

Workpackage 4:

Assessment of Member States' autism policies

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With the support of
the European Union



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

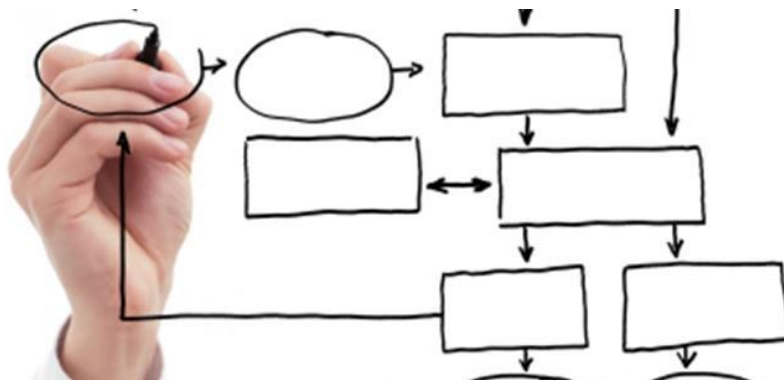
- Identification of **existing policies and the level of support** in the European Union **to respond to issues faced by autistic people** and their families
- Identification of **gaps and challenges by surveying interested stakeholders**
- The core areas covered are: healthcare, education, access to employment and to lifelong support.



Methodology of the mapping

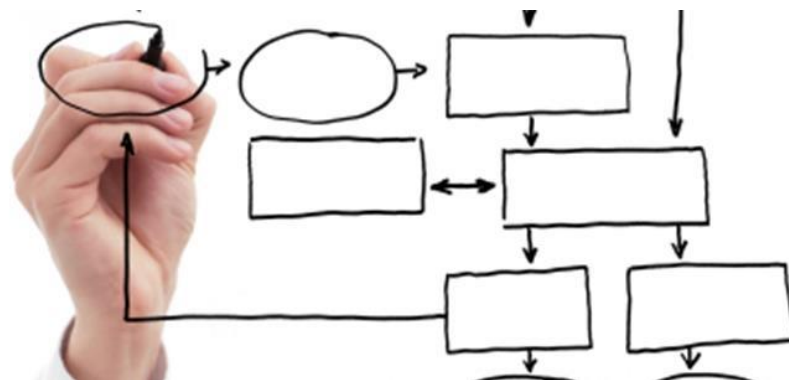
The **UN Convention on the Rights of Persons with Disabilities (UNCRPD)** – ratified by the EU and 27 EU member States - serves as a benchmark to assess the respect of the rights of people with autism.

- 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.



Current response to autism needs

- 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.

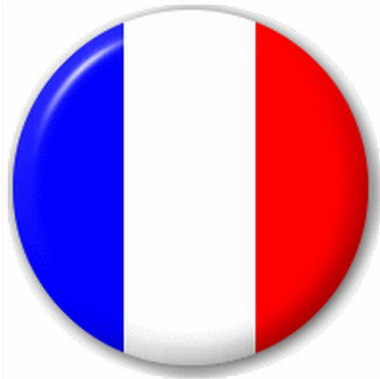


Autism strategies across the EU

- 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 3rd 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 4th 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)

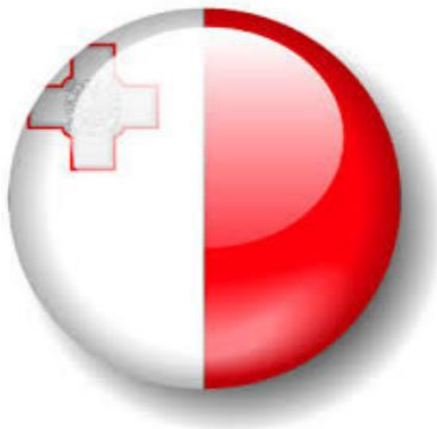
- Aims at improving the quality of life through:
 - early screening and diagnosis
 - adult training
 - family support
- Particular focus on education and employment of autistic people



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

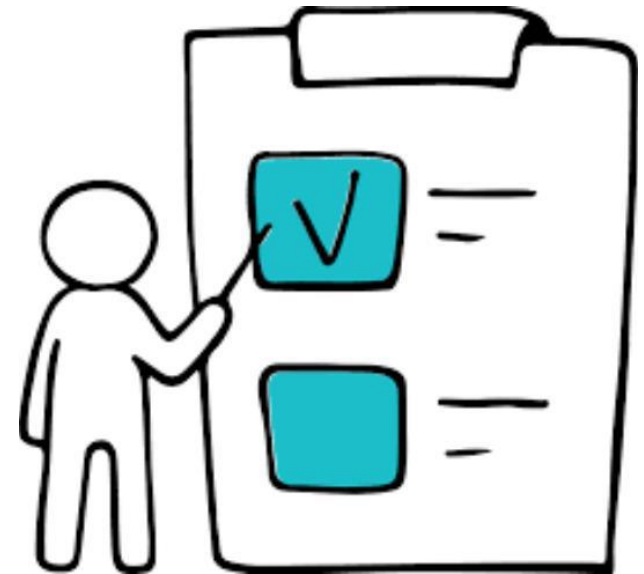


MALTA (2017)

- 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

Initial conclusions on autism strategies

- 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

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:

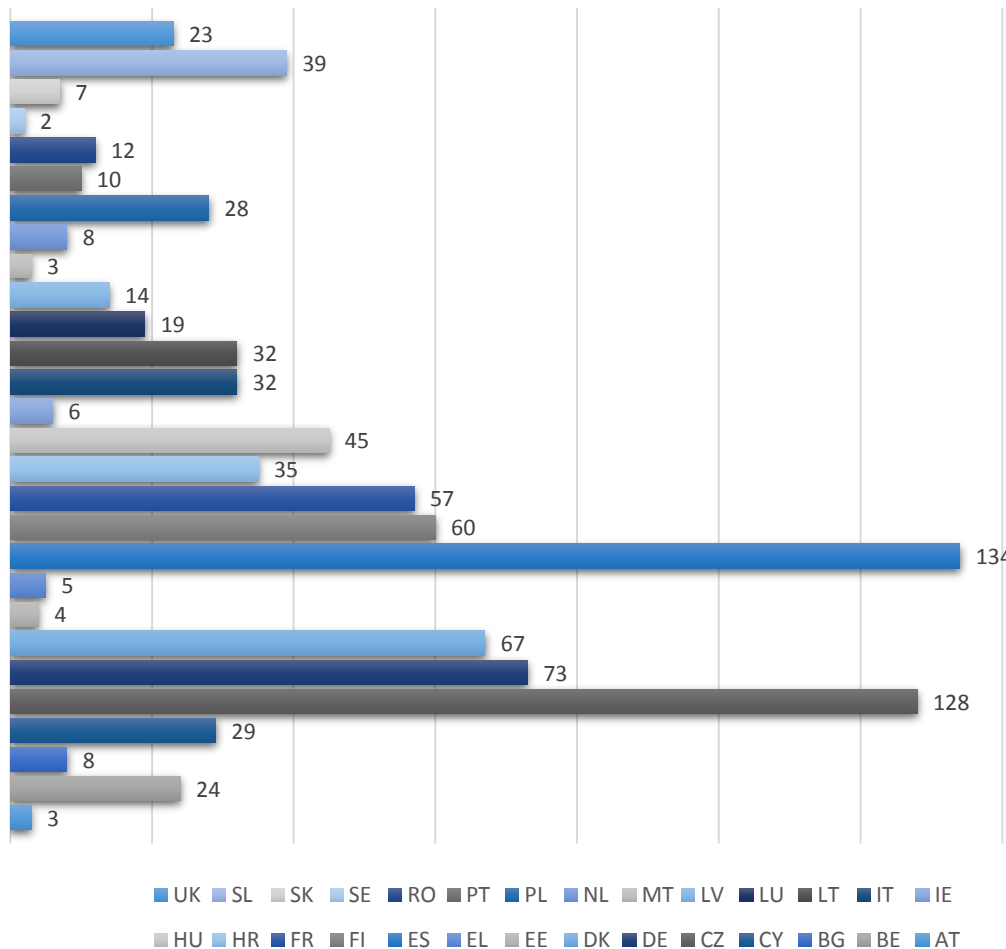
- English
- French
- Spanish
- German
- Italian
- Portuguese
- Dutch
- Polish



- Bulgarian
- Romanian
- Finnish
- Croatian
- Greek
- Hungarian
- Czech

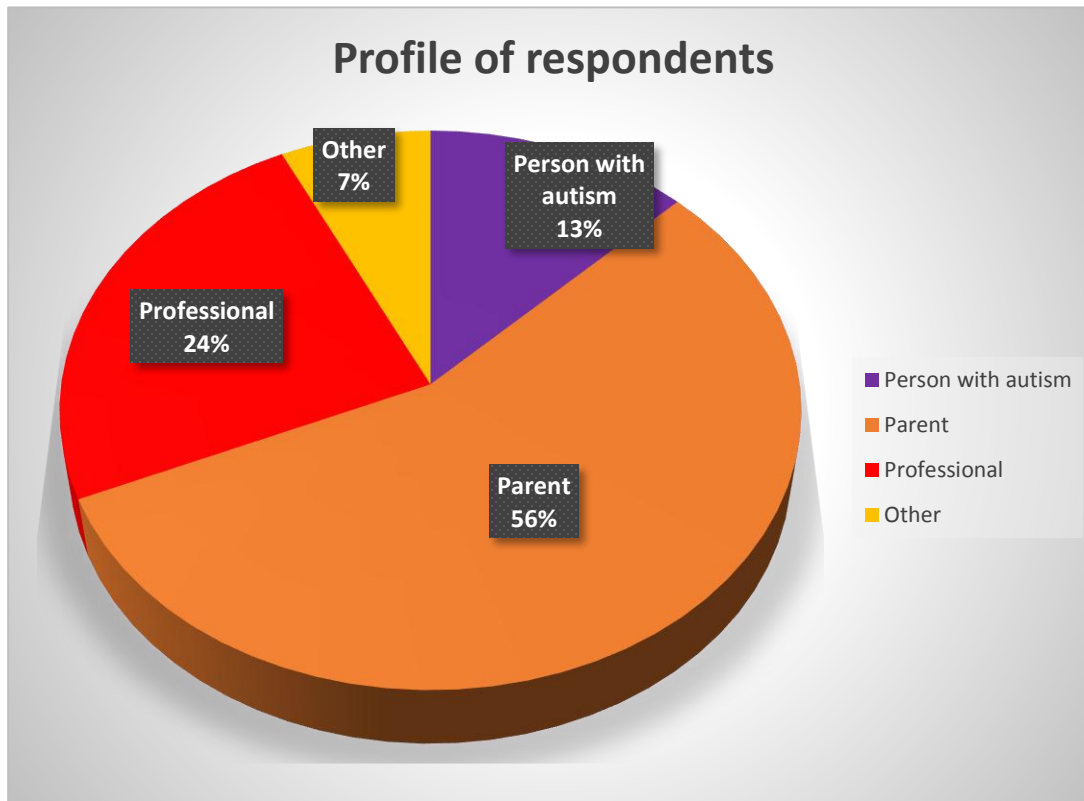
The online survey reach

Number of respondees by country



In total **907** people from the **European Union** replied to the survey

The online survey reach



Most of the respondents were **parents of autistic people (56%)**.

This was followed by **professionals (24%)**.

Autistic people made up 13% of respondents.

Priorities according the respondents:

- Access to diagnosis
- Access to education
- Access to healthcare
- Access to services
- Access to employment
- Access to justice

A large, red, rectangular stamp with a distressed, ink-like texture. The word "PRIORITY" is written in bold, uppercase letters across the center of the stamp, which is tilted slightly to the right.

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**





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Thanks for your listening

Aurélie Baranger

Director of Autism-Europe