

12th Conference of the Baltic Child Neurology Association

31 May 2013 - 01 June 2013
Kaunas, Lithuania

Dear Health Ministers of the European Community countries,

Autism Spectrum Disorder (ASD) is a significant public health challenge. Current estimates are that approximately 1% of the US and UK population has ASD, which, if one were to extrapolate, means 5 million people in EU member state countries are on the autism spectrum. These current estimates show that ASD is more common than childhood cancer, juvenile diabetes and paediatric AIDS combined. It is a great challenge to health care providers in the Baltic States as well. Being a quite new entity in our list of diagnoses, autism and other ASD require a totally different attitude to diagnostics and management, from search for etiology and early comprehensive evaluation of symptoms, to multidisciplinary family-targeted medical, social and educational management and smooth transfer to comprehensive care in adulthood.

For at least the past 30 years, there has been an increasingly global response to health problems. A new global health policy "Health for All in the 21st Century" confirmed several new goals. One of them says: To ensure access for all to essential health care of good quality.

WHO's "Targets for Health for All" are still important and have to be kept in mind while organizing or assessing health care services. Target 1 "Equity in health", Target 2 "Health and quality of life", Target 3 "Better opportunities for people with disabilities", and Target 7 "Health of children and young people" are directly related (among other things) to the organization and quality of services for children that have developmental disabilities.

The People's Health Assembly has created the People's Health Charter which asserts that health is a human right and that "health and human rights should prevail over economic and political concerns" and declares that „governments have a fundamental responsibility to ensure universal access to quality health care, education and other social services according to people's needs, not according to their ability to pay“.

The 12th Baltic Child Neurology Conference (BCNA) took place in Kaunas, Lithuania on May 30-June 1, 2013 (www.bcna2013.com). The conference has been included into the list of meetings of non-governmental organizations and social partners related to Lithuania's Presidency of the Council of the European Union. Workshop "Childhood autism: challenges and opportunities" was organized as a pre-conference event on May 28-29, with participation of world famous specialists in autism and speakers (prof. C. Gillberg, dr. E. Billstedt, dr. M. Mintz), child neurologists, child psychiatrists and psychologists from the Baltic countries, also representatives of parents' organizations and the representative of the Ministry of Health of the Republic of Lithuania. Not only the modern concepts on the diagnostics and comprehensive management of children with autism and ASD have been thoroughly presented by the outstanding experts, but also the situation in providing medical, social and educational care for children with autism have been reviewed and discussed.

The participants of the Workshop and the delegates of the BCNA conference approved the suggestion to address the Health Ministers of EU countries regarding the care for children with ASD in the Baltic countries, and the message is provided below.

- There is no reliable statistical data about the prevalence of ASD because of misdiagnosis (due to several reasons) and absence of registers.
- Services for autistic children and their families are poor and not properly developed.

- Reliable diagnostic tests and effective therapeutic programs are not implemented into clinical practice. The psychosocial and educational management often depend on the financial possibilities of the families, thus for many autistic children qualified specialized care is not accessible.
- The services are centralized and poor or not available at all at the community level. There is lack of qualified specialists, especially child psychiatrists and speech and language therapists.
- The public and professional awareness of ASD is low, and this results in delayed diagnosis and interventions, also recognition and management of concomitant disorders (like attention deficits/hyperactivity and other behavioral disorders, mental retardation and speech and language disorders, epilepsy, etc.).
- Pedagogues and social workers have poor understanding of ASD, and this affects integration and education of autistic children.
- The out-dated regulations regarding medical and social care (including rehabilitation, education and social care) often even not mention the diagnosis of autism, therefore the diagnosis of childhood autism is often hidden under another name as "mental retardation", or is changed to another psychiatric diagnosis (especially when he/she reaches adult age) just in order to preserve the patient's right to access the services.
- Social integration of these patients in adulthood is extremely poor due to the lack of day-care centers, and their life is often limited to home environment, thus also affecting the whole family life. Disability allowance often is the only social help.
- The services for children with ASD and their families may not be proper without close inter-sectorial collaboration of Healthcare, Social care and Education ministries and other governmental institutions.

Thus, on behalf of child neurologists from Lithuania, Latvia and Estonia, on behalf of our patients and their families we kindly ask you for the encouragement of the following steps aimed at developing of comprehensive medical/rehabilitation/habilitation and education/social services for children with developmental disorders in general and for autistic children in particular:

1. Revision of the present health care, social care and educational services for persons with the diagnosis of autism or ASD.
2. Development of competence centers that would collect and share evidence based information about diagnostics and management, run registers of ASD and would be responsible for high-quality training provision for parents, carers and professionals to encourage the dissemination of good practice.
3. Setting up services all over the country for children with ASD and make therapies available and accessible to everyone close to home.
4. Stimulating research in the field of autism (prevalence, etiology, etc.).
5. Development of proper policies, regulatory documents and guidelines, that would be in concordance with the above mentioned international documents, European Charter for Persons with Autism (*attached*) and UN declarations on human, children and disability rights.

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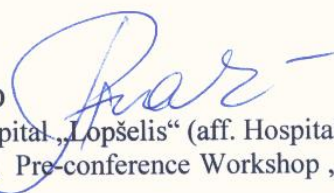


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CHARTER FOR PERSONS WITH AUTISM

People with autism should share the same rights and privileges enjoyed by all of the European population where such are appropriate and in the best interests of the person with autism.

These rights should be enhanced, protected, and enforced by appropriate legislation in each state.

The United Nations declaration on the Rights of Mentally Retarded Persons (1971) and the Rights of Handicapped Persons (1975) and other relevant declarations on Human rights should be considered and in particular, for people with autism the following should be included.

1. THE RIGHT of people with autism to live independent and full lives to the limit of their potential;
2. THE RIGHT of people with autism to an accessible, unbiased and accurate clinical diagnosis and assessment;
3. THE RIGHT of people with autism to accessible and appropriate education;
4. THE RIGHT of people with autism (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected;
5. THE RIGHT of people with autism to accessible and suitable housing;
6. THE RIGHT of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence;
7. THE RIGHT of people with autism to an income or wage sufficient to provide adequate food, clothing, accommodation and the other necessities of life;
8. THE RIGHT of people with autism to participate, as far as possible, in the development and management of services provided for their wellbeing;
9. THE RIGHT of people with autism to appropriate counselling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interest of the individual with all protective measures taken;
10. THE RIGHT of people with autism to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual;
11. THE RIGHT of people with autism to accessible transport and freedom of movement;
12. THE RIGHT of people with autism to participate in and benefit from culture, entertainment, recreation and sport;
13. THE RIGHT of people with autism of equal access to and use of all facilities, services and activities in the community;
14. THE RIGHT of people with autism to sexual and other relationships, including marriage, without exploitation or coercion;
15. THE RIGHT of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights;
16. THE RIGHT of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution;
17. THE RIGHT of people with autism to freedom from abusive physical treatment or neglect;
18. THE RIGHT of people with autism to freedom from pharmacological abuse or misuse;
19. THE RIGHT of access of people with autism (and their representatives) to all information contained in their personal, medical, psychological, psychiatric and educational records.

Presented at the 4th Autism-Europe Congress, Den Haag, May 10th, 1992.
Adopted as a Written Declaration by the European Parliament on May 9th, 1996.

Autism-Europe

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