

## Workpackage 4:

# Assessment of Member States' autism policies

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#### 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.

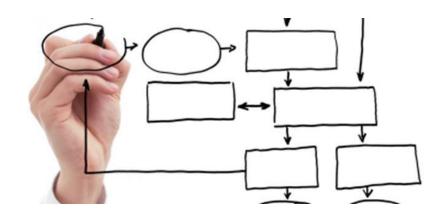




#### Methodology of the mapping

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

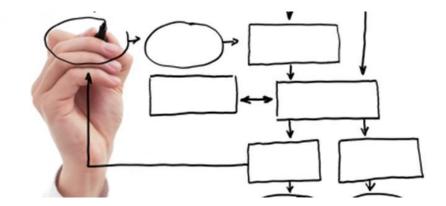






#### Methodology of the mapping

- 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 autismspecific 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





The financial support of this measure is still insufficient, and better personnel assistance up to

- The active employment policy of the Federal Government focuses on the assistance of The across employment purcy or the February unsumment rocurses on the assistance or occupational participation of disabled or severely disabled people. The German Social law occupational purscipations of examine or assessed or severely disabled people. The cumment where we offers several possibilities for grants for disabled or severely disabled people. Accompanied worstional trainings for example pursue the aim that young people with disabilities pass an occasional transings for example parties the aim that young propie with onautities pass on inclusive apprenticative. There are also special programmes for young people with resource opportunities from one was special programmes for young proper will disabilities, who need specific assistance to complete their apprenticaship. A wide range of disastrous, who need specific authorative to compare uner approximations, it was range or possibilities of assistance for people with disabilities who would like to reintegrate into the presentations of executation for purpose with transformer with sections are so reconstruct mino one labour market is also available. There are specialised vocational training centres and vocational promotion centres on autism<sup>18</sup>:
- Within the framework of the activities of the national action plan and the in writin for namesens of the attitutes of the national action pair and the implementation of the UM Convention on the Rights of Persons with Disabilities the Federal Government also the un conseniors on one nigrous or revisions were unsurrows the receive conseniorest and commits for the sensitivation of employers concerning the issues of people with disabilities. commission on amanuacion or employers concerning the reason or process with unautimes.

  On the one hand projudices shall be reduced and on the other hand employment
- Relating to the situation of disabled people on the regular labour market the Federal neutring to the actuation or enabled people on the regular smooth markets the feture of Government doesn't share the view that the integration of disabled people is dissatisfying. constrained outside a state the view that the integration or unstitute proper is unsurelying. The number of severely disabled people in employment with mandatory social security the normer so weren't unature people to temporary their mannerous social security contributions is constantly rising (about 1.152.000 in 2014; that are 42% more than 2002 in commissions is currently rainty sension analysis of season, was are the sension of companiory employment and companiorly levies was introduced). The waster the system of components ampropriate and components of a second components of the component situation of severely disabled people is not satisfactory yet, but is currently onempayment anusum or severally discover people is not seminatury yes, until a currency improving. In relation to the general unemployment the reduction of the unemployment of



GENERAL

The first thing that one should take into consideration when looking at the case of Greece is the extent the mass using other one entandable may be a supplied to bear the brunt of austerity since the start of the financial crisis. to which makes people more had to deer the stant or sustemy since the same or the intensive time. Following ballout talks is 2015 with other Member States and creditors, the final agreement outlined plans for welfare benefits to be cut by 60%, main pensions by 6% and supplementary pensions by 28×2.44. Citizens with disabilities were among the most affected by these cuts, alongside low-income

Greece's ability to implement its disability policies therefore has to be seen in this context of austerity and sharp cuts to support offered to persons with disabilities. Furthermore, in a country where the and sharp costs to support ordered to persons and disabilities. Furthermore, or a country water one average unemployment rate in late 2015 was registered at 24.6% and far higher still for young

With the support of the European Union







#### 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 contantly 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



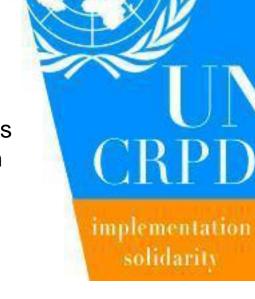






#### Current response to autism needs

- 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

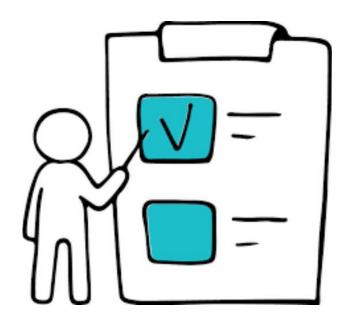






#### Initial conclusions on autism strategies

- 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 bout 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

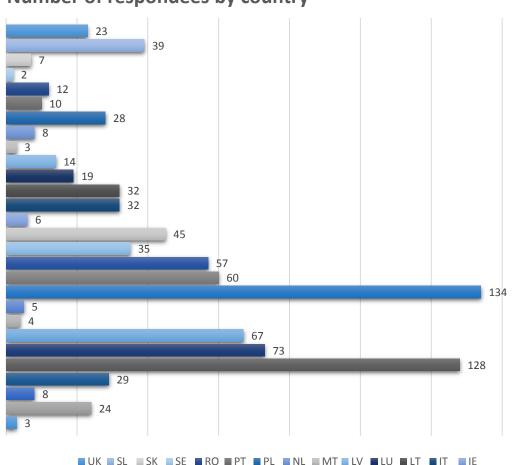






## The online survey reach

#### Number of respondees by country



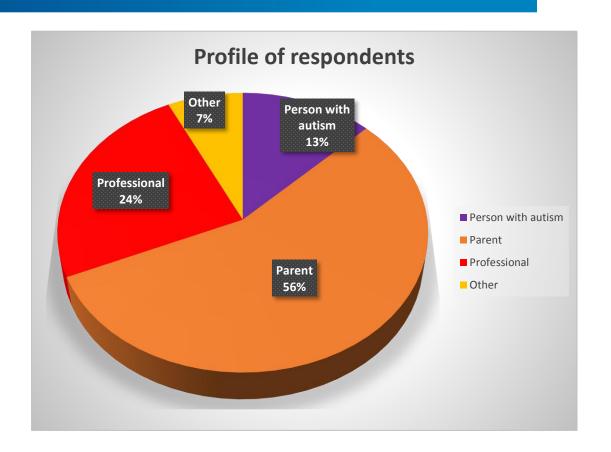
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In total **907 people from the European Union**replied to the survey





#### 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% 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











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## Thanks for your listening

**Aurélie Baranger** 

Director of Autism-Europe



With the support of the European Union

