

Advancing Inclusive and Evidence-Based Therapies for Autism in Europe

European Economic and Social Committee

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About Autism-Europe



- International association whose main objective is to advance the rights of autistic people and their families and to help them improve their quality of life.
- Autism-Europe brings together more than 90 associations from 40
 European countries, and liaise with European and international institutions.



About Autism-Europe



- Ensure full implementation and respect of the rights and the effective participation of autistic people, notably by supporting the implementation of the UN Convention on the Rights of persons with Disabilities;
- Promote a **rights and evidence-based approach to autism** working together with autistic people, their families, professionals and decision-makers;
- Encourage research on autism, exchange of best practices and information on rights and evidence-based interventions, as well as support and habilitation services





THE COUNTDOWN IS ON

14	0	15	32	33
WEEKS	DAYS	HOURS	MINUTES	SECONDS

Join us in Dublin in September for our three-day international congress guided by an inclusive and neuroaffirmative approach!



Intervention vs cure

Autism is a lifelong condition and the concept of a cure is offensive for many autistic people and their families. An intervention should **never aim to 'treat autism' or make an autistic person appear more 'normal', by reducing visible autistic traits** (e.g. forcing people to avoid stimming or sustain eye contact).

Essential to make society more accessible and inclusive for autistic people. It is also important that non autistic people learn to communicate better with autistic people (double empathy concept).

A range of interventions can support autistic people in their daily lives. Any intervention must consider outcomes that are ethically sound and meaningful to autistic people themselves.



Vital to combat pseudo-science and quackery

Widespread misinformation targeting autistic people and their families:

Dangerous therapies and unsupported biomedical interventions with possible serious adverse events, such as bleach enemas, hyperbaric oxygen, chelation, or stem-cell therapies, etc.

Dispelled theories linking vaccines to autism.



Access to evidence-based information is a prerequisite for self-determination

It is essential to **empower autistic people and their families to make informed choices** about the intervention and support they receive.

Autistic people must also be **actively involved** in setting the **goals** of their intervention and in their **on-going evaluations**.



Individualisation is crucial to any intervention

There is no single intervention equally effective for all autistic people. A **person-centered approach** to intervention and support is essential due to diversity of autistic people and their individual circumstances.

Various interventions can be combined depending on the needs of the person.

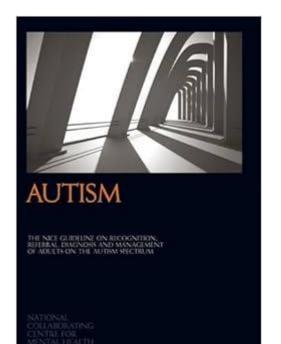
Autistic people should have access to support and interventions that are appropriate for their age, needs, interest and wishes, in order to optimise their quality of life.



Bridging the gap between knowledge and practice: training of professionals is essential

Despite advancements in scientific knowledge about autism interventions, and the existence of reliable guidance, **important disparities subsist regarding the availability and quality of support and intervention**.

Many autistic people still do not have access to evidence-based support due to lack of trained professionals.



European Child & Adolescent Psychiatry https://doi.org/10.1007/s00787-020-01587-4

ORIGINAL CONTRIBUTION

ESCAP practice guidance for autism: a summary of evidence-based recommendations for diagnosis and treatment

Joaquin Fuentes 10 · Amaia Hervás 20 · Patricia Howlin 30 · (ESCAP ASD Working Party)







Bridging the gap between knowledge and practice



Committee on the Rights of Persons with Disabilities

Concluding observations on the combined second and third periodic reports of the European Union*

« (c) Promote compulsory training on specific and evidence-based habilitation strategies for autism, and adopt quality assessment systems for habilitation services focused on inclusion, participation and users' quality of life."



Research gap on impact of interventions on long term quality of life

More scientific evidence is needed to understand the effectiveness and impact of interventions so that autistic people and their families can make informed decisions about what might work for them.

Most autism research on intervention focuses only on short-term goals and limited outcome measures.

More research is needed on long-term potential, quality of life, characteristics of autistic people for which some intervention work, and effective interventions for disadvantaged and underserved groups.

Research should be designed and conducted with the **full participation autistic people as part of the core research team.**



Implications for policy at the EU level

- We need concrete and targeted policies and actions to foster the acceptance, inclusion and well-being of autistic people in society in all areas of life (WHO, European Parliament Resolution on Harmonising the Rights of autistic people 2023, CRPD 2025)
- Need to ensure a common understanding of what constitutes good practices and rights and evidence-based interventions
- Promote training, not only initial but also continuous training of professionals, as well as peer support delivered by autistic professionals
- Ensure that the diversity of autism is addressed (including the gender dimension or the needs of underserved groups)
- Promote research with the full participation of autistic people, as beneficiaries but also as full members of the reseach team



Thank you



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