

**Work package title:** WP4: Autism Policies in the EU

**Presentation title:** Autism Policies in the EU

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**Update on activities:**

- Autism-Europe completed a comprehensive literature review of autism-specific and autism-relevant policies and legislation in place throughout the EU. Some of the key tendencies observed were:
  - An uneven response to needs of autistic people throughout Europe
  - Considerable policy change in different Member States in preparation for or after ratification of the UN Convention on the Rights of People with Disabilities.
  - Slow but gradual deinstitutionalisation is taking place
  - Slowly increasing inclusion of autistic children in mainstream education
  - Measures for employment taking shape, but implementation is still unsatisfactory
  - Over the last decade, some countries and regions have **adopted autism-specific policies**. It varies from **single policies to all-encompassing national autism plans or strategies**.

Research and consultation show that successful autism strategies have the following characteristics:

- **Practical approach**
  - 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.
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- A survey was launched to support the findings of the literature review, available in 15 languages and responded to by over 900 people from every EU Member State.
  - Through the survey several common challenges were identified across the European Union, such as: late or inadequate diagnosis, poor access to interventions, need for training of professionals, lack of proper lifelong education, lack of social habilitation, poor access to the labour market, social exclusion and lack of awareness, lack of implementation of the existing legislation. It confirmed the literature review findings.
  - The findings were also supported through a stakeholder consultation, which took place in Sardinia, Italy, in May 2016, with 50 representatives from European autism associations;

**Key learning:**

***What worked well***

-Good accessibility to resources for the development of the literature review, close cooperation with grassroots organisations throughout the EU for the elaboration and quality-control of the research, and good feedback during consultations.

-The survey provided good qualitative data on the challenges linked to autism across Europe.

***What could be done differently***

- For the literature review : need to take into consideration the possible bias on the way information is presented according to the author of the source text and reflect on how to address this bias the next steps.
- The response rate for the survey was uneven throughout Europe: dissemination could have been more intense.

**Next steps:**

- We will officially close the survey soon and finalise our analysis of the results to be presented alongside the literature review and stakeholders consultation.
- The results of this mapping exercise will feed into the design of the draft recommendations for a European public health plan for autism. In order to do so, we will identify which common gaps and needs across the Europe Union can be addressed at the European level. We will take into account both the European added value and the EU competences. (M20-25)
- We will then carry on further consultation on the draft recommendations with a wide range of key stakeholders, both online and via focus groups meetings, in order to gather feedback and release the final version of the recommendations for a public health plan for autism (M25-M30)
- The final recommendations will be presented to the European commission and the national decision-makers during the final workshop (M33).