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European Days of Autism: Putting Autism on the EU member States' political agenda

The European Days of Autism will be celebrated during the first week end of October. At this occasion, Autism-Europe would like to recall some basic facts about Autism, such as its high prevalence rate and the lack of adapted care for persons with autism. Autism-Europe also welcomes the latest policy developments meant to improve the quality of life and respect of the rights of persons with autism in several EU member states.

Autism is a significant lifelong disability, due to multiple medical causes, interfering with the normal development and functioning of the brain, identifiable in very early childhood. Autism deeply affects the way the person communicates and relates with his or her environment. It is characterized by a triad of symptoms: impairments in social interaction; impairments in communication; and restricted interests and repetitive behavior.

Autism can affect any family, regardless of ethnic or social class, and it is four times more frequent in males than in females.

There is now converging evidence that, using current diagnostic criteria, many more individuals, in many different countries are being diagnosed with Autistic Spectrum Disorders (ASD). Rigorous surveys from North America found that about 1 in 150 8-year-old children in multiple areas of the United States had an ASD. Epidemiological studies from Europe point to a similar figure among children (0,9 per 150, or 60 per 10.000). Autism is therefore not a rare condition. **The Member States of the European Union and the Council of Europe should therefore pay a particular attention to autism considering the high prevalence of this disability.**

At the occasion of European Day of Autism, Autism-Europe will hold a high-level international conference in Madrid on October 3rd. The objective is to raise awareness of the rights of persons with ASD and the necessity of providing them with life-long quality support services. **Nowadays there is indeed a dramatic shortage of adapted, evidence-based services for persons with ASD.**

However, Autism-Europe would like to highlight a number of positive policies and legislative developments as regard Autism across the EU. Indeed, across several EU member States, autism has been put on the political agenda. These initiatives pave the way for improving the life of persons with Autism in Europe.

In Hungary, a 5-years Strategy for Autism has been commissioned by the Ministry of Social Affairs and Labour and drafted by experts as a recommendation under the supervision of the Hungarian Autistic Society. The Strategy aims at improving care for

persons with ASD notably by developing specific services for persons with ASD, improving diagnosis, as well as access to education (including training for adults). One of the objectives is also to train staff to care for persons with ASD and to provide support for families. Another target is to develop employment opportunities for persons with ASD. At the moment, the government has released a draft governmental decree for its implementation.

In the UK, the Adult Autism Strategy, which will be published early next year, will set out the Government's plans to tackle the isolation, discrimination and inequality routinely experienced by many adults with autism. It will detail the steps that need to be taken locally and nationally to achieve real change. This is the first time that a Government has committed to producing a strategy specifically to improve outcomes for adults with autism.

In France, the first anniversary of the French Plan for Autism 2008- 2010 was celebrated in May 2009. This plan with a budget of 187 million Euros aims at increasing availability of adapted educational settings for children with ASD while promoting innovative methods of care for them. The emphasis is also laid on improving diagnosis.

In Italy and Spain, governments have adopted guidelines on Autism in close cooperation with the stakeholders including associations of families of persons with ASD. Nevertheless efforts should be made for their enforcement at regional and local level.

In Portugal, an important law (3/2008 published on 7 January 2008) on Inclusive Education reinforces the previous law and provides that every child must go to public school. Article 25 is devoted especially to the education of children with autism and creates Unities of Structured Teaching where they can receive special support so they are able to follow the regular classes in their schools. In 2009, 1080 children with autism (5 to 14 years old) are included in Portuguese public schools in about 180 units.

Meanwhile, in Greece, following a law adopted in 2008, children with Autism are recognized for the first time as requiring, like children with other disabilities, special education by specialized teachers in mainstream schools. However, the Ministry of Education has repeatedly failed to implement this law, by providing partial, delayed or inadequate special educational support, on the grounds of lack of funds or adequately trained teachers. In June 2009, after numerous parents' complaints, the Independent Authority of "Citizens Advocate" has issued a Statement recognizing the violation of the law by the State and proposing specific measures to ensure its application.

Evelyne Friedel, President of Autism Europe, has hailed these various policy developments as significant steps toward the full recognition of the rights of persons with ASD. She called for the full implementation of these initiatives as well as their replication across other EU member states. Indeed **Autism-Europe considers that in Europe - but also outside Europe - there is an urgent need for sharing knowledge and best practices between countries for achieving better conditions of life for persons with ASD.**

Autism-Europe is an international association whose main objective is to advance the rights of persons with autism and their families and to help them improve their quality of life.

Autism-Europe's overarching mission is indeed to improve the quality of life of all persons with autism and their families by promoting and defending their rights. This is achieved through:

- **Representing persons with autism towards all European institutions**
- **Promoting awareness on the appropriate care, education, and well-being of persons with autism**
- **Promoting the exchange of information, good practices and experience.**

Autism-Europe constitutes a European network which ensures effective liaison between approximately 80 member associations of parents of persons with autism in 30 European countries, governments and European and international institutions.

In order to implement its objectives, Autism Europe has built strategic alliances with social partners to maximise its impact on EU policies. Autism-Europe is a founding member of and strictly collaborates with the European Disability Forum and the Platform of European Social NGOs.

Autism-Europe has also established a structured dialogue with the European Institutions of the European Union, and of the Council of Europe, as well as with the World Health Organisation.

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