IMPLEMENTING UN CRPD FOR THE AUTISM SPECTRUM CONDITIONS

Warsaw, 22 September 2016
Wroclaw, 23 September 2016
What is Autism-Europe?

Autism-Europe is an international association. We aim to advance the rights of people on the autism spectrum and their families and to help them improve their quality of life.

Autism-Europe brings together over 80 autism associations and hundreds individual members in more than 30 European countries, as well as governments and European and international institutions.
What is Autism-Europe?

Autism-Europe has established a structured dialogue with the European Institutions and is also active towards the World Health Organisation (WHO).

Autism-Europe enjoys NGO participative status with the Council of Europe and, in July 2002, lodged a collective complaint with the European Committee of Social Rights, becoming the first disability NGO to undertake such action.

To maximise its impact on European Union policies, Autism-Europe also works in strategic alliances with other relevant organisations. Autism-Europe is a founding member of several international umbrella NGOs active in disability and social protection such as:

- the European Disability Forum (EDF) of which it holds the Vice-Presidency,
- the World Autism Organization (WAO),
- the European Coalition for Community Living (ECCL) and
- the Platform of European Social NGOs.

In order to implement its objectives and maximise its impact on EU policies, Autism-Europe has built strategic alliances with European social partners.
World Autism Awareness Day (WAAD)

On December 18, 2007, the United Nations General Assembly adopted Resolution 62/139, tabled by the State of Qatar, which declares April 2 as World Autism Awareness Day (WAAD) in perpetuity. This United Nations resolution is one of only three official disease-specific United Nations Days and will bring the world’s attention to autism spectrum, a condition present in tens of millions. The World Autism Awareness Day resolution encourages all Member States to take measures to raise awareness about autism spectrum throughout society and to encourage early diagnosis and early intervention. It further expresses deep concern at the high prevalence rate of autism spectrum among children in all regions of the world and the consequent developmental challenges.

European campaigns
Each year, Autism-Europe works together with our member organisations to conduct campaigns to raise awareness of autism spectrum and the rights of people on the autism spectrum across Europe.

Activities and events in Europe
Autism-Europe members organise a wide range of events and activities across Europe to mark World Autism Awareness Day each year.

http://www.autismeurope.org/activities/world-autism-awareness-day/
Thank you!

Thank you for your support in previous years, it's your participation that makes the difference!

Let's make it happen together!
European Union and UN CRPD

UN Convention on the Rights of Persons with Disabilities was ratified by the European Union in 2010, it is the first legally binding core international human rights instrument to which the EU is a party. Also ratified by all EU Member States, but Ireland.

It is the first treaty that allows for continuous national oversight of the human rights situation, differently from earlier UN human rights instruments.

In order to implement it, the EU adopted the Disability Strategy with 8 areas of priority:

- Accessibility
- Participation
- Equality
- Employment
- education and training
- social protection
- Health
- External action
In 2012, the United Nations General Assembly unanimously adopted Resolution 67/82: "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities".

WHO resolution on autism
In May 2014 the 67th World Health Assembly adopted a resolution on “Comprehensive and Coordinated Efforts for the Management of Autism” (WHA67.8).

The resolution makes a call to “develop or update and implement relevant policies, legislation, and multi-sectorial plans, supported by sufficient human, financial and technical resources to address issues related to autism” (para 1.2)

Policy context

European Parliament Written Declaration on Autism

In September **2015**, the European Parliament officially adopted the Written Declaration on Autism, co-signed by **418** Members of the European Parliament (MEPs).

The document calls on the European Union and its Member States to adopt a European strategy for Autism.

Policy context

European Accessibility Act

Published by the Commission on the 2 December 2015.

Autism-Europe’s position paper highlights the need for the Act to present clear and precise accessibility criteria for persons with disabilities, including autism spectrum.

Detailed requirements are necessary for the legislation to be properly transposed by the member states and to ensure efficient harmonisation of accessibility of goods and services throughout the EU.

It followed on from recommendations given to the EU by the United Nations Committee on the Rights of Persons with Disabilities to swiftly adopt the European Accessibility Act with the participation of people with disabilities.

**Autism Spectrum Disorders in Europe** is a new, trans-European programme involving university, charities and expert institutions to increase understanding of autism spectrum.

In ASDEU, Autism-Europe is responsible for:
- **assessing** health, education and existing social policies in Member States to support people on the autism spectrum from all ages, communities and affected families.
- developing a **public health plan** addressing autism.

**Common challenges** across many countries of the European Union were reflected in the literature review that was conducted, consultation and responses to the survey:

- Late or inadequate diagnosis
- Poor access to interventions
- Lack of proper lifelong education and vocational training opportunities
- Lack of social habilitation
- Lack of access to employment
- Social exclusion
- Lack of awareness

[http://asdeu.eu/](http://asdeu.eu/)
The ratification of the UNCRPD by the EU and all but one Member State (Ireland) has had an impact on autism service provision:

- Slow but gradual **de-institutionalisation** is taking place across the EU;
- In almost all Member States there is evidence of increasing inclusion of children with disabilities in **mainstream educational settings**;
- Measures to assist disabled people in accessing the **labour market** seen throughout the EU, but **implementation uncertain**.

Mapping of autism policies in the European Union

- Over the last decade, some countries and regions have adopted autism-specific policies. It varies from single policies to all-encompassing **national autism plans or strategies**;
- Currently some Member States have national autism plan or strategies and some have **autism-specific legislations** (France, the UK, Hungary and Denmark, Italy and Ireland). Two countries are currently developing strategy or legislation (Spain and Malta);
- In other countries, autism-recommendations are implemented via more mainstreamed instruments.

www.asdeu.eu
ASDEU – Conclusions

Research and consultation show that autism strategies having a positive impact have the following characteristics:

- Practical approach: identification of the specific needs of people concerned (children, young people, adults on the autism spectrum, but also families and carers).
- Thus designed in close partnership with autism organisations, and generally after public consultation.
- Flexibility to allow for revision without recurring to formal procedures
- Requirements for on-going monitoring
- Direction and co-ordination of services at national and regional levels
- Adequate public funding for their implementation.

ASDEU next steps
- To enhance consultation throughout the next phases of ASDEU WP4 implementation, with interested stakeholders
- To identify what common gaps and needs across Europe can be best addressed at the EU level (European added value)
- Prepare policy recommendations for a public health plan for autism to be addressed to the European commission

www.asdeu.eu
Celebrating 10 Years of the Convention on the Rights of Persons with Disabilities

The Convention’s aim is to “protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”

The UN Committee on the Rights of Persons with Disabilities monitors how countries that have ratified the Convention are doing by reviewing them regularly and issuing concrete recommendations on how violations can be tackled and rights upheld.

http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPD10.aspx
Convention on the Rights of Persons with Disabilities
Last Updated: 26 Aug 2016

Country Status
- State Party (166)
- Signatory (21)
- No Action (11)

Definition and meta-data: http://www.ohchr.org/Documents/issues/HRIndicators/MetadataRatificationStatus.pdf
For application of treaties to overseas, non-self-governing and other territories, shown here in grey, see https://treaties.un.org

Note: The boundaries and the names shown and the designations used on these maps do not imply official endorsement or acceptance by the United Nations. Final boundary between the Republic of Sudan and the Republic of South Sudan has not yet been determined. Dotted line represents approximately the Line of Control in Jammu and Kashmir agreed upon by India and Pakistan. The final status of Jammu and Kashmir has not yet been agreed upon by the parties.
Optional Protocol to the Convention on the Rights of Persons with Disabilities

Last Updated: 26 Aug 2016

Country Status

State Party (88)
Signatory (20)
No Action (81)

Definition and meta-data: [http://www.ohchr.org/Documents/issues/HRIindicators/MetadataRatificationStatus.pdf](http://www.ohchr.org/Documents/issues/HRIindicators/MetadataRatificationStatus.pdf)
Source: Database of the United Nations Office of Legal Affairs (OKA) [https://treaties.un.org](https://treaties.un.org)
For application of treaties to overseas, non-self-governing and other territories, shown here in grey, see [https://treaties.un.org](https://treaties.un.org)

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On 5 June 2014, the European Union published its first report on the implementation of the UN CRPD.

The report outlines adopted measures, but does not include an assessment of their actual implementation and of the budget available to do so. In this sense, it also lacks self-criticism.

The report presents a too strict view of the competences of the EU and of the actions in which the EU as a whole or the European Commission have been involved and have had impact on the rights of persons with disabilities.

The report does not address the diversity of persons with disabilities.

EU report on implementation

EDF Alternative report on implementation
Persons on the autism spectrum 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 on the autism spectrum have enhanced their discrimination, dependency from others, poverty and social exclusion.

The impact of CRPD

The CRPD monitoring process and the Committee’s concluding observations:

• give AE the opportunity to lobby for more support and better services for persons on the autism spectrum at EU level.

• call on all of us to undertake more efforts to improve the EU policies and actions that can have a concrete positive impact on the lives of persons with disabilities and their families.
General Comments on UN CRPD

General Comment No 1
Article 12: Equal recognition before the law (Adopted 11 April 2014)

General Comment No 2
Article 9: Accessibility (Adopted 11 April 2014)

General Comment No 3
Article 6: Women and girls with disabilities (Adopted 26 August 2016)

General Comment No 4
Article 24: Right to inclusive education (Adopted 26 August 2016)

http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx
General Comments No. 4

General comment No. 4 (2016) on Article 24: Right to inclusive education

“[…] persons with disabilities are now recognised under international law as right-holders, with a claim to the right to education without discrimination and on the basis of equal opportunities. […]”

2 [...]: Sustainable Development Goal (SDG) 4 also affirms inclusive quality and equitable education. […] only inclusive education can provide both quality education and social development for persons with disabilities, and a guarantee of universality and non-discrimination in the right to education.

3 [...] Many millions of persons with disabilities continue to be denied a right to education, and for many more, education is available only in settings where they are isolated from their peers and receive an inferior quality of provision.”

**Poland and CRPD**

**Convention** on the Rights of Persons with Disabilities signed by Poland on 30 Mar 2007 **ratified** on 25 Sep 2012.

Poland has **not yet signed or ratified the Optional Protocol of UN CRPD**.

By becoming parties to the Optional Protocol, States recognize the competence of the **Committee to receive complaints** from individuals alleging violations of any of the provisions of the Convention.

The Optional Protocol (art. 6) also provides the Committee with the opportunity to undertake **inquiries** if it receives reliable information indicating grave or systematic **violations** of the Convention in a particular State party.

Autism-Europe v. France, complaint No. 13/2002

Autism-Europe claimed that the failure to take the necessary steps to ensure the right to education of children and adults with autism resulted in violations of the right of persons with disabilities to independence, social integration and participation in the life of the community, the right of children and young persons to social, legal and economic protection and the prohibition on discrimination.

The Committee stated that the State did not conform with the Charter.

Self-advocacy

Self-advocacy

Self-advocacy is the **defence of their rights in first person** and refers to the civil rights movement of persons with disabilities, born from the larger civil rights movement of the '60s and '70s. People with disabilities have the right to take control of their lives, talking for themselves, they can always ask for the support of others.

Self-advocacy and UN CRPD

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall **closely consult with and actively involve persons with disabilities**, including children with disabilities, through their representative organizations.”

Article 4, paragraph 3 of the Convention on the Rights of Persons with Disabilities
"37. The Convention on the Rights of Persons with Disabilities has accelerated the process of establishing organizations of self-advocates with intellectual disabilities, of autistic persons and of other individuals who may need extensive support to express their positions.

Organizations of parents and relatives of persons requiring support have often played a role in providing such support and one can find organizations that include parents as well as self-advocates. The role of parents in such organizations should increasingly move towards the provision of support, with self-advocates in full control.

States need to ensure that the will and preferences of persons with disabilities themselves are given priority.[...]

The definition of neurodiversity was formulated by the Australian Judy Singer, published on New York Magazine in 1998.

It is the idea that we are all neurologically different, that people on the autism spectrum do not have a disease but rather a developmental profile with a different cognitive development and a delayed social/emotional development, a unique set of characteristics, which can manifest as difference, disability, or gifts/skills, from person to person and within the same person.

Each person has the right to develop in their own way and at their own pace, not on the basis of what the outside world considers necessary developmental steps attached to specific physical ages.

Person centred is one of the keys to helping people believe in themselves.
Autism-Europe is open to comprise members from the whole autism spectrum, including organizations led by self-advocates. Informal meetings among AE members and local self-advocates groups are conducted regularly.

In 2015 during an AE board meeting, self-advocates held a workshop "Involving self-advocates" on how to ensure that autism organizations are representative of the whole spectrum.


In 2016 one self-advocate was elected as the vice-president of AE and one AE full member has chosen to have a self-advocate represent them for all AE meetings and activities.

In some European countries organizations led exclusively by self-advocates already exist for many years.

Publications, activities, meetings and governing bodies of autism organizations have to be as accessible as possible by people from whole autism spectrum, implementing UN CRPD, fulfilling in practice disability movement historical right: "NOTHING ABOUT US WITHOUT US".
Malta

In May 2016 it became the first country to adopt an **autism acceptance law** to aim for **autism acceptance, not just awareness**, acknowledge the existence of **undiagnosed adults** on the autism spectrum, and promote research into **ageing** on the autism spectrum.

Provisions include:

- to create awareness raising initiatives for the general public
- to empower persons within the autism spectrum
- to maximize the potential for children and adults through their personal autonomy and active citizenship;
- to identify the socio-economic, psycho-educational and health needs of persons within the autism spectrum

Unfortunately, the **Act lacks** strong provisions with regard to **employment**, due to domestic political considerations.

An Autism Support State Plan and further regulations will set out the details.
Hungary
After autism national strategic plan they now have professional figures specifically trained about autism spectrum.
But it is still lacking quality of education and there are still special schools.

Italy
Law on the autism spectrum was approved in 2015, which places treatment for autism among the essential services provided by the Italian healthcare system. It also updates guidelines for prevention, diagnosis and care and promotes research in the field.
In Italy there is inclusive mainstream school for all but often there is lack of qualified personnel.

Belgium
Francophone Belgium adopts an Autism Plan, a common, proactive policy to improve the care and living conditions of all individuals concerned (children, adults, families etc.).
The main objective is to enable individualised and life-long support and ensure inclusion in society through four common lines of action:
1. An inventory of the lack of solutions for people on the autism spectrum or dependency needs
2. The screening and the diagnosis of disability
3. Information and awareness
4. Training
New mental health strategy for England announced

Development of a “care pathway” for autism which should help autistic people get a timely autism diagnosis and accessible mental health support.

Although autism is not a mental illness, many autistic people struggle with mental health problems, such as anxiety or depression, and rely on mental health services for support.

This is in large part in response to the National Autistic Society’s diagnosis campaign.

UN Special Rapporteurs call for an end to discrimination of people on the autism spectrum

Speaking ahead of World Autism Awareness Day in April 2015, United Nations human rights experts highlighted the need to end discrimination against people on the autism spectrum, and celebrate diversity.

In many countries people on the autism spectrum lack access to services which would support, on an equal basis with others, their right to health, education, employment, and living in the community.

When available, services are too often far from human rights friendly or evidence-based. Therefore, they asked for more accessible and inclusive services to be made available to people on the autism spectrum with urgency and on a global scale.

WHO's mental health action plan 2013-2020

“Globally, for instance, annual spending on mental health is less than US$ 2 per person and less than US$ 0.25 per person in low-income countries, with 67% of these financial resources allocated to stand-alone mental hospitals, despite their association with poor health outcomes and human rights violations.”
http://www.who.int/mental_health/publications/action_plan/en/

The Human Rights Committee, in its 2014 General Comment No. 35
"emphasizes […] the particular harms that may result in situations of involuntary hospitalization. States parties should make available adequate community-based or alternative social-care services for persons with psychosocial disabilities, in order to provide less restrictive alternatives to confinement. […] Any deprivation of liberty must […] be applied only as a measure of last resort and for the shortest appropriate period of time […]. The procedures should ensure respect for the views of the individual and ensure that any representative genuinely represents and defends the wishes and interests of the individual."
WHO's World Health Assembly in its autism resolution of May 2014 committed "to shift systematically the focus of care away from long-stay health facilities towards community-based, non-residential services".


The Working Group on Arbitrary Detention (WGAD), in 2015 reaffirms: "The denial of legal capacity of persons with disabilities and detention in institutions against their will, without their consent or with the consent of a substituted decision-maker constitutes arbitrary deprivation of liberty in violation of international law. [...] Persons with disabilities shall be provided with legal or other appropriate support [...] peer support mechanisms, so that individuals receiving services in mental health facilities or residential facilities of any kind may be informed about their rights and remedies under domestic and international law, including those contained in the present Basic Principles and Guidelines, and organizations may act on behalf of those detained against their will. [...]"

http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session30/Documents/A_HRC_30_37_ENG.docx
CONCLUDING COMMENTS

Equality and non-discrimination (art. 5)
Issues: lack of qualified support as indirect discrimination
Solutions: need of equal treatment legislation and duty to provide reasonable accommodation

Children with disabilities (art. 7)
Issues: our children more likely to be victims of abuse, bullying, violence than other children
Solutions: to raise awareness and to develop support services in local communities for boys and girls using European Structural Investment Funds

Awareness raising (art. 8)
Issues: invisibility of autism and stigmatisation of persons and their parents
Solutions: to combat prejudice

Equal recognition before the law (art. 12)
Issues: denial of legal capacity on the basis of autism; lack of support in decision making and empowerment
Solutions: to ensure that all persons in autism spectrum deprived of their legal capacity can exercise all rights
CONCLUDING COMMENTS

Liberty & security, exploitation (art. 15-18)
Issues: to prohibit involuntary detention and treatment
Solutions: to include the disability perspective in EU policy on violence, abuse and exploitation

Living independently and being included in the community (art. 19)
Issues: social difficulties and challenging behaviours; need for intense and qualified support and empowerment
Solutions: de-institutionalisation, communities, co-housing; to monitor ESI Funds and to suspend them if there is violation of fundamental rights

Freedom of expression and opinion, and access to information (art. 21)
Issues: communication difficulties
Solutions: to provide information in accessible languages, formats and technologies, including easy-to-read-and-to-understand formats with pictures

Education (art. 24)
Issues: to provide quality education and social development simultaneously
Solutions: inclusive mainstream education by qualified personnel and peer support
CONCLUDING COMMENTS

Health (art. 25)
Issues: to ensure quality health care for all
Solutions: need of accessible information, reasonable accommodation; training of professionals

Work and employment (art. 27)
Issues: the most excluded from the labour market: 90% without employment
Solutions: to measure the employment and to increase employment rate in open labour market

Adequate standard of living and social protection (art. 28)
Issues: need for high level of support and assistance; unemployment and inactivity
Solutions: need to prevent effects of austerity measures on the adequate standard of living

Participation in cultural life, recreation, leisure and sport (art. 30)
Issues: lack of social interaction; exclusion from playing and activities
Solutions: inclusive sport, cultural and leisure activities