

Workpackage 4:

Towards a public health plan for autism

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Why an EU approach?



- **Common challenges** have been identified across Europe in relation to health and autism
- By working at the European level we can **foster cooperation and share good practices** to overcome these challenges.
- **Harmonisation in various fields** would help autistic people and their families to more easily exercise right to **free movement**.
- **Avoiding duplication** of projects and actions in relation to autism and **better use of existing resources**

Added value of action at EU level

- A strategy ensures a **global and coherent approach** to addressing a public health concern, by ensuring that action is taken in the **EU's areas of competence** to complement what is being done on a national level
- It enables the **branching into other policy areas**, beyond health, to complement the support offered to citizens
- Emphasis can be put on **funding joint research** and sharing **results across borders**. It also streamlines research by **avoiding repetition** and **highlighting gaps** that need to be researched further



Added value of a strategy at the EU-level

- A strategy in the area of health can develop **harmonisation** across EU Member States, and **benchmark minimum standards** for support and protection
- EU strategies can help assist Member States in developing their **own, complementary, national strategies**
- It provides a **platform for sharing good practices** throughout the EU



EU strategies in other areas of public health

Current EU Health Strategies

- The EU currently has public health strategies for **Cancer, Alzheimer's and dementia, mental health and rare diseases**
- The following are a list of key objectives and characteristics shared by the strategies and plans the EU has already embarked upon:



Common objectives and characteristics

- 1) **Reduce inequalities throughout Europe:** reducing the differences between the highest-performing Member States, and those facing the greatest difficulties. In the strategies, there is common emphasis on providing platforms for **sharing information, best practice, and benchmarking.**
- 2) **Branch into other policy areas:** A horizontal approach is underlined as necessary, bringing to light the importance of operating via policy areas other than health.



Common objectives and characteristics

3) Focusing on research: As well as offering funding opportunities, the strategies seek to **coordinate research approaches throughout the EU to avoid repetition**, as well as to **spot gaps in EU research and to try to fill them**. Importance is also typically given to research into biomarkers, allowing for earlier diagnosis.

4) Clearly identifying the prevalence of each condition in Europe, in order to give a more accurate picture of how many people are affected.



Common objectives and characteristics

5) Setting up working groups composed of different stakeholders: establish expert groups to offer advice to Member States and to assist them in improving their levels of care.

6) Understanding economic burden of conditions: in order to better understand how preventative or assistive programmes could have an economic as well as social benefit.

Common objectives and characteristics

7) Assisting Member States in developing national plans: As the plans typically span areas of competence held by Member States, the strategies encourage Member States to develop their own national strategies, created to work alongside and complement that existing at the EU level.

8) Launching pilot projects in Member States: The strategies typically foresee exploring various initiatives by launching pilot projects in various Member States to test different ideas before launching them on a wider scale.



Actions for autism at the EU level might therefore include:

- (1) **Encouraging Member States to adopt cross-sectoral national strategies** or action plans to respond to the needs of autistic people, in line with the UNCRPD and international recommendations;
- (2) **Promoting the coordination between Member States** of all relevant policies in the field of autism;
- (3) **Producing guidelines to harmonise practices** and promote quality of support care and inclusion across Europe;



Actions at the EU level might therefore include:

- (4) **Adopting principles of best practices** and fostering exchange between Member States;
- (5) **Promoting training of professionals** across sectors;
- (6) **Supporting research and networks of experts** and partnering for progress across the EU;
- (7) **Supporting and involving representative NGOs** throughout the process.



Specific recommendations for an EU autism health strategy

1) Screening and diagnosis

- Development and adoption of **EU guidelines on gold-standard screening and diagnosis instruments and criteria** across all EU Member States
- **Promote adequate screening and foster access to diagnosis**, including by promoting access to adequate resources to professionals .



2) Post-diagnosis support

- Developing and adopting **EU guidelines on evidence-based, rights-based intervention for autism**, based on existing guidelines at national and international levels;
- Foster **adoption of reasonable accommodation of health care premises (including somatic health, dental care, emergency and preventive services)** and diagnostic instruments needed to ensure persons with autism access to health care of the same quality as other people;
- Promoting the **training on autism needs and accessible communication in the curricula of health professionals** and other relevant staff



Access to inclusive adapted education

- Monitor the access to education of pupils with autism and **collect data and statistic across EU countries on their access to mainstream education**
- Promote **the use of EU Structural Funds to support the training of school staff on teaching;**
- Establish **common standards on the qualification of support teachers and assistants** for autistic pupils and students.
- **Developing and adopting guidelines on the prevention of abuses and bullying against children** with autism in segregating and mainstream settings;



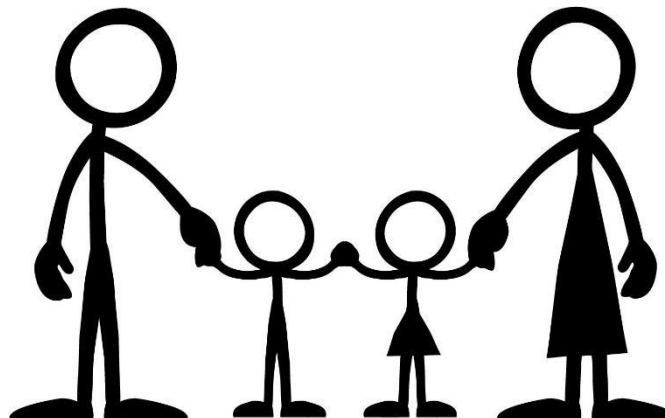
Access to individualised support and inclusion throughout the lifetime (including access to employment)

- Developing and adopting EU guidelines on evidence-based, rights-based interventions for autism, based on existing guidelines at national and international levels;
- Developing minimum quality standards for habilitation and rehabilitation services and programmes for autistic persons of any age in the EU;
- Adopting quality assessment systems for habilitation services which are centered on outcomes in terms of inclusion, participation and quality of life of the users;
- Promoting measures to foster the employment of autistic people.



Support for families

- EU initiatives to ensure that the families of autistic children receive the support and assistance they may need to raise their children at home and prevent institutionalisation;
- Explicitly include the need to train parents and other relatives in evidence-based, rights-based strategies in guidelines on treatment for autism, to prevent involuntary abuses by families.
- Support and train families in their children's rights, needs and sound education strategies to empower them



Training of professionals

- Adopting European guidelines on rights-based approaches for autism to prevent inhumane and degrading treatments against autistic people;
- Compulsory training on specific and evidence-based habilitation strategies for autism, as well as on ethical issues in the curricula of all the habilitation professionals;



Independent living and community-based services



- Promote access to quality support and services across the EU to render community living possible;
- development of a quality binding system, which complies with article 19 of the UN CRPD, in order to prevent Member States from using freedom of movement of persons, goods and services to undermine the right of persons with autism to live in their community;

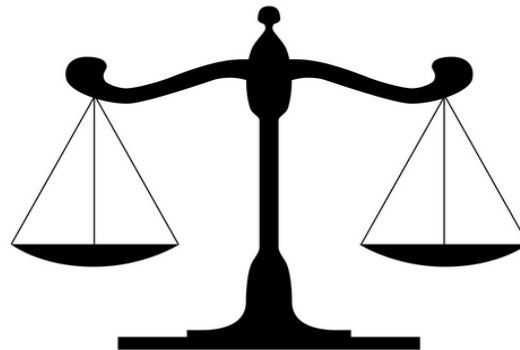
Empowerment of autistic people and their families

- Support representative organisations to promote their rights



Legal capacity and access to justice

- Promoting adoption of appropriate procedural accommodations needed at all stages of judicial proceedings to ensure effective participation of persons with autism, including meaningful and accessible communication, information, support and access to victims' support services;
- Promoting Member States to integrate appropriate capacity building programmes in education curricula of persons with autism to recognise and report abuses and to access justice;
- Funding systematic training for professionals working in the field of justice administration, including prison officers and policemen, on the alternative/augmentative communication modes used by persons with autism and on the CRPD rights-based approach;
- Banning or supporting an in-depth reform of Judicial Psychiatric Hospitals depriving autistic people of their most basic rights.



Research into autism

- Produce an up-to-date and comprehensive evaluation of the prevalence rate of autism in the EU
- Foster research that promotes a better quality of life of people on the autism spectrum



Awareness-Raising

- Celebrate World Autism Awareness Day (2 April) at the EU level every year and encourage MSs to do the same in a co-ordinated way;
- combat stigma and prejudice against autistic people through awareness raising campaigns in collaboration with representative DPOs;
- Include awareness raising of the rights and needs of autistic people in light of the CRPD in a Communication to EU institutions and to Member States.



**Is there support for such a
plan at the EU level?**

Towards a European Strategy

- The 67th World Health Assembly adopted a resolution on “Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders” (ASDs) on May 24th 2014.
- The resolution was cosponsored by more than 50 countries and supported by all.
- Resolution WHA67.8 on “autism” recommended to Member States “to develop or update and implement relevant policies, legislation, and multisectoral plans, supported by sufficient human, financial and technical resources to address issues related to ASD” (para 1.2)



Towards a European Strategy

In September 2015, the European Parliament officially adopted the **Written Declaration on Autism**.

The Written Declaration was launched by MEP Nicola Caputo from Italy, and was co-signed by 418 Members of the European Parliament (MEPs).



In 2015: the Written Declaration of the European Parliament on autism

○ The Written Declaration calls on the European Union and its Member States to adopt a **European strategy for autism** that will:

- Support **accurate detection and diagnosis** across Europe
- Promote **evidence-based treatment** and support for **all ages**
- Foster **research and prevalence studies**
- Encourage the **exchange of best practices**



Thanks for your listening

Aurélie Baranger

Director of Autism-Europe



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