Workpackage 4:
Assessment of Member States’ autism policies

29 January 2018
Madrid, Spain

WP4 – Task 4.2 Lead: Aurélie Baranger, Autism-Europe
Team: Haydn Hammersley, Autism-Europe
Project Coordinator: Manuel Posada de la Paz
Objectives of work package 4

Autism-Europe is responsible for the ASDEU work package 4 on autism policies in the EU. Its objectives are to:

- Assess health, education and existing social policies in Member States to support people with autism from all ages, communities and affected families.

To do this Autism-Europe produced a mapping through a literature review and a stakeholders consultation.

This document outlines the key policies at EU and national level to support autistic people and their families.

- Make recommendations for a public health plan on autism
Objectives of the mapping

- Identification of existing policies and the level of support in the European Union to respond to issues faced by autistic people and their families.
- Identification of gaps and challenges by surveying interested stakeholders.
- The core areas covered are: healthcare, education, access to employment and to lifelong support.
The **UN Convention on the Rights of Persons with Disabilities (UNCRPD)** – ratified by the EU and 27 EU member States - serves as a benchmark to assess the respect of the rights of people with autism.

- Countries reports submitted to the **UN Committee on the Rights of Persons with Disability** and alternative reports from civil society groups feeding into the UN monitoring process is part of the documents reviewed.

- At a later stage, **UNCRPD focal points** in the ministries of the member states were also contacted to provide feedback on the data reported.
Methodology of the mapping

- We conducted a literature review of reports on autism and disability policies.
- The majority of statistical data has been taken directly from reports by national experts operating within the Academic Network of European Disability Experts (ANED).
- It was also submitted to various autism organisations for review across the European Union.
Structure of the mapping

- It is set out as a reference document.
- It provides information on the existing policies and legal framework in the field of disability and autism at the EU level and beyond.
- There is a section dedicated to autism-specific strategies, legislation and policies in various Member States.
Structure of the mapping

- There is a section for each Member State about the legislation and policies relevant to autistic people into three areas: healthcare, education and access to employment.
Input from stakeholders

• The information specific to each country was sent to the UNCRPD designated national focal points (typically within national ministries) and to civil society groups in the Member States for their feedback.

• We received input from: Austria, Belgium, Croatia, Cyprus, the Czech Republic, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Luxembourg, Malta, Netherlands, Poland, Portugal, Slovenia, Spain, Sweden and the UK.
• Policies in the domain of autism are constantly evolving across the EU. During the course of our research, several significant policy developments happened throughout the EU Member States.

• For the document to remain as accurate as possible, it needs to be constantly updated.

• **Stakeholder involvement is essential** to alert us on new developments, and the state of play of implementation.
Current response to autism needs

- The current response to the needs of people with autism and their families across the European Union is very diverse.
- The policy and legislative frameworks in place to ensure the respect of autistic people’s rights and improve their quality of life are far from uniform.
- The ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) has had an impact on policy and autism service provision at national levels.
- One of the main impacts of the UNCRPD is the gradual deinstitutionalisation taking place across the continent, in line with Article 19.
In most Member States, there is evidence of increasing inclusion of children with disabilities in mainstream educational settings, as well as measures to assist disabled people in accessing the labour market.

But people on the autism spectrum tend to remain amongst the most excluded group, notably due to a lack of awareness about autism and the complexity of their support needs.
Over the last decade, to tackle existing challenges, 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 strategy or legislations

In other countries, autism-recommendations are implemented via more mainstreamed instruments.
Examples of strategies in Europe

**France (1st plan 2005)**
- The 3\(^{rd}\) Plan Autisme (2013-2017) focused on:
  - early detection and diagnosis
  - strengthening and adaptation of support on a lifelong basis
  - support for families
  - continued research
  - awareness raising and training
- the 4\(^{th}\) Plan aims to continue to diversify the supply of schooling for young autistic people

**WALES, UK (2008)**
- The Welsh strategy is often presented as a good example. It has a central focus on:
  - the development of adequate services
  - services designed on evidence of prevalence and needs
  - services integrated at the local, regional and national level
  - raising awareness
Examples of strategies in Europe

DENMARK (2008)
• Based on the respect of autistic people’s human rights, as enshrined in the CRPD
• Promotes the right to inclusion and participation in society through adequate services

HUNGARY (2008)
• Aims at improving the quality of life through:
  ➢ early screening and diagnosis
  ➢ adult training
  ➢ family support
• Particular focus on education and employment of autistic people
Examples of strategies in Europe

**SPAIN (2015)**
- Described as primarily seeking to improve:
  - diagnosis
  - support at different stages of a person’s life
  - inclusion, accessibility and autonomy

**MALTA (2017)**
- Malta’s new Act to Empower Persons within the Autism Spectrum’s key focus is:
  - improving health, wellbeing and living conditions of people on the autism spectrum
  - ensuring full adherence to the UNCRPD
For countries/regions with an autism plan/strategy, these seem to bring about a positive impact and change for people on the autism spectrum.

Even if they do not necessarily achieve all their objectives towards the full respect of the rights of people with autism.
Research and consultation show that autism strategies having a positive impact notably 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.
Wider stakeholders consultation
The mapping was completed by:

- Running a **stakeholder consultation** with our member organisations throughout Europe, by email and through focus groups

- Launching a supporting **online survey** for the wider autism community to let us know their life experiences, and priorities.
Online survey to assess the needs of the autism community

- Autism-Europe launched an electronic **survey** to complement the information obtained in the literature review.
- The results of the survey are placed in the annex of literature review.
- The survey indicates **how aware citizens are of the laws and policies in their country**, how affective they think they are, and whether they believe they are being implemented.
- The survey also asked respondents to identify gaps.
Assessing the needs in the EU

The online survey carried out by AE in 2016 was composed of 10 questions.

It was made available in 15 languages:

- English
- French
- Spanish
- German
- Italian
- Portuguese
- Dutch
- Polish
- Bulgarian
- Romanian
- Finnish
- Croatian
- Greek
- Hungarian
- Czech
In total **907 people from the European Union** replied to the survey.
Most of the respondents were parents of autistic people (56%).

This was followed by professionals (24%).

Autistic people made up 13% or respondents.
Priorities according the respondents:

- Access to diagnosis
- Access to education
- Access to healthcare
- Access to services
- Access to employment
- Access to justice
Initial survey conclusions

The last question allowed people in Europe to give feedback on what changes they want to see in their country.

Some of the most common replies:

- Need to *speed up diagnosis* in young children
- Need for *harmonised guidelines for diagnosis* in Europe.
- Need to *improve diagnosis of adults*
- Need for a specific contact person or a ‘One stop shop’ in all countries for any question related to autism
- Need for *uniform rules throughout different countries* to allow for freedom of movement.
- Need for *training* of General Practitioners, paediatricians and teachers.
Survey conclusions

People also mentioned the need for:

• Fostering employment and training, and offering reasonable accommodation
• Establishing more vocational schools for young people with autism
• Provide support for autonomy
• Improved care and access to care
ASDEU has received funding from the European Commission in the framework of the Health and Consumers, Directorate-General.
Thanks for your listening

Aurélie Baranger
Director of Autism-Europe