the development or temporary regression in language and social skills and repetitive stereotyped patterns of behaviour. In addition, it is frequent for individuals with an autism spectrum disorder to show a range of other non-specific problems such as fears or phobias, sleeping and eating disturbances, temper tantrums and aggression. Self-injury (such as wrist biting) is fairly common, especially when there is an associated intellectual developmental disorder.
5. Available scientific evidence suggests that various factors, both genetic and environmental, contribute to the onset of autism spectrum disorders by influencing early brain development.

EPIDEMIOLOGY AND BURDEN OF AUTISM SPECTRUM DISORDERS

6. Recent reviews estimate a global median prevalence of 62/10 000, that is one child in 160 has an autism spectrum disorder 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.

7. Regional estimates of prevalence are available for the European Region and the Region of the Americas only and do not differ statistically: for Europe, the median rate is 61.9/10 000 (range 30.0–116.1/10 000) and for America, the median rate is 65.5/10 000 (range 34–90/10 000). By contrast, in many parts of the world, including Africa, prevalence estimates are either unavailable or preliminary. With the exception of China, countries with a relatively large evidence base are high-income countries. A few studies have been conducted in middle-income countries and no prevalence estimate is available from any low-income country.

8. Neurodevelopmental impairments in communication, social interaction and cognition seriously hinder daily functioning of people with autism spectrum disorders and severely impede their developmental, educational and social attainments. Autism spectrum disorders account for 0.3% of all disability-adjusted life years.

9. Autism spectrum disorders impose a huge emotional and economic burden on families. Caring for children with these disorders is demanding, especially in contexts where access to services and support are inadequate. Worldwide, most individuals with such a disorder and their families do not receive any care from health or social care systems.

10. Initial data from studies in the United Kingdom of Great Britain and Northern Ireland and the United States of America indicate that estimated lifetime costs of caring for individuals with autism spectrum disorders lie between US\$ 1.4 million and US\$ 2.4 million per case according to the level of intellectual impairment. The reduction in family earnings due to the need to provide care for family members with autism spectrum disorders compounds the problem.

KEY CHALLENGES AND PRIORITIES

11. Responses to autism spectrum disorders should be based on the cross-cutting principles and approaches of universal access to and coverage by services, human rights, evidence-based practice, life-course approach, multisectoral approach and empowerment of persons with autism spectrum disorders and their families.

12. Priorities for national actions are as follows:

(a) to strengthen effective leadership and governance, by:

(i) developing, strengthening, updating and implementing national policies, strategies, programmes and laws on the needs of persons with autism spectrum disorders, within the broader mental health context and in line with evidence, best practices, the Convention on the Rights of Persons with Disabilities and other international and regional human rights conventions;

(ii) allocating a budget, across all relevant sectors, that is commensurate with identified human and other resources required to implement agreed-upon, evidence-based plans and actions;

- (iii) engaging stakeholders from all relevant sectors, including persons with autism spectrum disorders and other developmental disorders, their carers and family members, in the development and implementation of policies, laws and services;
- (b) to provide comprehensive, integrated and responsive health and social care services in community-based settings, by:
 - (i) mainstreaming monitoring and promotion of child development into primary health care services in order to ensure early detection of autism spectrum disorders and other developmental disorders;
 - (ii) systematically shifting the focus of care away from long-stay health facilities towards non-specialized health settings with increasing coverage of evidence-based interventions for autism spectrum disorders and using a network of community-based mental health services, including day care and primary care, support of people with autism spectrum disorders living with their families, and supported housing;
 - (iii) integrating and coordinating a holistic approach to health promotion, rehabilitation, care 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 autism spectrum disorders within and across general health and social services through service user-driven treatment plans and, where appropriate, with the active engagement of families and carers;
 - (iv) improving opportunities for education, employment, inclusion and participation, and access to social welfare services, by promoting inclusive education, vocational training, and supported-employment programmes, and provision of social support to parents, promotion of parent's support groups, and opportunities for respite care;
 - (v) deepening the knowledge and improving the skills of general and specialized health workers to enable delivery of evidence-based, culturally appropriate and human rights-oriented mental health and social care services for children, adolescents, and adults with autism spectrum disorders, by introducing care for individuals with autism spectrum disorders and other childhood mental disorders into undergraduate and graduate curricula, and through training and mentoring of health workers in the field, particularly in non-specialized settings, in order to promote early detection and management of autism spectrum disorders, including evidence-based psychosocial interventions, such as parent skills training and behavioural analytic approaches, and referral as appropriate to other levels of care and services;
 - (vi) proactively identifying and redressing disparities in access to services;
- (c) to implement strategies for health promotion and prevention of life-long disabilities associated with autism spectrum disorders, by:
 - (i) developing and implementing multisectoral approaches for the promotion of health and psychosocial well-being of persons with autism spectrum disorders, the prevention of associated disabilities and co-morbidities, and reduction of stigmatization, discrimination and human rights violations, and that are responsive to specific needs across the lifespan and integrated into the national mental health and health promotion policies;

- (d) to strengthen information systems, evidence and research, by:
- (i) improving health information and surveillance systems in order to capture data on autism spectrum disorders and other developmental disorders and to collate, routinely report and use data disaggregated by sex and age so as to be able to measure progress in broadening access to services to individuals affected by autism spectrum disorders;
 - (ii) improving research capacity and academic collaboration for research on autism spectrum disorders, particularly their social and public health aspects and operational research with direct relevance to development and implementation of scalable, comprehensive, community-based models of early intervention. This strengthening of research capacity may entail the engagement of all relevant stakeholders, including persons with autism spectrum disorders and their carers, and the establishment of centres of excellence.

INTERNATIONAL CONTEXT AND THE SECRETARIAT'S ACTIVITIES

13. Autism was brought to the attention of Member States and the United Nations General Assembly in 2007. In January 2008, the General Assembly adopted resolution 62/139 which designated 2 April as World Autism Awareness Day. The subsequent observation of that Day has substantially increased international awareness on autism spectrum disorders. On 12 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".¹ It encourages Member States *inter alia* to enhance access to appropriate support services and equal opportunities for inclusion and participation in society for persons with autism spectrum disorders, developmental disorders, and associated disabilities. It recognizes that, in order to develop and implement feasible, effective and sustainable intervention programmes for addressing such disorders, an innovative, integrated approach would benefit from a focus *inter alia* on enhancing and increasing research expertise and service delivery. It also calls upon States to ensure inclusive education systems and to enable the learning of life and social development skills.

14. In May 2012, childhood mental disorders, which include autism spectrum disorders and other developmental disorders, were considered by the Sixty-fifth World Health Assembly which adopted 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. It urged Member States *inter alia*, according to national priorities and within their specific contexts, to develop and strengthen comprehensive policies and strategies that address the promotion of mental health, prevention of mental disorders, and early identification, care, support, treatment and recovery of persons with mental disorders. It also requested the Director-General to develop a comprehensive mental health action plan, in consultation with Member States. The Executive Board at its 132nd session, in January 2013, approved the process proposed by the Director-General for the finalization of that plan for submission to the Sixty-sixth World Health Assembly.²

15. Member States of the South-East Asia Region recognized the need to promote stronger and coordinated actions in the Region and globally for improving access to high-quality care for children with autism spectrum disorders and other developmental disorders by adopting the Dhaka Declaration on Autism Spectrum Disorders and Developmental Disorders (26 July 2011). Furthermore, the

¹ Resolution 67/82.

² See the summary record of the third meeting of the Executive Board at its 132nd session; see also document A66/10.

Regional Committee for South-East Asia at its sixty-fifth session adopted resolution SEA/RC65/R8 on comprehensive and coordinated efforts for the management of autism spectrum disorders and developmental disabilities (Yogyakarta, Indonesia, 4–7 September 2012).

16. Representatives of Member States in the European Region, meeting at a conference on children and young people with intellectual disabilities (Bucharest, 26–27 November 2010), committed themselves to improving the health care of such children and young people in order to enhance their lifelong development, inclusion and full participation in society. Member States subsequently identified priorities for coordinated efforts by adopting the WHO European Declaration and Action Plan on the Health of Children and Young People with Intellectual Disabilities and their Families at the sixty-first session of the Regional Committee for Europe (Baku, 12–15 September 2011).¹

17. Member States of the Eastern Mediterranean Region adopted at the fifty-seventh session of the Regional Committee a resolution on maternal, child and adolescent mental health: challenges and strategic directions 2010–2015.² In it the Regional Committee urged Member States to integrate delivery of mental health services, especially for mothers, children and adolescents, within the existing health care system at all levels, enhance mental health literacy through intersectoral collaboration, review and update, or develop as necessary, national mental health policies, legislation, strategies, and plans to ensure that the provisions of the regional strategic directions on maternal, child and adolescent mental health are reflected, and mobilize the necessary resources.

18. The Secretariat's actions fall into the following main areas, and the most salient activities are summarized below.

Advocacy

19. The Secretariat has provided continued support to initiatives aiming to increase awareness on the public health relevance of autism spectrum disorders and other developmental disorders, including the United Nations World Autism Awareness Day and the launch of two regional autism networks: the South Asia Autism Network and the South-East European Autism Network.

20. Partnerships have recently been established with civil society organizations committed to improving services and increasing public awareness about autism, such as Autism Speaks, and workplans for collaborative action have been developed.

Information and surveillance

21. The Secretariat has contributed to compiling data on autism spectrum disorders through the following projects.

- A global survey on resources for child mental health was conducted in 2005,³ and in 2011 a similar survey of child, adolescent and maternal mental health resources was undertaken in the

¹ Resolution EUR/RC61/R5.

² Resolution EM/RC57/R.3.

³ *Atlas: child and adolescent mental health resources: global concerns, implications for the future*. Geneva, World Health Organization, 2005.

Eastern Mediterranean Region.¹ Their findings revealed that few resources are directed towards management of autism spectrum disorders or even mental health care in general. Moreover, the scarce resources that are available are often inefficiently used and inequitably distributed.

- The Mental Health Gap Action Programme's Evidence Resource Centre contains systematic reviews of the evidence for effective interventions for prevention and management of developmental disorders including autism spectrum disorders. This regularly updated resource is publicly accessible.² Early interventions that can be applied in primary and secondary health care settings have proved to be effective in improving the overall functioning of individuals with autism spectrum disorders and their long-term outcomes, and offer significant returns on investment with benefits that include regained productivity of both individuals with autism spectrum disorders and their carers. Such interventions include comprehensive behavioural treatment and parent-mediated interventions.

22. In addition, the Secretariat has contributed estimates of the global prevalence of pervasive developmental disorders and the construction of a research agenda on developmental disorders.

Policy, law and human rights

23. The Secretariat has provided guidance on the formulation of mental health policies and strategies that include consideration of autism spectrum disorders. It has also provided support towards the design of policies and programmes that can improve the lives of people with disabilities and facilitate implementation of the United Nations Convention on the Rights of Persons with Disabilities. Through WHO's QualityRights project the Secretariat has strengthened national capabilities to assess and improve quality and respect of human rights in outpatient and inpatient mental health services.

Service development

24. The Secretariat is providing support to Member States for improving access to health care and social support services. The Mental Health Gap Action Programme aims to expand services for mental, neurological and substance use disorders in countries, especially those where resources are constrained. It covers developmental disorders, including autism spectrum disorders, and promotes the integration of services for mental health care into routine health care at all levels of the health system, including community settings. Evidence-based clinical guidelines for assessment and management of developmental disorders and other priority conditions by non-specialist health care providers at primary and secondary health care levels have been developed and issued.³

ACTION BY THE EXECUTIVE BOARD

25. The Executive Board is invited to note this report.

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¹ *Atlas: child, adolescent and maternal mental health resources in the Eastern Mediterranean Region*. Cairo, WHO Regional Office for the Eastern Mediterranean, EMRO Technical Publications Series 39, 2011.

² http://www.who.int/mental_health/mhgap/evidence/en/ (accessed 4 April 2013).

³ *mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings: Mental Health Gap Action Programme (mhGAP)*. Geneva, World Health Organization, 2010.