

Alternative Report on the CRPD Implementation by the EU

CONTEXT

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

Autism-Europe (AE) is the European organisation gathering more than 30 National advocacy associations of persons with Autism Spectrum Disorders and parents of persons who need support to represent themselves across the EU and beyond. Autism spectrum disorder (ASD), also referred to as "autism", is a complex neurodevelopmental disorder. It is characterized by major and global deficits in social interaction and communication and the presence of repetitive behaviours. Autism has a childhood onset but persists into adolescence and adulthood, affecting the cognitive, emotional, educational and social attainments of persons affected, thereby bringing significant hardship to them and to their families. Autism symptoms vary in every person, ranging from mild to severe. Individuals with autism are significantly more likely to have intellectual disability and other mental and physical conditions than typically developing children. No data are available at EU level on the support needs of persons with ASD.¹

The mission of Autism-Europe is to ensure that the enjoyment of human rights by persons with Autism Spectrum Disorders, 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). This report has been written by the AE secretariat with the support of its representative at EDF and Executive Committee members, 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 UN CRPD Committee by providing more information on existing

¹ 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.

gaps in the CRPD implementation of the rights of persons with ASD by the European Union.

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

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. Persons with ASD are still discriminated against in many areas of life, even among persons with other disabilities. The austerity measures that have been adopted by EU Member States (MSs) to deal with the financial and economic crisis, including the shortage of appropriate and adequate services, support and reasonable accommodations to the particular needs of persons with ASD have enhanced their discrimination, dependency from others, poverty and social exclusion.

Article 1: Purpose

Autism spectrum Disorders (ASD) are lifelong developmental disability that affect the functioning of the brain, characterized by impairments in social interaction, problems with verbal and non-verbal communication and restricted, repetitive behaviour, interests and activities. Due to the complexity of the manifestation of ASD and lack of any known cure, persons with ASD require a multidimensional and multidisciplinary approach. The CRPD promotes and protects the human rights of all persons with disabilities, including all individuals with ASD. The **European Disability Strategy 2010-2020** is the EU instrument to empower people with disabilities so that they can fully enjoy their rights and participate in society on an equal basis with others, with actions in eight priority areas: accessibility, participation, equality, employment, education and training, social protection, health and external action. Nevertheless, there is no evidence of impact of the Strategy in the enjoyment of their human rights by persons with ASD at EU level. Persons with ASD continue to face the same or even more 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.

Because of the complexity of their needs the great majority of persons with ASD require qualified support and services to develop their potential and independence skills and to be

guaranteed their full enjoyment of human rights without discrimination. Nevertheless, the austerity measures that have been adopted by EU MSs to deal with the financial and economic crisis, including indiscriminate cuts to health care services, educational support and social services are hindering the enjoyment of human rights by persons with ASD by, inter alia, denying 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 increased dependency of adults with ASD from others in the long term. Lack of life-long appropriate behavioural and educational, intervention and of adequate support and services are enhancing their poverty and social exclusion. In some countries, austerity measures resulted in a trend towards blending community-based services in big-size, segregating services.

The EU 'Report on the implementation of the UN Convention on the Rights of Persons with Disabilities by the European Union' notes that EU law does not provide for a harmonised definition of disability and persons with disabilities, resulting in significant disability prevalence differences from a MS to another².

Disparities in criteria and definitions cause inequalities. Persons with ASD are particularly exposed to such inequalities, as EU Member States use varying criteria and different definitions of ASD. In some EU countries, ASD are even not recognised as a disability, notably in those countries where the medical approach to disabilities certification and access to benefits is prevalent.

Autism-Europe therefore strongly supports the EDF recommendations related to the implementation of the CRPD purpose, and calls on the EU:

- *to include in the Disability Strategy 2020, the need for a rights-based, evidence-based definition of ASD, as well as a recommendation to MSs to adopt such definition, as well as consequent strategies and concrete measures aimed at removing barriers hindering the full enjoyment of human rights by persons with ASD in any area covered by the Strategy.*
- *to issue a EU Recommendation to ensure that austerity measures and indiscriminate cuts are not applied to policies and actions which are essential for persons with ASD to enjoy the rights enshrined in the UN CRPD on an equal footing as others (including persons with other disabilities).*

Article 2: Definitions

Denial of reasonable accommodation constitutes discrimination.

² Statistical information on population of persons with disabilities in the EU. Data source: EU-SILC UDB 2011 and Eurostat (Eurobase).

As mentioned in the EDF alternative report, the European Court of Justice recognised that reasonable accommodation plays an essential role in combating disability based discrimination. This is particularly true for persons with ASD. Because of their particular way of communicating, functioning in a social context and perceiving sensory inputs, persons with ASD need reasonable accommodation in any setting where they live, study or work. Reasonable accommodations for them are a pre-condition for inclusion and participation. The denial of providing reasonable accommodation is however not defined as a form of discrimination in the 2000 Employment Equality Directive. Moreover, the denial of providing reasonable accommodation is defined in the employment field only.

It is therefore essential for persons with ASD that this form of discrimination is made explicit in the Directive and beyond the Directive, for increased compliance with Articles 2 and 5 CRPD.

Autism Europe therefore:

- *joins EDF recommendation to the EU to issue a Recommendation to Member States to interpret definition of denial of reasonable accommodation in the Employment Equality Directive 2000/78 in light of the CRPD, and therefore as a form of disability based discrimination.*
- *further recommends the EU to extend such interpretation of denial of reasonable accommodation to any area covered by the EU Disability Strategy, including education and health care settings, to meet the specific needs of persons with ASD, whose inclusion and participation depends on reasonable accommodations of the environment.*

Article 3: General principles

In its report the EU argues that the principle of non discrimination is enshrined in the Article 10 of the TFEU, which declares the EU aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation when defining and implementing its policies and activities.

Nevertheless the CRPD's general principles³ go far beyond the concept of non – discrimination. As noted in the EDF alternative report, the CRPD principles are not considered in any legislative initiative or specific actions taken by the European

³ General principles (Art. 3 CRPD) : Respect for inherent dignity, individual autonomy including the freedom to make one's own choices and independence of persons; Non-discrimination; Full and effective participation and inclusion in society; Respect for difference and acceptance of persons with disabilities human diversity and humanity; Equality of opportunity; Accessibility; Equality between men and women; Respect for the right of children with disabilities to preserve their identities

Commission. Moreover the diversity of disability or of other factors such as the level of the support needed are not taken into consideration, in contrast with the UN CRPD⁴.

Autism Europe therefore calls on the EU to ensure that new and existing EU legislation, regulation and policies:

- *are systematically harmonized with the UN CRPD, not only in the field of non-discrimination, but also in other areas, such as Education and health care, which are crucial for persons with ASD.*
- *protect the rights of persons with ASD or other disability with intense support needs.*

Article 4: General obligations

The existing EU law relating to the rights of persons with disabilities, and in particular the Employment Equality Directive and the EU package of Passenger Rights are not effective in protecting and promoting the rights of persons with ASD. For instance, the provision of reasonable accommodation in the Directive refers only to the work and vocational training environment, not to the educational environment. The scope of the directive is too restrictive to promote access to the labour market for people with ASD since without reasonable accommodation of educational settings and programmes, persons with ASD cannot obtain the qualification needed to access employment on equal footing with other people, including workers with other disabilities.

Moreover, there is a need to adapt the legal framework on standardisation of goods and services in order to extend its scope to standards for services, as the Directive 98/34/EC only applies to standards for products, and the Regulation on European Standardisation⁵ does not comply with the general obligations of CRPD towards persons with ASD. The primary objective of standardisation declared in the Regulation is the definition of voluntary technical or quality specifications with which current or future products, production processes or services may comply. Nevertheless, the Regulation specifies that the standards of services should be market-driven.

For persons with ASD appropriate services providing qualified, evidence-based, lifelong support are vital for achieving equal opportunities, inclusion and participation. Market-driven standards of services for persons with ASD cannot ensure the compliance of

⁴ Preamble, letter (J)

⁵ Regulation (EU) No 1025/2012 of the European Parliament and of the Council of 25 October 2012 on European standardisation, amending Council Directives 89/686/EEC and 93/15/EEC and Directives 94/9/EC, 94/25/EC, 95/16/EC, 97/23/EC, 98/34/EC, 2004/22/EC, 2007/23/EC, 2009/23/EC and 2009/105/EC of the European Parliament and of the Council and repealing Council Decision 87/95/EEC and Decision No 1673/2006/EC of the European Parliament and of the Council Text with EEA relevance

service systems with the CRPD obligations. Lack of EU standards for habilitation services triggers huge inequalities across EU countries, hindering the mobility of persons with ASD and their families across the EU. Common standards for services, including for staff qualification, which are driven by evidence of effectiveness in promoting inclusion and participation of persons with ASD, need to be established at EU level in consultation with representative organisations of persons with ASD.

Autism-Europe therefore supports the EDF recommendations related to the implementation of article 4 CRPD, and further recommends the EU:

- *to include persons with ASD and to ensure compliance with the UN CRPD when undertaking and funding training seminars for professionals and staff working with persons with disabilities in the EU;*
- *to reform the European Regulation on Standardisation in order to extend its scope to the Standardisation of services and staff qualifications according to a rights-based, evidence-based approach to ASD.*

Article 5: Equality and non-discrimination

As noted in the EDF report, 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).

The EU anti-discrimination legislation only addresses discrimination on the ground of disability in the field of employment and vocational training. Moreover, it does not protect persons with disabilities who need specific and intense support, including persons with ASD, even in employment and vocational training areas. The 2014 Commission report on the implementation of the Employment Equality Directive found that further efforts are needed to implement the Directive in practice, in particular through policy actions, awareness raising and training. These actions are crucial for persons with ASD to achieve equal access to employment on an equal footing with others, including persons with other disabilities. The adoption of a Directive which would extend this protection to other areas of life is therefore urgently needed.

Autism-Europe therefore supports the EDF recommendations on the implementation of article 5 CRPD; and further recommends the EU:

- *to adopt the proposed anti-discrimination Directive, as amended by the European Parliament, which aims to protect persons with disabilities, regardless of the level*

of support needed, against discrimination in social protection, health care and (re) habilitation, education, as well as access to and supply of goods and services;

- *to take specific account of persons with ASD and of their need for qualified and intense support and for reasonable accommodations when undertaking and funding training seminars for professionals and staff working with persons with ASD in the EU, for families of persons with ASD, for civil servants, private organisations, trade unions, equality bodies and ombudspersons.*

Article 7: Children with disabilities

The promotion of children's rights is an integral part of EU fundamental rights objectives set out by EU law. Children' rights are mentioned in Article 3 of the TFEU and Article 24 of the EU Fundamental Rights Charter.

Children with ASD are 4 to 10 times 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. Children with ASD 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 ASD across the EU do not enjoy equal opportunities to access to early diagnosis and intervention to prevent further disabilities (see article 25 in this report), as well as to adequate and appropriate support to education (see in this report article 24). In some EU countries children with ASD are subjected to unacceptable and harmful intervention practices (see articles 14-17 in this report).

The family is the natural environment for the growth and well-being of children, including children with ASD. Families of children with ASD 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.

Autism Europe supports the EDF report recommendations and further calls on the EU:

- *to take initiatives to ensure that the families of children with ASD receive the support and assistance they may need to rear their children at home and prevent institutionalisation;*
- *to develop and adopt guidelines on the prevention of abuses and bullying against children with ASD in segregating and mainstream settings;*

Article 8: Awareness-raising

Persons with ASD usually display unusual behaviours. Nevertheless ASD, unlike such disorders as Down syndrome, has no outward physical characteristics to signal that affected persons have a significant disability.

It makes persons with autism especially vulnerable to stigmatization, which hinders their inclusion and participation. Stigmatized people have less access to appropriate support and services, educational opportunities, paid jobs, and adequate health care.⁶ In some EU countries parents of persons with ASD are exposed to blame and prejudices stemming from the disproved “Refrigerator mother” theory. These prejudices or other disproved theories on ASD have engendered harmful treatments or neglect of the needs of persons with ASD, in contradiction with the existing national guidelines on intervention for ASD adopted in a number of EU countries.

ASD also occurs 4 times more frequently in boys than in girls. As a consequence, the particular features of ASD in girls can be misunderstood and their particular needs neglected.

The need to raise awareness of ASD has been recognised by the United Nations, which in December 2007 adopted a Resolution establishing the World Autism Awareness Day (WAAD).⁷ A coordinated multi-pronged approach that focuses on increasing awareness of governments on the need to provide persons with ASD of any age, appropriate and high quality services is recommended to meet the growing needs of individuals with ASD and their families.

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

Autism-Europe therefore supports the EDF recommendations on the implementation of article 8 CRPD; and further recommends the EU:

⁶ 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

⁷ 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.

- *to celebrate at EU level the World Autism Awareness Day every year on 2 April, and to encourage MSs to do the same in a co-ordinated way;*
- *to include awareness raising of the rights and needs of persons with ASD in light of the CRPD and of the UN resolution “Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders and other developmental disorders” (A/Res/ 67/L.33) in a Communication to EU institutions and to Member States calling for a commitment to include disability and its gender perspective, in all mainstream campaigns, key speeches and events of EU institutions’ leaders dealing with internal and external policies and the different EU funding programmes.*

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.

Global impairment of communication skills, and mainly of receptive communication, is a core feature of ASD, ranging from dumbness with incapacity to understand any form of communication to major difficulties in understanding abstract concepts, double sense words, jokes and paraphrases. Persons with ASD, even the most affected ones, can learn to communicate through training in alternative/augmentative communication modes and methods which are tailored to their individual needs and level of functioning. However verbal language and written texts remain the most inaccessible ways of communication to persons with ASD. As a consequence, most information, including on transport systems, services, urban environment and public buildings, are not accessible to persons with ASD, although such information are absolutely necessary to them because of their frequent sense of direction problems.

Official documents, including those related to the EU legislation, policies and measures impacting the lives of persons with ASD, are written in a jargon which is not accessible to persons with ASD, even to those with highest levels of functioning. Lack of accessible information hinders independence, decision-making, choice and freedom of movement of persons with ASD.

Potentially, the most important piece of legislation to explicitly tackle accessibility is the future European Accessibility Act (EAA), which is expected to cover the accessibility of a wide range of goods and services in the internal market of the EU. Accessibility requirements barely take into account the accessibility of information through standardized direction signs and signals in public transport and in public buildings and urban

environment, as well as the translation of relevant documents in easy-to-read/understand or other alternative-augmentative formats.

As for accessibility to information and communication, the Commission proposal for a Directive on the Accessibility of Public Sector Bodies' Websites addresses internet communication technologies only. Lack of information on EU policies presented in an accessible way challenges the efforts of DPOs representing persons with ASD and persons with other intellectual disabilities to involve self-advocates. It hinders their possibility to represent themselves and enhance their dependency on others.

Autism-Europe supports the EDF recommendations on the implementation of article 9, and further urges the EU to address accessibility of information and communication, through:

- *the adoption of standardized direction signs and signals in transport systems, public services and buildings in the forthcoming European Accessibility Act;*
- *the translation of relevant documents on EU legislation, policies and measures impacting the lives of persons with ASD in easy-to-understand formats;*
- *the inclusion of the same obligations to MSs at national level in the forthcoming Accessibility Act.*

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 and psychosocial disabilities are at high risk of human rights abuse, including violations of the right to life. There is a growing research-based consensus that institutionalization is an active source of harm and that 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. Persons with ASD are the most exposed to abuses in institutional and other settings because of challenging behaviours they may exhibit and because of their major and global communication difficulties, 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, even because of the misconception of their lives as "unworthy to be lived".

Moreover, persons with ASD or similar conditions remain significantly more subject to common health risk factors related to diet, weight and physical inactivity, as well as epilepsy, cerebral palsy, sensory impairment, mental health problems and challenging behaviour, resulting in significantly lower life expectancy overall⁸. 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, people with ASD tend to receive health care of lower quality that is not adapted to their needs and have a lower life expectancy. In 2008, Danish researchers found that the mortality risk among the autism population is twice as high as the general population.⁹ Children with autism have a significantly higher risk of falls, burn-related injuries and injuries from crashes.¹⁰

As a consequence, Autism-Europe strongly supports the EDF recommendations 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.

Autism- Europe further recommends the EU to raise awareness and promote training of health professionals:

- *on the general health care needs and on the particular manifestations of pain and discomfort of persons with ASD;*
- *on reasonable accommodations of health care premises and diagnostic instruments needed to ensure persons with ASD access to health care of the same quality as other people.*

Article 11: Risk and humanitarian emergency

As noted in the EDF report, the EU has competence to carry out activities and formulate a common policy in the area of humanitarian aid, within the framework of its External Action policy. 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

⁸ World Health Organisation - Europe : Better health, better lives: children and young people with intellectual disabilities and their families, 2010.

⁹ Svend Erik Mouridsen, Henrik Brønnum-Hansen, Bente Rich, Torben Isager: Mortality and causes of death in autism spectrum disorders. An update. Focus on Autism and Other Developmental Disabilities, Sage, 2011

¹⁰ Jane Pickett, Ellen Xiu, Roberto Tuchman, Geraldine Dawson, Clara Lajonchere, Mortality in Individuals With Autism, With and Without Epilepsy. Focus on Autism and Other Developmental Disabilities, Sage, 2011

include persons with disabilities in EU humanitarian policies and programmes, no data are available on the inclusion of persons with disabilities in EU-funded humanitarian aid projects.

With regard to civil protection, the EU missed the opportunity to include the needs of persons with disabilities in the European Union Civil Protection Mechanism in the field of civil protection, and in particular of persons with ASD. Because of their major communication and orientation problems, persons with ASD who need intense support are particularly exposed to high risk in emergency situation. The most disabled can even actively oppose to evacuation due to their unawareness of danger and resistance to change. For instance, a young man with ASD refused to leave his home, severely teetered after the earthquake at L'Aquila in 2012. A child with ASD opposed to escape from his burning home because he was fascinated by flames he provoked by playing with a lighter.

Autism-Europe supports the EDF recommendations concerning the inclusion of persons with disabilities in guidelines for the management of risk situations and monitoring through specific indicators, and further recommends:

- *to include understanding and management of autism behaviour in emergency situation in regular training on humanitarian aid and civil protection at the EU External Action Service and Commission.*
- *to establish standardized protocols and procedures to aid persons with ASD 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

As noted in the EDF report, the European Union 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, indirectly 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 persons with ASD, are often denied or restricted their legal capacity on the basis of disability. The majority of national legislations, policies and practices across EU MSs deny the recognition of legal capacity to persons with ASD and other severe intellectual or psychosocial disabilities and maintain them under

guardianship. Though some persons with ASD need intense support to be represented, substituted decision making regimes are not in line with the CRPD rights-based approach. Even the most advanced new legislations implementing the right to equal recognition before the law in the EU MSs include the concept of incapacity of persons with intellectual or psychosocial disabilities to take decisions. Few establish the duty to provide these persons the support they need to take informed decisions and to be represented, if needed, in the respect of their will and preferences.

Autism-Europe therefore supports the EDF recommendations and further recommends the EU to include in a future Communication to prohibit discrimination on the basis of disability and/or legal capacity status, in line with Article 12 CRPD, the recognition of the validity of any form of communication to express choices and decisions and the need to train supporters to decision making in the use of augmentative/alternative communication modes and methods which are used by persons with ASD.

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 into contact with a criminal justice system. Of relevance for persons with disabilities are the common minimum standards for procedural rights for victims of crime or persons suspected or accused of crime included in the EU Victims' Rights Directive (Article 22).

Because of their major and global communication difficulties, persons with ASD 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 the strange/unusual behaviour they often exhibit, persons with ASD or other similar conditions are deemed to be dangerous, though they are far more likely to be victims than perpetrators of violent crime¹¹. Because of stigma and prejudice they are subjected to indefinite detention and forced treatment. In addition, because of their important difficulties with communication persons with ASD and other similar conditions encounter major barriers to initiate any procedure, to report or even to recognize abuses and bullying, and to access to victim support services. Their testimonies are not taken in account because they are not credited as reliable persons or because they do not have access to verbal communication.

As the EDF report notes, the new EU 2014-2020 Fundamental Rights and Citizenship Programme includes actions to “prevent and combat all forms of violence against children, young people and women, as well as violence against other groups at risk”. However, this funding programme does not explicitly include the recognition of the high risk of abuses

¹¹ Appleby, et al., 2001

and crimes, and in particular of sexual abuses and robberies, which persons with ASD are particularly exposed to because of their major difficulties in understanding other people's intentions.

Autism-Europe therefore supports the EDF recommendations, and further stresses the need for:

- *ensuring the appropriate procedural accommodations needed at all stages of judicial proceedings to ensure effective participation of persons with ASD in the justice system, including meaningful and accessible communication, information, support and access to victims' support services;*
- *including appropriate capacity building programmes in education curricula of persons with ASD to recognize and report abuses and to access to justice;*
- *funding systematic training for the professionals working in the field of justice administration, including prison and policemen, on the alternative/augmentative communication modes used by persons with ASD and on the CRPD rights-based approach;*
- *combating stigma and prejudice on dangerousness and reliability of persons with ASD through awareness raising campaigns in collaboration with representative DPOs;*
- *banning or supporting an in-depth reform of Judicial Psychiatric Hospitals depriving the inmate persons of their most basic rights.*

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

As noted in the EDF alternative report, 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 persons with ASD. 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.

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 cruel and inhuman treatments, violence and abuse in segregating or even mainstream services. Abuses against children with ASD may also occur in families that are not properly supported and trained on ASD features and strategies to prevent abuses¹², or in families of adults with ASD that are left alone to face their increasing needs for independence and challenging behaviours resulting from forced inactivity and frustration.

Segregating institutions regularly use physical or pharmacological constriction practices towards persons with ASD and similar conditions¹³ 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.

In some EU countries treatments violating the integrity of children with ASD are being applied and recommended for children and adolescents with ASD, especially those showing associated challenging behaviours. The most known unethical therapy currently applied to children with ASD is the "Packing", which consists of wrapping the child in towels soaked in cold water, with the alleged goal to "allow the child to rid him/ herself progressively of its pathological defence mechanisms against archaic anxieties". It has been widely condemned by the international scientific community.¹⁴ Another example of unethical and dangerous treatment is the use of bleach enemas under false belief it will cure ASD.

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

Autism-Europe therefore strongly supports the EDF alternative report recommendations, and further recommends the EU

- *to adopt European guidelines on rights-based approaches for ASD to prevent inhuman and degrading treatments against persons with ASD ;*
- *to explicitly include in guidelines on treatment for ASD the need to train parents and other relatives living with persons with autism on evidence-based, rights-based*

¹² Code of good practice on prevention of violence against persons with autism, Autism-Europe, 1998

¹³ Cage beds: inhuman and degrading treatment in four EU accession countries. Budapest, Mental Disability Advocacy Centre, 2003.

¹⁴ Against *Le Packing*: A Consensus Statement, Journal of the American Academy of Child and Adolescent Psychiatry, vol. 50, Number 2, February 2011

strategies to prevent and manage challenging behaviours, in order to prevent involuntary abuses in families.

Article 18: Liberty of movement and nationality

EU citizenship gives the individual additional rights and protection, such as the right to vote and stand in EU elections and the right to free movement within the EU.

Autism-Europe shares the EDF concerns related to the need to properly support refugees with disabilities, and in particular persons with ASD, 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.

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

Autism-Europe therefore supports the EDF report recommendations and further urges the EU:

- *to revise the Directive 2004/38 to better comply with the obligations enshrined in Art. 18 CRPD and in the Preamble, letter (J);*
- *to ensure that persons with ASD can transfer their social protection and disability benefits to another Member State in order to exercise their freedom of movement.*

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.

Because of the high prevalence of ASD, of the complexity of their needs and of its impact on affected persons, their families and the society as a whole, coherent policies and measures would be needed at EU level to empower persons with ASD to live independently and participate in the community. Because, of the challenging behaviours they may exhibit and of prejudice on their capacity to live independently, persons with ASD, and in particular the most severely affected ones, are at higher risk of institutionalisation. Timely and ongoing access to appropriate and adequate individualized support is a precondition for 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 children with ASD does not contribute to prevent their institutionalisation.

EU funding instruments (e.g. European Structural and Investment Funds) can be used to promote transition from institutional to community-based services, in all the EU MSs. However institutionalisation of persons with ASD is a wide-spread phenomenon across the EU. The trend is growing in countries that are subjected to austerity measures and cuts to services. Indeed indiscriminate cuts to social, educational and habilitation services adopted in EU MSs increase the shortage of suitable community-based living options and triggers a trend towards their conglobation in large-size institutions. Even more alarmingly EU structural funds have sometimes been used to refurbish institutions where people with ASD are severely neglected.¹⁵

Moreover, the use of ESIF is not sufficient to promote the transition towards community-based services for persons with ASD. 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 persons with ASD to live independently with the adequate support.

In some EU countries, the support and care of adults with ASD is mainly based on delegation to families¹⁶. This approach leads to the isolation of the whole family and of the person with ASD at home, as well as to institutionalisation of adults with ASD in the long term, when families cannot face any more their evolving needs and independence wishes.

The phenomenon mentioned in the EDF report of the frequent placement of French persons with disabilities in Belgian services, in particular in the area of long-term care,

¹⁵ *EU Structural Funds Used to Maintain Institutions in Central and Eastern Europe*, By Eilionoir Flynn, in *Disability, EU & International*, 2011

¹⁶ 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

concerns mainly persons with ASD. French public authorities prefer to banish persons abroad than to create in France services that meet the needs, preferences and choice of persons with ASD and of their families, thus violating the right of persons with ASD to live included in their communities. On 21 December 2011, France and the Walloon Region signed a cross-border framework agreement on provision of services for French children and adults with disabilities in Belgium. By refusing to create and finance appropriate services in France, the state creates a discriminatory situation and breaches its non-discrimination obligation.

The cross-border flow from France to Belgium of children and adults with ASD, and their consequent alienation from their families and communities, relays not only on the shortage of community-based services in France, but even on the prevalent adoption in France of approaches to ASD whose effectiveness in fostering the development of independence skills, inclusion and participation has been disproved. In order to counteract the increasing trend to move children and adults with ASD to more qualified services with trained professional abroad, 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 outcomes for the beneficiaries in terms of inclusion, participation and choice is vital for persons with ASD, because of their major difficulties to report dissatisfaction and to express their preferences and choice. As noted by EDF in its report, the document adopted by the Social Protection Committee in 2010, establishing quality principles and criteria for social services, is not legally binding and not broadly implemented across EU countries.

Autism-Europe strongly supports the EDF report recommendations, and further recommends the EU to:

- *ensure equal opportunities for persons with ASD to develop their full individual potential and independence skills through equal access to quality support and services*
- *support and train families of children with ASD in their children's rights, needs and sound education strategies to empower parents and prevent their institutionalisation;*
- *address the specific needs of persons with ASD in the development of 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 persons with ASD to live in their community;*
- *include among quality criteria of care the support and training to families of children and adults with ASD.*

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.

Mobility is a significant area of restriction for persons with ASD. 63% of people with autism have a profound or severe mobility restriction and need help or supervision to move around. Restrictions to transfer social security benefits from Member States of origin when moving to a different EU Member State temporarily, difficulties in getting disability status recognised and additional bureaucratic burdens when moving to a different Member State permanently, affect particularly freedom of movement of persons with ASD within the EU, because of their needs of intense and qualified support to move around.

Disparities in ASD definitions across the EU MSs¹⁷ and their medical approach undermine the right to freedom of movement of persons with ASD and of families of children with ASD, as they determine inequalities in the recognition of disability-specific and individual needs of persons with ASD and in the provision of appropriate early intervention and quality services across the EU MSs.

Autism-Europe therefore supports the recommendations of the EDF report, and further recommends the EU:

- *to take steps to harmonise intervention protocols for children with ASD across the EU;*
- *to tackle inequalities related to intra-EU mobility, including the mutual recognition and provision of benefits, reasonable accommodation, individually tailored support, education and habilitation programmes which are absolutely needed by persons with ASD to be included and to participate in society.*

Article 21: Freedom of expression and opinion, and access to information

The EU has shared competences on consumer protection according to Article 169 of the TFEU. Information provision is one of the core rights under the 2011 Directive on Consumer Rights.

¹⁷ 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

Major and global communication difficulties of persons with ASD, 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.

Autism-Europe supports the EDF report recommendations to provide information in alternative formats to persons with disabilities, and to support the adoption of standardized signals and symbols across EU countries, as well as the diffusion of the use of easy-to-understand information.

Article 23: Respect for home and family

The EU has adopted Regulation 1259/2010 on divorce and legal separation, creating legal certainty for divorce and separation cases of couples residing in two different Member States. However, this Regulation fails to address the stigma, negative image and barriers that parents with disabilities face with regards to legal custody.

Parents of persons with ASD, and in particular mothers, are exposed to blame and prejudices stemming from the disproved “Refrigerator mother” theory, attributing to mothers the responsibility of triggering autism in their children. The persistence of prejudices based on “Refrigerator Mother” theory among general public and legal system professionals have detrimental effect on family life and on legal decisions in separation or divorce proceedings, which are frequently against mothers of children with disabilities, or deprive parents legal custody based on the presumption that they are unable to rear their children with ASD.

The use of Facilitated Communication (FC), a disproved approach that consists in physically assisting people with autism to communicate by supporting his/her hand or the arm as they type out messages on a keyboard or letterboard, has frequently lead to alienation of children with ASD from their families based on alleged communications of abuses by parents through this method, though a consistent number of research studies have demonstrated that the responses produced through this technique are controlled by the facilitators¹⁸.

Autism-Europe supports the EDF report recommendations and further recommends the EU to develop and broadly diffuse European guidelines on evidence-based, rights-based intervention for ASD, in order to overcome prejudices against parents and abuses stemming from disproved theories on ASD across EU countries

¹⁸ Jacobson, J. W., Mulick, J. A., & Schwartz, A. A. (1995). A history of facilitated communication: Science, pseudoscience, and atiscience. (Science Working Group on facilitated communication). *American Psychologist*, 50, 750-765

Article 24: Education

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

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 inclusion¹⁹, regardless of the nature and origin of their disability and irrespective of their age²⁰. Persons with ASD are still discriminated against in the field of education across the EU, as pupils and students with ASD, especially those in need of intense support are often excluded or do not have adequate access to education services.

In a European survey across 11 EU countries²¹, only 4 countries declared that all children with ASD participated in public education programs. In the rest of the countries, most children with ASD are trained at home (54%) and some also in social services and /or private therapies (27%). Most of the countries (81%) stated that they have an inclusion model among their SEN schooling systems. However among the 9 countries that stated they had inclusive education, 7 countries declared that they also had separate education systems (special schools and mainstream schools). The proportion of children with autism being educated in either mainstream or special schools in France is significantly lower than that of other children, whether or not having a disability²². In 2006 the Ministry of Education announced that 64% of children with autism in France received no form of schooling, a figure which has not been updated since. Less than 20% of children with autism had access to mainstream schooling in 2011-2012. Because of the lack of suitable places and facilities, the French state has helped to finance the schooling of children and adolescents with autism in specialized classes run by trained professionals in Belgium. This means that a number of children and adults with ASD are forced to leave France due to a lack of places. In 2011, France and the Walloon Region signed a cross-border

¹⁹ 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)

²⁰ European committee of social rights : Decision on the merits No. 13/2002 Autism-Europe v. France, 4 November 2003

²¹ 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

²² European committee of social rights : Decision on the merits No. 13/2002 Autism-Europe v. France, 4 November 2003

framework agreement on provision for French children and adults with disabilities in Belgium. By funding the schooling of children with autism in specialized classes in Belgium, run by trained professionals, and by refusing to create and finance such classes in France, the state creates a discriminatory situation in France and breaches its non-discrimination obligation.²³

Autism spectrum disorders present unique educational needs that are qualitatively different from other special needs and require specific understanding and approaches to meet them²⁴. For persons in need of intense educational support, such as persons with ASD, the effectiveness of education is jeopardized by the lack of competences of teachers on educational strategies to respond to their major learning difficulties. In Italy, where legislation does ensure the integration of all children and adolescents with disabilities in mainstream schools, by assigning to them a consistent support, the school staff concerned are usually not adequately trained. High turnover of support teachers and their frequent employment under precarious contracts do not ensure regular teaching nor consistent implementation of suitable teaching programmes. Lack of training in autism of school staff indirectly disadvantage persons with ASD and therefore constitutes discrimination.

It has been demonstrated that 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 adopting adequate legislation, policies and measures and without providing adequate funding to support the transition and to ensure appropriate support and accommodation to pupils and students with ASD in mainstream schools.

According to the UN CRPD, persons with disabilities must have access to all levels of education including life-long learning. Nevertheless, 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. As an example, even in Italy, where inclusion of children with disabilities is granted by law, among students with autism, only 6.7% have access to upper schools, and only 3.3% to vocational training

²³ European committee of social rights : Decision on the merits Complaint No. 81/2012. European Action of the Disabled (AEH) v. France. Adopted 11 September 2013

²⁴ 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)

Autism-Europe supports the EDF report recommendations, while stressing the need to pay specific attention to persons with ASD, because of the high level of support and of school staff competence they need. Moreover, AE recommends the EU to:

- *promote the use of ESF to fund the training of school staff on teaching and communication strategies for persons with ASD;*
- *monitor the access to education of pupils with ASD;*
- *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 children and adults with ASD;*
- *establish common standards on the qualification of support teachers and assistants for pupils and students with ASD.*

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. For the period 2010–2015, the European Disability Strategy included an action on promoting equal access to health care systems and raise disability awareness and specific knowledge among health professionals.

The EU has failed to give sufficient attention to the ASD perspective in its relevant health instruments. The 2011 European legislation on cross-border health care does not guarantee patients with ASD access to the same quality health care as their peers without disabilities or with other disabilities across the EU Member States, since it has failed to include the provision of reasonable accommodations and the training of health professionals to cope with general and specific health care needs of persons with ASD in health care systems.

Current national data show an ASD prevalence of 1/100²⁵, meaning that ASD occur more commonly than Down's syndrome, cystic fibrosis, and several childhood cancers. Based on current prevalence data, the United Nations²⁶ and the WHO²⁷ identified autism as an

²⁵ Denmark, Parner & coll., 2008, Sweden, Ferneel and Gillberg, 2010, UK, Baird & coll. 2006, Newschaffer CJ, Croen LA, Daniels J et al. The epidemiology of autism spectrum disorders. *Annu Rev Public Health.* 2007;28:235–58.

²⁶ 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

emerging public health issue which demands an immediate and organized response²⁸. To achieve the goals of increased awareness, early detection and intervention and better quality of life for people with ASD through their lifespan requires a coordinated approach. This approach should promote the delivery of immediate, tangible benefits to individuals with ASD and their families, while continuing to support broader systemic changes to enable sustainable solutions for the community.

There is no cure for autism, but research on the efficacy of early and intensive behavioural interventions suggests that developmental trajectories can be positively altered, particularly with respect to language and cognitive development^{29 30}. A growing body of evidence emphasizes that early detection of ASD, when followed by appropriate diagnosis and assessment and by intensive behavioural and educational intervention, can make a significant positive impact on long term outcomes for persons with ASD and their families. It is therefore important to identify and refer children with ASD as early as possible to Early Intervention Programmes. Nevertheless, delays in diagnosis of autism are very common across EU countries. An European study across 11 EU countries³¹ showed that the age at which diagnosis of autism is obtained varies depending on the subtype but the averages and most common answers are: 3-4 years old for AD (72%), 5-6 years old for AS (36%) and 3-5 years old for PDD-NOS. A survey conducted in Italy³² has shown that 45.9% of children with ASD obtain a diagnosis after 1 to 3 years after the first manifestations of the disorders, while 13.5% waited for the diagnosis more than 3 years.

The shortage of sound early diagnosis and intervention services deprives children with ASD of equal opportunities to develop their potential and to achieve social inclusion and participation in adulthood. Lack of early diagnosis and intervention services provided by

²⁷ 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.

²⁸ 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

²⁹ Warren, Z., McPheeters, M. L., Sathe, N., Foss-Feig, J., Glasser, A., & Veenstra- VanderWeele, J. (2011). A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics*, 127(5), e1303-e1311

³⁰ Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., Donaldson, A., and Varley, J. (2010). Randomized controlled trial of the early Start Denver Model, a developmental behavioral intervention for toddlers with autism: Effects on IQ, adaptive behavior, and autism diagnosis. *Pediatrics*, 125(1): 17-23.

³¹ 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

³² 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

public health systems and lack of knowledge and skills among health professionals^{33 34} can result in parents investing significant amounts of their own resources in ineffective interventions.³⁵ Some public health services in EU countries still adopt disproved treatments for children with ASD, sometimes violating their rights and dignity (see in this report Articles 14-17 and 23). A more wide-spread information and training of physicians and paediatricians on the early signs of ASD 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.

People with ASD across the EU still have unequal access to general health care services and health promotion interventions compared with the general population and even compared to persons with other disabilities, as well as unmet general and specific health care needs related to associated conditions (e.g., Angelman syndrome, fragile X syndrome, tuberous sclerosis, epilepsy) or to ageing, as persons with ASD have a greater risk of experiencing health problems as they get older. A majority of persons with ASD are not able to communicate pain or discomfort, making difficult to detect warning signs of medical problems. They can manifest them through challenging behaviours, that can be misunderstood or mistreated. Challenging behaviours can be exacerbated by sensory abnormalities, fear and anxiety that diagnostic and intervention procedures may induce in persons with ASD, interfering with the diagnosis and in some cases resulting in the provision of erroneous treatment.

Concrete measures are therefore needed to cope with the specific difficulties of persons with ASD 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 persons with ASD are vital to ensure equal access to healthcare to persons with ASD.

Autism-Europe supports the EDF report recommendations, and further calls on the EU to combat health inequalities towards persons with ASD across EU countries by:

- *facilitating equal access for persons with ASD across the EU to general health care, by developing and adopting guidelines on reasonable accommodations meeting the*

³³ Bakare MO, Ebigbo PO, Agomoh AO, Eaton J, Onyeama GM, Okonkwo KO, Onwukwe JU, Igwe MN, Orowigho AO, Aguocha CM. (2009) Knowledge about childhood autism and opinion among healthcare workers on availability of facilities and law caring for the needs and rights of children with childhood autism and other developmental disorders in Nigeria. *BMC Pediatr.* 9:12. doi: 10.1186/1471-2431-9-12.

³⁴ Daley TC, Sigman MD. (2002). Diagnostic conceptualization of autism among Indian psychiatrists, psychologists, and pediatricians. *J Autism Dev Disord.* 32(1):13-23

³⁵ Xiong N, Yang L, Yu Y, Hou J, Li J, Li Y, Liu H, Zhang Y, Jiao Z. (2011). Investigation of raising burden of children with autism, physical disability and mental disability in China. *Res Dev Disabil.* Jan-Feb;32(1):306-11. doi: 10.1016/j.ridd.2010.10.003.

specific needs of persons with ASD in healthcare services and facilities, including dental care, emergency and preventive services;

- *promoting common standards for early detection, diagnosis and interventions for ASD across the EU through the development and adoption of EU guidelines on gold-standard screening and diagnosis instruments and criteria as well as on sound intervention approaches across EU MSs;*
- *promoting the training on accessible communication and information forms and formats to persons with ASD in curricula of health professionals and staff, for facilitating the diagnosis of general health problems and ensuring informed consent to medical treatments*
- *recognizing ASD as a public health issue and undertaking a commitment to action in order to provide a consequent and coordinated response across the EU.*

Article 26: Habilitation and rehabilitation

Habilitation and rehabilitation services fall under the definition of social services of general interest (SSGIs). EU competence in the field of habilitation and rehabilitation is not clearly defined as in some cases it has supporting competences and in others it is shared with Member States.

For persons with ASD, 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 to persons with ASD appropriate habilitation programmes may correspond to mistreatment and result in many people becoming unnecessarily dependent.

As the social and communication impairments seen in ASD are biologically determined and persist throughout the lifespan, social and communication habilitation of persons with ASD require continuity and specific strategies.³⁶ Behavioural or cognitive-behavioural strategies are to date the only ones supported by scientific evidence to be effective in enhancing the capacity to learn, communicate and relate to others while reducing the severity and frequency of disruptive behaviours, and preventing the occurrence of additional disabilities, such as intellectual disability and challenging behaviours.

All too often across EU countries 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 fund and implement physical habilitation and rehabilitation programmes under

³⁶ National Institute of Mental Health – NIMH: Autism Spectrum Disorders, 2004

health system provisions, while they do not implement social and vocational habilitation services for persons with ASD or require to the person or his/her family relevant financial contribution to their costs. Many persons with ASD across EU countries do not have access to proper habilitation programmes tailored to their specific and individual needs. A survey conducted in Italy³⁷ has shown that 30% of persons with ASD do not have access to any habilitation programme.

Austerity measures have exacerbated the shortage of habilitation services for persons with ASD 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 persons with ASD and their families from moving across the EU.

The cost of autism over the lifespan has been estimated to 3.2 million dollars per person³⁸, 60% in adult services.³⁹ Timely access to social habilitation programmes is vital to the growth and development of the individuals with ASD, improving their opportunities to participate in the community, reducing the level of support needed later in life and the cost of lifelong care by 2/3⁴⁰.

Autism-Europe supports the EDF report recommendations and further calls on the EU:

- *to promote and support, including through the use of ESIF, compulsory training on specific and evidence-based habilitation strategies for ASD, as well as on ethical issues in the curricula of all the habilitation professionals; .*
- *to develop minimum quality standards for habilitation and rehabilitation services and programmes for persons ASD of any age;*
- *to develop and adopt EU guidelines on evidence-based, rights-based intervention for ASD, based on existing guidelines at national and international level;*
- *to 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.*

³⁷ 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

³⁸ Arch Pediatric Adolesc Med. 2007;161:343-349: The Lifetime Distribution of the Incremental Societal Costs of Autism. Michael L. Ganz, Harvard University School of Public Health Department of Society, Human Development, and Health 677 Huntington Avenue Boston, MA 02115

³⁹ Autism Society estimate

⁴⁰ Government Accounting Office Report on Autism 2007

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 persons with ASD by the Directive is poor, because reasonable accommodation is not provided in workplaces and vocational training.

Failure to impose the application of reasonable accommodation to educational facilities and services challenges the opportunities of persons with ASD to acquire job qualifications, thus excluding them from the labour market. 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.

The European Union Statistics on Income and Living Conditions 2012 (EU-SILC) does not provide disaggregated data by disability. However, some national survey shows that ASD is an important factor affecting employment rates of persons affected and their families. In the UK, only 15% of people with autism are in full time employment.⁴¹ According to a survey conducted in Italy⁴², 10% only of adults with ASD 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 in the EU SILC 1012. The same survey shows that 26% of mothers of children with severe ASD lost their job (compared to 0.6% of fathers), while 27.1% reduced their work time (compared to 10.5% of fathers). ASD 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”.

Young people with ASD are even disregarded by the Recommendation of the Council of the European Union for quality of traineeship in the EU, as accessibility and reasonable accommodation are not included among the criteria to provide a high quality traineeship programme in the EU.

Autism-Europe supports the EDF report recommendations, and further call on the EU:

- *to monitor the employment, unemployment and inactivity rates of persons with ASD , and their access to vocational training programmes and traineeship opportunities;*
- *to support awareness raising campaigns among employers and trade unions on needs of adjustments, abilities and potential of persons with ASD to work;*

⁴¹ Source : National Austistic Society (UK)

⁴² 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

- *to promote training of employment services to enable them to match employment opportunities and work environments with the individual and particular skills and needs of persons with ASD.*

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 persons with ASD from enjoying them.

As an example, according to an Italian survey, 50% adults with ASD 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 ⁴³. The need for support and assistance of persons with ASD has been evaluated in 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 persons with ASD have therefore additional parenting and assistance costs. The higher assistance burden has a strong impact on work and career opportunities and income of relatives living with persons with ASD. 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 persons with ASD and their families.

Autism Europe supports the EDF recommendations of EDF report and further recommends

- *to include in the EU-SILC data collection disaggregated data by disability, taking into consideration the intense needs for support and assistance of persons with ASD and the enhanced risk of poverty of their families, even compared to families of persons with other disabilities and milder support needs;*
- *to develop and adopt poverty reduction programmes and measures for persons with ASD and their families.*

⁴³ Censis: La dimensione nascosta delle disabilità, 3° rapporto di ricerca, 2012

Article 29: Participation in political and public life

In the majority of EU Member States, the deprivation of legal capacity of citizens with disabilities results in losing their right to vote. Only in a minority of countries, persons deprived of legal capacity are not deprived of their right to vote. However, for the large majority of persons with ASD, election campaigns, information materials, voting procedures and voting ballots are not accessible because of their communication impairment and learning difficulties, so that they cannot enjoy their right to vote regardless of legal incapacitation.

As noted by EDF in its report, 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 persons with ASD are missing.

Autism Europe supports the EDF report recommendations, in particular concerning the adoption of a Recommendation to Member States on the right of European citizens with disabilities to vote, and calls on the EU to take in due account the need for accessible communication, voting procedures and ballots, as well as the need of support in voting of persons with ASD.

Article 30: Participation in cultural life, recreation, leisure and sport

The EU has supporting competences in the area of culture, tourism and sport and plays a significant role via its funding programmes, such as the Erasmus plus.

Access to sport activities in the mainstream is crucial to persons with ASD 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. As noted by EDF in its report, the EU funded Special Olympics & Youth Paralympics are positive initiatives but they do not allow inclusion of persons with ASD in mainstream sport activities. Persons with ASD 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 ASD communication needs, behaviour features and management strategies should be available in the mainstream sport facilities.

Autism-Europe supports the EDF report recommendations and further calls on the EU:

- *to promote training on ASD in the curriculum of sport trainers and coaches;*
- *to include the participation of persons with ASD in mainstream sport activities as a*

priority in EU funded relevant programmes, in particular Erasmus plus.

Article 31: Statistics and data collection

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

Available data on prevalence of ASD are even more limited and less reliable than those on disability. 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 survey⁴⁴, 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 has been, or was currently being developed in their country. Denmark is the only country having an ASD national case registry.

Every country shows its own case ascertainment procedure and prevalence results, which indicates the need for a common framework in Europe. Diagnoses may be recorded in different ways in case notes and centralised data collections, and diagnostic terms are used in different ways. Moreover in epidemiological studies of prevalence of ASD, case finding methods vary. 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.

Prevalence of ASD as a combined group is substantially greater than previously recognised, for example, a study carried out in Denmark showed a statistically significant increase in cumulative incidence of reported ASD diagnoses across specific birth years⁴⁵ but reasons for this observed pattern is still unknown. ASD prevalence is generally accepted as ranging from 45 to 67 cases per 10,000 but the most recent papers show an increase in prevalence estimates raising figures of up to 116.1 cases per 10,000 children⁴⁶. This variability may be due either to methodological factors (Medical Research Council, 2001) or to real differences, which is challenging to disentangle since ASD are defined by patterns of behaviours.

⁴⁴ 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

⁴⁵ Atladóttir HO et al, 2007

⁴⁶ Kuehn BM, 2007, Rice CE et al, 2007, Van Naarden Braun K et al, 2007, Baird G. et al.2006

Parallel to the growing prevalence of ASD is its cost to individuals, families and society. Because of the high prevalence of ASD and of its impact on affected persons, their families and the society as a whole, coherent policies and measures would be needed at EU level to empower persons with ASD to live independently and participate in the community.

In February 2005, the European Commission for Health and Consumer Protection Directorate-General stated the following conclusions on ASD:

- the EU lacks good data to test hypotheses on secular changes in the incidence of autism. Because of specific methodological limitations, the high prevalence rates reported in recent autism surveys in the EU and in the USA cannot be used to derive absolute conclusions on this issue.
- An ASD response policy is necessary in the EU.
- More complex monitoring systems than those currently in place are needed to address the issue of changes in the prevalence of ASD.

Autism-Europe supports the EDF report recommendations, and calls on the EU and EUROSTAT:

- *to standardize diagnostic definition and record of ASD, as well as case finding and data collection methods,*
- *to collect disaggregated data by disability, including on persons with ASD, based on a common definition and record of ASD;*
- *to encourage Member States to do so;*
- *to fund initiatives at EU level to collect reliable data on and monitor the prevalence of ASD.*