

2023 Activity Report







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Cover picture(s): Autism-Europe's event "Building inclusive education and employment for autistic people" | Autism-Europe's photo exhibition

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Executive Summary

In 2023, Autism-Europe celebrated its 40th anniversary with the motto "Building an inclusive Society for autistic people". Autism-Europe (AE) was founded in 1983 to create a European network of autism organisations focused on advocating for the rights of autistic people and promoting their quality of life. Currently, AE represents 90 national and regional associations from 40 countries and holds the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as its guiding principle. Autism-Europe joins and amplifies the voices of autism organisations, self-representatives, and their relatives.

AE works closely with European institutions and with other civil society organisations to ensure that the concerns and needs of the autistic community are accurately represented across the political landscape and sectors (including education, employment, access to independent living and support in the community, healthcare, and inclusion). As such, AE continues to support the development and implementation of the European Strategy for the Rights of Persons with Disabilities (ESRPD).

Throughout the year, we have been delighted to contribute to positive developments at the EU level, such as the proposal for the upcoming European Disability Card. This card will be particularly valuable in supporting freedom of movement within the EU, especially for individuals with so-called "invisible" disabilities. Another milestone was the adoption of the European Parliament's "Resolution on Harmonising the Rights of Autistic People". This resolution encompasses key priorities identified by our members and constitutes a strong call to action. We will follow up on it.



AE cooperates with other EU-level networks and organisations within the disability sector, such as the European Disability Forum (EDF), the European Expert Group on the Transition from Institutional to Community-Based Care (EEG), the Social Platform, the European Platform for Rehabilitation (EPR), the European Association of Service Providers for Persons with Disabilities (EASPD), etc.

AE is also a platform for its members and key stakeholders to exchange research and good practices in the field of autism. In this regard, AE regularly develops mutual-learning events, trainings, conferences, and roundtables that foster innovative discussions from a diverse perspective. AE's European and international projects focusing on improving the quality of life of autistic people in several areas (such as access to healthcare, employment, and education) also serve to develop tangible results for the autism community, professionals, and wider public.



#Autismday2023





Autism-Europe's strategic objectives for 2023

- To engage in regular dialogue with the European Commission and policymakers at the European and national levels in the framework of the implementation of the EPSR (European Pillar of Social Rights) and the ESRPD (European Strategy for the Rights of Persons with Disabilities 2021-2030). Autism-Europe has striven to ensure the mainstreaming of autistic people and their families' concerns, in view of the realisation of their rights in relation to accessibility, education, employment, inclusion, health, independent living, decent standard of living, access to legal capacity and voting as well as protection from violence.
- To foster ongoing participation of national and local members in decision-making processes and ensure that the diversity of the autism spectrum is represented in all activities carried out by Autism-Europe.
- To advocate for the European Disability Card to be recognised in all EU
 Member States and used by autistic people in Europe.
- To advocate and monitor the implementation and mainstreaming of the ESRPD and EPSR at national level, notably through data collection to inform the European semester, influencing the country-specific recommendations.



- To mainstream autistic people's perspective in the work of the disability movement and other CSOs and integrate cross-cutting and intersectional issues in AE's work through ongoing cooperation with other EU level networks, including the European Disability Forum and its expert groups, the Social Platform and the European Expert Group on Deinstitutionalisation.
- To regularly disseminate relevant information on EU policy and autism to promote sharing of knowledge towards improving the quality of life and advancing the rights of autistic people in Europe.
- To promote knowledge-sharing and capacity-building with autism organisations across Europe and other stakeholders, encouraging exchange, cooperation, and information-sharing to foster a better quality of life for autistic people.
- To combat stereotypes around autism and disability, raising awareness about autism and disability rights through our annual awareness-raising campaign, promoting acceptance, inclusion, and participation.



Key Activities

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

1.1. Autism-Europe contributed to the drafting of the <u>resolution on</u>

<u>'Harmonising the rights of autistic people'</u>, which was adopted by the European Parliament on 4 October 2023.

The resolution was drafted after Confederación Autismo España (AE member) submitted a petition before the European Parliament Committee on Petitions in February 2023, requesting that the European Disability Card include autistic people, as many still face the challenge of having their disability status recognised.

• Main output: Autism-Europe liaised with several Members of the European Parliament to inform them about the concerns and priorities of the autistic community. AE ensured that autistic people with different levels of support were represented, as well as girls, women, members of the LGBTIQ+ community, and ethnic minorities. Among other points, AE successfully advocated for the resolution to underline the lack of regulation regarding harmful and unproven therapies that target autistic people and their families.





The resolution – greatly echoing Autism-Europe's long-standing advocacy – emphasises that progress should be made across sectors, including access to diagnosis, healthcare, education, employment, accessibility and provision of reasonable accommodation, legal capacity, lifelong support in the community, deinstitutionalisation, culture and sport, training of professionals across sectors, research, fight against violence, and forced sterilisation.



LINK 80th edition

1.2. Autism-Europe continued its active participation alongside the European Commission and Member States through the EU Disability Platform

Autism-Europe has been a member of the EU Disability Platform since it was established in 2021 with the aim of gathering civil society organisations, EU institutions, and representatives of Member States to implement the UNCRPD as well as the ESRPD.

In 2023, AE participated in the Platform's quarterly meetings and in the activities of the different subgroups on the Employment Package, the European Disability Card, and Accessible EU.

Main output: Autism-Europe voiced the concerns and needs of the autistic community on the topics of employment, inclusion, and access to the European Disability Card, among others. More information about the activities of the EU Disability Platform can be found here.







Employment package presented at the European Day of People with Disabilities

1.3. Autism-Europe contributed to the Disability Employment Package

In its role as a member of the employment subgroup of the Disability Platform, AE contributed to the development of the Disability Employment Package by providing feedback and contributing to the dissemination of the different deliverables.

Main outputs:

Contribution to the Disability Employment Package deliverable 'Catalogue
of positive actions to encourage the hiring of persons with disabilities and
combating stereotypes' by providing input on a good practice example
regarding the employment of autistic people.

Download the document here.

 Contribution to the Disability Employment Package deliverable 'Ensuring reasonable accommodation at work' by providing input regarding accommodations for autistic workers.

Document available soon here.



1.4. Autism-Europe's contributed to the European Disability Card consultation process

In April 2023, Autism-Europe provided input advocating for the rights and needs of the autistic community to the European Commission regarding the European Disability Card (recognition of diagnosis, barriers for people with invisible disabilities, observations regarding the implementation, etc.) AE also shared this opportunity to provide feedback with the autism community through its website, newsletter, and social media.

• Main outputs: <u>Autism-Europe's input form</u> to the European Commission on the public consultation process.

1.5. Autism-Europe participated in the launch of AccessibleEU: the new European resource centre for accessibility

As a member of the Disability Platform subgroup AccessibleEU, AE attended the meetings of the group throughout 2023 and closely followed updates.

 On 4 July 2023, Autism-Europe attended the launch of AccessibleEU, a resource centre created by the European Commission as one of the flagship initiatives of the SRPD 2021-2030. Accessible EU offers information, guidance and support in the implementation of accessibility tools in different



areas such as transport, buildings, information, audio-visual media, and communications. Read AE's article on the event here.



1.6. Autism-Europe set up an expert group on social services of excellence for autistic people to inform the European Commission's SRPD 2021-2030

Autism-Europe set up an expert group on social services of excellence for autistic people to inform the following flagship initiative of the ESRPD: 'Framework for Social Services of Excellence to improve the quality of community-based services for persons with disabilities'. The group includes internationally renowned autism experts as well as self-advocates.

 An initial meeting was held on 27 October 2023 and the members from around Europe have collaborated on a draft position paper that will be submitted to the European Commission during 2024.

1.7. Autism-Europe attended the European Day of Persons with Disabilities

Autism-Europe attended the European Day of Persons with Disabilities (EDPD) on 30 November - 1 December 2023.

• The EDPD is co-organised by EDF and the European Commission to mark the International Day of Persons with Disabilities. Autism-Europe's delegation of representatives and staff members attended the two-day event alongside 400 policymakers, experts and advocates. AE representative Ben Rowsome called for more support for autistic people in the labour market during the event. AE celebrated that the AccessCity2024 awards highlighted cities that focus on accessibility for the autistic community. More information about AE's participation in the event available here.





1.8. Autism-Europe responded to the European Commission's consultation on its initiative to support the development and strengthening of child protection systems in the EU

In 2023, the European Commission launched an initiative on the integration of child protection systems in the EU within the framework of the EU Strategy of the Rights of the Child. The initiative aimed at strengthening child protection systems by identifying gaps across the EU and providing recommendations on how to best utilise EU funds, policies, and laws towards this aim.

 Main output: Autism-Europe joined other disability organisations in submitting feedback on this initiative as part of the European Commission's public consultation process. In this feedback, AE explained that disabled children are at higher risk of abuse and violence and that there is currently a lack of access to education and autism training for professionals working in the field of child protection and law enforcement.



1.9. Autism-Europe's contribution to the 'comprehensive approach to mental health' consultation and attendance of the DG EU Health and Food Safety conference during World Mental Health Day

In February 2023, Autism-Europe had contributed to the call for evidence of the 'comprehensive approach to mental health'. In its response, Autism-Europe, welcomed the European Commission's growing commitment towards mental health and welcomes the upcoming initiative for a comprehensive approach to mental health. In line with Mental Health Europe, Autism-Europe called for a European Mental Health Strategy, with a clear timeline, adequate budget, objectives, as well as indicators to monitor progress. It is essential that the strategy will be anchored in a rights-based perspective and the psychosocial model of understanding mental health to address social determinants, structural barriers and provide tailored support.

• Find Autism-Europe's response to the call for evidence of the comprehensive approach to mental health <u>here</u>.

Autism-Europe attended the EU Health and Food Safety conference celebrating the European Commission's new 'comprehensive approach to mental health' on 10 October 2023, World Mental Health Day. Autism-Europe joined other civil society organisations in welcoming this approach as a first step to ensure a cross-sectoral perspective on mental health issues. AE also celebrated that the event highlighted the lack of support available for autistic people in this field.

Read more about the event and AE's take <u>here.</u>





EU Health and Food Safety conference, 10 October 2023 © Mental Health Europe

1.10. Autism-Europe joined 16 European organisations by signing a joint statement calling for urgent measures to address underinvestment and staff shortages in long-term care

Starting in 2023, the UN marked 29 October as the International Day of Care and Support, recognising the fundamental role of support and care work. As Autism-Europe continues to advocate for autistic people to access community-based, person-centred, affordable, and quality care in line with the provisions of the UNCRPD this joint statement amplified the organisation's message.





• Main output: Joint statement 'Building up European care capital: sustainable investment, not burdensome costs' addressing Member States (MS) and EU institutions. The statement calls to ensure that service provision is in line with the UNCRPD, urging the European Care strategy to be fully and adequately transposed by all MS in order to address the urgent need for qualified staff, support provision, and adequate recognition of caregivers, among other issues. Read the statement and AE's position on the issue here.

1.11. Autism-Europe joined 8 civil society organisations and issued a joint statement on the draft recommendation for the promotion of voluntary measures in the framework of CD-BIO's 7 June meeting

 Autism-Europe joined the European Disability Forum (EDF), Mental Health Europe (MHE), Inclusion Europe, the European Network of (Ex-)Users and Survivors of Psychiatry (ENUSP), the Validity Foundation, the European Association of Service Providers for Persons with Disabilities (EASPD), the Society of Social Psychiatry P. Sakellaropoulos, and the International Disability Alliance in welcoming CD-BIO's work on the request of the Committee of Ministers to commit to improving the protection and autonomy of persons in mental health care services.

While the joint statement recognises certain improvements, it crucially highlights a certain number of lacking considerations to ensure that coercion in mental healthcare services disappears. Read AE's article on the subject and the joint statement here.





1.12. Autism-Europe cooperated with Members of the European Parliament (MEPs)

Throughout 2023, AE continued its advocacy work by cooperating with MEPs through events and activities in order to raise awareness of autism, advocate for the rights of autistic people as well promote and encourage initiatives that support their needs across sectors (such as education, employment, inclusion, independent living, etc.)

- 28 March 2023: in honour of World Autism Awareness Day, Autism-Europe held a one-week photo exhibition. All featured photographers were autistic or family members of autistic people. For the inauguration, Autism-Europe welcomed several speakers: president of the European Parliament Roberta Metsola, co-host MEP Rosa Estaràs, MEP Dolors Montserrat, MEP David Lega and several of the featured photographers. All MEPs underlined the need to support autistic people and their families across Europe. Read more about the event and discover the exhibition booklet here.
- 30 March 2023: Autism-Europe co-hosted alongside MEP Rosa Estaràs a conference in the European Parliament under the theme of Autism-Europe's World Autism Awareness Campaign 'Building an inclusive society for autistic people'. Among the speakers were MEP Rosa Estaràs, Peter Vermeulen and Vincent Grimaldi de Puget, María Pindado from Autismo España as well as self-representatives José Cansado Estaràs and Joan Jesús Bisbal Mora. The conference provided attendees with a wide range of presentations, including discussions on policy, research, advantages of neurodiversity in the workplace, and first-hand experience accounts. Read more about the event here.







Autism-Europe inaugurate World Autism Awareness Day with a conference at the European Parliament



24 May 2023: Autism-Europe co-hosted alongside MEP Chiara Gemma a
conference in the European Parliament on the theme of 'Building
inclusive education and employment for autistic people'. The event took
place a day after the European Parliament of Persons with Disabilities and
featured several of Autism-Europe's projects as well as best practice
examples and accounts from self-representatives. Read more about the
event here.



Autism-Europe's EPPD-side event "Building inclusive education and employment for autistic people"



1.13. Autism-Europe provided input to the Party of European Socialists (PES) as part of their consultation process prior to the EU-elections

Autism-Europe is always open to provide input and feedback to policymakers and stakeholders and in 2023, PES contacted AE for input that would inform their campaign manifesto for the 2024 European elections.

- Autism-Europe submitted written input to PES in the framework of their Civil Society Dialogue to inform their 2024 European election manifesto in June 2023. This input detailed EU policy priorities for the autistic community for the next European elections, including political participation, adequate support, community-based living, accessibility, empowerment, etc.
- Autism-Europe joined other civil society organisations on 18 October 2023 at PES' headquarters in Brussels to discuss policy priorities. AE attended a follow-up meeting consultation on 2 February 2024, advocating to ensure accessible services for autistic people and their families.



In October 2023, meeting with PES to inform them of our priorities for autistic people as a followup to written consultation.



1.14. Autism-Europe continued its advocacy work supporting Ukrainian autistic and disabled people

Autism-Europe continued to work alongside Ukrainian member 'Child with Future' during 2023.

- Autism-Europe's active webpage on support for autistic Ukrainian refugees can be accessed <u>here</u>.
- The active Facebook page dedicated to supporting autistic people in Ukraine and autistic refugees by centralising information across several countries can be accessed <u>here.</u>





Autism-Europe participated in the fifth European Parliament of Persons with Disabilities that took place on 23 May 2023 at the European Parliament in Brussels. Pietro Cirrincione – Autism-Europe's autistic board member and representative of Autism-Europe's delegation during the event – called for urgent diplomatic efforts to end the war in Ukraine, as disabled citizens need urgent support in all crises. Cirrincione called for individualised support for Ukrainian autistic refugees, who suffer permanent trauma from the war. He ended his intervention by appealing to EU powers: 'When Ukraine is reconstructed, EU support should not be put into segregated and inaccessible services'.

Inna Sergiyenko, from our Ukrainian member <u>Child With Future</u> presented the preliminary results of a survey they conducted on the impact of the war in Ukraine and the situation of autistic refugees and their families during AE Annual General Assembly meeting in May.

Autism-Europe's intervention is available online <u>here.</u>



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



2.1. Autism-Europe organised bi-monthly online roundtables: 'Afternoon of good practices'

AE organised five roundtables in 2023 addressed to member organisations and relevant stakeholders in order to share good practices across Europe that support and promote the rights of autistic people. These roundtables also offer the opportunity for participants to network and share experiences on the topic.

The number of registered participants averaged 70 per session.

Main outputs:

- 26 January 2023: National/regional strategies for autism and experiences
 of co-production with policy-makers (part 1). Speakers: Jacqueline
 Campbell (united head of autism and learning disabilities, Scottish
 government), Charlene Tait (Scottish Autism, deputy chief executive),
 and Adam Harris (AsIAm CEO, Ireland)
- 31 May 2023: National/regional strategies for autism and experiences of co-production with policy-makers (part 2). Speakers: Ana Terrón Berbel (delegate for public affairs, Autismo España, Spain) and Zsuzsanna Szilvasy (Mars Foundation CEO, Hungary)



- 21 September 2023: Promoting accessibility. Speakers: Gadea Paredes on 'Cooperation between AENA and Autismo España for further universal accessibility for autistic people in airport environments' (Spain); Christine Flintoft-Smith on 'Creating more accessible public places for autistic people, examples of best practice from the National Autistic Society' (UK); Ainhoa Basarrate and Paula Fernández on the 'ErrazTEA project: expert team in inclusive cognitive accessibility and validation' (APNABI Autismo Bizkaia, Spain); Aline Hizette on 'Initiatives for the accessibility of shops and museums in Luxemburg' (Fondation Autisme Luxembourg, Luxembourg); Aitana García Lage on 'Accessibility network: a step towards improving accessibility throughout our community' (Galician Autism Federation, Spain).
- 26 October 2023: How to assess the quality of support services for autistic adults. Speakers: Hannelore Bout on 'The National Autistic Society Autism Accreditation standards' (National Autistic Society, UK); María Merino Martínez on 'The quality of life indicators guide' (Autismo Burgos & Fundación Miradas, Spain); Marcos Zamora on 'Quality management system to assess autism-specific organisations and services' (Autismo Sevilla, Spain); Maria Wroniszewska on 'Using the "What does good look like" resources produced by the University of Kent' (Synapsis Foundation, Poland).
- 14 December 2023: Accessibility to health services for autistic adults.

 Speakers: Guillermo Benito Ruiz on 'Barriers and facilitators to healthcare for autistic people in Spain (Autismo España, Spain); Aitana García and Cristina Couto on 'Healthcare improvement programme for patients on the autism spectrum by the Galician Autism Federation' (Federación Autismo Galicia, Spain); Mary Doherty on 'Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings' (University College Dublin School of Medicine, Ireland); Stéphanie Baz on 'Promoting access to treatment and health for people with disabilities' (Coactis Santé, France).



2.2. Autism-Europe delivered training for its members on key EU policies

- Autism-Europe's Study visit, 5 May 2023 (Stockholm, Sweden): AE members visited the office of the <u>Swedish Disability Rights Federation</u> to attend a workshop hosted by our member association Autism Sweden. It was a great opportunity to learn about the activities and priorities of our Swedish member and learn more about the situation of autistic people and their families in Sweden. Topics discussed included access to education and lifelong service provision as well as the recently adopted Swedish national guidelines for autism. We also had an exchange about gender bias in autism diagnosis, and our host highlighted the particular challenges faced by autistic girls and women, as well as for the elderly on the autism spectrum.
- Autism-Europe's Annual General Assembly, 6 May 2023 (Stockholm, Sweden): Autism-Europe delivered training to its members on the European elections and the advocacy goals of the organisation in this regard. AE reviewed key stakeholders and policymakers at EU level and outlined key actors and activities for the Parliament elections of 2024 – including drafting pledges, joining other disability organisations in joint advocacy goals, and contacting political parties, think tanks and EU media outlets.
- Autism-Europe's Council of Administration, 7 May 2023 (Stockholm, Sweden): AE delivered training to its members on the European Strategy for the Rights of People with Disabilities. AE outlined the flagship initiatives of the strategy as well as the areas in which AE will be involved and provide input, such as the expert working group on social services of excellence for persons with disabilities, the European disability card, the disability platform, or the disability employment package.



 Autism-Europe's Council of Administration, 2 December 2023 (Brussels, Belgium): AE delivered training to its members on the topic of the European Disability Card, discussing its scope as well as the recent updates regarding the adoption process and AE's input that was submitted to the European Commission.





3. Collaboration and cooperation with other EU-level networks and stakeholders

3.1. Autism-Europe collaborated with the European Disability Forum

Autism-Europe is a full member of the European Disability Forum (EDF) and is part of its elected board of directors. During 2023, AE contributed to EDF's events and activities.

Main activities:

- April 2024: EDF published an article for World Autism Awareness Day (WAAD), highlighting AE's 2023 campaign as well as the events that were organised at the European Parliament to celebrate this international day (photo exhibition inauguration event and conference). Read EDF's article here.
- 23 May 2023: AE's delegation participated in the European Parliament of Persons with Disabilities (organised by EDF at the European Parliament) and advocated for autistic refugees as well as disabled people more widely to access necessary support. Autism-Europe's intervention is available here.



Pietro
Cirrincione from
Italy calling for
assistance for
Ukrainian
refugees with
disabilities.



April 2023: AE provided feedback for EDF's Manifesto on the 2024
 European elections. Read the final manifesto that was adopted during
 the 5th European Parliament of Persons with Disabilities here.



9-10 June 2023: Autism-Europe representative from Ireland Ben
Rowsome attended the European Youth Event 2023 in Strasbourg
(France) as part of EDF's Youth Committee. AE advocated for making
events accessible to disabled participants and contributed to
discussions on the accessibility of Europe's current labour market. More
information about AE's involvement in the event available here.



Autism-Europe representative from Ireland Ben Rowsome attended the European Youth Event 2023 in Strasbourg



 June 2023: Autism-Europe joined EDF's campaign against forced sterilisation of people with disabilities. AE published an article on the subject, outlining current legislation and overviewing the position of several Member States on this subject.

Read AE's article on the campaign and its significance for the autism community <u>here</u>.

- 10 November 2023: AE director Aurélie Baranger and AE and EDF board member Pietro Cirrincione delivered a training to EDF staff on accessibility, acceptable language, employment as well as support/accommodations in the workplace for autistic people.
- 30 November 1 December 2023: AE attended the European Day of Persons with Disabilities, co-organised by EDF and the European Commission to mark the International Day of Persons with Disabilities. Please refer to section 1.7. of this report for more information.



3.2. Autism-Europe received training from Inclusion Europe

On 20 October 2023, Inclusion Europe delivered a training on Easy-to-Read for Autism-Europe's members of staff to support Autism-Europe's efforts to produce accessible information for the users of AE's website, publications, and social media.



3.3. Autism-Europe cooperated with the Social Platform

Autism-Europe is a full member of the Platform of European Social NGOs (Social Platform), participating in members' meetings.

3.4. Autism-Europe's role in the European Expert Group on the Transition from Institutional to Community-based Care

The European Expert Group (EEG) on the Transition from Institutional to Community-based Care tracks policies in relation to deinstitutionalisation, advocates for family and community-based support, and monitors that EU funds are not used to promote institutionalisation of disabled people, but rather support services in the community that foster independent living. AE is a full member of the EEG.

- In 2023, AE participated in the meetings and events of the EEG, closely following the updates regarding deinstitutionalisation around the EU. One of the key activities was the study session organised by the European Expert Group on the transition from institutional to community-based care that took place on 12 October 2023. It brought together professionals, people who are institutionalised, their families and representative organisations to discuss the shift toward meaningful inclusion in the community.
- In early 2024, AE became co-chair of the EEG alongside COFACE.

3.5. Autism-Europe collaborated with the European Platform for Rehabilitation

Autism-Europe and the European Platform for Rehabilitation (EPR) organised a joint event on the subject of employment for autistic people on 25 October 2023.



• 25 October 2023: AE and EPR co-organised the 'Autism at Work: Overcoming Challenges, Driving Change' webinar. This two-hour event reviewed the challenges, opportunities and current trends regarding the employment of autistic people. Both organisations presented their EU projects that foster access to the labour market for autistic people. EPR members Heliomare (The Netherlands) and Theotokos Foundation (Greece) as well as Autism-Europe members Autismo España (Spain) and Help Autism (Romania) presented their advocacy work and programmes that support and promote the employment of autistic people. Policy Officer at the DG for Employment, Social Affairs and Inclusion at the European Commission then provided a policy perspective to the discussion as well as updates on the ESRPD. Access the agenda of the event here.

3.6. Autism-Europe collaborated with ADHD Europe

Autism-Europe collaborated with ADHD Europe in 2023 in the framework of the R2D2-MH (Risk and Resilience in Developmental Diversity and Mental Health) Horizon Europe research project, which started in 2022.

• More information about the project in section 6.16 of this report.

3.7. Autism-Europe collaborated with Autism Alliance of Canada

Autism Alliance of Canada organised a side-event to the United Nations' 16th session of the Conference of State Parties to the Convention on the Rights of Persons with Disabilities entitled 'Challenges, Best-practices, and a Way Forward: Looking at National Autism Strategies through the lens of the Convention on the Rights of Persons with Disabilities'. The event was held at the United Nations' headquarters in New York and was also broadcasted online.

 AE President Harald Nederland participated in the event and was one of the key speakers. Read more about the event <u>here.</u>



4. Awareness-raising and dissemination



Autism-Europe continued its awareness-raising and dissemination work throughout 2023 as it is integral to AE's advocacy. AE shared knowledge, research, guidelines, news, and policy updates throughout its various communication channels to a diverse audience – including policymakers and stakeholders at EU and national levels, self-representatives, members of the autistic community, and professionals.

4.1. Autism-Europe continued its dissemination work through its online channels

Autism-Europe continued to disseminate relevant EU developments, news, research, etc. through its online channels to its members and wider audience. Throughout 2023:

- AE sent 4 newsletters (in English and French) to over 7.2K recipients.
 Access our newsletters and 3 newsflashes here.
- AE continued to publish articles and events on its website (available in English and French). AE's website had 50K visits in 2023. Access AE's website here.
- AE continued to grow its social media presence and by the end of the year, AE had 1,883 new followers throughout its different social media outlets (5.45% increase compared to 2022)
- AE also sent 4 newsletter in Easy to Read in EN and FR. Available <u>here</u>.



• FACEBOOK

• INSTAGRAM

• TWITTER / X

• LINKEDIN in

• YOUTUBE

NEW FOLLOWERS	PROFILE VISITS	REACH
710	7.8K	50.4K
400	3.2K	4.OK
227	2.6K	-
359*	1.7K*	-
187	-	-

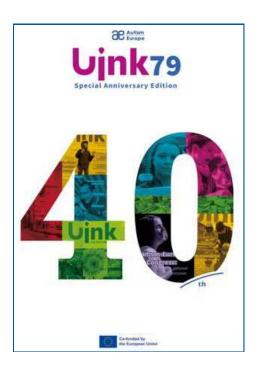
^{*}from March until December



4.2. Autism-Europe's LINK magazine publications

Autism-Europe publishes the LINK magazine to inform the wider autism community about relevant European policy and legislation as well as good practices and research in the fields of inclusion, accessibility, and support. Each edition is produced in English and French. The magazine is distributed online and in print to its subscribers.

- In 2023, AE published the 79th issue of the LINK magazine, distributing 1300 copies. This edition of the LINK magazine celebrated the organisation's 40th anniversary, reviewing AE's journey in advocacy and overviewing both the achievements and necessary progress across sectors.
- The 80th issue of the LINK magazine includes articles on the European
 Disability Card, the adoption of the 'Resolution on harmonising the rights
 of autistic persons' by the European Parliament, the subject of access to
 higher education and healthcare as well as an analysis of homelessness
 among the autistic population, among other topics.







4.3. Autism-Europe's 'Building an inclusive society for autistic people' 2023 campaign

Since the United Nations declared in December 2007 that World Autism Awareness Day would be celebrated on 2 April, Autism-Europe has conducted international campaigns to raise awareness and advocate for the rights and quality of life of autistic people. In 2023, Autism-Europe launched a Europe-wide campaign under the theme 'Building an inclusive society for autistic people', drawing attention to the progress but especially the building blocks that are needed to ensure that society is truly inclusive of autistic people.

In 2023, AE also celebrated its 40th anniversary, highlighting the achievements made since 1983 as well as the work that is ahead to advocate for autistic people's rights and quality of life.





• Read more about the campaign <u>here</u>, including the manifesto, communications toolkit, and campaign activities – such as the photo exhibition representing autistic experiences at the European Parliament, the opening event of the exhibition as well as a conference organised with MEP Rosa Estaràs. The opening event of the photo exhibition was attended by Members of the European Parliament, including EP President Roberta Metsola, Rosa Estaràs, David Lega, etc., participants, and a wide range of civil society representatives. The photographers featured in the exhibition were all autistic or family members of autistic people. To find out more about these events, please refer to section 1.12 of this report.









Autism-Europe launches a one-week photo exhibition at the European Parliament, April 2023.





4.4. Autism-Europe worked with its members in preparation for the upcoming multi-annual 'Not Invisible' autism awareness campaign

Autism-Europe worked alongside its members to establish the objectives of the future multiannual awareness raising campaign. AE carried out a redesign of the awareness raising campaign in 2023:

From June 2023-December 2023: 6 focus groups were organised with AE members to establish campaign priorities, a creative agency 'Hello Tomorrow' was selected to carry out the redesign alongside AE and members were consulted on the theme and final results, notably via a workshop to define the main features of the visual identity.

Read more about AE's 'Not Invisible' campaign <u>here</u> (objective of the campaign, advocacy goals, press release, activities, pledge for European parliament candidates, etc.)







4.5. Autism-Europe was featured in European and international news outlets

Engaging with the media is part of Autism-Europe's awareness-raising efforts. In 2023, Autism-Europe was featured and interviewed by several international media outlets, including:

- **5 October 2023**: AE was featured in Euractiv's piece on the EU Resolution 'Harmonising the rights of autistic people', particularly regarding AE's work advocating against harmful and unproven treatments. AE was also quoted for its reaction to the resolution. Read the article <u>here</u>
- 24 November 2023: AE's director, Aurélie Baranger, was interviewed as
 part of Euronews's article on recent research regarding autistic people's
 lower life expectancy. Read the Euronews article here and the one
 published on yahoo!news here. Read AE's own take on the subject <a href=here.

4.6. Preparing Autism-Europe's upcoming International congress in Dublin (Ireland)

The Scientific Committee for Autism Europe Congress 2025 hosted by Aslam in Dublin was announced and held meetings in 2023. Aslam is determined to see autistic people represented on every level of the event. Autistic doctors, researchers and psychiatrists continue to lend their expertise to understand the needs and improve the lives of the autistic community. More information: AslAm announces Scientific Committee for Autism Europe Congress 2025 - AslAm



5. Network organisation and management

Autism-Europe (AE) is an association gathering almost 90 national and regional associations advocating for the rights of autistic people from 40 countries, including 26 from the European Union.



Autism-Europe's statutes have been drafted to ensure the Council of Administration represents every country of the European Union that is part of AE's membership. All of Autism-Europe's members have the right to participate in the Annual General Assembly (AGA). Every two years, the AGA elects the Council of Administration (CA). Half of the Council of Administration is renewed every two years. The Council of Administration elects AE's President amongst its members, who must be an autistic person or an autistic person's parent.

5.1. Autism-Europe's governing bodies' meetings

Autism-Europe's Annual General Assembly and first Council of Administration meetings took place on 6-7 May 2023 in Stockholm (Sweden) and online.

Study visit 5 May: AE members visited the office of the <u>Swedish Disability</u>
 <u>Rights Federation</u> to attend a workshop hosted by AE's member
 association Autism Sweden on the activities, priorities and situation of
 autistic people and their families in Sweden.



 Annual General Assembly 6 May: AE's 2023 work programme and budget were adopted, as well as the report of activities from 2022, developed under the EU Citizens, Equality, Rights, and Values Programme. AE members were also updated on the different EU projects the organisation is involved in.





Stockholm, May 2023.



Inna Sergiyenko, from AE's Ukrainian member 'Child With Future', presented the preliminary results of a survey they conducted on the impact of the war in Ukraine and the situation of autistic refugees and their families.

AE members received training on the upcoming European elections in 2024 and discussed AE's advocacy priorities in this regard as well as AE's future awareness campaigns. AE members also discussed upcoming themes for the capacity-building 'Afternoons of good practice' workshops that AE hosts.



In 2023, AE welcomed three new members during the AGA: <u>Federació</u>

<u>Catalana d'Autisme (Spain)</u> as an affiliated member, <u>AO 'SOS Autism'</u>

<u>(Moldova)</u> and <u>Together and Healthy Public Union (Azerbaijan)</u> as associated members.

AE celebrated its 40th anniversary with its members, alongside its current and three former presidents, Zsuzsanna Szilvasy, Evelyne Friedel, and Donata Vivanti. The attendees shared their insights regarding the evolution of Autism-Europe over the past decades and the future challenges for the autism community.

• Council of Administration 7 May: AE's Irish member Aslam presented the latest updates regarding the next Autism-Europe International Congress that will take place in Dublin (Ireland) in 2025.





AE International Congress 2025

Additionally, a new representative from Autism Switzerland, Romane Garcia, was coopted to the Council of Administration.

Read more about AE's Annual General Assembly and first Council of Administration meeting <u>here.</u>

Autism-Europe's second Council of Administration meeting took place on 2-3 December 2023 in Brussels (Belgium) and online.

 AE delivered training to its members on the recent updates of the European Disability Card (including predicted timeline, scope, etc.)
 Members from countries participating in the pilot project of the card shared their experiences and discussed concerns as well as opportunities.



Adam Harris, CEO of AsIAm (Ireland), then shared with the members the theme of the Autism-Europe international congress that will take place in Dublin (Ireland) in 2025: 'Quality of life: research policy and practice'. The theme was chosen through a consultation process with the European autism community.

AE staff proceeded to share with members the visual identity of AE's future multiannual awareness campaign 'Not invisible' and discussed how to engage in the 2024 European elections.

 The members of the Council of Administration approved President Harald Neerland for a second term. Neerland presented his renewed executive committee, which includes Marta Roca and Stef Bonnot-Briey as vice presidents, Liga Berzina as Secretary, Adam Harris as treasurer, Zsuzsanna Szilvasy as former president and Monique Post.

Read more about AE's second Council of Administration meeting of 2023 here.

5.2. Autism-Europe continued promoting self-advocacy within its network and activities

AE continuously strives for autistic people to have a strong presence in its governing bodies and activities. Almost half of the members of AE's newly elected executive committee (three people out of seven total) are autistic. AE also always strives for self-advocates to participate in the organisation's activities, from focus groups to events at the EU level.





HARALD NEERLAND
PRESIDENT | NORWAY



ZSUZSANNA SZILVASY
VICE PRESIDENT | HUNGARY



MARTA ROCA
VICE PRESIDENT | SPAIN



BONNOT-BRIEY

VICE PRESIDENT | FRANCE



LIGA BERZINASECRETARY | LATVIA



TOMASZ MICHAŁOWICZ

TREASURER | POLAND

Autism-Europe's Executive Committee in 2023





AURÉLIE BARANGER
DIRECTOR



CARMEN CLEMENTE
COMMUNICATIONS AND
CAMPAIGNS MANAGER



CHRISTIAN TAKOW

ADVOCACY & PROJECT OFFICER



MAGALI VLAYEN
TRANSLATOR & SECRETARY



ETXANE O. SCOTTPROJECT AND RESEARCH OFFICER



CAMILLA LOMBARDICOMMUNICATIONS OFFICER

Autism-Europe's Secretariat in 2023





Autism-Europe continued to work on EU-funded projects alongside partners from across Europe that promote the quality of life of autistic people and seek to provide opportunities for the autism community. All information relating to current and past projects that AE has been involved in can be accessed through <u>AE's website</u>.

6.1. DiGiTool (Digital Inclusive Tool)

The DiGiTool (Digital Inclusive Tool) project trained teachers (mainstream and special education) to work with autistic students, using Information and Communication Technologies (ICT). The project, funded by the Erasmus+ Programme, started in 2021 and ended in 2023.

In 2023, AE participated in the development of the project results
 (including the training toolkit) and was responsible for its dissemination,
 which included sharing the outcomes with a European-wide audience
 and organising a final multiplier event at the <u>European Parliament on 24</u>
 <u>May 2023</u>. Visit the <u>project's website</u> for more information about the
 results and participating partners.





6.2. INFUSE (Seeding competences and harvesting work inclusiveness for adult autistic people)

The INFUSE project developed a best practice model to support access to employment for autistic people in the agricultural sector, supporting and training autistic participants and professionals in this field of work. This one-year Erasmus+ pilot project started in 2022 and ended in 2023 and was implemented in Italy.

 In 2023, AE developed the <u>best practice compendium</u> of programmes and services supporting autistic people in employment across Europe and reviewed the training course and evaluation plan. AE also coordinated the project's dissemination results and organised a final multiplier event at the European Parliament on 24 May 2023 (for more information about this event, please refer to section 1.12 of this report). Visit the <u>project's website</u> for more information about the results and participating partners.



6.3. WIN-WITH-U (Workplace inclusion and employment opportunities for youth with autism)

The WIN-WITH-U project developed training and learning modules for employers and autistic jobseekers to effectively support autistic jobseekers and employees to access and thrive in the workplace. This Erasmus+ project started in 2020 and ended in 2023.





In 2023, AE was involved in project activities and supported the
dissemination of project results, which culminated in a <u>final multiplier</u>
event at the <u>European Parliament on 24 May 2023</u>. Visit the <u>project's</u>
website for more information about the results and participating
partners.

6.4. Autism Friendly Spaces: The Employability Twist

The Autism Friendly Spaces – The Employability Twist project developed trainings for autistic people to identify their skills and strengths and for employers to adapt their workplaces to be autism-friendly. It also provided job support for autistic people during the job search and onboarding processes and designed a protocol for workplaces to be certified as an autism-friendly space. The final project result is a policy paper analysing the current situation of autistic people in the labour market in several countries and at the EU level. The paper also issues recommendations to national and European policymakers. This Erasmus+ project started in 2022 and will end in 2024.

In 2023, AE co-developed the final policy paper and reviewed the
additional project results. AE also supported the dissemination of project
activities (including on social media) and organised the final multiplier
event of the project at the European Parliament on 30 January 2024
alongside MEP Alex Agius Saliba (more information about the event here)
Visit the project's website for more information about the results and
participating partners.





6.5. Talenti Latenti

The Talenti Latenti project has developed a comparative analysis of skills validation systems around Europe and provided training to professionals in the fields of employment and VET on skills validation for neurodivergent people. The project has also provided training to families of autistic people and people with other disabilities, thereby sharing information on how to support their relative in the process, ensuring that more disabled people have access to skills validation and certification systems. This Erasmus+ project started in 2021 and will end in 2024.

In 2023, AE co-developed the training materials and drafted the parent training modules (which included <u>a training video</u>). AE also provided a training event on the subject of skills validation – the recording of the event can be accessed <u>here</u>. AE also coordinated the dissemination activities of the project, organising a final multiplier event of the project at the European Parliament on 30 January 2024 alongside MEP Alex Agius Saliba (more information about the event can be found <u>here</u>)

Visit the <u>project's website</u> for more information about the results and participating partners.





6.6. Autism-IncluDi: Autism inclusion in distance learning

The Autism-IncluDi project is creating a competences framework and trainings for the use of ICT tools in education, both for in-person and online learning. This Erasmus+ project started in 2022 and will end in 2024.

 In 2023, AE co-developed the competence framework and training programme and coordinated the dissemination of the project as well as the policy recommendation paper (to be completed in 2024). Visit the <u>project's website</u> for more information about the results and participating partners.



6.7. IDEAL: Inclusive Digital Education for Autistic People Learning

The IDEAL project will provide a platform in 6 European languages with accessible digital tools (such as Apps and other digital resources) for autistic people, their support networks, and professionals. Communication, education, social skills, health management, functional skills, and entertainment will be some of the core areas of the platform. This Erasmus+ project started in 2022 and will end in 2024.

 In 2023, AE carried out focus groups to research the digital needs of autistic people and drafted a report with the findings, which informed AE's research work for the repository of digital tools. AE also coordinated the dissemination activities of the project. Visit the <u>project's website</u> for more information about the results and participating partners.





6.8. SACREE: Sport and Autism, from a scientific diagnosis to the creation of a pedagogical European model

The SACREE project is developing research that evaluates autistic people's access to sport activities and the various considerations – including motor abilities and psychosocial implications – of practising different types of sport for people on the autism spectrum. The project has developed the first version of a programme for sport facilities to learn about autism and the accommodations that could be needed to provide safe and inclusive sport practices. The second and revised version of the programme – reviewed by expert professionals and autistic people – will be available in 2024. This Erasmus+ project started in 2022 and will end in 2025.

 In 2023, AE carried out focus groups to research the needs and barriers that autistic people with different support needs experienced when accessing sport activities. AE also participated in the drafting of the first version of the programme and coordinated the dissemination activities of the project. Visit the <u>project website</u> for more information about the results and participating partners.





6.9. My Virtual World - 3D job training for autism

The My Virtual World project has developed training for employers, educators, and trainers using 3D technology to showcase the barriers that autistic people face in the workplace as well as the practices that can be adopted to promote inclusive employment. The project's outcomes include adapting VET programmes to suit the skills of individual autistic learners through VR and providing a 3D environment platform for VET professionals. This Erasmus+ project started in 2022 and will end in 2024.



 In 2023, AE contributed to the drafting of the training materials (including the online toolkit and methodology) and supported partners in the dissemination activities of the project. Visit the <u>project's</u> website for more information about the results and participating partners.

6.10. Autism Spectrum Pathways – Inclusivity beyond formative education and in the workplace

The Autism Spectrum Pathways project has developed national research reports as well as an international research report reviewing legislation, policies, and practice regarding access to employment for autistic people. The project will also develop an employment guide, training modules for autistic jobseekers, VET professionals and employers, a digital map of autism organisations and autism-friendly companies as well as a YouTube page of video testimonies showcasing autistic people's access to employment. This Erasmus+ project started in 2023 and will end in 2025.



In 2023, AE carried out focus groups to research
the barriers to accessing or staying in
employment for autistic people as well as
current opportunities. AE drafted a national
report and contributed to the international
report. AE is currently coordinating the
employment guide and supporting the
dissemination activities of the project. Visit the
project's website for more information about the
results and participating partners.



6.11. GREEN ASC VET - Metautism

The Autism Spectrum Pathways project has developed national research reports as well as an international research report reviewing legislation, policies, and practice regarding access to employment for autistic people. The project will also develop an employment guide, training modules for autistic jobseekers, VET professionals and employers, a digital map of autism organisations and autism-friendly companies as well as a YouTube page of video testimonies showcasing autistic people's access to employment. This Erasmus+ project started in 2023 and will end in 2025.



 In 2023, AE developed research analysis in preparation for the training programme and coordinated the dissemination plan and activities alongside the project coordinator. Visit the <u>project's website</u> for more information about the results and participating partners.



6.12. Neurodivergent - Optimising learning outcomes for young adults with Asperger's in VET

The Neurodivergent project will provide training to educational professionals on how to approach and support students on the autism spectrum and improve their educational experience. This Erasmus+ project started in 2020 and ended in 2023. The Neurodivergent project developed training for VET professionals as well as reports analysing the inclusion of people on the autism spectrum in the workforce.

 Visit the <u>project's website</u> to learn more about project activities and participating organisations.





6.13. EMPOWER – Design and evaluation of technological support tools to empower stakeholders in digital education

EMPOWER is a European interdisciplinary research project funded by the Horizon Europe programme and led by the University of Valencia (Spain), that will develop a unique technological learning platform to enhance personalised education of children with neurodevelopmental conditions. It will create a novel educational platform with a game-based approach and new paradigms suggesting that executive function and emotional self-regulation are two key sets of skills to target in the educational support of neurodivergent students. This Horizon Europe project started in 2022 and will run until 2025.



 In 2023, AE coordinated the dissemination of project results. Visit the project's website for more information about the results and participating partners

6.14. CANDY: Comorbid analysis of neurodevelopmental disorders and epilepsy

CANDY is a Horizon 2020 project that is researching rare and common genetic variants that are shared in many neurodevelopmental disorders, exploring the possibility that immune dysregulation and the microbiome may play a role. It started in 2020 and will end in 2024. This project could point to personalised treatment to better healthcare treatment for people with neurodevelopmental conditions, including autism.

 To learn more about the project results and the participating organisations, visit the project's website <u>here</u>.

6.15. AIMS-2-TRIALS - Innovative Medicine Studies-2-Trials

The AIMS-2-TRIALS project is funded by Innovative Medicines Initiative 2 Joint Undertaking and Horizon 2020, among other grants. It is researching how autism develops from before birth into adulthood, studying biomarkers and their role in the development of different conditions.





The aim of this project is to provide innovative research to better the healthcare support for autistic people. The project consortium – including autism representatives, non-profit organisations, universities and research institutes, public bodies, SMEs, pharmaceutical industries, and associations – will work with representatives of the community to integrate their views into its future work.

 To learn more about the project results and the participating organisations, visit the project's website <u>here</u>.

6.16. R2D2-MH (Risk and Resilience in Developmental Diversity and Mental Health)

R2D2-MH is a Horizon Europe research project, which started in 2022 and will end in 2027. The project aims at researching risk and resilience factors associated with the mental health of people with different neurodevelopmental conditions, including autism, ADHD, and intellectual disability. The project is being co-created alongside self-representatives.

• To learn more about the project activities and the different organisations involved, visit the project's website <u>here.</u>



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