

Report of activities Highlights from 2024

**Council of administration
Brussels, 2/11/2024**

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Director

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1.- Contributing to evidence-based regulation, policies and reforms



1. -Contribution to EU civil dialogue through structured contacts with the European commission



AE is is one of the 14 civil society organisations selected to take part in the **EU Disability Platform** alongside the European commission and the representatives from governments

In 2024, we took part in the regular meetings of the platform and its subgroups and notably contributed on issues related to employment and community-based services.

On 5 July, AE director also met with **the Director General of DG EMPL** and other Civil Society Organisations and highlighted the need to follow-up on the EP resolution on autism



1. -Contribution to EU civil dialogue through structured contacts with the European commission



In July, Autism-Europe provided its initial feedback in relation to **Monitoring, evaluation, and revision of the European Strategy for the Rights of People with Disabilities.**

Notably calling for strong follow-up action and sufficient investment as well as adequate regulations in the next Multiannual Financial Framework to promote the rights of people with disabilities and support inclusion in the community.

2. Autism Research mentioned in Political Priority for Commission 2024-29



On 18 July 2024, President Von der Leyen included Autism research in her set of political guidelines for 2024-2029.

AE issued a statement, to welcome this in line with a key demand of our EU election pledge.

AE highlighted the need to include autistic people and their representative organisations in research.

We noted concern with overall lack of mention of disability in the Guidelines.



2 – Commission Commitment to a common approach to autism



17th September Commissioner-Designate for Health, Olivér Várhelyi, received a mission letter from Ursula Von der Leyen that included a commitment to a **'common approach' to autism**.

This is welcome by AE but we highlighted the importance of considering autism as a neurodevelopmental disability rather than a disease.

This common approach must meaningfully involve autistic people, their families and representative organisations at all stages.

We will follow-up with DG SANTE and MEPs in the Public health committee



3 - European Disability Card and Parking Card



The European Disability Card and Parking Card directives were adopted on **14th of October** by the Council of the European Union.

AE has been actively involved throughout the consultation process and will now support implementation at national level alongside EDF.



4 – Contributing to the work of the AccessibleEU Resource Centre

AccessibleEU Resource Centre hosted an event on 2 July at the ONCE Foundation HQ.

AE participated in a panel discussion dedicated to “users of urban environment”, highlighting how to make urban spaces accessible for autistic people.





5 - Guidelines on Reasonable Accommodation at work



The Commission published these Guidelines under the Disability Employment Package.

The guidelines were prepared with the help of the Disability Platform members including AE.



6- European Commission's Framework for Social Services of Excellence for Persons with Disabilities.



Presentation of the preliminary position of AE working group at an event organised by ENIL in April, in presence of the European commission and MEPs.

Participation in the subgroup of the disability platform.



7- Joint Statement on European Care Strategy: Call for full transparency in its implementation



Following the call on 8 April for a European Long-term Care Platform, AE and 17 other organisations urged national governments and the Commission to ensure open and transparent reporting mechanisms for the Strategy in a joint statement on the 4th of June.

This action is a crucial first step to guarantee the transparency and openness needed for the successful implementation of the European Care Strategy.



8- Call for an Equality-Centred Policy Cycle



Call issued in July for European Union leaders to continue to prioritise efforts to guarantee the founding values of equality and non-discrimination, upholding the Union of Equality.

AE is among **133 CSO's** calling for, among other things, a Commissioner for Equality and Fundamental Rights to be appointed.



9- World Mental Health Day – Call for substantive action

JOINT STATEMENT

World Mental Health Day

**Deliver on Promises and Honour
Commitments on Mental Health**

To mark World Mental Health Day **10th October 2024**, AE in **Joint Statement**, called for action by:

European Commission: to develop a Strategy on Mental Health

Member States: to elaborate on actions plans with a cross-sectoral approach

European Parliament: to establish an Intergroup on mental health



10- Responses to various ad hoc consultations



- European Observatory on Health Systems and Policies' **survey on health priorities for the EU** ahead of the new European Commission
- EDF consultation on **Carriage of assistance dogs in air travel**
- EDF **position paper on the revision of the TSI – PRM** (accessibility of railway system)
- EDF alternative report on the EU's implementation of the UNCRPD ahead of review (on-going)



11- AE represented by Italian Members at G7 meeting



On 14-16th October the G7 held the first-ever ministerial meeting on disability in Italy.

The **Solfagnano Charter** was adopted on day 3. It contains commitments under 8 priority areas for the G7 countries to advance the CRPD.

AE's Italian members, including ANGSA and ANFASS, were represented at the meeting in various ways.



2.- Capacity building, mutual learning and exchange of good practices

With the support of
the European Union





2-1 AE International congress 2025

14th Autism Europe International Congress
11th-13th September 2025 | Dublin, Ireland

Quality of Life - Research, Policy and Practice



Call for abstracts and contributions launched on 15th October

Deadline: 10th January 2025

2-2 Online round tables: Afternoon of Good practices



Themes addressed in 2024

- March: Inclusive advocacy practices in associations
- April: Initiatives to foster independent living
- September : Ageing
- Upcoming session on Thursday 14th November 24 -16.00 CET:
Accessibility of higher education

The Afternoon of
**Good
Practice**

Still time to submit proposals for the session on emergency response!



2.4– Training for AE members

- European elections 2024
- Training on the latest developments in the European Strategy for the Rights of People with disabilities

Study visit – Aslam - Dublin





3. Reinforcing cooperation with other EU-level networks



3.1.- Cooperation with the European Disability Forum

AE had regular cooperation with EDF to mainstream the perspective of autistic people through representation in:

- EDF board: Pietro Cirrincione
- EDF Youth Expert Group : Ben Rowsome

Contribution to various consultations and meetings

- Including EDF Project on access to health:

Open **Study on guidance to increase access to healthcare for people with disabilities,**





3.2.- European Expert Group on the transition from institutional to community based care

The EEG monitors policies in relation to deinstitutionalisation and released a Statement on the European Care Strategy.

AE became co-chair of the network in March 2024 for a year.

Recent statement:

EEG statement
on the Belgian Presidency Conference
“European Child Guarantee: from
engagement to reality”

The EEG supports the Belgian
Presidency’s conference urging
National Action Plans to prioritize
prevention and early intervention to
be monitored at national and EU level



EUROPEAN EXPERT GROUP ON THE TRANSITION
FROM INSTITUTIONAL TO COMMUNITY-BASED CARE

Upcoming event on
DI for children on 14/11!



3.3. European Social Platform



We are founding member of this large network that promotes social justice in Europe.



3.4- Coface Europe



We contribute to the 'Care alliance' chaired by COFACE to support the carer's rights



3.5.- ADHD Europe

Regular contacts and exchange throughout the year



And other ad-hoc cooperation with other CSOs such as EASPD or ENIL



3.6.- International cooperation



Harald Neerland, President of Autism-Europe was invited to the 2024 biennial meeting ("Université d'Automne") of ARAPI in October, to take part in a round-table about involving autistic people with high support needs in research.



4.- Awareness-raising and dissemination

4.1- Disseminating news on autism, and relevant EU developments online



- **English e-newsletter:** 6,3K subscribers
- **French e-Newsletter:** 1,2K subscribers
- **ETR newsletter EN:** 68 subscribers

*Other targeted communications: WAAD and fundraising, dedicated newsletters, newflashes, Press releases, event invitations, news flashes

Newsletter #96

October 2024



More than
17K followers



More than
9.5 followers



More than
3.7 k followers

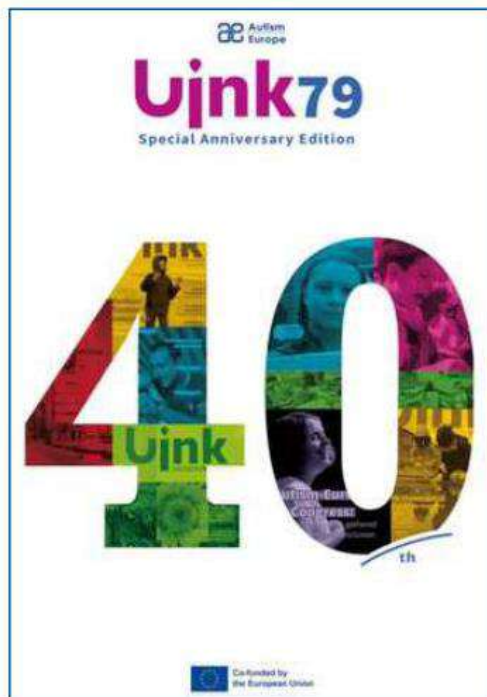


More than
1.9 k followers



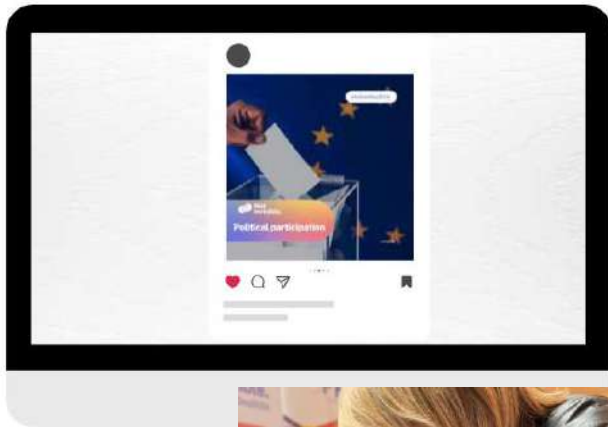
More than
1.3 followers

4.2- Disseminating news on autism, and relevant EU developments online





4.3-New multiannual 'Not invisible' campaign designed in 2023& launched in 2024!





4.3 - European Elections and AE's Pledge

2024 EUROPEAN ELECTIONS
PLEDGE FOR AUTISM



#AutismNotInvisible was kicked off in the **European Parliament** and gained wide support in the context of the European Parliament elections.

Gathered signatures of **83 MEPs and MEP candidates** from **15 EU countries**.

26 MEPs from nine EU countries got (re-)elected – around a third of those that endorsed Autism-Europe's pledge.

4.3- Celebrating Neurodiversity Pride Day with #AutismNotInvisible



Autism-Europe celebrated Neurodiversity Pride Day (16 June) by promoting the **#AutismNotInvisible** campaign

Contributed an article to the European Network on Independent Livings first **Neurodiversity Pride day Newsletter**

Promoted our **pledge in support of Autistic Rights** and the implementation of the **European Parliament Resolution on harmonising the rights of autistic persons**



5.- Network organisation and management



5.1- AE's governing bodies meetings

- **Annual General assembly and Council of administration – May 2024 in Dublin**
- **New members in 2024** : AFG Autisme from France, De Nederlandse Vereniging voor Autisme (NVA) from the Netherlands (full members), Autismo Andalucia from Spain (affiliated member) and ANFFASS from Italy and Autism Unlimited from the UK (associated members)





AE Executive Committee 2024- 2027



Harald Neerland
President



Zsuzsanna Szilvasy
Vice President



Marta Roca
Vice President



Stéfany (Stéf) Bonnot-Briey
Vice President



Liga Berzina
Member



Adam Harris
Treasurer



Monique Post
Member



AE Secretariat 2024



Aurelie Baranger -
Director



Magali Vlayan –
Translator ad secretary



Christian Takow –
Advocacy and Project
Officer



Anne Rensma –
Communications and
Campaigns Manager



David Eton – Project and
Policy Officer



Aoife McGarry – Projects
and Research Officer



Fernanda Buriola –
Communications and Project
Officer



5.- EU projects

[Access all the information on our current and past projects on our website](#)



AIMS-2 TRIALS



Innovative Medicine Studies-2-Trials (2018-2025) – 2 year extension!

Research project on biomarkers indicating development of particular characteristics

- AE role: **Policy and supporting dissemination and involved in A-reps**
- Participation in relation to **stakeholder engagement and policy engagement**
- **Survey** Access EU on services results being analysed – policy paper in preparation
- **Survey** 10 points for change (adaption, translation, proofreading, dissemination)



CANDY



Comorbid Analysis of Neurodevelopmental Disorders and Epilepsy (2020- 2024)

- Project is following a trail of rare and common genetic variants shared in many neurodevelopmental disabilities and conditions and possibility that immune dysregulation and microbiome at some point plays a role in them
- AE is involved in the dissemination alongside ADHD Europe



R2D2

Risk and Resilience in Developmental
Diversity and Mental Health- R2D2



- Coordinator : Institut Pasteur
- Improve the MH outcomes across the lifespan for young Neurodevelopmental diversity individuals based on: (i) enhanced molecular and neurobiological understanding of risk and resilience to poor MH outcomes for neurodivergent people; (ii) redefinition of mental health and functioning by co-creation of acceptable outcome measures with stakeholders.
- AE involved in the co-production process as an associated organisation
- **Several delegates for the co-creation group:** 2 delegates for the adult group (1 autistic adult + 1 parent); for the youth group : 2 delegates between 15-18 year old



IDEAL



IDEAL – Inclusive Digital Education for Autistic People Learning

- The IDEAL Erasmus+ project started in 2022 to address the lack of accessible online tools, trained professionals and educational methodologies adapted to autistic people with different support needs
- IDEAL is developing an adapted platform with digital resources for autistic people, their families and professionals (communication, social skills, functional skills, health management, etc.) that will be fully accessible for autistic people.
- AE developed the Dissemination Plan
- IDEAL website is online [The project \(idealearning.eu\)](https://idealearning.eu)



SACREE



**SACREE- Sport and Autism, from a scientific diagnosis
to the CREation of a pedagogical European model
(2021-2024)**

- The SACREE programme aims at improving the daily lives of autistic people by promoting the inclusive practice of sport activities
- AE leads the **dissemination and sustainability of the project** and facilitates the exchange of information and best practice across Europe



ASD-Includi

Autism Inclusion in Distance Learning- ASD-IncluDi (2022-2024)

- The ASD-IncluDi project is an innovative proposal aiming to enhance the teaching and training techniques currently used in special needs education systems, by using specifically developed ICT and IoT tools
- The project will produce: i) a Competence Framework accompanied by guidelines to develop training content for curricula, ii) the Training Courses for the target groups of the project (special needs educators students and teachers in HEI, professionals and caregivers), iii) Training tool environment supplemented by assistive ICT tools and iv) Policy Recommendations



Empower



Design and evaluation of technological support tools to empower stakeholders in digital education (2022-2025)

- Empower project will design a technological platform to support autistic children with executive function and emotion regulation aiming to help teachers better address their needs
- The project will inform future developments of the potential of technologies in education
- AE is the lead partner for dissemination. Main results will be presented at the congress



My Virtual World 3D Job Training for Autism



- Adapt VET programmes to the skills and abilities of individual autistic learners, as well as to the labour market needs
- Developed a VET programme using digital technologies in Virtual Reality (VR)
- The open-source 3D-environment platform enables VET trainers, educators and employers to experience the barriers faced by autistic jobseekers
- The project closed in August and all results are available on the platform



Autism Spectrum Pathways 2023-2025



- International and national research reports on current state of play of employment barriers and opportunities for autistic people
- Expert-reviewed employment guides for autistic jobseekers, VET schools and employers
- Learning modules on employment for autistic jobseekers, VET teachers/trainers and employers
- European-wide digital map of autism associations and companies already employing or who are willing to employ autistic candidates
- Videos of successful pathways/experience to employment



Green ASC VET (2023-2026)



Green
ASC VET

- Manual of competences for teachers and trainers working with autistic people as a framework for quality programmes
- XR solution and videos for autistic people to make independent career choices based on different career profiles (VR, AR, etc.)
- Simulators to develop skills for professional pathways
- Continuous awareness-raising campaign about the need for inclusive employment of autistic people



EASY



EASY – Employability for Autistic Youth

- The EASY Erasmus+ project started in 2023 to create tools to support the development of employability skills for autistic people.
- This project has already developed a Guidebook and an Activity book for youth workers to use with autistic learners.
- AE developed the Dissemination Plan



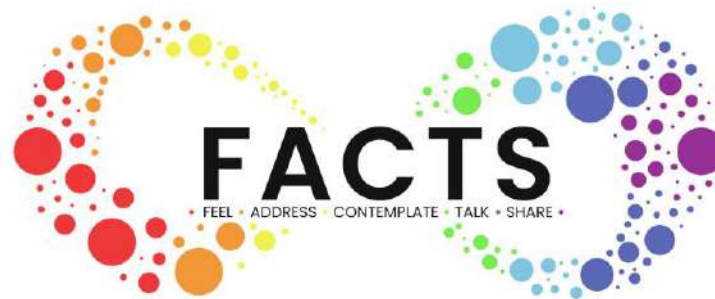
Self-Determination & Inclusion by Theatre



- Project launched October 2023 and will run until October 2025
- SDIT aims to promote self-determination and social inclusion for autistic people through theater, enhancing their communication, social skills, and self-advocacy.
- Inclusive theater workshops, training for theater professionals, and public performances to promote empathy and inclusion.
- Autistic people, theater practitioners, family members, and support organizations across Europe.



F.A.C.T.S



- Project launched November 2023 and will run until April 2026
- Enhance access to information and support for autistic people regarding sexuality and gender identity through education, advocacy, and awareness.
- Improved understanding, autonomy, and well-being for autistic people regarding sexuality, alongside more inclusive and supportive professional practices.
- Autistic people, professionals working with them, and their support networks across Europe.



Points of Connection



- Project launched October 2023 and will run until March 2026
- Enhance community inclusion and quality of life for autistic young people (ages 18-25) through accessible services and fostering social connections.
- Conduct quality-of-life research, support development of autism-friendly services, create mixed peer groups, and facilitate awareness campaigns and collaborative projects.
- Autistic young adults, neurotypical peers, service providers, caregivers, and educators.

 **COMPASS**

- Project launched September 2024, will run until August 2026
- A user-friendly Advocacy Guide offering clear, practical advice on how to navigate the legal system and advocate for autistic individuals' rights.
- An Online Life Journey Map, which visually outlines the key stages of an autistic person's life and the services available at each stage.
- Dissemination of these resources across multiple languages, tailored to the legal contexts of Hungary, Belgium, Serbia, Latvia, and Romania.

Discussion





**Co-funded by
the European Union**

Thank you for listening

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