

Summary report on the

Meeting on autism spectrum disorders

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Rome, Italy
16–18 November 2015



**World Health
Organization**

Regional Office for the Eastern Mediterranean

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1. Introduction

Autism spectrum disorders are characterized by difficulties in interacting with others, communicating thoughts and feelings, building social relationships, as well as by repetitive behaviours and narrow and intense interests. In addition to these core features, a range of other behaviour problems are common, such as anxiety, depression, sleeping and eating disturbances, attention issues and aggression or self-injury. Intellectual disability is observed in the majority of children with autism spectrum disorders and seizures are present in an estimated 30% of the autistic population. Given the severe social disability affecting all patients, including the ones with no intellectual disability, autism spectrum disorders require early and intensive multidisciplinary interventions involving health and social services, schools, and families over the life course of the individuals. This implies a high burden of disease and very high costs for the health system.

Epidemiological studies of autism do not yield a consistent picture, as a large variability in prevalence rates across and within different geographical areas is reported. To disentangle the factors underlying such variability, multisite epidemiological population-based studies involving ethnically diverse population groups would be important. Such studies need to have a common protocol for classification and assessment of autism spectrum disorders and adequate power to generate comparable estimates of the prevalence of autism spectrum disorders in diverse populations as well as to identify specific environmental and genetic/epigenetic risk factors and biomarkers.

In January 2008, the United Nations General Assembly adopted resolution 62/139 which designated 2 April as World Autism Awareness Day. The subsequent observation of the Day has substantially increased international awareness on these disorders. On 12 December 2012, the

General Assembly adopted a resolution entitled “Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders developmental disorders and associated disabilities”. It encouraged Member States 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. WHO’s Comprehensive Mental Health Action Plan 2013–2020 adopted by the Sixty-sixth World Health Assembly in May 2013, and a resolution (EM/RC57/R.3) of the 57th session of the Regional Committee for the Eastern Mediterranean on maternal, child and adolescent mental health all emphasize a strong response to the needs of persons with developmental disorders including autism spectrum disorders.

In May 2014 the Sixty-seventh World Health Assembly adopted a resolution on comprehensive and coordinated efforts for the management of autism spectrum disorders, calling on Member States to “increase capacity of health and social care systems, as appropriate, to capture data on autism spectrum disorders and other developmental disorders, provide services for individuals and families with autism spectrum disorders and other developmental disorders”.

In light of the global developments taking place, the Istituto Superiore di Sanità of Italy, Autism Spectrum Disorders Network (AUTISM-NET), AUTISM SPEAK and the WHO Regional Office for the Eastern Mediterranean collaborated in conducting a survey. The aim was to assess the health and social care policies and capacities of mental health and social care systems for provision of care for autism spectrum disorders.

The survey was subdivided in two parts. The first part was primarily directed at national health authorities, collecting information on demographics, child and adolescent mental health financing, services and human resources for children and adolescents with autism spectrum disorders, and the education system. The second part was primarily directed at health professionals working with individuals with autism spectrum disorders, and collecting information on surveillance, diagnosis and management, data collection and registry, and parents' associations.

Subsequent to the survey, a meeting on autism spectrum disorders was organized on 16–18 November 2015 in Rome, Italy, by the Istituto Superiore di Sanità in collaboration with the AUTISM-NET, AUTISM SPEAK and WHO. It was attended by representatives of specialized autism centres that had participated in the survey from 8 countries of the WHO Eastern Mediterranean Region: Egypt, Islamic Republic of Iran, Kuwait, Morocco, Oman, Qatar, Saudi Arabia and the United Arab Emirates. Also in attendance were representatives from selected southern European specialized centres. The objectives of the meeting were to:

- share the results of the survey;
- initiate the development of the study protocols for early detection of autism spectrum disorders and a planning guide for the delivery of comprehensive care, across sectors and target age groups, for persons with autism spectrum disorders and other developmental disorders; and
- train the participating centres in conducting multisite screening of children from 12 to 36 months of age.

2. Summary of discussions

Usually, the diagnosis of autism spectrum disorders is first made in children between 4 and 5 years of age, despite the fact that standard tests are able to clearly detect the two main core symptoms at 24 months. Moreover, parents are signalling signs of these disorders before the first year of age, indicating the possibility to early detect autism spectrum disorder well before the actual age. The survey results and the discussions during the meeting highlighted that autism spectrum disorder diagnosis in countries of the Eastern Mediterranean Region is performed at 3 years $\pm$ 6 months, as early as (if not earlier than) in most European countries. However, the questionnaires point out some critical issues, such as the lack of standardized screening protocols and diagnostic tools, need for raising awareness and specific training programmes for professionals. Some countries (e.g. Morocco) have a well-child surveillance protocol for the ages of 1, 3, 6 and 12 months but not after this age. Others (e.g. Egypt and Saudi Arabia) have only screening for social, emotional and cognitive development at 6, 9, 18 and 24 months and well-child surveillance programmes but there is no screening specifically devoted to observe and detect early signs of autism spectrum disorders. In contrast, some countries (e.g. the Islamic Republic of Iran) have a specific national screening programme.

Another important issue is the need for standardizing screening protocols/tests. At present there are no adapted and culturally relevant screening measures in countries of the Region. M-CHAT, a standard validated test available in Arabic, is the preferred screening tool. However, several countries are using only red flags or Q-CHAT.

The availability of a standard assessment protocol (and relative timeline) for screening, diagnosis and clinical evaluation, supported by training programmes for health care providers aimed at harmonizing the application of such instruments, would allow overcoming variability in estimates across the countries, races/ethnicities and socioeconomic strata.

Early identification leading to early diagnosis is not conceivable without ensuring for children with autism spectrum disorders access to evidence-based interventions for optimal development and outcomes. The survey results show heterogeneity among countries with respect to treatments: the most common interventions provided are speech/language therapy and pharmacological treatment (8 countries out of 8), behavioural and social skill treatments (7 out of 8), parent training/counselling (6 out of 8), and occupational therapy (5 out of 8). Importantly, most of the interventions are totally or partially free.

It was also emphasized that the intervention programmes have been developed only in urban areas, thus children, adolescents and adults with autism spectrum disorders living in rural areas cannot benefit from such programmes. In addition, no international guidelines or established intervention programmes are available in countries of the Region.

Altogether, these critical issues and the discussions during the meeting indicate the need to implement a revised version of the questionnaire (e.g. adding questions on diagnostic tools and on management of adult patients), and to disseminate the survey more widely, involving more than one centre per country.

Results of the expanded survey could inform the development of a public health framework to standardize protocols and policies on

autism spectrum disorders in countries of the Eastern Mediterranean Region. The framework would need to cover the following domains.

- early detection: screening (best methods; define references, references to contextualize in the different countries)
- diagnosis
- early intervention (evidence-based): social, education, health
- support for families

3. Recommendations

To countries

1. Implement training programmes for professionals and parents. 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), are essential to strengthening human resource capacities in countries.
2. Scale up clinical services. A local autism multi-agency strategy group (defined in the NICE guidelines as ‘the autism team’) should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, parent and care service users and the voluntary sector.
3. Raise public awareness on autism spectrum disorders in order to reduce the stigma associated with such disorders.

To countries and partners

4. Define common study protocols for screening and early detection. The assessment protocol (and its timelines) for screening,

diagnosis and clinical evaluation should be selected and shared across countries.

To the WHO Regional Office for the Eastern Mediterranean

5. Revise the questionnaire according to the discussions in the meeting and conduct an expanded survey in more countries with involvement of multiple centres in the Region.
6. Based on the survey results, finalize and disseminate a public health framework for action on autism spectrum disorders in countries of the Region.

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