

#AutismDay2022

# “A happy journey through life”



## Manifesto

It is estimated that 7 million people are on the autism spectrum in Europe. The campaign “A happy journey through life” was launched in 2022 by Autism-Europe and its members across Europe. It aims at highlighting the needs and wishes of autistic people and their families with regard to key issues such as personal choice, education, employment, as well as adequate support for inclusion in the community, independent living and health, to ultimately improve their quality of life.

This manifesto highlights some of the key areas where actions are required so that autistic people can enjoy their rights throughout their lifetime, in line with the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD). It calls for a holistic approach and coordination of policies across sectors with the active inclusion and participation of autistic people and their families, both at national and EU-levels. Autistic people must be considered in all their diversity and intersectional forms of discrimination (for example linked to gender, race, sexual orientation) must be addressed so that they can live happy and fulfilling lives.

At a time when Europe is facing the war in Ukraine and its tragic consequences, it is also essential to recall that the rights of autistic people in humanitarian crisis, including armed conflict, must be respected.

### **Promoting self-determination, social inclusion and community support services for autistic people**

UNCRPD Article 12 recognizes that persons with disabilities have legal capacity on an equal basis with others. In other words, an individual cannot lose his/her legal capacity to act simply because of a disability.

Yet, many EU countries restrict the legal capacity of autistic people, depriving them of fundamental rights and choice, such as the freedom to make their own medical decisions, sign contracts, or seek justice when harmed.

At the same time, UNCRPD article 19 and the European Pillar of Social Rights (EPSR) principle 17 include provisions on independent living and inclusion in society for people with disabilities.

Institutionalisation of autistic people is unfortunately a wide-spread phenomenon across the EU. Alarmingly, EU structural funds have been used to refurbish institutions where disabled people are neglected. It was the basis of a complaint to, and eventual decision by the European Ombudsman in 2019. Also, the latest EU funding mechanism in the wake of the COVID-19 does not follow the same strict rules as other EU funding and could result in investments in institutions.

In some EU countries, the support and care of autistic adults is still mainly based on delegation to families. This approach leads to the isolation of the whole family and of the person on the autism spectrum at home, as well as to institutionalisation of autistic adults in the long term, when families cannot face any more their evolving needs.

Autism-Europe calls on key decision-makers at EU and national levels to promote access to autonomy and life in the community for autistic people in cooperation with their representative organisations, by:

- ensuring access to legal capacity for all autistic people, by promoting supported decision-making and autonomy.
- promoting timely and ongoing access to appropriate and adequate individualized support to develop choice and independence skills to empower autistic people to live independently and participate in the community
- using the checklist of the European Expert Group on Transition from Institutional to Community-based care to foster quality support services in the community
- using European Funds to promote the availability of quality, affordable community-based services for autistic people
- ensuring training of services providers so that they are equipped to adequately support autistic people to live independently with the adequate support
- making society more autism friendly and accessible as a whole by fighting prejudice and stigma and building understanding of autism

### **Promoting the rights of autistic children**

The United Nations Convention on the Rights of the Child (UNCRC) article 2, the UNCRPD article 7 and the EPSR principle 11 have provisions pertaining to the rights of children with disabilities.

The Strategy on the Rights of the Child, the European Child Guarantee and the European Strategy for the Rights of Persons with Disabilities of the European Commission aim to promote equal opportunities for children at risk of poverty or social exclusion, respond to the needs of children with disabilities and provide better access to mainstream services and independent living.

Autism-Europe calls on key decision-makers at EU and national levels to promote the rights of autistic children in cooperation with their representative organisations, by:


- identifying and referring autistic children as early as possible to evidence-based Early Intervention Programmes
- developing and adopting EU guidelines on evidence-based and rights-based intervention for autism
- referring autistic children to inclusive and adapted early childhood education and care (ECEC)
- prohibiting disproved and dangerous treatments for autistic children violating their rights and dignity
- providing the necessary support to families of autistic children to fulfil their parenting responsibilities
- empowering families to meet children's needs and to participate in every relevant decision, education and intervention programmes concerning their children, in order to prevent their institutionalisation
- including autistic children systematically in EU decision-making processes and in civic and democratic life

### Promoting access to lifelong education for autistic people

The UNCRPD article 24, UN's Sustainable Development Goal 4 and the EPSR (principle 3) have provisions in relation to education for people with disabilities

In its Strategy for the Rights of Persons with Disabilities 2021-2030, the European Commission commits to support EU Member States to further develop their teacher education systems to address shortages of teachers in Special Needs Education and competences of all education professionals to manage diversity in the classroom and develop inclusive education. The Commission calls on EU Member States to support the development of inclusive schools that can become a reference in inclusive and innovative teaching and learning across the EU and to ensure that their education systems at all levels comply with the UNCRPD to advance on supported learning in inclusive mainstream settings.

Autism-Europe calls on key decision-makers at EU and national levels to promote access to adequate support for autistic learners in the education system, notably by:

- providing autistic learners with adequate reasonable accommodation and individualised support
  - promoting flexible curricula in education
  - enabling educational staff to understand autistic thinking and learning across different abilities and genders, through adequate training.
  - making all educational facilities, including vocational training providers and universities accessible to autistic people
  - developing understanding and acceptance of autism, and tackling bullying
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## Promoting equal opportunities to access employment for autistic people

The UNCRPD Article 27, UN's Sustainable Development Goal 8 and the EPSR principle 4 include provisions on work and employment for people with disabilities. In its Strategy for Persons with Disabilities 2021-2030, the European Commission commits to publishing a package to improve labour market outcomes of persons with disabilities, seeking cooperation with the European Network of Public Employment Services, social partners and organisations of persons with disabilities such as Autism-Europe.

Autism-Europe calls on key decision-makers at EU and national levels to promote access to employment for autistic people in cooperation with their representative organisations, by:

- collecting data and monitoring the number of autistic people in employment
- developing autism employment pathways in a variety of sectors
- developing programs to promote the employment potential of autistic people to employers
- running pilot programs for apprenticeships to foster gold standards
- supporting research, social investment and initiatives to foster inclusion at work for autistic people
- supporting awareness-raising actions regarding the skills and competences of autistic people as well as their specific needs in terms of reasonable accommodation, starting from the recruitment phase


## Promoting equal access to healthcare for autistic people

UNCRPD article 25, UN's Sustainable Development Goal 3 and EPSR principle 16 have provisions pertaining to access to health(care) for people with disabilities.

For the period 2021–2030, and in reaction to the COVID-19 pandemic, the Strategy for Persons with Disabilities has included the European Health Union in which all EU countries prepare and respond together to health crises, and countries work together to improve prevention, treatment and aftercare for diseases. The strategy also highlights that “persons with invisible disabilities [...], do not always receive the tailored support needed nor do women and refugees with disabilities.”

For example, testing, treatment and hospitalisation as well as outpatients and inpatients services were often inaccessible for autistic people and their families during the COVID-19 pandemic. Intensive care unit (ICU) triage protocols in many European countries (directly or indirectly) resulted in discriminatory exclusions of persons on the autism spectrum and those with intellectual disabilities from lifesaving treatments.

Autism-Europe calls on key decision-makers at EU and national levels to promote equal access to healthcare for autistic people in cooperation with their representative organisations, notably by:

- fostering adoption of reasonable accommodation of health care premises (including somatic health, mental health, reproductive 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;
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- promoting systematic training on autism needs, reasonable accommodation and accessible communication in the curricula of health professionals and other relevant staff.

## Addressing the rights and needs of autistic people in humanitarian crisis

UNCRPD article 11 relates to the protection in humanitarian crisis of people with disabilities.

Recent tragic events in Europe like flooding triggered by climate change which led to death of people with disabilities (in Germany) and armed/political conflicts which led to forced relocation/seeking refuge (from Belarus and Ukraine) exposed autistic people to unforeseen emergency worsening their situations.

Regarding civil protection, the disability inclusion in humanitarian action remains insufficient in the EU. Autistic people are particularly exposed to high risk in emergency or in armed conflicts.

Autism-Europe calls on key decision-makers at EU and national levels to address the rights and needs of autistic people in humanitarian crisis in cooperation with their representative organisations, by:

- ensuring that autistic people and their families receive adequate protection and relocation
- ensuring that autistic people and their families benefit from support through community-based services
- protecting autistic people from violence, abuse and ill-treatment
- giving autistic people and their families full access to basic services including water and sanitation, social support, education, healthcare, transport and information, including on disability rights.

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**Autism-Europe** 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 90-member autism organisations in 40 European countries, including 25 Member States of the European Union, governments and European and international institutions.

