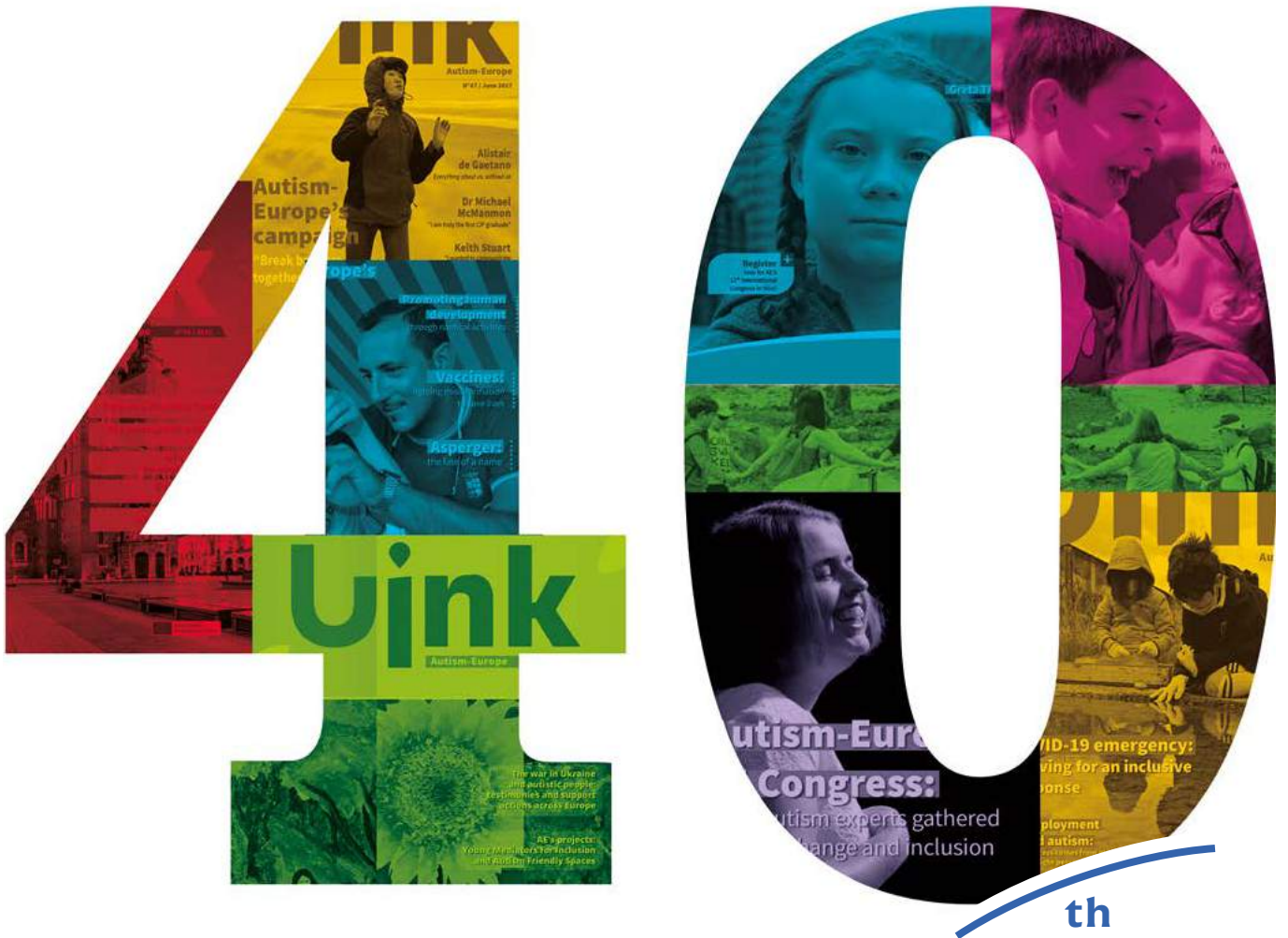


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Special Anniversary Edition





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More news at: www.autismeurope.org



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Past and present Presidents of Autism-Europe: Zsuzsanna Szilvasy, Evelyne Friedel, Donata Vivanti and Harald Neerland, with AE Director, Aurélie Baranger, on the occasion of the 40th anniversary celebration at the Annual General Assembly 2023, in Stockholm (Sweden)

Special Edition



Dear friends,

Welcome to this special anniversary edition of LINK, which offers a retrospective of 40 years of advocacy to advance the rights of autistic people in Europe, enhance their quality of life, and build a more inclusive society. It covers key areas of concerns for the autism community ranging from access to diagnosis, education, employment, support services in the community, etc.

The past 40 years have been marked by notable advances towards a better understanding and a rights-based approach to autism. At the EU level, the adoption of the AE Charter of Rights of people with autism by the European Parliament, the ratification of the UN Convention of the Rights of Persons with Disabilities, and the recent adoption of the European Resolution for the harmonisation of the rights of autistic people - to name but a few - mark undeniable progress towards this goal. Moreover, the awareness of autism in society has improved, which has led to a better understanding of the needs of autistic people and the challenges they face, and the progressive development of more targeted policy responses to address them.

However, as we all know, much work remains to be done to ensure the full realisation of autistic people's rights. Access to training and employment, housing and living support, financial support, access to quality education, social inclusion policies and practices, quality evidence-based therapies, support for carers of autistic people, early access to diagnosis, awareness of autism among professionals (doctors, teachers, etc.), anti-discrimination policies and practices, and enjoyment of legal capacity thanks to adequate support remain some of the key priorities we have to continuously strive for, as identified by Autism-Europe members in a survey carried out for this special issue.

Since 1983, Autism-Europe has evolved as an organisation. Nowadays, our network brings together almost 90 member organisations from 40 European countries. Parents and autistic people work alongside in our governing bodies and strive together to voice the diverse needs of the autistic community in a united movement.

We would like to thank all members, supporters and friends who have helped us over the past 40 years. We look forward to continuing to cooperate with you towards our shared goals of ensuring that each autistic person feels valued, respected, and included in society and can fully enjoy their rights.

Sincerely,

Director,
Aurélie Baranger



President,
Harald T. Neerland



The journey towards a better understanding and a rights-based approach to autism across Europe

Improving the quality of life of autistic people and advocating for their rights is at the core of Autism-Europe's mission, and it is inextricably linked to the global fight to advance the rights of people with disabilities at the European and international levels. Over the years, AE has been a pioneering organisation in the autism sector, voicing the needs and expectations of autistic people and their families as well as fostering cooperation with all relevant stakeholders towards further recognition of their rights. While plenty remains to be achieved in that respect, here are a few landmarks.

In the 70s and 80s, awareness about autism was slowly increasing among professionals and the general public across Europe. The DSM-III, published in 1980, established autism as a separate diagnosis. However, although scientific research on autism was still in its early stage, many unreliable theories, and potentially dangerous practices in the field of autism were already emerging.

In this context, where parents were struggling to find reliable scientific information that could help them to understand and support their children, several associations of families from various countries joined together to hold the first 'European Conference of Associations of Parents' in Ghent in 1980. The aim was to encourage the exchange of knowledge among researchers, medical doctors and other professionals active in the field of autism. As a result, information about causes, diagnosis, care, management and education also became more available to parents, which fuelled their activities.



Photo from Florian Popa for the WAAD2023 photo exhibition at the European Parliament

During the preparation of a second Congress in 1983, the associations involved decided to create a permanent umbrella association named Autism-Europe. Initially, Autism-Europe was comprised of 23 national and regional associations.

Under its first president, Jean Charles Salmon (from Belgium), the organisation identified its three main functions as monitoring, advocacy, and recommendation, or more specifically:

1. 'to observe closely the treatment of, and care provided for, people with autism;
2. to lobby those responsible for the treatment and status of people with autism;
3. to create proposals with the aim to promote the well-being and interests of people with autism.'

Autism-Europe : A few key dates

- 1980** Publication of DSM III, recognising autism as a separate diagnosis
- 1980** 1st 'European Conference of Associations of Parents' in Ghent
- 1981** United Nations' International Year of Disabled Persons

The UN's push for disability rights globally

Autism-Europe was founded in the context of a changing public understanding of disability. A new concept in relation to disability was emerging, called 'the social model of disability' (as opposed to the 'medical model of disability'), which aimed to redefine disability to focus on the relationship between people and their environment.

This evolution is notably reflected in the work conducted by the United Nations to promote the rights of disabled people with specific policy actions, first the Declaration on the Rights of Mentally Retarded Persons (1971), followed by the adoption of a second disability-specific instrument, the Declaration on the Rights of Disabled Persons (1975). These declarations are the first UN instruments that specifically address persons with disabilities. The UN declared 1981 to be the 'International Year of Disabled Persons' with the aim to raise awareness of the rights of people with disabilities, including autistic people. These rights included full participation in society and living conditions equal to those of other citizens, as well as an equal share in the improvements in living conditions resulting from social and economic development.

Following that year, the United Nations introduced a 'World Programme of Action concerning Disabled Persons' and the 'Decade of Disabled Persons as a long-term plan of action' from 1983 to 1992, with the aim to promote new public policies around the world which would remove social barriers for people with disabilities. The decade was concluded with the establishment of the 'International Day of Persons with Disabilities', now celebrated each year on 3 December around the world. In 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) were adopted. The Rules served as a guidance for policy-making, taking action to remove obstacles and creating equal opportunities for people with disabilities in society.

Championing disability rights across Europe

In the 80s and 90s, the work of Autism-Europe echoed these advances and AE published the 'Charter of rights for persons with autism', which outlined a set of fundamental rights for autistic people to enable their participation and inclusion in society. The Charter was presented at the AE Congress of The Hague in 1992, where all member countries ratified and approved its 19 points. It was decided that for the Charter to have any relevance or credibility, it must have political endorsement by receiving a seal of approval from the European Parliament. After a successful advocacy campaign, on 9 May 1996, the President of the European Parliament announced that it was approved as a written declaration.

The 90s were also very significant in the development European policies, including from the perspective of disability. In 1993, the European Union (EU) was officially founded when the Maastricht Treaty entered into force. Disability activists wanted this treaty to include a reference to disability, but this initiative did not succeed. In 1997 however, disability activists were successful in getting a specific reference to discrimination on the grounds of disability in the Amsterdam Treaty (article 13). This reference became the legal basis for the future development of European non-discrimination legislation around disability. Without it, no such legislation would have been possible at the EU level. Autism-Europe participated in the advocacy efforts to gain this anti-discrimination article. Autism-Europe also conducted a campaign amongst disability organisations and election candidates for the European Parliament to raise awareness about how this article could be used to support people on the autism spectrum and with other disabilities.

In 1993, the European Commission also began to establish formal structures for consultation with disabled people and their representative organisations, and awarded funding to Autism-Europe to act as a bridge between its members and European institutions. Following the UN's initiative, the first 'European Day of Disabled People' was held in Brussels, with an event bringing together people with disabilities from all over Europe and the aim to raise awareness about issues for people with disabilities. This day is now marked every year in Brussels. In addition, the first 'European Parliament of Persons with Disabilities' was held in Brussels. Delegates from organisations representing persons with disabilities from all over Europe met with European Parliament leaders, MEPs and EU decision makers to discuss issues for people with disabilities.

Gilbert Huyberechts, AE President, with Juan Roca (Autisme la Garriga) as Barcelona prepares to welcome the 5th International congress.

Landmark collective complaint on the right to education in France before the Council of Europe

In 1988, AE was also granted consultative status by the Council of Europe, which gave our organisation the possibility to bring a collective complaint before this human rights organisation. Thus, AE – keen to explore new legal avenues to ensure the full realisation of autistic people's rights – launched the first collective complaint before the Council of Europe on behalf of people with disabilities in 2002 (Autism-Europe v. France, complaint No. 13/2002, see more information in the section on education). In 2004, the Council of Europe publicly announced its decision, whereby France was condemned for failing in its educational obligations to persons on the autism spectrum under the revised European Social Charter.

Following the decision, the French government launched its first Autism Plan. This led to the creation of new facilities and better inclusion in mainstream schools for autistic children. Progress made by the French Government in this regard is regularly reviewed by the Council of Europe and the decision continues to be quoted by French autism organisations to demand the respect of their rights. This first collective complaint also paved the way for similar actions in the field of disability to denounce the lack of adequate measures to foster the inclusion of disabled people.

After this landmark decision, the Committee of Ministers of the Council of Europe adopted in 2009 a 'Recommendation on the education and social inclusion of children and young people with autism spectrum disorders' on the basis of the work achieved by an ad-hoc committee in which Autism-Europe actively participated.

The Convention on the Rights of Persons with Disabilities (UNCRPD) and subsequent disability strategies

In 2006, the United Nations General Assembly adopted the first international treaty dedicated to people with disabilities, the UN Convention on the Rights of Persons with Disabilities (UNCRPD). For the first time, representatives from civil society and national human rights organisations from all regions of the world had taken part in the drafting process. AE was one of the stakeholders involved, alongside the European Disability Forum. The UNCRPD reaffirms that all people with disabilities, including autism, must enjoy all human rights and fundamental freedoms. It is based on the social model of disability, and clarifies and qualifies how all categories of rights apply to people with disabilities. It identifies areas where adaptations have to be made for people with disabilities to effectively exercise their rights, including accessibility of communications, which is essential to allow the participation and inclusion of autistic people. It is legally binding for countries that ratify it.

The Convention has been ratified by most countries in Europe, including all members of the European Union. For the first time, the EU became party to an International Human rights treaty by ratifying it in 2010. Therefore, the provisions of the UNCRPD must be implemented in all the EU countries and also at the EU-level, within all the EU's fields of competences. In order to implement the UNCRPD, the EU adopted the European Disability Strategy 2010-2020 that identified eight main areas of action: accessibility, participation, equality, employment, education and training, social protection, health, and external action in order to mainstream disability across a wide range of policy areas. Autism-Europe advocated for its adoption, alongside the European Disability Forum, with the objective of fostering mainstreaming of disability rights at the EU-level.



Evelyne Friedel at Autism-Europe's 11th International Congress in 2016 (Edinburgh, Scotland)



30 March 2007 - Signing Ceremony of the UNCRPD, General Assembly Hall, United Nations Headquarters, New York. Overview of the General Assembly Hall. (Photo Credit: UN Photo/ Paulo Filgueiras)

Autism-Europe : A few key dates

- 1983** Autism-Europe is founded - Jean Charles Salmon becomes the first President of Autism-Europe
- 1983** 2nd Autism-Europe international congress in Paris
- 1983 1992** United Nations' Decade of Disabled Persons as a long-term plan of action

World Autism Awareness Day

On 18 December 2007, the United Nations General Assembly adopted resolution 62/139, which declares 2 April as World Autism Awareness Day (WAAD) in perpetuity. Since then, Autism-Europe has worked alongside its member organisations to carry out awareness-raising campaigns on autism and the rights of autistic people across Europe. Since 2013, AE has carried a series of campaigns:

- **World Autism Awareness Day 2023**
'Building an inclusive society for autistic people'
- **World Autism Awareness Day 2022**
'A happy journey through life'
- **World Autism Awareness Day 2020-2021**
'I can LEARN. I can WORK'
- **World Autism Awareness Day 2019**
'A New Dynamic for Autism. I ∞ autism'
- **World Autism Awareness Day 2017- 2018**
'Break barriers together for autism'



- **World Autism Awareness Day 2016**
'Respect, Acceptance, Inclusion'
- **World Autism Awareness Day 2015**
'Autism. Stop discrimination.'
- **World Autism Awareness Day 2014**
'Autism and work. Together we can.'
- **World Autism Awareness Day 2013**
'Autism. More common than you think'

Pictures on the top:
European Commissioner for Employment and Social affairs, Marianne Thyssen, grants support to our WAAD campaign 2016
2016 'Respect, Acceptance, Inclusion' campaign

Towards a more targeted response to the needs of autistic people

Most European countries have since then also adopted disability strategies to support the implementation of the UNCRPD provisions. However, progress on the ground for autistic people and their families has remained limited, notably due to a lack of understanding about autism and the nature of their support needs. Numerous autism organisations across Europe have therefore been advocating for more autism-specific policies and strategies.

As a result, over the past 15 years, various countries and regions in Europe have adopted autism plans and strategies to try to address the urgent needs of autistic people, among which are Denmark, Hungary, England, France, Wales, Northern Ireland, Scotland, Spain and more recently Malta as well as Bavaria (Germany).

Autism-Europe : A few key dates

- 1988** Autism-Europe is granted consultative status by the Council of Europe
- 1988** 3rd Autism-Europe international congress in Hamburg
- 1988** First issue of LINK magazine



2011 High-Level Meeting on Disability: Presidents of Commission, Parliament and European Council join forces with the European Disability Forum, including Donata Vivanti, then vice-President of EDF, with her son Giulio, to discuss the first European Disability Strategy

Strong backing from the European Parliament and on-going cooperation with the European Commission

AE has been advocating for a strategic approach to autism at the EU-level and in September 2015, the European Parliament officially adopted the Written Declaration on Autism, co-signed by 418 Members of the European Parliament. The document, co-drafted by Autism-Europe, calls on the European Union and its Member States to adopt a European strategy for autism that would support accurate detection and diagnosis across Europe, promote evidence-based treatment and support services for all ages, foster research and prevalence studies, and encourage the exchange of best practices.

Since then, AE has continued to build momentum for a European approach to address the support needs of the autism community in various areas of life. AE notably contributed to the work of an international consortium, the ASDEU programme, a pilot project funded by the European Parliament. AE formulated recommendations spanning several areas to address the needs of autistic people in Europe that were presented in January 2018: screening and diagnosis, access to health, education, individual lifelong support, employment, training of professionals, independent living, legal capacity, empowerment of autistic people and their families as well as research.

In 2023, following a petition submitted to the European Parliament by our Spanish organisation Autismo España and thanks to constant advocacy from Autism-Europe towards Members of the European Parliament, the European Parliament adopted a Resolution on 'Harmonising the rights of autistic people'. The strong backing from the European Parliament is a clear signal to all EU policy-makers to design and adopt policies that mainstream the needs of autistic people and allow them to fully enjoy their rights.

Equally fundamental to our policy work is our close cooperation with the European Commission, which has – together with the European Parliament – recognised our organisation as a key disability network, thereby engaging with us through structured social dialogue. The European Commission is the institution that has the responsibility to propose policies and legislation at the EU-level.

Autism-Europe : A few key dates

- 1988** Gilbert Huyberechts becomes President of Autism-Europe
- 1989** Autism-Europe conducts the 'Rain Man Operation'
- 1991** Parents Exchange Programme in 5 European countries

Autism-Europe has therefore been consulted on the design phase of the current European Strategy for the Rights of People with Disabilities, including through direct meetings with the European Commissioner for Equality. During the consultation, AE advocated for the European Union to mainstream the concerns of autistic people and take into account the diversity of disability, including those with high support needs, as well as to promote all forms of accessibility (including communication). As a result, the European Commission released in March 2021 the EU Strategy for the rights of persons with disabilities 2021-2030 (ESRPD) that emphasised the need to cater for the diversity of disabilities 'which are often invisible'. Autism-Europe is one of the 14 civil society organisations selected to take part in the Disability Platform established at the end of 2021, alongside representatives from EU Member States and European institutions, to cooperate for the implementation of the ESRPD. AE ensures that the views of autistic people and their families are represented in this important forum.



Antonio Tajani, President of the European Parliament opens AE photo exhibition on the occasion of WAAD 2018 campaign "Break Barriers for autism", together with AE President Zsuzsanna Szilvasy and Spanish MEP Rosa Estaràs



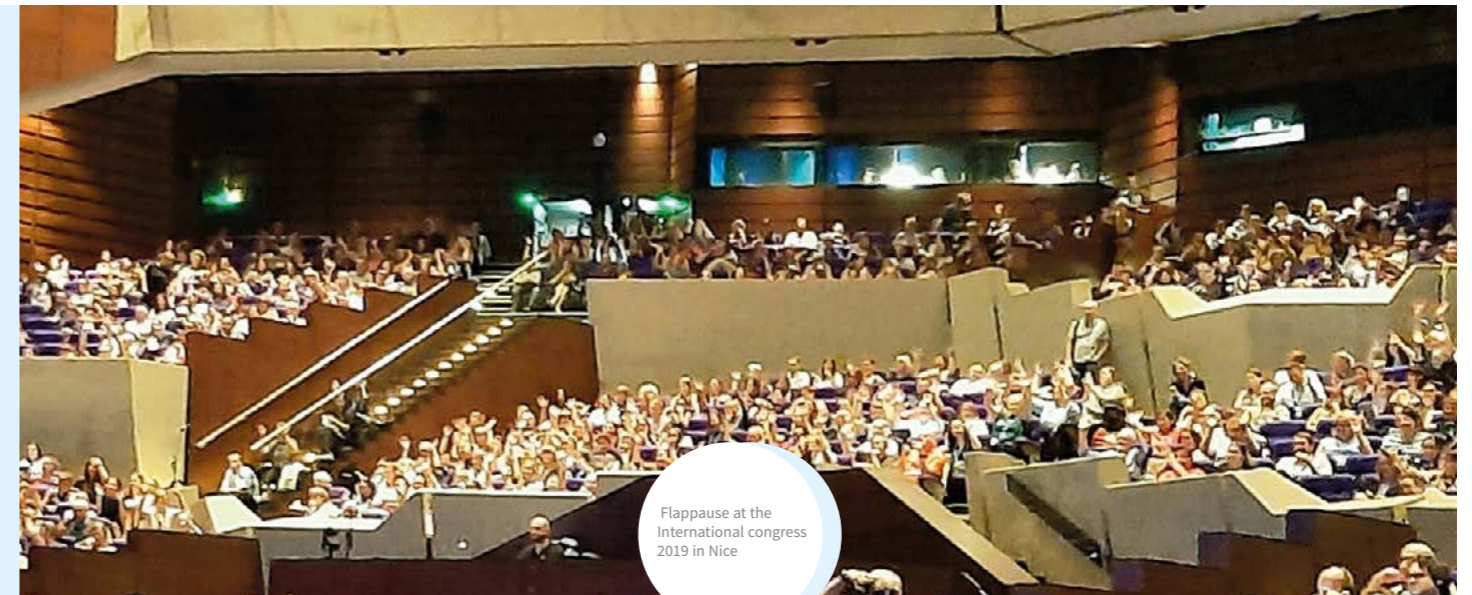
Conference at the European Parliament on the occasion of the adoption of the Written Declaration on Autism in 2015 with representatives from the European Parliament and the European commission

Working in strategic partnerships and fostering alliances

Over the years, Autism-Europe has striven to work in partnerships and foster cooperation with other like-minded organisations. AE is co-founder of two leading organisations, the Social Platform and the European Disability Forum. Established in 1995, the Social Platform is the alliance of representative European networks of non-governmental organisations (NGOs) active in the social sector. The network promotes social justice and participatory democracy by voicing the concerns of its member organisations. The Social Platform and its members are committed to the advancement of the principles of equality, solidarity and non-discrimination, as well as the promotion of respect for fundamental rights, within Europe and in particular the European Union.

In 1996, after several years of development, the European Disability Forum (EDF) was officially formed as the representative voice of people with disabilities in Europe before the European institutions. Autism-Europe was one of the key founding members of this new coalition, which took on a crucial role in the development of policies relevant to people with disabilities at the European level. EDF represents 80 million people with disabilities in Europe and works to ensure that political decisions concerning people with disabilities are taken with and by people with disabilities, following the motto: 'Nothing about us without us'.

For Autism-Europe, it was imminently clear that working in coalition with EDF would be essential to making important strides at the policy level for autistic people in Europe. Involvement in EDF is also necessary to ensure that autism is understood as a disability (not a rare disease, as it was in the past understood to be) and to ensure that the needs of people requiring a high level of support are adequately represented within the disability movement. For this reason, Autism-Europe has remained closely involved in EDF since its founding.



Flappause at the International congress 2019 in Nice

Autism-Europe's international congresses

Since its creation, AE has consistently organised congresses every 3 to 4 years. These events are held with the intention of developing and sharing the latest research, information and best practices in the field of autism in close cooperation with autistic people, researchers, professionals and relatives from around Europe. The diversity of the participants is one of the strengths of our events. The discussions and outcomes of these congresses have also played a key role in assisting Autism-Europe to represent autistic people before EU institutions. The congresses are landmark events that help to shed light on autism in the host countries and support the advocacy of our organising member at national level.

Over the years since the first congress in 1980, Autism-Europe's congresses have developed a strong reputation as a reliable source of up-to-date information about autism within the autism community:

Autism-Europe international congresses:

- 1980 : Ghent
- 1983 : Paris
- 1988 : Hamburg
- 1992 : The Hague
- 1996 : Barcelona
- 2000 : Glasgow
- 2003 : Lisbon
- 2007 : Oslo
- 2010 : Catania
- 2013 : Budapest
- 2016 : Edimburgh
- 2019 : Nice
- 2022 : Cracow



Upcoming congress 2025:
Dublin (Ireland)

Autism-Europe : A few key dates

- 1992 United Nations establishes 3 December as International Day of Persons with Disabilities
- 1992 4th Autism-Europe international congress in The Hague where the 'Charter of Rights for Persons with Autism' is presented
- 1993 Adoption of the 'Standard Rules on the Equalization of Opportunities for Persons with Disabilities'

Autism-Europe : A few key dates

- 1993 The European Commission begins formal consultation with Autism-Europe and provides a grant to support the organisation
- 1993 The first European Parliament of Persons with Disabilities is held
- 1995 Autism-Europe is one of the co-founders of the Social Platform

The evolution of autism diagnostic criteria and the ongoing fight for support recognition

The diagnostic criteria for autism have evolved over time, with changes and updates made in both the Diagnostic and Statistical Manual (DSM) and the International Classification of Diseases (ICD). This evolution is linked to the growing awareness of autism in society and its prevalence. How autism is defined and assessed has wide-ranging implications regarding which kind of support and recognition autistic people can access in society.

Autism was first described by Leo Kanner in 1943 and Hans Asperger in 1944 as a childhood psychiatric disorder characterised by social and communication difficulties. The first two editions of the DSM (DSM-I and DSM-II), published in the mid-20th century, did not include specific criteria for autism. Instead, autistic people were often diagnosed 'with childhood schizophrenia.'

With the adoption of the DSM-III in 1980, autism was officially recognised as a separate diagnostic category. The criteria included impairments in social interaction and communication, as well as repetitive behaviours. The revision introduced by the DSM-III-R (1987) and DSM-IV (1994) refined the diagnostic criteria for autism and introduced the term 'autistic disorder'. They also included subtypes such as 'Asperger's disorder' and 'pervasive developmental disorder not otherwise specified' (PDD-NOS) to include a broader range of autism-related conditions.

The DSM-5, the most recent edition of the DSM, merged several subtypes of autism, including Asperger's disorder and PDD-NOS, into a single category called 'autism spectrum disorder' (ASD). The criteria focus on two core domains: social communication deficits and restricted, repetitive patterns of behaviour.

The ICD-10, published in 1992, included diagnostic codes for autistic disorder and related conditions. ICD-11, released in 2022, aligns more closely with the DSM-5 criteria by using the term 'autism spectrum disorder', emphasising the importance of social communication difficulties and repetitive behaviours in the diagnosis.

These changes in diagnostic criteria reflect a growing understanding of the complexity and diversity of autism. The shift toward the unified term 'autism spectrum disorder' in both the DSM-5 and ICD-11 acknowledges that autism forms a continuum and allows for a more comprehensive and flexible approach to diagnosis. However, a growing body of evidence shows that these criteria tend to exclude people with milder traits as well as girls and older individuals more than the DSM-IV did.



The Autism in Pink project's objective was to raise awareness of autism in women and girls, delegates including AE VP Isabel Cottinelli together with former chair of the EP disability intergroup Richard Howitt

From diagnosis to functioning and quality of life in autism

Traditionally, autism has been viewed and assessed from the clinical symptomatology perspective. However, the field continues to evolve with ongoing research, for example through recent work to make use of the International Classification of Functioning, Disability and Health (ICF) published in 2001 to better account for people's ability to function in their daily life and better assess quality of life.

Indeed, in 2001, the World Health Organisation published a guide that could serve as a platform for a comprehensive, standardised clinical assessment of functioning. The Centre of Neurodevelopmental Disorders at Karolinska Institutet (in collaboration with the World Health Organisation and several other groups) defined several core sets for autism.

Functioning is an individual's ability to participate and engage in everyday life and meet society's demands and expectations – it is about what a person can do within the context of their environment. Functioning is important to consider when seeking to understand the health and quality of life of autistic people. Rather than focusing solely on diagnosis and symptoms, functioning provides a holistic perspective on people's real-life abilities and challenges. This approach has been praised for reconciling the biomedical and neurodiverse paradigms. This model could help to better allocate services and support targeted to a person's individual needs, beyond the diagnosis.

Autism-Europe : A few key dates

- 1996** 5th Autism-Europe international congress in Barcelona
- 1996** The European Parliament adopts Autism-Europe's 'Charter of Rights for Persons with Autism' as a written declaration
- 1996** Autism-Europe is one of the co-founders of the European Disability Forum
- 1997** Discrimination on the grounds of disability is entered in the Amsterdam Treaty thanks to disability activists

Striving for recognition of support needs and disability status

As autism is usually described as being an invisible disability, autistic people often face multiple challenges when getting their disability status recognised in order to gain access to adequate support and social protection. It is compounded by the fact that access to diagnosis is often delayed in most European countries – in particular for adults, women, girls and people of colour.

To be compliant with the UN CRPD, a disability assessment should take environmental factors into account. It should explore how these factors hinder the person's full and effective participation in society on an equal basis with others. The assessment should consider the barriers that a person encounters and their needs.

However, currently across Europe, the method for assessing disability, granting benefits, and providing social protection to citizens with disabilities varies substantially. The different disability assessment systems lead to a lack of common understanding of what disability is and who qualifies for social protection. For example, an autistic person may qualify as being 'disabled' in one country but not in another. There are different types of qualifying criteria, assessment methods, assessors and supporting evidence required.

Meanwhile, the EU treaties provide citizens with the right to freedom of movement. As EU citizens, all nationals of the Member States of the European Union have the right to move freely within the European Union and to enter and reside in any EU Member State. Today, 17 million EU citizens live and work abroad in another EU country. However, this mobility is extremely limited for persons with disabilities, notably because changing country entails jeopardising access to disability benefits as well as social support and protection.

Therefore, we are advocating for mutual recognition of disability assessment between EU Member States so that people can retain their disability status when moving to another EU country.



Credit : Florian Popa

The EU Disability Card: a key step forward to improve the mutual recognition of disability status in Europe

The European Disability Card – currently under negotiation – is a step in the right direction, as it will serve as proof of disability status across all EU countries. According to the proposal currently under discussion at the EU-level, it will grant cardholders equal access to special conditions and preferential treatment anywhere in the EU. The special conditions apply when using public transport, attending cultural events and visiting museums, leisure and sports centres, amusement parks, and more.

The European Card will complement national disability cards, which will continue to be granted by national authorities, based on their own criteria.

The proposal for an EU Disability Card is a landmark for the disability movement in Europe that has been advocating for it for the past decade. Autism-Europe welcomes this progress to improve the free movement of persons with disabilities and the mutual recognition of the disability status across Europe. However, it covers only temporary travel (tourists and people on short stays). Therefore, we will continue to advocate for people not to have to restart the reassessment process for their disability status from scratch when moving permanently to another EU country, as it can be particularly lengthy and complex for autistic people.



Image from the European Commission website for the launch of the European Disability Card proposal. September 2023.

Autism-Europe : A few key dates

- 1998** Publication of 'Code of Good Practice on the Prevention of Violence Against Persons with Autism'
- 1998** 1st edition of Autism-Europe's scientific publication 'People with Autism Spectrum Disorder. Identification, Understanding, Intervention'
- 2000** 6th Autism-Europe international congress in Glasgow



Championing the right to education for autistic people: an ongoing pursuit

Inclusion in education with adequate support and accommodation is paramount for autistic people, whose needs and strengths require tailored and individual approaches within educational settings. Autism-Europe has long been campaigning for access to education for all, including autistic people with high support needs. In recent years, across Europe, Member States have adopted various strategies and policies to address the inclusion of autistic students, following the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The right to education for autistic people in Europe is a complex and evolving issue and Autism-Europe keeps advocating for its full realisation.

One of AE's key milestones regarding the promotion of the right to education was the launch of the first collective complaint before the Council of Europe on behalf of people with disabilities in 2002 (Autism-Europe v. France, complaint No. 13/2002). Autism-Europe was represented by Evelyne Friedel (Evelyne later became the president of Autism-Europe from 2008 to 2011). In March 2004, the Committee of Ministers of the Council of Europe made public the decision taken by the European Committee of Social Rights of 4 November 2003 whereby France was found to have failed to fulfil its educational obligations to autistic people under the European Social Charter. This was primarily due to the significantly lower enrolment of autistic children in both mainstream and specialised schools compared to other children, with or without disabilities. Additionally, the chronic lack of care and support facilities for autistic adults was identified as a critical issue.

The Council of Europe's decision put pressure on France and other countries in the Council of Europe to live up to their obligations under the European Social Charter European Social Charter by providing education for people on the autism spectrum, both within mainstream and specialised schools, according to the needs of each autistic person. Even though the decision referred specifically to the case of autistic people, its scope goes well beyond this group by reasserting the right to education for all people with disabilities, regardless of their support needs. Subsequent to this decision, the Committee of Ministers of the

Council of Europe adopted in 2009 a Recommendation on the education and social inclusion of children and young people with autism spectrum disorders on the basis of the work achieved by an ad-hoc committee in which Autism-Europe actively participated. The adoption of the UN CRPD, with Article 24 stating that the education system should be inclusive at all levels, providing accommodations and individualised support to persons with disabilities, was another crucial step towards the realisation of the right to education.

Autism-Europe : A few key dates

- 2000** Adoption of the European Commission directive 2000/78 on anti-discrimination in employment including on the grounds of disability
- 2000** Donata Vivanti becomes President of Autism-Europe
- 2002** Autism-Europe launches first collective complaint before the Council of Europe (Autism-Europe v. France complaint no. 13/2002) against France for violation of autistic people's rights

Education is primarily the responsibility of individual EU Member States, and it is not a core competence of the European Union, so the situation varies across countries. Many European countries have made significant strides in promoting inclusive education for autistic people in recent years and have developed inclusive education policies aimed at providing equal opportunities for students with disabilities, including autism.

However, a striking example of the challenges that remain across Europe is that despite France's condemnation based on AE's collective complaint (and subsequent additional condemnations), partial or total exclusion of children with disabilities from the school and education system in France remains a reality. This is illustrated by Marentree.org, a campaign platform launched by our affiliated French member UNAPEI – and supported by AE – that gathers testimonials of autistic people and their families deprived of their right to education.

While there appears to be a prevailing trend toward recognising and actively implementing the right to education for autistic people, it remains a significant challenge throughout Europe. Despite the development of specific policies, there are concerns about the availability of adequate reasonable accommodation and support, with considerable disparities in quality and access among different countries.

The COVID-19 pandemic and the resulting shift to remote learning have highlighted the pressing need to tailor information and communication technologies as well as digital tools to the requirements of autistic individuals. Consequently, several ongoing European projects in which Autism-Europe is involved are dedicated to addressing this issue, IDEAL being one of the most recent.

Autism-Europe also remains committed to providing support to our members as they engage in education-related initiatives and advocacy at the national level. This includes our Europe-wide campaign 'I can learn. I can work,' which ran from 2020 to 2021, focusing on enhancing access to employment and education for autistic people.



Credit : Florian Popa

COVID-19

In 2020-2021, the COVID-19 pandemic disrupted the lives and services of autistic people and their families across Europe. It narrowed schooling options even more for autistic pupils in Europe.

AE conducted a survey to assess the effects of the lockdown measures on the daily lives of autistic people and their families, including access to education, and published a report with our findings and recommendations. We have also been advocating for the rights and needs of autistic people to be adequately addressed in the response and recovery plans of the EU and the Member States.

AE's EUROPEAN PROJECTS ON EDUCATION



www.autism-includi.uom.gr



www.project-empower.eu



www.idealearning.eu



www.digitool-autism.eu



www.ivea-project.eu



www.ipa2project.eu

Autism-Europe : A few key dates

- 2003** 7th Autism-Europe international congress in Lisbon
- 2004** France is condemned by the Council of Europe following Autism-Europe's collective complaint no. 13/2002 for failing in its educational obligations to persons on the autism spectrum under the revised European Social Charter
- 2005** Autism-Europe co-establishes the European Coalition for Community Living (ECCL)

Access to work and employment

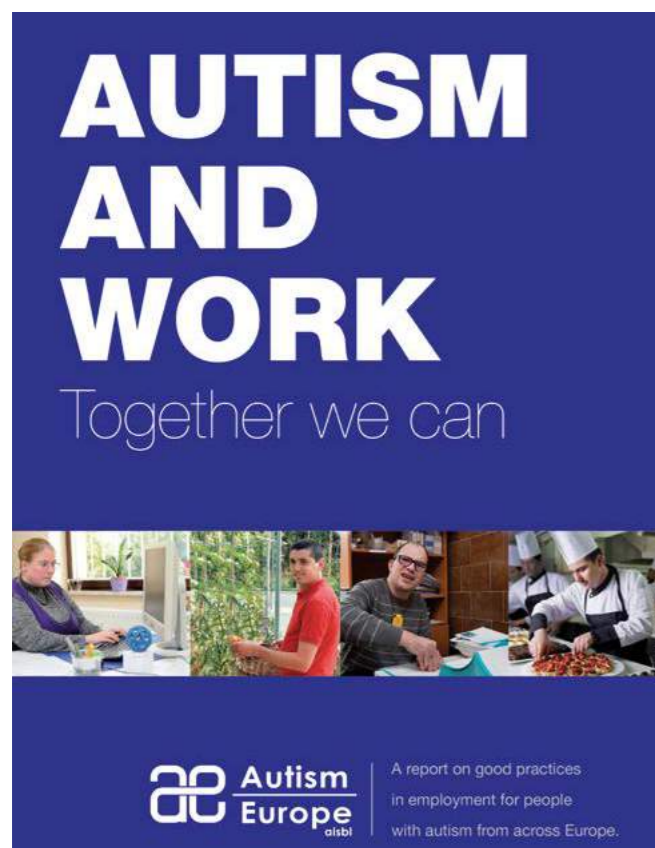
Work is universally considered as one of the main ways in which we participate in society. Despite advances in promoting access to employment for people with disabilities and protecting these rights in international and European legislation (Article 27, UNCRPD), the autistic community still remains disproportionately excluded from the labour market across Europe, even compared to the disabled population as a whole. The issue of access to employment has become particularly pressing in recent years as generations of autistic adults experience discrimination to access the world of work. In fact, studies suggest that 75% to 90% of autistic people are unemployed. Thus, it is both noteworthy and unsurprising that access to employment is at the top of the agenda for our members, as showcased in this edition's survey. Access to employment has therefore become one of the priorities of Autism-Europe, notably through continuous advocacy, campaigning efforts and mutual learning.

Fighting for the right to access meaningful employment for autistic people has long been one of the key pillars of Autism-Europe and its members' work. In 1992, our Charter for Persons with Autism insisted on this right in Article 10. In the past decade, Autism-Europe has carried out various advocacy and awareness campaigns to fight for the right to access meaningful employment for autistic people – including people with higher support needs. Our World Autism Awareness Day (WAAD) campaign of 2014 'Autism and work. Together we can' and more recently our campaign 'I can LEARN. I can WORK' in 2020-2021 focused on the right to work.

The cornerstone of AE's campaigns is to raise awareness of the skills of autistic people in the workplace, while informing about their accommodation needs. AE advocates for the adoption and

adequate implementation of legislation and policies that support access to employment, including positive actions for autistic people. As such, informing decision-makers and key stakeholders at the EU-level, such as the European Parliament and the European Commission, about the current challenges and solutions are crucial to ensure progress.

From a purely legal standpoint, advancements have been made in the field of employment for people with disabilities, therefore also for autistic people. The Universal Declaration of Human Rights in 1948 stated that 'Everyone has the right to work, to free choice of employment' (Article 23.1). The Charter of Fundamental Rights of the European Union (2000), that became legally binding through the Treaty of Lisbon in 2009, includes the rights to access employment and non-discrimination in the EU. Also in 2000, a crucial landmark was the adoption of the 2000/78/EC Directive (General framework for equal treatment in employment and occupation), specifying that discrimination in employment on the grounds of disability (and notably the denial of reasonable accommodation) is illegal. Henceforth, all EU Member States passed legislation to transpose this directive.



AE Report on autism and employment published in 2014 in the framework of the campaign "Autism and Work. Together we can".



Autism-Europe : A few key dates

- 2006** The United Nations' General Assembly adopts the UN Convention on the Rights of Persons with Disabilities (UNCRPD)
- 2007** 8th Autism-Europe international congress in Oslo during which Autism-Europe presents the 'Position paper on care for persons with autism'
- 2007** Council of Europe Resolution ResAP (2007)4 on the education and social inclusion of children and young people with autism



Photo from Joanna Musial for the WAAD2023 photo exhibition at the European Parliament

The ratification of the UN CRPD across the EU and at the EU level, which includes Article 27 on work and employment, has further strengthened the legal basis to tackle discrimination. Several EU Member States have also adopted national autism strategies or plans that address the issue of employment.

This national focus lends itself to targeted actions and national funds being allocated for this purpose specifically, promoting employment opportunities by increasing awareness and understanding, providing financial support to people on the autism spectrum, publishing guidelines for employers and even funding employment programmes for autistic jobseekers. However, autism organisations across Europe tend to underline a lack of accountability and follow-up for these measures as well as insufficient or delayed financial investment.

Enhanced policy scrutiny at the EU level regarding access to employment for autistic people

In 2015, in its Concluding Observations of the first review of the implementation of the UN CRPD by the EU, the CRPD committee highlighted the fact that the unemployment rate of people with intellectual and/or psychosocial disabilities remains disproportionate, and called for more action in the matter. This conclusion echoed AE's 2014 campaign 'Autism and work. Together we can' and the alternative report submitted by AE during the review process.

Further scrutiny was given to this issue when Autism-Europe was invited to present the state of play and its recommendations for the employment of autistic people before the European Parliament Committee on Employment and Social Affairs in 2019. As a result, the issue of autism and employment was added to the work priorities of the committee. After an in-depth consultation with Autism-Europe, promoting employment opportunities for autistic people was debated in the European Parliament together with the European commissioner for Equality during a plenary session in June 2021. Members of the European Parliament called for strategic actions to comply with the EU employment objectives.

Autism-Europe also cooperated – alongside other EU disability organisations – with Members of the European Parliament in 2020 to draft their 'Report on the implementation of Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation in light of the UN CRPD' and formulated recommendations to enhance its implementation. Crucially, this was also the first time that a European Parliament's report included an Easy-to-Read version drafted jointly by Autism-Europe and Inclusion Europe.

Creating momentum for more action on employment at the EU level

Following these advocacy efforts and in line with recommendations formulated by Autism-Europe, the current European Strategy for the Rights of Persons with Disabilities 2021-2030 (ESRPD) promotes more targeted actions in the field of employment. One of the flagship initiatives of the Strategy is the 'Disability Employment Package' seeking to promote social inclusion through employment for disabled people. A core issue identified by Autism-Europe is that there needs to be better understanding of what constitutes reasonable accommodation for autistic people in the workplace. It is a pre-requisite to provide them with the right support to apply, perform or advance in the workplace on an equal footing with others in line with the provisions of the 2000/78/EC Directive and the UN CRPD.

Ensuring reasonable accommodation in the workplace is one of the core objectives of disability legislation in EU Member States (for example, it has recently been included in the Belgian constitution). Today, 24 EU Member States offer support for companies to provide reasonable accommodation for disabled workers, ranging from tax reductions to grants. AE therefore welcomes that one of the objectives of the EU Disability Employment package is to shed light and provide guidance on what constitutes reasonable accommodation to employers, including for people with invisible disabilities, such as autism.



Farm4Autism by Carlo Giustini for the WAAD2023

Autism-Europe : A few key dates

- 2007** On 18 December, the United Nations' General Assembly adopts resolution 62/139, declaring 2 April as World Autism Awareness Day (WAAD) indefinitely
- 2007** One Million for Disability campaign by the European Disability Forum to request European anti-discrimination legislation
- 2007** European Union signs the UN Convention on the Rights of Persons with Disabilities



Special hearing of AE at the European Parliament Committee on Employment and Social Affairs in 2019

The importance of mutual learning and sharing of good practices

Sharing knowledge and good practices are key to foster change and Autism-Europe has also striven to highlight the issue of employment in its international congresses. Many of our projects have also focused on addressing the specific needs of autistic people in accessing employment, including people with higher support needs: IVEA, Autism Spectrum Pathways, WIN-WITH-U, Autism-Friendly Spaces - Employability, and INFUSE have been some of our Erasmus+ projects focusing on this topic.

Various international, national, and local companies across Europe focus on coaching and supporting autistic people towards employment, and their success proves the benefits of employing autistic people with personalised support in place. Autistic people with higher support needs face additional challenges and greater unemployment rates, but certain supported employment

initiatives implementing adapted vocational training and employment paths have demonstrated the importance of taking a strengths-based approach to autism in the workplace.

This retrospective has shown that while it is important to acknowledge the considerable progress made in the last decades in terms of legislation, policy, and awareness, current unemployment rates for autistic people are unacceptable. Inclusive hiring practices, a societal shift in the perception of autism, inclusive education, sufficient financial backing and binding measures are just some of the objectives that have to be accomplished in the years to come. Strong advocacy in this sector continues to be needed in order to keep employment for autistic people a key priority, reiterating that this right is at the very foundation of an inclusive society and that effective measures must translate from legislation into reality.



Visit of AE delegates to the decorative Art Museum with professional autistic guides in Madrid in 2017

Autism-Europe : A few key dates

- 2008** European Commission issues proposal for an EU anti-discrimination directive in all aspects of life, outside the field of employment (to date the directive is still blocked by the Council)
- 2008** Evelyne Friedel becomes President of Autism-Europe
- 2009** Council of Europe recommendation on the education and social inclusion of children and young people with autism CM/Rec(2009)9

Promoting the right to live in the community with adequate support

Since its foundation, promoting deinstitutionalisation and access to quality community-based services for autistic people have been key priorities for Autism-Europe. A lack of support often leads autistic people to live in isolation and/or heavily dependent upon their families. Across Europe, many autistic people also remain forced to live in large residential institutions in which their fundamental rights are denied. Autism-Europe advocates for the right to independent living thanks to housing and living support appropriate to people's individual needs, as well as the right to choose their own living circumstances. To date, there is still an overall lack of availability of support services and independent living solutions especially as people age. AE and its members are continuously striving for change, notably by supporting policy developments, research, and innovative initiatives in the field.

Since 2010 in the EU, the UNCRPD protects the right for disabled people to live independently with adequate support and to be included in the community through Article 19. It is a powerful legal basis to allow people with disabilities 'to live in the community [...] to choose their place of residence and where and with whom they live', a right Autism-Europe has extensively advocated for since its foundation. The 1992 Charter of Rights declared 'the right of people with autism to live independent and full lives' and 'the right of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution'.

In 2003-2004, AE joined other leading associations of people with disabilities and mental health issues and participated in the pioneering 'Included in Society' research project. The analysis of over 2,500 institutions underlined the widespread abuse across Europe in these settings, where in many cases residents remained isolated, deprived of care, segregated from society and suffered inhumane conditions. The report, which identified autistic people as being among the most affected by institutionalisation, called for deinstitutionalisation and the provision of quality community-based residential services for disabled people by outlining policy recommendations.

This momentum continued with the publications from the 2007 'Deinstitutionalisation and Community Living - Outcomes and Costs' project, which outlined the benefits of community-based services in terms of provision of support and potential impact on other sectors such as healthcare and employment, provided they are adequately funded and their staff highly trained. As we continue to advocate for today, this project underlined that a successful transition into community-based services should always uphold disabled people's right to choose where, with whom and how they live, taking into account their evolving needs. While deinstitutionalisation is a fundamental first step, quality services in the community must take a person-centred approach without replicating an institutional model of care, meaning that a range of support should be made available, including support for family care and personal assistance.

These research projects unequivocally paved the way for organised advocacy in this sector. As a result of the 'Included in Society' Project, AE contributed to setting up the European Coalition for Community Living (ECCL), headed by the European



Credit : National Autistic Society (UK) (right) Giulia Manfroni

Network for Independent Living. The ECCL helped to push deinstitutionalisation high on the EU agenda. As a result, the then EU Commissioner for Employment and Social Affairs, Vladimir Špidla from Czechia, convened in February 2009 the independent Ad Hoc Expert Group on the transition from institutional to community-based care. It became the European Expert Group for the Transition from Institutional to Community-Based Care (EEG), of which AE is now a full member. EEG actively advocates for family and community-based support to substitute institutionalisation by lobbying for the EU and Member States to uphold in practice fundamental human rights legislation, such as the UN CRPD and the UN Convention on the Rights of the Child.

Autism-Europe : A few key dates

- 2009** Entry into force of the Treaty of Lisbon, the EU Charter of Fundamental Rights becomes binding
- 2010** 9th Autism-Europe international congress in Catania
- 2010** The EU ratifies the UNCRPD
- 2010** Launch of the European Disability Strategy (2010-2020) at the EU-level



Towards Inclusion Conference marking the 10 years of the EEG in 2019

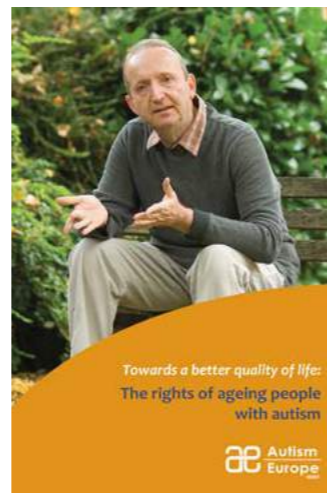
The work of these advocacy networks has been fundamental to mandate that EU funds are allocated to rights-compliant initiatives. The EEG also provides essential resources on how best to ensure the transition out of institutions. The EEG's recent 2020 study on the Transition from Institutional Care to Community-Based Services in 27 EU Member States worryingly highlighted that the number of institutions has not significantly decreased in the last decade, with almost 1.5 million people still living in institutions. Significantly, lack of investment and underfunding has especially affected people with intellectual disabilities and higher support needs, as they continue to be housed in institutions or in smaller facilities replicating institutional models of care.

Access to quality care and support services becomes a more pressing challenge as autistic people age. Their support needs evolve and additional health issues often arise. Additionally, as their family members – who are usually their primary caregivers – also enter old age, autistic people and their families across Europe face a dire lack of solutions to support them. AE published a research report on this issue back in 2012, highlighting challenges but also good practices in this area. Aging on the autism spectrum was also a key topic at the 11th Autism-Europe International Congress 2016 in Edinburgh. Overall, a great number of European services for adults with complex support needs have extensive waiting periods that reach years, and in certain areas, there is a complete lack of options. Unavailable or inaccessible support, such as personal assistance, respite care or adequate residential facilities continuously end up isolating families. Due to the lack of adequate support, too many carers suffer from an unbearable responsibility and a permanent state of anxiety, not least about the future, when they will no longer be able to provide the necessary support to their relatives. This inexistent or inadequate level of support – also for numerous undiagnosed autistic adults – inevitably increases their social exclusion, as research has shown that many even experience homelessness. In our alternative report for the second review of the EU by the CRPD Committee in 2022, AE continued to underline the urgency of this issue, as the EU shares with Member States the competence for the promotion of independent living and inclusion in the community.

The EU has made recent strides in this direction by focusing one of its flagship initiatives of the 2021-2030 Strategy for the Rights of Persons with Disabilities around developing a 'specific framework for Social Services of Excellence' and several Member States have made deinstitutionalisation and independent living a priority in

their autism strategies. Yet, autistic people, and especially those with high support needs, continue to face institutionalisation as access to quality services and independent living remain out of reach. In the meantime, our advocacy at European level and our members' work at national and local levels will continue to keep this issue at the very top of the political agenda, representing autistic people's basic human rights.

Access to services for people on the autism spectrum is not limited to community-based living. As UN CRPD Articles 10, 11, 18, 20, 29, 30 show, people with disabilities have the right to accessible transport, sport, leisure, culture, emergency services, etc. Naturally, those within these services interacting with autistic people need to be trained. Autism-Europe and its members have been strongly campaigning for law enforcement professionals to receive training on how to interact with autistic people. The ALERRT Autism on the line! project (2020-2022) piloted training for first responders encountering autistic people in an emergency situation.



Report on Ageing published in 2012

Autism-Europe : A few key dates

- 2012** Zsuzsanna Szilvasy becomes President of Autism-Europe
- 2013** 10th Autism-Europe international congress in Budapest
- 2015** Autism-Europe publishes an alternative report for the first review of the EU by the CRPD Committee
- 2015** The European Parliament officially adopts the 'Written Declaration on Autism'

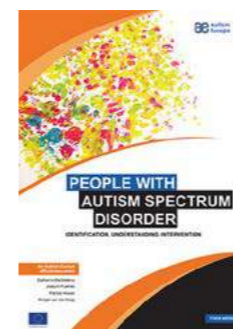
Promoting access to evidence-based information and fighting dangerous 'cures'

One of the priorities of Autism-Europe is to fight against harmful, unapproved and unethical practices targeting autistic people and their families. Autism-Europe strives to share information of current evidence-based knowledge about autism with a wide audience, to improve general understanding and impact positively on practice and policy in Europe. We also advocate for banning dangerous so-called autism therapies across Europe.

In September 2019, Autism-Europe released the third edition of its publication 'People with Autism Spectrum Disorder. Identification, Understanding, Intervention' first published in 1998. This document provides an overview of current evidence-based knowledge and practice around autism and was co-authored by Catherine Barthélémy, Joaquín Fuentes, Patricia Howlin and Rutger Jan van der Gaag. This document is addressed to autistic individuals, their families and members of their wider support networks, including support workers, clinicians and policy makers. To increase accessibility, the publication includes an Easy-to-Read section.

It highlights major areas of knowledge, ranging from processes involved in identification and diagnosis, to understanding the underlying mechanisms and causes of autism. One of its objectives is to help recognise and tackle disparities that exist within Europe regarding public access to evidence-based knowledge. It also aims to inform clinical guidelines of good practice across Europe, in terms of developing practical strategies of support for autistic people.

Based on current best evidence, it recommends four fundamental principles of good practice to support autistic individuals: individualisation (diversity, personalised support); structure (predictability, stability); intensity and generalisation (not sporadic or short-term, but systematic and across settings). It highlights the value of individualised lifelong support plans, which should account for every individual's personal needs. This approach focuses on setting attainable goals, in view of achieving a good quality of life.

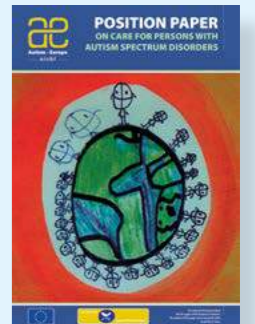


To foster access to evidence-based information across Europe, AE advocates for the adoption of EU guidelines on gold-standard screening and diagnosis instruments and criteria across all EU Member States, as well as EU guidelines on evidence-based, rights-based intervention for autism, based on existing guidelines at national and international levels.

Position paper on care for persons with autism

Another example of cooperation with professional organisations is Autism-Europe's 'Position paper on care for persons with autism', which was presented and officially adopted at the 8th International Congress of Autism-Europe (Oslo, 2 September 2007). This position paper outlines a rights-based approach to providing care for autistic people, specifically in the areas of habilitation, healthcare, education and social inclusion.

It was drafted in cooperation with the International Association of Child and Adolescent Psychiatry and Allied Professions (IACAPAP) and the European Society for Child and Adolescent Psychiatry (ESCAP) and is a powerful stance to adopt a rights-based approach to autism.



Autism-Europe : A few key dates

- 2016** 11th Autism-Europe international congress in Edinburgh
- 2017** Autism-Europe becomes a full member of the European Expert Group on transition from institutional to community-based care
- 2018** Autism-Europe presents a set of recommendations for a public health plan for autism in the context of the ASDEU initiative, a pilot project by the European Parliament

Example of mobilisation of the international scientific community: the case of 'Packing'

AE works to alert the international community regarding unethical practices, as it was for example the case for 'Packing'. Coinciding with the 9th International Autism-Europe Congress held in Catania, Sicily in October 2010, internationally renowned experts in the field of autism took a strong stance and called

for banning this practice in a 'Consensus Statement' published in the Journal of The American Academy of Child & Adolescent Psychiatry. This alleged therapy consists of wrapping the patient (wearing only underclothes or naked in the case of young children) several times a week during weeks or months in towels soaked in cold water (10°C to 15°C). This statement was released as the French Public Health High Council had failed to ban the practice. A few years later, it was finally banned in France.



Presentations of the ASDEU recommendations to representatives of Member states in January 2018

Improving the response to the healthcare needs of autistic people

The right to health for people with disabilities, including people on the autism spectrum, is enshrined in Article 25 of the UN CRPD (United Nations' Convention on the Rights of Persons with Disabilities). However, a 2016 large-scale study conducted in Sweden evidenced that autistic people die on average 16 years earlier than the general population. In his reaction, Chief Executive Jon Spiers of UK charity Autistica then denounced in Autism-Europe's LINK 65 that many autistic people would never see their fortieth birthday.

In the context of the ASDEU initiative funded as a pilot project by the European Parliament, AE presented in January 2018 a set of recommendations for a public health plan for autism. It notably called for the systematic provision of reasonable accommodation in all healthcare premises and diagnostic instruments needed to ensure autistic people's access to healthcare of the same quality as other people, as well as ensuring training on autism needs and accessible communication in the curricula of health professionals and other relevant staff. Autism-Europe thus welcomes the fact that the EU's Strategy for Persons with Disabilities 2021-2030 highlights that when it comes to healthcare 'persons with invisible disabilities [...] do not always receive the tailored support needed.'

Autism-Europe reiterated in its 2022 Alternative Report to the periodic review of the European Union's implementation of the UN CRPD that autistic people across the EU still have unequal access to general healthcare services, including reproductive healthcare. Autism-Europe also recommended this year an

ambitious EU mental healthcare strategy. Mental health issues and psychosocial disabilities experienced by autistic people may be the result of lack of an autism diagnosis, an inadequate intervention plan, as well as a chronic lack of understanding, accessibility and support in the community. Anxiety and depression are major co-occurring mental health issues especially for autistic adolescents and adults, which can have a significant negative impact on their executive functioning (organising, studying, working, etc.). The ambitious implementation of the 2023 European Commission's comprehensive approach to mental health might be able to lead the way.

As Autism-Europe enters its fifth decade since its foundation, we reiterate our call for an improved healthcare system in the EU that meets the needs of autistic people.

Autism-Europe : A few key dates

- 2019** Adoption of the European Accessibility Act
- 2019** 12th Autism-Europe international congress in Nice
Harald Neerland becomes President of Autism-Europe
- 2020** Covid-19 pandemic spreads across Europe and AE raises awareness of the difficulties faced by autistic people and their families
- 2021** Launch of the European Strategy for the Rights of people with Disabilities 2021-2030

Autism in the media over the last 40 years: how has social perception of autism evolved?

'Nothing about us without us' is the motto of the disability movement and it also applies to media representation. The portrayal of autistic people in the media, especially in TV series and movies, is a powerful way to influence and build understanding in society. Over the last forty years, Autism-Europe and its members have been working tirelessly to improve the situation at the European and national levels.

When it comes to media representation of disabilities, such as autism, we have witnessed a growing trend over the last decades. Since the 80s, media (and social) representation of autistic people has evolved gradually, with an increased presence of autistic characters in movies and TV series in the last years, reflecting the general perception of autism in society.

The Rain Man Operation in the 80s

In 1988, the first Oscar-awarded movie featuring autism, *Rain Man*, was released. It gave autism a visibility never seen before, but also created the autistic savant trope (pairing autism with extraordinary abilities such as the prodigious memory exhibited by the main character Raymond Babbitt) that still impacts the autistic community today. Indeed, even if the so-called savant syndrome is real, it is considered rare as it is estimated that only 10% of autistic people have savant abilities.

Nonetheless, Autism-Europe members seized this opportunity to raise awareness and funds in their own countries by working with film distributors to organise gala premiere sessions of the movie around Europe. In 1989, the film was released on video, and a text was inserted in each videotape in Italy, Portugal, Greece and Sweden to encourage audiences to support their local autism organisation.



Autism-Europe : A few key dates

- 2021** European Parliament debates employment opportunities for autistic people with Equality Commissioner during plenary session after in-depth consultation with Autism-Europe
- 2021** Autism-Europe becomes a member of the newly established EU Disability Platform alongside the European Commission, Member States and 13 other NGOs
- 2022** Autism-Europe calls for support for Ukrainian autistic people and their families following the Russian invasion

President of the European Parliament, Roberta Metsola, opens the photography exhibition 'Building an inclusive society for autistic people' alongside AE President Harald Neerland and fellow MEPs. The exhibition featured artwork from several autistic photographers from across Europe.



And since then?

Almost 40 years have passed since *Rain Man*, and the situation is improving – although some very stereotypical tropes remain. The autistic savant character is still present in TV series like *The Good Doctor* (following a brilliant surgeon) and *Atypical* (following a brilliant teenager), both released in 2017, which also perpetuate the stereotype that autistic people are predominantly white and male. This idea is of course untrue: lower autism rates in women and ethnic minorities can be attributed to a lack of access to diagnosis as well as biased assessment tools, among other factors. Additionally, like Dustin Hoffman in *Rain Man*, none of the actors playing the autistic main roles in both TV series are autistic people.

On the other hand, a growing number of productions in the last few years have depicted autism in a more diverse light, and are often praised for the performances of the autistic actors playing leading characters. It is notably the case for independent dramas *Mozart and the Whale* (2005), *Adam* (2009), and *Mary and Max* (2009) to TV series *As we see it* (2022) and *Everything's Gonna Be Okay* (2020), as well as the Bollywood movie *My Name Is Khan* (2010), the documentary *Autism in Love* (2015) and the award-winning movie *Life, Animated* (2016). Recently, Pixar produced a short animated film called *Loop* for Disney+ (2020), in which a young autistic girl Renee – who is non-verbal – was played by autistic actor Madison Bandy, who is mostly non-speaking, showing an inspiring example of inclusion in the film industry.

The shift in media perception of autism in our society has been possible thanks to the tireless awareness-raising efforts of autism associations and self-advocates. Autistic people and their families deserve ownership of their stories. To this end, Autisme-Europe seeks to encourage the artistic expression of people on the autism spectrum. This is particularly the case thanks to the art exhibitions held on the occasion of our congresses in cooperation with our Spanish member association Autismo Burgos. In 2023, Autisme-Europe also honoured the work of autistic photographers in an exhibition held at the European Parliament and opened by its President. In the future, we would like to see more diverse media characters, reflecting the infinite range of autistic people's experiences.

Autism-Europe : A few key dates

- 2022** 13th Autism-Europe international congress in Cracow
- 2022** Autism-Europe publishes an alternative report for the second review of the EU by the CRPD Committee
- 2022** The European Commission proposes a European Disability Card
- 2023** The European Parliament adopts a Resolution on 'Harmonising the Rights of Autistic People'





Members gathered in Zagreb, Croatia for the Annual General Assembly in 2017

Autism-Europe: 40 years of history, and what about the future?

As we celebrate 40 years of Autism-Europe, it is evident that society has undergone a significant evolution since 1983 in its approach and understanding of autism. For this special 40th anniversary edition of the LINK magazine, we launched a survey among our members to collect their perspectives about the past and the future of the autistic community across Europe. What are their wishes for the future?

Since its foundation under Belgian law in 1983, Autism-Europe (AE) has progressively grown as a more diverse and representative organisation. It started as an association representing 23 national and regional associations to an international umbrella association bringing together almost 90 member organisations from 40 European countries.

AE represents an estimated 7 million people throughout Europe, with self-advocates and families playing a central role in the organisation. AE is recognised by the European institutions as a key representative network of autistic people and their families.

What did AE members say about this evolution?

And what are their wishes and goals for the future?

During the past 40 years, AE members have been tirelessly fighting at the national level to guarantee autistic people's rights and support.

According to the respondents of AE's 40th anniversary survey, AE's membership has proven to be very useful in terms of community and networking, sharing of knowledge and best practice on autism, and advocacy and awareness-raising at the European level.

'Being a member of Autism-Europe means having a unified voice in Europe.'

However, there is still a long way to go to improve the quality of life of autistic people. When it comes to state-funded support, the majority of the respondents said it is still low in 2023.



Credit: Ana Isabel Munguia

AE members highlighted the following current priorities for the autism community, in order of importance:

- | | |
|---|---|
| 1) Training and employment (65.52%) | 11) Enjoyment of legal capacity thanks to adequate support (27.59%) |
| 2) Housing and living support (62.07%) | 12) Self-representation of autistic people (27.59%) |
| 3) Financial support (55.17%) | 13) More high-quality scientific research (24.14%) |
| 4) Access to quality education (55.17%) | 14) Awareness & understanding among the general public (24.14%) |
| 5) Social inclusion policies and practices (55.17%) | 15) Recognition of autism by governments/national health departments (20.69%) |
| 6) Quality evidence-based therapies (48.28%) | 16) Technologies to support autistic people (13.79%) |
| 7) Support for carers of autistic people (44.83%) | 17) Recognition of autism as a disability (10.34%) |
| 8) Early access to diagnosis (31.03%) | |
| 9) Awareness-raising of autism among professionals (doctors, teachers, etc.) (31.03%) | |
| 10) Anti-discrimination policies and practices (31.03%) | |

Many wishes for the future were expressed via the survey:

'I wish autistic people to be able to enjoy the exact same rights as the general population in all areas of their lives.'

'I wish to see a society that is flexible and open-minded, where everyone can fit. A society that is supportive, generous and open with those with higher needs of support. A society that understands and supports the families of individuals on the spectrum.'

'I wish for more employment opportunities for autistic people, more knowledge about autism in schools and society, more qualified autism specialists.'

'I wish that autistic people can live like others based on their wishes and needs with good housing, meaningful activities/work and financial circumstances that provide a good standard of living. That autistic children can grow up without being considered 'wrong' and with access to a school that is adapted to the students' challenges and strengths.

That it becomes a matter of course that autistic people are included in all decision-making processes that concern them, as well as in research on autism and in development of support.'

'I wish for improved access to employment, increased financial support and to improve the legislation regarding legal capacity.'

'I wish that autistic people in Europe would have the same chance as everyone else. That the invisible barriers autistic people face in European society would be removed. That every autistic person would be accepted 'as they are' - equal, valued and respected.'

'I wish autistic people to be seen as valuable member of the society, get the necessary support from state as well as from their community and be happy.'

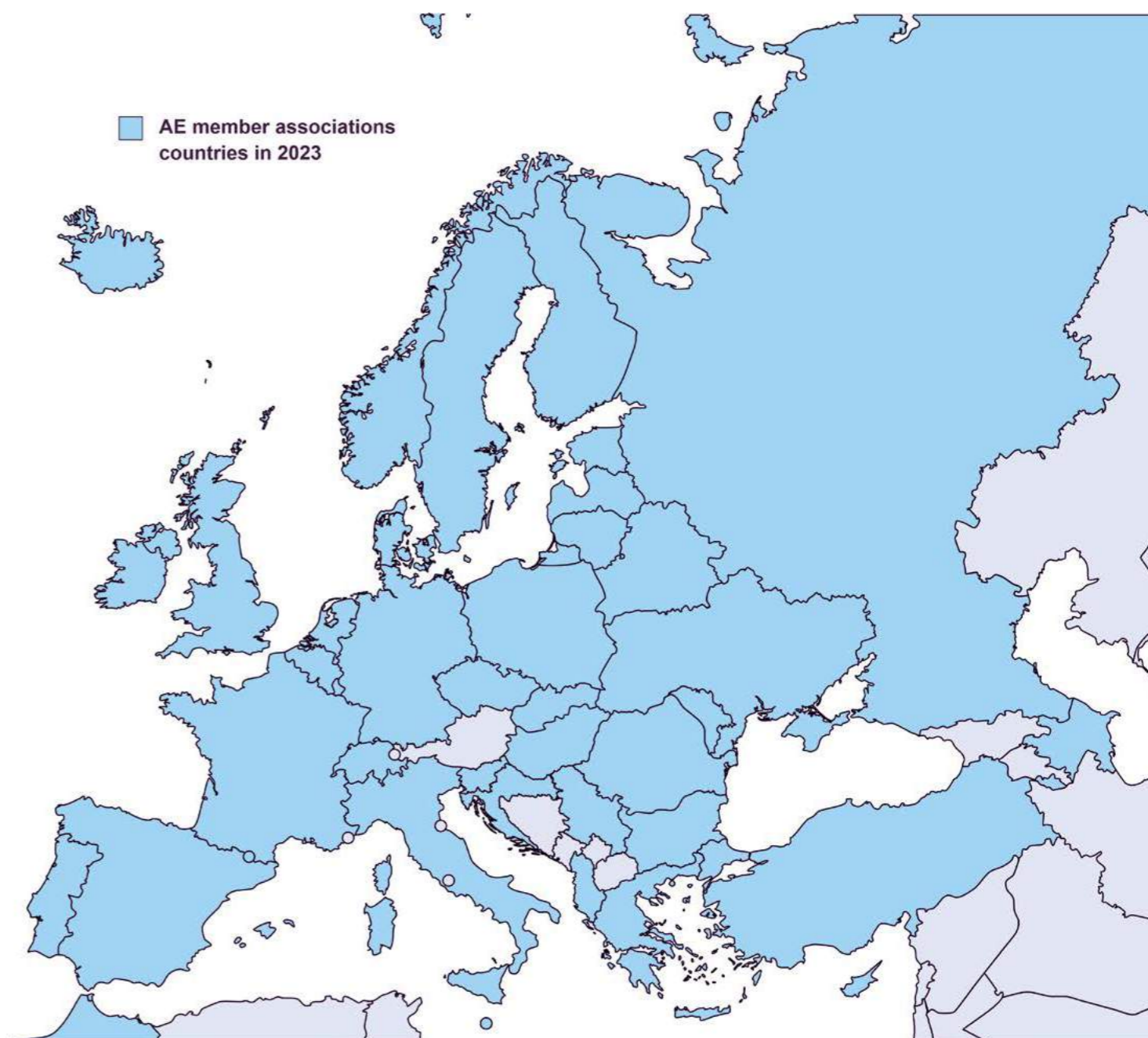
'Changing the narrative and frame about autism, getting a more nuance responding and an end to all abuse however caused.'

'I wish autistic people's voice in society is articulated and heard.'

'I wish for acceptance, understanding of the uniqueness / individual approach, and more support from government to realise the rights of autistic people.'

'I wish that autistic people had access to accommodation in the field of education and employment to achieve independence, autonomy and self-determination.'

Credit: Florian Popa



created with mapchart.net

Member Associations of Autism-Europe

FULL MEMBERS

National associations of autistic people and parents

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