# **Item 6.1: Autism Spectrum Disorders (ASD)**

### **Background**

Document <u>EB133/4</u> was prepared by the WHO Secretariat at the request of a Member State. The report commences with an overview of ASD including clinical features, diagnostic criteria and epidemiology.

Under the heading 'key challenges and priorities' the report considers: policy leadership and governance (policy, funding, consultation); service development (early detection in PHC services, community based services, holistic approach, inclusion in all sectors of social practice, training staff, reducing disparities in access); prevention (especially against stigmatisation); and information, evidence and research.

The report reviews various considerations of ASD at the international level including:

- UNGA Resolution <u>A62/139</u> (2008) which designates April 2 as World Autism Awareness Day;
- the <u>Dhaka Declaration on Autism Spectrum Disorders and Developmental</u>
  <u>Disabilities</u> which arose out of a meeting in Dhaka in July 2011 which was organised by a number of groups including SEARO of WHO, the Government of Bangladesh (with the personal involvement of Prime Minister, Sheikh Hasina Wazed), academics and Autism Speaks (a US based international advocacy group);
- Resolution <u>SEA/RC65/R8</u> adopted (Sept 2012) by the SEARO RC of member states in the SEA Region of WHO;
- UNGA Resolution <u>A67/82</u> (2013) on the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities.

In addition the report refers to discussions in EURO on the care of people with intellectual disability, and EMRO on maternal, child and adolescent mental health.

The final section of the report describes how the WHO Secretariat continues to contribute in this area, including advocacy, information and evidence, human rights, and guidance on service development.

#### **PHM Comment Pre-EB**

The main locus of responsibility for dealing with ASDs lies at the national level although research into causes, prevention and management is international. WHO has a role in providing policy and technical advice and helping to raise the profile of the spectrum for governments, researchers and funders and public.

This report, to be noted at the EB and considered in a revised form at the WHA67, provides very broad guidelines for member state governments to consider in developing national and sub-national policies around autism.

However, it is not self-evident that a medically dominated body such as WHO is the central repository of expertise in relation to ASDs. The mhGAP program within the

Secretariat (where responsibility for ASD lies) has traditionally had a biomedical psychiatric orientation which clearly has limitations in approaching this group of disabilities. A search for autism on the WHO website produces more references to the alleged association with vaccination than any substantive technical papers on ASDs.

# **Consideration by the Executive Board**

The Board was invited to note the report (<u>EB133/4</u>) and consider draft resolution (EB133/Conf./1 Rev.1, not posted) which was co-sponsored by 50 member states.

The focus of the debate in the first instance was the Secretariat report.

Qatar, Namibia (on behalf of the AFRO member states), Iran, Republic of Korea, Nigeria, Maldives, Albania, Croatia, Suriname, Panama, Uzbekistan, Egypt, Argentina, India, Belarus, Bangladesh, Indonesia, Cameroon, Rumania, Costa Rica, USA, Canada, Myanmar, Algeria, Libya, Tunisia, China, Portugal, Madagascar, Sudan, Russia all spoke in support of the Secretariat report and the proposed resolution.

Most of the contributions were statements of in-principle support but not very substantive. Many member states emphasised that they are expecting the Secretariat to provide policy advice, support for training, and advocacy for research.

Bangladesh noted that they had suggested the item in the first place and were gratified by the support they had received from other member states. Bangladesh highlighted the role of Sheikh Hasina Wazed, the daughter of the prime minister in driving the continued consideration of autism. Bangladesh spoke of their role in sponsoring the Dhaka conference in 2011.

Namibia commented that the establishment of World Autism Dayhad created new opportunities for the First Lady's office in Namibia and emphasised the importance of working with civil society.

Croatia and Belgium emphasised the importance of working with parents. Argentina spoke about the burden on families and the wider cost to society and emphasised appropriate training for professional staff. The delegate from the Russian Federation spoke of having a grandson with autism and spoke about the challenges facing the family, the importance of early diagnosis and the role of PHC in early diagnosis and on-going support.

The USA expressed concern that the focus on ASD should not lead to the neglect of other child development disorders and emphasised the need for an integrated comprehensive approach. The US raised for discussion the belief that there is some kind of association between childhood vaccination and autism (which, the US stated, had been scientifically proven to be a false association). WHO has the responsibility to clearly state this is erroneous. The US proposed that the resolution include a sentence on this.

Egypt challenged the US proposition that the vaccination autism story is false and suggested that perhaps the evidence is not as clear as the US suggested. Zimbabwe also asked for a clearer outline of the evidence.

The Secretariat advised that the Strategic Advisory Group of Experts on Immunisation (SAGE) has looked at evidences several times. This has been done along with national

committees and there was no evidence that autism might be linked with vaccination. Every time there is new evidence it is studied again.

The DG expressed the view that the link of immunization to autism was fiction science based on fabricated evidence. She argued that we need to take a strong stand, or parents will continue to believe false evidence. She recognised the omission of any reference to immunisation in the report and the draft resolution. She promised that WHO's advice will be revised if and when new evidence comes available.

Egypt argued that any reference to the lack of evidence should be qualified, no scientific evidence to this time.

Switzerland and Belgium expressed concern of the financial costs to the Organisation if it is committed to taking further programmatic steps in relation to ASD. The DG shared their concerns and commented on the difficulty of depending on donors for 80% of budgeted revenue. Action on autism will be included in the mental health action plan but if it is not supported by donors she will return to the governing bodies.

Following the general debate there was a more focused consideration of the draft resolution (which had not been posted in advance). Amendments discussed included stronger reference to health systems, research and public awareness, and the lack of evidence regarding vaccination.

The resolution as amended (<u>EB133.R1</u>) was adopted for consideration by the Assembly in May 2014.

### **PHM Comment Post EB**

Autism is a major social challenge globally. Decent service systems (including informal networks of support) can make a big difference to the lives of people who are affected by autism, including families. Community attitudes to autism, intellectual disability and disability generally are very significant determinants of the material and emotional support that families can access. There are deep uncertainties about the causes of autism and the best ways of diagnosing and managing it (in its wide range of manifestations).

WHO could play a significant role in providing policy advice for governments and service providers; supporting access to training; supporting public communication; and encouraging research and development. WHO's roots in the biomedical paradigm might constitute something of a limitation in its ability to serve these functions. The dependence on donor funding is a further limitation.

It appears that <u>Autism Speaks</u>, a civil society advocacy organisation based in the US, has played an important part in putting autism more firmly on the public agenda, nationally (in the US) and internationally, since 2005. The <u>co-founders</u> of Autism Speaks have deep roots within US corporate philanthropy; they also have a grandchild who is on the spectrum.