

# 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**

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

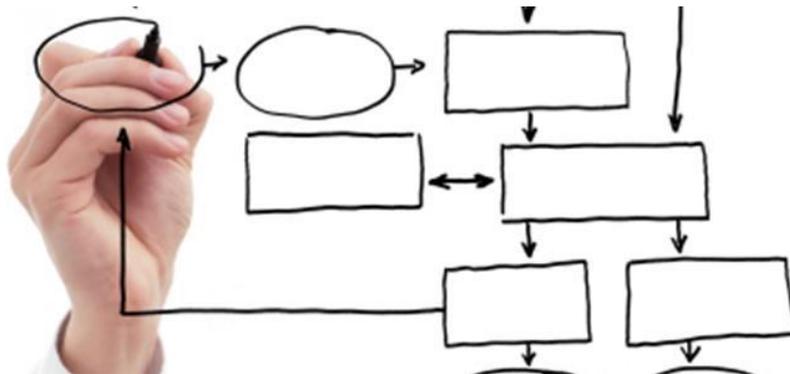
- Identification of **existing policies and the level of support** in the European Union **to respond to issues faced by autistic people** and their families
- Identification of **gaps and challenges by surveying interested stakeholders**
- The core areas covered are: healthcare, education, access to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



# Methodology of the mapping

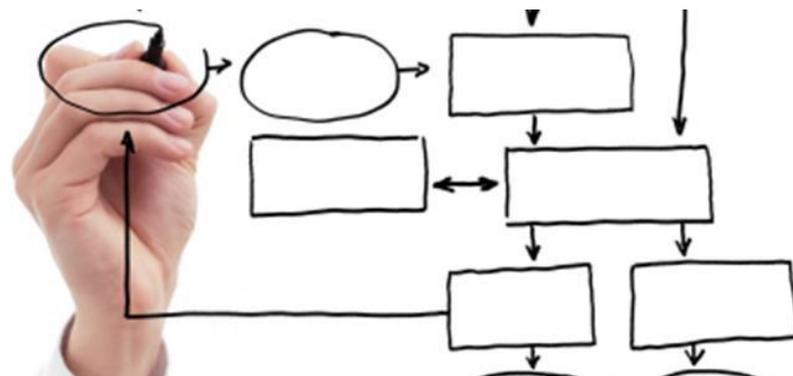
The **UN Convention on the Rights of Persons with Disabilities (UNCRPD)** – ratified by the EU and 27 EU member States - serves as a benchmark to assess the respect of the rights of people with autism.

- 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.



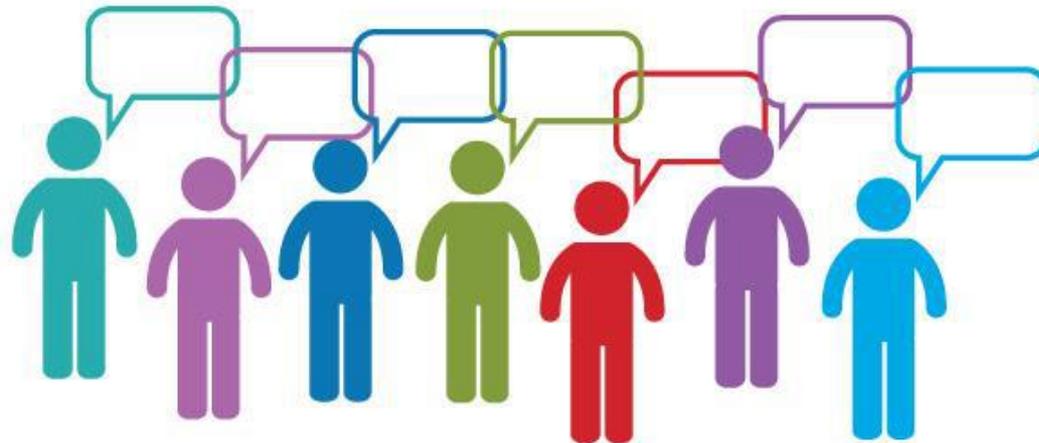
# Structure of the mapping

- 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.

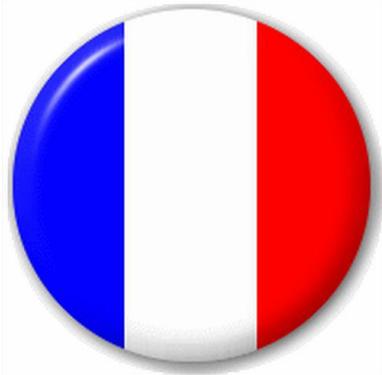


# Autism strategies across the EU

- 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 3<sup>rd</sup> 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<sup>th</sup> 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)

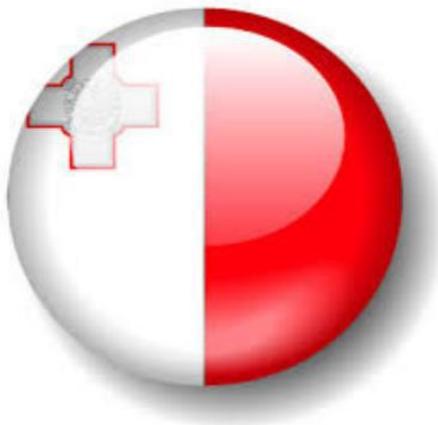
- Aims at improving the quality of life through:
  - early screening and diagnosis
  - adult training
  - family support
- Particular focus on education and employment of autistic people



# 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

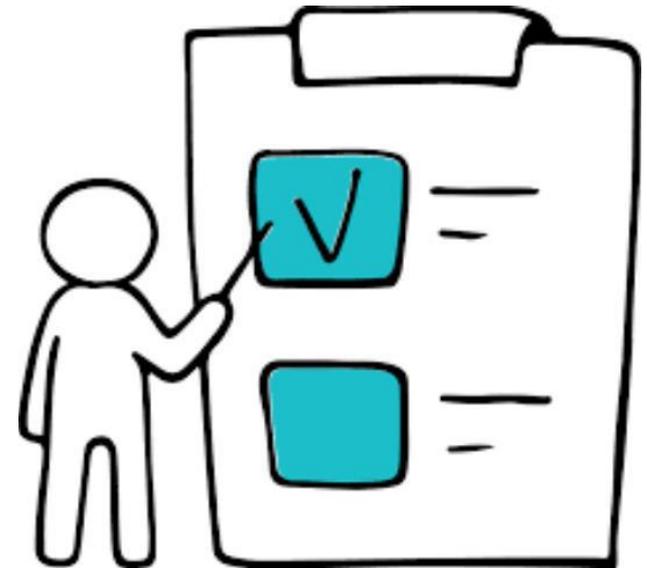


## MALTA (2017)

- 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:

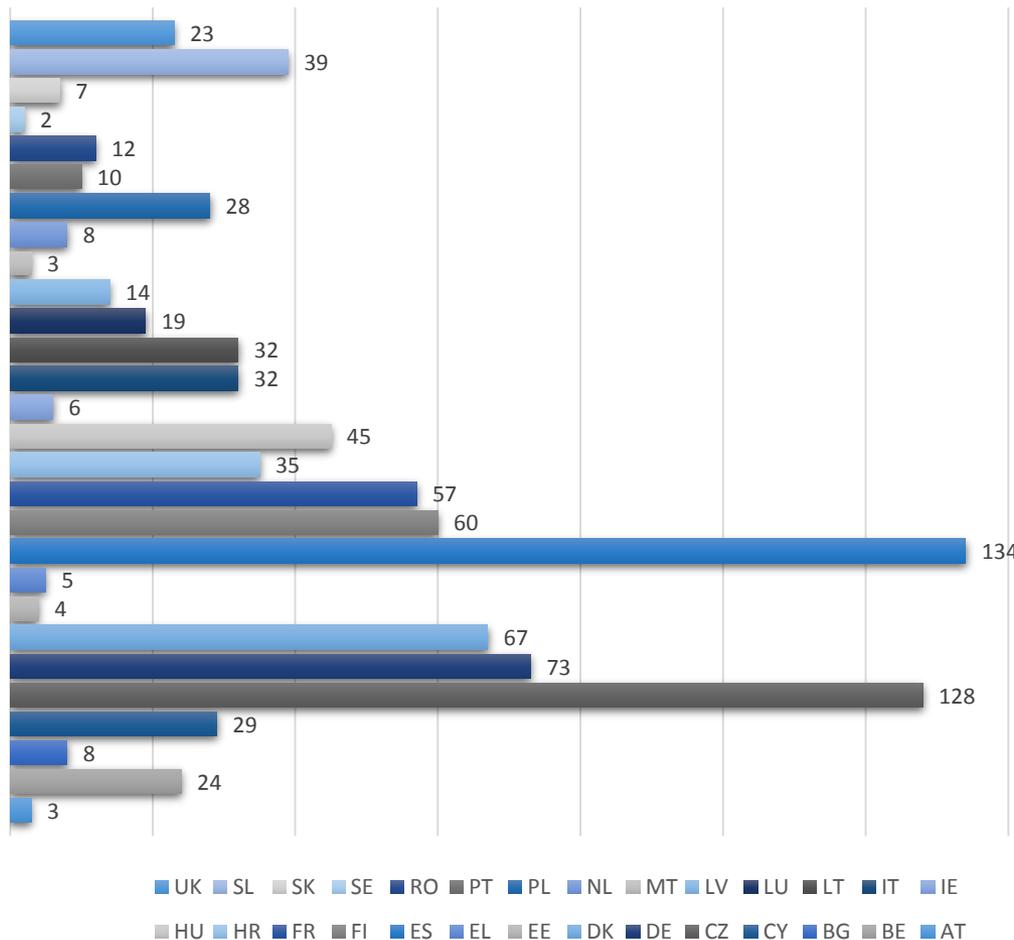
- English
- French
- Spanish
- German
- Italian
- Portuguese
- Dutch
- Polish



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

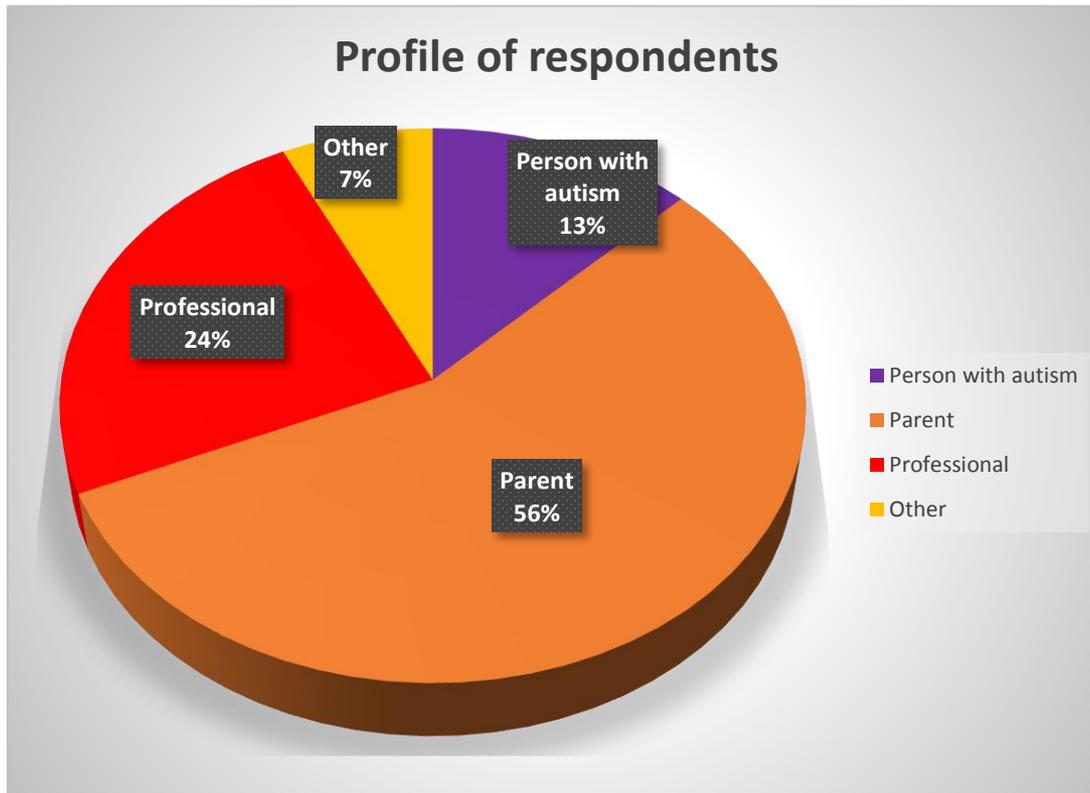
# The online survey reach

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**





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