



Autism-Europe's feedback on
the roadmap for the Disability
rights strategy for 2021-30

November 2020

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

It ensures effective liaison among almost 90-member autism organisations from 40 European countries, including 26 Member States of the European Union, governments and European and international institutions.

According to prevalence studies, it is estimated that at least **5 million 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 no one size fits all solution to accommodate the needs of autistic people.

Across Europe, the basic needs of many autistic people are still not being met. 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 and to allow them to fully exercise their rights as EU-citizens**, such as intra-EU mobility.

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 community-based support services and to foster accessibility for autism across all sectors**.

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. We welcome the fact that the future European disability strategy will aim at supporting the full implementation of the convention at the EU-level and in the member states. To this end, disability rights should be adequately mainstreamed in other key policy instruments, such as the European Pillar of Social rights or the Child guarantee, Gender Equality Strategy, the Youth 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.

The strategy should **have a well-resourced monitoring mechanism**, with CPRD focal points in all EU institutions and agencies, and an **efficient coordination mechanism** within and between the institutions. In order to monitor progress clear benchmarks and indicators are necessary as well as **adequate data collection**, disaggregated by types of disabilities, gender and age. Persons with **disabilities and their representative organisations should be supported to meaningfully participate** in the implementation up to the evaluation of the strategy.

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

- **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
- Promote the use of EU Funding Programmes including EaSI, Erasmus+, ESF+ and InvestEU to fund **the transition to fully inclusive education**, notably training of staff on teaching and communication strategies for autistic people;
- Promote inclusive education, while ensuring **access to individualised and specialised support for people requiring a higher level of support**, taking into consideration their evolving capabilities;
- Uphold commitment to 'make lifelong learning and mobility a reality' for all by **making relevant programmes, such as Erasmus+, accessible to autistic people**
- **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
- **Support transition** between the various education levels and employment
- **Support the adoption of common standards for educational staff** on the qualification of support teachers and assistants for autistic students and other types of disabilities;
- Support the development of guidelines on the prevention of **abuses and bullying**;
- Lead by example and improve the **inclusiveness of European schools**.

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

- Adoption of clear **EU guidelines for the provision of reasonable accommodation for workers with disabilities**, covering all types of disability
- **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**
- Workers with disabilities must be paid at least minimum wage
- Share **best practices** among member states.

- Accessibility

Challenges faced by autistic people:

- Lack of awareness of the accessibility needs of autistic people
- Barriers to participation in community life due to a lack of “autism friendly environments” (including across schools, workplaces and public spaces, such as train stations, hospitals and airports).
- Accessibility needs of autistic people in relation to cognitive and/or social differences: including a need for routine/predictability, and sensory processing difficulties such as delayed or single channel processing (i.e. not being able to process all sensory input, such as hearing, seeing and feeling where their body is in space, simultaneously)
- Accessibility and support needs of autistic people in relation to common co-occurring mental health conditions: e.g. anxiety can escalate in new/unknown environments or situations, or when an unexpected event or sudden change occurs in the environment

Recommendations for actions

- An **ambitious transposition and implementation of the European Accessibility Act (EAA)** in the member states
- **Complement the limited scope of the EAA** via other legislative instruments
- Accessibility requirements need to take into account access needs of autistic people
- Availability of documents in easy-to-read/understand or other alternative-augmentative formats.
- **Expand the scope of the EU disability card**
- Creation of an **EU Access Board**

Diagnosis and disability assessment

Challenges faced by autistic people:

- Lack of adequate screening programmes for autism and long waiting times due to lack of resources 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 autism diagnosis across Europe, hindering freedom of movement

Recommendations for actions

- **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 disability entitlement, 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 (early) evidence-based, rights-based interventions for autism**, based on existing guidelines at national and international levels to be followed by member states
- Promote the **availability and affordability of early intervention services**
- Foster **access to adequate assistive technology**
- 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
- Foster **accessibility and reasonable accommodation of healthcare services** (including somatic health, mental health, dental care, emergency and preventive services)
- 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 – and ensure proper monitoring
- 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:

- Promote adequate **support in the community and assistance** so that families can raise their children at home and prevent institutionalisation;
- Families of autistic children to receive **adequate information about the disability entitlements 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:

- 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
- Ensure the **right to vote for all EU-citizens with disabilities**
- 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 coercive treatment** in mental health care and psychiatry 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:

- 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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