

# **AE Alternative Report for the second review of the EU by the CRPD Committee**

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## CONTEXT

This alternative report is submitted by Autism-Europe (AE) on the occasion of the European Union's second report to the UN Committee on the Rights of Persons with Disabilities.

Autism-Europe (AE) is a European organisation gathering almost 90 autism advocacy associations of autistic people and parents of persons who need support to represent themselves across 40 countries in the EU and beyond. Autism, or autism spectrum disorder (ASD), is a complex neurodevelopmental disability. It refers to a broad range of conditions characterised by challenges with social skills, repetitive behaviors, speech and nonverbal communication. Autism has a childhood onset and persists into adolescence and adulthood, each autistic person has a distinct set of strengths and challenges. Some autistic people may require significant support in their daily lives, while others may need less intense support. Individuals with autism are significantly more likely to have intellectual disability and other mental and physical conditions than typically developing children. Limited data are available at EU level on the support needs of autistic people.<sup>1</sup>

The mission of Autism-Europe is to ensure that the enjoyment of human rights by autistic people, representing a particularly discriminated population even among persons with disabilities, is not neglected or forgotten in EU legislation, policies and measures aimed at implementing the UN CRPD.

Autism-Europe is full member of and works closely with the European Disability Forum (EDF) and AE also contributed to EDF alternative report and endorses its findings and questions.

This report has been written by the AE secretariat and includes the comments received by AE members during discussions at the AE Governing Bodies meetings. The purpose of the AE alternative report is to strengthen and to complement the EDF alternative report to the CRPD Committee by providing more information on existing gaps in the UNCRPD implementation of the rights of autistic people by the European Union.

The AE alternative report has a special focus on inequality areas concerning autistic people. It examines the implementation of the UN CRPD towards autistic people in the EU's legislative and policy work, lists the main concerns and provides recommendations to improve implementation of the CRPD rights for autistic people in the EU.

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<sup>1</sup> A survey conducted in Australia by the Australian Bureau of Statistics has shown that 74% of persons with ASD have profound or severe core activity limitation and need help or supervision with communication, mobility or self-care. 68% of persons with ASD have profound or severe communication restriction and cannot understand or be understood by others at all, or have difficulty being understood or understanding others and communicate more effectively using non-verbal forms of communication. The highest support is needed in the cognitive and emotional tasks (81%). The second area where high support is needed is communication (62%). Mobility is the third most significant area of needs for support, 63% of people with autism having a profound or severe mobility restriction and needs for help or supervision to move around.

As an introductory remark, AE's alternative report highlights that the overall purpose of the UN CRPD - to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, including those who need more intense support- has not been achieved today in the European Union. Autistic people are still discriminated against in many areas of life. Since 2020, autistic people and their families have been particularly affected by the Covid-19 crisis, which enhanced the shortage of appropriate and adequate services, support and reasonable accommodations to address the particular needs of autistic people and have enhanced their discrimination, dependency from others, poverty and social exclusion.

## **ARTICLE 1: PURPOSE**

Autism is a lifelong developmental disability characterized by impairments in social interaction, difficulties with verbal and non-verbal communication and restricted, repetitive behaviour, interests and activities. Autistic people require a multidimensional and multidisciplinary approach to address their needs. The CRPD promotes and protects the human rights of all persons with disabilities, including all individuals on the autism spectrum. The Strategy for the Rights of Persons with Disabilities 2021-2030 is the EU instrument which aims is to progress on all areas of the United Nations Convention on the Rights of Persons with Disabilities, both at EU and Member State level. The goal is to ensure that persons with disabilities in Europe, regardless of their sex, racial or ethnic origin, religion or belief, age or sexual orientation:

- enjoy their human rights,
- have equal opportunities,
- have equal access to participate in society and economy,
- are able to decide where, how and with whom they live,
- can move freely in the EU regardless of their support needs,
- no longer experience discrimination.

Because of the complexity of their needs the great majority of autistic people require qualified support and services to develop their potential and independence skills and to be guaranteed their full enjoyment of human rights without discrimination. Over the past two years, autistic people and their families have been particularly affected by the Covid-19 pandemic and the impact of the lockdown and various restrictions on access to autism support services, education, as well as healthcare<sup>2</sup>. It contributed to deny them equal opportunities to achieve their optimal developmental potential and to participate in society. The shortage of early screening, diagnosis and intervention programmes and services are resulting in loss of opportunity, notably adequate support. Lack of life-long appropriate behavioural and educational, intervention and of adequate support and services are

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<sup>2</sup> Autism-Europe. (2020). Impact of COVID-19 on autistic people and their families across Europe. [https://www.autismeurope.org/wp-content/uploads/2020/12/Impact-of-COVID-19\\_report-Autism-Europe\\_December-2020.pdf](https://www.autismeurope.org/wp-content/uploads/2020/12/Impact-of-COVID-19_report-Autism-Europe_December-2020.pdf)

enhancing levels of poverty and social exclusion.

As a result of the implementation of the previous strategy there is limited evidence of impact of the Strategy in the enjoyment of their human rights by autistic people at EU level. Autistic people continue to face the same barriers in their participation as equal members of society in the areas covered by the Strategy, notably in accessibility of information, employment, education and training, health and social habilitation, even compared to persons with other disabilities.

Despite its commitment to address the diversity of disability needs, there is little information as to how – in practice - the EU intends to adequately address the specific needs of diverse groups. Also, some EU institutions do not provide adequate channels for the participation of disabled people, such as the Council of the European Union.

***Suggested questions:***

- Does the European commission intend to release an action plan for the implementation of the UNCRPD that takes into account the diverse needs of people with disabilities, including autistic people?
- How will it foster systematic consultation of organisations of people with disabilities across all policies and ensure that the diversity of disability is represented?

**ARTICLE 5: EQUALITY AND NON-DISCRIMINATION**

The European Union has a clear competence to combat discrimination based on disability when developing and implementing its policies and activities (Article 10, Treaty on the Functioning of the EU - TFEU33) and to adopt legislation to combat such discrimination (Article 19 TFEU).

However, to date the EU anti-discrimination legislation only addresses discrimination on the ground of disability in the field of employment and vocational training through the [Council Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation](#). Moreover, it does not protect persons with disabilities who need specific and intense support, including autistic people, even in employment and vocational training areas.

The EU law creates a hierarchy between the different discrimination grounds as it offers additional protection against discrimination on the ground of sex and racial or ethnic origin in other areas of life, such as social protection including social security and healthcare, social advantage, education, and access to and supply of goods and services. and overlooks individualities as religion or belief, age, disability and sexual orientation.

The adoption of the proposed horizontal antidiscrimination Directive to cover discrimination on the grounds of disability, age, religion or belief, and sexual orientation in the areas of

social protection, healthcare, (re)habitation, education and the provision of goods and service is therefore urgently needed.

**Suggested question:**

- Which measures will the EU take to ensure that autistic people are protected against discrimination in all areas of life, including areas of social protection, healthcare, rehabilitation, education and the provision of goods and services?

**ARTICLE 6: WOMEN WITH DISABILITIES**

Overall autistic women face widespread discrimination in all fields of life. They face barriers to accessing education and employment on an equal footing with others, denial of their reproductive rights and the freedom to make their own choices, and a lack of involvement in policy making on matters that concern them.

It is evidenced that for a range of reasons autistic women are less likely to be diagnosed or are identified much later than their male counterparts. Living with unidentified autism places significant mental strain on autistic girls and women, and prevent access to support.<sup>3</sup> They are also at higher risks of being victim of sexual abuse and violence.<sup>4</sup>

**Suggested question:**

- How will the EU ensure that the perspective of women and girls with disabilities are included in the implementation and evaluation of its Disability Rights Strategy 2021-2030 and Gender Equality Strategy 2020-2025, notably groups that are particularly invisible, such as autistic women?
- What actions do the European commission foresee to address the additional challenges faced by disabled women, in particular women on the autism spectrum?

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<sup>3</sup> Zener, D. (2019), "Journey to diagnosis for women with autism", *Advances in Autism*, Vol. 5 No. 1, pp. 2-13. <https://doi.org/10.1108/AIA-10-2018-0041>

<sup>4</sup> Ohlsson Gotby, V., Lichtenstein, P., Långström, N., & Pettersson, E. (2018). Childhood neurodevelopmental disorders and risk of coercive sexual victimization in childhood and adolescence - a population-based prospective twin study. *Journal of child psychology and psychiatry, and allied disciplines*, 59(9), 957–965. <https://doi.org/10.1111/jcpp.12884>

## **ARTICLE 7: CHILDREN WITH DISABILITIES**

Almost 20% of the European population are children.<sup>5</sup> There is limited available data on children with disabilities, including autistic children. The 'Our Europe, Our Rights, Our Future' report found that one in three children in the EU have experienced some form of differential treatment with more than half of these being children with disabilities (physical, intellectual, sensory or autism).<sup>6</sup>

The promotion of children's rights is an integral part of EU fundamental rights objectives set out by EU law. The past years brought new policy developments at EU level. The European Commission published a new comprehensive Strategy on the Rights of the Child as well as a Council Recommendation establishing a European Child Guarantee, to promote equal opportunities for children at risk of poverty or social exclusion. Moreover, the EU published the European Strategy for the rights of persons with disabilities which ensures to respond to the needs of children with disabilities and provide better access to education, mainstream services and independent living.

The EU Strategy on the Rights of the Child indicates that the European Commission will ensure access to inclusive education, to health services, accessible ICT and assistive technologies for children with disabilities<sup>7</sup>. Nevertheless, it does not set clear actions which will ensure that the national public and private sector will respect the needs of children with disabilities including autistic children in every aspect of life.

Unfortunately, the voices and views of children with disabilities and autistic children are still not systematically considered in the EU decision-making processes. In particular, autistic children are not adequately included in the civic and democratic life.

Children with autism across the EU do not enjoy equal opportunities to access early diagnosis and intervention to prevent further disabilities (see article 25 in this report), as well as adequate and appropriate support to education (see in this report article 24). In some EU countries children with autism are subjected to unacceptable and harmful intervention practices (see articles 14-17 in this report). During the Covid-19 pandemic, autistic children experienced additional difficulties as they lost access to their usual activities and support services<sup>8</sup>.

Children with autism are also disproportionately represented in institutions. Segregation, marginalisation, isolation in segregating facilities or even in unsupported families enhance children's vulnerability to abuses. Children with autism are 4 to 10 times more likely to be victims of abuse than other children, because major communication problems and so-called challenging behaviours increase vulnerability to abuse or neglect, even compared to children with other disabilities.

The Child Guarantee, the core EU initiative to tackle child poverty, access to housing, to healthcare, to nutrition and early childhood education, explicitly refers to children with

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<sup>5</sup> European Commission (2021), The EU Strategy on the Rights of the Child and the European Child Guarantee.

<sup>6</sup> ChildFund Alliance, Eurochild, Save The Children, UNICEF, World Vision (2021), "Our Europe, Our Rights, Our Future".

<sup>7</sup> European Commission (2021), The EU Strategy on the Rights of the Child

<sup>8</sup> Autism-Europe (2020), Impact of COVID-19 on autistic people and their families across Europe.



disabilities as a disadvantaged group. Some UN data indicate that 1 to 3 children in institutions are disabled<sup>9</sup>, with autistic children representing an important part of these children. It is reported that 66.7% of disabled children live in institutions in France, and 77% in Hungary. We therefore regret that the child guarantee lacks a commitment to support deinstitutionalisation in all Member States.

The family is the natural environment for the growth and well-being of children, including autistic children. Families of autistic children need and should receive the necessary support and assistance to fulfil their parenting responsibilities. They should be empowered to meet their children's needs and to participate in every relevant decision, education and intervention programme concerning their children, in order to prevent their institutionalisation.

***Suggested questions:***

- How will the EU ensure meaningful consultation of autistic children and of their representative organisations regarding decisions affecting their lives, notably concerning the design, implementation and review of its Child Rights Strategy and Child Guarantee for Vulnerable Children as well as in the annual European Forum on the rights of the child?
- How will the EU ensure that families of autistic children will receive the support and assistance they may need to rear their children at home and prevent institutionalisation?

**ARTICLE 8: AWARENESS-RAISING**

Autistic people are acutely aware of being stereotyped, judged, and discriminated by others in society according to research. Autistic people also show signs of internalizing stigma, rendering them more vulnerable to low self-worth and poorer mental health.<sup>10</sup> Widespread stigmatisation hinders their inclusion and participation. They have less access to appropriate support and services, educational opportunities, paid jobs, and adequate health care.<sup>11</sup> In some EU countries parents of autistic people are still exposed to blame and prejudices stemming from the disproved “Refrigerator mother” theory. These prejudices or other disproved theories on autism have generated harmful treatments or neglect of the needs of autistic people, in contradiction with the existing national guidelines on intervention for autism adopted in a number of EU countries.

Autism is also more frequently diagnosed in boys than in girls. As a consequence, the particular features of autism in girls can be misunderstood and their particular needs

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<sup>9</sup> UN (2019), *Global study on children deprived of liberty*

<sup>10</sup> Han, E., Scior, K., Avramides, K., & Crane, L. (2022). A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Research*, 15( 1), 12– 26. <https://doi.org/10.1002/aur.2652>

<sup>11</sup> Lindsay A. Allerton, Vicki Welch, Eric Emerson : Health inequalities experienced by children and young people with intellectual disabilities. A review of literature from the United Kingdom. *Journal of intellectual disabilities*, 2010



neglected.

The need to raise awareness of autism has been recognised by the United Nations, which in December 2007 adopted a Resolution establishing the World Autism Awareness Day (WAAD).<sup>12</sup> A coordinated multi-pronged approach that focuses on increasing awareness of governments on the need to provide autistic people of any age, appropriate and high quality services is recommended to meet the growing needs of autistic individuals and their families.

The UN resolutions on autism have not triggered any official action at the EU level. No public awareness-raising campaign on the rights and needs of autistic people in light of the CRPD have been launched in the EU.

***Suggested question:***

- What measures will the EU take to combat widespread prejudice and stigma against autistic people?

## **ARTICLE 9: ACCESSIBILITY**

The EU has many competences, both directly and indirectly with regards to accessibility, since it is wide-ranging and covers many issues.

The most important piece of legislation to explicitly tackle accessibility is the European Accessibility Act (EAA) adopted on 17 April 2019. It must be transposed by Member States by 28 June 2022 and applied from 28 June 2025 in most part. The Act sets new EU-wide minimum accessibility requirements for a limited range of products and services.

While the Act is a significant step to make the EU fully accessible for persons with disabilities, it falls to address accessibility of transport vehicles and infrastructure especially in urban transport. The built environment was included only as a voluntary clause for Member States, and other essential products and services such as household appliances were not covered at all. This means persons with disabilities will still face significant barriers to accessing the built environment, products and services on daily basis.

A core issue for many autistic people is communication, and mainly receptive communication ranging from not understanding any form of communication to major issues in understanding abstract concepts, metaphors, figurative speech and paraphrases. Autistic people, even those with complex support needs, can learn to communicate through training in alternative/augmentative communication modes and methods which are tailored to their individual support needs. However, verbal language and written texts can often remain

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<sup>12</sup> The Resolution calls for all countries to celebrate WAAD every April 2nd and “encourages Member States to take measures to raise awareness throughout society, including at the family level, regarding autism (A/Res/62/139, World Autism Awareness Day). In December 2012, the UN general Assembly adopted a further resolution “Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders and other developmental disorders” (A/Res/ 67/L.33). This resolution states that awareness needs to be accompanied by provision of care. Despite what is known about the growing prevalence of ASD and their high costs to society, systems of care are still inadequate to address the needs of individuals with ASD and their families.

inaccessible ways of communication to autistic people. As a consequence, most information, including on transport systems, services, urban environment and public buildings, are not accessible to autistic people, although such information is absolutely necessary to them because of their frequent orientation issues.

Some legislative progress was made in the EU regarding accessibility to information and communication. This includes the transposition and implementation of the Web Directive. It establishes rules to ensure improved accessibility of the websites and mobile applications of public bodies in the EU Member States to persons with disabilities. Although this Directive applies only to Member States, the EU institutions are encouraged to comply with its requirements.

Yet, in most of EU countries equal access to information and communication still constitutes a barrier to the full participation of persons with disabilities in all aspects of life. Official documents, including those related to the EU legislation, policies and measures impacting the lives of autistic people, are written in a jargon which is not accessible to autistic people, even to those with less complex support needs. Lack of accessible information hinders independence, decision-making, choice and freedom of movement of autistic people.

Lack of information on EU policies presented in an accessible way challenges the efforts of organisations representing autistic people and persons with intellectual disabilities to involve self-advocates. It hinders their possibility to represent themselves and enhance their dependency on others. A particularly inaccessible process is the development of harmonised European standards due to the lack of inclusiveness of the European standardisation system.

### **Suggested questions:**

- What legal measures does the EU foresee to address accessibility needs of disabled people outside of the limited scope of the European Accessibility Act?
- What steps has the EU taken to ensure that all EU institutions, bodies, and agencies follow the obligations of the Web Accessibility Directive?
- What measures will the EU take to ensure that all its communication with EU citizens is accessible to those with disabilities, including through the provision of all relevant documents on EU legislation, policies and measures impacting the lives of autistic people in easy-to-understand formats?

### **ARTICLE 10: RIGHT TO LIFE**

The EU has the competence to carry out actions to support, coordinate or supplement the actions of Member States in the area of the protection and improvement of human health. Human dignity and the right to life are founding values of the European Union.

As mentioned in the EDF report, persons with intellectual, psychosocial disabilities and autism are at high risk of human rights abuse, including violations of the right to life. Institutionalization is an active source of harm and institutions foster inhumane, dehumanizing, coercive and abusive forms of experience, including forced treatment, abuse of medications, violence, unhygienic conditions, use of physical constraints, that systematically harm physical and mental health and can result in reduced life expectancy, or in the worst cases, in early death. Autistic people are the most exposed to abuses in institutional and other settings because of 'challenging behaviour' they may display and because of their communication issues, which make easier to exert abuses against them without being discovered. All too often, there is no effective investigation into the circumstances of the early death of these persons.

Moreover, autistic people or those with intellectual and psychosocial disabilities remain significantly more subject to common health risk factors related to diet, weight and physical inactivity, as well as epilepsy, cerebral palsy, sensory issues, mental health problems and self-harm. They experience greater barriers in accessing appropriate health care and, even when treated, are at high risk of receiving poor care, including for their frequently unrecognized or misrecognized manifestations of pain or discomfort. Because of these barriers to equal access to healthcare, autistic people tend to receive health care of lower quality that is not adapted to their needs and have a lower life expectancy (see art. 25).<sup>13</sup>

During the recent pandemic, COVID-19 testing, treatment and hospitalisation as well as outpatients and inpatients services were often inaccessible for autistic people and their families. 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 in countries such as in Belgium or in the UK.<sup>14</sup>

*As a consequence, Autism-Europe strongly supports the EDF questions to the EU to research and collect information into deaths in institutions and promote the opening of investigations with effective sanctions for perpetrators (both state and non-state) and elimination and abolition of practices and treatment which put at risk people's lives.*

## **ARTICLE 11: RISK AND HUMANITARIAN EMERGENCY**

The EU has competence to carry out activities and formulate a common policy in the area of humanitarian aid. In the field of civil protection, the EU has competences to carry out actions to support, coordinate or supplement Member States' actions. Notwithstanding efforts to include persons with disabilities in EU humanitarian policies and programmes, no

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<sup>13</sup> Hirvikoski, T. at al. (2016) Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 208, 232–238.

<sup>14</sup> Autism-Europe, (2020) [Impact of COVID-19 on autistic people and their families across Europe](https://www.autismeurope.org/wp-content/uploads/2020/12/Impact-of-COVID-19_report-Autism-Europe_December-2020.pdf). Retrieved here: [https://www.autismeurope.org/wp-content/uploads/2020/12/Impact-of-COVID-19\\_report-Autism-Europe\\_December-2020.pdf](https://www.autismeurope.org/wp-content/uploads/2020/12/Impact-of-COVID-19_report-Autism-Europe_December-2020.pdf)

data are available on the inclusion of persons with disabilities in EU-funded humanitarian aid projects.

The Directorate-General for European Civil Protection and Humanitarian Aid Operations (DG ECHO) published a [Guidance Note on the Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations](#) in February 2019. Surprisingly, the new EU Disability Rights Strategy has no mention of how the Guidance will be mainstreamed in the strategy's actions and implementation in all Member States. The [EU Strategy on Adapting to Climate Change](#) (2021) has no reference on persons with disabilities in terms of key actions and recommendations.

With regard to civil protection, the disability inclusion in humanitarian action remains insufficient in the EU. Because of their major communication and orientation problems, autistic people who need intense support are particularly exposed to high risk in emergency situation. Some autistic people can even actively oppose to evacuation due to their unawareness of danger and resistance to change.

#### **Suggested questions:**

- Will the EU make sure that autistic people's needs in emergency situations are included in regular training on humanitarian aid and civil protection, and that all EU-funded projects under DG ECHO are inclusive of autistic people?
- What measures is the EU taking to establish standardized protocols and procedures to aid autistic people during and after emergency situations and natural catastrophes while respecting their rights and dignity, in consultation with representative DPOs?

#### **ARTICLE 12: EQUAL RECOGNITION BEFORE THE LAW**

The EU has a clear competence to combat discrimination based on disability when developing and implementing its policies and activities (Article 10 TFEU) and to adopt legislation to combat such discrimination (Article 19 TFEU). Furthermore, the EU has competence in the areas of employment, consumers' rights, access to justice, health, freedom of movement, data protection and, in areas such as independent living and the right to vote and stand for elections where persons with disabilities whose legal capacity has been denied or restricted are unable to enjoy and exercise their rights in these fields.

Equal recognition before the law falls directly within this competence as persons with disabilities, and in particular autistic people, are often denied or restricted their legal capacity on the basis of disability. Many national legislations, policies and practices across EU Member States deny the recognition of legal capacity to autistic people and with other severe intellectual or psychosocial disabilities and maintain them under guardianship. Though some autistic people need intense support to be represented, substituted decision making regimes are not CRPD compliant. Even new legislations implementing the right to equal recognition before the law in the EU Member States include the concept of incapacity of persons with intellectual or psychosocial disabilities to take decisions. Few establish the

duty to provide these persons with the support they need to take informed decisions and to be represented, if needed, in the respect of their will and preferences.

**Suggested question:**

- What initiatives will the EU take to foster the abolishment of substituted decision-making systems and their replacement by supported decision-making methods adapted to the communications needs of autistic people (including through the use of augmentative/alternative communication modes and methods used by autistic people)?

**ARTICLE 13: ACCESS TO JUSTICE**

The EU has shared competences in the area of freedom, security and justice and has taken significant steps to ensure that EU citizens are respected when they come in contact with the criminal justice system. The new EU Strategy on victims' rights (2020-2025)<sup>15</sup> published in 2020 and the EU Strategy on the rights of the child include specific mentions of the rights of victims with disabilities but urgent action is needed for their effective transposition and implementation. Because of their communication difficulties, autistic people are often excluded from participation in legal proceedings due to lack of accessible information and communication or because their legal capacity has been removed or restricted.

Because of stigma and prejudices towards the unusual behaviour they often exhibit, autistic people are deemed to be dangerous and subjected to indefinite detention and forced treatment<sup>16</sup>, though they may be at less risk for offending than the general population, and more likely to be victims of crime.<sup>17</sup> In addition, because of their important difficulties with communication autistic people encounter major barriers to initiate any procedure, to report or even to recognize abuses and bullying, and to access victim support services. Their testimonies are not taken into account because they are not credited as reliable persons or because they do not have access to verbal communication. A 2017 research highlighted that autistic adults and parents of autistic children who had experienced criminal justice systems as witnesses or defendants were dissatisfied with the process<sup>18</sup> due to lack of accommodation.

Autistic youth usually lack of sufficient accommodation in the juvenile justice procedures which lead to inadequate court decisions. Communication difficulties, high level of stress and challenges with social interaction make autistic children incapable of defending themselves.<sup>19</sup> In 2016, the European Parliament and the Council published the Directive

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<sup>15</sup> European Commission (2020), *EU Strategy on victims' rights (2020-2025)*.

<sup>16</sup> Archer, N. and Hurley, E.A. (2013), "A justice system failing the autistic community", *Journal of Intellectual Disabilities and Offending Behaviour*, Vol. 4 No. 1/2, pp. 53-59. <https://doi.org/10.1108/JIDOB-02-2013-0003>

<sup>17</sup> Beadle-Brown, J, Richardson, L, Guest, C. (2014) *Living in Fear: Better Outcomes for People with Learning Disabilities and Autism*. Canterbury: The Tizard Centre, University of Kent.

<sup>18</sup> King, C., Murphy, G.H. A Systematic Review of People with Autism Spectrum Disorder and the Criminal Justice System. *J Autism Dev Disord* **44**, 2717–2733 (2014). <https://doi.org/10.1007/s10803-014-2046-5>

<sup>19</sup> Yu, Y., Bradley, C.C., Boan, A.D. *et al.* Young Adults with Autism Spectrum Disorder and the Criminal Justice System. *J Autism Dev Disord* **51**, 3624–3636 (2021). <https://doi.org/10.1007/s10803-020-04805-9>



(EU) 2016/800 on procedural safeguards for children who are suspects or accused persons in criminal proceedings, it is protecting the fundamental rights of children with disabilities in the justice system.

Despite the existing legislation, it is unclear to which extent the rights of person with disabilities and of children with disabilities are respected and protected in the criminal justice systems across the EU. The European Commission will publish a report regarding the implementation of the Directive in 2022. The European Commission needs to focus on having monitoring indicators and data specifically for children with disabilities and autistic children aiming to improve access to justice for every individual.

The European Commission intends to foster the Digitalisation of justice in the EU, a priority that notably emerged due to the Covid-19 pandemic<sup>20</sup>. Autistic people find it harder than others to use online services. Many people with learning disabilities and/or autism may not have a formal diagnosis, but they still need support. Services should be flexible in equating support to needs rather than a diagnosis<sup>21</sup>. The way the digitalization of justice would become accessible for every autistic person in EU is still unclear.

### **Suggested questions:**

- How will the EU monitor the implementation of its directives to make sure that appropriate procedural accommodations are provided to ensure effective participation of autistic people in the justice system, including meaningful and accessible communication, information, support and access to victims' support services?
- How will the initiatives on digitalisation of justice make sure to address the specific needs of autistic people?
- Will the EU promote systematic training for the professionals working in the field of justice administration, including prison and policemen, on the alternative/augmentative communication modes used by autistic people and on the CRPD rights-based approach?

## **ARTICLE 14: LIBERTY AND SECURITY OF PERSON, ARTICLE 15: FREEDOM FROM TORTURE OR CRUEL AND INHUMAN OR DEGRADING TREATMENT OR PUNISHMENT, ARTICLE 16: FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE, AND ARTICLE 17: PROTECTING THE INTEGRITY OF THE PERSON**

The EU has shared competences in the area of freedom, security and justice and has a mandate to frame a common policy on asylum, immigration and external border control, as

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<sup>20</sup> European Commission (2020), Digitalisation of justice in the European Union-A toolbox of opportunities

<sup>21</sup> Hollomotz, A., & TALBOT, J. (2021). Designing solutions for improved support within health, social care and criminal justice for adults with learning disabilities and/or autism who have offended. *The Howard Journal of Crime and Justice*, 60(2), 185-208.

well as on common safety concerns in public health matters and supporting competence in health protection.

In most European countries, compulsory psychiatric detention and/or treatments are legally permitted on grounds linked to the existence of an actual or perceived psychosocial or intellectual disability, mainly towards persons exhibiting strange or challenging behaviours, such as autistic persons. In some countries, compulsory treatment orders (CTOs) are used without the consent or even against the will of the person. Furthermore, unequal detention regimes for people with psychosocial disabilities exist in Judicial Psychiatric Hospitals as part of penal systems.

AE is opposing the Draft Additional Protocol to the Council of Europe (CoE)'s Convention on Human Rights and Biomedicine, better known as the Oviedo Convention, which is a European legally binding instrument on the protection of human rights in the biomedical field. Despite its name, the "Draft Additional Protocol concerning the protection of human rights and dignity of persons with a mental disorder with regard to involuntary placement and involuntary treatment" would not protect such persons and would authorize some forms of involuntary placement and treatment. So far, despite being a key partner of the CoE, the European Union has not taken a position against the Draft Additional Protocol.

Because of the so-called challenging behaviours they may exhibit, or simply because abuses are unlikely to be reported, autistic people in Europe are also at higher risk of cruel and inhuman treatments, violence and abuse in segregating or even mainstream services. Abuses against autistic children may also occur in families that are not properly supported and trained on autism features and strategies to prevent abuses, or in families of adults with autism that are left alone to face their increasing needs for independence and behaviours resulting from forced inactivity and frustration.

Segregating institutions regularly use physical or pharmacological constriction practices towards autistic people and similar conditions <sup>22</sup>with the justification to prevent harm to themselves or others, in reality because they do not provide the intense and qualified support requested to prevent and manage so called challenging behaviours in the respect of the person's most basic rights.

In some EU countries, treatments violating the integrity of autistic children are being applied and recommended for children and adolescents with autism, especially those showing associated challenging behaviours. Examples of unethical and dangerous treatment are the use of bleach enemas under false belief it will cure autism.

The EU fails to address the incidences of torture and inhuman or degrading treatment that all people, including autistic persons, face in Europe today.

### **Suggested questions:**

- What steps is the EU taking to oppose the draft additional protocol to the Oviedo Convention and promote voluntary measures in EU Member States?

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<sup>22</sup> Care Quality Commission (2021) Out of Sight. Who care? A review of restraint, seclusion and segregation for autistic people, and people with a learning disability and/or mental health condition.



- Is the EU planning to promote the adoption of common European guidelines on rights-based approaches for autism to prevent inhuman and degrading treatments against persons with autism?

## **ARTICLE 18: LIBERTY OF MOVEMENT AND NATIONALITY**

Autism-Europe shares the EDF concerns related to the need to properly support refugees with disabilities, and in particular autistic people, because of the complexity of their needs, and because of stigma and prejudice on the dangerousness of their behaviours, which are likely to expose them to undue placement in detention centres and not receive adequate support, including information and communication in accessible formats.

EU citizenship gives the right to free movement within the EU to work and study (Article 3(2) of the [Treaty on European Union](#) (TEU) and Articles 4(2)(a), 20, 26 and 45-48 of the [Treaty on the Functioning of the European Union](#) (TFEU).

However, the lack of mutual recognition of autism diagnosis and disability status across Europe, as well as the lack of portability of their disability allowances prevent autistic people and their families to access to support in their new country of residence and prevent them from exercising their freedom of movement.

Disparities in autism definitions across the EU Member States<sup>23</sup> and their medical approach trigger inequalities in the recognition of disability-specific and individual needs of autistic people and in the provision of appropriate early intervention and quality services across the EU Member States.

Autism-Europe notes that the Directive 2004/38 provides under Article 24(2) that Member States are not obliged to grant social assistance to non-economically active EU citizens during the first three months of residence in their territory. Moreover, in specific cases where authorities have a reasonable doubt that the EU citizens concerned may become an unreasonable burden on their social assistance system, they may terminate the right of residence of the persons concerned.

EU citizens are entitled to social assistance in the same way as nationals of the host Member State after five years of legal residence only. Art. 24(2) of the Directive 2004/38 is therefore likely to hinder the right to free movement and residence within the EU persons of autistic people because of their need for intense support and of the related costs (see report on article 1, Purpose). Article 24(2) of the Directive 2004/38 therefore does not comply with the implementation of Art. 18 CRPD, read in conjunction with the Preamble, letter (J), stating

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<sup>23</sup> European Commission Health & Consumer Protection, Directorate C - Public Health and Risk Assessment, C2 - Health information "Some elements about the prevalence of Autism Spectrum Disorders (ASD) in the European Union", 2005

that no exception to the enjoyment of rights set out in the CRPD is acceptable based on the intensity of the support needed.

### **Suggested questions**

- What initiatives will the EU take to ensure that all funding and measures regarding migration are disability inclusive and that persons with disabilities are not arbitrarily detained?
- How does the EU intend to tackle inequalities related to intra-EU mobility, in particular issues related to the lack of mutual recognition of autism diagnosis and disability status?
- How will the EU address the difficulties linked to the transfer of social protection and disability benefits to another Member State?
- Will the EU revise the Directive 2004/38 to better comply with the obligations enshrined in Art. 18 CRPD and in the Preamble, letter (J)?

## **ARTICLE 19: LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY**

EU competence for the promotion of independent living and inclusion in the community is shared with Member States.

Coherent policies and measures are needed at EU level to empower people on the autism spectrum to live independently and participate in the community. Because of the so called challenging behaviours they may exhibit and of prejudice on their capacity to live independently, autistic people, and in particular those with complex support needs, are at higher risk of institutionalisation. Timely and ongoing access to appropriate and adequate individualized support would help them to develop choice and independence skills and self-determination needed to live independently. Lack of support, information and training to families on how to meet the specific and complex needs of autistic children can contribute to institutionalisation.

Unfortunately, institutionalisation of autistic people is thus a wide-spread phenomenon across the EU. Funding cuts to social, educational and habilitation services adopted in EU member states have increased the shortage of suitable community-based living options and triggered a trend towards their conglomeration in large-size institutions. EU funding instruments (e.g. European Structural and Investment Funds) should be used to promote transition from institutional to community-based services, in all the EU member States. It is foreseen in their Guiding Regulations that EU Member States must have a strategy to implement the UNCRPD provisions. However, alarmingly EU structural funds have been used to refurbish institutions where disabled people are completely neglected. It was the basis of a complaint to, and eventual decision by the European Ombudsman in 2019. The

checklist of the European Expert Group on Transition from Institutional to Community-based care, where Autism-Europe is member, is a useful tool for the European Union on how to avoid funding institutions.

Also, the EU has created another funding mechanism in the wake of the COVID-19 crisis called the “Recovery and Resilience Facility” that does not follow the same strict rules as other EU funding, and could result in investments in institutions.

Moreover, the use of European Funds is not sufficient to promote the transition towards community-based services for autistic people. A change of mentality of services providers, the whole population and families themselves is also crucial to fight prejudice and stigma on the capacity of autistic people to live independently with the adequate support.

In some EU countries, the support and care of autistic adults is mainly based on delegation to families<sup>24</sup>. 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 and independence wishes.

One example known for a long time is the frequent placement of persons with disabilities from France in services in Belgium, which concerns mainly autistic people. The French government has announced that they would end the practice of subsidising the care of disabled people in Belgium, however little is being done to create the necessary services in France.<sup>25</sup>

The cross-border flow from France to Belgium of autistic children and adults, and their consequent alienation from their families and communities, is due not only to the shortage of community-based services in France, but also to the lack of available evidence-based intervention and support fostering the development of independence skills, inclusion and participation. In order to allow access to qualified support across the EU, it is necessary to harmonise quality assessment systems across EU countries and to adopt person-centred quality criteria which comply with Article 19 CRPD. The adoption of service quality criteria addressing the beneficiary's outcomes in terms of inclusion, participation and choice is vital for autistic people. It is all the more important due to their major difficulties to report dissatisfaction and to express their preferences and choice. Established quality principles and criteria for social services are not legally binding and not broadly implemented across EU countries.

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<sup>24</sup> CENSIS.Fondazione Serono : La dimensione nascosta delle disabilità. Terzo rapporto di ricerca. La domanda di cura e di assistenza delle persone affette da Sclerosi Multipla, da Disturbi dello spettro Autistico e delle loro famiglie, 2012

<sup>25</sup> "Le contribuable finance les structures en Belgique", alerte Jean Pierre Delelis, père d'adulte handicapé (francebleu.fr)

### **Suggested questions:**

- Is the EU planning to have guidance on the use of EU funds for persons with disabilities, in the form of an official EU guidance document?
- What steps will the EU take to ensure equal opportunities for autistic people to develop their full individual potential and independence skills through equal access to quality support and services?
- Will the EU address the specific needs of autistic people by developing a quality binding system which complies with article 19 CRPD, in order to prevent Member States from using freedom of movement of persons, goods and services to undermine the right of autistic people to live in their community?

### **ARTICLE 20: PERSONAL MOBILITY**

The EU has shared competences with Member States in the area of transport which also includes Passengers' Rights, one of the areas where EU legislation is very prominent and far-reaching. The EU can also enhance personal mobility by promoting mutual recognition of social security rights as well as standardisation of goods and services to facilitate cross-border movements.

The rights of passengers with disabilities are still not fully protected and the provision in [Regulation 1177/2010](#) to allow travelling with an assistant for free has not been systematically included in the other Regulations on passengers' rights. There are a lot of differences between transport operators regarding the travelling conditions with a personal assistant and which types of disabilities are eligible for such assistance.<sup>26</sup>

Mobility is a significant area of restriction for autistic people. 63% of people with autism have a profound or severe mobility restriction and need help or supervision to move around.

### **Suggested question:**

- How will the EU ensure that autistic passengers enjoy the same level of rights to access rail, waterborne, air, bus and coach transport, as other citizens by relevant EU Regulations and EU funding, notably by ensuring that all transport infrastructure are adapted to their communications needs and by giving them the possibility to travel with an assistant for free if needed?

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<sup>26</sup> Discrepancy across the railway companies regarding the right to travel with a personal assistant: for example on [Thalys website](#) (trains between Belgium, France, Germany and the Netherlands), it is clearly mentioned that (only) wheelchair users can benefit from a reduced fee for their assistant, while with [SNCF](#) (train in France) it is based on the % of disability and does not discriminate according to the type of disability.

## **ARTICLE 21: FREEDOM OF EXPRESSION AND OPINION, AND ACCESS TO INFORMATION**

Major and global communication difficulties of some autistic people, mainly in receptive communication, require that any relevant information is made accessible to them through the use of alternative/augmentative communication modes and methods that fit with their communication style, including standardized signals and symbols and easy-to understand formats.

### **Suggested question:**

- How is the EU going to foster the use of alternative communication formats for autistic people, especially the use of Easy-to-read format?

## **ARTICLE 23: RESPECT FOR HOME AND FAMILY**

In 2019, the Work-Life Balance Directive entered into force aiming to address the work-life balance challenges faced by working parents and carers<sup>27</sup>. There is concerns about the effective transposition of the ‘carer’s leave’ for parents providing support to their child and the ‘flexible working arrangements’ into national legislations, and the actual impact it can have on families given the lack of ambition in various member states. The EU Child Guarantee<sup>28</sup> is an additional policy initiative to support family life and support families with disadvantaged backgrounds who live under poverty and social exclusion. The Child Guarantee will provide financial support to families in need, aiming to bring separated families back together-deinstitutionalisation- and diminish child poverty.

The COVID-19 pandemic exacerbated the challenges of disabled people being separated from their families as containment policies led to lack of access to people living in institutions as well as temporary border closures which for example separated families in France from their autistic relatives living in institutions in Belgium (cf art 19) as Autism-Europe’s 2020 COVID-19 impact report found<sup>29</sup>.

The EU has announced its intention to create a new [European Care Strategy](#). This Strategy would cover the long-term care needs for persons with disabilities across their lifespan, as well as support for families.

### **Suggested questions:**

- What initiatives will the EU take to support and empower families of autistic people and prevent their institutionalization, notably through the new care strategy?

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<sup>27</sup> European Parliament and Council of Europe (2019), [Directive on work-life balance for parents and carers](#)

<sup>28</sup> European Commission (2019), [European Child Guarantee](#)

<sup>29</sup> Autism-Europe (2020), Impact of COVID-19 on autistic people and their families across Europe

- How will the Child Guarantee support families of autistic people to reduce their risk of poverty and social exclusion? What are the key actions for autistic children living in institutions due to poverty?

## **ARTICLE 24: EDUCATION**

The EU has supporting competence in the field of education. It should encourage cooperation among Member States and support their actions.

Children and young people with autism spectrum disorders should enjoy equal opportunity for educational interventions that are appropriate to their needs and work towards social inclusion<sup>30</sup>, regardless of the nature and origin of their disability and irrespective of their age<sup>31</sup>. However, autistic people are still discriminated against in the field of education across the EU, especially those in need of intense support are often excluded or do not have adequate access to education services.

Autistic learners present unique educational needs that are qualitatively different from other special needs and require specific understanding and approaches to meet them. For autistic persons in need of intense educational support, the effectiveness of education is jeopardized by the lack of competences of teachers on educational strategies to respond to their major learning difficulties. A recent study conducted in Croatia, the Republic of North Macedonia and Poland focused on experiences of teachers working directly with children with autism in both mainstream and special schools. More than 20% of the respondents had received no specific course in autism during their initial teacher education and an overwhelming majority – 93% of both mainstream and special school teachers identified a need to access further teacher education opportunities regarding autism, notably regarding theory, relevant practical strategies and mentorship/supervision.<sup>32</sup>

Over the past years, education systems across the European Union have evolved, to move towards inclusive models. Enrolment in adequate inclusive education settings from an early stage increases the probability of the students with disabilities to continue in higher education<sup>33</sup>. The EU Strategy on the Rights of Person with Disabilities and the EU Strategy on the Rights of the Child both promote inclusive education within key actions. A Toolkit for

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<sup>30</sup> Council of Europe, Recommendation CM/Rec(2009)9 of the Committee of Ministers to member states on the education and social inclusion of children and young people with autism spectrum disorders (Adopted by the Committee of Ministers on 21 October 2009)

<sup>31</sup> European committee of social rights : Decision on the merits No. 13/2002 Autism-Europe v. France, 4 November 2003

<sup>32</sup> Natalija Lisak Šegota, I. Lessner Lištiaková, J. Stošić, J. Kossewska, J. Troshanska, A. Petkovska Nikolovska, T. Cierpiałowska & D. Preece (2022) Teacher education and confidence regarding autism of specialist primary school teachers, European Journal of Special Needs Education, 37:1, 14-27, DOI: [10.1080/08856257.2020.1829865](https://doi.org/10.1080/08856257.2020.1829865)

<sup>33</sup> European Agency for Special Needs and Inclusive Education (2018), Evidence of the Link Between Inclusive Education and Social Inclusion: A Review of the Literature.



inclusion in early childhood education and care has been published in 2022<sup>34</sup>. However, there is no comprehensive action plan to tackle existing inequalities in education across Member States.

The financial crisis has negatively influenced efforts towards inclusive education. Austerity measures in EU countries such as Greece and Portugal, found to have a negative impact on the inclusive education of autistic students<sup>35</sup>. Budget restrictions in education are likely to place persons who need more support and accommodations to learn, such as autistic people, at a disadvantage. In some countries, Article 24 CRPD is used as a justification to cut funds to special schools without adopting adequate legislation, policies and measures and without providing adequate funding to support the transition and to ensure appropriate support and accommodation to autistic pupils and students in mainstream schools

Families of autistic children thus struggle to access appropriate and inclusive public education with suitable supports and accommodations for the needs of the autistic learner as evidenced by a recent survey conducted by AE.

COVID-19 pandemic impacted students with disabilities who have not had access to the technological equipment they needed to access education<sup>36</sup>. Online education proved to be inaccessible for a majority of autistic children<sup>37</sup>. The transition to at-home learning was difficult for parents and autistic children as parents struggled to balance work and home life, while being deprived of support to foster the learning of their autistic children.

The EU adopted the [Digital Education Action Plan \(2021-2027\)](#) ‘a renewed European Union (EU) policy initiative to support the sustainable and effective adaptation of the education and training systems of EU Member States to the digital age’<sup>38</sup>. It is key that the digital transformation in the field of education is inclusive of learners with disabilities.

Indeed, failure to provide access to reasonable accommodation in education to autistic people prevent them from acquiring job qualifications, thus also exclude them from the labour market at a later stage. Under the Employment Equality Directive, persons with disabilities are protected against discrimination at the condition that they have the requested level of qualification. As a consequence, equal opportunities and non-discrimination in employment can only be achieved if the right to quality education is granted at all levels.

### **Suggested questions:**

- How will the EU promote adequate conditions for the education of autistic learners?

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<sup>34</sup> Commission européenne, Direction générale de l'éducation, de la jeunesse, du sport et de la culture, (2021). *Toolkit for inclusive early childhood education and care : providing high quality education and care to all young children*, Publications Office. <https://data.europa.eu/doi/10.2766/399018>

<sup>35</sup> Van Kessel, R., Siepmann, I., Capucha, L., Paschalis, A. K., Brayne, C., Baron-Cohen, S., ... & Roman-Urrestarazu, A. (2021). Education and austerity in the European Union from an autism perspective: Policy mapping in Ireland, Portugal, Italy, and Greece. *European Policy Analysis*, 7(2), 508-520.

<sup>36</sup> European Commission (2021), Enhancing Learning Through Digital Tools and Practices: How Digital Technology in Compulsory Education Can Help Promote Inclusion

<sup>37</sup> Autism-Europe (2020), [Impact of COVID-19 on autistic people and their families across Europe](#).

<sup>38</sup> European Commission (2021), [Digital Education Action Plan \(2021-2027\)](#)



- Will the EU make sure that EU funds are used to support the training of educational staff on teaching and communication strategies for autistic people, as well as common standards for their qualifications?
- How is the EU going to ensure that the digital transformation of education and vocational training will be accessible for all autistic learners?
- How will EU collect comparable, disaggregated by disability, data and statistic across EU countries on access to mainstream school, to primary and secondary education, to vocational training and to employment of autistic people?

## **ARTICLE 25: HEALTH**

In the healthcare field, the EU shares competence with EU Member States and complements Member States' policies to improve public health across the EU. In recent years, the United Nations<sup>39</sup> and the WHO<sup>40</sup> identified autism as an emerging public health issue which demands an immediate and organized response<sup>41</sup>.

For the period 2021–2030, and in reaction to the COVID-19 pandemic, the European Commission's Strategy for Persons with Disabilities (ESRPD 2021-2030) 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.

While beating cancer is emphasized by the Commission, the ESRPD 2021-2030 also highlights that "persons with invisible disabilities (such as chronic pain or intellectual disabilities), with rare diseases or with cancer, that often lead to impairments, do not always receive the tailored support needed nor do women and refugees with disabilities."

Indeed, a large-scale study conducted in Sweden evidenced that autistic people die on average 16 years earlier than the general population. Autistic adults with a learning disability were found to die more than 30 years before non-autistic people.<sup>42</sup> Healthcare professionals need to know how to properly accommodate the needs of autistic patients through reasonable adjustments. Autistic people across the EU still have unequal access to general health care services and health promotion interventions compared with the general

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<sup>39</sup> United Nations. Resolution adopted by the General Assembly on 12 December 2012. (2013). Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities. [http://www.un.org/ga/search/view\\_doc.asp?symbol=A/RES/62/139](http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/62/139)

<sup>40</sup> World Health Organization. (2010). mhGAP Intervention Guide for mental, neurological and substance use disorders in non-specialized health settings. [http://www.who.int/mental\\_health/evidence/mhGAP\\_intervention\\_guide/en/index.html](http://www.who.int/mental_health/evidence/mhGAP_intervention_guide/en/index.html).

<sup>41</sup> Wallace S, Fein D, Rosanoff M, Dawson G, Hossain S, Brennan L, Como A, Shih A. (2012). A global public health strategy for autism spectrum disorders. *Autism Res.* 5(3):211-7

<sup>42</sup> Hirvikoski, T. et al. (2015). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 207(5)

population and even compared to persons with other disabilities, as well as unmet general and specific health care needs related to associated developmental, mental, physical health conditions (e.g., Angelman syndrome, fragile X syndrome, tuberous sclerosis, epilepsy, AD(H)D, anxiety, depression, behavioural or sleeping issues, motor or eating difficulties, diabetes, hypertension, obesity, cardiovascular issues, etc.<sup>43</sup>) or to ageing, as autistic people have a greater risk of experiencing health problems as they get older. Furthermore, there is lack of key reproductive healthcare due to misconception about autistic people's sexuality.

There is a lack of awareness of medical professionals that commonly attribute a symptom or behaviour to the disability instead of looking for the actual health problems, which also happened during the COVID-19 pandemic. A majority of autistic people are not able to communicate pain or discomfort, making it difficult to detect warning signs of medical problems. They can manifest them through so called challenging behaviours, that can be misunderstood or mistreated. Challenging behaviours can be exacerbated by sensory sensitivities, fear and anxiety that diagnostic and intervention procedures may induce in autistic people, interfering with the diagnosis and in some cases resulting in the provision of false treatment.

Thus we regret that insufficient attention has been given to the perspective of autistic people in EU health instruments. For example, the 2011 European legislation on cross-border health care does not guarantee patients on the autism spectrum access to quality healthcare, due to the lack of provision of reasonable accommodation and training of health professionals dealing with general and specific health care needs of autistic people in health care systems.

Concrete measures are needed to cope with the specific difficulties of autistic people during medical examination and intervention. Reasonable accommodations of the health care environment to their communication needs and sensory abnormalities, individual support during hospitalisation and skilled health professionals to identify the unusual manifestations of pain or illness in autistic people are vital to ensure equal access to healthcare to autistic people.

The delays in accessing early autism diagnosis and intervention services deprives children on the autism spectrum of equal opportunities to develop their potential and to achieve social inclusion and participation in adulthood<sup>44</sup>. Lack of early diagnosis and intervention services provided by public health systems and lack of knowledge and skills among health

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<sup>43</sup> Malik-Soni et al. (2021) Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatric Research* <https://doi.org/10.1038/s41390-021-01465-y>

<sup>44</sup> According to the conclusion of the EU funded project ASDEU released in 2018: Diagnosis is still a big problem in Europe, and more resources are needed to facilitate early detection: Research showed that the average age first concerns about autism are identified is 25.3 months, while on average, diagnosis does not happen until 44.4 months – 19 months later. Most parents (68.8%) indicated delays of more than six months to access a diagnostic service. Only 44.8% of families reported that professionals informed them about their child's specific needs and 20% of families said they did not receive any information at the time of diagnosis. Families evaluated detection services negatively in terms of the attention professionals gave to parents' concerns. [WP1 \(asdeu.eu\)](http://asdeu.eu)

professionals<sup>45</sup> can result in parents investing significant amounts of their own resources in ineffective interventions. Some public health services in EU countries still adopt disproved treatments for autistic children, sometimes violating their rights and dignity. A more widespread information and training of physicians and paediatricians on the early signs of autism and systematic adoption of gold-standard instruments for screening and early diagnosis are therefore needed, as well as more attention to the parents' concerns and their involvement in the diagnostic process.

At the present time, the strongest evidence for interventions for young autistic children comes from large-scale, randomised trials of developmentally based approaches designed to facilitate social communication between very young children and their parents<sup>46</sup>. Early detection of autism, when followed by appropriate diagnosis and assessment and by behavioural and educational intervention, can make a significant positive impact on long term outcomes for autistic people and their families. It is therefore important to identify and refer autistic children as early as possible to Early Intervention Programmes. Nevertheless, delays in diagnosis of autism are still very common across EU countries.

### **Suggested questions:**

- Will the EU facilitate equal access for autistic people across the EU to general healthcare, by supporting the development of guidelines on reasonable accommodations that address the specific needs of autistic people in healthcare services and facilities, including dental care, emergency and preventive services?
- Will the EU promote common gold standards for early detection, diagnosis and interventions for autism across the EU through the development and adoption of EU guidelines?
- What will the EU do to promote the training on accessible communication for autistic people in the curricula of health professionals and staff, including for understanding the manifestations of pain and discomfort of autistic people, to facilitate the diagnosis of general health problems as well as to ensure informed consent to medical treatments?

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<sup>45</sup> Lipinski, S. et al. (2021) A blind spot in mental healthcare? Psychotherapists lack education and expertise for the support of adults on the autism spectrum. *Autism*. 1–13. <https://doi.org/10.1177/13623613211057973>

<sup>46</sup> Fuentes, J., Hervás, A., Howlin, P. et al. ESCAP practice guidance for autism: a summary of evidence-based recommendations for diagnosis and treatment. *Eur Child Adolesc Psychiatry* 30, 961–984 (2021). <https://doi.org/10.1007/s00787-020-01587-4>

## **ARTICLE 26: HABILITATION AND REHABILITATION**

Habilitation and rehabilitation services fall under the definition of social services of general interest (SSGIs).

For autistic people, habilitation is not an option, but the condition to overcome their major communication and social difficulties, to enjoy equal opportunities for employment and participation in the community, to achieve independence, self-determination and the capacity to assert their own preferences and choices in their everyday lives. Denying autistic people appropriate habilitation programmes equals to mistreatment and results in many people becoming unnecessarily dependent.

As the social and communication difficulties seen in autism persist throughout the lifespan, social and communication habilitation of autistic people require continuity and specific strategies.<sup>47</sup> All too often across EU countries, medication and/or therapies based on unproven theories, are provided instead of sound, evidence-based habilitation programmes. Some countries arbitrarily limit the intensity and duration of habilitation programmes instead of adapting them to the individual needs. Other countries fund and implement physical habilitation and rehabilitation programmes under health system provisions, while they do not foster the provision of social and vocational habilitation services for autistic people or require the person or his/her family a financial contribution to their costs.

In recent years, austerity measures have exacerbated the shortage of habilitation services for autistic people and/or enhanced the financial contribution requested to the person or his/her family. Inequalities in the availability, affordability quality and intensity of habilitation services among EU countries prevent autistic people and their families from moving across the EU. A recent Irish survey related to the assessment of the level and nature of unmet service needs of children and adolescents on the autism spectrum as well as debt related to meeting needs of such families in Ireland highlights that 74% of children and adolescents did not receive one or more services in the previous 12 months. 33% of families incurred debt in the previous 12 months specifically due to the child's/children's condition resulting in an average autism-related family debt of €3,260 per year<sup>48</sup>. Many autistic people across EU countries do not have access to proper habilitation programmes tailored to their specific and individual needs. A survey conducted in Italy<sup>49</sup> has shown that 30% of autistic people do not have access to any habilitation programme.

### **Suggested questions:**

- Will the EU promote and support the availability of affordable quality habilitation services, including through the use of EU funds as well as the compulsory training on

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<sup>47</sup> National Institute of Mental Health – NIMH: Autism Spectrum Disorders, 2004

<sup>48</sup> Áine Roddy, Ciaran O'Neill.(2020) Predictors of unmet needs and family debt among children and adolescents with an autism spectrum disorder: Evidence from Ireland, Health Policy, Volume 124, Issue 3. <https://doi.org/10.1016/j.healthpol.2020.01.005>

<sup>49</sup> CENSIS.Fondazione Serono : La dimensione nascosta delle disabilità. Terzo rapporto di ricerca. La domanda di cura e di assistenza delle persone affette da Sclerosi Multipla, da Disturbi dello spettro Autistico e delle loro famiglie, 2012

specific and evidence-based habilitation strategies for autism, as well as on ethical issues in the curricula of all the habilitation professionals?

- Will the EU develop minimum quality standards for habilitation and rehabilitation services and programmes for autistic people of any age?
- Will the EU support the development and adoption of EU guidelines on evidence-based, rights-based intervention for autism, based on existing guidelines at national and international level?
- Will the EU promote the adoption of quality assessment systems for habilitation services which are centred on outcomes in terms of inclusion, participation and quality of life of the users?

## **Article 27: Work and employment**

The EU has shared competence in the field of employment of persons with disabilities. Persons with disabilities are protected against discrimination in employment and occupation by the Employment Equality Directive 2000/78. However, the protection of autistic people by the Directive is insufficient as an employer may simply justify a decision not to hire a person on the autism spectrum because the training and adaptations required for that person, especially if in need of complex support, would impose a disproportionate burden.

In 2021, the European Parliament adopted a report on the Employment Equality Directive in light of the UNCRPD calling on the European Commission and the EU Member States to prepare clear EU guidelines on reasonable accommodation. Moreover, the Commission should launch infringement procedures and encourage Member States to ensure that a sanction system is in place in case of non-provision of reasonable accommodation.

Eurostat does not provide any disaggregated data by disability. However, some national surveys show that autistic persons and their families are particularly vulnerable to unemployment. In the UK, the Office for National Statistics published data in 2021 that indicate that just 22% of autistic people are reported in paid work - the lowest employment rate among all people with disabilities.<sup>50</sup> When employed, autistic people tend to be in low-wage positions that do not meet their qualifications. According to a survey conducted in Italy<sup>51</sup>, 10% only of autistic adults have some form of employment, mainly sheltered or supported employment, compared to 47.9% of persons with disabilities and to 71.5% of persons without disabilities reported by Eurostat. The same survey shows that 26% of mothers of autistic children with complex support needs lost their job (compared to 0.6% of

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<sup>50</sup> Source : National Autistic Society (UK) <https://autism.org.uk/what-we-do/news/new-data-on-the-autism-employment-gap>

<sup>51</sup> CENSIS.Fondazione Serono : La dimensione nascosta delle disabilità. Terzo rapporto di ricerca. La domanda di cura e di assistenza delle persone affette da Sclerosi Multipla, da Disturbi dello spettro Autistico e delle loro famiglie, 2012

fathers), while 27.1% reduced their work time (compared to 10.5% of fathers). Autism have therefore an impact on gender equality as well as on poverty and exclusion of their families, it is referred to as “discrimination by association”.

**Suggested questions:**

- How will the EU monitor the employment and unemployment rates of autistic people, and their access to vocational training programmes and traineeship opportunities?
- Will the EU prepare clear EU guidelines on reasonable accommodation to foster the implementation of the EU Employment Equality Directive as part of their employment package?
- What will the EU do to support awareness among employers and employee representatives on needs of adjustments, abilities and potential of autistic people to work?
- In which way can the EU promote training of employment services to enable them to match employment opportunities and work environments with the individual and particular skills and needs of autistic people?
- How will the proposed EU Directive on Minimum Wage help reduce pay disparities between persons with and without disabilities in the EU, and how will it foster better quality of life and social protection for autistic workers?

**ARTICLE 28: ADEQUATE STANDARD OF LIVING AND SOCIAL PROTECTION**

Social protection systems, poverty reduction programmes and access to disability related social security benefits fall under the shared competences between the EU and Member States.

Social services are important tools for the implementation of public policies in the field of social protection, non-discrimination, the fight against poverty and exclusion. Austerity measures have affected social services for persons with disabilities, enhancing the burden of their support and assistance on their families, as well as the risk of poverty because of the highest financial contribution requested to access services. Because of the complexity and intensity of their support needs, the increase in personal contribution to be paid to services may exclude many autistic people from enjoying them.

As an example, according to an Italian survey, 50% autistic adults do not have access to any service or support, 27% of adults and 13,7% of adolescents remain all day segregated at home without participating in any external activity <sup>52</sup>. The need for support and assistance of autistic people has been evaluated at 17.1 hours/day for children and 15 hours/day for adults. The provision of such support and assistance falls mainly on families. Families of

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<sup>52</sup> Censis: La dimensione nascosta delle disabilità, 3° rapporto di ricerca, 2012



autistic people have therefore additional parenting and assistance costs. According to a Northern Ireland study, the unemployment in families directly affected by autism is up to 20% higher than in other families. Many parents give up work to care for their children. The cost of bringing up a child with autism is estimated to be six times greater than for other children.<sup>53</sup> Even in countries that do have programmes to combat child poverty through support for families, there are no special measures to take into consideration the additional costs and the enhanced risk of poverty for autistic people and their families.

**Suggested questions:**

- Can the EU foster the collection of disaggregated data by disability in the European Statistics on Income and Living Conditions (EU-SILC) conducted by Eurostat?
- How can the EU support the development of poverty reduction programmes and measures for autistic people and their families, notably through EU funds?

**ARTICLE 29: PARTICIPATION IN POLITICAL AND PUBLIC LIFE**

In some EU Member States, some people with disabilities are automatically excluded from political participation and thus denied the right to vote, in other member states the deprivation of legal capacity of citizens with disabilities results in losing their right to vote.

The right to vote in European elections is protected in Article 20 (2) (b) of the Treaty on the Functioning of the European Union, and Articles 39 and 40 of the EU Charter of Fundamental Rights. About 800 000 EU citizens from 16 Member States were facing deprivation of the right to participate in elections of the European Parliament due to their disabilities<sup>54</sup>.

For the large majority of autistic people, election campaigns, information materials, voting procedures and voting ballots are not accessible because of their communication impairment and learning difficulties, therefore they cannot adequately enjoy their right to vote regardless of legal incapacitation. They remain largely excluded from initiatives such as the Conference on the Future of Europe which aims at gathering the views and ideas of EU citizens.

Accessibility standards of voting procedures and ballots focus only on persons with physical and visual impairments. Reasonable accommodation measures for persons with intellectual disabilities and autistic people are missing.

**Suggested questions:**

- How does the EU plan to support the right to vote and ensure that European elections are accessible to autistic people?

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<sup>53</sup> [Autism kids 'face life of poverty if they don't get help' - BelfastTelegraph.co.uk](http://BelfastTelegraph.co.uk)

<sup>54</sup> European Economic and Social Council (2019), 'The real right of persons with disabilities to vote in European Parliament elections'



- What actions will the EU take to ensure that accessible voting procedures as well as participation in decision making will become a reality for autistic people?

## **ARTICLE 30: PARTICIPATION IN CULTURAL LIFE, RECREATION, LEISURE AND SPORT**

The EU has supporting competences in the area of culture, tourism and sport and can promote specific actions notably through its funding programmes, such as the Erasmus plus.

Access to sport activities in the mainstream is crucial to autistic people as gross motor ability is generally one of their strengths. Sport activities may therefore be the only area of life where they can enjoy equal opportunities and be successfully included. Autistic people should therefore have access to sport activities in the mainstream with the reasonable accommodation and the support needed to develop sport abilities and enhance their performances. Trained sport coaches and trainers on communication needs, behaviour features and management strategies should be available in the mainstream sport facilities.

### **Suggested questions:**

- Does the EU intend to promote training on autism in the curriculum of sport trainers and coaches?
- Does the EU intend to foster the participation of autistic people in mainstream sport activities as a priority in EU funded relevant programmes?

## **ARTICLE 31: STATISTICS AND DATA COLLECTION**

The EU has shared competence with its Member States to produce statistics.

Available data on prevalence of autism are even more limited and less reliable than those on disability. No central recording of autism cases is available at EU level. The few epidemiological studies that have been conducted on autism at national level in the EU Member States are very difficult to compare, because of different application of diagnostic criteria from a country to another, even using standard systems.

The European Commission Directorate-General for Health and Food Safety was in charge of the technical follow up of a study on Autism Spectrum Disorders in Europe (ASDEU), a EU-funded pilot project, completed in September 2018. One of its objectives was to provide an estimate of Autism prevalence in Europe and test and identify the best methods to implement an autism surveillance programme in Europe to provide standardised prevalence estimations. ASDEU recommended establishing population-based registries with the capacity to routinely monitor and oversee larger cohorts of children as the optimal approach to monitor autism prevalence in Europe<sup>55</sup>. Unfortunately, no follow-up action has been

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<sup>55</sup> Access the main conclusions : [ASDEU - Findings](#)

initiated by the European commission since the conclusion of the study to support prevalence monitoring.

The Commission has agreed with the Member States on a list of European Core Health Indicators (ECHI indicators) including indicators on long-term activity limitations based on Eurostat data. Eurostat produces and disseminates statistics on disability, but the prevalence of autism in each Member State is not included in this list. In its Strategy for the Rights of Persons with Disabilities 2021-2030, the Commission highlights the importance of more comprehensive data collection on the situation of persons with disabilities.

**Suggested questions:**

- How will the EU standardize diagnostic definition and record of autism, as well as case finding, screening and data collection methods (such as the recommended population-based registries) to monitor the prevalence of autism?
- How will the EU foster the collection of disaggregated data by disability?