

Autism Spectrum Disorders in the European Union – ASDEU: Work Package 4. ASD policies in the EU

TASK 4.2- To develop a public health plan addressing ASD. Final Report – 25.6.18

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Objectives

Aims to assess existing social and health policies in Member States to support people with autism of all ages and in all communities, as well as their families, and then to develop a public health plan addressing autism.

Key Findings

The literature review found that over the last decade, to tackle existing challenges, some countries and regions have adopted autism-specific policies, varying from single policies to all-encompassing national/regional plans or strategies.

According to the literature, autism strategies having a positive impact have the following characteristics:

- Practical approach: identification of the specific needs of people concerned (children, young people, adults on the autism spectrum, but also families and carers).
- Thus designed in close partnership with autism organisations, and generally after public consultation.
- Flexibility to allow for revision without recurring to formal procedures
- Requirements for on-going monitoring
- Direction and co-ordination of services at national and regional levels
- Adequate public funding for their implementation.

The initial consultation phase highlighted the fact that a holistic approach is needed to address the challenges faced by people on the autism spectrum across the life-cycle. Having a public health autism policy at the EU-level would address EU-wide challenges in relation to access to diagnosis and evidence-based effective therapies, as well as general healthcare. Additionally, promoting the health and well-being of autistic people also requires a cross-sectoral approach to autism, including in non-health public policy areas.

Actions at the EU level might therefore include:

- (1) Encouraging Member States to adopt cross-sectoral national strategies or action plans to respond to the needs of autistic people, in line with the UNCRPD and international recommendations;
- (2) Promoting the coordination between Member States of all relevant policies in the field of autism;
- (3) Producing guidelines to harmonise practices and promote quality of support care and inclusion across Europe;
- (4) Adopting principles of best practices and fostering exchange between Member States;
- (5) Promoting training of professionals across sectors;
- (6) Supporting research and network of experts and partnering for progress across the EU;
- (7) Supporting and involving representative NGOs throughout the process.

Recommendations according to areas of priority:

Promote common standards for screening, timely diagnosis and harmonise diagnosis training by:

- Promoting the development and adoption of EU guidelines on gold-standard screening and diagnosis instruments and criteria across all EU Member States and ensure access to adequate resources for professionals.

Improve post-diagnosis support by:

- Developing and adopting EU guidelines on evidence-based, rights-based intervention for autism, based on existing guidelines at national and international levels;
- Fostering the adoption of reasonable accommodation of health care premises (including somatic health, dental care, emergency and preventive services) and diagnostic instruments needed to ensure persons with autism access to health care of the same quality as other people;
- Promoting the training on autism needs and accessible communication in the curricula of health professionals and other relevant staff;
- Promoting access to evidence-based and accessible information for autistic people and their families, in line with EU guidelines.

Improve access to inclusive adapted lifelong education by:

- Monitoring the access to education of pupils with autism and collecting data and statistic across EU countries on their access to mainstream schools, to primary and secondary education, to vocational training, university and to employment;
- Promoting the use of EU Structural Funds to fund the training of school staff on teaching and communication strategies for autistic pupils;
- Establishing common standards on the qualification of support teachers and assistants for autistic pupils and students;
- Developing and adopting guidelines on the prevention of abuses and bullying against children with autism in educational settings.

Improve access to individualised support and inclusion throughout a person's lifetime, including at transitional stages of life, and for the elderly by:

- Developing minimum quality standards for habilitation and rehabilitation services and programmes for autistic persons of any age in the EU;
- Adopting quality assessment systems for habilitation services which are centred on outcomes in terms of inclusion, participation and quality of life of the users;
- Providing independent living and quality community-based services in order to foster deinstitutionalisation;
- Promoting measures to foster the employment of autistic people.

Empowering people with autism and their families

- Promoting legal capacity and access to justice through supported-decision making
- Promote adequate and accessible consultation with autistic people and their families on all issues affecting them
- Support their representative organisations to allow them to effectively participate in the policy-making process and all relevant areas of actions.

Improve training of professionals by:

- Adopting European guidelines on rights-based approaches for autism to prevent inhumane and degrading treatments against autistic people;
- Making training on specific and evidence-based habilitation strategies for autism, as well as on ethical issues, compulsory.

Improve support for families by:

- Providing sufficient training for families in their children's rights, needs and sound education strategies;
- Ensuring that families of autistic children receive sufficient support and the assistance they may need to raise their children at home.

Researching autism by:

- Producing an up-to-date, comprehensive evaluation of the prevalence rate of autism in the EU;
- Fostering research that promotes a better quality of life taking into consideration priorities identified by people on the autism spectrum and their families.

Awareness-Raising and promotion of inclusion by:

- Celebrating World Autism Awareness Day (2 April) at the EU level every year;
- Combating stigma and prejudice against autistic people through awareness-raising campaigns.

Methodology

Autism-Europe conducted a literature review looking at legislative support for autistic people and their families at the EU, Member State and regional level, and also consulted national disability contact points in EU member States' ministries.

Autism-Europe's research was also supported by a stakeholder consultation conducted through focus groups and an online survey (answered by over 900 respondents in 28 countries).