



October 2010

European Days of Autism: A future for Autism

The European Days of Autism were celebrated at the beginning of October 2010 together with the Autism-Europe IX International Congress in Catania entitled "A Future for Autism". On that occasion, Autism-Europe raised awareness about the fact that nowadays persons with autism and their families very often lack the support they need to live a dignified life. As the population is ageing, persons with Autism and their families are faced with very complex difficulties and a lack of adapted services. Action is therefore required to ensure that persons with ASD benefit from the same opportunities as the rest of the European citizens.

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 and of AE IX International Congress in Catania, 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 throughout their lives.**

Autism does not only affect children but also adults who often do not benefit from the adequate support to live an independent life. People with ASD, as the rest of the European population, grow older which implies the need to provide adapted services and care, in particular after their families' death or breakdown.

Recent surveys led in the UK show that Adults with autism are often unable to access the right support, and consequently often become dependent on their families. 61% of adults with autism rely on their families for financial support, over 40% live at home with their

parents. Most provision for adults with ASD comes from families, as a matter of fact, but when family care is not available any more an alternative support must be provided. The provisions for elderly persons with ASD should not be simply a “parking”, but ensure them to be respected citizens and participate in community activities as anyone else.

ASD features do not necessarily improve with age, mainly if persons with ASD did not have access to proper education and habilitation programmes. On the contrary, elderly persons with ASD can show more complex needs in terms of health care and support. **As a consequence, ageing of persons with ASD implies not only the need for a life-long qualified support, but also enhanced intensity of the care in their elderly age.**

In contrast, many elderly persons with ASD or other complex dependency needs disabilities are placed in large, segregating institutions, as well as young adults with ASD or other complex dependency needs disabilities, whose families are not likely to be able to ensure fundamental rights to life-long, effective education, habilitation and inclusion. To their detriment, neither the community nor the policy makers in many cases are ready to accept to support adequately long-term dependency and to provide the financial and professional resources needed. **The issue of ageing of persons with ASD opens therefore a wider debate on the de-institutionalization process and its meaning for persons with ASD.**

The needs of ageing people with autism are the same as those of other ageing people: economic, social, residential and affective, but aggravated by the neurological, physiological and psychological factors linked to their specific condition.

Autism-Europe would like to highlight and support the recent initiatives of several European institutions to raise awareness about the challenges of an ageing population. **In particular, on 8 July 2009 the European Council’s Committee of Ministers addressed a recommendation on ageing and persons with disabilities to Member States.** It should be underlined that this recommendation makes a clear distinction between “ageing people with disabilities” and “older people with disabilities”. The first group refers to people who grow old having experienced a disability for much of their lives, sometimes from birth. For the second group, disability is first experienced at a relatively advanced age. **The broad outlines of the Council of Europe new recommendation aim at promoting autonomy and an independent life of ageing people with disabilities ; enhancing the quality of services and ensuring equal access to those services.**

During the opening ceremony of AE IX International Congress, Evelyne Friedel, President of Autism Europe, reminded that the Council of Europe indicates that ageing of people with disabilities, particularly of those requiring more intensive support, compels Member States to adopt innovative approaches. This is particularly relevant for persons with ASD due to their complex needs. **On the occasion of Autism-Europe’s IX International Congress, she welcomed the recent innovations in the field of evidence-based treatments and interventions for persons with ASD. She also calls on Member States to take concrete actions to improve the conditions of life for persons with autism - including elderly people - and to cooperate at European and International level to promote the exchange of information and best practices.**

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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This publication is supported by the Directorate-General for Employment, social affairs and equal opportunities of the European Commission under the Programme PROGRESS. For more information see:
http://ec.europa.eu/employment_social/progress/index_en.html

