

# Uink Anniversary edition

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English edition

1983-2013

## 30 years of Autism-Europe



- 30 years of improvements for people with autism across Europe
- How we helped our members to achieve changes
- What our members think - survey results

This paper includes  
summaries in  
easy-to-read language.



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For Diversity



Against Discrimination

 **Autism  
Europe**  
aisbl

**Autism Europe aisbl**

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# Editorial



Dear friends,

Welcome to this special edition in celebration of the 30th anniversary of Autism-Europe! It all began in the early 1980s as the idea of some passionate parents who wanted to better understand their children and to ensure they would have the best possible quality of life. To this end, Autism-Europe has consistently promoted a rights- and evidence-based approach to autism, working together with people who have autism and their families, professionals and political decision-makers.



To further advance the rights of people with all types of disabilities, Autism-Europe has also actively taken part in shaping a unified and strong movement of people with disabilities in Europe, alongside other organisations.

We have come a long way since 1983; the broader community is becoming more aware of autism and people with disabilities have gained better recognition of their rights. However, much work remains to be done to ensure the full implementation of their rights and the effective participation of people with disabilities in European society.

We would like to thank all our supporters and friends who have helped us over the past 30 years and continue to strive with us for the respect of the rights of people with autism, and to ultimately enable them to live fulfilling lives in the community.

Sincerely,  
Zsuzsanna Szilvásy  
President

Aurélie Baranger  
Director

## About Autism-Europe



Autism-Europe represents an estimated 5 million people who have autism throughout Europe. Our aim is to help them improve their quality of life by standing up for their rights.

We work with our members (more than 80 member associations in 30 countries) to:

- Advocate for the rights of people with autism before the European institutions;
- Monitor European laws and policies;
- Promote appropriate education and evidence-based therapies and support;
- Promote the exchange of information, good practices and experience in the field of autism;
- Promote awareness of autism.

We bring our members together regularly to discuss issues and policies that affect people with autism and represent their views to policy-makers at the EU level.

We also hold an international congress every three years, publish *LINK* magazine, newsletters, advocacy reports and toolkits and run campaigns to raise awareness about autism.

More information: [www.autismeurope.org](http://www.autismeurope.org)

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# 30 years

## of action for autism in Europe



Photo: UN Photo



Images: (top) Greece signing the UNCRPD, with European Disability Forum President, Yannis Vardakastanis (far left); (middle) Autism-Europe Director, Aurélie Baranger, and Pietro at the European Day of People with Disabilities in 2010; (bottom) World Autism Awareness Day in Kecskemét, Hungary. Image: (below) World Autism Awareness Day in Breclav, Czech Republic.

What has changed for people with autism and their families across Europe over the past 30 years? Have policy and legislative changes made a difference to their everyday lives?

Changes to policies, legislation and practices often occur as a result of many small steps over time, so their impact is not always easy to assess. That is why it is worth stopping to examine what has been achieved over the past 30 years and to celebrate these gains.

This special edition of LINK magazine aims to highlight the evolution of the situation faced by people with autism and their families since Autism-Europe began back in 1983. These are highlighted through accounts of our past activities and the results of a survey of Autism-Europe members. Some of our members' personal experiences over the past 30 years are also profiled in this edition. On these pages, the progress that has occurred in awareness, legislation, diagnosis, education and support is illustrated, along with some of the ongoing challenges for people with autism.

Above all, this edition would not be possible without the many dedicated parents, self-advocates and volunteers who have contributed to the achievements of Autism-Europe over the past 30 years. Just as it is impossible to distil 30 years of history into 28 pages, it is also impossible to name and thank all of the people who have contributed to Autism-Europe's achievements.

Over the past 30 years, across Europe, people with disabilities have gained better recognition as full citizens. Some people with autism now have access to early intervention, adapted and individualised education, employment and support services. It is clear that over this time the advocacy of Autism-Europe and our members across Europe has made a difference.

Yet, when considering the improvements over the last three decades, it is also clear that many challenges remain. For example, the majority of families affected by autism in Europe still struggle to access fundamental things like diagnosis by qualified professionals and evidence-based therapies.

After 30 years, the mission of Autism-Europe is far from complete, but people with autism and their families have worked hard together to bring positive changes to legislation, policies, practices and attitudes, and this is really worth celebrating.



Photo: Petra Stroulahova

# 1983 - 1992

## How we began...

As the condition of 'autism' was slowly becoming known among professionals and the general public across Europe, several associations of parents of people with autism from various countries joined together to hold the first 'European Conference of Associations of Parents' in Ghent in 1980. At this time, scientific research on autism was less advanced than today, and many detrimental non-evidence based theories and practices in the field of autism were emerging. In this context, where parents were struggling to find reliable scientific information that could help them to understand and support their children, the Ghent congress offered a forum for information and discussion.

Following the first congress, Autism-Europe was founded in 1983 by a group of national and regional parents' 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:

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

## Shifting views on disability

Autism-Europe was founded in the context of a changing public understanding of all disabilities. The public conception of disability at this time is often described as 'the medical model of disability' in which people with disabilities are viewed as 'objects' of charity, medical treatment and social protection. A new conception of disability was emerging, called 'the social model of



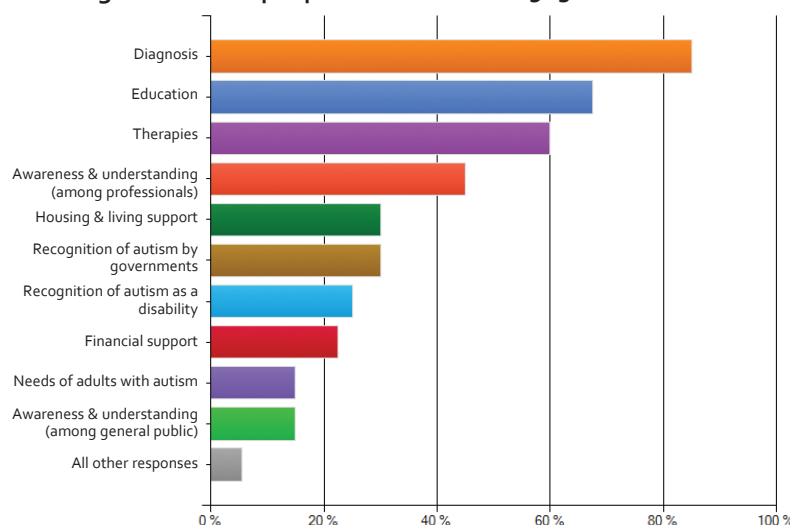
## Autism

Autism is a complex lifelong disability that affects the development and functioning of the brain. People who have autism experience difficulties with social interaction and communication and often display restricted interests and repetitive behaviour. Autism is a 'spectrum disorder', which means that the symptoms vary between individuals, ranging from mild to severe.

In Europe, approximately 1 in 150 people have autism.

**More information:**  
[www.autismeurope.org](http://www.autismeurope.org)

## Most urgent needs of people with autism in 1983.



*This diagram is based on responses to the 30th anniversary member survey by Autism-Europe, which asked the question: 'In 1983, which of the following issues do you think were the most urgent for people with autism in your country? (maximum 5 choices)'.*

**1980** First European congress by parents of children with autism held in Ghent.

**1981**

United Nations International Year of Disabled Persons.

Greece joins the European Economic Community.

**1983**

Founding of Autism-Europe.

Jean Charles Salmon becomes the first President of Autism-Europe.

Autism-Europe congress held in Paris.

United Nations Decade of Disabled Persons begins.



Map: European countries whose national autism association was a member of Autism-Europe in 1983.

disability', which aimed to redefine disability with a focus on the relationship between people with disabilities and their environment. This understanding is based on the idea that social barriers must be removed to enable people with disabilities to participate fully in society. This reconception of disability views people with disabilities as 'subjects' who are capable of being active members of society who can represent themselves and exercise their rights.

### United Nations policy action on disability

The United Nations had declared 1981 to be the 'International Year of Disabled Persons' with the aim to raise awareness of the rights of people with disabilities, including people with autism. 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 invoke new public policies around the world which 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 December 3, around the world.

### Autism-Europe's international congresses

The newly formed organisation also took on the role of organising further congresses, every 3 to 4 years. These events were held with the intention of developing and sharing the latest research, information and best practices in the field of autism among researchers, professionals, parents and people with autism from around Europe. The discussions and outcomes of these congresses have also played a key role in assisting Autism-Europe to represent people with autism before the European Union institutions.

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 among the autism community. Congress speakers have included top researchers in the field such as Sir Michael Rutter, Dr Eric Schopler, Dr Lorna Wing, Prof. Simon Baron-Cohen, Prof. Rita Jordan, Dr Fred Volkmar, Dr Joaquin Fuentes, Prof. Patricia Howlin, Prof. Tony Charman, Prof. Francesca Happé and many more.

### Congress, 1980

#### Ghent, Belgium

In June 1980, the 'First European Conference of Associations of Parents' was held, bringing together over 400 participants. The congress aimed to encourage the exchange of knowledge among researchers, medical doctors and other professionals in the field of autism.

The programme focused on autism in early childhood, therapies, parental involvement, support for families and concerns for the future of children with autism. As a result, information about causes, diagnosis, care, management and education also became more available to parents and fuelled their advocacy activities across Europe. The congress concluded that the condition of autism did not differ across national borders; the same condition was being identified among people in many countries.

<p><b>1986</b></p>	<p><b>1988</b></p>	<p>Autism-Europe congress held in Hamburg.</p>	<p>First issue of LINK magazine.</p>	<p>Autism-Europe granted consultative status by The Council of Europe.</p>
<p>Spain and Portugal join the European Economic Community.</p>			<p>Gilbert Huyberechts becomes President of Autism-Europe.</p>	<p><b>1989</b></p> <p>Autism-Europe conducts the 'Rain Man Operation'.</p>



Images: (above) Selected editions of LINK magazine, from 1988 to present.

The second congress was held in Paris in 1983 and the third in Hamburg in 1988. In the years in between, much work was done to organise a congress in London, but due to funding difficulties, this congress was never realised.

### LINK magazine

In 1988, Autism-Europe produced the first LINK magazine and launched it at the third congress in Hamburg. The magazine (published in English and French) aimed to provide the latest information on autism to a wide audience including parents, professionals and policy makers in the time between the congresses.

### Recognition from the European institutions

In 1988, Autism-Europe was granted consultative status by the Council of Europe. This status recognises and enables Autism-Europe to speak as a representative of people with autism in Europe, through a range of channels from simple consultations to co-operation on specific projects. Notably, this status also entitles an organisation to bring a collective complaint before the Council of Europe.

### Working collaboratively in Europe in the 1980s

In the 1980s, Autism-Europe did not have any paid staff, it was entirely run by volunteers; mainly parents and relatives of people with autism, including the second president, Gilbert Huyberegts (from Luxembourg). The organisation was charged with the difficult job of coordinating a transnational network of members with very limited financial resources. While computers and technology were beginning to make changes to the way we live and work in the late 1980s, many barriers related to the costs of communication and coordination remained.

Despite the limited resources, Autism-Europe continued to collaborate with member organisations, holding small and medium sized events, such as the 'European conference on educational approaches to autism' in Mons, Belgium, in 1989, and the 'Seminar on juridical protection of people with autism' in Barcelona, Spain, in 1990.

## Congress, 1983

### Paris, France

The '2nd European Conference of National Societies for Persons Handicapped as a result of Autism or Childhood Psychosis' was held in June 1983, this time attracting over 1,200 participants from 22 countries. The main aim was to raise awareness among the European authorities and the general public about the needs and challenges of people with autism who experience childhood psychosis. Parents and professionals from across Europe were invited to share the results of their research, their experiences and their concerns about the future of children with autism from a social, medical and educational perspective.



1991

Parents Exchange Programme in 5 European countries.

Soviet Union dissolved. End of the Cold War.

1992

Autism-Europe congress held in The Hague.

Charter for Persons with Autism adopted by the congress.

Survey on the situation of adults with autism across Europe.

Adoption of the Maastricht Treaty, Treaty on the European Union.

Meanwhile in Eastern Europe, during the late 1980s and early 1990s the fall of the Soviet Union meant the communist period was coming to an end and parents of people with autism were forming associations.

## The Rain Man Operation

In 1989, Rain Man, the seminal film about a man with autism and his younger brother, was released. This film created awareness of autism on a global scale, as well as attracting criticism from some over the fact that the majority of people with autism do not have savant abilities as portrayed in the film. In any case, Autism-Europe members seized this opportunity to raise awareness and funds in their countries, by working with the film's distributors to organise gala premiere sessions of the film around Europe. Later that year, when the film was released on video, a text was inserted into each video cassette in Italy, Portugal, Greece and Sweden encouraging viewers to give support to their local autism organisation.

## Parents exchange programme on services for adults

In 1991, Autism-Europe conducted a 'Parents' Exchange Programme' in which a group of parents from five European countries (Denmark, Ireland, Holland, Great Britain and Germany) visited and analysed services for adults with autism in these countries. As part of the project, an academic study was also conducted, comparing the situation in four countries: Belgium, the Netherlands, the United Kingdom and France.

## Survey on the situation of adults with autism in Europe

In the same year, Autism-Europe conducted a survey on the situation of adults with autism in Europe among member associations. The results indicated that reasonable levels of social and legal protection were available, yet there was a lack of access to diagnosis and specialised services. In addition, many adults with autism were confined to psychiatric hospitals or forced to remain under the care of their families, instead of living independently.



*Images: Selected images from previous Autism-Europe congresses.*



## Congress, 1988

### Hamburg, Germany

As Autism-Europe's congresses had developed a strong reputation among autism researchers and parents, this one attracted 1,760 participants.

The programme was focused on the exchange of medical, educational, legal and practical experience, and included workshops where representatives of governments and social services had the opportunity to learn about measures to support people with autism in other countries.

At this time, Autism-Europe had 34 member associations, who all participated in planning and organising the congress.

## Congress, 1992

### The Hague, The Netherlands

The congress in The Hague was an historic occasion. The congress' 1,500 participants unanimously adopted the 'Charter of rights for persons with autism', produced by Autism-Europe, which outlined a set of fundamental rights for people with autism to enable their participation and inclusion in society.

It was also the first time that a person with autism was featured as a speaker at an Autism-Europe congress. Temple Grandin described her experiences as a person with autism, focusing on visual thinking and sensory and communication difficulties.

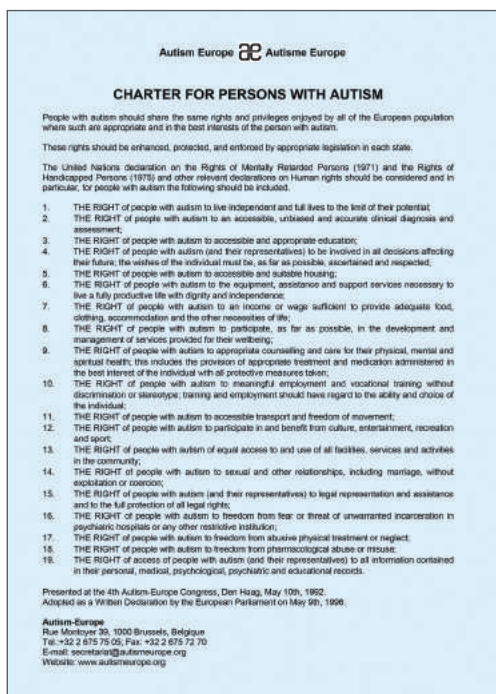
In addition, this congress welcomed the participation of representatives from parts of Eastern Europe who had the opportunity to attend an international congress of Autism-Europe for the first time.

# 1993 - 2002

## People with disabilities get better recognition in Europe

This decade was very significant in the development of all kinds of European policies, including those related to 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 unfortunately 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 was the legal basis for the development of European non-discrimination legislation around disability. Without it, no such legislation would be possible at the EU level. Autism-Europe participated in 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 of how this article could be used to support people with autism and other disabilities.

In 1993, the European Commission began to establish formal structures for consultation with people with disabilities and their representative organisations, and awarded funding to Autism-Europe to act as a bridge between its members and the European institutions. 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, in which 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. This event has since been held approximately once per decade. Representatives of Autism-Europe have attended these events over the past 20 years to ensure that the views of people with autism are included.



## Charter of rights for people with autism

After a long process of discussion and debate, Autism-Europe members agreed on the text of a 'Charter for Persons with Autism'. The charter, which outlines a comprehensive set of rights in all aspects of life specifically for people with autism, was presented at Autism-Europe's international congress in 1992, where it was adopted unanimously by the community of parents, researchers and professionals who were present at the event. Following on from that, Autism-Europe decided that for the charter to have relevance and credibility at the European level, it must also have political endorsement. Autism-Europe therefore embarked upon a campaign to gain political support and approval for the charter. After many months of members and staff lobbying MEPs for their support, the charter was adopted as a written declaration by the European Parliament in 1996, giving it recognition at the highest level in Europe and making it one of Autism-Europe's greatest achievements.

Images: (top) The increasing use of computers and technology by people with autism; and (bottom) The Charter for Persons with Autism that was adopted as a written declaration by the European Parliament in 1996.

1993	Autism-Europe gains funding from the European Commission and hires first staff member.	1995	Autism and Computer Applications Conference.	1996	Charter for Persons with Autism adopted by the European Parliament as a written declaration.
	European Union is founded.		Austria, Finland and Sweden join the EU.		Schengen Agreement creates free movement of people across 7 European countries.



Map: European countries whose national autism association was a member of Autism-Europe in 1993.

## Technology and autism

As the internet was beginning to reshape our world, in 1995 Autism-Europe was at the forefront of the movement for technologies for autism, with the organisation of an 'Autism and Computer Applications Conference' in Nice, France. The conference covered new topics such as assistance with communication and education, technology for diagnosis and assessment of learning capacities.

## Founding of the European Disability Forum

After some years in development, the European Disability Forum (EDF) was officially formed in 1997 as the representative voice of people with disabilities in Europe, before the European institutions. Autism-Europe was one of the key founder members of this new coalition which took on a crucial role in the development of policy 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 gains at the policy level for people with autism 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 with severe communications impairments/in need of a high level of support are adequately represented within the disability movement. For this reason, Autism-Europe has remained closely involved in EDF ever since its founding, and has held the vice presidency of EDF since 2005.

## Exhibitions of art by people with autism

In 1997, Autismo Burgos created the first international exhibition of artworks by people with autism. Held alongside seminars on autism, the exhibition brought public recognition to the skills of people with autism. The exhibition then travelled to other cities in Europe, where thousands more people could see the works and gain a new perspective on people with autism. Since

## Congress, 1996

### Barcelona, Spain

The memorable fifth congress in Barcelona followed the theme, 'Hope is not a dream', and attracted 1,700 participants. The congress covered topics including the delivery of high quality services for people with autism of all ages according to their needs, the effects of stress on the whole family and ways in which support can be provided, psychological research into autism, and biological and biomedical research.

Parents and self-advocates shared their experiences and professionals shared the results of the latest research. Some of the issues that were highlighted included implementation of the rights of people with autism in the design and implementation of services for their benefit, the need to safeguard the rights of people with autism through legislation and the key role advocacy organisations in the development of modern perceptions of autism.

<p><b>1997</b></p>	<p>Autism-Europe members begin international exhibitions of art by people with autism.</p>	<p><b>1998</b></p>	<p>Publication of 'Code of Good Practice on the Prevention of Violence Against Persons with Autism'.</p> <p>Autism-Europe congress held in Glasgow.</p> <p>Survey of Autism-Europe members to determine organisational priorities.</p>	
	<p>Disability activists gain anti-discrimination article in the Amsterdam Treaty.</p>	<p>Founding of the European Disability Forum.</p>	<p>Founding of the World Autism Organisation.</p>	<p>EU adopts the first anti-discrimination directive in the field of employment.</p>



Images: (top) art exhibition winners at the Autism-Europe International Congress in Oslo, Norway, in 2007; (bottom) Former Autism-Europe President, Gilbert Huyberechts, with the Duchess of Luxembourg at the founding of the World Autism Organisation.

that time, Autism-Europe members have organised many international art exhibitions displaying works by people who have autism, including as part of Autism-Europe’s international congresses.

## Evolving as an organisation

In 1993, when Autism-Europe gained funding from the European Union, Autism-Europe’s first employee was hired; Anne-Sophie Parent, who worked as the organisation’s director until 1999. While the staff grew to a total of five people at one point, the staff of the Brussels office remained very small and the representatives on the Council of Administration – all volunteers – primarily remained parents of people with autism. The role of self-advocates (people with autism who are able to advocate for themselves) also began to grow within Autism-Europe, as the congresses featured more people with autism.

The Schengen Agreement, in 1995, opened the borders of seven European countries to enable free movement of people. Along with increasing use of the internet, this assisted Autism-Europe members to meet and hold discussions in the years that followed.

In 1998, Autism-Europe supported the foundation of the World Autism Organisation with the intention to promote the rights of people with autism at the international level, in collaboration with autism organisations from around the world.

In 2000, Autism-Europe launched a survey among the members to determine Autism-Europe’s objectives and priorities. The results identified three main activities to be developed: scientific information, collaborative European projects and the newsletter.

In 2000, Autism-Europe’s third president, Donata Vivanti (from Italy), also began her term, which lasted until 2008.

## Congress, 2000

### Glasgow, United Kingdom

Following on from the theme of the congress in Barcelona, ‘Hope is not a dream’, the congress in Glasgow adopted the theme, ‘Making our dream reality’. This congress aimed to be more accessible to people with autism, offering them a more prominent role in the whole event.

The congress featured examples of good practices in the field of autism and practical applications of research, as well as service models, ethical and legal issues, education, biology, psychology, diagnosis, and personal and family stories.

An international art exhibition of people with autism, titled ‘Artism 2000’, was held as part of this congress. This initiative was followed by further art exhibitions at subsequent Autism-Europe congresses.

## Accurate information, reports, toolkits, position papers

In the context where many aspects of autism are still not well understood by experts, Autism-Europe’s members have always had a strong need for accurate, up-to-date information about autism. They also had a strong need for well-articulated documents from a rights-based perspective that could support their advocacy efforts for people with autism, both in their own countries and at the European level. During the 1990s and early 2000s, Autism-Europe published two significant documents; the ‘Code of good practice on the prevention of violence against persons with autism’ in 1998; and the ‘Description of Autism’ in 2000. These documents were developed in collaboration with many members as well as professionals.

## Founding of the Platform of European Social NGOs

In 2001, a new organisation was launched to advance the principles of equality, solidarity, non-discrimination and respect for the fundamental rights of all people within Europe; the Platform of European Social NGOs. Seeing the importance of working with other organisations with similar goals when advocating for the rights of people with autism before the European institutions, Autism-Europe was a founding member of this new alliance of representative NGOs from around Europe.

Publication of ‘Description of Autism’.

Donata Vivanti becomes President of Autism-Europe.

2001

Collective complaint against France before the Council of Europe (Autism-Europe v. France, complaint no. 13/2002).

Founding of the Platform of European Social NGOs.

# 30 years

## What has changed for people with autism and their families?

The situation faced by people with autism is very different across the many countries and regions of Europe. Earlier this year, Autism-Europe conducted an online survey among our members to find out more about the changes that have occurred for people with autism in their countries, and the kind of changes they want to see in the future.

The survey respondents represented 36 autism organisations in 26 European countries, and had been involved in autism organisations in their own countries for an average of 20 years. In addition, almost half had been involved in Autism-Europe for 10 years or more.

In this section, and throughout this publication, the results of this survey provide details of some of the ways that life has improved for people with autism over the past 30 years and how Autism-Europe has helped to achieve these improvements.

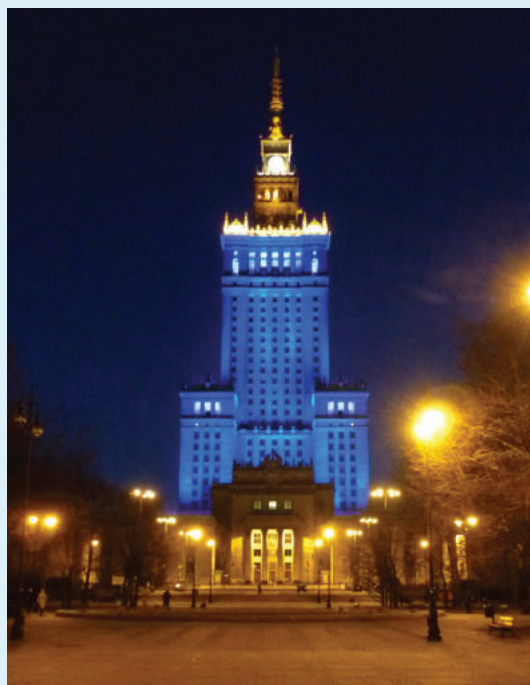


# Improved quality of life for people with autism

## Autism-Europe's major achievements

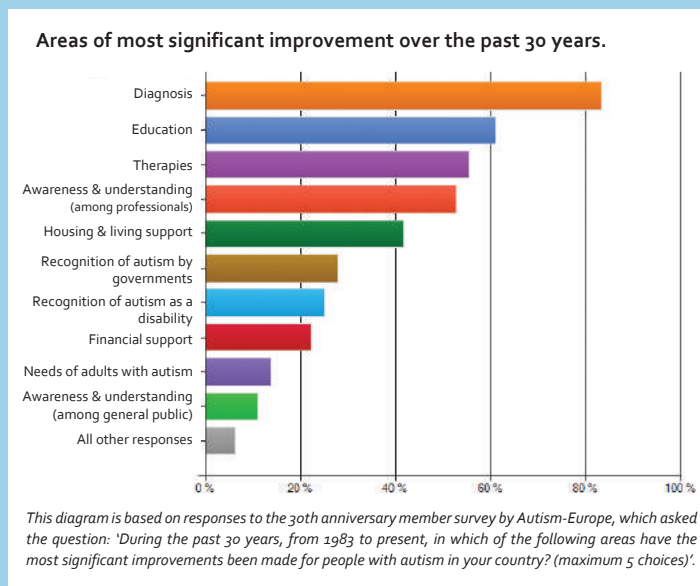
Autism-Europe has made some milestone achievements for people with autism and their families during the past 30 years:

- Charter of rights for persons with autism adopted as a written declaration by the European Parliament (1996);
- Landmark decision of the Council of Europe (Autism-Europe v. France, complaint No. 13/2002) whereby France was condemned to have failed its educational obligations to persons with autism under the revised European Social Charter (decision announced in 2004);
- Council of Europe Recommendation CM/Rec(2009)9 to member states on the education and social inclusion of children and young people with autism spectrum disorders, drafted with expertise from Autism-Europe;
- United Nations Convention on the Rights of Persons with Disabilities drafted with participation from Autism-Europe (2007);
- Increased awareness of autism throughout Europe (since 1983).



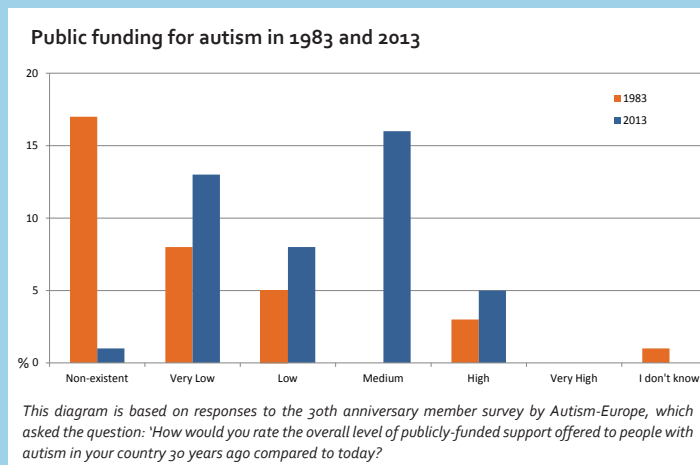
## Improvements in all areas

Many changes to policies and practices related to autism have occurred across Europe since 1983. The results of an online survey of Autism-Europe members indicates the areas in which the most significant improvements were made.



## Increased funding to support people with autism

There is no doubt that supporting the needs of people with autism costs money. Autism-Europe members have had to advocate for public funding to make therapies, services and other forms of support accessible. While it is clear that much more funding is needed across Europe, we can also recognise the huge gains that have been made so far.



Images: (left) The Palace of Science & Culture in Warsaw, Poland, lit up in blue as part of the 'Light it up blue' initiative for World Autism Awareness Day; (opposite page) World Autism Awareness Day in Breclav, Czech Republic.

# People with autism across Europe

## Our members' achievements in their countries

Across Europe, our members work tirelessly to improve the lives of people with autism in their own countries. While all of their accomplishments could not fit in this publication, here are some of the most significant achievements they have reported from the past 30 years.

*"Autism-Europe's Charter for Persons with autism was passed by the National Parliament."*

- Poland

*"A national autism strategy."*

- Hungary

*"Changes in legislation for people with autism."*

- Czech Republic

*"Government recognition of autism in adults (not just children)."*

- Ukraine

*"Early diagnosis."*

- Luxembourg

*"Early detection and the possibility to diagnose all ages also girls."*

- Denmark

*"Deinstitutionalisation."*

- Norway

*"'Team Autism' in which professionals from different areas work together around a person with autism."*

- Sweden

*"Development of services for the whole life cycle of the person with autism."*

- Spain

*"Day care centres where people with autism who have finished school receive care and assistance according to their special needs."*

- Austria

*"Co-housing project for adults."*

- Italy

*"Opening the Centre for Autism (a school and residential care facility) in 1983."*

- Croatia

*"Law 3/3008 - Compulsory education for people with disabilities, including autism, in public schools."*

- Portugal

*"Special schools for people with autism."*

- Czech Republic

*"We've trained over 1,000 professionals from the whole country since 1993."*

- Poland

*"Establishing an autism faculty in a university."*

- Hungary

*"Recognition of autism among relevant professionals."*

- Greece

*"Health and support plan for the whole family."*

- Denmark

*"A summer education camp for caregivers."*

- Norway

*"Self-advocacy: people with Asperger syndrome being represented at all levels in the organisation."*

- Sweden





# Members to achieve changes in their countries

## Sharing good practices and networking

Joining other organisations from around Europe can also be a very effective way to share good practices and learn from the experiences of others. Here is what some of our members told us about how being a member of Autism-Europe has been useful in helping them to improve quality of life for people with autism in their countries.

*"Connection with more experienced people."*

- Ukraine

*"Providing working models for my organisation."*

- Kuwait

*"The contact with other affected parents; the feeling we are not alone."*

- Spain

*"Study visits and support in advocacy."*

- Poland

*"Examples of good practices from other organisations, and knowledge of their experiences and achievements are valuable for an organisation from a country without any experience in this field."*

- Romania

*"Experiencing how other countries deal with issues like health, education, residential care and other issues relating to people with autism."*

- Greece

*"Networking, sharing views, opinions and solutions."*

- Iceland

*"Exchange visits organised by Autism-Europe gave us knowledge to build up services for people with severe autism in Luxembourg. Without Autism-Europe, we would not have the structures and services that we have today."*

- Luxembourg



Images: (top) World Autism Awareness Day in Hungary; (middle) the European Commission, Brussels; (bottom) Autism-Europe's Council of Administration members sharing their knowledge and providing input for policy documents. Image: (opposite page) Autism-Europe representative, Donata Vivanti, with Adam Kósa MEP, at the European Day of People with Disabilities in 2012.

## And more...

As our members indicate, Autism-Europe has assisted them in many other ways as well, for example:

*"Support."*

- Ireland

*"The website."*

- France

*"The congresses."*

- Sweden

# 2003 - 2012



Autism-Europe representative, Evelyne Friedel, at the United Nations in New York.

## Congress, 2003

### Lisbon, Portugal

Within the framework of the European Year of People with Disabilities 2003, the congress in Lisbon focused on the themes: 'thinking the future', 'ensuring a life worth living', 'providing a better quality of life', 'fighting for justice' and 'living with autism'.

The congress also featured a special session for parents titled, 'Living with autism', in which experts answered questions that had been raised by parents via an online forum.

An international art exhibition of people with autism, titled 'Another perspective', also took place alongside this congress.

## Collective complaint on the right to education in France

Autism-Europe 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). Autism-Europe was represented by Evelyne Friedel, a lawyer with a son who has autism (Evelyne later became the president of Autism-Europe from 2008 to 2011). In 2004, the Council of Europe publicly announced its landmark decision, whereby France was condemned to have failed its educational obligations to persons with autism under the revised European Social Charter. 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 by providing education for people with autism, both within mainstream and specialised schools, special schools according to the needs of each person with autism. Even though the decision referred specifically to the case of people with autism, its scope goes well beyond this group by reasserting the right to education for all people with disabilities, regardless of the severity of the disability. 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 children with autism. Progress made by the French government against this, and subsequent plans, is regularly reviewed by the Council of Europe.

## European Year of People with Disabilities

The 'European Year of People with Disabilities 2003' provided an opportunity to raise awareness of the rights of people with autism. This year, designated by the European Union, aimed to drive forward the political agenda for the full inclusion of people with disabilities. During the year, Autism-Europe produced a series of position papers on the topics of inclusion, health, education, employment and ageing. Some of these were produced on the basis of extensive surveys conducted among members of Autism-Europe and other relevant organisations. These position papers were later published in a booklet and distributed widely across Europe, as well as translated by some member organisations into their own languages.

## European Coalition for Community Living

In 2005, following on from the 'Included in Society' project, Autism-Europe joined other organisations that are concerned with deinstitutionalisation of people with disabilities, to form the European Coalition for Community Living. This coalition advocates for and monitors progress towards deinstitutionalisation in Europe, and promotes the development of comprehensive, quality community-based living situations for people with disabilities.

## The One Million for Disability campaign

In 2007, Autism-Europe participated in the 'One Million for Disability' campaign led by the European Disability Forum (EDF). The campaign called on the European Union to protect people with disabilities from discrimination in all aspects of life. The campaign utilised the 'right to initiative' provided in the European Union's Lisbon Treaty, in which requests from EU citizens for new EU legislation and policies can be considered by the European institutions if one million citizens' signatures are collected in support of the

2003	Autism-Europe congress held in Lisbon.	Included in Society Project begins.	Side-by-Side Project begins.	'Position Papers' (on inclusion, health, education, employment and ageing) produced.	2004 Council of Europe decision (Autism-Europe v. France) condemns France for failing in its educational obligations to people with autism.
European Year of People with Disabilities.		Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia and Slovenia join the EU.			



Map: European countries whose national autism association was a member of Autism-Europe in 2003.

request. More than one million signatures were collected and EDF was the first organisation to successfully carry out such a campaign. Shortly after, the European Commission proposed a directive to combat discrimination on all grounds, outside the field of employment (which was already covered by existing EU legislation). However, the directive was blocked by some Member States and thus far has not been adopted.

### United Nations Convention on the Rights of Persons with Disabilities

After four years in negotiation, in 2006 the United Nations General Assembly adopted a new convention specifically for people with disabilities. The Convention on the Rights of Persons with Disabilities (UNCRPD) reaffirms that all people with all types of 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 people with autism. It is legally binding for countries that ratify it.

The Convention has been ratified by most countries in Europe as well as the European Union, therefore must be implemented in these countries and within the EU's fields of competence.

### World Autism Awareness Day

In 2007, the United Nations General Assembly designated April 2 as World Autism Awareness Day; an annual day to raise awareness of autism at the international level. This day has since been marked in Europe and around the world with all kinds of events and activities including art exhibitions, conferences, ceremonies, balloon releases, flash mobs, concerts, film festivals and the 'Light It Up Blue' initiative (instigated by US organisation, Autism Speaks), in which buildings around the world are lit with blue lighting to raise awareness of autism. Autism-Europe has participated in awareness raising events and supported our members activities on this day by providing media campaign materials.



Photo: © European Union

### The European institutions

The European Union (EU) is a political and economic union of 28 member states.

There are three main political institutions of the European Union:

- the European Parliament, which represents the EU's citizens and is directly elected by them;
- the Council of the European Union, which represents the governments of the individual member states. The Presidency of the Council is shared by the member states on a rotating basis;
- the European Commission, which represents the common interests of the EU, and is the main executive body.

Together, these three institutions produce the policies and laws that apply throughout the EU.

*(continued on next page)*

<p><b>2005</b></p>	<p><b>2006</b></p>	<p><b>2007</b></p>	
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Founding of the European Coalition for Community Living.

United Nations General Assembly adopts the Convention on the Rights of Persons with Disabilities (UNCRPD).

Publication of 'Autism & case law: Protecting the right to education for children with autism spectrum disorders'.  
 Publication of 'Fighting for the right to education of persons with autism spectrum disorders: Toolkit for parents and self-advocates'.

First 'European Days of Autism' event.

In principle, the Commission proposes new laws, and the Parliament and Council adopt them. The Commission and the member states then implement them, and the Commission ensures that the laws are properly applied and implemented.

The European Commission regularly consults civil society organisations, including Autism-Europe, when drafting EU laws and policies, and monitoring their implementation.

On a larger geographical scale, the Council of Europe currently includes 47 member states, 28 of which are members of the European Union. It is a political organisation, that is separate from the European Union. It aims to promote democracy and protect human rights and the rule of law in Europe. All of its member states have signed up to the European Convention on Human Rights and the European Social Charter, which aim to protect human rights and guarantee fundamental freedoms.

Autism-Europe is one of the NGOs that has been granted consultative status with the Council of Europe. This status allowed Autism-Europe to lodge a collective complaint about infringements of the European Social Charter in France in 2002. Autism-Europe is regularly consulted by the Council of Europe and has been involved in its Committee of Experts on the Education and Integration of Children with Autism.



Image: Autism-Europe representatives, Donata Vivanti and Giulio Vivanti (back row, second and third from the right) at a high level meeting in Brussels in 2011 to ensure that the UNCRPD is implemented throughout the European Union. They joined representatives of the European Disability Forum and other disability organisations to meet with President of the European Commission, the President of the European Parliament and the President of the European Council.

## European Days of Autism

Each year since 2007, Autism-Europe has organised high level events in the beginning of October under the title of the 'European Days of Autism'. These events have brought members together with policy makers and external stakeholders to share knowledge and raise awareness of a specific topic related to autism. The first European Days of Autism featured a conference at the European Parliament, hosted by MEP, Kathy Sinnott, to raise awareness of autism among relevant European Union policy makers. Subsequent European Days of Autism events have been held in Budapest, Madrid, Prague and Lyon, with additional events organised in various countries by Autism-Europe members.

## Council of Europe support for education for children with autism

Following the collective complaint on the right to education in France in 2002, the Council of Europe established a group of experts – of which Autism-Europe was a member – to look into the issue of access to education for children with autism. This resulted in the Council of Europe's 'Resolution ResAP (2007)4 on the education and social inclusion of children and young people with autism', which was adopted as a recommendation in 2009 (CM/Rec(2009)9). While these are not binding for the members of the Council of Europe, they apply pressure to implement policies and adopt adequate legislation to promote access to evidence-based education and promote inclusion of people with autism.

## Financial crisis and funding cuts

In response to the financial crisis that hit the world economy in 2008, governments around Europe began to make significant cuts to public expenditure. These cuts have since reduced the support and resources that people with autism depend on, including health, housing and education. Autism-Europe has worked with the European Disability Forum and the Platform of European Social NGOs to advocate for improvements in social support during this time in which many Europeans need it most.

## Implementation of the UN Convention in the EU

After ratifying the United Nations Convention on the Rights of Persons with Disabilities in 2010, the European Union launched the 'European Disability Strategy 2010–2020'. The strategy aims to fulfil the EU's commitment to the UN Convention, making it easier for people with disabilities to go about their daily lives and enjoy their rights like other EU citizens. The strategy provides a framework for action at the European and national levels, in the areas of accessibility, participation in society, equality, employment, education and training, and health. Autism-Europe contributed to the development of this strategy by presenting the views of people with autism and their families during the European Commission's official consultations as well as via our participation in the European Disability Forum.

In accordance with the strategy, in 2011, work began on the development of the European Accessibility Act which aims to work alongside the European Single Market Act to improve the accessibility of goods and services for people with disabilities. Again, Autism-Europe presented the views of people with autism and their families on this act during the European Commission's official consultations, emphasising the importance of accessible communication, which is clearly described in the UN Convention.

Autism-Europe congress held in Oslo. Adoption of the 'Position paper on care for persons with autism spectrum disorders: A rights-based, evidence-based approach'.

Deinstitutionalisation and Community Living Project begins.

Publication of 'Training modules for policy decision makers and professionals of services for persons with autism spectrum disorders (ASD) and other complex dependency needs disabilities'.

Council of Europe Resolution ResAP (2007)4 on the education and social inclusion of children and young people with autism.

United Nations General Assembly designates April 2 as World Autism Awareness Day.

One Million for Disability campaign by the European Disability Forum to request European anti-discrimination legislation.

Bulgaria and Romania join the EU.

To further ensure that the EU lives up to its commitments under the United Nations Convention on the Rights of Persons with Disabilities, in 2011 a high level meeting was held between the European Disability Forum and the three presidents of the European institutions (the Parliament, the Commission and the European Council). Autism-Europe was represented at this meeting by the vice President of the European Disability Forum, Donata Vivanti (former president of Autism-Europe), and her son Giulio, a young man with autism who is in need of a high level of support.

## Study visits to schools and support services around Europe

Since Autism-Europe's Council of Administration meetings have been held at various locations around Europe, each one of these has included a study visit to a local school and / or support service, with the aim to share knowledge and best practices among our members.

## Becoming an even more representative organisation

During recent years, Autism-Europe's membership has become more representative in several ways. In 2010, two adults with autism joined Autism-Europe's Council of Administration as self-advocates, representing people with autism who can speak for themselves (among the existing group that is primarily composed of parents who represent people with autism in need of a high level of support). Meetings between members of Autism-Europe's Council of Administration and self-advocate groups are also now conducted regularly in various countries.

In 2012, the Council of Administration voted to allow non-European autism associations to join Autism-Europe, and the first non-European member association, the Kuwait Center for Autism, joined.

The fourth president of Autism-Europe, Zsuzsanna Szilvasy (from Hungary), also began her term in 2012; an example of the increasing participation of representatives from Eastern Europe in the organisation. Encouraging the participation of organisations from the enlarged European Union (and beyond) has been an ongoing priority of Autism-Europe.

In addition, the secretariat of Autism-Europe in Brussels recently hired two new staff members, primarily to work on European projects, but also to improve Autism-Europe's communications.

## Highlighting the needs of ageing adults with autism

During 2012, the European Year for Active Ageing and Solidarity between Generations, Autism-Europe took the opportunity to raise awareness of the needs of ageing adults with autism. As the first people in Europe who were diagnosed with autism are now beginning to reach middle and old age, their needs have become quite urgent. Yet these needs have not been addressed at all in most parts of Europe. During this year, Autism-Europe held a series of events, including a high level conference, around the theme of autism and ageing during the 'European Days of Autism' in Lyon, France. A report was also published, titled 'Towards a better quality of life: The rights of ageing people with autism', which aimed to articulate the issues faced by ageing people with autism across Europe and provide examples of good practice to meet their needs. In addition, Autism-Europe was also a member of a coalition of NGOs coordinated by AGE Platform Europe that aimed to highlight a range of issues in relation to ageing across Europe during this year.



Images: (top) a discussion forum with adults with autism in Prague, Czech Republic; (middle) Autism-Europe representative and self-advocate, Pietro, at the European Parliament of People with Disabilities in 2012; and (bottom) an Autism-Europe study visit to a school in Istanbul, Turkey.

## Congress, 2007

### Oslo, Norway

The congress in Oslo followed the theme, 'A world of possibilities', and attracted 1,200 participants from around the world.

The congress discussed and adopted the 'Position paper on care for persons with autism spectrum disorders: A rights-based, evidence-based approach' which was drafted by Autism-Europe in conjunction with associations of professionals and researchers in the field of autism.

An international art exhibition of people with autism, titled 'Dialogues in colour', took place during this congress.

2008	New Bridges to Autism Project begins.	2009	Autism Connections Europe Project begins.	Publication of 'Persons with Autism Spectrum Disorders – Identification, Understanding, Intervention'.
	Financial crisis strikes the world economy.		Proposal for an EU anti-discrimination directive in all aspects of life, outside the field of employment.	Council of Europe recommendation on the education and social inclusion of children and young people with autism CM/Rec(2009)9.



Images: (top) Illustration by Oscar Saiz Domínguez (a young Spanish artist with autism); (bottom) participants in the Autism Connections Europe project.

## Collaborative European projects for people with autism

Following the survey among members in 2000 (in which they encouraged further involvement in projects at the European level), Autism-Europe began to engage in more European projects, of various kinds, to improve the quality of life of people with autism. These collaborative projects have been funded by the European Union and involved autism organisations, universities and other relevant organisations from across Europe.

### Included in Society Project (2003 – 2004)

This project conducted research into the living situation of people with disabilities in Europe, then developed policy recommendations for deinstitutionalisation and the development of quality residential services for people with disabilities.

### Side-by-Side Project (2003 – 2005)

The Side-by-Side Project produced and implemented a comprehensive online training course about autism for families of people with autism and non-specialist staff of relevant organisations.

### Deinstitutionalisation and Community Living – Outcomes and Costs Project (2007)

This project aimed to collate information on the number of people with disabilities living in residential institutions in 28 European countries, comparing the costs of institutions and community-based services and identifying successful strategies for transition into the community.

### New Bridges to Autism Project (2008)

This project aimed to contribute to the inclusion of adults with autism in educational and social activities across Europe, through a range of means including a festival, exhibition, conferences, the promotion of good practices and the production of teaching and learning materials.

### Autism Connections Europe Project (2009 – 2011)

This project aimed to increase social inclusion of adults with autism from across Europe by making social connections via Facebook and in-person meetings, as well as participation in self-advocacy activities.

### FIRST Project (2011 – 2014)

The FIRST Project is developing a tool, called Open Book, to assist people with autism to adapt written documents into a format that is easier for them to read and understand.

### ASC-Inclusion Project (2011 – 2014)

This project is developing interactive computer games to help children with autism understand and express emotions through facial expressions, tone-of-voice and body gestures.

### SEAD Project (2012 – 2015)

The SEAD Project (Sexual Education for Adults with Disabilities, their parents and staff) is developing new and creative ways to effectively educate people with learning disabilities about sexual health and relationships.

### Count Me In Project (2012 – 2014)

This vocational education and training project will create tools for relevant educators to include people with learning disabilities in arts and cultural activities and promote opportunities for them in the labour market.

## Congress, 2010

### Catania, Italy

In Catania, 1,200 researchers, professionals, parents and self-advocates gathered for this congress around the theme, 'A future for autism'.

This congress attracted an unprecedented level of interest from professionals and researchers in the field of autism, making the highest standard of scientific knowledge accessible to participants.

An international art exhibition of people with autism, titled 'Touches of Autism', was also a feature of this congress.

2010	Two adults with autism join Autism-Europe's Council of Administration as self-advocates.	Autism-Europe congress held in Catania.	Publication of 'The right to healthcare and habilitation for persons with ASD: Toolkit for parents, self-advocates and advocacy organisations'.	2011	FIRST Project begins.	ASC-Inclusion Project begins.
	European Union ratifies the UN Convention on the Rights of Persons with Disabilities.	European Union launches European Disability Strategy 2010–2020.			Work begins on the European Accessibility Act.	

## Providing reliable information on autism and supporting advocacy

During the latter half of this decade, Autism-Europe produced numerous reports, toolkits and information resources to support our members to defend the rights of people with autism at national and local level. Some of these include:

- 'Autism & case law: Protecting the right to education for children with autism spectrum disorders' (2006);
- 'Fighting for the right to education of persons with autism spectrum disorders: Toolkit for parents and self-advocates' (2006);
- 'Position Papers' (2006) – A collection of position papers on inclusion, health, education, employment and ageing;
- 'Position paper on care for persons with autism spectrum disorders: A rights-based, evidence-based approach' (2007);
- 'Training modules for policy decision makers and professionals of services for persons with autism spectrum disorders (ASD) and other complex dependency needs disabilities' (2007);
- 'Persons with Autism Spectrum Disorders – Identification, Understanding, Intervention' (2009) – An updated version of the 'Description of autism' which was published in 2000;
- 'The right to healthcare and habilitation for persons with ASD: Toolkit for parents, self-advocates and advocacy organisations' (2010);
- 'Towards a better quality of life: The rights of ageing adults with autism' (2011).

Images: (below) Selected publications from Autism-Europe; (above, right) Autism-Europe representatives, Donata Vivanti, former President, Aurélie Baranger, Director, and Pietro, self-advocate.



## Representing people with autism before the European institutions

Since its creation, the European Union has regarded the fight against discrimination as one of its most pressing missions. Initially the emphasis was placed on preventing discrimination on grounds of nationality or gender. Since the adoption of the Amsterdam Treaty in 1997, the EU's powers have expanded to include action against discrimination on other grounds, including disability. In that context, the European Union considers that civil society organisations act as essential intermediaries between citizens and the European institutions.

The United Nations Convention on the Rights of Persons with Disabilities (which has been ratified by the European Union) also reaffirms that "States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations".

Autism-Europe is recognised by the European institutions as one of the key organisations representing people with disabilities and is regularly consulted in the development of relevant EU legislation and policies. Autism-Europe provides advice on the current situation, needs and expectations of people with autism, including those requiring a high level of support and unable to represent themselves. In recent years, the involvement of self-advocates and their participation in high level meetings and conferences on behalf of Autism-Europe has been promoted.

2012

Autism-Europe welcomes non-European members.

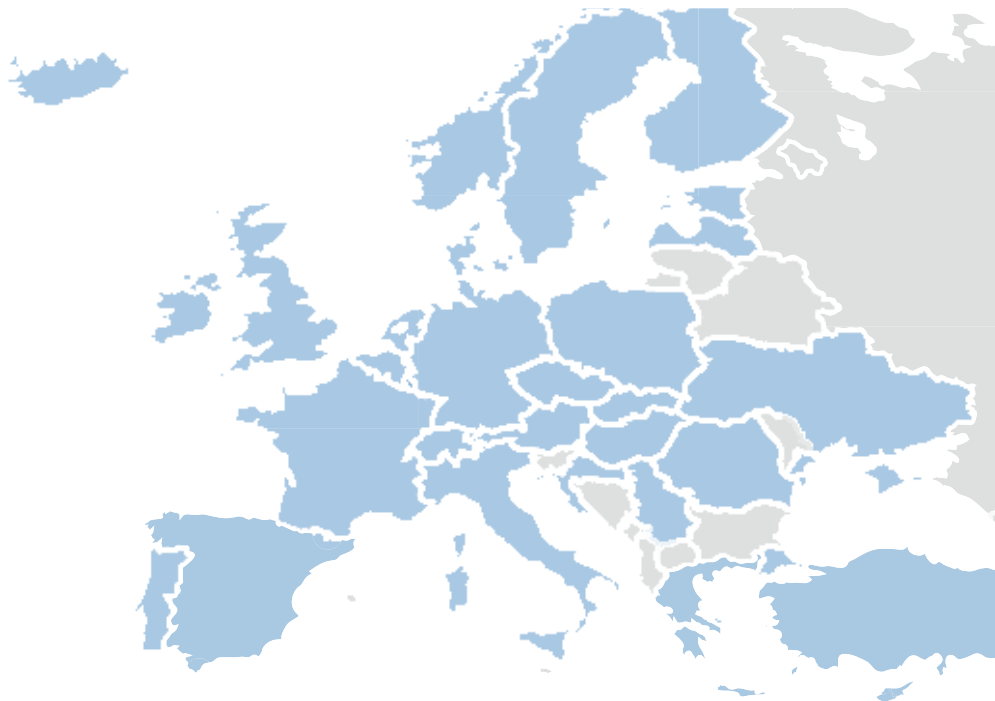
SEAD Project begins.

Count Me In Project begins.

Publication of 'Towards a better quality of life: The rights of ageing adults with autism'.

Zsuzsanna Szilvasy becomes President of Autism-Europe.

# 2013 & beyond



Map (above): European countries whose national autism association is a member of Autism-Europe in 2013.

## European Year of Citizens 2013

During the European Year of Citizens 2013, Autism-Europe is an official member of the European Year of Citizens Alliance and will focus on raising awareness of the rights of people with autism as citizens of the European Union.

## Challenges for the future

While the United Nations Convention on the Rights of Persons with Disabilities has been a profound achievement of the disability movement around the world in recent years, its implementation is far from being completed and this remains a major task for Autism-Europe and our members. As European policies evolve, research into autism advances and new technologies are developed, we also expect to face many unforeseen challenges in future. To address these challenges, ensuring Autism-Europe's financial sustainability in the context of cuts to social budgets across Europe is fundamental. Whatever the future brings, through policy, advocacy, projects, awareness raising and new initiatives, we will continue to strive for a better quality of life for people with autism.

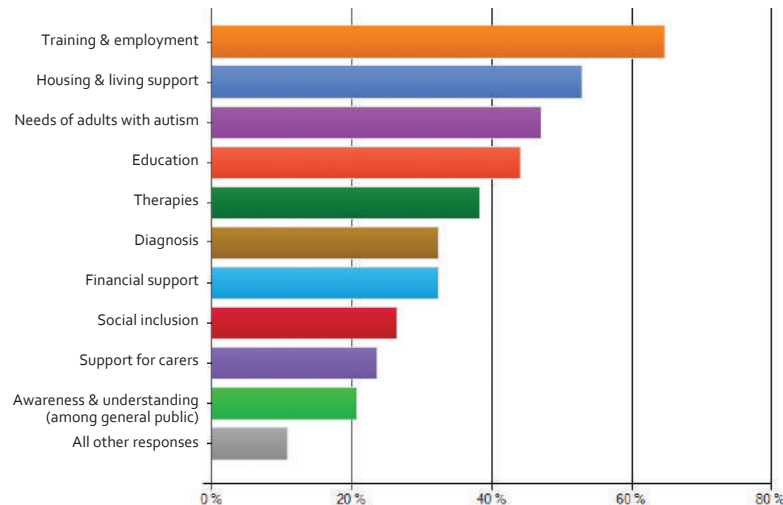
## Congress, 2013

### Budapest, Hungary

This Congress will be an historic occasion, celebrating both the 10th Autism-Europe International Congress and the 30th anniversary of Autism-Europe.

Following the theme 'New dimensions for autism', the programme will include sessions on new fields of knowledge and research for people with autism, including new information and communications technologies and ensuring quality of life for people with autism as they get older.

### Most urgent needs of people with autism in 2013.



This diagram is based on responses to the 30th anniversary member survey by Autism-Europe, which asked the question: 'In 2013, which are the most urgent issues faced by people with autism in your country? (maximum 5 choices)'.

2013

Autism-Europe congress held in Budapest.

Croatia joins the EU.

# Birthday wishes

A birthday would not be complete without making a wish before blowing out the candles on the cake. As part of our 30th anniversary survey, we asked Autism-Europe members: *If you could make three wishes for the future of people with autism in Europe, what would these be?* Here are some of their wishes.

*"That each person with autism could have the necessary support to live an independent life."*

*"To become full citizens (who are empowered to fully enjoy their rights)."*

*"Society to accept them as they are."*

*"To be recognised and appreciated for their otherness."*

*"That anti-discrimination and social inclusion policies and practices are in force in every country."*

*"That every person with ASD has access to adequate diagnosis, therapies, education and training."*

*"That abusive and ineffective therapies for autism no longer exist."*

*"Clear rules for professionals from the World Health Organisation to prevent ineffective therapies."*

*"Access to good schools where the staff have a good knowledge of autism and how to adapt."*

*"Access to proper housing."*

*"More employment opportunities."*

*"More recognition of individual needs (not treating autism as a homogeneous condition)."*

*"Financial support for people with autism and their families."*

*"More research to better understand autism."*

*"Maximise the participation of people with autism in all events and activities of Autism-Europe."*

*"To have a representative in Parliament."*

*"Adequate training of professionals."*

*"Access to education, health and care for people with autism in European countries other than their own."*

*"Equal standards in services for people with autism living in all European countries."*

*"More support for people with autism in Eastern Europe."*

*"That the causes of autism will be understood and officially recognised."*



# Easy to read history of



In 1983 a group of parents of people who have autism created an organisation called Autism-Europe.

In 1983, many people in Europe did not know about autism, including doctors.

Autism-Europe aims to:

- protect the rights of people with autism and their families.
- share knowledge about the best ways to support people with autism.
- tell people about autism.
- improve laws and policies in Europe so that people with autism can have a better quality of life.



Every few years, Autism-Europe holds an international congress.

These congresses are big meetings where people share the latest research and information about autism.



In 1988, Autism-Europe started publishing a magazine called LINK.

This magazine provides news and information about autism.

In 1992, Autism-Europe created a charter of rights for people with autism.

This charter described the rights of people with autism in all aspects of life, including health, housing, education and work.



In 1996, the European Parliament supported this charter.

In 1997, Autism-Europe helped to create a new organisation called the European Disability Forum.

# Autism-Europe

The European Disability Forum aims to improve policies in Europe so that people with all types of disabilities can have a better quality of life.

It is important for people with disabilities to work together for their rights.

In 2006, the United Nations created a new agreement between many countries.

This agreement is called the Convention on the Rights of Persons with Disabilities.

It describes the ways that people with autism and other disabilities sometimes need support so that they can enjoy their rights.

The European Union and most countries in Europe have signed this Convention.

These countries must make sure that people with disabilities get the rights listed in the Convention.

Every year since 2007, April 2 is celebrated as World Autism Awareness Day.

On this day, people in Europe and around the world tell other people about autism.

Autism-Europe has been involved in many projects. For example:

- projects to take people with disabilities out of big institutions and allow them to live in the community with the support they need.
- a project to help people with autism make friends.
- a project to create a computer programme that teaches people with autism about emotions.

Autism-Europe also produces many reports and information to explain and defend the rights of people with autism.



## Easy to read information

This information follows the European standards for making information easy to read and understand.

It is designed for people who have an intellectual disability.

**More information:**  
[www.inclusion-europe.com/etr/](http://www.inclusion-europe.com/etr/)

# Member Associations

## FULL MEMBERS

(national associations of people with autism and parents)

### ARMENIA

#### AUTISM OVERCOMING

Yerevan, Armenia  
9 Arshakuniats St.,  
Tel : +374 91 41 59 83  
+374 91 73 90 12  
Emails : mark-as@mail.ru;  
gabillit@yahoo.com

### AUSTRIA

#### RAINMAN'S HOME

Semeperstrasse 20/2 - 6  
1180 Wien  
Tel : + 43 1 478 64 34  
Fax: + 43 478 91 95  
Email : rainmans.home@aon.at  
Website : http://rainman.at/

### BELGIUM

#### A.P.E.P.A.

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B-5100 Jambes  
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Fax : + 32-81-74-43-50  
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# XI Autism-Europe International Congress



Image courtesy of  
[www.conventionedinburgh.com](http://www.conventionedinburgh.com)

**The National Autistic Society** is proud to have been selected as the hosts for the **XI Autism-Europe International Congress**.

We look forward to seeing you in the beautiful city of Edinburgh in 2016!

**La National Autistic Society** est fière d'avoir été sélectionnée pour accueillir le **XIème Congrès International d'Autisme-Europe**.

Nous avons hâte de vous recevoir dans la belle ville d'Edinbourg en 2016!

*Accept difference. Not indifference.*

[www.autism.org.uk](http://www.autism.org.uk)