

Why do we need a European strategy for autism?

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With the support of
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What is Autism-Europe?



Representing an estimated 7 million people in Europe

- International association whose main objective is to **advance the rights of people on the autism spectrum and their families** and to help them improve their quality of life.
- Autism-Europe brings **together almost 90 associations from 38 European countries**, as well as governments and European and international institutions.

Autism in Europe

Around **5 million people in the European Union** are on the autism spectrum, **the vast majority is not included in society**

Facing very **similar challenges**, such as :

- Lack of timely **diagnosis** (for children)
- Lack of access to **inclusive education**
- **Unemployment** (double compared to the other kind of disabilities)
- Often facing **discrimination** and **violence**
- Lack of **support** throughout their lifetime to enjoy fully their **rights**

World health Organisation Resolution WHA67.8 on autism

- The 67th World Health Assembly adopted a resolution on “**Comprehensive and Coordinated Efforts** for the Management of Autism Spectrum Disorders” (ASDs) on May 24th 2014.
- Co-sponsored by more than 50 countries and supported by all.
- Recommended to Member States “to develop or update and implement relevant policies, legislation, and multisectoral plans, supported by sufficient human, financial and technical resources to address issues related to ASD” (para 1.2)

European parliament written declaration 2015

The European Parliament called for a **European strategy** to support and encourage:

- accurate **detection and diagnosis** of children and adults with autism
- **research** on autism
- prevalence studies
- exchange of **best practices** regarding **evidence-based interventions** for children with autism
- **support and habilitation services** for adults

Survey carried out in 2016

Some of the most common issues identified by autistic people:

- 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 2016

- Fostering **employment and training**, and offering reasonable accommodation
- Establishing **more vocational schools** for young people with autism
- Provide support for **autonomy throughout the lifetime**
- Improved **care and access to care**



Differences amongst countries

Across Europe, we observe variations regarding the following aspects:

- Different levels of **scientific knowledge**
- Families faced with **quackery** and unproven theories about autism
- **Medical abuse, violence** and **bullying**
- **Adult population** with a wrong diagnosis, **invisible**, experiencing lots of **suffering** in life because they ignore they are on the autism spectrum
- Lack of **services** and **benefits**
- Lack of experience and structures to **advocate for their rights** (both for people on the autism spectrum directly and their families)

The future we want

- **Inclusion in society** in every aspects of life (education, employment, leisure, sport, health, support services to live in the community, etc.).
- A **cultural change** and **positive action** from all actors (including from EU institutions – for example to hire staff on the autism spectrum).
- **Accessibility** taking into consideration the specific needs of autistic people (e.g. visual and alternative means of communication, adapted informed consent, sensory aspects)

The future we want

- **Nothing about us, without us!** – including in research, **direct involvement in deciding research priorities**
- Respect of our choices, priorities, values and dignity as an **ethical duty**
- Implementing **person-centered life project** and fostering real supported **decision-making** to increase **independence** and **autonomy**

Thanks for your listening

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Vice-president
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