



Autism-Europe's evaluation of
the European Disability Strategy
2010-2020. Recommendations
for the future disability strategy

November 2019

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Recommendations for the future disability strategy

Autism is a lifelong disability, notably associated with difficulties in social communication and social interaction as well as sensory difficulties, such as increased or reduced sensitivity to light and sound. According to prevalence studies, it is estimated that at least **5 millions of people are on the autism spectrum in the European Union**. Autism forms a 'spectrum', which means that each person will experience autism differently. There is not one size fits all solution to accommodate the needs of autistic people.

Available data show that autistic people face **very high level of discrimination in all aspects of life**, from lack of access to education to high level of unemployment and lack of access to healthcare. It has been evidenced that autistic people die on average 16 years younger than the general population. A holistic approach and **some targeted actions are needed to tackle the many challenges they face in their everyday life**.

Enabling people on the autism spectrum to live long and fulfilling lives as autonomously and independently as possible, requires a **change of mind-set in society to support their active participation and inclusion**. It also entails to **create and maintain the necessary support services and to foster accessibility for autism across all sectors**.

The ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) by the European Union brought about the creation of the European Disability Strategy 2010-2020, and some positive policy-developments have been initiated, such as the adoption of the European Accessibility Act. However, so far the impact of these initiatives on the lives of people on the autism spectrum has been very limited. It is therefore essential that the European Union continues its efforts to **promote disability rights and equal opportunities for all, including those with invisible disabilities and complex support needs**.

Therefore, Autism-Europe calls for an **ambitious EU disability strategy beyond 2020** that leaves no one behind and **takes into account the diversity of disability, support and accessibility needs**. The EU has a leading role to play to facilitate the implementation of the UNCRPD across all EU member states, and beyond. The future European disability strategy should aim at supporting the full implementation of the convention at the EU-level and in the member states. It should also be consistent with the objectives of the Sustainable Development Goals (that mentions disability 11 times) and the European Pillar of Social Rights that has adequately mainstreamed.

Actions conducted at the EU level can have significant added value to combat discrimination and help reduce inequalities between EU-countries, also in areas of shared competences. The advancement of the rights of persons with disabilities through the full implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) requires **effective mainstreaming of the disability perspective across all policy fields**. To ensure this horizontal perspective, we recommend to designate Disability Focal Points in all Directorates General and agencies of the European Commission, as well as across all EU institutions. The central focal point should be placed in the Secretary general of the European commission owing to the transversal nature of disability. It is also key to have an **efficient interinstitutional coordination** as well as **adequately resourced monitoring mechanism**. It also entails that **disability and the UNCRPD provisions should be systematically mainstreamed into all relevant policies**, such as the Gender Equality Strategy, the Youth Guarantee and the Child Guarantee **and all its funding schemes**. The EU should also take concrete action for the **adoption of a horizontal antidiscrimination directive** protecting people with disabilities from discrimination in all areas of life.

Given the specific challenges and high level of discrimination faced by autistic people across the European Union, we call on the European commission to support actions toward the full realisation of their rights, notably by:

- Encouraging Member States to adopt adequately resourced cross-sectoral national strategies or action plans to respond to the needs of autistic people, in line with the UNCRPD and international recommendations
- Promoting the coordination between Member States of relevant policies in the field of autism
- Harmonising practices, promoting community-based services and benchmark necessary levels of quality across all EU countries
- Adopting principles of best practices and foster exchange between member states to respond to the needs of autistic people in various fields of life
- Promoting training of professionals in autism across all relevant sectors
- Supporting research to improve the quality of life and inclusion of autistic people
- Fighting stereotypes and raising awareness
- Supporting and involving autistic people, their families and their representative NGOs through continuous structured dialogue

Specific areas of action to be considered

Access to education

Challenges faced by autistic people:

- Across the EU, a recent survey conducted by AE has shown that the level of support for autistic learners in inclusive education across all levels is limited, and if present often inadequate
- Lack of understanding of autistic learners' individual needs and what is adapted support and reasonable accommodation
- Lack of flexibility of education curriculum and infrastructure to use autistic learners' strengths
- Lack of vocational training opportunities and lifelong learning opportunities
- High level of school exclusion and drop-out

Recommendations for actions at the EU-level

- **Monitor the access to education of autistic learners and collect data and statistic** across EU countries on their access to mainstream schools, to primary and secondary education, to vocational training and to employment
- **Ensure access to individualised and specialised support in education** taking into consideration the evolving capacities of autistic learners to tackle the issue of early school-leavers
- Uphold commitment to 'make lifelong learning and mobility a reality' for all by **making relevant programmes, such as Erasmus+, accessible to autistic people**
- Promote the use of **EU Funds to foster training of education staff** on teaching and communication strategies for autistic learners
- **Establish common standards on the qualification of support teachers and assistants** for autistic pupils and students
- Develop and **adopt guidelines on the prevention of abuse and bullying** against children on the autism spectrum in segregating and mainstream settings

Access to employment

Challenges faced by autistic people:

- Less than 10% of autistic people are in employment (mostly employed in low-paid jobs or in sheltered settings), this is significantly lower than the average employment rate of disabled people
- Most of autistic people with high support needs are not in education, employment and training and are not counted in statistics (i.e. live in institutions or in unsupported families)

- Unemployment also affects disproportionately autistic people with above-average level of general education as evidenced by research
- Lack of awareness of employers regarding the skills and potential of autistic people
- Lack of adequate provision of reasonable accommodation at work

Recommendations for actions at the EU-level

- Adoption of a **binding legislation harmonising obligations for employers** and national/regional governments throughout the EU regarding the **provision of reasonable accommodation** for workers with disabilities
- **Improve data collection on employment rate** of people with disabilities, including by types of disability and **set ambitious targets for the next period**
- Use the **European Social Fund Plus (ESF+)** to **foster inclusion of persons with disabilities** in society and improve opportunities, including in the field of employment
- **Harmonisation of disability assessment recognition** to allow persons with disabilities to enjoy **freedom of movement** and work abroad on an equal footing with others
- **Support research, social investment and initiatives** to support inclusion at work of autistic people
- Ensuring that the **Youth Guarantee can properly support young persons with disabilities**.
- Lead by example and increase **work experience schemes for autistic adults in EU institutions**
- Support **awareness-raising of employers about the potential of autistic workers**
- Encourage member states to **address the issue of benefits trap**
- Share **best practices** among member states.

Diagnosis and disability assessment

Challenges faced by autistic people:

- Lack of adequate screening programmes
- Very long waiting times due to lack of capacity of diagnostic services delaying access to necessary support
- Lack of harmonised diagnosis guidelines across the EU
- Lack of qualified professionals able to make screening and diagnosis
- Lack of mutual recognition of diagnosis across Europe, hindering freedom of movement

Recommendations for actions at the EU-level

- **Promote the adoption of common EU standards for screening, early detection, diagnosis and interventions for autism** across all EU Member States, based on the most successful models available.
- **Promote training of professionals at various levels** – through the development of basic training and specialisation curricula
- **Tackle inequalities related to intra-EU mobility** by addressing issues related to **mutual recognition of disability status** that give access to the provision of benefits, reasonable accommodation support and services tailored to individual needs, education and habilitation programmes.

Access to habilitation and healthcare

Challenges faced by autistic people:

- Lack of availability of evidence-based interventions to support inclusion
- Ineffective (and sometimes potentially harmful) interventions for autism are available in certain EU Member States
- Issues related to the inadequate use of drugs for children and adults on the autism spectrum
- General health care needs of autistic people (both physical and mental) are not satisfactorily met

Recommendations for actions at the EU-level:

- Support the development of **EU guidelines on evidence-based, rights-based interventions for autism**, based on existing guidelines at national and international levels to be followed by member states;
- Foster **access to adequate assistive technology**
- Foster **accessibility and reasonable accommodation of healthcare services** (including somatic health, mental health, dental care, emergency and preventive services)
- Promote the inclusion of **compulsory training** on specific and evidence-based habilitation strategies for autism, as well as on ethical issues in the curricula of all the habilitation professionals
- Promote **training in autism and accessible communication in the curricula of all healthcare professionals** and other relevant staff

Access to individualised support in the community

Challenges faced by autistic people:

- Lack of access to individualised support focusing on positive outcomes
- Poor availability of affordable, flexible, quality and comprehensive community-based services (in line with European guidelines) leading to institutionalisation
- Lack of inclusion and support for autonomy and self-determination
- Insufficient support at transitional stages of life, e.g. for the transition from education to employment and/or meaningful activities in the adult age
- Ageing and autism – insufficient support for adults, including elder people

Recommendations for actions at the EU-level:

- Ensure that EU funds are not invested in the construction or refurbishment of institutional care settings
- EU funds to be **dedicated to the transition towards community-based care ensuring self-determination and social inclusion of autistic people** and their families
- Support the development of **services to support transition**
- Support the adoption of **quality assessment systems** for support services which are **centred on outcomes in terms of inclusion, employment, participation and quality of life**
- Development of a quality binding system, which complies with article 19 of the UN CRPD, in order to prevent Member States from using freedom of movement of persons, goods and services to undermine the right of persons with autism to live in their community

Support for families

Challenges faced by autistic people and their families:

- Poor availability of affordable, flexible, quality, comprehensive community-based services to support parents and siblings
- Insufficient information and training for families
- Reported cases of parents being falsely accused of abuse or neglect, instead of being provided with support, due to social workers' lack of knowledge and understanding of autism

Recommendations for actions at the EU-level:

- Promote adequate **support in the community and assistance** so that families can raise their children at home and prevent institutionalisation;
- EU initiatives to ensure that the families of autistic children receive **adequate information** about the benefits and support available,
- Promote the **availability of evidence-based and rights-based trainings** – that are context sensitive - for parents and other relatives to foster a positive approach to autism.
- **Train social and welfare services** about autism so that families receive adequate support
- **Adopt a European initiative on long-term care** that is compliant with the UNCRPD and promote evidence-based recommendations for the development of long-term care and support services across the EU and the key quality principles to be ensured;
- Promote **the recognition of the status and rights of family carers**

Enhance and safeguard legal capacity and access to justice

Challenges faced by autistic people:

- Most of current European legislations are not in line with the principle of respect of the legal capacity of autistic people which hinders access to a series of rights: right to vote, to sign contracts, etc.
- Lack of accessibility of the justice system

Recommendations for actions at the EU-level:

- Promote a **reform of the guardianship system to allow the exercise of legal capacity by autistic people**, giving them access to supported decision-making systems and ensuring that adequate safeguards are in place
- Promote adoption of **appropriate procedural accommodations needed at all stages of judicial proceedings** to ensure effective participation of people on the autism spectrum, including meaningful and accessible communication, information, support and access to victims' support services;
- Promote **systematic training for professionals working in the field of justice administration**, including prison officers and policemen, about autism as well as the alternative/augmentative communication modes used by autistic people and on the CRPD rights-based approach;
- Ban or support an in-depth reform of Judicial Psychiatric Hospitals depriving autistic people of their rights.

Support awareness-raising and understanding

Challenges faced by autistic people:

- Continued need to fight stigmatization and prejudices in all spheres of society (amongst the general public, decision-makers, in the media, etc.).

Recommendations for actions at the EU-level:

- Continued need to fight stigmatization and prejudices in all spheres of society (amongst the general public, decision-makers, in the media, etc.).
- Celebrate World Autism Awareness Day (2 April) at the EU level every year and encourage Member States to do the same in a co-ordinated way
- Combat stigma and prejudice through awareness raising campaigns and initiatives to develop understanding of autism in collaboration with autistic people and their representative organisations
- Promote awareness of the rights and needs of autistic people in light of the CRPD towards EU institutions and to Member States.

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