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Autism-Europe

N°71 / June 2019

Autism-Europe's campaign

Stepping forward
for inclusion

Promoting human development

through nautical activities

Vaccines:

fighting misinformation
to save lives

Asperger:

the fate of a name

Architecture:

Creating atmospheres
for autism



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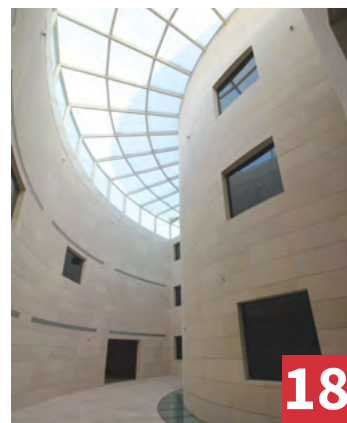
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More news at:
www.autismeurope.org



Rue Montoyer 39, B-1000, Brussels, Belgium

Tel.: +32-2-6757505 • Fax: +32-2-6757270

E-mail: secretariat@autismeurope.org

Bank Account GBL BNP Paribas

IBAN : LU12 0030 0913 1082 3000 / BIC : BGLLLULL



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Collaborators

Editorial Committee: Aurélie Baranger, Zsuzsanna Szilvasy, Evelyne Friedel, Pietro Cirrincione, Harald Neerland, Maria Wroniszewska, Claude Schmit, Marta Roca

Writing, editing & coordination: Cristina Fernández, Thomas Moran, Christian Takow.

Translation: Magali Vlayen

Layout & Printing: mmteam srl - +32-495-52-32-92 - Frédéric Maigret

Cover: Since 2007, NAVE ITALIA has traveled nearly 40,000 nautical miles with the aim of enhancing the quality of life of 4,840 young people with disabilities, including autism, by developing greater emotional well-being, independence, self-advocacy and social understanding. Picture by NAVE Italia for Autism-Europe.

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Autism-Europe's staff during one of the awareness raising activities at the EU Parliament.

Dear readers,

Everyone on the autism spectrum has a place in our community. Nobody, whatever the level of support they may need, should be forgotten or left behind in the push towards the full enjoyment of their rights. It concerns all aspects of life, and it requires to develop understanding in society and the necessary support systems to ensure that everyone can be included and participate.

Every sector has to contribute to make society more autism-friendly. For example, in this issue, you will discover how the airport of Venice is becoming more accessible and how buildings can be conceived in order to be more welcoming for autistic people. You will also learn about the grassroots project “I belong” that aims at promoting the inclusion of autistic young people in activities developed by the local community.

Advocating for a better quality of life and the respect of the rights of people on the autism spectrum require to consider ethical issues linked to autism. The work conducted by a recently established network can help us reflect on some of the key questions that are being debated within the autism community. Ethical reflection must be central to research. The recent controversial revelations about Hans Asperger as well as the long-lasting impact of fraudulent theory around autism and vaccines, highlighted in this issue, just serve as a reminder that it is an essential aspect, never to be neglected.

These topics, and more, will also be discussed during the 12th International Congress of Autism-Europe, which is organized in cooperation with Autisme France, in Nice. The 2019 congress' motto is “A new Dynamic for Change and Inclusion”, in keeping with our aspiration that international scientific research on autism should be translated into concrete changes and foster social inclusion for autistic people of all ages and needs.

On the occasion of this three-day event, people from all over the world will come together to share the most recent developments across the field of autism. We hope that many interested stakeholders can meet on this occasion to exchange and reflect on how to shape better lives for autistic people.

Enjoy the reading,



Zsuzsanna Szilvasy
President



Aurélie Baranger
Director



Hundreds of people gathered in Madrid to support the campaign, at an event organized by AE's member Confederación Autismo España.

Stepping forward for inclusion

Autism-Europe's (AE) campaign "A New Dynamic for Autism" is still active and it has already broken all previous records. Receiving support from more than 30 countries worldwide, the campaign has achieved in making its voice heard by the United Nations (UN) Committee on the Rights of Persons with Disabilities in Geneva, and has raised its demands to both former and upcoming Members of the European Parliament from 19 different countries.

To mark World Autism Awareness Day, AE launched a Europe-wide awareness raising campaign "A New Dynamic for Autism" to call for policies that support the urgent needs of people on the autism spectrum across the European Union, in the context of the upcoming European Parliament elections.

To raise awareness of the objectives of the campaign, AE encourages supporters to make the infinity symbol, which symbolises neurodiversity, strength and unity. As well as making progress to improve the quality of life for autistic people and their families, which can only be achieved with mutual respect, and understanding.

The official video of the campaign was created in partnership with *Autismo España* and features actress Nadia de Santiago ('Cable Girls' on Netflix). It encourages society to embrace diversity and highlights the fact that we can all contribute to the inclusion of autistic people. AE also

released a campaign toolkit that explains the objectives of the campaign. The toolkit includes communication materials and strategies in more than 14 different languages, as well as in Easy-To-Read format.

Raising our demands at the UN in Geneva

On April 1, a dialogue session was held in the UN in Geneva between members of the UN Committee on the Rights of Persons with Disabilities and autistic advocates on the side lines of the Committee's 21st Session. It was organised by AE – with the support of the Government of Malta. It addressed some of the key challenges faced by autistic people and ways of improving the implementation of UN Convention on the Rights of Persons with Disabilities (UN CRPD). All speakers on the panel were people on the autism spectrum.

Nigel Borg, from Malta, presented his experiences and difficulties to have his needs addressed in education.

Stéf Bonnot-Briey, a French member of AE's Council of Administration, spoke of the need for autistic persons to access the world of employment on an equal basis with others.

Heta Pukki, the chair of the board of ASY – Autistic Spectrum Finland, shared her experience of connecting with autistic people from many countries and finding that lack of access to services was a common theme.

Finally, Olivier Zimmerman, a Swiss advocate attached to *Autisme-Genève*, spoke of the challenges autistic persons face in Switzerland and the importance of not merely focusing on awareness through the lighting up of landmarks, but in ensuring that society has a proper awareness and understanding of autism.

Informing and liaising with MEPs

On April 2, 47 Members of the European Parliament (MEPs) from 19 different countries came to the Autism-Europe's stand at the European Parliament in Brussels to take part in the campaign "A New Dynamic for Autism" and expressing their support. Ahead of the European Elections (for the next mandate of the European Parliament from 2019 to 2024), 81 MEP candidates from 18 countries signed our pledge and committed to support autism-friendly European Union policies, while they are in office.

AE wants upcoming MEPs to commit to:

1. supporting autistic people of all ages and needs, and their families, in their parliamentary work;
2. supporting measures for the full inclusion of autistic people in society, and for the full respect of their rights as outlined in the United Nations Convention on the Rights of Persons with Disabilities;
3. supporting the removal of barriers preventing autistic people

from partaking in education, employment and other areas of life that can foster greater autonomy;

4. supporting investment in EU initiatives that favour the social inclusion of autistic people and support for their unique needs;
5. supporting the promotion of diagnosis and early, science-based interventions for autistic children;
6. being open to discussing issues important to the autism community with representative autism organisations.

How do you act to support autism?

As part of its awareness campaign 2019, AE runs an online competition "A new dynamic for autism" giving participants two months to share the most innovative ongoing actions to build a more inclusive society for autistic people across Europe, before the competition closes.

Among the more than seventy entries from all around the world submitted to the competition, the Croatian project "Transition to integration program for children with autism" won the competition with over 4,000 votes.

Since its implementation in 2008 at the mainstream kindergarten "Bajka" in Zagreb, this project aims at reaching full and effective inclusion of children on the autism spectrum through individualised training and social support of all participants involved in the process. Their formula for effective inclusion employs the combination of evidence-based interventions, active parent participation, and daily interactions with neurotypical peers.



Image of the online competition "A New Dynamic for Autism".



Participants at the AE's General Assembly in La Spezia

Over 50 members from 14 countries met in La Spezia at AE's General Assembly

On May 4 2019, Autism-Europe (AE) held its Annual General Assembly in La Spezia, Italy, with the participation of 55 members, representing individuals and associations from 14 different countries.

Updates regarding the activities carried out by Autism-Europe in 2018, as well as its 2019 Work Programme and finances, were presented during the meeting held in the Salvador Allende Center. AE Director, Aurélie Baranger delivered a training on the European Semester and its cycle – and in particular how it can be used as a vehicle to support the implementation the European Pillar of Social Rights. It is particularly relevant for civil society organizations, that can contribute to annual country-specific recommendations being made to Member States, in key areas of priorities for AE, such as access to education.

AE's Vice-president, Pietro Cirrincione, also presented the report "Person-Oriented Research Ethics", elaborated in 2019 by a task force from the organization Autism Ethics Network (AEN). Ethics in autism research is an area of high relevance that will be addressed during AE upcoming congress. During a workshop session, participants analysed the impact of AE's awareness-raising campaign in 2019 and discussed about possible topics and strategies for the next one. The meeting concluded with the election of a new affiliated member association from Spain, Autism Navarra Association, and a declaration of president elect Harald Neerland, whose mandate will be effective as of January 1st, 2020.

The next day, on May 5th, members of the Council of Administration (CoA) received an update about the organization of the upcoming 2019 congress and voted on the venue for the next AE international congress to be held in 2022. The later will be officially announced

during the closing ceremony of AE's Congress in Nice, in September 2019. The CoA also welcomed two new members by co-optation: Adam Harris representing the Irish Full member AsIAm and Yevgeniy Bondar representing the Russian association Autism Regions, also a full member.

Participants to this meeting – kindly hosted by AE's member *Il domani dell'autismo* – enjoyed a study visit of two inclusive touristic facilities that employ and provide training to autistic people, Luna Blu and Sant'Anna Hostel.

Both facilities are part of the AUT AUT (*Autonomia Autismo*) project, supported by the homonymous Foundation AUT AUT. Established in 2017 by the Carispezia Foundation, A.G.A.P.O. Onlus, and AE's member *Fondazione Il Domani dell'Autismo*, AUT AUT was created to foster the full inclusion of young autistic people and their families by giving them the opportunity to work in the hospitality sector, in the touristic region of La Spezia.

Located in the city of La Spezia and inaugurated on May 3rd, 2019 in the presence of AE's Director Aurélie Baranger, Luna Blu is a modern structure that offers hospitality to tourists, including people on the autism spectrum and their families. "It is an initiative that embodies AE's values of inclusion by providing access to vocational training and work in the community. This weekend we will be here with our members from 38 countries to discover this initiative, hoping that these promising practices can inspire other countries", Baranger said.



Health
Commissioner
Vytenis Andriukaitis,
at a press conference
for a stronger EU
cooperation against
vaccine preventable
diseases in 2018.

Fighting misinformation and vaccine hesitancy to save lives

Vaccines are vital to improving public health and are key in the fight against infectious disease. In many countries, vaccines have led to the elimination of diseases that often proved deadly, such as measles, mumps, rubella, and polio. Despite this positive impact, a slow-burning opposition to vaccination exists and autism is often featured in these misinformation campaigns. Here we look at this dangerous phenomenon and what is being done to promote confidence in vaccine safety.

Today, more than 100 million children are vaccinated annually against diseases and it prevents an estimated 2.5 million deaths worldwide. However, there has been a +300% increase in measles cases globally since 2018 (from around 28,000 in 2018 to 112,000 in 2019) as vaccination coverage has dropped. This is partly due to the movement of people campaigning against vaccination safety.

In March 2019, Eurobarometer carried out a poll involving 27,524 respondents from across the European Union that showed that a large proportion of the European population is sceptic regarding vaccines:

- 56% of Europeans agree that vaccines are important to protect not only yourself but also others;
- 52% of Europeans agree that vaccines are definitely effective in preventing these diseases;
- 48% of Europeans believe that vaccines cause severe side effects;

- 38% of Europeans think that vaccines should be coordinated at the national level;
- 34% of Europeans do not see the need for getting a vaccination.

The EU takes action to boost vaccination and avoid a major public health crisis

At the European level, insufficient vaccination coverage rates have been identified as a key transnational issue, and the EU is promoting vaccination as one of their priorities 2016-2020.

Vaccination policy is a competence of national authorities, but the European Commission assists EU countries in coordinating their policies and programmes.

The European Council adopted in December 2018 a Recommendation to strengthen the EU cooperation on vaccine-preventable diseases. The initiative aims to tackle

vaccine hesitancy, improve coordination on vaccine procurement, support research and innovation, and strengthen EU cooperation on vaccine-preventable diseases.

EU countries are encouraged to develop and implement national vaccination plans with initiatives to improve coverage, and to introduce routine vaccination status checks. Germany has for example announced in July 2019 that measles vaccinations will be made mandatory for children mandatory from March 2020, in order to halt the resurgence of the disease. Parents will have to prove that their children are vaccinated before they can be admitted to kindergartens or school and violations will be fined with up to €2,500.

On 12 September 2019, the European Commission will hold a Global Vaccine summit in Brussels in order to strengthen cooperation in this field.

An employee works in an animal vaccine production laboratory during a visit by Member of the EU Commission Corina Cretu at the Fraunhofer Institute for Applied Polymer Research.



The link between autism and vaccination disproved by several studies

Waning vaccine confidence explains the low vaccination rates and is largely to blame on the anti-vaccine movement who have been campaigning for around 20 years. The measles, mumps, rubella (MMR) vaccine controversy began in 1998 when fraudulent research was published, then retracted in the medical journal *The Lancet*. The study was written by Andrew Wakefield who claimed that the MMR vaccine caused autism. His methodology only looked at 12 children and focused on discrediting this vaccine. The result of this research has caused a lot of damage at several levels, highlighted in an article from 2011 entitled *“Wakefield’s article linking MMR vaccine and autism was fraudulent”*, published in the *British Medical Journal*. Following a review of the study, Andrew Wakefield was struck off the UK’s General Medical Council register and was found ‘not fit to practice’.

The MMR vaccine link to autism has been further disproved by a recent large scale study carried out in Denmark, published in the *American College of Physicians’ journal ‘the Annals of Internal Medicine’* on 05 March 2019. The study, entitled *“Measles, Mumps, Rubella Vaccination and Autism: A Nationwide Cohort Study”* was carried out by Novo Nordisk Foundation and the Danish Ministry of Health, analysed 657,461 children born 01 January 1999 – 31 December 2010. It found that *“MMR vaccination does not increase the risk for autism, does not trigger autism in susceptible children and is not associated*

with clustering of autism cases after vaccination.” This follows other Danish research in 2002 and a WHO study which showed there was no link between the MMR vaccine and autism, despite creating panic among parents.

Unfortunately, the effect of this iniquitous assault on vaccines has meant that some diseases which had almost entirely disappeared, have now seen a resurgence in pockets which create epidemics.

The low vaccine coverage in recent years has generated a +300% increase in measles cases globally since 2018 (around 28,000 in 2018 to 112,000 in 2019)

In a UN meeting dedicated to the issue in June 2019, Facebook committed to address misinformation by reducing all information emanating from a page or group who promote anti-vaccination propaganda. In practice, by demoting so called “anti vax” groups or pages in the search results as well as refusing to accept advertising from anti vax groups and disabling fundraising tools for anti vax groups on the Facebook platform. This commitment from Facebook is crucial to halt the spread of misinformation.

A large measles epidemic has affected the EU/EEA Member States in the past three years, with 44,074 cases reported by 30 Member States between 1 January 2016 and 31 March 2019.

This is a high number of cases compared to the previous three years (2012–2015), according to a report issued by the European Centre for Disease Control and Prevention (ECDC).

Vytienis Andriukaitis, EU Commissioner for Health and Food Safety, said:

“According to the objectives set by the World Health Organization, measles should have been eliminated in the European region already by 2000. However, Europe is still far from being a measles-free continent. These numbers are just unacceptable, especially given that an effective vaccine against the disease has existed since the 1960s.”

What are vaccines?

Well, vaccines are “a biological preparation that improves immunity to a particular disease. A vaccine typically contains an agent that resembles a disease-causing microorganism, and is often made from weakened or killed forms of the microbe, its toxins or one of its surface proteins.”

It is often said that vaccines have been a victim of their own success by eliminating diseases such as diphtheria or polio, to the point whereby these diseases have disappeared from public memory, especially in Western spaces such as the USA or Europe.

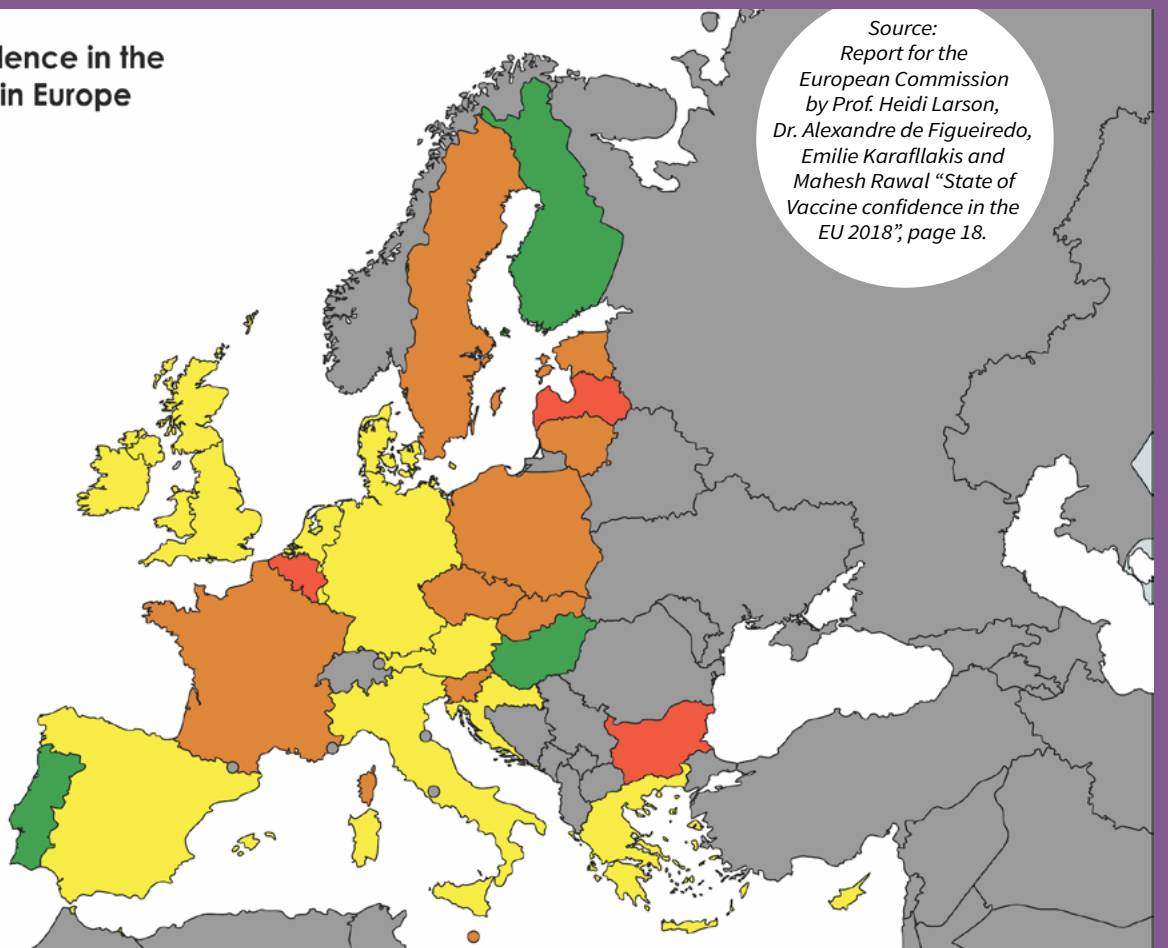
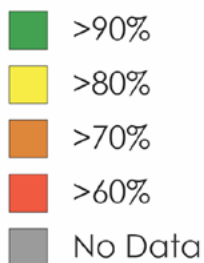
How does it work?

The vaccine “stimulates the body’s immune system to recognize the agent as foreign, destroy it, and “remember” it, so that the immune system can more easily recognize and destroy any of these microorganisms that it later encounters” (according to the WHO definition).

The first measles vaccine was developed in 1963. At the time, it is thought that measles cost around 2.6 million lives a year globally. In 2017, around 110 000 people die from measles every year globally (most of these cases are children under 5).

[Source: the WHO]

Level of confidence in the MMR vaccine in Europe



Despite being undermined, high confidence in the safety of MMR vaccine prevails as the EU average is 80.6%: Portugal (95.8%), Hungary (90.4%), Finland (90.1%) are top countries where levels of confidence are high in contrast to lower levels of confidence in Latvia (68.4%), Bulgaria (65.6%), and Belgium (64.9%).



Introducing autism ethics

“Is autism ethics limited to the ethical treatment of autistic people in clinical and research practices?”

Jo Bervoets, on behalf of the Autism Ethics Network, explains why it should be understood much more broadly.

Autism research has long focused on *explaining autism* by bringing it back to a specific cause. As such it was, and it largely still is, dominated by research in what are known as the *exact sciences*. Nevertheless, when autistic adults started to advocate for themselves, research in the *human sciences* became ever more prominent. With it the attention was directed towards *understanding autistic people*. A discussion then emerged between those targeting a cure for autism and others seeing autism as a potential positive identity. Against this background, the Autism Ethics Network (AEN, for mission see Box on the left) was founded in 2016: to move beyond this opposition and to bring researchers from various scientific disciplines together to connect explanatory approaches of autism to an improved understanding of persons with autism. Below we illustrate why this mission is ethical, what new questions it raises and how autism ethics (the mission, not the organization!) requires research to be cooperative with a focus on bringing out autistic *lived experiences*.

A key question raised by autistic self-advocates is whether autism is a disorder in the first place. Some people argue that autism is a positive identity, and not necessarily a disorder or disease. Others challenge this view and claim that those advocating for autism as a positive identity cannot speak for all those diagnosed with autism. As summarized in “The ethics of autism” (Hens, Robeyns, and Schaubroeck 2019) this brings up a profoundly ethical issue: “Is it possible to mitigate the real suffering that many autistic people experience while at the same time valuing the specific autistic way of seeing the world?”. This question cannot be answered without cooperation across scientific disciplines and without an active autistic participation co-setting the research priorities, see (Fletcher-Watson et al. 2019). However, given the heterogeneity of autism it is also necessary to investigate the lived experiences of those diagnosed across the spectrum, including those less able to weigh in on research priorities. Such research, for instance (Van Goidsenhoven 2017; Hens and Langenberg 2018), highlights that an autism diagnosis both has an explanatory value with respect to everyday problems faced and the separate value of recognizing and understanding one’s neurodiverse identity.

The Autism Ethics Network is an international platform that unites researchers and individuals inspired by a desire to understand autism and promote sharing of knowledge and collaboration. We believe that a transdisciplinary and inclusive approach is necessary for an ethical approach to autism and autistic individuals, and strive to surpass reductionist frames of thinking.

We welcome researchers from different fields, such as sociology, philosophy, psychology, psychiatry, the arts, anthropology, but this list is non-exhaustive. Of course, people living on the autism spectrum are very welcome to contribute.

The AEN is a scientific research group supported by the Flemish Fund for Scientific Research (FWO).

More information:

<https://autismethics.com>



Autism Ethics
Network members at
the Inside Out conference.

From left to right:

Leni Van Goidsenhoven (UAntwerp,
KULeuven), Nicola Shaughnessy
(UKent), Jo Bervoets (autistic
collaborator of the AEN, UAntwerp),
Gert-Jan Vanaken (KULeuven) and
Katrien Schaubroeck (UAntwerp).

Photograph courtesy of
Dr. Rocio von Jungenfeld
(UKent).

In the AEN, we believe that oversimplified answers tend to blur very real ethical challenges that are to be addressed in order for research to be meaningful for the persons with autism and their environment. Within the space of a short article we can't address all these challenges. Instead we provide a short description of the main clusters of challenges raised in (Hens, Robeyns, and Schaubroeck 2019). First, and in line with seeing autism as an identity or a disorder, a key issue is what purpose the interventions that are researched serve. Do they target a supposedly problematic autistic personality trait or focus on a set of problems that may, temporarily, appear in the everyday reality of autistic people? This is a specifically challenging question as diagnoses are often decided by adults on behalf of children and some interventions irreversibly shape experiences throughout their lifetimes. This leads to a second cluster related to the foundational ethical question: what is required to be able to live a good life? Is it required to be able to 'feel' the same way as neurotypical people feel or is an autistic outlook just a, neurodiverse, way of experiencing interpersonal engagement? Finally, addressing such questions drives us to a key issue: who can speak for all autistic people given that the diversity within the spectrum includes a great many who do not speak in traditional ways. How can we bring out their voices in fair ways, without paternalism and stigmatisation?

As far as these questions are concerned the AEN believes we are now only scratching the surface. However crucial ethical treatment of persons with autism as research subjects is, autism ethics shouldn't be limited to a deontological code of autism research. It should at least also include active participation of autistic people in all stages of research. And finally, in line with the AEN mission different scientific domains need to cooperate in order to do justice to the everyday autistic experience. In this light we draw specific attention to co-creation across the full diversity of the spectrum also bringing out the voices of those who do not 'speak' in traditional ways. A key element here is creative expression, one key topic of the Inside Out conference organized at the University of Kent with support of the AEN (see the picture above).

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Hans Asperger, a controversial figure

Asperger cooperated with the Nazi regime, including sending children to the Spiegelgrund clinic (in the picture), which participated in the «euthanasia» programme.

Research into the paediatrician Hans Asperger (1906-1980) has been undertaken since Lorna Wing in 1981 used the Austrian's name to describe part of the autism spectrum. Over the past few years, historians have made some controversial revelations that have deeply affected the autism community.

It came as a shock for many in the autism community when medical historian Herwig Czech, from Vienna's Medical University, published in 2018 an academic paper entitled *Hans Asperger, National Socialism, and "race hygiene" in Nazi-era Vienna* in the open access journal *Molecular Autism* last year. According to the medical historian, the paediatrician was an active participant of the Nazi regime, assisting in the Third Reich's so-called euthanasia programme and supporting the concept of racial hygiene.

Taking on Czech's findings, U.S. historian Edit Sheffer, in her book *Asperger's Children. The Origins of Autism in Nazi Vienna*, presents in the same year as the study of Austrian colleague, the first comprehensive history of the links between autism and Nazism, with vivid storytelling and wide-ranging research. Next to transferring certain "autistic" children deemed untreatable to Spiegelgrund, Vienna's infamous child-killing centre, Sheffer points out that Asperger and his colleagues endeavoured to mould other children into productive citizens.

Enrico Valtellina, Italian philosopher on the autism spectrum and researcher in the history of psychiatry, describes Edith Sheffer's dedication to the topic with having an autistic son. Her book connects Hans Asperger with the Nazi regime and *Aktion T4*, the program for the elimination of people with disabilities, and *Lebensunwertes Leben*, translated as, 'lives unworthy of life'. In a review published last year in Italian in the cultural magazine

Doppiozero, Valtellina puts Sheffer's book into perspective with various works already published on the topic. They include *The Origins of Nazi Genocide. From Euthanasia to the Final Solution* (1995) by Henry Friedlander and the novel *The Chosen One* (2016) by Steve Sem-Sandberg, focusing exactly on the institution at the centre of Sheffer's research: Spiegelgrund. Even before these accounts, Asperger had already been associated with Nazism.

In the conclusion to *Asperger Syndrome or High-Functioning Autism* (2001), Eric Schopler proposes the demise of Asperger for possible collusion with the Third Reich. Valtellina thinks that Schopler's view is not supported by sufficient evidence. Moreover, the Italian philosopher goes that far to call Edit Sheffer's book a fictional dilution of Herwig Czech's research, as it follows around a series of hypothesis based on clinical files and psychological dynamics of victims and perpetrators.

For Valtellina, when Sheffer suggests a new lens on the Third Reich – as a diagnosis regime –, she reveals a lack of knowledge of the history of psychiatry. Evidently, she did research exclusively on the German-speaking area and only about the period in question. However, she seems to have neglected the literature on the subject, such as the now classic works as James Trent's *Inventing the feeble mind: A history of mental retardation in the United States* (1994) and Patrick McDonagh's *Idiocy: a cultural history* (2009), among many others. In fact, the limited purpose of Sheffer's volume, dealing with how the extermination of disabled children was carried out in Austria, and the possible role of Hans Asperger, makes us lose sight of how that chapter of German history is absolutely in line with what was happening in the rest of the Western world. The sterilization of disabled people, practiced at Spiegelgrund was systematically implemented even after the war in Western countries, until the mid-1970, even in northern Europe. Valtellina fears that, at the light of a wider history, a reading like that of Sheffer risks, in spite of its right intentions, to conceal the Third Reich's agenda of suppression of disabled people as a rationally planned political project.

On the other hand, Jill Escher, president of the San Francisco and Bay Area Autism Society, U.S, in a blog entry on the association's homepage entitled *The Horrifying History of Hans Asperger* from last year praises the powerful effect of the narrative presented by Sheffer has. This is because "the book is almost an argument for why Asperger's actual work, as opposed to the post-hoc mythologizing of it, has so little bearing on today's understanding of autism. The "autism" of Asperger is actually his term "autistic psychopathy," an amorphous and variable politico-psychiatric concept referring mainly to impulsive and nonconforming behaviour. From Asperger's rough description of this ill-defined trait, combined with his own admissions of irrelevance, the origins of "autism" as we know it today in 2018 can hardly be said to have a root in wartime Vienna. (...) But surely Asperger's work must have some relevance to the history of autism, no? I certainly have a hard time finding it and in truth, after reading this excellent and devastating book, it hardly seems important."

In his review of Edith Sheffer's book, University of Cambridge's Autism Research Centre Director, Professor Simon Baron Cohen, published last year in the science journal *Nature*, points to the fact that "when Lorna Wing coined the term Asperger's syndrome, none of us was aware of Hans Asperger's active support of the Nazi programme (...). *Asperger's Children* should be read by any student of psychology, psychiatry or medicine, so that we learn from history and do not repeat its terrifying mistakes. The revelations in this book are a chilling reminder that the highest priority in both clinical research and practice must be compassion."

In an article by British newspaper *The Guardian* on the revelation by Herwig Czech, Carol Povey - director of AE's member the National Autistic Society -, is quoted saying: "Obviously no one with a diagnosis of Asperger syndrome should feel in any way tainted by this very troubling history."

Nonetheless, these findings will probably have an impact on the language Autism-Europe uses in the future to describe autism, and our organisation will make sure that this language is always in line with the wishes of the autistic communities and follows the United Nations Convention on the Rights of People with Disabilities (UNCRPD) key principles, especially one on "Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity".



Asperger's Children. The Origins of Autism in Nazi Vienna

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Author: Edith Sheffer

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Genres: Biography,
Autobiography

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Members of Fondazione Oltre il Labirinto and SAVE Group S.p.A. at the launch of the Autism-Friendly Service in Marco Polo Venice Airport on April 2, 2019.

Autism, traveling through the airport

For people on the autism spectrum, air travel can be a very difficult experience, as well as being a completely new experience, in some cases. Thanks to the support of Autism-Europe's member *Oltre il Labirinto Foundation*, Venice Airport is part of the project "Autismo, in viaggio verso l'aeroporto" (Autism, traveling through the airport), conceived by *Ente Nazionale per l'Aviazione Civile (ENAC)*. It is one positive example of making airports more accessible for autistic people.

The aim of this project is to facilitate the passage through the airport as much as possible by providing assistance services but also, through some simple recommendations and elementary strategies aimed at carers, to help children and adults on the autism spectrum to prepare and experience safely their journey.

Before the trip

- Request the dedicated assistance to the airline, travel agency or tour operator (whether at the time of booking or purchase of the ticket and, in any case, at least 48 hours before departure), who have the obligation to pass on this information to the travel company in the airport of departure, arrival, and any transit in between.
- Inform the airline in advance if the autistic person must follow a special diet, if there are any food intolerances or particular allergies. It will be important to point out his/her particular needs.
- Prepare the person well in advance to face the journey with peace of mind. To help you do this, Venice Airport has introduced on its website a series of images that show

the internal and external spaces of the airport describing the atmosphere that could be there from the first moment of accessing the airport (crowd, noise...).

- Go on a pre-visit by booking at the airport website.
- Mitigate the impact with the unfamiliar context and prepare the person for the fact that there will be noise and the place may be crowded.
- Show, if possible, images or videos (available on the internet) of the airport infrastructure and of the built environment.
- Ensure the presence of friendly people who can help
- Try to play down this moment by describing it as an opportunity to play a game.
- Reassure the person that he/she will have access to the pleasant places of the airport: bars, restaurants, book shops, newspapers, games and gadgets.
- Explain in a positive way the presence of signs, luminous symbols, and sudden voice messages.
- Prepare the person for take-off which are noisy events, explaining that they are a characteristic part of the journey and

the route by bus or 'finger' (the approach tunnel) for boarding the aircraft.

- Create a badge for the person, useful in case of loss, with his/her data: photograph, name, surname, nationality, contact details of family members and the accompanying person.

Arrival at the airport

- Indicate who are the helpful people who can provide assistance and how they are dressed.
- Inform about the passage through the security gates, the possibility of sudden sound signals and the possible search.

Before boarding

- If you like, it is useful to provide the person with sweets or chewing gum that will help to relieve any problems of pressurization during the flight.

More information:

<https://www.veniceairport.it/informazioni-di-viaggio/autismo.html>

Promoting human development through nautical activities

Since 2007, NAVE ITALIA, the two-masted sailing vessel of the 'Tender To Nave Italia' ONLUS Foundation (NNTI), has traveled nearly 40,000 nautical miles with the aim of enhancing the quality of life of 4,840 young people with disabilities, including autism, by developing greater emotional well-being, independence, self-advocacy and social understanding.

Funded in 2010 by the Yachting Club Italia and the Italian Navy, the not-for-profit organization NNTI collaborates with several public health services to carry out this unique project, in order to promote maritime culture and navigation at sea as tools for education, training and rehabilitation within hospitals and non-profit organizations from across Europe.

Known on an international scientific level as the "NAVE ITALIA Methodology", the programme combines the key principles of inclusion with a personalized therapy based on commitment, shared emotions aroused by adventure, and respect for rules and hierarchies, thanks to the Ministry of Defence and the Military staff. A total of 6,275 people have already benefited from the programme, including health and social workers, doctors, nurses and educators. Each navigation project involves 45 people (between 16 and 22 beneficiaries, 22 sailors of the Italian Navy, and a project manager from the Foundation).

Every year, some groups of autistic youngsters benefit greatly from the individual attention and daily mentoring they have from staff who understand their condition and can provide adequate support. When working together, the crew and therapists are able to create an environment where youngsters feel safe to experiment with new coping skills, practice social interaction, develop executive functioning, and improve their daily living skills.

The individualized plan includes:

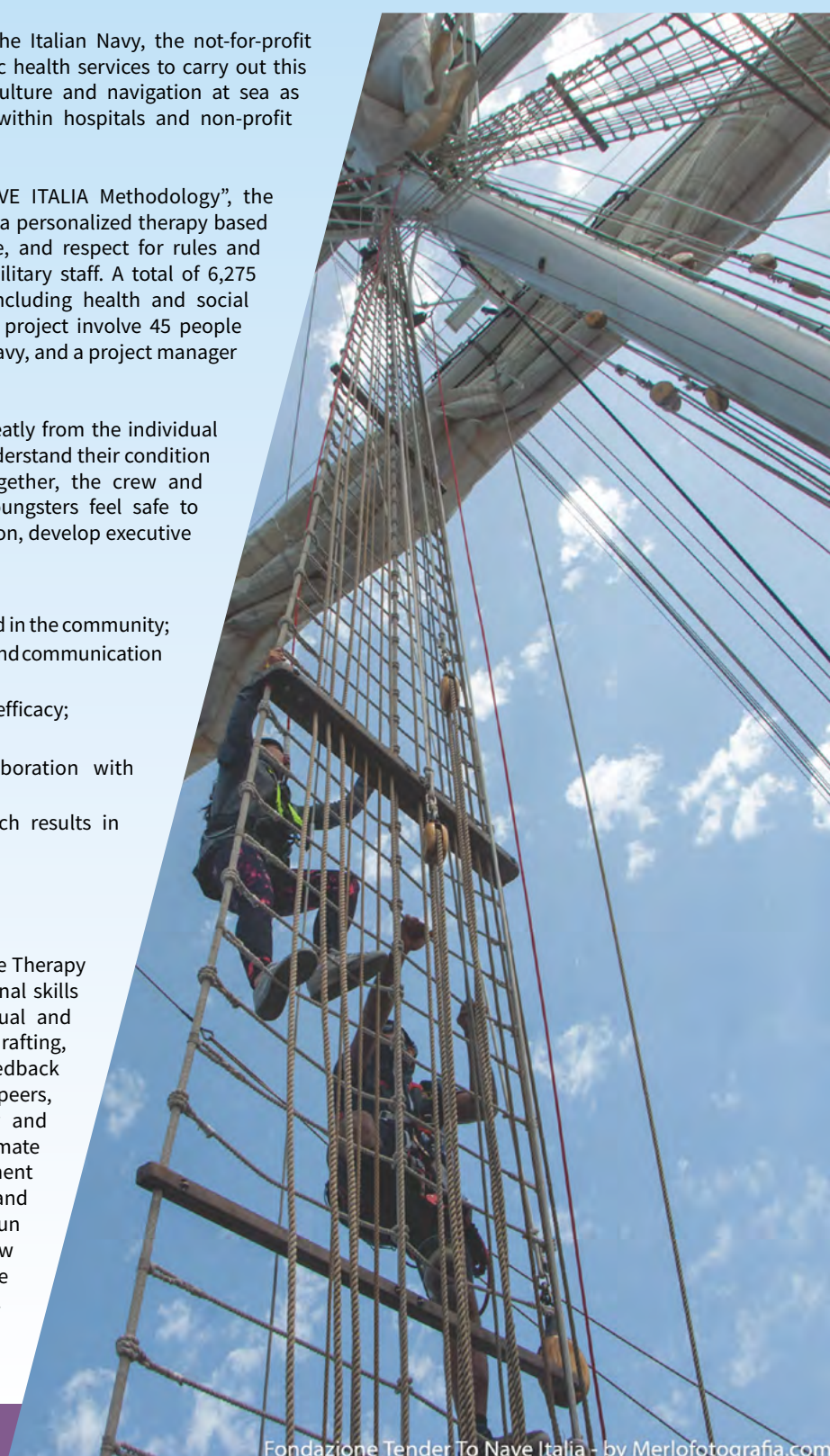
- Comprehensive, multidisciplinary assessment on-site and in the community;
- Individualized training in social, emotional, behavioural, and communication skills;
- Activities that enhance confidence, motivation, and self-efficacy;
- Therapy goals that are updated on a daily basis;
- Consistent communication with parents and collaboration with professionals after sailing;
- Ongoing functional assessment of each student which results in recommendations for the future.

Adventure Therapy programmes

NAVE ITALIA is one of the initiatives based on the Adventure Therapy (AT) programme that was designed to improve intrapersonal skills and relationships using activities which involve individual and group problem-solving and challenging tasks. With sailing, rafting, skiing or trekking, almost always, there is instant feedback provided by nature, their own actions and those of their peers, with unending support and instruction from the crew and other professionals. Because of the safe and positive climate created by all who take part, the sense of accomplishment and the beauty of the surroundings, an optimal learning and practice environment is created. NAVE ITALIA can be fun and exciting. It is a great way to learn and practice new behaviors, to improve interpersonal skills, to overcome personal challenges and to deal with painful emotions. It teaches valuable life lessons, such as the importance of cooperating with others, working as a team, and the impact of natural consequences due to poor choices.

More information: <https://www.naveitalia.org/>

Fondazione Tender To Nave Italia - by Merlo fotografia.com





Children and young autistic people taking part in different community activities in the framework of the project.

“I Belong”, a project to promote inclusion and innovation

Many children and young people on the autism spectrum live on the margins of society. In the case of low-income families, they may be excluded from society on various grounds (due to their gender or other disabilities and aspects of their identity). To deal with this situation, the project “I Belong” was conceived by the Portuguese association *Inovar Autismo*.

Under the United Nations Convention on the Rights of Persons with Disabilities and the Convention on the Rights of the Child, all children have the right to have a voice and to participate in their communities, on equal terms with others. According to the scientific literature, the development of children with disabilities tends to be enhanced when they are included in regular contexts. Moreover, it is well known that children without disabilities also benefit greatly from contact with difference and diversity.

When parents try to include their autistic children in regular community activities, most of these community groups are not prepared to admit them. More often than not, the enrolment of these boys and girls is refused.

Furthermore, almost all social institutions that operate in the

area of Setúbal and Évora (Portugal) develop specific activities catering for autistic children in a segregated environment, and supervised by therapists. This perpetuates a sense of exclusion, stigmatization, discrimination and early institutionalization. In light of this situation, the Portuguese association *Inovar Autismo*, launched the project “I Belong - Promoting innovation: from paradigms to practices”.

This project aims to promote the participation of children and young people with autism in activities developed by the local community, and on equal terms with their peers. Through an innovative methodology, the project includes personalized support to the autistic person, training and coaching within the community context to include persons with autism, resource adaptation in activities and support to the families.

An innovative methodology

The methodology is innovative as it is based on personalized support, indelibly respecting the interests, dreams and aspirations of each autistic person as well as the family's support needs. It is innovative also in terms of how it carries out training, qualification and habilitation of the technicians within the various contexts where the activities will take place.

First of all, *Inovar* asks the autistic person and his/her family which types of activities they would like to do on holiday or more generally, throughout the year. Then, *Inovar* presents the project to the community organizations, providing training for them, and establishing a plan of action.

A wide range of partnerships have already been established with public and private institutions such as municipalities, tennis and football clubs, leisure centres, theater groups, music schools, sailing clubs, or horse riding clubs in the local area.

The project features the participation of children and young people with autism in community activities over the school holidays (Christmas, Easter and summer holidays), but also the inclusion in activities that take place during the school year. The association *Inovar* is now supporting the participation of two young autistic people throughout the year in a theater group and a sailing club.

A success story

A first pilot project was launched in 2017 and, since then, the methodology has been adjusted and improved. "I Belong" has had fantastic moments for all involved. One of the most striking moments was when a young autistic boy captivated the other children because he enjoyed reading stories aloud. Every day, after lunch, the boy used to read stories for the whole group that participated in sports summer camp of the Setubal Tennis Club. This same boy also showed his colleagues that he had no fear of canoeing because he was the first to take the oars and get into the canoe. Another autistic boy, in need of a high level of support, was able to go karting.

Almost all the staff working with the partner community organizations had no experience dealing with young people on

the autism spectrum but, in the end, all of them were pleased with the results of their experience.

The project has three evaluation stages: before, during, and after its implementation. Interviews were conducted with autistic people and/or their families. In addition, evaluation questionnaires were given to several partners participating in the community organizations, such as schools, sports clubs, municipalities, theater groups, and leisure activity centres.

The project is proving to be successful. Each participant, even the ones needing the highest level of support, participate in activities with their neurotypical peers under the same conditions. *Inovar* found that personalized support was the key factor of the success of the project.

The inclusion of these people in the regular structures of the community will lead to a process of empowerment within each context, with transformative effects on the wider social structures and among all the actors involved.

The "I Belong" project, has contributed to the inclusion of dozens of children and young people on the autism spectrum in their community and has shown to the families, institutions, and municipalities that inclusion is possible even for the most challenging cases.

*The "I Belong" project
will be presented at the
12th Autism-Europe Congress
held in Nice in
September 2019.*

More information:

<https://www.inovarautismo.pt/>

Creating atmospheres for autism

Fig.2

In architecture, atmospheres are the sensorial qualities a space emits and are an immediate form of physical perception recognised through emotional sensibility. I have been considering how atmospheres could provide more meaningful spaces for autistic people helping them to make more sense of, and to be at ease in their environment. By Simon Humphreys.

‘**A**utistic people are bombarded with sensory stimuli. They perceive everything without filtration and selection, this leads to the perception of the whole scene as a single entity with all the details perceived but not processed simultaneously’ (Olga Bogdashina 2011).

Sometimes people on the autism spectrum can become fixated with a sense, visually with an object or view, by the smell of something or an underlying sound or hum which we cannot perceive, the abrasiveness of something touching them, or the taste of a thing which sometimes may not even be food.

Sometimes this can unsettle, agitate or comfort and often they have difficulty discriminating or understanding this experience.

We can consider these unique sensory qualities reviewing our own responses to how light falls on or enters a building or the sound, touch and smell of a building. We need to align with the sensory moods of autism, so for example we avoid sharp shadows, introduce light in a more subdued manner, reduce drama and background noise, consider texture more than normal, avoid repetition and even introduce smell into our design methodology.

It is also important to understand that some seek and some avoid sensory inputs so spaces need to reflect this with flexibility, allowing stimulation to come and go, providing places to escape, withdraw and recharge.

How an autism-friendly building looks like?

The spaces in the Abu Dhabi Autism Centre (Fig 1) use sandblasted limestone for walls and floors which has soft acoustic qualities, a texture which is a pleasure to touch, a pleasing natural odour and a calm appearance. Light is introduced in a subdued manner through etched glass that reduces sharp shadow and glare. All these sensory experiences combined create a soothing atmosphere.

In the Abdullatif Al Fozan Autism Centre (Fig 2) the communal halls have discreet subdued lighting that dims the

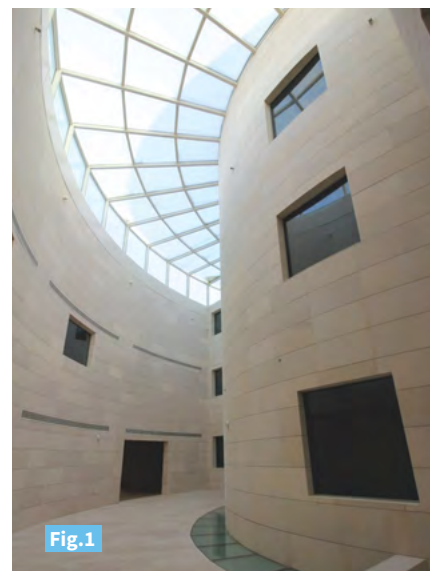


Fig.1

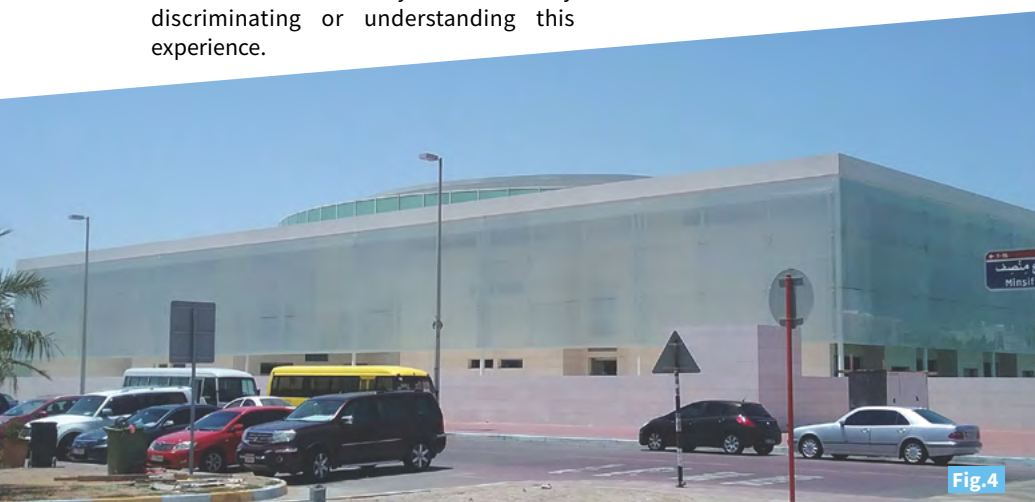


Fig.4

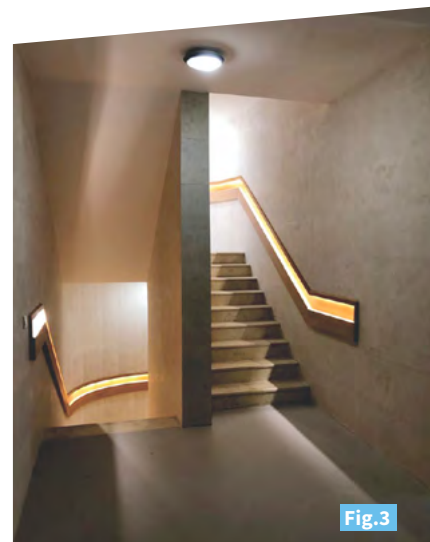


Fig.3

sharpness of vision and invites unconscious peripheral vision which integrates us with the space rather than focused vision which pushes us out of the space.

If a building or space emits a calm predictable atmosphere it offers the user more emotional distance to understand their environment allowing an openness to engage in opportunities and not be distracted or confused. Calm can subdue and uplift at the same time making people more at ease.

The Al Fozan Autism Centre provides a calmer sensual experience for vertical movement limiting detail and materials with soft lighting offering guides and soothing direction (Fig 3).

The Abu Dhabi Autism Centre (Fig 4) displays a calm simple aesthetic. The use of a sandblasted non reflective glass brie soleil diffuses strong light, sharp shadows and glare softening the impact on surfaces, unifying forms and bringing sameness and order to the building.

I have always felt that one of the most important aspects of a building is movement, how we get from one place to another, how we negotiate and orientate ourselves in a building. For autism this can present many emotional meaningful moments, barriers, transitions and distractions. A subtle seamless process of movement, responding to the distinct proxemics of autism reduces these barriers. Feeling comfortable and at ease moving around a building reduces tension and expectation.

The Early Intervention Autism Centre for Transforming Autism (Fig 5) uses a single curved wall to define movement and assist orientation. This simple wall/route separates four therapy pavilions from the busy support spaces and offices.

In the Abu Dhabi Autism Centre soft forms provide a seamless gentle movement around the building with subdued natural lighting, limited detail and materials (Fig 6).

The materials of architecture put flesh onto the structure. It is not just visual matter it is also textural and can have natural odours and beautiful sound qualities. The selection of these materials should be considered in a multi-sensory manner, be limited in pallet and detail so to provide low arousal solutions across all the senses.

Materials create architectural atmospheres they set the mood for our appreciation and enjoyment of spaces - they can distract, excite, calm or subdue. They also combine interacting with texture, colour, temperature and tone all of which create a calm atmosphere and mood. How they combine also needs careful thought, applying simple detail design solutions which reinforce the mood.

Excitable spaces such as the swimming pool in the Abu Dhabi Autism Centre (Fig 7) has a calm atmosphere due to the limited number of materials and removal of superfluous detail.

The Autism Hub in Jersey (Fig 8) uses a single material throughout its exterior and limits detail to convey sameness and coherence. Proportion in architecture has an impact that sometimes we don't quite understand or perceive but we recognise if something is not right as it affects the atmosphere. Ancient proportional systems resonate with something within the human mind and heart which recognises beauty in a very direct and intuitive manner. When we see a natural form such as a sunflower we automatically see its beauty. The Greeks developed this theme provided by nature through a mathematical equation providing a proportion that humans intuitively find pleasing. This is known as the Golden Proportion.

I try to use this understanding of proportion in all my buildings as it sets the mood and atmosphere for harmony not only for the volume of spaces but also the acoustics of the space. Fig 9 applies the proportional system to the plan of the residential unit for autism in The Channel Islands.



Fig.5

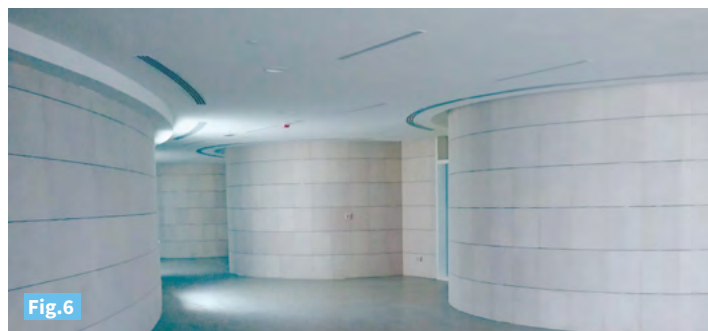


Fig.6



Fig.7



Fig.8



Fig.9

Simon Humphreys Riban

has for many years specialised in the design of buildings for autistic people. He has researched and developed concepts and design guidelines for autism specific environments working with specialists from within the autism world. His experience is also personal having lived for many years with his brother Mark who was autistic. Currently the practice is visible in projects across Europe, The Middle East and USA.

More information: www.simonhumphreys.co.uk

seeing the unseen

*a documentary about women on the
autism spectrum*



“Seeing the Unseen”

On the occasion of World Autism Awareness Day 2019, Autism-Europe’s member the Icelandic Autistic Society (Einhverfusamtökin), in cooperation with Eyjafilm and Kraumar production, premiered a documentary film where 17 brave women on the autism spectrum share their stories.

This documentary looks at the role that autism plays in these girls and women’s lives and the conditions that these women live in. Producers talk with the women themselves and also with specialists and professionals who work with these women on a daily basis. They look for answers to the question as to why these women seem to be invisible to society. They also look at how the lack of support and lack of understanding affects the lives of these women and their families. Autistic women are gifted individuals with many talents that can easily benefit society, but they need to be given a chance.

The objective of this documentary is to create global acceptance of autistic women, who in so many ways remain invisible to society, by providing informative and educational insights into their lives. By doing so, they wish to educate both professionals and the general public about how autism affects girls and women.

Inaccurate and late diagnosis can lead to serious health problems, and generate a poor quality of life as well as a lack of well-being. Without a diagnosis there is no proper support for autistic women nor are they offered equal opportunities in life. It is so important

that we, as a society, work against prejudice and empower autistic women, enabling them to share their many strengths and talents with the world, making it a better place.

**The documentary is now available
with English subtitles on
Vimeo on demand:**

<https://vimeo.com/ondemand/seeingtheunseen>

- **Contact:** sigrun@einhverfa.is
- **Follow them** on @unseenaustism on Facebook and Twitter



Children and professionals at the summer camp organized by ANA in 2018.

Working to ensure full inclusion for people on the autism spectrum in Navarre

Navarre Autism (ANA) is a Spanish non-profit association created by a group of families with children on the autism spectrum. Since 2012, ANA provides them with comprehensive, tailored support and services to improve their quality of life and facilitate their inclusion in society as full citizens.

With more than 300 members, the aim of ANA is to ensure that over 250 autistic people between the ages of 18 months and 30 years, have the chance to develop a life as full and happy as possible. ANA also works to build a society that recognizes, respects and promotes participation, equality, and for people on the autistic spectrum to be included as full citizens as much as possible.

ANA adapts its services to the needs of each person throughout the year, including summer periods. To do this, ANA employs a multidisciplinary team specialized in autism including 13 psychologists, six teachers, two speech therapists, one social worker, two occupational therapists, one technical coordinator and the director of the association, in addition to the Board of Directors made up of five mothers of autistic children. The services provided by ANA are the following:

- Diagnosis and diagnostic reporting;
- Therapeutic intervention;
- Sensory integration;
- Summer and Christmas School with Therapeutic Interventions;
- Inclusive social skills in the natural environment;
- Adapted sports (judo, kayaking, swimming, skiing, and personal training).

After holding several meetings over five years with the Department of Health of the Government of Navarre, with presentations in the Parliament of Navarre, and negotiations with all the political groups, ANA managed to get a specific budget approved in 2016 that finances 100% of the therapy for autistic people with no age limit.

Furthermore, ANA works intensely in raising awareness. ANA is a very committed association with the "Awareness and Dissemination Programme" and therefore offers a series of services aimed at raising awareness about autism at all levels of society and in public institutions, in order to eliminate myths and preconceived ideas. Information about autistic spectrum is provided, existing resources are reported and needs analyses are performed. Moreover, they have already placed 10,000 pictograms in 10,000 establishments throughout the region of Navarre, signposting of town halls, government buildings and even the Red Cross headquarters.

One of ANA's future objectives is to ensure that adults on the autism spectrum have the necessary resources to be able to lead as much of an autonomous life as possible, as well as to promote their inclusion as full members of a fair and supportive society. To do so, ANA has already begun to work with public administration to create a specific autism centre for people who

Specialised services for families

ANA is committed to managing, promoting and defending a comprehensive resource model that generates opportunities throughout the entire life of an autistic person, and for their family. ANA aims at being a reference point for autism by sharing its knowledge with media who focus on disability issues, and society in general via its services for families:

- Intensive total immersion-training for families throughout Spain;
- Therapeutic intervention with on-line tutoring for families from all over Spain;
- Training for families at home;
- Training for families and professionals;
- Online training open all year round for families and professionals.

need more support on a day-to-day basis, as well as in the creation of supervised flats within the community, close to their families, to develop their independence.

Autismo Navarra is an affiliated member of Autism-Europe.

More information:
www.autismonavarra.com

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 vaikiai (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: autisme@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.)

Wetlevreden 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 Dubininskaya 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

Spoločnosť na pomoc osobám s
autizmom (S.P.O.S.A.)

Namestie 1.maja 1.
POBOX 89
810 00 SK- Bratislava 1
Phone + 421 915 703 708
E-mail: spona@changenet.sk
Website: www.spona.sk

SPAIN

Asociación de padres de niños y niñas

autistas de Bizkaia (APNABI)

Sabino Arana, 69
E -48012 Bilbao
Tel: + 34-94.475.57.04
Fax: + 34-94.476.29.92
Email: autism@apnabi.org
Website: http://www.apnabi.org/

Autismo Burgos

C/ Valdenunez, 8
E - 09001 Burgos
Tel: + 34-947.46.12.43
Fax: + 34-947.46.12.45
Email: autismoburgos@autismobur-
gos.ES
Website: www.autismoburgos.org

Autismo-España

C/ Garibay 7, 3º izq
E - 28007 Madrid
Tel: + 34-91.591.34.09
Fax: + 34-91.594.18.31
Email: confederacion@autismo.org.es
Website: www.autismo.org.es

Federacion Española De Autismo
(F.E.S.P.A.U.)

c/ Garibay 7, 3º Dcha.
28007 Madrid
Tel: + 34.91.290.58.06/04
Fax: + 34.91.290.58.10
Email: autistas@fespau.es
Website : www.fespau.es

Gautena

P.O. Box 1000
E - 20080 San Sebastian
Tel: + 34-943.21.53.44
Fax: + 34-943.21.52.39
Email: info@gautena.org
Website: www.gautena.org

SWEDEN

Autism- och Aspergerförbundet

Bellmansgatan 30
S- 118 47 Stockholm
Tel: +46 8 702 05 80
Fax: + 46.86.44.02.88
Email: info@autism.se
Website: www.autism.se

SWITZERLAND

Autisme Suisse

Association de Parents
Neuengasse 19
2501 Biel
Tel: 032 322 10 25
Email: sekretariat@autism.ch
Website: www.autismesuisse.ch

UNITED KINGDOM

National Autistic Society (N.A.S.)

393 City Road
London EC1V 1NG
Tel: + 44.20.7833.2299
Fax: + 44.20.7833.9666
Email: nas@nas.org.uk
Website: www.nas.org.uk

Scottish Autism

Hilton House, Alloa Business Park
Whins Road
Alloa FK10 3SA - SCOTLAND
Tel: + 44.1.259.72.00.44
Fax: + 44.1.259.72.00.51
Email: autism@scottishautism.org
Website: www.scottishautism.org

AFFILIATED MEMBERS

(regional associations of people with
autism and parents)

BULGARIA

Autism Today Association

1738 Sofia
2 Vitosha Street
Tel: +359 896699274, +359 886808819
Email: autismtodayaba@gmail.com
Website: www.autismtoday-bg.eu

ESTONIA

Estonian Autism Society (E.A.S.)

Rahu 8
EST - Tartu 50112
Tel: + 372.557.9980
E-mail: autismeesti@gmail.com

FRANCE

Abri Montagnard

F - 64490 Osse-en-Aspe
Tel: + 33.5.59.34.70.51
Fax: + 33.5.59.34.53.21
Email: ritathomassin@neuf.fr
Website: http://fratrieabri.free.fr/

Union Régionale Autisme-France
Poitou-Charentes

Maison des Associations
12 Rue Joseph Cugnot - 79000 Niort
Tel: + 33.06.52.65.41.61
E-mail : urafpc@autisme-poitoucharentes.fr
Website: www.autisme-poitoucharentes.fr

Dialogue Autisme

BP 248
45162 Olivet Cedex
Tel: +33 02 38 66 34 75
Fax: +33 02 38 66 34 75
Email: dialogueautisme@orange.fr
Website: www.dialogueautisme.com

ITALY

Associazione Nazionale Genitori Soggetti Autistici Lombardia (ANGSA Lombardia)

Via B. Rucellai 36
20126 Milano MI
Tel: + 39-02-67.49.30.33
Fax: + 39-178-2282858
Email: segreteria@angsalombardia.it
Website: www.angsalombardia.it

Fondazione Oltre Il Labirinto Onlus

Mario PAGANESSI
Via Botteniga, 8
31100 Treviso
Tel/Fax: +39-345-5510560
Website: www.oltrelabirinto.it

Associazione Diversamente Onlus

Via Caterina Segurana, 12
09134 Cagliari Pirri
Tel: 0039 (0)3338944791
Email: info@diversamenteonlus.org
Website: www.diversamenteonlus.org

Fondazione Il Domani Dell'autismo

Via Nuova 45 – 19020 – Bolano
Phone +39(0) 187 933297
Mobile: +39(0) 349 3564409
Email: presidenzafondazioneautismo@gmail.com
segreteriafondazioneautismo@gmail.com
Website: www.fondazioneildomani-dell'autismo.it (under construction)

LATVIA

The Latvian Autism Association

Terbatas 28-15, LV-1010 Riga
Email: info@autisms.lv
Website: www.autisms.lv

PORTUGAL

Associação Portuguesa para as Perturbações do Desenvolvimento e Autismo (A.P.P.D.A.-Lisboa)

Rua José Luis Garcia Rodrigues
Bairro Alto da Ajuda
P - 1300-565 Lisboa
Tel: + 351.21.361.6250
Fax: + 351.21.361.6259
Email: info@appda-lisboa.org.pt
Website: www.appda-lisboa.org.pt

SLOVENIA

Zveza NVO za avtizem Slovenije

(Association of NGOs Slovenia)
Tržaška cesta 2
1000 Ljubljana
Email: zveza.avtizem@gmail.com
Website: https://www.zveza-avtizem.eu/

SPAIN

Asociación Navarra de Autismo (ANA)

Monasterio de Urdax 36, 1º B
31011 Pamplona
Email: info.ana@autismonavarra.com
Website: http://www.autismonavarra.com/

Autismo Galicia

Rua Home Santo de Bonaval no 74-baixo
E - 15703 Santiago de Compostela
Tel: + 34.981.589.365
Fa : + 34.981.589.344
Email: info@autismogalicia.org
Website: www.autismogalicia.org

Fundacio Congost Autisme

Ronda del Carril 75
08530 - La Garriga - Barcelona - Spain
Tel: +34-93-871.47.57
Fax: +34-93-871.48.02
Email: congostautisme@autisme.com
Website: www.autisme.com

Nuevo Horizonte

Avda de la Comunidad de Madrid, s/n
E - 28230 Las Rozas de Madrid
Tel: + 34.91.637.74.55
Fax: + 34.91.637.77.62
Email: asociacion@nuevohorizonte.es
Website: www.nuevohorizonte.es

Fundacion Mas Casadevall (FMCA)

Apartat de Correus 172
E-17820 Banyoles (El Pla de l'Estany-Girona)
Tel: +34.972.57.33.13
Fax: +34.972.58.17.12
Email: info@mascasadevall.net
Site internet : www.mascasadevall.net

Autismo Sevilla

Avda. del Deporte s/. 41020 Sevilla.
Tel: +34 954 40 54 46
Fax: 954 40 78 41
Email: asociacion@autismosevilla.org
Website: www.autismosevilla.org

SWITZERLAND

Autisme Suisse Romande

av. de la Chablière 4
CH - 1004 Lausanne
Tel. +41 21 646 56 15
E-mail: info@autisme.ch
Website : www.autisme.ch

UNITED KINGDOM

Autism Initiatives

Sefton House, Bridle Road
Bootle, Merseydide, L30 4XR
Tel: + 44.151.330.9500
Fax: + 44.151.330.9501
Email: ces@autisminitiatives.org
Website: www.autisminitiatives.org

Autism Anglia

Century House – Riverside Office Center
North Station Road, Colchester
Co1 1RE Essex
Tel: +44 (0) 12 06 577678
Fax: + 44 (0) 1206 578581
Email: info@autism-anglia.org.uk
Website: www.autism-anglia.org.uk

Autism Northern Ireland (N.I. Autism/ PAPA)

Donard, Knockbracken Healthcare
Park, Saintfield Road
Belfast BT8 8BH
Tel: + 44.28.9040.1729
Fax: + 44.28.9040.3467
Email: info@autismni.org
Website: www.autismni.org

Autism East Midlands

Mr. Philip Carpenter
Unit 31 Craggs Industrial Estate
Morven Street
Creswell
Workshop
Nottinghamshire S80 4AJ
Tel: 0044 (0)1909 506 678
Email: info@autismeastmidlands.org.uk
Website: www.autismeastmidlands.org.uk

ASSOCIATE MEMBERS

ALBANIA

Fondacioni Femijeve Shqiptare

Rr. "Deshmoret e 4 Shkurtit", Pall.
nr. 30
Kati II, pas Akademise se Arteve
Tirane Albanie
Tel: + 355.4.2270663
Email: info@albanianchildren.org
Website: www.albanianchildren.org

FRANCE

E.D.I. Formation

2791 Chemin de Saint Bernard, bât. F
06220 VALLAURIS
Tel: + 33 4 93 45 53 18
Fax: + 33 4 93 69 90 47
Email: edinfos@wanadoo.fr
Website: www.ediformation.fr

Union Nationale des Associations de

Parents et Amis de Personnes Handicapées Mentales (U.N.A.P.E.I.)

15, Rue Coysevox
F - 75876 Paris Cedex 18
Tel: + 33.1.44.85.50.50
Fax: + 33.1.44.85.50.60
Email: public@unapei.org
Website: www.unapei.org

MALTA

Inspire

(The Eden & Razzett Foundation)

Bulebel
Zejtun
ZTN 3000
Malta
Tel: +356 21807708
Website: www.inspire.org.mt

THE NETHERLANDS

Dr. Leo Kannerhuis

Houtsnipaan 1 Postbus 62
6865 ZH Doorwerth
Tel: + 31.26.33.33.037
Fax: + 31.26.33.40.742
Email: info@leokannerhuis.nl
Website: www.leokannerhuis.nl

POLAND

Fundacja Wspólnota Nadziei

(Community of Hope Foundation)

Więckowice, ul. Ogrodowa 17
32-082 Bolechowice
Tel: +48.12.378.43.58 Fax:
+48.12.378.43.59
Email: biuro@farma.org.pl
Web Site: www.farma.org.pl

Synapsis Foundation

Ul. Ondraszka 3
02-085 Warszawa
Tel/fax: +48.22.825.77.57
Email: fundacja@synapsis.waw.pl
Website: www.synapsis.waw.pl

Jim Foundation

Ul. Tatrzńska 105
93-279 Łódź
Tel: 0048 42 643 46 70
Email: Help@Jim.org
Website: www.jim.org
Facebook: https://www.facebook.com/jimhelp/

RUSSIA

Our Sunny World (Solnechny Mir)

Rehabilitation Centre for Disabled
Children
Leskova 6B
Moscow 127349
Tel: 007 (0)499 2680206
Website: http://solnechnymir.ru

TURKEY

Tohum Foundation

Cumhuriyet Mah. Abide-i Hürriyet Cad.
No: 39
34380 Şişli-İstanbul
Email: info@tohumotizm.org.tr
Phone: +90 212 248 94 30
Fax: +90 212 248 94 36
Website: http://www.tohumotizm.org.tr/

UKRAINE

Child With Future

21/16, Skovorody Str.
Kyiv 04070
Ukraine
Tel: +38 (044) 585 36 08
Email: info@cwf.com.ua
Website: www.cwf.com.ua

UNITED KINGDOM

AT-Autism

20-22 Wenlock Road
N1 7GU London
Email: info@atautism.org
Phone: +44 7961 803 435
Website: https://www.atautism.org/

NON EUROPEAN MEMBERS

KUWAIT

Kuwait Centre For Autism

P.O. Box 33425
Al-Rawda 73455
Kuwait
E-mail: kwautism@gmail.com

MOROCCO

A.P.A.E.I.

Rue 9 Avril - Maârif
Casablanca
Tel: + 212.(0)5 22.25.81.43
Fax: + 212.(0)5 22.25.57.11
E-mail: Ass_apaei@hotmail.fr

SAUDI ARABIA

Qudurati Centre

AL Qassim
Buraydah
Al Montazah Area
South of al Montazah Garden
Tel: + 966 1 638 18555 :
+ 966 505 283 433 (mobile)
Fax: + 966 1 638 23433
Email: qudurati@hotmail.com;
mustafa681@hotmail.co.uk



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