

AUTISM EUROPE'S ANSWERS TO THE LIST OF ISSUES ON THE EU REPORT TO THE UN COMMITTEE ON THE RIGHTS OF PERSONS WITH DISABILITIES

Autism-Europe (AE) is the European organisation representing more than 80 member associations of parents of people with autism in more than 30 European countries, including more than 20 Member States of the European Union. The mission of AE is to ensure that persons with Autistic Spectrum Disorders (ASD) fully access fundamental and human rights through their active involvement in the development and implementation of policy in Europe. AE is a founding member of the European Disability Forum (EDF).

With this submission, AE aims to complement the European Disability Forum's answers to the list of issues on the EU report to the UN Committee on the Rights of Persons with Disabilities (CRPD) with additional information from the point of view of persons with ASD, their parents and their representative organisations in Europe. We hope that our answers to the List of Issues will be a useful input to the Constructive Dialogue of the EU which takes place on 27 and 28 August 2015.

Our main analysis can be found in the AE alternative report, where an extensive overview of the implementation of the CRPD at the EU level from the perspective of persons with ASD, their parents and their representative organisations is given.

1. Article 5, Equality and non-discrimination (question 9, List of Issues).

Please provide a timescale for when the Council will adopt the additional Equal Treatment Directive to extend the existing EU anti-discrimination legal framework to areas outside the field of employment, referred to in paragraph 40 of the Report.

The EU recognises in its reply to the List of Issues that anti-discrimination legislation is inconsistent in its scope and creates a hierarchy between the different grounds of discrimination. Persons with disabilities are only protected against discrimination in employment and vocational training, but even in these fields the anti-discrimination Directive 78/2000 does not protect persons with disabilities who need specific and intense support, including persons with ASD. It creates therefore a hierarchy even between persons with different disabilities. Moreover, persons with ASD are discriminated, even among persons with other disabilities, in many fields, such as information and communication, education, healthcare, social and vocational habilitation and employment, because of the intensity of their support needs.

The Equal Treatment Directive must have a scope of application which covers all the areas of life as established in Article 5 CRPD, as well as all persons with disabilities, as established in Article 4 CRPD. It should therefore take specific account of discrimination against persons with disabilities who need intense support, and ensure its compliance with

the CRPD, including strong mechanisms for sanctions and remedies to punish non-compliance. Higher sanctions and injunctive reliefs in cases of discrimination against persons with intense support needs, such as persons with severe autism and with multiple disabilities, should be put in place.

2. Article 6, women and girls with disabilities (question 10, List of Issues).

Please indicate what measures were taken to carry out the recommendations to “tackle intersectional discrimination on the grounds of gender and disability covering education, employment, poverty, health, violence, forced sterilisation and access to justice” (paragraph 180).

EDF already mentioned in its answer to the list of issues that the European Commission has withdrawn the Maternity Leave Directive. EDF has also stressed that family members of children with disabilities are not provided with the opportunity to work flexible hours or to receive other forms of support.

Mothers of children with ASD are forced to leave their jobs to take care of their children because of the complexity of their needs. The EU should also urge Member States to develop and implement comprehensive policies for supporting mothers of children with ASD and help them support their intense and complex support needs, in order to ensure them equal opportunities of employment and of financial independence.

3. Article 7, Children with disabilities (question 11, List of Issues).

Please indicate what measures were taken to tackle “challenges in the practical implementation of legal provisions resulting in obstacles faced by children with disabilities in their day-to-day life” (paragraph 189).

Autism can bring significant economic hardships to families. Austerity measures recommended by the European Union have worsened the standards of living for families of children with ASD. Cuts in support and mainstream services have contributed to their disproportionate representation in institutional settings. Segregation, marginalisation, isolation in segregating facilities or even in unsupported families enhance children’s vulnerability to abuses. Children with ASD are 4 to 10 more likely to be victims of abuse than other children, because major communication problems and challenging behaviours increase vulnerability to abuse or neglect, even compared to children with other disabilities.

EU policies need to be developed addressing the needs for support and assistance for families of children with ASD to fulfil their parenting responsibilities, including the empowerment to meet their children’s needs, to participate in every relevant decision concerning their children, to involve their children in decisions according to their maturity and to respect their wishes.

In some EU countries children with ASD are subjected to unacceptable intervention practices violating their physical and psychological integrity and preventing them to fully develop their potentials. The EU should urge member States to adopt evidence-based, rights-based intervention for ASD in order to respect their dignity and to ensure them opportunities to achieve independence and participation in their communities.

4. Article 8, Awareness-raising (question 12, List of Issues).

Please indicate what concrete and systematic awareness raising and training initiatives has the European Union taken since its' ratification of the Convention to ensure that it is known and used at all EU levels and within all institutions and agencies, including for example the European Economic and Social Committee (EESC) and Committee of the Regions (COR)?

Art. 8.1 (b) CRPD requires to combat stereotypes, prejudices and harmful practices relating to persons with disabilities. The EU's reply to the List of Issues lists some important EU actions of awareness-raising on the rights of persons with disabilities that they have been carrying out for the past 20 years. However, these actions lack awareness-raising on stigma, inequalities, harmful treatments, lack of opportunities and gaps in the enjoyment of CRPD rights faced by persons with ASD across the EU countries. Parents of persons with ASD, and in particular mothers, are still exposed to blame and prejudices stemming from the disproved "Refrigerator mother" theory, which is still widespread among the non-expert people. This false theory attributes to mothers the responsibility of determining autism in their children. The persistence of such prejudices have detrimental effect on family life and on legal decisions in separation or divorce proceedings, which are frequently against mothers of children with ASD, or deprive parents legal custody based on the presumption that they are unable to rear their children with ASD. Moreover the use of a disproved approach, called Facilitated Communication, has frequently lead to alienation of children with ASD from their families based on alleged communications of abuses by parents.

The UN recognized the specific challenges faced by persons with ASD and their families by promoting the celebration of the World Autism Awareness Day¹ and by adopting a specific Resolution² to address the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders.

The development of a comprehensive campaign is needed to raise awareness on the fighting the particular stigma and prejudice against persons with ASD in Europe and on

¹ UN Resolution "62/139. World Autism Awareness Day"; adopted by the General Assembly on 18 December 2007

² UN Resolution « Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders and other developmental disorders”, adopted by the General Assembly on 5 December 2012.

addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders.

5. Article 11, Situations of risk and humanitarian emergencies (Questions 15 and 17, List of Issues).

Please explain how the Directorate-General for Humanitarian Aid and Civil Protection (ECHO) ensure that humanitarian aid and relief from the EU are inclusive of and accessible to all persons with disabilities. In particular, please provide information about refugees with disabilities in the European Union.

Please clarify whether there are protocols in place for the protection of all persons with disabilities, including those with communication difficulties, in the event of a natural disaster or in other situations of risk or humanitarian emergencies. If so, to what extent have persons with disabilities and their representative organizations been actively participating in all steps and procedures of them?

Because of their major communication and orientation problems persons with ASD who need intense support are particularly exposed to high risk in emergency situation. Most EU emergency services remain accessible only by using voice, with the result that millions of citizens, such as persons with ASD and major global communication impairments are excluded from life-saving services. The most disabled ones can even actively oppose to evacuation because of their unawareness of danger and resistance to change.

EU civil protection policy and programmes should specifically include ASD in a structured way to ensure that emergency services, including the '112' single European emergency phone number, are accessible for all persons with ASD and other major communication difficulties. EU guideline should be elaborated to ensure that appropriate civil protection protocols are adopted to protect persons with ASD in emergency situations in the respect of their rights and dignity. Specific indicators monitoring the inclusion of persons with ASD should be applied to the outcomes of EU funded civil protection projects. The representative organisations of persons with ASD should be involved in the development of these EU policies, indicators and protocols, as well as in the monitoring of funded projects.

6. Article 12, Equal recognition before the law, 14, Liberty and security of the person; and 15, Freedom from torture or cruel, inhuman or degrading treatment or punishment.

As noted by EDF, it is disappointing that the Committee has not asked any questions in the EU List of Issues on articles 12, 14 and 15 CRPD.

Many persons with ASD across EU countries, are under partial or full guardianship because of their difficulties to understand information and social rules, to communicate their wills and choices, to represent themselves, to sign or to express their consent in other

ways, to manage and adapt their behaviors to the social context. Persons with ASD whose legal capacity has been denied or limited are unable to enjoy and exercise their rights to take any decisions affecting their lives in any setting, including social, healthcare and habilitation services, on where and with whom to live and on treatments they receive through informed consent.

Because of the challenging behaviour they may exhibit or simply because abuses are unlikely to be reported, persons with ASD in Europe are at higher risk of incidences of cruel and inhuman treatments, violence and abuse in segregating or even mainstream services. Abuses against children and adults with ASD may also occur in families that are not properly informed, trained and supported.

In some EU countries treatments violating the right to liberty are regularly applied to persons with ASD on the basis of actual or perceived disability and of disability-based challenging behaviors, including involuntary detention in psychiatric hospitals and mandatory outpatient treatments. Segregating institutions regularly use physical or pharmacological constriction practices towards persons with ASD 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 challenging behaviours in the respect of the person's most basic rights.

7. Article 19: Living independently and being included in the community (Question 22, List of Issues).

Please explain how European funding, especially the European Structural and Investment Fund (ESIF), is used to ensure, protect and promote the inclusion of persons with disabilities in their local communities? How are representative organisations of persons with disabilities involved in the policy-making, implementation, monitoring and evaluation of the use of that funding?

8. Article 19, Living independently and being included in the community (Question 23, List of Issues).

In 2012, the European Union Agency for Fundamental Rights (FRA) published a report on the right to independent living. Please indicate what measures were taken to carry out the recommended "efforts on de-institutionalisation accompanied by reforms in the areas of education, healthcare, employment, culture and support services" (paragraph 106).

The institutionalisation of persons with ASD has been exacerbated by the austerity measures and indiscriminate cuts to social, educational and habilitation services adopted in EU MSs, increasing the shortage of suitable community – based living options and triggering a trend towards their conglomeration in large-size institutions. Lack of support, information and training to families on how to meet the specific and complex needs of children with ASD does not contribute to prevent their abandonment and institutionalisation, to promote their inclusion and participation in the community on an equal footing with other children.

EU policies should promote the harmonization of quality assessment systems of services for persons with ASD, adopting person-centered quality criteria in compliance with Article 19 CRPD. The EU should urge members States to adopt such quality systems and criteria and to develop CRPD compliant standards of services for persons with ASD.

The cross-border flow of French persons with ASD from France to Belgian services, in particular in the area of long-term care, relays on the shortage of community-based services in France. But it is also due to the prevalent adoption in France of approaches to ASD whose effectiveness in fostering the development of independence skills, inclusion and participation of people with autism have been disproved, against the will and preferences of families.

Measures should be taken at EU level to prevent member States using freedom of movement to undermine the right of persons with disabilities to live independently in their communities.

9. Article 24: Education (Questions 27 and 28, List of Issues).

Please indicate what concrete initiatives the European Union has taken to ensure that the funding instruments and the actions of Member states towards fulfilment of the education targets within the Europe 2020 Strategy promote inclusive quality education. In what way are representative organisations of persons with disabilities involved in the monitoring at EU and Member State level?

Please clarify whether there are disability specific indicators in the Europe 2020 strategy when pursuing the target on education.

Persons with ASD are still discriminated in the field of education across the EU, even compared with persons with other disabilities. Pupils and students with ASD, especially those in need of intense support are often excluded or do not have adequate access to education services. The financial crisis has negatively influenced efforts towards inclusive education. Budget restrictions in education are likely to place persons who need more support and accommodations to learn, such as persons with ASD, at a disadvantage and thus result in a difference in treatment, i.e. in an indirect discrimination based on disability. In some countries, Article 24 CRPD is used as a justification to cut funds to special schools without providing adequate funding to ensure appropriate support and accommodation to pupils and students with ASD in mainstream schools. Access of young persons and adults with autism to vocational training in EU countries is even lower than access to compulsory education or non-existent. The difficulties that adults with autism encounter when it comes to their occupational integration are linked to gaps in their occupational skills deriving from a significant lack of proper education and vocational training. An indicator on access to education for persons with ASD should be included in the EU economic strategy to develop specific measures to address the gap between

students with ASD and other students, and to develop adequate responses to their specific educational needs.

Autism spectrum disorders present unique educational needs that are qualitatively different from other special needs and require specific understanding and approaches to meet them³. For them the effectiveness of education is challenged by lack of competences of teachers on educational strategies to meet their major learning difficulties. Lack of training on autism of school staff indirectly disadvantages persons with ASD and therefore constitutes a discrimination.

Comparable data disaggregated by disability and statistics should be collected across EU countries in order monitor the access to all level of education of children and adults with ASD. The EU should develop common standards on the qualification of support teachers and assistants for pupils and students with ASD, including sound skills on teaching and communication strategies for persons with ASD. The EU should urge member States to undertake specific initiatives to reduce school dropout of students with ASD and to promote their inclusive education through the use of ESF, including to enhance the competences of school staff on special education and communication needs of pupils and students with ASD.

10. Article 25, Health (question 29, List of Issues).

Please explain how the European Union can prevent disability-based discrimination in health care service provision and ensure the training of the health care professionals on human rights of persons with disabilities, in the view of its' shared competences with the EU Member States in the field of health care.

Major social, communication and adaptive difficulties, frequent sensory abnormalities and challenging behaviours result in discrimination and exclusion of persons with ASD from general health care services and health promotion interventions compared with the general population and even with persons with other disabilities. The Directive 2011/24, on the application of patients' rights in cross-border healthcare, requires Member States to provide accessibility of hospitals for persons with disabilities. Nevertheless the Directive does not take into account the need of reasonable accommodation of medical settings, instruments and procedures to the specific needs of persons with ASD.

A majority of persons with ASD are not able to communicate pain or discomfort. Medical problems in these people may be manifested through challenging behaviours, and be misunderstood or mistreated. All these factors make it difficult to detect warning signs and to treat health problems in persons with ASD. Because of the lower quality of healthcare they receive, persons with ASD have a lower life expectancy.

³ 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)

Notwithstanding the evidence of the significant impact that early detection, diagnosis and intensive behavioural and educational intervention can make on long term outcomes for persons with ASD and their families, delays in diagnosis are very common across EU countries. The lack of adequate training for healthcare professionals and misconceptions about the health care needs of persons with ASD are also major barriers to access early diagnosis and timely intervention, as well as general health care services.

The European Commission has specifically included ASDs in its public-health work plans since 2005. Nevertheless, the EU should also promote the provision of reasonable accommodation in the health care facilities, including individual support during hospitalisation, as well as the availability of skilled health professionals to identify the unusual manifestations of pain or illness in persons with ASD and to ensure the access to early diagnosis and timely intervention services to all children with ASD across the EU.

11. Article 26: Habilitation and rehabilitation (Question 30, List of issues)

Please explain what measures the European Union can take to ensure equal access to habilitation and rehabilitation services for nationals of an EU Member State who are persons with disabilities, after they have moved to another Member State.

EU law prohibits discrimination in the provision of health care services only if based on racial or ethnic origin, or on gender. No regulation at EU level ensures equal access to habilitation and rehabilitation services across EU Member States. This lack of protection from inequalities in access to habilitation services across EU Member States is detrimental for persons with ASD, who require continuous and specific evidence-based strategies of social and communication habilitation programmes. Access to proper habilitation services for persons with ASD varies widely across EU countries. In many EU countries, only a minority of persons with ASD have access to proper habilitation programmes tailored to their specific and individual needs. All too often medication or pretended therapies based on unproven theories, or a combination of both, are offered instead of sound, evidence based habilitation programmes. Some countries arbitrarily limit the intensity and duration of habilitation programmes instead of admeasuring them to the individual needs. Other countries do not provide social and vocational habilitation programmes to persons with ASD or request a financial contribution to the person or his/her family relevant to cover the costs. Austerity measures have exacerbated the shortage of habilitation services for persons with ASD in some EU countries and/or enhanced the financial contribution requested to the person or his/her family.

In order to promote equal access to habilitation services for persons with ASD moving from an EU country to another, the EU should make use of its standardization processes to ensure the development of quality systems and criteria for habilitation/rehabilitation

programmes and services for persons with ASD, as well as to develop and adopt EU guidelines on evidence-based, rights-based intervention for ASD.

12. Article 27 – Work and employment (Questions 31 and 32, List of Issues).

Please provide precise data on amount of money invested in wage subsidies for workers with disabilities employed at the open labour market, in work place adaptations at the open labour market and in the hiring of work place assistants for workers with disabilities employed at the open labour market.

Please indicate what concrete steps the European Union has taken to ensure that persons with disabilities are prioritised in all EU policy-making and implementation on employment, such as the Europe 2020 strategy and the EU funding instruments, and that the effect is measured in a comparative way across the EU Member States?

At EU level, the employment rate of persons with ASD is significantly lower compared to people without disabilities or to people with other disabilities. Some 10% of persons with ASD have some form of work compared to 47,9% of persons with disabilities who are employed and to 71,5% of persons without disabilities. The Employment Equality Directive does not recognize the denial of reasonable accommodation as a form of discrimination and does not impose reasonable accommodations in vocational training facilities and traineeship programmes.

EU should aim at bridging the employment gap between persons with ASD and persons with other disabilities/without disabilities in the open labour market by adopting specific strategies and funding instruments to promote the employment of persons with ASD, as well as supported employment schemes.

13. Article 31, Statistics and data collection (Question 37, List of Issues).

Please indicate what steps the European Union and its competent institutions, including EUROSTAT (such as in EU-SILC), is taking to implement the Convention and its human rights based approach to disability in the collection of data in all fields of life

No central recording of ASD cases is available at EU level. The few epidemiological studies that have been conducted on ASD 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. In a European survey⁴, across eleven countries, representing more than 250 million inhabitants, only six out of eleven countries (Portugal, Scotland, France, England, Czech Republic and Denmark) stated that an ASD prevalence study of diagnosed ASD cases had been, or was currently being developed in their country. Denmark is the only country having an ASD national case registry.

⁴ European Autism Information System (EAIS) Report on the 'Autism Spectrum Disorders Prevalence Data and Accessibility to Services. Manuel Posada, Patricia Garcia Primo, Maria José Ferrari and Maria Concepción Martín-Arribas. Research Institute for Rare Diseases, Instituto de Salud Carlos III, Madrid. March 2007

Every country shows its own case ascertainment procedure and prevalence results. Diagnoses may be recorded in different ways, case finding methods vary from a country to another. A precise assessment of the current situation of ASD prevalence and trends concerning people with ASD across Europe is therefore not possible. Even less comparable data are available on discrimination of persons with ASD, violence, access to services and barriers to quality education, employment and participation in society.

Current available data collections at EU level are not disaggregated by type of disability. Often, data are collected via phone interviews or surveys which are not accessible for all persons with major communication problems, including persons with ASD.

The EU should carry out and promote collection and dissemination of reliable disaggregated data by disability status to provide information on the prevalence and situation of persons with ASD across the EU, including on barriers hindering the full enjoyment of their rights. Data gathering should be carried out in an accessible way for all children and adults with ASD.