

Activity Report

2024





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Annual Report 2 2024





Editorial team

Aoife McGarry Editoral advisor

Aurélie Baranger Co-author and editor

Christian TakowEditoral advisorDavid EatonEditoral advisor

Isaure Mercier Co-author, editor and designer **Fernanda Buriola** Co-author, editor and designer



Autism-Europe team at the European Parliament on World Autism Awareness Day 2024, on April 2, 2024.

Cover picture(s): Pictures from the launch of the Proposal for the European Commission's Framework for Social Services of Excellence for Persons with Disabilities, ENIL on April 9th, 2024, WAAD 2024 and AE council of administration November 2024 in Brussels.

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Executive Summary

In a year marked by the European elections, Autism-Europe (AE) has worked to keep autism firmly in the public spotlight and to advance the rights of autistic people. Founded in 1983, Autism-Europe is an umbrella organisation of over 90 national autism associations, self-advocates, and families in 40 countries. For more than 40 years, AE has been dedicated to improving the lives of an estimated 7 million autistic people in Europe.

AE works closely with European institutions and civil society organisations to ensure the needs and concerns of the autistic community are heard and addressed, across various sectors such as education, employment, access to independent living, community support services, healthcare and inclusion. AE grounds its work in the UN Convention on the Rights of People with Disabilities (UNCRPD) and is committed to advancing the implementation of the European Strategy for the Rights of Persons with Disabilities (ESRPD) across all Member States.

In 2024, AE carried out its mission to encourage policy change and foster public awareness. AE began the year by celebrating a major advance for the freedom of movement of people with disabilities with the adoption by the European Council of the European Disability Card and Parking Card law, the result of 10 years of advocacy by the disability movement.



Ahead of the EU elections, AE and its members launched its new multiannual 'No invisible' campaign at the European Parliament to ensure autism is duly addressed in the next EU political agenda. Many members and candidates to the European Parliament across Europe endorsed AE's pledge and committed to advance its objectives in their upcoming mandate.

As we start of a new political cycle, both the Commission's new political guidelines for 2024-2029 and the European Commissioner for health's roadmap mentioned autism among their priorities in the autumn.

AE collaborates 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), among others.

AE serves as a platform for its members and key stakeholders to share autism research and best practices. In this regard, AE regularly organises mutual-learning events, training sessions, conferences, and roundtables that foster innovative discussions from diverse perspectives. AE is also actively preparing for its International congress to be held in Dublin in September 2025. AE's European and international projects focus on improving the quality of life of autistic people in various areas, such as access to healthcare, employment, and education. These initiatives aim to develop tangible results for the autism community, professionals, and the wider public.



Strategic objectives for 2024

- To engage in regular dialogue with the European Commission and policymakers, both at the European and national levels, to implement the European Pillar of Social Rights (EPSR) and the European Strategy for the Rights of Persons with Disabilities 2021-2030 (ESRPD). Autism-Europe has striven to ensure the concerns of autistic people and their families are mainstreamed to advance the realisation of their rights in relation to education, health, inclusive employment, accessibility and independent living, decent standard of living, access to legal capacity and voting, as well as protection from violence.
- To foster the 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 and monitor the implementation and mainstreaming of the ESRPD and EPSR at the national level, notably through data collection to inform the European semester, influencing the country-specific recommendations.
- To push for the recognition and full implementation of the European Disability Card across all EU Member States, contributing to remove barriers to the free movement of persons with disabilities.
- To promote the inclusion of autistic people, their families, and representative organisations in all decision-making processes that impact their lives, and advocate for accessible elections.



- To integrate the perspectives of autistic people 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 promote mutual learning, 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 challenge stereotypes around autism and disability by organising multiannual awareness-raising campaigns, and promoting acceptance, inclusion, and participation.



Autism-Europe members at our 2024 Annual General Meeting and meeting in Dublin, Ireland, May 10-12, 2024.



Key activities

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

AE's role involves providing expertise to ensure autistic people's concerns are considered in all relevant policy-making. Since 2021, Autism-Europe has actively participated in the EU Disability Platform, collaborating with civil society organisations, Member States, and EU institutions to uphold the rights outlined in the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and support the implementation of the European Strategy for the Rights of Persons with Disabilities (ESRPD).

1.1 Autism-Europe's advisory role towards the European Commission, notably in the context of the EU Disability Platform

Since 2021, AE has been an active member of the Disability Platform and has worked alongside 13 civil society organisations, representatives of Member States, and EU institutions to uphold the rights outlined in the UNCRPD and the ESRPD. In this role, AE provides expertise to ensure that autistic individuals are included in all policy discussions on disability inclusion.

- In 2024, AE participated in the Platform's quarterly meetings and contributed its in-depth knowledge to various subgroups, including those focused on the Social Services of Excellence, the Employment Package, Independent Living, and the European Disability Card.
- In July, AE Director met with Mario Nava Director General of DG EMPL alongside others CSOs and highlighted the need to follow up on the European Parliament resolution on Harmonising the rights of autistic people adopted in October 2023.



Main output: In July, AE provided feedback on the Monitoring, Evaluation, and Revision of the European Strategy for the Rights of People with Disabilities. AE called for stronger follow-up actions, sufficient investment, and adequate regulations in the next Multiannual Financial Framework to promote the rights of people with disabilities and support inclusion in the community. For more information about the activities of the EU Disability Platform, click here.

1.2. Autism-Europe celebrated a major advance for the freedom of movement: the adoption of the European Disability Card and Parking Card



The year began with the adoption by the European Council of the European Disability Card and Parking Card legislation, the result of 10 years of advocacy by the disability movement.

This achievement marks a crucial step in advancing mutual recognition of disability status across Europe and improving mobility for disabled persons within the European Union for travel and short stays.

Over the years, AE has continuously been involved throughout the consultation process to voice the needs of the autism community.

AE will now support its implementation at the national level, alongside the European Disability Forum. You can read more about this milestone agreement and AE position here.



1.3. Autism-Europe worked with its expert group on Social Services of Excellence for autistic people to inform the EU flagship initiative

In 2023, Autism-Europe set up an expert group on social services of excellence for autistic people to inform the flagship initiative of the ESRPD in relation to a '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. AE continued to work with the group to define its position paper on the topic, which informed its work in the framework of the Disability subgroup on the topic.

In April 2024, Autism-Europe presented the position of its autism expert working group, at an event at the European Parliament organised by ENIL, which gathered a wide range of CSOs and European Commission's representatives. AE stressed the challenges autistic people encounter in accessing quality social services, such as disability recognition and access to diagnosis. They called for the development of autism-friendly services, specific training, and improved coordination in social service delivery. You can read more about the event here.







1.4. Autism-Europe supported better labour market outcomes for autistic people

On 30 January, hosted by Member of European Parliament (MEP), Alex Agius Saliba from Malta, Autism-Europe (AE) discussed the promotion of employability for autistic people in Europe and shared results from initiatives conducted across Europe. MEP Agius Saliba called for the implementation of existing legislation safeguarding the right to employment for autistic people across Europe through concrete actions.

Autism-Europe's director Aurelie Baranger underlined that developing access to employment for autistic people requires a multipronged approach. It should include access to vocational training, accessibility and reasonable accommodation in the recruitment process as well as in the workplace and adequate recognition of autistic's people skills. Monika Chaba, policy officer at the Directorate Employment and Social Affairs of the European Commission presented the work conducted in the framework of the Employment Disability Package unveiled by the Commission.





In the context of the package, the European Commission published a set of guidelines on Reasonable Accommodation in the workplace in June, with recommendations ranging from inclusive recruitment to safe and healthy working conditions. These guidelines aim to help employers fulfill their obligation to adopt effective, practical, and tailored work practices that meet the needs of all employees. As part of the Disability Platform subgroup on the employment work package, AE shared key recommendations and practical examples of good practices to foster inclusive and accommodating workplaces where autistic people can thrive. More information about the activities related to the 'Reasonable accommodation at work guidelines' can be found here.

Main output:

- Reasonable Accommodation in the workplace
- Watch the conference: <u>Developing the Employability of</u>
 Autistic People in Europe, <u>Policy and Practice</u>





1.5. Autism-Europe's contribution to the newly published EU Guidance on Independent Living for Persons with Disabilities

In November, the European Commission released its flagship 'Guidance on Independent Living and Inclusion in the Community of Persons with Disabilities in the Context of EU Funding'. This document provides recommendations to Member States on how to use EU funding to support the transition to independent living for persons with disabilities. It is a significant first step in ensuring the right of individuals to live outside of care institutions and to be fully included into their communities.

Main output: As both a member and co-chair of the European Expert Group (EEG), AE played an active role in supporting the elaboration of the guidelines. In April, AE provided input and analysis from the autism community so that the guidance is rooted in lived experience.





You can read more about AE's position on the new EU guidance on independent living here.

1.6. Autism-Europe's demands reflected in the EU Commission guidelines and Commissioner roadmap for the next five years

On 17 September 2024, European Commission President Ursula von der Leyen unveiled the European Commissioners designates, their portfolios and mission. AE warmly welcomed the European Commission's commitment to work towards a 'common approach' to autism at the EU level as stated in the portfolio of the Commissioner for Health. It echoes Autism-Europe longstanding call for a coordinated and strategic response to meet the needs of autistic people at the EU, national and regional level. In line with international recommendations, AE calls for the EU 'common approach' to be holistic, rights-based, adequately funded and promote a cross-sectoral policy response to address the pervasive discrimination experienced by autistic people in all fields of life.

An EU common approach must be designed and implemented in full cooperation with representatives of autistic people and their families. Therefore, AE looks forward to working closely with the European Commission and all interested stakeholders in all future steps. It is also crucial that equality and advancing disability rights remain at the forefront of the European Union's agenda.



In 2024, another milestone was the recognition of autism research as a key political priority for the 2024-2029 policy guidelines of the European Commission published in July. This marks a key opportunity to promote research that meets the needs of autistic people and their families to improve their quality of life. However, AE - alongside other disabled people's organisations - was concerned about the initial lack of any mention of disability in the European Commission guidelines. You can read more about AE's position here.

However, Ms. Lahbib, the European Commissioner-designate for Preparedness, Crisis Management, and Equality, stressed in her opening statement the importance of deinstitutionalisation and the need to improve social support for disabled people, two key priorities for the disability movement.



Main output: read AE statements:

- AE welcomes autism research as a priority in the future mandate of the European Commission and calls for a clear commitment for disability rights
- AE welcomes the European Commission's commitment to a common approach to autism and calls for disability rights to remain at the forefront of EU's agenda



1.7. Autism-Europe called for accessible elections and raised awareness of MEP candidates in the framework of its campaign 'Not invisible'.

Accessibility and addressing the needs of autistic people was a key focus of Autism-Europe's work during the EU elections. AE collaborated with the European Disability Forum to raise awareness of the legal and practical barriers that prevent millions of persons from exercising their rights to vote and stand for elections as other EU citizens.

Throughout 2024, AE's advocacy work included liaising with (candidates) Members of the European Parliament to voice the needs of the autism community and keep its priorities at the top of the agenda.

At the beginning of April 2024, Autism Awareness Month, Autism-Europe organised an event at the European Parliament to launch its new campaign 'Not invisible', to raise awareness among MEPs about the specific challenges, barriers, and discrimination that autistic people face in their daily lives. AE's call to action aimed to reclaim the narratives and increase the involvement of autistic people, their families, and their representative organisations in all decisions affecting their lives.





Main output:

• In 2024, AE published a <u>pledge</u> for endorsement and held an information stand at the EP for a week, to inform MEPs, EP employees, and the general public about AE's priorities, such as access to employment or the upcoming European Disability Card. AE's staff also invited EU policymakers to support its vision for the next five years. With the help of AE's member associations, AE's campaign received wide support: 83 MEPs and candidates from 15 EU countries signed the pledge, and a third, 26 MEPs from 9 EU countries, were (re-)elected.









Autism-Europe also engaged with different candidates and parties on various occasions:

- After the general 2023 Party of European Socialists (PES) Civil Society Dialogue Meeting to inform the party's manifesto, in February 2024 Autism-Europe along with other civil society organisations and trade union was invited by PES to provide targeted input on welfare and public services. Autism-Europe used the opportunity to focus on the importance of accessibility and quality and affordable support services.
- Autism-Europe was also invited along various members of the civil society and trade unions and other interest representatives to meet PES lead candidate and former European Commissioner for Jobs and Social Rights Nicolas Schmitt, while PES supported Autism-Europe campaign 'Not Invisible".
- In June 2024, Autism-Europe joined the Autism Advisory Council of Malta and Dr Alister de Gaetano along with the European Council for Autistic People (EUCAP) and a number of European election cross party candidates from Malta discussing the issues autistic people face across Europe.







1.8. AE contributed to the work of AccessibleEU Resource Centre

<u>AccessibleEU</u> is one of the flagship initiatives of the Strategy for the Rights of Persons with Disabilities 2021-2030. It is a resource Centre on accessibility working on areas such as built environment, transport, information and communication technologies to ensure the participation of persons with disabilities in all areas of life on equal basis with others. AE cooperated with the AccessibleEU Resource Centre to enhance the visibility of their activities.

In July, AccessibleEU Resource Centre hosted an event at the ONCE Foundation Headquarters in Madrid. AE was represented by its Spanish member in a panel discussion on "users of urban environment", highlighting the need to make urban spaces more accessible for autistic people and presenting various good practices initiatives from across Europe.

Main outputs:

• Autism-Europe's intervention here.





1.9. Autism-Europe was represented at the first-ever G7 on inclusion and disability

In October, the first-ever <u>G7 Ministerial Meeting</u> focused on Inclusion and Disability took place in Assisi, Italy. Over 100 organisations, together with people with disabilities and their families, attended the event to discuss the importance of accessibility in all aspects of life. G7 members adopted <u>the Solfagnano Charter</u>, a document that sets priorities and demonstrates their commitment to disability inclusion.



Autism-Europe was represented by its Italian members, including ANGSA and ANFFAS, who made meaningful contributions to this high-level forum, including running a stall, hosting exhibitions and providing the catering for the official dinner. You can read more about the event <u>here</u>.

1.10. Autism-Europe was represented at the annual European Day of Persons with Disabilities (EDPD) event

At the end of November, Autism-Europe attended the annual flagship event organised by the European Commission and the European Disability Forum. This year's meeting celebrated significant milestones, such as the launch of the second phase of the Disability Strategy 2021-2030.

AE member Pietro Cirrincione took the floor to stress the importance of meaningful participation of autistic people and their representative organisations in policy making. Pietro expressed concerns about the absence of autistic people in current processes and emphasised the need to involve them in shaping the EU's common approach to autism and research. Click here to read more on the EDPD event and here to watch the recordings.





1.11. Autism-Europe invited to speak at high-level events during the European Parliament Disability Rights Week

On 3 December 2024, <u>the International Day of Persons with Disabilities</u>, Autism-Europe, alongside various representatives and activists of the European Disability Forum (EDF), the European Union of the Deaf (EUD) and the European Disability Card (EDC) Fan met in Brussels with European Parliament President Roberta Metsola.

They collectively urged her to continue upholding her commitment to the rights of all persons with disabilities across Europe. Autism-Europe's director, Aurélie Baranger, emphasised the need for accessible communication and Easy To Read EU documents to enable autistic people and persons with intellectual disability to fully exercise their political rights.



On the same day, Autism-Europe's director spoke at a hearing of the European Parliament Committee on Employment and Social Affairs about access to education and employment, before representatives from the upcoming Polish EU Presidency, the European Commission, service providers, and the European Disability Forum (EDF). AE emphasised the need to address the accessibility barriers autistic people face in education, training, and employment. You can rewatch Autism-Europe's intervention at the European Parliament Committee on Employment and Social Affairs here.





Joint-statements



1.12. Autism-Europe signed a statement calling for full transparency in the implementation of the European Care Strategy

The 2022 Council Recommendation, and the broader EU Care Strategy, pave the way for the transformation of the care sector and the creation of person-centred, community-based care and support systems in all Member States.

Together with 17 European organisations, AE signed a joint statement calling on the European Commission and Member States to ensure open and transparent reporting mechanisms to efficiently monitor its implementation. You can read the call here.

1.13. Autism-Europe joined the call for an Equality-Centred Policy Cycle

Along with 140 civil society organisations across the EU, Autism-Europe called on EU policy makers to include equality and non-discrimination as central priorities in the EU work programme for the next five years. These organisations also advocated for the appointment of a Commissioner for Equality and Fundamental Rights to strengthen the EU commitment to safeguard all its citizens' rights. You can read the call here.



1.14. On World Mental Health Day, Autism-Europe co-signed a statement to strengthen EU actions on mental health with 32 European organisations

On 10th October, Autism Europe joined Mental Health Europe (MHE) and 32 civil society organisations in a joint statement calling on the European Commission to keep its promises and fulfil its commitments on mental health. The organisations urged the EC to develop a holistic European strategy on mental health that fully addresses the socio-economic and environmental determinants of mental health. You can read the joint-statement here.

JOINT STATEMENT

World Mental Health Day

Deliver on Promises and Honour Commitments on Mental Health





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

In 2024, Autism-Europe continued to prioritize capacity-building, mutual learning, and the exchange of good practices among its members and stakeholders. In 2024, AE was excited to announce the launch of the call for abstracts and contributions for the AE International Congress 2025.

AE also invited members and partners to contribute to the Afternoon of Good Practices, focusing on key themes such as inclusive advocacy practices in associations (March), initiatives to foster independent living (April), ageing (September), and the accessibility of higher education (November).

Additionally, AE remained committed to empowering its members through targeted training sessions. These include preparations for the EU elections in 2024 and updates on the latest developments in the EU Strategy for the Rights of People with Disabilities.

2.1. Autism-Europe prepares for its upcoming International Congress 2025

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

Quality of Life - Research, Policy and Practice











The 14th Autism Europe International Congress in Dublin, Ireland is fast approaching! With the theme "Quality of Life - Research, Policy and Practice", the event will bring together experts, advocates and individuals from across Europe to promote understanding and inclusion for autistic people. It will provide a global platform to discuss a broad range of topics, from the latest scientific advances to cutting-edge information on education, advocacy and awareness.



• In 2024, AE made important progress on the event's programme of activities. Keynote speakers have been invited to deliver presentations. AE members had the opportunity to visit the congress venue and discuss its accessibility. In October, AE also launched a call for abstracts and contributions from people with lived experience across all disciplines (examples include sciences, arts, humanities, social sciences). The AE Scientific Committee defined the main themes of the programme, focusing on key areas such as: improving physical and mental health, understanding ageing in autistic people, supporting autistic people to thrive and find meaning in life, vocation and employment. You can read more about the programme here.

2.2. Autism-Europe organised bi-monthly online roundtables: the Afternoon of Good Practices

This year, AE organised four roundtables tailored for member organisations and relevant stakeholders. The objective was to facilitate the sharing of experience and good practices across Europe to promote the rights of autistic people. This year's themes focused on:

- Inclusive advocacy practices in associations
- Initiatives to foster independent living
- Ageing
- Accessibility in higher education

These roundtables provide a platform for exchanging information regarding best practices across Europe, exchanging information on the experiences of autistic people and their families across Europe, deepening awareness of our members when designing new projects and services.





Main outputs:

- March Autism-Europe's Afternoon of Good Practices on inclusive advocacy: <u>Programme and presentations here</u>
- April Autism-Europe's Afternoon of Good Practices on independent living: <u>Programme and presentations here</u>
- September Autism-Europe's Afternoon of Good Practices on ageing: <u>Programme and presentations here</u>
- November Autism-Europe's Afternoon of Good Practices on access to higher Education: <u>Programme and</u> presentations here

2.3. Autism-Europe delivered study visit and trainings for its members on key EU policies

On May 10th, AE members attended a study session conducted by our Irish member AsIAm. We learned about their work to advocate for an inclusive society for autistic people that is accessible, accepting and affirming. The AsIam policy team shared the work they conduct to support the Autistic community and their families to fully engage in Irish life and build the capacity of society to facilitate true inclusion.





We notably heard about the key results of their <u>Same Chance Report 2024</u> that explores the experiences of autistic people and families in Irish society, from participating in social and family life to accessing day-to-day amenities and services. AE members also heard from Ireland's Minister for Disabilities Anne Rabbit regarding the Irish government's Autism Innovation Strategy.

AE delivered training during the AGA in Dublin on 11 May to its members on:

- The European Commission's initiative for social services of excellence for persons with disabilities, a flagship initiative of the EU Strategy for the Rights of People with Disabilities
- The 2024 European elections and the advocacy approach of the organisation in this regard. AE reviewed key stakeholders and policymakers at the EU level and outlined key actors and activities for the European Parliament elections – including a pledge, joining other disability organisations in joint advocacy actions and contacting MEP candidates.

2.4. Fostering mutual learnnig and networking through Autism-Europe's speed dating

During the members' meetings in Dublin and Brussels, participants were invited to take part in a speed dating activity to enhance mutual learning, share information about areas of expertise and interest, as well as, current priorities and achievements. It gave the opportunity to members to become more familiar with the national and regional contexts of their peers and to explore possible areas of cooperation.







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

In 2024, Autism-Europe (AE) continued to strengthen its collaborative efforts with various EU-level networks and stakeholders, ensuring the inclusion and representation of autistic individuals in key policy discussions and initiatives.

As a founding member of the European Disability Forum (EDF), AE actively participated in EDF's events and activities, contributing valuable insights and expertise to various working groups and consultations. AE's involvement extended to the Social Platform, where it highlighted the need for UNCRPD-compliant long-term care and advocated for a rights-based approach to service delivery. Additionally, AE co-chaired the European Expert Group on the transition from institutional to community-based care, promoting community living for autistic people. Throughout the year, AE has also been actively cooperating with a range of other CSOs to contribute to events and statements.

3.1. Autism-Europe collaborated with the European Disability Forum

Autism-Europe is a founding and full member of the European Disability Forum (EDF) and is part of its elected board of directors. During 2024, AE contributed to EDF's events and activities.



Main activities:

- AE worked regularly with EDF to include the perspective of autistic people in its activities. AE's representation was also made possible thanks to the active involvement of its members Pietro Cirrincione, EDF's board member, and Ben Rowsome, member of the EDF Youth Expert Group.
- AE brought its expertise to various working groups, notably the Health Study Guidelines and Cancer Survey Report. It also contributed to a range of consultations, including on the carriage of assistance dogs in air transport, the <u>position paper</u> on the revision of the TSI PRM (accessibility of the rail system) and the EDF <u>alternative report</u> on the review of the EU's implementation of the UNCRPD.



- AE also liaised with EDF to raise awareness around "World Autism Day"
- AE continued to actively advocate in the context of the "Withdraw Oviedo" campaign and co-signed EDF's <u>statement</u> on approval of the draft recommendation on respect for autonomy in mental healthcare along with the European Association of Service Providers for Persons with Disabilities, the European Network of (Ex-)Users and Survivors of Psychiatry, Mental Health Europe, and Inclusion Europe.

AE is a co-signatory to the EDF's <u>open letter</u> to Commissioner Hadja Lahbib to keep up the momentum on disability rights.

3.2. Autism-Europe cooperated with the Social Platform

Autism-Europe is a full member of the Platform of European Social NGOs (Social Platform) , , participated in members' meetings and contributed to various consultations.







We were also an invited panellist at the public policy debate 'The Future of <u>Long</u> <u>Term Care</u>' on December 4th alongside other key stakeholders. We highlighted the lack of support services for <u>autistic</u> people and their families across Europe to live included in the community. We recalled that:

- Long-term care should be UNCRPD compliant and adhere to guidelines on independent living;
- A rights-based approach, self-determination, and individualisation must be central to care and service delivery to empower people with disabilities and other care receivers to lead dignified and fulfilling lives;
- Training in autism is essential All professionals should receive training that is informed by autistic-lived experience;
- Adequate resources should be available to support and fund the care workforce;



Output: Click **here**to discover the main takeaways
from the event.

3.3. Autism-Europe co-chairs the European Expert Group (EEG) on the transition from institutional to community-based care

The EEG monitors policies related to deinstitutionalisation and promotes community living in Europe. Autism-Europe has been a dedicated member for years, actively supporting community-based services for autistic people. In February, AE took over the rotating co-chairing of the group alongside COFACE Families Europe for a year.



Main outputs:

In May, the EEG released a statement focusing on preventing the institutionalisation of children. You can read the EEG's statement here

In June, AE co-chaired the <u>EEG Civil Dialogue</u> <u>Meeting between the European Commission</u> and the European Expert Group on the <u>transition from institutional to community-based care.</u> More information.

In November, the EEG organised an online study to collect examples of alternative practices and make recommendations to Member States to better support families and prevent institutionalisation. More information here.



3.4. Autism-Europe joined the Long Term-Care alliance initiated by COFACE Families Europe

• AE contributed to the 'Care Alliance' chaired by COFACE to support career's rights, joining over a dozen of European networks of social care, service providers (of people with disabilities) and other relevant civil society organisations that meet on a monthly basis to exchange on relevant updates regarding European long-term care policies. Autism-Europe co-signed two relevant statements in March to call for implementing the right to long term care as outlined in principle 18 of the European Pillar of Social Rights and in June on more transparency when implementing the European Care Strategy



3.5. Autism-Europe continued support for Ukrainian autistic and disabled people

AE continued its advocacy work with **Child with Future for Ukraine**, its Ukrainian member whose mission is to provide comprehensive support for autistic people and their families. In 2024, AE provided platforms and resources to support autistic persons and people with disabilities in Ukraine and on the move.

- EUCAP's Autism Active webpage for information on solidarity, peer support, and resources for Ukrainian refugees can be accessed here.
- The active Facebook page centralises information on available resources and support for autistic people in Ukraine and refugees can be accessed **here**.

During the Annual General Assembly, we learned about the situation of the autistic community in Ukraine from our member Child with Future, who discussed their activities during the war, and provided insights into the present challenges faced by Autistic people and their families in Ukraine. AE supported David Higgs MBE about his plan to do a documentary to highlight the difficulties faced by autistic Ukrainians during the war and to provide concrete relief to local organisations.

3.6. Autism-Europe's international cooperation

Autism-Europe has engaged with a wide range of stakeholders throughout the year.

For example, mid-August a delegation from South Korea, including disability researchers/academic, representatives of service providers for people with disabilities, disabled activists and a journalist visited the Autism-Europe secretariat in Brussels for a mutual learning opportunity to explore ways to achieve a digitally inclusive society.





Team BADA was part of the "2024 Global Challenges for Youth With Disabilities (Dream Team)" programme in South Korea. They intended to analyse the digital inclusion of EU policy initiatives, with a specific focus on how to integrate these into education and employment for people with disabilities. Topics discussed included the efforts and developments surrounding the European Accessibility Act in the lead-up to its implementation, Autism-Europe's work on digitalisation and Al.



In October, Harald Neerland, President of Autism-Europe, was invited to the biennial conference ("Université d'Automne") of ARAPI, the French Autism Research Association, to mark its 40th birthday. He was part of a round table discussion on the inclusion of autistic people in need of a high level of support in research. You can read more about the event here.





4. Awareness-raising and dissemination

Autism-Europe continued its awareness-raising and dissemination work throughout 2024 as it is integral to its 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. AE also launched its new multiannual awareness-raising campaign 'Not invisible'.

4.1. Autism-Europe's online dissemination efforts in 2024

Autism-Europe kept sharing important updates about the latest EU developments, news and research with its large community through various social media channels. These efforts aim to keep EU and national decision-makers, self-representatives, members of the autism community, and professionals, well-informed and engaged.

- AE sent 4 newsletters (in English and French). You can access our newsletters and newsflashes <u>here</u>.
- AE also sent 8 newsletters in Easy to Read in EN and FR. Available here.
- AE kept publishing articles and events on its website (available in English and French). AE's website had 51,000 visits in 2024. Visit AE's website here.
- AE's social media presence continued to grow, with a total number of 34,810 followers across different platforms by the end of the year. Facebook achieved an impressive reach of 58,800, while LinkedIn recorded a total of 63,205 impressions.

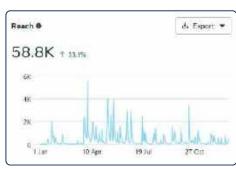
• Facebook: 17,311 followers

• YouTube: 1,630 followers

• LinkedIn: 2,365 followers

• Instagram: 3,980 followers

X / Bluesky: 9,524 followers



The number of reach on Facebook grew 33.1%.



4.2. Autism-Europe's LINK magazine publications

Autism-Europe publishes the LINK magazine to inform the wider autism community about relevant European policies and legislation, as well as best practices and research in inclusion, accessibility, and support. Each edition is available in English and French and is distributed online and in print to subscribers.

- In 2024, AE published the issues 81 the LINK magazine which includes articles on accessible tourism and related EU iniatives, the lived realities of autistic people in Ukraine, AE's 'Not Invisible' Campaign, and facts and myths about bilingualism.
- LINK 82 includes highlights about political developments marking the start of a
 new policy cycle at the EU-level, following the recent European parliament
 elections. It also addresses the critical issue of emergency and crisis situation
 for autistic people.





4.3. Autism-Europe launched its 'Not Invisible' awareness campaign on World Autism Awareness Day

Starting in 2024, Autism-Europe is running a multi-annual awareness-raising campaign under the motto 'Not invisible'. This new campaign has been designed through an in-depth co-production process with our mmebers. The theme has a double objective:

- It seeks to draw attention to the fact that autistic people's needs are often made invisible in many areas. We want to raise awareness of the barriers and discrimination that autistic people face to advocate for their human rights to be upheld and supported in all areas of life, in line with the UN CRPD. We call for a society where autistic people are fully recognised and get the understanding, acceptance, and full enjoyment of their rights they deserve.
- It aims to highlight that while autism is often described as an "invisible" disability, autistic people, their representative organisations and their support networks should be empowered and visible in all spaces and matters that concern them. Nothing about autistic people should be done without autistic people.

In 2024, the campaign had special focus on autism visibility in the European elections, while spreading key messages covering a wide range of topics – from access to employment to the European Disability Card. Through these messages, we aimed to raise awareness of autistic people's struggles and strengths, which remain often invisible for most parts of our societies.







- On World Autism Awareness Day 2024, MEP Rosa Estaràs Ferragut from Spain hosted Autism-Europe at the European Parliament in Brussels to launch 'Not invisible' and unveil our information stand. It was a great opportunity to engage with MEPs, in particular those running for election and to invite them to sign a pledge to support the rights of autistic people during their mandate. You can read more about the campaign here, including the pledge, communications toolkit, and campaign activities.
- So far, the campaign recorded involvement across Belgium, Croatia, Cyprus, Germany, Greece, Hungary, Ireland, Italy, Latvia, Luxembourg, Malta, the Netherlands, North Macedonia, Poland, Romania, Serbia, Slovenia, Spain, and Turkey.
- AE's campaign also appeared in the streets of Cagliari in Sardinia, thanks to the efforts of our Italian members Diversamente Odv.







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

Examples of press items:

- https://dublinpeople.com/news/dublin/articles/2024/11/15/dcc-autism-friendly-officer/
- https://www.unesco.org/sdg4education2030/en/articles/meet-hari-autistic-minimally-speaking-multilingual-phd-student-changing-landscape-disability
- https://www.rtvslo.si/dostopno/clanki/svetovni-dan-avtizma-2-april/703592
- https://startupcafe.ro/ghid-angajare-firme-persoane-autism-htm-29828
- https://diarioresponsable.com/opinion/37218-el-talento-neurodivergente-aporta-beneficios-a-las-empresas
- https://www.viaempresa.cat/es/empresa/specialisterne-transformando-empresariat-con-diversidad-inclusion-laboral_2199155_102.html
- https://www.elmostrador.cl/noticias/opinion/2024/03/05/la-inclusion-laboral-de-personas-en-el-espectro-autista-un-desafio-de-cambio-y-crecimiento/
- https://www.larazon.es/sociedad/expertos-piden-romper-mitos-asociados-autismo-asperger-acabar-estigma 2024021665cf24ab82085c000181b01c.html
- https://www.diarioestrategia.cl/texto-diario/mostrar/4778853/dia-mundial-concienciacion-autismo-entendamos-neurodiversidad
- https://lequotidien.lu/a-la-une/olivia-diagnostiquee-autiste-a-25-ans-tout-mon-monde-a-change/
- https://informations.handicap.fr/a-autisme-etre-bilingue-peut-il-compliquer-la-donne-36849.php
- https://fr.news.yahoo.com/tu-ne-tueras-point-pourquoi-diffusion-telefilm-samuel-le-bihan-france-2-fait-debat-080156312.html
- https://www.quotidianosanita.it/cronache/articolo.php?articolo.id=126249
- https://elperiodic.ad/entrevista/maite-benitez-05-02-2024/
- https://www.politico.eu/article/german-liberals-eu-top-candidate-autistic-scholz-remarks/

TV:

• https://www.francetelevisions.fr/et-vous/notre-tele/a-ne-pas-manquer/tu-ne-tueras-point-27822

Radio

• https://www.radiofrance.fr/franceculture/podcasts/la-question-du-jour/autisme-un-nom-pour-combien-de-maladies-6318960





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 of the European Union.

Autism-Europe's statutes have been drafted to ensure the Council of Administration offers a balanced representation of European countries. All of Autism-Europe's members have the right to participate in the Annual General Assembly (AGA). Every two years, the AGA elects half of the Council of Administration (CA). 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

The Autism-Europe's Annual General Assembly and the first Council of Administration meetings took place in Dublin (Ireland) and online on 10, 11 and 12 May, 2024.

- Study visit, 10 May: AE members visited the Royal Dublin Society (RDS), the venue for Autism-Europe's International Congress 2025, to assess the accessibility of the venue. AslAm hosted a workshop to introduce the team to their activities, priorities, and the situation of autistic people in Ireland.
- Annual General Assembly, 11 May: AE's work
 programme and budget were adopted. The report
 of activities and updates on European projects
 from 2023 was also adopted.





In 2024, AE welcomed four new members during the AGA: 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 staff then presented their activities on AE's multi-annual awareness-raising campaign 'Not invisible', and discussed ways to get involved in the 2024 European elections.
- David Higgs, MBE, an award-winning autistic writer, investigative journalist
 and photographer, presented his documentary project on the impact of
 war and violence on Ukraine's autistic community. Read more about AE's
 Annual General Assembly and first Council of Administration meeting here.



Autism-Europe's second Council of Administration meeting (CA) took place in Brussels (Belgium) and online on 2 and 3 November 2024. It was a great opportunity to collectively reflect on AE's priorities beyond 2025. AE also organised a specific session with members to review current EU autism strategies and identify good practices. The weekend concluded with a side event spotlighting two projects: Autism Spectrum Pathways and Autism IncluDi.



5.2. Autism-Europe's received a donation from the Turkish Charity Foundation

In April 2024, AE was honored to receive a donation from <u>Salih Tatlici Foundation</u>. This will support AE's ongoing efforts to improve the lives of autistic people and their families throughout Europe.



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



AE continuously strives for self-advocates 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 self-representatives.

AE also always strives for self-advocates to participate in the organisation's activities, from focus groups to events at the EU level.





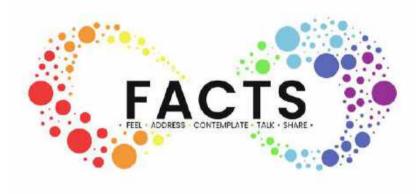
6. EU transnational projects

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. F.A.C.T.S: Feel, Address, Contemplate, Talk, Share project (2023-2026)

In November 2023, Autism-Europe launched a new European project that aims to enable service providers, administrative and sexual education professionals working with autistic people to provide adequate advice and guidance on sexual identity and gender. This is a significant step towards promoting the sexual rights and bodily autonomy of autistic people and fostering a more inclusive society.

In 2024, AE was involved in the project activities and launched the <u>project's</u> website.







6.2. IDEAL: Inclusive Digital Education for Autistic People Learning (2022-2024)

IDEAL is an Eramus + 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.

In 2024, IDEAL launched its final product: a digital open source <u>platform</u> with accessible digital tools for autistic people (apps, training, and resources), their support networks, and professionals. This platform is available in 6 European languages and focuses on the core areas of communication, education, social skills, health management, functional skills and entertainment.

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

6.3. SACREE: Sport and Autism, from a scientific diagnosis to the creation of a pedagogical European model (2022-2025)



The SACREE Erasmus+ 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 Sacree project aims at improving the daily lives of autistic people by promoting the inclusive practice of sport activities and will develop a programme directed to sport facilities to learn about autism and adaptations to meet the needs of autistic people for safe and inclusive sport practices. AE was involved in the development of the first version of the programme and is leading the dissemination and sustainability of the project. Visit the <u>project website</u> for more information about the outcomes and partners involved.



6.4. Autism Spectrum Pathways – Inclusivity beyond formative education and in the workplace (2023-2025)

The Autism Spectrum Pathways project (2023-2025) is a two-year Erasmus+ project aimed at improving employment access for autistic people. Experts have produced international and national research reports on legislation, policy, and practices, identifying barriers and opportunities for autistic people. Based on these results, they have developed learning modules on employment for autistic jobseekers, VET trainers, and employers. The project's objective is to share best practices, digital training tools, successful employment stories, and create a European digital map of autism associations and companies that employ or are willing to employ autistic candidates.

- In 2024, the <u>'ASP Employment Guide</u>' was launched to share knowledge on autism in the workplace, addressing the needs of autistic people, and highlighting the benefits of autism in the workplace. It aims to promote better practices for autism-inclusive recruitment and reasonable accommodation in training and employment.
 - At the beginning of November,
 Autism-Europe hosted their Multiplier
 Event for the project in Brussels. The
 event included an introduction and
 presentation of the project by the
 project coordinator Felicia Jibson.
 Followed by a presentation of project
 deliverables by AE staff and other
 project partners from Romania,
 including a video interview with
 Robert, a Romanian autistic man who
 gained employment through the
 project with support from AE's
 member association Help Autism.





6.5. GREEN ASC VET - Metautism (2023-2026)

This three-year project aims to boost the inclusive employment of autistic people by providing vocational education and training tailored to their needs. It focuses on modernising career guidance and skills training. Partners from across Europe are working together to develop professional development resources for teachers and trainers as well as XR solutions, VR videos, and skills simulators to support and enable autistic people to make informed, independent career choices.

- In 2024, AE coordinated the project's dissemination and the production of a <u>podcast</u>, developed to empower autistic VET students and job seekers.
- In November, partners met in Neckargemünd,
 Germany, for the Transnational Partnership
 Meeting and visited the SRH BBW, an institution for
 vocational rehabilitation, specialising in the training
 and retraining of young people with special needs
 or disabilities.



You can discover more about the project by visiting the website <u>here</u>.



6.6. CANDY: Comorbid analysis of neurodevelopmental disorders and epilepsy (2020-2024)

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. This project could point to personalised treatment to better healthcare treatment for people with neurodevelopmental conditions, including autism.

 AE is involved in the dissemination alongside its partner ADHD Europe. To learn more about the project results and the participating organisations, visit the project's website <u>here</u>.



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

EMPOWER is an interdisciplinary European research project funded by Horizon Europe. Led by the University of Valencia (Spain), it aims to better support the learning, emotional and behavioural difficulties of children with neurodevelopmental conditions, including autism. One of the main outputs of the project is a new learning platform tailored to these children's needs. It will feature educational games and resources which particularly focus on executive function and emotional self-regulation, two key skills for neurodivergent children.

In 2024, AE coordinated the
 dissemination of project results
 and participated in the
 consortium activities. You can
 visit the <u>project's website</u> for
 more information about the
 results and participating partners.



6.8. R2D2-MH - Risk and Resilience in Developmental Diversity and Mental Health (2022-2027)

R2D2-MH is a Horizon Europe research project led by the Institut Pasteur. It aims to explore risk and resilience factors associated with mental health in people with different neurodevelopmental conditions, including autism, ADHD and intellectual disability.

AE has been involved in the project from its inception, as it is being co-produced with self-advocates. AE benefit from the expertise of several of its delegates in the adult group co-production group. To find out more about the project activities and the different organisations involved, visit the project's website <u>here</u>.



6.9. AIMS-2-TRIALS – Innovative Medicine Studies-2-Trials (2018-2025)

The AIMS-2-TRIALS research project is funded by Innovative Medicines Initiative 2 Joint Undertaking and Horizon 2020, among other grants. It is a large EU-funded grant bringing autism scientists together from across Europe to research 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.

AE's role is to support policy development and dissemination efforts. AE is also involved with autism representatives, with some of our board members involved in the A-reps.

Main outputs:

The results of the Survey Access EU on services were analysed and highlighted in an academic journal publication. They will in turn be used to support our advocacy.

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





6.10. My Virtual World 3D Job Training for Autism (2022-2024)

Autistic people face a higher rate of unemployment than other people with disabilities, according to recent estimates. The My Virtual World Erasmus+ project aims to improve the labour market inclusion of autistic job seekers through the use of digital technologies. Partners developed Vocational Education and Training (VET) programmes tailored to the skills, needs, and abilities of autistic learners. This innovative approach uses virtual reality to help VET trainers, educators, and employers understand the challenges faced by an autistic job seekers.

Outcomes of the project include the adaptation of vocational training (VET) programmes to suit the skills of individual autistic learners through virtual reality (VR) and a 3D environment platform for vocational training professionals. In 2023, partners released a handbook titled "My Virtual World - 3D Job Environment for Autistic People – Methodology and Training Curriculum" which covers a range of topics to spread awareness and understanding among employers and autistic employees for meaningful workplace inclusion.

By 2024, the VR tool was completed with scenarios for job interviews with reasonable accommodations (breaks, quiet room, questions sent in advance), first day at work and social interactions. These scenarios can be accessed using Oculus glasses or a phone app. AE contributed to the consortium's activities, the development of training materials (including an online toolkit and a methodology), and supported the dissemination work. The project ended in August and all results are available on the project's website.







6.11. Autism-IncluDI: Autism Inclusion in Distance Learning (2022-2024)

The Autism-IncluDi project focuses on addressing the needs of autistic students in higher education who participate in distance learning. Its goal is to make digital transformation more inclusive and develop innovative teaching methods. The project targets special educators, parents, and children with special needs and disabilities. A competence framework, along with guidelines for developing training content for curricula, has been created. This includes both online and face-to-face training, with resources available in five languages to support the integration of ICT tools in education.

• Throughout the project, AE contributed to the development of materials and policy papers and coordinated their dissemination. In 2024, AE also organised a conference in Brussels in November with the project coordinator on site. Read more about the event here and the project's outcomes here.

6.12. Points of Connection: Autism in the Community (2023-2026)

Points of Connection is an Erasmus+ project whose main objective is to improve the inclusion of autistic young people within their communities. The project places particular emphasis on accessibility and services (culture, leisure, education), with recommendations made in consultation with young people. Activities include evaluating the quality of life of autistic young people in different countries, conducting research to better understand their needs, and developing guidelines to make services more accessible and encourage a sense of belonging.

 In 2024, AE took part in the activities of the project and reviewed the guidelines for the "Quality of Life" measure. You can read more about the partners on the <u>project's</u> website.





6.13. Talenti Latenti (2021-2024)

This Erasmus+ project, The Talenti Latenti, has developed a comparative analysis of skills validation systems across Europe and provided training to employment and vocational training professionals on skills validation for neurodivergent people. The project has also provided training to families of autistic people and people with other disabilities, sharing information on how to support their loved ones in the process and ensuring that more disabled people have access to skills validation and certification systems.



 In 2024, AE coordinated the dissemination activities of the project and organised a final multiplier event of the project at the European Parliament on 30 January 2024 together with MEP Alex Agius Saliba (more information about the event can be found here).

6.14. EASY - Employability for AutiStic Youth (2023-2026)

The EASY Erasmus+ project is a three-year initiative developed to tackle the high unemployment rate among autistic people and address the lack of tailored guidance and opportunities available to them. The consortium is dedicated to producing high-quality capacity-building sessions and materials to improve the employability skills of autistic youth. The project's focus is on developing both formal and informal education resources to meet a broad range of needs and promote inclusive employment practices.

- In 2024, the Employment Journey guide and Informal Activity Workbook were published as a guidebook for youth workers to support the job-seeking process for young autistic people. It includes an activity workbook with informal activities to teach autistic youth.
- AE is leading the dissemination of the project and the exchange of information and good practice across Europe. You can read more on the project's <u>website</u>.







6.15. SDIT - Self- Determination & Inclusion by Theatre (2023-2025)

The SDIT project aims to promote the empowerment and social inclusion of autistic people through theatre to improve their communication, social and self-advocacy skills. The project design and pilot courses for 36 theatre workers in Portugal, Spain and Italy, as well as inclusive theatre workshops and public performances to promote empathy and inclusion.

 In 2024, AE was involved in project activities and the dissemination strategy. In February, AE participated in the kick-off meeting in Lisbon. In September, AE met with partners in Cagliari, Italy to discuss the results of the focus group and the next steps for the training course. You can read more on the project's website.

6.16. COMPASS - Navigating the Spectrum (2024 – 2026)

The Compass project aims to empower families and support networks of autistic individuals by providing essential advocacy tools and legal guidance. The project develops an Advocacy Guide and an Online Life Journey Map to help parents navigate critical areas such as education, healthcare, housing, and employment. These resources will be available in multiple languages and tailored to the legal contexts of Hungary, Serbia, Latvia, and Romania.

In early October 2024, AE was involved in the kick-off meeting in Budapest. AE also worked on the research and literature review for the first phase of the project. You can read more on the project's <u>website</u>.





Autism-Europe's Executive Committee in 2024



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ZSUZSANNA SZILVASY
VICE PRESIDENT | HUNGARY



MARTA ROCA
VICE PRESIDENT | SPAIN



STÉFANY (STÉF)
BONNOT-BRIEY
VICE PRESIDENT | FRANCE



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ADAM HARRISTREASURER | IRELAND



MONIQUE POSTMEMBER | THE NETHERLANDS



Autism-Europe's Secretariat in 2024



AURÉLIE BARANGER
DIRECTOR



ANNE RENSMA

COMMUNICATIONS & CAMPAIGNS

MANAGER



CHRISTIAN TAKOW
ADVOCACY & PROJECT OFFICER



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AOIFE MCGARRY
PROJECT & RESEARCH OFFICER



FERNANDA BURIOLA

COMMUNICATIONS & PROJECT

OFFICER



DAVID EATONPOLICY & PROJECT OFFICER



Contact



+32(0)2 675 75 05



secretariat@autism-europe.org



autism-europe.org











Rue Montoyer, 39 Brussels, 1000 Belgium