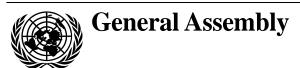
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Request for the inclusion of an item in the provisional agenda of the sixty-seventh session

Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders and other developmental disorders

Letter dated 5 July 2012 from the Permanent Representative of Bangladesh to the United Nations addressed to the Secretary-General

Pursuant to rule 13 of the rules of procedure of the General Assembly, I have the honour to request the inclusion in the provisional agenda of the sixty-seventh session of the Assembly of an item entitled "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders and other developmental disorders". I also have the honour to request that the item be considered directly in plenary meeting.

In accordance with rule 20 of the rules of procedure of the General Assembly, an explanatory memorandum in support of the request above (annex I) and the relevant draft resolution (annex II) are attached.

I have the honour to request that the present letter and its annexes be circulated as a document of the General Assembly.

(Signed) A. K. Abdul Momen





Annex I

Explanatory memorandum

- 1. Autism spectrum disorders are a group of complex neurodevelopmental disorders characterized by deficits in social interaction and communication and the presence of repetitive behaviours. Autism symptoms vary by person and range from mild to severe. Individuals with autism are significantly more likely to have intellectual disability and other mental and physical conditions than their typically developing peers. Similar to other developmental disorders, autism has a childhood onset but persists into adolescence and adulthood, affecting the cognitive, emotional, educational and social attainments of persons affected, thereby bringing significant economic hardship to their families. Owing to the complexity of the manifestation of autism spectrum disorders and the lack of any known cure, treatment for the disorders requires a multidimensional and multidisciplinary approach.
- 2. Autism spectrum disorders and other developmental disorders transcend geographic, economic and cultural boundaries. Over the past several decades, there has been a considerable increase in the prevalence of autism spectrum disorders. Today, an estimated 1 in 88 children have autism in the United States of America, with comparable prevalence estimates in other regions of the globe.
- 3. Parallel to the growing burden of autism spectrum disorders is their cost to individuals, families and society. A recent study estimated the individual lifetime cost of autism to be \$1.4 million and the annual societal cost to be \$137 billion. While less is known about the costs of autism in low- and middle-income countries, existing literature from resource-poor countries suggests that total costs to families, including medical and non-medical costs, and to society, including lost productivity, are likely to be substantial.
- 4. In recent years, countries have experienced reductions in infant and maternal mortality and improved child survival due, in part, to national commitments to achieving the Millennium Development Goals and the financial contributions of Governments, international institutions and private foundations to achieving universal immunization and halting the spread of HIV/AIDS, malaria and other infectious diseases. In many countries, improved survival has contributed to an epidemiologic transition, whereby the disease burden shifts from communicable to non-communicable diseases. As a consequence, more children will be and are being diagnosed with an autism spectrum disorder.
- 5. A major barrier to improving the health and well-being of children and families touched by autism is the paucity of knowledge and expertise to recognize the symptoms and identify autism spectrum disorders and other developmental disorders. The absence of effective screening, in turn, limits access to care and early interventions. Once populations are screened, there is a similar problem associated with the dearth of trained human resources. Treatment programmes by trained therapists are quite effective, particularly when the diagnosis is made early and subsequent interventions are begun. In general, when intervention is timely, up to 10 per cent of children with autism can fully recover and nearly 90 per cent show sustained post-intervention benefits. Treatment, however, takes training. Moreover, it is often required over a lifetime, as are the accompanying clinical and social services. Without effective programmes, appropriate solutions that improve the

2 12-41266

quality of life of individuals with autism spectrum disorders and their families do not reach them.

- 6. In December 2007, Qatar led and facilitated the adoption of General Assembly resolution 62/139 on World Autism Awareness Day. In that resolution, the Assembly invited all countries and associated groups to observe World Autism Awareness Day every 2 April and encouraged Member States to take measures to raise awareness throughout society, including at the family level, regarding children with autism. In the five years since the adoption of the resolution, global autism efforts have gained considerable momentum.
- 7. On 3 April 2012, for example, the Permanent Mission of Bangladesh to the United Nations, the United States Mission to the United Nations and the Permanent Mission of the State of Qatar to the United Nations co-hosted with Autism Speaks a United Nations panel discussion on the theme "Delivering answers through inclusive international collaboration". The event served as a platform to bring the international community together in an effort to shed light on autism's effect on families around the world and on the measures being taken by leaders to better facilitate the provision of resources and services.
- 8. For the second year in a row, the Secretary-General unveiled United Nations Postal Administration commemorative "autism awareness" postage stamps.
- 9. Similarly, Mrs. Ban Soon-taek, the wife of the Secretary-General, in her fourth year of attendance, joined the event entitled "World focus on autism" on 20 September 2011. First spouses and dignitaries, including ministers of health, from more than 30 countries around the globe joined the annual event to raise global awareness and share best practices for countries, communities and families struggling with this non-discriminative disorder.
- 10. Unfortunately, while awareness of autism spectrum disorders and other developmental disorders in developed countries is high, the same cannot be said for many developing ones, in particular the least developed countries. This is due in part to a lack of local needs assessment, including data on the prevalence of autism and related conditions. National plans to address the needs of individuals with autism and their families cannot be fully developed without a comprehensive picture of the system of care for these individuals, including existing resources across all sectors (e.g. health, education and social welfare) and at multiple levels (e.g. family and community).
- 11. Awareness needs to be accompanied by the provision of care. Despite what is known about the growing prevalence of autism spectrum disorders and other developmental disorders and their high costs to society, systems of care for children in most developing countries, in particular the least developed countries, are either non-existent or woefully inadequate to address the needs of individuals with autism spectrum disorders and other developmental disorders and their families. For instance, the World Health Organization reports that the global median percentage of Government health budget expenditures dedicated to mental health is 2.8 per cent. Globally, spending on mental health is less than \$2 per person, per year, and less than \$0.25 in low-income countries. While mental health care is only one part of the range of services for individuals with autism spectrum disorders and other developmental disorders, these figures nonetheless highlight the resource constraints

12-41266

faced by Governments in providing even the most basic of health services to their populations.

12. Ultimately, meeting the growing needs of individuals with autism spectrum disorders and other developmental disorders and their families will require a coordinated, multipronged approach at the global level that focuses on increasing awareness by building knowledge, advocating that Governments invest in child development and address disorders and building the capacity of national systems to provide appropriate and high-quality services.

Suggested emphasis of the proposed General Assembly resolution on a coordinated global response to autism spectrum disorders and developmental disorders

- 13. A General Assembly resolution in support of a coordinated, multipronged global response to autism and other developmental disorders will greatly advance the interests and well-being of millions of individuals and families living with autism. The Dhaka Declaration on Autism Spectrum Disorders and Developmental Disabilities, unanimously adopted by participants at a conference held in Dhaka on 25 and 26 July 2011 on the theme "Autism spectrum disorders and developmental disabilities in Bangladesh and South Asia", should serve to inform the content of such a proposed solution. It is suggested that the following objectives be emphasized in the proposed resolution:
- (a) To build capacity to provide care to those affected. This will include training service providers at all levels of health, education and social welfare systems, including parents, professionals, paraprofessionals and other lay care providers;
- (b) To strengthen public health related research to inform policy development and dissemination/implementation. This will include prioritizing and supporting epidemiology studies, including prevalence, as well as research to identify and implement evidence-based methods for early treatment and lifelong management.
- 14. To achieve those objectives, the proposed resolution will suggest the following mechanisms:
- (a) Involvement of (call to action to) all United Nations agencies. In order to enhance the potential impact of the resolution, especially given the voluntary country-level reporting, having all relevant United Nations agencies involved is essential. Since autism spectrum disorder and other developmental disorders are essentially health conditions, the World Health Organization will need to take on a key role;
- (b) **Development of a funding capacity/mechanism**. Having dedicated resources will facilitate and accelerate progress in achieving the objectives of the resolution. The structure of such a fund/mechanism will be developed and refined at upcoming meetings for the proposed global fund;
- (c) **Voluntary periodic reporting**. States, as well as United Nations organizations, will be requested to report progress in implementing the resolution annually or biennially on a voluntary basis.

4 12-41266

Annex II

Draft resolution

Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders and other developmental disorders

The General Assembly,

Guided by the purposes and principles enshrined in the Charter of the United Nations,

Recalling the 2005 World Summit Outcome and the United Nations Millennium Declaration, as well as the outcomes of the major United Nations conferences and summits in the economic, social and related fields,

Recalling also the Declaration of Alma-Ata, the Ottawa Charter for Health Promotion, 1986, and subsequent relevant resolutions of the World Health Assembly and the Regional Committees,

Recalling further the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, according to which individuals with disabilities should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the individual's active participation in the community, as well as the full enjoyment of all human rights and fundamental freedoms on an equal basis with other individuals,

Affirming that ensuring and promoting the full realization of all human rights and fundamental freedoms for all persons with disabilities is critical to achieving the internationally agreed development goals,

Aware that autism is a lifelong developmental disability that affects the functioning of the brain and is characterized by impairments in social interaction, problems with verbal and non-verbal communication and restricted, repetitive behaviour, interests and activities,

Deeply concerned by the prevalence and high rate of autism in children in all regions of the world and the consequent development challenges to long-term health care, education, training and intervention programmes undertaken by Governments, non-governmental organizations and the private sector, as well as its tremendous impact on individuals, their families, communities and societies,

Recognizing that individuals with autism spectrum disorders and other developmental disorders and their families often face major challenges associated with stigma, isolation and discrimination, as well as a lack of access to health-care and education facilities,

Recognizing also that the attention received by policymakers and public health experts and the consequent allocation of resources have so far been inadequate to address the treatment gap for developmental disorders, and that stronger concerted efforts are required,

Recognizing further that early diagnosis, appropriate research and effective interventions are vital to the growth and development of the individual,

12-41266

Concerned that the burden of autism spectrum disorders and other developmental disorders has been demonstrated to be higher than many other socially recognized health problems, using the disability-adjusted life year metric, which measures the burden of disease as a function of prevalence, functional impairment, chronicity and age of onset,

Realizing that the burden of autism is particularly acute in the developing world, where poverty, malnutrition, poor education, inadequate maternal and child health care, and frequently blatant discrimination complicate the challenges for individuals and families with autism, as well as for the health, education and social welfare systems trying to meet their needs,

Recognizing that technical guidance material on autism spectrum disorders and other developmental disorders has been developed by the World Health Organization,

Noting the adoption by the sixty-fifth World Health Assembly on 25 May 2012 of resolution 65.4 on the global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level, in which the World Health Assembly urged member States to give appropriate priority to and to streamline mental health, including the promotion of mental health, the prevention of mental disorders and the provision of care, support and treatment in programmes addressing health and development, and to allocate appropriate resources in that regard,

Recognizing that a major barrier to improving the health and well-being of individuals and families touched by autism is the paucity of knowledge and expertise to recognize the symptoms of autism and identify autism spectrum disorders and other developmental disorders,

Recognizing also that the absence of effective screening limits access to care and early interventions,

Recognizing further that without effective programmes, the emergence of appropriate solutions that improve the quality of life of individuals with autism spectrum disorders and other developmental disorders and their families will not occur,

Acknowledging efforts undertaken by Governments and international health actors to tackle the problem, including the commemoration of World Autism Awareness Day, which have led to increased international public concern for autism and other developmental disorders,

Highlighting the need to invest in the treatment of developmental disorders, including autism, in keeping with the theme of World Mental Health Day for 2011, "The great push: investing in mental health",

- 1. Welcomes the international conference jointly organized by the Government of Bangladesh, the World Health Organization and the Autism Speaks Global Autism Public Health Initiative, which culminated in the adoption of the Dhaka Declaration on Autism Spectrum Disorders and Developmental Disabilities on 25 July 2011;
- 2. Recognizes that, in order to address autism spectrum disorders and other developmental disorders, an innovative, integrated development approach is

6 12-41266

required that focuses on increasing public and professional awareness of autism spectrum disorders and other developmental disorders; increasing research expertise and international collaboration through training of autism and disability researchers, with a focus on epidemiology, screening and early diagnosis, and treatment; and enhancing service delivery by providing training to service providers and non-professionals in early diagnosis and interventions;

- 3. *Encourages* Member States to take measures to raise awareness throughout society, including at the family level, of individuals with autism spectrum disorders and other developmental disorders;
- 4. Calls upon Governments to strengthen their mental health services and prepare them for the task of attending to the needs of people with developmental disorders, including autism;
- 5. *Urges* the United Nations system, including the World Health Organization, international financial institutions and other relevant United Nations agencies, to provide appropriate and adequate technical support and assistance to Member States in the implementation of actions towards increased public awareness and scientific evidence and improved health-care services for children with autism spectrum disorders and other developmental disorders, in the context of integrated case services for individual mental health;
- 6. Requests other international, bilateral and non-governmental organizations, the private sector, civil society, foundations and philanthropic organizations to support the Governments in implementing the provisions of the present resolution;
- 7. Deeply appreciates the offer of the Government of Bangladesh and the Autism Speaks Global Autism Public Health Initiative to convene an international conference on the subject during the first quarter of 2013 to take stock of and chart the way forward on the implementation of the provisions of the present resolution;
- 8. Calls upon all United Nations agencies, in particular the World Health Organization, civil society and philanthropic organizations to help countries to prepare voluntary country reports;
- 9. Requests the Secretary-General to bring the present resolution to the attention of all United Nations organizations and relevant stakeholders and to submit to the General Assembly at its sixty-eighth session a report on the implementation of the present resolution under an item entitled "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders and other developmental disorders".

12-41266