

## **CONTRIBUTION TO THE CONSULTATION ON THE FUTURE "EU 2020" STRATEGY**

Autism is a complex lifelong disability, due to multiple medical causes, interfering with the normal development and functioning of the brain, identifiable in very early childhood. It deeply affects the way the person communicates and relates with his or her environment and is often combined with mental disabilities. **Autism is not a rare condition**: considering the whole spectrum of autistic disorders (ASD), it nearly affects 6/1000 of population. Autism can affect any family, regardless of ethnic or social class. This means that Europe (including all members of the Council of Europe) counts around 5 million people with autism.

The Strategy EU 2020 is being prepared during “the worst economic and financial crisis in decades”. Persons with autism – or with other kind of disabilities - and their families are very often the first ones to be affected by an economic downturn. But, we also know that persons with autism suffer from exclusion even in better times because they are denied access to education, adapted care and services in the community.

Due to the complexity of their needs, they form an especially vulnerable group even among persons with disabilities. As underlined by the Council of Europe, people with autism are often subject of more serious discriminations. Although good models exist, people with autism are still, in great majority, deprived from personalised specialised education and treatment which would enable them to truly improve. This deprivation generates much suffering and additional difficulties, and constitutes a form of discrimination. We would like to point out that the new Lisbon Treaty includes a legally binding Charter of Fundamental Rights. Autism-Europe therefore calls on the principle of **anti-discrimination** to be included and mainstreamed in the Strategy.

For guaranteeing their full dignity, people with autism should not be considered nor treated as a population that is not able to achieve goals such as independence and self-determination like any other EU citizens. Autism-Europe considers that “**fostering social inclusion**” should be one of the core objectives of the strategy. Autism-Europe calls on the reinforcement of the disability dimension at the EU level and also strongly supports the proposal of a “**Disability pact**” put forward by the European Disability Forum.<sup>1</sup> Since the current EU Disability Action Plan is coming to an end, the Disability pact is meant to mainstream and give a clear long term direction to disability policy at European level. In addition, on 26 November 2009, the Council decided on the European Community becoming a party to the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD binds the States Parties to a revision of all existing legislation, policies and programs to ensure they are in compliance with its provisions.

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<sup>1</sup> Proposal for a European Pact on Disability - [http://cms.horus.be/files/99909/MediaArchive/library/EDF\\_proposal\\_for\\_a\\_European\\_Disability\\_Pact.doc](http://cms.horus.be/files/99909/MediaArchive/library/EDF_proposal_for_a_European_Disability_Pact.doc)



Autism-Europe also would like to address the following recommendations in the framework of the consultation for the **"EU 2020" STRATEGY**:

<b>Creating value by basing growth on knowledge</b>
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- 1- Combating exclusion and poverty of persons with ASD and their families** by structuring **effective education** and **health systems** which are equipped to deal with the special needs of persons with ASD in term of life-long education and habilitation

The document emphasizes that the drivers of the EU2020 will focus on “Creating value by basing growth on knowledge” notably by “strengthening education”.

For people with ASD, education represents a lot more than a basic right and way to create value. Education is necessary to compensate for the great difficulties that people with autism have in extracting meaning from simple experiences, something most other people are capable of without specific educational support.

The Resolution ResAP(2007)4 of the Council of Europe on the education and social inclusion of children and young persons with ASD mandates the member states to adopt legislation and policies to mitigate the effects of the disorder and to facilitate social integration, improve living conditions and promote the development of independence of individuals with this disorder, by providing equality of opportunity and appropriate educational interventions. Eighteen specific recommendations are defined.

The severity of their disability means that persons with ASD require life-long training, adapted to their specific needs in the fields of:

- education, to develop not only work competencies, but also the social and personal skills needed to access professional training and a job, albeit a protected one.
- professional training,
- continuous teaching

Many of those that are lucky enough to enjoy adapted training are subsequently able to work. Conversely, the absence of early, individualised and continuous training has irreparable consequences on the development of the person and their ability to gain employment at an adult age.

- 2- Improve the qualification of the staff** providing education and care to persons with ASD through structured training on specific education/habilitation strategies for ASD to be included in the University curricula of health and education professionals



Compulsory training on specific intervention strategies for ASD, as well as on ethical issues and the rights-based approach to ASD should be included in the curricula of all professionals.

A lack of trained staff can lead not only to inadequate intervention but also to improper or inappropriate use of pharmaceutical drugs and to pharmacological abuse, often without the informed consent of parents or against their will.

- 3- Strengthen education** of children and adults with ASD through the adoption of evidence-based educational strategies meeting the special needs of persons with ASD, according to up-to-date, sound research studies in the field of neuro-sciences and cognitive functioning in ASD

Intensity of intervention is not sufficient to ensure equal opportunities for persons with ASD. Intervention should also meet quality criteria in terms of research-sound, evidence-based approaches.

Good-practice guidelines have been produced by expert committees in Europe. These include the National Institute of Health of Spain and the Scottish Intercollegiate Guidelines Network, which have reviewed all available evidence for the great variety of treatments advocated for ASD. The UK Departments for Education and Skills and for Health have also produced good-practice guidance for the education of students with ASD.

These position statements coincide well with similar guidelines arising from other parts of the world, such as the U.S.A., Canada and Australia. It can be said, without ambiguity, that we now have a shared vision on treatment for persons with ASD. In consequence, those individuals and organizations that propose radically contrary approaches must assume the moral and legal responsibility that results from practicing outside the main framework now accepted by the most prestigious and responsible professional bodies of the world.

Those who ignore these well established guidelines run the risk of being accused of discriminating against citizens with ASD, and of preventing them from accessing their basic human rights to health and education. Much has been learned over the past few years about those practices that are supported by current scientific knowledge and those that are not, and about which programmes make a real difference to the lives of individuals with ASD. Unfortunately, this knowledge has not yet been incorporated into general practice across Europe. Thus, there remains an unethical gap between knowledge and opportunities, and it is still evident that very few European citizens with ASD receive the state-of-the-science support to which they could and should be entitled.

Children with ASD should be referred for free appropriate education from pre-school age. A specialized educational approach should engage the pupil in systematically planned, developmentally-appropriate educational activities, according to identified objectives on the basis of the child's best interest, motivation, strengths and needs, whilst also taking into account the priorities of the family.



The needs for support of persons with ASD depend on the individual circumstances and change over time with age and environmental demands. ASD features do not necessarily improve with age, mainly if they 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.

- 4- Support research programmes in the field of ASD** in order to enhance the efficacy of education and habilitation strategies for persons with ASD and foster their inclusion and active participation in society.

The Commission working document underlines the necessity of an effective and well-resourced European **Research Area** in order to achieve a “sustainable Growth”. Autism-Europe believes that growth should not be the only driver in the field of research. Indeed, research is key to improve the lives of persons with ASD, as well as millions of persons with disabilities or illnesses in the European Union.

The scientific reliability of the intervention is not an extraneous or a secondary factor in combating discrimination and in fostering the social inclusion and participation of persons with ASD.

Bad practices that are based on misconceptions of autism or on unproven theories and dubious efficacy can lead to serious problems in the well-being or physical health of persons with ASD and have irreparable consequences on the development of the person and their ability to achieve independence, social inclusion and a dignified life at an adult age.

Newer and more effective ways of counteracting the negative consequences of these disorders on the quality of life of persons with ASD are needed. Discovering better ways of treating and perhaps preventing these disorders should be made a health priority. But the substantial needs of this group of citizens do not imply that all research proposals should be carried out.

Research programs need to be carefully assessed. Ethical committees must assure, with special care in these cases, that the potential benefit is much greater than the risk involved and that a fair due process has taken place.

<b>Empowering people in inclusive societies</b>
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- 1- Create new high quality jobs** in the field of life-long education and care for persons with ASD in order to facilitate the transition from school system to work, both in sheltered setting or open labor market, depending on the individual needs and skills (case managers, job coaches)



Autism-Europe appreciates the emphasis laid on training and life-long learning, indeed the lack of training and of adapted support, explains to a large extent why people with autism or a complex dependency needs disability are almost entirely absent from the labour market and remain totally dependent on the support of their families in the long-term.

New models of services are needed allowing for more flexibility, individualized support, and person-centered planning, with the aims of fostering the maximum development of the individual potentials while respecting the individual wishes and priorities and involving parents and/or other family members as active partners.

Adequate support at the workplace (adaptation of the environment, supervision by professionals, tasks appropriate to their disability...) is an essential condition for people with autism or a complex dependency needs disability to benefit from the services that do exist for people with disabilities, such as sheltered workshops.

### **Conclusions**

Autism-Europe welcomes the opportunity to share its view on the future strategy to voice the concerns of persons with Autism Spectrum Disorders. It is important that expectations of all citizens, including persons with complex needs disabilities, are taken into account to shape future EU policies.

We hope that further consultation of stakeholders will be sought over the coming months before adopting the EU 2020 strategy.

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The organization Autism Europe (AE) assures the liaison among 85 associations of parents of people with autism in 35 European countries.

Autism Europe's statutory mission is to improve the life of all persons with autism by promoting their rights. It is achieved through:

- representing persons with autism towards all EU institutions;
- promoting awareness on appropriate care, education, and well-being of persons with autism;
- promoting the exchange of information, good practices and experience;
- drafting guides of good practices and recommendations for public authorities, parents and professionals in charge of persons with autism.

*Autism-Europe receives the support of the Directorate-General for Employment, social affairs and equal opportunities of the European Commission under the European Community Programme for Employment and Social Solidarity PROGRESS*