

# Uink

Autism-Europe

N°70 / December 2018

## Autism-Europe

### Campaign

“A New Dynamic  
for Autism”

### Greta Thunberg

Next generation green activism

### ASDEU's

recommendations on  
autism research policy  
and practice in the EU

### Register

now for AE's  
12<sup>th</sup> International  
Congress in Nice!

### Community

### Living

in Scandinavian countries

Funded by the  
European Union



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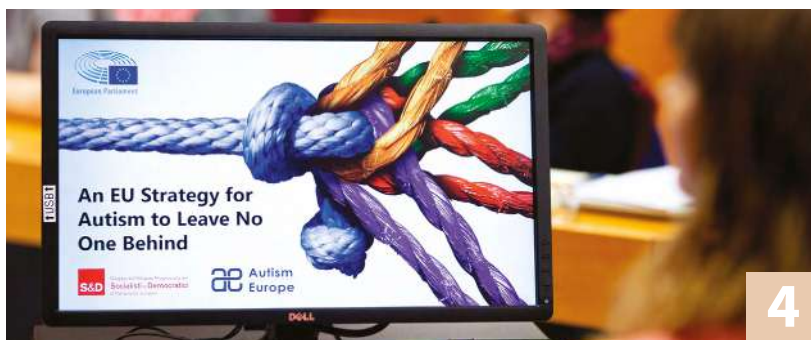
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**Cover:** Greta Thunberg describes herself as “16-year-old climate activist with Asperger”. She has gained praise for ‘standing up for ordinary people’, particularly those who often deal with the consequences of pollution. Picture by Jewan Abdi for Autism-Europe.

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# Edito

*Autism-Europe had a diverse delegation of members at the European Day of Persons with Disabilities conference, held in December 2018, including self-advocates and family members from various countries to advance the rights of autistic people.*

Dear friends,

In 2015, world leaders came together to sign up to 17 Global Goals – the Sustainable Development Goals (SDGs)– that have the potential to end poverty, to reduce inequality and to tackle climate change in 15 years.

At the heart of the goals is a commitment to ensure that “no one is left behind” and that no goal is considered met unless met for all. That’s because, although we have witnessed progress in the fight against poverty and injustice, too many people – the most impoverished, those that are excluded, disadvantaged and at risk of violence and discrimination – remain excluded. Autistic people are too often amongst them.

When it comes to climate, it is nevertheless a young autistic girl, Greta Thunberg, who has been at the forefront of the fight to remind world leaders about the need to take urgent action in recent months, knowing that too much is at stake for our future, and that hope and words alone cannot suffice. She has impressed the world-stage with her determination and her belief that: “no one is too small to make a difference”. You will discover in these pages how she considers autism contributed to shape her activism.

“Leaving no one behind” was also the motto of the conference we held in the European Parliament in September 2018. We called on the European institutions to take action to address the needs of autistic people in Europe, throughout their lifetime. We do hope that policy-makers will take the urgent actions needed to make autistic people more than second-class citizens and we will be particularly active advocating towards our future members of the European Parliament during our campaign: “A New Dynamic for Autism” in the coming months.

Like Greta, we believe that no one is too small to make a difference, and we invite all of you to join us in our campaign to promote a more inclusive and fairer society for autistic people.

Enjoy the reading,



**Zsuzsanna Szilvasy**  
President



**Aurélie Baranger**  
Director



# ASDEU provides recommendations for research, policy and practice in the EU

**The Autism Spectrum Disorders in Europe (ASDEU) Programme came to an end in September 2018. The final results were released which included specific recommendations, the most promising directions for future research, important gaps between practice frameworks and their delivery. ASDEU key policy recommendations were presented in the European Parliament at the conference “An EU Strategy for Autism to Leave No One Behind”, in which Autism-Europe called for the adoption of a holistic EU autism strategy.**

**T**he programme’s most important legacy will be its contribution to the development of future autism research, policy and practice. Through discussions with member states, the ASDEU findings are being used to work towards the inclusion of autism, part of the agenda of the Steering Group on Health Promotion, Disease Prevention and Management of Non-Communicable Diseases. The latter provides expertise to the European Commission on developing and implementing activities in the field of health promotion. It also fosters exchanges of relevant experience, policies and practices between the Member States. To support this, the programme reports and findings have been made available on the Steering Group’s Europa good practice portal. This also means that ASDEU information can be accessed by academics, practitioners, policy and decision makers across Europe.

ASDEU focused on researching autism prevalence, costs, diagnosis and

interventions throughout Europe, and presented findings in the following areas:

- prevalence of autism in 12 countries in the European Union
- economic and social costs of autism
- improvement of early detection programmes and professional training
- biomarkers for autism
- improvement of understanding of diagnosis
- comorbidity

## ASDEU key findings

In relation to the prevalence and screening of the population for autism, ASDEU found that establishing population-based registries with the capacity to routinely monitor and oversee larger cohorts of children is the optimal approach to monitor autism prevalence in Europe.

The EU-funded project also looked at methods for screening large amounts of people for autism. It found that a screening programme, such as the Spanish model, could be transferable to other countries. This is because all countries have regular medical check-ups for children under two in primary care, and because all countries except Denmark have a version of the Modified Checklist for Autism in Toddlers, the instrument for autism screening. Although a screening program in young children is feasible, long-term assessment of local experiences is required to provide information on impact and cost-effectiveness.

Assessment of the situation in Europe regarding early detection was done via a systematic review, focus groups and surveys of families and professionals. Regarding early detection, the research highlighted that 66.4% families experienced a delay of more than 6 months for a diagnosis. Families also reported many issues impeding access

## ASDEU in numbers

Autism Spectrum Disorders in Europe (ASDEU) was a three-year pilot project funded by the Directorate-General of Health and Food Safety (DG-SANTE). Launched in 2015, its overall aim was to increase understanding of and improve responses to the needs of people on the autism spectrum.

- 12 autism prevalence studies in 23 geographical areas
- 600,000+ children, 2,700+ teachers and 700+ schools involved
- 139 new autism cases identified
- 29 focus groups with 226 participants in 10 European countries
- 3 systematic reviews
- 10 online surveys each translated into 10+ languages
- 6,000 online survey respondents
- Legislations and policies analysed in 28 countries
- Partnership with 22 key European and national autism organizations from 15 countries, including Autism-Europe

to early intervention (by involving health authorities clinicians and families in population screening programmes with procedures that include social and non-social signs, as well as potentially biomarkers);

ASDEU recommends : - To improve coordination of the diagnosis procedures to minimise delay and offer better support to families and – to improve access to early Intervention, to be made available for every child as soon as possible - to promote better training of professionals and support the active participation of families.

ASDEU also looked at the provision of care for autistic people across Europe, including the elderly. The survey revealed that there was a lack of alignment between recommendations and actual experience, in particular in the area of services staff training in autism, basic customer service, post diagnosis support and transition between adolescent to adult services.

Ideally each country should: - support activities to reduce gaps between services recommendations and actual community practices; - promote activities to reduce uneven capacities and gaps in adult services (especially healthcare, managing transitions, especially the adolescent

to adult transition) and – foster training programs in autism for adult services staff, including health care.

Policy recommendations addressed to the European Commission includes encouraging EU Member States to adopt cross-sectoral national strategies to respond to the needs of autistic people, in line with the United Nations Convention on the Rights of Persons with Disabilities and international recommendations, as well as promoting transnational cooperation.

**More information:** <http://asdeu.eu/>

## AE calls for the adoption of a holistic EU autism strategy

On the 25 September 2018, Autism-Europe's conference "An EU Strategy for Autism to Leave No One Behind" highlighted key recommendations issued by the ASDEU project, following its research into autism prevalence, early detection, ageing and the social costs of autism in different EU countries and regions. The Maltese government also shared its experience in adopting an autism Act at the national level and voiced their support for an EU strategic approach.

Held in the European Parliament in Brussels, the conference was organized by Autism-Europe and hosted by Member of the European Parliament (MEP) Nicola Caputo. The event gathered more than 40 EU and national policy-makers, persons on the autism spectrum, parents, professionals, NGOs and other interested parties from 14 different countries to hear about the research findings of the ASDEU Programme as well their implications for policies and practice.

Autism-Europe's Director, Aurelie Baranger, stressed the fact that public health plan for autism should follow a holistic approach, as promoting the health and well-being of autistic people at all ages requires a cross-sectoral approach, including in non-health public policy domains.



*Participants at the conference in the European Parliament*





©Autism-Europe

Logo and gesture of the campaign.

# Join our campaign “A New Dynamic for Autism”!

Each year, Autism-Europe works together with its member organisations to conduct campaigns that raise awareness of autism and the rights of autistic people across Europe. As part of its long-running awareness campaign launched around World Autism Awareness Day 2019, Autism-Europe is focusing on the theme “A New Dynamic for Autism. I ∞ autism”.

In 2019, the campaign theme and visual are also closely linked to Autism-Europe’s 12th International Congress, taking place in Nice, France, in September 2019 under the theme “A new dynamic for change and inclusion”. In order to highlight the congress’ global message (raising awareness for autism and understanding, promote a rights-based approach to autism, and share knowledge and experiences), the slogan of the campaign is “A New Dynamic for Autism”.

The slogan is versatile and can adapt to different contexts across the EU, and be applied to different domains to encourage positive change in various areas of life. Therefore, the campaign slogan “A New Dynamic for autism” is complimented by the statement “I ∞ autism” (read “I infinity/love autism”), echoing the Congress’ logo.

- **Raise global awareness of autism** in society and promote better understanding of how to include and support autistic people.
- **Raise awareness of policy makers** and notably candidates for the European Parliament elections 2019 and ask them to pledge support to address barriers faced by autistic people in Europe.
- **Building bridges between the EU level and national actors** to engage efficiently with the EU and ultimately to voice and promote the interest and rights of autistic people.

## The campaign toolkit

In February 2019, Autism-Europe released a campaign toolkit, a document bringing together materials, strategies and recommendations on how you can contribute to build momentum by conducting a successful awareness raising campaign.

All the campaign materials can be translated and adapted into any language (editable files are available in the case of visual materials). AE encourages you to translate these materials and can provide you with some assistance for doing this, if necessary. It is also possible to add the logo of your organization, together with the one of AE.

## How can I support the campaign?



For the campaign we will be asking the autism community (followed by the general public, including high-profile figures) to do one or more of the following things:

1. Make the infinity symbol with your hands, or for example, by forming the infinity sign with a group of people.
2. Get your smartphone or camera.
3. Take a picture, video or story of yourself doing this.
4. Explain the action you are taking to support an inclusive society for autistic people.
5. Share it on social media using the #AutismDay2019 hashtag.

## More information:

[www.autismeurope.org/what-we-do/world-autism-awareness-day/current-campaign/](http://www.autismeurope.org/what-we-do/world-autism-awareness-day/current-campaign/)

# AE's Council of Administration gathers ahead of EU Days of Persons with Disabilities

**To mark the European Days of Persons with Disabilities (EDPD), Autism-Europe held its Council of Administration meeting on December 1 and 2. Almost 40 representatives from 18 countries from Europe and beyond gathered in Brussels. They exchanged on how to best address the issues faced by autistic people and their families, prior to the events organised by the European Commission on the occasion of the EDPD, with the theme “A New Dynamic for Autism. I ∞ autism”.**

**T**he first day, the meeting included the participation of Alejandro Moledo from the European Disability Forum (EDF) and Chiara Giovannini from ANEC (the European consumer voice in standardization), who delivered an interactive training on the standardization process to participants. Following the recent initial agreement on the European Accessibility Act, Autism-Europe aims at building the capacity of its members to get involved in the standardization process – which plays a big role in making goods and products accessible.

At this meeting, representatives of European autism organisations also discussed and voted on various issues related to AE's activities. Executive Committee member Harald Neerland was elected as future President of Autism-Europe, his mandate will run from May 2019 to 2024. Current president Zsuzsanna Szilvasy will continue to hold office until 2020.

To conclude the meeting, our member the APEPA and Veronique Lenoir (from the SUSA Foundation) presented the Belgian initiative “Participate !”, an online platform, both in Dutch and in French, to empower parents of autistic children who have just

received a diagnosis and want to access easy-to-read information on autism and evidence-based practices, as well as useful advice and tools, through documents and explanatory videos.



*Participants of the meeting*

## Invitation to Autism-Europe's 2019 Annual General Assembly

### La Spezia, Italy.

**In accordance with the statutes of our organisation, we are pleased to invite you to Autism- Europe's Annual General Assembly, which will take place in La Spezia, Italy, on May 4<sup>th</sup> 2019.**

#### The agenda will include:

- Presentation of the executive committee report
- Presentation of the activity report: 2018
- Presentation of the financial report: 2018
- Presentation of the work programme: 2019

An Autism-Europe Council of Administration meeting and side activities will also be organized.

The meetings will be hosted by *Fondazione Il Domani Dell'autismo*. All the working documents related to these meetings will be emailed to registered participants at a later date.



**For more information,**  
please contact Autism-Europe's Secretariat:  
[secretariat@autismeurope.org](mailto:secretariat@autismeurope.org)

More than 250 professionals, autistic people, relatives, decision-makers, journalists and other interested parties attended the four IPA+ multiplier events.

Pictured: the event in Belgrade



# IPA+: a training for professionals working with autistic people

**Established in 2016 to develop a pilot training for professionals working with persons on the autism spectrum (independently of their area of knowledge), the Erasmus+ project IPA+ (Inclusion of People with Autism in Europe. Towards a specialised training model for professionals) gathered partners from Spain, Serbia and Portugal, as well as Autism-Europe.**

**T**aking into account the diversity of the profiles of autistic people, as well as the current approaches and intervention models in autism that are restructuring support services and the role of professionals, the IPA+ project proposes a new educational strategy to qualify professionals to support autistic people in different contexts and spheres of life.

The project has brought together academics, multidisciplinary professionals, parents and self-advocates from various autism organisations from Spain (Project coordinator Polibienestar from the University of Valencia and *Asociación de Padres de Personas con Autismo-Autismo Burgos*), Portugal (the Portuguese Federation of Autism) and Serbia (the Serbian Society of Autism). Those involved come from various backgrounds and have a wide set of skills.

Project partners have created and trialled a comprehensive set of training programmes for professionals who need to acquire the foundational knowledge to work with autistic people and an expert level for those who want to gain specialist knowledge

and skills. The training has a lifelong perspective and follows an evidence-based approach. The final IPA+ curriculum and toolkit is freely available on the project website in English, French, Spanish, Portuguese and Serbian.

The training has been developed based on the findings of a literature review, as well as interviews with 48 multidisciplinary and international professionals through focus groups and a Delphi study with 28 participants (including people on the autism spectrum, relatives, trainers and professionals), both of which aimed at providing an accurate view of the needs and expectations regarding the curricular requirements for such a training course.

## IPA+ curriculum and toolkit

Participating in the IPA+ modules will help professionals to grow in confidence, assisting them in making and implementing strategies to meet the needs of the autistic people they work with. Self-help strategies will also help them ease stress associated with their professional activity.



## The content of the courses is based around the following topics:

- How to recognise autism
- Science-based or evidence-based content
- How to support autistic people and their families
- What repetitive behaviours mean and how to work with autistic people
- How to design and implement individualised plans
- How to interact with families and involve them in the care or intervention
- How to supervise and evaluate autistic people
- How to collaborate and communicate with other professionals
- How to intervene with people on the autism spectrum
- Promotion of quality of life: independence, social aspects, etc.
- Self-care (or well-being) of professionals

### Impact of the IPA+ project

Since 2016, the IPA+ project has delivered 6 face-to-face training sessions to around 100 professionals in Spain, Portugal and Serbia.

By the end of 2018, more than 250 professionals, relatives, decision-makers, journalists and other interested parties attended the four different IPA+ multiplier events held in Lisbon, Belgrade, Burgos and Brussels, aiming at raising awareness about the importance of education in autism for professionals and sharing the work and expertise of the project partners to a wider audience.

Before each event, project partners held discussions with national, regional and local key stakeholders (such as representatives of the government, the municipality, NGOs, universities, institutions for education and/or disabilities, etc.), to discuss about the importance of sustaining the legacy of the IPA+ training after the project's completion.

### IPA+ international event in Brussels

On 08 November 2018, Autism-Europe, as partner of the project, hosted the conference "Autism-Training professionals to foster inclusion", giving professionals from different countries the opportunity to learn more about available training on autism online, independently of their area of knowledge.

Participants from the USA, UK, Ireland, France, Belgium and other European countries gathered to know more about the results of the work undertaken by the consortium, and learn from the expert guest trainer from the UK, Linda Woodcock, director of AT Autism (you can learn more about this new associated member through the dedicated article in this issue).

**More information and training materials available on:**  
[www.ipa-project.eu](http://www.ipa-project.eu)

### Advertisement



autismediffusion.com

#### DES OUTILS ADAPTES AUX BESOINS SPECIFIQUES DES PERSONNES AVEC AUTISME

**AFD - Autisme Diffusion** est une société française créée en 2005 à l'initiative du papa d'un enfant autiste.

**AFD - Autisme Diffusion** édite et diffuse des livres et commercialise du matériel éducatif et pédagogique, des produits sensoriels, du matériel d'évaluation, des jeux éducatifs, des DVD à destination des personnes atteintes du trouble du spectre autistique et à destination des professionnels de santé, des établissements spécialisés et des familles.

Sa motivation : mettre à la disposition du plus grand nombre des supports répondant aux besoins spécifiques des personnes avec autisme afin de leur permettre de mener une vie la plus sereine et épanouissante possible.

Des nouveautés sont proposées très régulièrement pour élargir sans cesse les possibilités de soutien et de progrès dans ce domaine.

#### TOOLS ADAPTED TO THE SPECIFIC NEEDS OF PEOPLE WITH AUTISM

**AFD - Autisme Diffusion** is a French company created in 2005 by the father of a child with autism.

**AFD - Autisme Diffusion** publishes and distributes books and sells educational and teaching material, sensory products, assessment material, educational games, DVDs for people with autism spectrum disorder and aimed at assisting health professionals, specialized institutions and families.

Its motivation: to provide appropriate solutions to the largest number of people in order to meet the specific needs of people with autism so that they can enjoy a life as serene and fulfilling as possible.

New products are proposed very regularly to constantly expand the possibilities of support and progress in this area.

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# Supporting students with a plus

**Since 2016, the Student+ program provides talent-oriented guidance, coaching and facilities for students on the autism spectrum at the Fontys University of Applied Science's School of Information and Communication Technology (ICT). Spread across Eindhoven and Tilburg (Netherlands), the program fosters inclusive education by backing students in developing their talents.**

Student+ was established to offer some extra support not only to autistic persons, but also to students with Attention Deficit and Hyperactivity Disorders (ADHD), anxiety or dyslexia. Furthermore, the program also supports students who encounter various barriers to productive study, for example students who have difficulty with planning and organizing their studies, with physical and/or psychological difficulties or students who combine their studies with top-class sport or informal care duties. Any ICT students affected by depression or suicidal thoughts, can naturally benefit from Fontys University's pool of in-house psychologists.

This initiative has been launched by Marlou Heskes, who has a son on the autism spectrum studying at the ICT School and requiring some extra support. Currently, the team is made up of seven young psychologists and 30 volunteer coaches. Roy Houtkamp is one of the Student+ psychologists and is also on the autism spectrum: "Despite the standard forms of help provided by Student+, the program works with people and thus sometimes adaptation to their support

programs are needed. Luckily, the team gets all the space and freedom they need to support each student as is necessary."

## How is the support provided?

Student+ offers support in a variety of ways. The team works together with student councillors and other bodies of support within the ICT department to make sure as much ground as possible is covered.

The Student+ team set up a special training scheme, available in a variety of subjects that cover everything students need to focus on their studies including planning, motivation, mindfulness, perfectionism, studying with dyslexia, studying on the autism spectrum, self-confidence, etc. Moreover, a group of students who all have trouble with planning and organizing get a space to share their learning experience.

A more ICT School focused support is the peer-to-peer group also known as buddy system. That means students from senior study years come in and meet the freshman students in order to give them their know-how. The seniors teach programming

languages and other technical skills that are important for their studies.

For ICT students, who have trouble writing papers, their thesis or presenting, there is 'Language Plus'. That means two language coaches (one for English and one for Dutch) give lessons in how to write (grammar, etc.) and how to present oneself. Last but not least, there are the study coaches, who are volunteers from all over with different backgrounds sharing one common interest in helping people.

*"We think it is important that all students have equal opportunities and inclusive education is our starting point. This means that education fits as much as possible for all students and not exclusively for students with disabilities. The Student+ facilities are for all students"*

**More information:** <https://www.studentplusfontysict.nl/>



# Community living in Scandinavian countries

**Norwegian Sociologist, Prof. Tøssebro, studied the development of the Scandinavian model of deinstitutionalisation from the 1950s to the present day. Based on the proceedings of one of his conference presentations, this article provides a brief summary of the deinstitutionalisation process in Scandinavian countries when two countries (Norway and Sweden) closed all institutions for persons with intellectual disabilities.**

Deinstitutionalisation is the name for the movement which shifts institutional care to a home-based or community-based care setting.

The 1950s were the heyday for institutions even though personalised care services have always existed in some form. The deinstitutionalisation movement began in psychiatric services and child protection services, then spread to other areas of public healthcare services. In the later years of the decade, a new optimism of the treatments available and other advances highlighted the learning potential of intellectually disabled people which influenced Scandinavian governments policy at the time.

The 1960s was a time of seismic debates on the existence of institutions. The dissatisfaction of institutions came from research that stated that they were environments with fewer stimuli and less opportunities to develop, and that they tended to generate societal responses which created more problems, instead of solving them. At this time, the deinstitutionalisation debate called attention to the appalling living conditions that some disabled people were subjected to in institutions. Some critics of institutions drew a parallel between the idea of segregating disabled people in society, to segregation under apartheid in South Africa and in the USA which was an ongoing system in those countries at the time. All this helped the deinstitutionalisation movement to gain momentum.

From the 1970s and the 1980s onwards, the deinstitutionalisation movement progressed with a further reduction in the total number of institutions, even though some remained open. In their place, personalised services provided by the local council were seen as the privileged alternative in Scandinavian

countries as providing this type of care was more expensive for the government. However, this extra cost was mainly due to the fact that there were more people receiving community care than those who were attending institutions. The deinstitutionalisation movement provoked a debate which even called into question the integrity of the welfare state. Such degrading and inhumane reports from institutions were incongruous with the idea of the 'welfare state', designed to preserve human dignity and protect vulnerable people, regardless of their intellectual disability.

*"Floorplan of Leighanna's apartment (see page 13)"*



©DNE Bank real-estate

The whole process from the 1950s saw the gradual shifting of social services provision going from the State level to the regional council then, from 1980-1990 to the local council level.

Since the reforms have been underway, the media have been an important driver for the deinstitutionalisation movement too, as they published several scandals which took place in these institutions.

Some years later, in the 1990s, following legal reforms initiated in the 1980s, Norway and Sweden closed all of their institutions for people with mental disabilities, which was the most radical reform in Europe. Shortly after, Finland, Denmark and

Iceland followed suit. At this time, the greatest change for adults occurred when the institutions were closed. In both countries, local governments were made fully legally responsible for services by the mid 1990s. This closure also heralded a new beginning as Scandinavian countries saw the construction of innovative models of housing, in these new concept “clustered” individual apartments. Regulations stated that everyone was entitled to their own full apartment with a bedroom, bathroom, sitting room and kitchen, that there should be no more than 3–5 apartments to a house, and that the house should be located on a residential street. The apartments were expected to comply with the general housing regulations and were typically rented from the local government.

It seems that residents’ living conditions had visibly improved and been upgraded. Each resident has their own apartment totalling 50m<sup>2</sup> with a kitchen, bathroom, etc. The norm is for 3 to 5 people living in a group who share the same building with one person per apartment. A number of people did not have their own apartment immediately after the new reforms were brought in, but now all of them do.

Parents, for most of the time, visit their son or daughter more often because individual apartments allow private visits. Staff say that conflict and problems among the residents have largely decreased, not necessarily because of the size of the groups, but because of the way the space is designed. As each person has their own apartment, interactions between residents take place only when they want and everyone can return to their own apartments should they wish, to have some alone time. Some see this phase as part of the latter stages of the deinstitutionalisation process.

A lot of research on deinstitutionalisation came to an end in the 2000s. However, documenting the living conditions for disabled people affected by deinstitutionalisation is important because it keeps the debate alive and for that, there needs to be continued research through data and evaluations.

Since October 2018, Autism-Europe (AE) is a full member of the European Expert Group on the Transition from Institutional to Community-based Care (EEG). It allows AE to raise the voice of autistic people and their families and bring additional expertise in the group of experts to advocate and support the development of community-based services.

Source: J. Tøssebro, Scandinavian disability policy: From deinstitutionalisation to non-discrimination and beyond, ALTER, European Journal of Disability Research 10 (2016) 111–123 <https://doi.org/10.1016/j.alter.2016.03.003>

# A day in the life of Leighanna

Leighanna is a woman of 21 who lives in Kongsberg, Norway. She was diagnosed in her childhood with autism and has an intellectual disability, needing a high level of support. She owns an apartment and receives care to suit her needs in accordance with Norwegian law. Her set-up is rare for a person who needs constant care as those who have similar needs, live in a group home.

Leighanna needs one-to-one care 24 hours a day, 7 days a week. She lives in her apartment and goes to the day centre in town which comes under “work”, although she does not do any paid work.

Since January 2015, a law was passed for those who “need personal care and long term care” the right to organise this type of care with a system of personal assistants. Her apartment should be within walking distance of their workplace, local shops, town centre (Kongsberg is a small town of 20,000 people) and library (as going to the library is her favourite activity).

Leighanna’s status is “disabled young person” and receives welfare payments of around €2,000 per month. This covers the cost of her rent for the apartment, heating, internet, housekeeping, as well as building taxes.

## Organisation of personalised care

Leighanna has the right to 146 hours of personal care per week. The night team is on hand should Leighanna need them –i.e. when Leighanna sleeps, they can sleep. The objective is for Leighanna to participate, within the range of possibilities, in the sort of household tasks necessary to run an apartment such as washing up, cleaning, and shopping for food and drinks.

The set-up to provide the support for Leighanna relies on non-professional assistants, generally students and such, and her family is managing to put in place their timetable and to ensure that the contributors are getting adequately trained as a result. There is a team of 9 to 11 rotational assistants and 4 to 5 other assistants can be used if necessary for special events.

## A note on Personal Assistants (PA)

The right to have your services organized with PA’s is founded in the Health and Care Services Act. Its objective seeks an active life in cooperation with others, and to significantly improve the person’s quality of life and ability to study or work. Both practical and personal assistance, in your home or outside, is included.

Self-determination is a key element in the system as gives the person control: who is going to assist him/her and what qualifications his/her assistants should have, what your assistants shall do, and where and when the assistance is to take place. PA’s were originally limited to persons with physical disabilities but, as mentioned, the right has been extended to people with cognitive challenges.



Leighanna,  
who needs  
one-to-one care  
24 hours a day,  
7 days a week, has the  
right to 146 hours  
of personal care  
per week

©Harald Thomander Neerland

## Leighanna's timetable

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
<b>Morning Team</b> (08:30 to 15:00) Individual care at her work (Unless she is too sick to go to work, the staff from the day centre come to her to look after her)					<b>Morning Team</b> (08:30 to 16:00)	
<b>Afternoon Team</b> (15.00 to 22.00)					<b>Afternoon Team</b> (16:00 to 22.00)	
<b>Night Team</b> (22.00 to 08.30)					<b>Night Team</b> (22.00 to 08.30)	

Over the past few years Harald Neerland, Leighanna's father, campaigns for several Norwegian organisations, and is a member of the Executive Committee of Autism-Europe and President-elect. He wrote this article for Autisme France.





Paula McGowan:  
"I hope doctors can realise when working with learning disabled patients that parents know their child's medical condition far more than they do and that they effectively communicate with all".

# Mandatory training to save lives

**In January 2019, the English National Health Service (NHS) released its Long Term Plan for the next 10 years, which includes commitments that could help to tackle inequality and improve health and care services for autistic people across the country. As part of the plan, all NHS staff will receive information and training on autism, in adherence to the Autism Act in England. This commitment was triggered by a petition signed by 50,000 citizens and started by Paula McGowan, whose teenager autistic son Oliver died after a reaction to anti-psychotic drugs.**

In October 2016, Oliver, autistic with cerebral-palsy, was taken into hospital with partial seizures and crucially, he was not to be given antipsychotic medicine. He died in hospital in November 2016 aged 18 years old. Since then, his mother Paula McGowan has started a campaign (#Oliverscampaign) to ensure that all NHS staff have adequate training. According to Public Health England, just 17% of areas report having an autism training plan for all health and care staff, and 10% have no plan at all to date.

## Recent policy developments

NHS Long Term Plan addresses training for NHS staff on Section 3.32: "(NHS staff) will receive information and training on supporting people with a learning disability and/ or autism. [...] By 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has a learning disability or autism. [...] to improve their awareness of, and support for, children and young people with learning disabilities, autism or both."

The plan deals with the issue of overmedication in Section 3.31 where it also states the NHS will "expand the Stopping over medication of people with a learning disability, autism or both and

*Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP) programmes to stop the overmedication of people with a learning disability, autism or both."*

## What does it mean for autistic and patients with disabilities?

The proposals in the NHS Plan are a step in the right direction with plenty of sensible measures, however, more concrete measures are needed to ensure that autistic people and disabled people's concern of mistreatment are addressed while they are receiving care in NHS hospitals. The 'digital flag' marker in each patient's record should be implemented sooner than the year 2023-24 mentioned in the study.

AE is member of the EU Alliance against Disability Cuts, a civil society coalition created to counter the disproportionate impact of the crisis on persons with disabilities. This coalition has documented the impact of the austerity measures on health and well-being of disabled people, and it is important that key NHS services which autistic people in England and Wales rely on receive adequate funding to fulfill their mission.



# Spain to transfer 35,000 children with disabilities to mainstream schools

**In May 2018, the UN Committee on the Rights of Persons with Disabilities issued a harsh report against Spain for systematically sending students to special education centres, a practice it regards as unfair school segregation. The national Government is now considering introducing the transfer into the new Education Act, as requested by an amendment submitted by the Spanish Committee of Representatives of Persons with Disabilities (CERMI).**

**M**any experts agree that it is beneficial for children to be included in mainstream schools and to be provided with the necessary resources and support to thrive. In most Member States of the European Union, there is evidence of increasing inclusion of children with disabilities in mainstream educational settings, as well as measures to assist disabled people in accessing the labour market. But people on the autism spectrum tend to remain among the most excluded group, notably due to a lack of awareness about autism and the complexity of their support needs.

The Spanish schooling system was denounced by the organizations of people with disabilities SOLCOM and CERMI. The UN Committee on the Rights of Persons with Disabilities opened an investigation in January 2017. After interviewing 165 people, the committee concluded, in a report published last May, that the country “has perpetuated a structural pattern of exclusion and discriminatory educational segregation, based on disability, which particularly affects people with intellectual and psychosocial disabilities and people with multiple disabilities.”

However, the prospect of transferring students away from special schools raises concern from some organisations supporting persons with disabilities and their families. Also, on the subject of the lack of resources and teacher training in the general network: “We must move towards an egalitarian and inclusive system, it is true, but today many autonomous communities do not guarantee specialized education and the individualized attention that students need”, says Ruth Vidriales, technical director of *Confederación Autismo España*, a member of Autism-Europe.

According to data published by the newspaper *El País* in January 2019, of the 217,275 Spanish students with disabilities enrolled in the 2016-2017 course in non-university education, 181,530 studied in mainstream schools alongside their fellow students without disabilities. But another 35,886, 17% of the total, did so in special education centers or in specific classrooms within mainstream schools, two methods rejected by the Committee on the Rights of Persons with Disabilities of the UN. In Spain, there are 477 special education centers: 59% are private (receiving some state-funding). While, public centres only make up 41%, but account for 58% of students.

## EU-wide survey on access to education

The purpose of Article 24 in the United Nations Convention on the rights of Persons with Disabilities stipulates that States Parties uphold the right of persons with disabilities to education. However, access to education remains problematic for autistic people in many EU Member States. For this purpose, Autism-Europe launched an EU-wide survey to assess the barriers to education faced by autistic people in the framework of its Strategy 2018-2021. The analysis of the results by the end of 2019 will allow AE to have a better picture of the state of play in Europe and help us formulate recommendations for policy-makers and key stakeholders, as well as highlight examples of good practices.



*Students in class in an inclusive pre-school*

*Greta sees her autism as “a gift”, not a disability, and attributes her direct and straight talking manner to her condition.*

©Jewwan Abdi

# Next generation green activism: Greta Thunberg

**She describes herself as “16-year-old climate activist with Asperger” on Twitter and goes on ‘school strike’ every Friday outside the parliament in Stockholm until climate change is made a priority by Swedish politicians. Recently, she participated in the TEDX event in Stockholm in November 2018, going on to address World Leaders at the UN COP24 in Katowice, Poland in December 2018, and more recently at the World Economic Forum in Davos January 2019.**

**T**he precocious activist has inspired thousands of young people around the world, with more and more young people continually joining the movement to strike for change. She credits the ‘school

strike’ idea from the aftermath of school shootings at Marjory Stoneman Douglas High School in Florida in February 2018, where the pupils refused to attend school unless stricter gun control measures were enforced.

The 16-year-old leader of the ‘school strike’ for climate, was diagnosed with Asperger’s syndrome, Obsessive Compulsive Disorder and Selective Mutism when she was 11 years old. Her idea of striking from school is something



she did on an individual basis, not within a group as she admits she is not good at socialising.

*“We are not very good at lying, and we usually don’t enjoy participating in this social game that the rest of you are so fond of”*

Although she acknowledges her inadequacy in social situations like many people on the autistic spectrum, the social implications of her actions so far, are effective and far reaching. Greta has gained praise for this movement which is ‘standing up for ordinary people’, particularly those who often deal with the consequences of pollution such as poor air quality and loss of green spaces, across the world. Greta sees her autism as “a gift”, not a disability, and attributes her direct and straight talking manner to her condition.

*“For those of us on the spectrum, almost everything is black or white”*

For her, climate change is seen as existential threat to life on earth. Why? Well, it is now clear that the amount of CO<sub>2</sub> being produced in the world is at an all-time high with the target set in the UN Paris agreement in 2015 of limiting global

increase in temperature to +1.5C unlikely to be met, and has led this teenager to protest with her ‘school’ outside the Swedish parliament until the government takes radical measures to address this existential threat.

Like many movements which capture the public’s imagination, Greta’s is visible on Twitter, Instagram and Facebook where she updates, retweets and spreads the message that action is needed now to put pressure on governments to do more. Through her various channels she relays evidence-based information and highlights school strike protests ranging from Helsinki in Finland to Ontario in Canada, and from Abuja, Nigeria to Palmerston North, New Zealand with locations growing in number all the time. As a supporter of groups such as ‘350.org’ and ‘WeDontHaveTime,’ who are serious about the need for action on climate change, Greta has brought the message these groups are trying to convey and amplified it to her generation.

As one of the EU’s 5 million autistic people, Greta knows the barriers that autistic people face in their daily life and for that, are often overlooked on account of their disability. However, judging by her actions, Greta is not willing to be overlooked and shows that she is capable of much more than simply being put into a box by society. This is evident by the fact that she was recently labelled by *Le Monde* as the ‘face and voice of a generation’ for her green activism.

Greta is descended from the Swedish scientist Svante Arrhenius (1859-1927) whose work in the study of chemistry led him to be awarded the Nobel Prize for Chemistry in 1903. His book ‘Worlds in the Making’ (1908) highlighted how CO<sub>2</sub> produced from coal that was being burned globally, could affect water vapour in the earth’s atmosphere and in turn, affect ocean acidification and the climate. It is only years later that these

ideas entered the public consciousness. At present, Greta is helping to raise global awareness about the issue and calling for immediate government action to limit the amount of CO<sub>2</sub> produced by her country.

When Greta gives a speech to an audience of activists or to decision-makers at International conferences, she is a positive role model for autistic people by ignoring the cynics and by standing up for what she believes in. She also believes that her condition gives her an advantage over non-autistic people which may well be true. Her actions as a climate activist so far suggest that she can see what most other people cannot see. In any case, her story resonates with what Gandhi once remarked:

*“Never apologise for being correct, or for being years ahead of your time. [...] Speak your mind. Even if you are a minority of one, the truth is still the truth”*

Greta is speaking her mind and is articulating something that many people feel about the planet, even if they do not or are unable to act. The tiny steps from this young Asperger’s person has now started a movement that is moving so fast, it will surely bring change in some form, the extent of which, remains to be seen.

**You can follow Greta on:**

- **Twitter here:** @GretaThunberg
- **Instagram:** gretathunberg





# 12<sup>th</sup>

## AUTISM-EUROPE International Congress 2019

A NEW DYNAMIC  
FOR CHANGE AND INCLUSION

www.autismeurope-congress2019.com

# Register now for Autism- Europe's 12<sup>th</sup> International Congress 2019!

**Autism-Europe's 12<sup>th</sup> International Congress will take place in Nice, France, between the 13 and 15 September 2019. It will be hosted by Autism-Europe member, *Autisme France*.**

In this twelfth edition of the Congress, abstract submissions were linked to the overall theme: "A New Dynamic for Change and Inclusion". The Congress welcomed submissions from researchers, practitioners, teachers, autistic individuals willing to share their personal experience, and other interested parties. Over 700 abstracts have been received and during the selection process value will be placed on robust and well-evidenced knowledge, including academic research and professional, as well as personal and collective experience within key topic areas.

### Confirmed Keynote speakers

- Prof. Simon Baron-Cohen (UK)
- Prof. Sven Bölte (Sweden)
- Stéf. Bonnot-Briey (France)
- Prof. Jean Decety (USA and France)
- Prof. Hilde Geurts (Netherland)
- Prof. Ami Klin (USA)

### The JiM Grant

Autism-Europe's member The JiM Foundation (Poland) offers once again a Grant to fund 30 places at the Congress. The objective is to award it to people who would not otherwise be able to afford the registration fee costs to attend the Congress. The JiM Foundation believes that "attending the Congress will help professionals, carers, family members and people on the spectrum, to broaden their horizons." The JiM Grant, will cover the Congress registration fees.

Fifteen of JiM Grants will be awarded to professionals who work with autistic people (such as: therapists, teachers, medical doctors, support workers and so on). The other fifteen of JiM Grants will be awarded to parents, carers, family members, students, as well as individuals on the autism spectrum.

The JiM Foundation will be accepting application forms until the 29th March 2019.

### More information:

[www.autismeurope-congress2019.com/en/](http://www.autismeurope-congress2019.com/en/)

### "Art & Autism" competition

Participants of "Art & Autism", an international art exhibition showcasing the work of people on the autism spectrum, will have the opportunity to see their creations shown during the Congress. Since 1997, Spanish association *Autismo Burgos* (Autism-Europe member) has organised this competition, which aims at stimulating creativity and artistic expression among autistic people. In this edition, only digital photos of the works will be shown, as opposed to the originals.

The objective is to arrange a virtual exhibition in May 2019 on the association's website. The general public will have the opportunity to see the works and vote for them online prior to the Exhibition in Nice. The works will then be presented in a slideshow and shown in print during the congress.

Participation forms and digital photos must be sent to *Autismo Burgos* before the 30th April 2019. Works (paintings) must be original and unpublished. The number of works is limited to one per participant.

# Cooperating closely with academia and the autistic community in the UK and beyond

**Founded in 2013, AT-Autism established itself as an international network of specialists in all aspects of autism and neurodevelopmental conditions working with children and adults, for individuals as well as families. Their network supports schools, public and non-governmental organisations in the United Kingdom and beyond.**

**F**ive years ago, a group of practitioners got together to set-up a formal network providing timely and efficient responses in relation to autism, through the exchange of best practices and expertise. Over the years, several of its current team members had – as individual practitioners – received requests to deliver training courses, share expertise, carry out assessments, and give advice or support. However, they were lacking the infrastructure to channel and respond appropriately to these requests.

Nowadays, AT-Autism offers conferences, seminars and courses on many aspects of autism and related topics. Its activities include specific approaches around ‘behaviours of concern’. It provides independent evaluation of programmes, services and support for organisations going through transition and change.

“Our ethos is respect for diversity and to promote inclusive practice through partnerships that develop local expertise and build capacity”

The courses of AT-Autism can be geared to the needs of specific groups, for instance, clinicians, teachers and educators, mental health

professionals, parents, local authority staff, police or inspection agencies. Its work includes advocacy, assessment, diagnosis and expert opinion, including for courts.

AT-Autism enjoys close links with academia. Many of its staff hold senior appointments at universities across the world. It also supports ethical research benefitting autistic people. It sponsors an annual prize for autism innovation at the University of Bath and helps to recruit research participants via its website. Its team also includes autistic associates and those with a close personal connection to autism.

## An expanding network across the world

Since its foundation, the network and the breadth of activities of AT-Autism have expanded. Its associates now include eminent internationally renowned experts in psychology, psychiatry, speech and language therapy, occupational therapy, social work and social care, architecture and design, music therapy, the law and other related disciplines.

The association is currently working across the UK, Malta, the Channel Islands, Greece, Ireland, Sweden, Denmark, Spain, the Middle East, China, Singapore and Australia. It has administrative bases in UK and Ireland.

An AT-Autism 2018 conference in London focused on autism and the criminal justice system. Conference places were sponsored to allow families or autistic people to participate when cost was a barrier.

**AT-Autism is an associated member of Autism-Europe.**

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



SW training- Director Simon Wallace. June 2018

©AT-Autism



# Promoting knowledge and experience in autism across Turkey

**Tohum Autism Turkey Early Diagnosis and Educational Foundation (Tohum Otizm Vakfi in Turkish) is a non-profit, non-governmental civil organization based in Istanbul that aims to deliver early diagnosis and promote social integration of children on the autism spectrum via special education. Established in 2003, the Tohum Autism Foundation currently has 29 members across Turkey.**

**T**he organisation strives to equip autistic children and their families, with necessary information and tools that will enable them to sustain lives that measure up to available contemporary standards. It is their mission to ensure the earliest possible access to diagnosis for autistic children as well as to intensive special education, and subsequently, their inclusion in educational and social environments.

Tohum does research and measures its progress which has borne many fruits for the community in Turkey. Between 2015 and 2017, they conducted the “Autism Knowledge and Perception of Individuals in Turkey” survey, a research project that was awarded with the Golden Award in Social Owl Category by Turkish Researchers’ Association.

## The “Continuing Education Department”

Through its “Continuing Education Department”, Tohum improves health and education services delivered regarding autism throughout Turkey. Up until now, this department has educated 12,644 teachers and 1,867 medical professionals from across Turkey. They provide guidance to students through the processes of diagnosis, enrolment and counselling. Tohum is committed to strengthening the body of qualified educators in the country through seminars, workshops, training sessions and programs to fill the gaps with world-class special education professionals.

Tohum also supports families by providing hands-on training sessions and awareness education, being there every step along the way.

When Tohum was founded in 2003, the word “autism” was not included in the Turkish lexicon at any level. The greatest hurdle for the Tohum Foundation was the complete lack of knowledge, experience and resources regarding autism. Therefore, they started off with a sense of urgency to create a general foundation that would enable, at the very least, the framework for early diagnosis. Today, Tohum is finally able to step out of its initial locus and share its know-how throughout the country.

Moreover, the establishment of “Turkish Autism Assembly” for which Tohum Autism Foundation played a critical role, facilitated a dialogue with the government and proved that NGOs could be the actors of change on a national level. After a great deal of effort, there is now an official “National Action Plan for Persons on the Autism Spectrum” (2016-2019)” in Turkey.

**Tohum Autism Foundation is an associated member of Autism-Europe**

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



## Here are a few facts on Tohum Autism Foundation:

Since 2006, 1,904 autistic children have been educated at the Tohum's Special Education School (of which 921 had scholarships).

For the first time in Turkey, 55,010 children were screened for early autism diagnosis. As of 2018, 9,010 children were screened, in Istanbul alone, within the framework of “Project for Development of Autism Scanning, Diagnosis and Education Model”.

A web-based, free-of-charge autism support service ([www.tohumotizmportal.org](http://www.tohumotizmportal.org)), with 30,247 members as of today, was established to support teachers and parents.

*Photo above : Tohum undertakes research and measures its progress which has borne many fruits for the community in Turkey.*

*Photo below : Tohum's Special Education School*

*At the moment, Autism Regions is focused on developing federal-level activities and disseminating local experience and best practices.*



## A powerful fellowship to advance the rights of autistic people across Russia

**Established in 2017, the “Association of non-profit organizations created by parents of children with autism spectrum disorders” (‘Autism Regions’ in English) is a national, nonprofit organization aiming to defend the rights and dignity of autistic people and their families from all across Russia. Based in Moscow and gathering 21 member associations to date, Autism Regions represents thousands of families and self-advocates that sometimes are thousands of kilometers away from each other.**

**T**he pooling of the members’ experience enables Autism Regions to interact with the government on the basis of their common principles: reliance on scientific and evidence-based approaches; friendliness, transparency, readiness to share experience, and willingness to unite with like-minded parents, and other people or entities; focussing on cooperation with the government and public institutions; supporting an individual approach for each autistic person; and an absence of commercial interests.

In these interactions, Autism Regions advocates for tackling the lack of a state provision that could offer lifelong support to autistic people; the need of accepting scientific and evidence-based practices for building such a system; the imperfections of legislation and administration in the field of the rights of persons with disabilities; and the significant issues in medical and educational professional communities (specifically the lack of sharing expertise from other countries and science, resulting in severe problems in all aspects of everyday life for a person on the autism spectrum).

### Autism Regions’ services

At the moment, Autism Regions is focused on developing federal-level activities and disseminating local experience and best practices throughout the following services:

- Inclusive education of autistic children in public schools: Each member of Autism Regions has achieved significant results in this area over the last several years by implementing a “Resource Classroom” inclusive model, in dozens of public schools across the country.

- Improving federal education: At the Ministry of Education of the Russian Federation, Autism Regions has been working with the office of the Deputy Minister on different legislative initiatives, in particular, improving the federal law on education and other federal acts in order to provide access to free public education in an inclusive environment for autistic students.

- Assisting Russian universities in developing educational programs and establishing research on autism: Autism Regions seeks to establish a program on autism and an autism research center/clinic at the Novosibirsk State University (NSU), with other examples of partnership involving universities based in Moscow and Ivanovo. In collaboration with the NSU, another staff-training program is live. The “Resource Classroom” programme includes a theoretical online course and includes a two-week hands-on training, with exposure to the real educational process in a mainstream primary school.

- Consulting families on legislative matters: A regional network of lawyers work on this consulting service for autistic people

and their families processing dozens of inquiries each month from various parts of Russia.

- Supporting adults with autism: In the cities of Voronezh and Ivanovo, some projects have been successfully carried out which implemented support for adults with autism i.e. the focus of accompanied residence and employment, the promotion of various models of social inclusion of adults with autism, and the support of vocational education.

- Organizing conferences, workshops and trainings for parents and professionals. The Association participated in organizing many important public events and trainings on autism. In October 2018, Autism Regions co-organized the 3rd International Scientific and Practical Conference “Autism. The Route Choice”, attended by more 1,200 participants from 74 regions of Russia.

- “Autism: Friendly Environment program” is working on development of friendly environment in the community: in museums, theatres, cafes, libraries, etc. The program is running with Autism Regions help. In particular, all the staff have been trained by the Association members.

**Autism Regions is a full member of Autism-Europe**



# Member Associations of Autism-Europe

## FULL MEMBERS

(national associations of people with autism and parents)

### BELGIUM

Association Pour l'Epanouissement des Personnes Autistes (A.P.E.P.A.)  
Rue du Fond de Malonne 127  
5020 Malonne  
Tel: + 32-81-74.43.50  
Fax: + 32-81-74.43.50  
E-mail: apepa@skynet.be  
Website: www.ulg.ac.be/apepa

### Vlaamse Vereniging voor Autisme (V.V.A.)

Groot Begijnhof 14  
B - 9040 Gent  
Tel: + 32.78.152.252  
Fax: + 32.9.218.83.83  
E-mail: vva@autismevlaanderen.be  
Website: www.autismevlaanderen.be

### CZECH REPUBLIC

Národní ústav pro autismus, z.ú. (NAUTIS)  
Brunnerova 1011/3  
163 00 Praha 17  
Tel.: +420 606 729 672  
E-mail: nautis@nautis.cz  
www.facebook.com/nautis.cz  
Website: www.nautis.cz

### CROATIA

Croatian Society For Autism (S.H.P.A.C.)  
Dvorniceva 6  
10000 Zagreb  
Tel: + 385-51.551.344  
Fax: + 385-51.551.355  
E-mail: lidijap@gzr.hr  
Website: www.autizam-ri.hr

### DENMARK

Landsforeningen Autisme  
Blekinge Boulevard 2  
2630 Taastrup  
Denmark  
Tel: +45 70 25 30 65  
E-mail: kontor@autismeforening.dk  
Website: www.autismeforening.dk

### FINLAND

Finnish Association for Autism and Asperger's Syndrome  
Nuijamiestentie 3 B  
00400 Helsinki  
Tel: + 358.10.315.2800  
E-mail: info@autismiliitto.fi  
Website: www.autismiliitto.fi

### FRANCE

Autisme France  
1175 Avenue de la République  
06 550 La Roquette sur Siagne  
Tel: + 33.4.93.46.01.77  
Fax: + 33.4.93.46.01.14  
E-mail: autisme.france@wanadoo.fr  
Website: www.autismefrance.org

### Sesame Autisme

53, rue Clisson  
F - 75013 PARIS  
Tel: + 33.1.44.24.50.00  
E-mail: contact@sesame-autisme.fr  
Website: https://sesameautisme.fr

### GERMANY

Autismus Deutschland  
Rothenbaumchaussee 15  
D - 20148 Hambourg  
Tel: + 49.40.511.56.04  
Fax: + 49.40.511.08.13  
E-mail: info@autismus.de  
Website: www.autismus.de

### GREECE

Greek Society for the Protection of Autistic People (G.S.P.A.P.)  
2, Athenas Street  
GR-10551 Athens  
Tel: +30.210.321.6550  
Fax: +30.210.321.6549  
E-mail: gspap@autismgreece.gr  
Website: www.autismgreece.gr

### HUNGARY

Hungarian Autistic Society (HAS)  
Fejér György u. 10. I./23.  
1053 Budapest  
Tel: +36 1 301 9067/354 1073  
Fax: +36 1 302 1094  
E-mail: autist@interpont.hu  
or info@esoember.hu  
Website: www.esoember.hu ;  
www.autista.info.hu ; www.aosz.hu

### ICELAND

Einhverfusamtökin  
Haaleitisbraut 11-13  
IS - 108 Reykjavik  
Tel: +354 562 1590  
E-mail: einhverfa@einhverfa.is  
Website: www.einhverfa.is

### IRELAND

Irish Society For Autism (I.S.A.)  
16/17 Lower. O'Connell Street  
IRL - 1 DUBLIN  
Tel: + 353.1.874.46.84  
Fax: + 353.1.874.42.24  
E-mail: admin@autism.ie  
Website: www.autism.ie

### Autism Spectrum Information Advice and Meeting Point (AsiAm)

84 Amiens Street  
IRL - 1 DUBLIN  
Email: info@asiam.ie  
Website: https://asiam.ie/

### LITHUANIA

Lietaus vaikai (Rain Children)  
Pylimo str. 14A/37  
01117 Vilnius  
Tel: +370 620 206 65  
E-mail: info@lietausvaikai.lt  
Website: www.lietausvaikai.lt

### LUXEMBOURG

Fondation Autisme Luxembourg  
68, route d'Arlon  
L-8310 Capellen  
Tel: +352-26 91 11 1  
Fax: +352-26 91 09 57  
E-mail: info@fal.lu ;  
communications@fal.lu  
Website: www.fal.lu

### MALTA

Autism Parents Association (APA)  
P.O.BOX 30  
Marsa  
MTP 1001  
Website: http://www.autismparentsas-sociation.com/  
Email: autismparentsassociation@gmail.com

### THE NETHERLANDS

Nederlandse Vereniging voor Autisme (N.V.A.)  
Wettevreden 4a  
NL 3731 AL De Bilt  
Tel: + 31.30.229.98.00  
Fax: + 31.30.266.23.00  
Email: info@autisme.nl  
Website: www.autisme.nl

### NORWAY

Autismeforeningen i Norge (A.I.N.)  
Postboks 6726 Etterstad  
N - 0609 Oslo  
Tel: + 47- 23 05 45 70  
Fax: + 47- 23 05 45 61/51  
Email: post@autismeforeningen.no  
Website: www.autismeforeningen.no

### PORTUGAL

Federacao Portuguesa De Autismo  
Rua José Luis Garcia Rodrigues  
Bairro Alto da Ajuda  
P-1300-565 Lisboa  
Tel: + 351.21. 3630040  
Fax: + 351.21.361.6259  
Email: fpda@fpda.pt  
Website: www.fpda.pt

### ROMANIA

Fedra  
Aurel Vlaicu street no 26 bis, floor no 1,  
Brasov County, Brasov  
Romania  
Email: contact@autismfedra.ro

### RUSSIA

Autism Regions Association  
90 Dubinskaya str.  
115093 Moscow  
Email: info@autism-regions.org  
Phone: +7 913 905 6322  
Website: autism-regions.org/

### SERBIA

Serbian Society for Autism  
Gundulicev venac Street, 38  
11 000 Belgrade, Serbia  
Tél : +381 11 3392 683  
Fax : +381 11 3392 653  
E-mail: autizamsrbija@sbb.rs  
Website : www.autizam.org.rs

### SLOVAKIA

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Website: www.spona.sk

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(regional associations of people with autism and parents)

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