Link

Autism-Europe

N°67 / June 2017

Alistair de Gaetano

Everything about us, without us

Autism-Europe's campaign

"Break barriers together for autism"

Dr Michael McManmon

"I am truly the first CIP graduate"

Keith Stuart

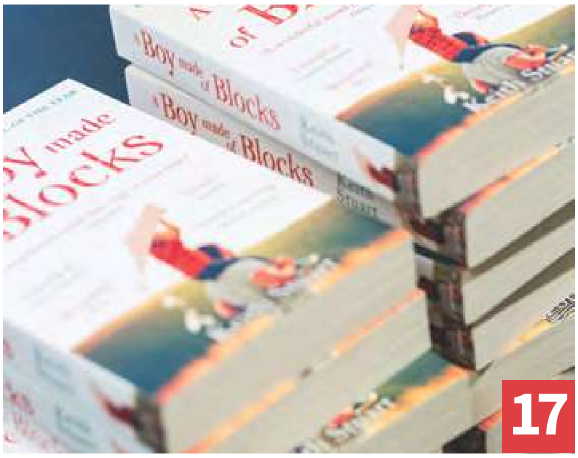
"I wanted to communicate with those who feel alone"

Sensory Processing Disorder

"The world hurts"

Funded by the European Union

Inside



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More news at:
www.autismeurope.org

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Cover: Pierre in harmony with the "frequency" of a windy storm, humming and singing and dancing around. This picture is part of the photo exhibition "Break Barriers Together for Autism- Let's build an accessible society", organised by Autism-Europe. © André Weisgerber

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Edito

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Dear readers,

"Break Barriers Together for Autism". This is the theme chosen by Autism-Europe for its new campaign to promote the full participation of autistic people in a society that is accessible to all.

Autism is often described as an invisible disability, and the same can be said for the barriers faced by people on the autism spectrum and their families. Despite this, the barriers that exist are numerous: barriers to communication, education, employment, independent living in the community, as well as stigma and prejudice, etc. Through this campaign we want to highlight the changes we must come together to push for. It is therefore aimed at a wide audience, first and foremost at policy makers, but also at all stakeholders in society, to act for the respect of neurodiversity.

Making our issues visible allows us to raise awareness. This was the purpose of the photography exhibition that was shown at the European Economic and Social Committee, where some of European civil society's strongest voices meet on a regular basis. This exhibition brought together the work of photographers from Luxembourg, Poland and the United Kingdom, and reflects the diversity of the autism spectrum. Its launch was preceded by a debate on access to employment. Many other activities have been implemented throughout Europe as part of the campaign, which will continue into 2018. We hope to be able to count on your support again.

Making our voice heard is also essential when asking for the necessary changes to be made. In this edition, you will discover a testimony by Alistair de Gaetano, a Maltese self-advocate, who shares his experience of monitoring the implementation of the UN Convention on the Rights of Persons with Disabilities during the Conference of States Parties. Alistair stresses the importance of demanding one's rights in a «firm» and «non-negotiable» way. He reminds autistic people and their allies of the importance of collective advocacy and acting together.

This call is at the heart of our mission to represent people with autism and their families at the European level. Our role is indeed to relay and amplify their expectations and needs throughout Europe in order to ensure their rights are respected. We are therefore pleased that our network is continuing to gain strength and that new associations and individuals are joining us to carry out this mission, because it is you who are our strength.

In addition, to further encouraging participation and information sharing across Europe and beyond, Autism-Europe has launched a new website with easy-to-read content, which we invite you to discover for yourselves and to enrich with your own knowledge and experience.

We hope you enjoy reading this edition!

Zsuzsanna Szilvasy
President

Aurélie Baranger
Director

“Break barriers together for autism”

People gathered in Madrid doing the campaign gesture on April 2.

©Autismo España

AE calls for the removal of barriers for autism to build an accessible society

On World Autism Awareness Day 2017 (April 2nd), Autism-Europe (AE) launched a long-running awareness campaign titled “Break barriers together for autism – Let’s build an accessible society”.

In its first stage, it sought to inform people of what accessibility barriers people with autism and their families typically face in society. From April 2, the campaign then worked as a call for action to decision makers, relevant professionals, business leaders and society as a whole, to work alongside the autism community in order to remove these barriers and open our society up to provide fuller inclusion of people on the autism spectrum.

The motto

The slogan “Break barriers together for autism - Let’s build an accessible society” is both a call for action, and equally an invitation to work on improving accessibility together in cooperation with autistic people. Breaking barriers to inclusion requires the guidance and experience of autistic people and their families, and they must be involved in the development of solutions for accessibility (“nothing about us, without us”).

It is crucial that decision-makers across Europe, as well as society as a whole, gain a better understanding of autism, and act to remove existing obstacles preventing the full inclusion and participation of autistic people.

Breaking through paper

To help show support for our campaign, AE asks people to symbolically break barriers by writing a short description of what makes society inaccessible for them on a banner or a piece of paper. They could then photograph or film themselves holding their banner, before showing themselves breaking through it or ripping it up.

To get people involved in the campaign, AE produced a toolkit indicating how to most effectively bring the subject to the attention of the general public.

In partnership with AE member Autismo España, a video-teaser was also produced in the framework of the campaign to generate interest and make people understand what the main topics are surrounding the promotion of accessibility for people with autism.

©Autismo España

Collage of pictures taken during the shooting of the campaign video.

Campaign background: Autism and the European Accessibility Act

The EU's current legislative context means that the subject of accessibility for persons with disabilities is high on the EU agenda. In line with the obligations set out by the United Nations Convention on the Rights of Persons with Disabilities' (UN CRPD), on the 2 December 2015 the European Commission published a proposal for a European Accessibility Act.

The European Accessibility Act proposed by the European Commission is currently being negotiated. The Act will set minimum accessibility requirements for a series of products and services across the European Union. Furthermore the 30 March 2017 also marked the 10th anniversary of the UNCRPD's opening for signature. The Convention's Article 9 states in particular that States Parties shall take appropriate measures to ensure persons with disabilities have access to the physical environment, to transportation, to information and communications, including ICT systems, and to other facilities and services open or provided to the public.

It is therefore a crucial time to bring to the forefront the access needs of people with autism. Although the Accessibility Act does not prescribe technical details regarding how to render a product or service accessible, it provides for the development of standards or technical implementing measures wherever more detail is needed. Beyond the Accessibility Act, considering universal access should be a key priority for States Parties to the UNCRPD.

AE has released a manifesto outlining the 2017 campaign's concrete aims. AE urges decision-makers, relevant professionals, business leaders and the general public to consult and to cooperate with people on the autism spectrum and their representative organisations to make society more autism-friendly in all areas of life, in order to ensure compliance with the UNCRPD. AE calls on policy makers at the EU and Member State level to ensure that a strong and effective Accessibility Act is adopted, in line with the recommendations of the disability movement.

Famous supporters

A wide array of public figures participated in the campaign. Sporting personalities, such as the players of FC Bayern München and Manchester City F. C, joined the campaign by symbolically breaking barriers for autism. A wide range of other stakeholders and public figures also publicly showed their support for the campaign, including the Queen of Spain Letizia.


©Autism-Europe

Football players joining the campaign. In the collage above (from left to right and from top to bottom), David Silva, Josep Guardiola, Fabian Delph, Kevin de Bruyne, Leroy Sané and Willy Caballero.

The power of social media networks

To help promote the campaign, Autism-Europe set up a Thunderclap. Thunderclap is programme that allows campaign organisers to register people's messages of support and to pre-programme them to be released simultaneously via social media on a given date.

In the case of the "Break barriers together for autism" campaign, all of the messages became visible on the morning of the 2 April. With the help of the Thunderclap, the campaign message achieved a total reach of over 345,131 social media users.

©EU Commission for Autism-Europe

European Commissioner Marianne Thyssen supporting AE's campaign.

Call for action extended to decision-makers

The European Commissioner for Employment, Social Affairs, Skills and Labour Mobility, Marianne Thyssen publicly showed her support by appearing with our campaign logo.

Furthermore, 15 Members of the European Parliament (MEPs) from 10 different European countries supported the campaign by symbolically breaking barriers for autism.

©Autism-Europe

Over 15 MEPs supported the campaign. In the collage above (from left to right and from top to bottom), Jana Žitňanská, Miriam Dalli, Brando Benifei, Nicola Caputo, Helga Stevens, Sirpa Pietikäinen, Florent Marcellesi, Remo Sernagiotto and Alozj Peterle.

World Autism Awareness Day at the UN

On the 31st of March, The UN held its 2017 Observance of World Autism Awareness Day. Key to the day's proceedings was the keynote speech given by Prof. Simon Baron-Cohen, Director of the Autism Research Centre - University of Cambridge. Along with major associations such as AE, Baron-Cohen calls for an investigation into the violation of human rights of people with autism, and to increase surveillance of the needs of autistic people, so that each year on World Autism Awareness Day we can look forward to seeing a reduction in such violations.

Autism-Europe attended the United Nations events in New York. The event, "Toward Autonomy and Self-Determination", discussed the path to ensuring access to self-determination and legal capacity for autistic people. AE Member of the Executive Committee Maria Wroniszewska spoke as part of the panel "Vocational Training and Employment: A Key to Independence and Self-Sufficiency".

The same day, AE President Zsuzsanna Szilvasy spoke at the event "Populations in Movement: Addressing the Opportunities and Challenges to Ensure Care and Services to Migrants with Autism and Developmental Disabilities", orga-nised by the United Nations Department of Public Information and the Department of Economic and Social Affairs.

©Autism-Europe

Secretary of AE's Executive Committee, Maria Wroniszewska, and AE President, Zsuzsanna Szilvasy, speaking at the UN

Reach and impact of the campaign (as of May 2017)

At least **12 countries** supported the campaign in some way:

- campaign materials have been translated in at least **15 different languages**;
- EU commissioner **Ms Thyssen** and **14 MEPs** from **10 different** countries supported the campaign;
- At least **25 different countries** (including non-European countries such as USA, Nigeria, India or Venezuela) made reference to the campaign online;
- **30k people** watched the **video** of the campaign on Facebook and YouTube;
- **354K social media reach** with Thunderclap (free version);

Two members of Autism-Europe's Executive Committee attended the United Nations events in observance of WAAD in New York as speakers

On World Autism Awareness Day, AE is therefore calling on people to join them in bringing home the crucial importance of breaking down barriers to accessibility for people with autism.

Engaging with people on the autism spectrum and hearing their experiences is key to understanding the hurdles still faced by the autism community, and it is only by working together that we can remove them, and foster a society in which everyone is included.

Aims of the campaign:

- Raise awareness of the accessibility issues faced by people with autism (by people with autism themselves)
- Let people know what they can do to foster a more accessible and inclusive society for autistic people;
- Support the adoption of the European Accessibility Act;
- Recall the principles of the UN Convention on the Rights of People with Disabilities to trigger the conditions for an inclusive society;
- Call for action to European decision makers, and civil society (including employers, educators, etc.) to work together and to foster more accessibility.

Building momentum throughout Europe and beyond

AE's members throughout Europe have already symbolically broken barriers and opened our society up to provide fuller inclusion of people on the autism spectrum. People from every corner of the continent joined forces to spread the campaign's message.

©Autism-Europe

People from every corner of Europe and beyond joined forces to spread the campaign's message. In the collage above (from left to right and from top to bottom), there are examples of supporters from Italy, Mexico, Croatia, Belgium, Luxembourg, Spain, Argentina, Serbia, FYR of Macedonia, Czech Republic and Lebanon.

More information and campaign materials:
http://www.autismeurope.org/what-we-do/world-autism-awareness-day/current-campaign/

A photo exhibition to mark World Autism Awareness Day

In the framework of its World Autism Awareness Day campaign 2017, Autism-Europe organised a photography exhibition in partnership with the European Economic and Social Committee (EESC). The topic of the exhibition is accessibility for people with autism in society.

Pictures have been taken by three photographers from the UK (Graham Miller- Photohonesty), Poland (Michał Awin from the JiM Foundation) and Luxembourg (André Weisgerber from *Fondation Autisme Luxembourg*), all aiming to help people understand what accessibility means for those on the autism spectrum and what kind of obstacles they face in their everyday lives. Ultimately, the exhibition also aims at celebrating human diversity and at triggering a reflection on how to create the conditions for better inclusion for all in the community.

The opening of the exhibition was held after a panel discussion about accessibility of the world of work for people on the autism spectrum which was held during the session of the EESC Section for Employment, Social Affairs and Citizenship. The event was attended by more than 130 civil society representatives from across the EU, and photographer Weisgerber was also present to welcome people to the opening of the exhibition.


©Michał Awin

Photograph from the exhibition


©Michał Awin

Michał Awin

"In my pictures you will find people with autism and Asperger's syndrome who, through their unique interests, are breaking barriers and going out into the world with the message that they are able to love, create and share their passion with other people. They excel in what they do, and it is this perfectionism that I hope to capture in my photographs.

I would like to show the strengths of people with autism, breaking all barriers and stereotypes."


©Graham Miller

Graham Miller

"In a world with millions of photographs being taken every day it's difficult to capture attention. It's only by first engaging with an audience that we can begin the process of education. That's why I aim to make my images thought provoking.

I feel privileged to have had my work exhibited at the EESC and to such a key audience. If I've caused one person to reassess their thoughts about autism, to become more understanding, then I will have achieved my goal."


©Graham Miller

Photograph from the exhibition


©André Weisgerber

Photograph from the exhibition

AE members attending our General Assembly in Zagreb.

AE's General Assembly and Council of Administration meetings take place in Zagreb

More than 60 participants from 24 countries attended Autism-Europe's (AE) General Assembly and Council of Administration meetings, held in Zagreb on May 6 and 7 2017 and hosted by the Croatian Union of Associations for Autism *(Savez Udruga Za Autizam Hrvatske -SUZAH)*.

Highlights of the meetings included participants welcoming two new members associations - Autismo Sevilla (Spain) and Fondazione Il Domani dell'Autismo ONLUS (Italy), updates about the projects and platforms in which AE is currently involved, discussions about Autism-Europe's next International Congress in Nice in 2019, as well as discussions on future work and priorities.

On May 5, AE members had the opportunity to meet Croatian policy makers (Zvjezdana Bogdanović, representative of the Ministry of Demographics, Family, Youth and Social Policy, Dunja Poljak Skoko, representative of the Ministry of Health and Edita Šimunović Dundović, representative of the Ministry of Science, Education and Sport) and other stakeholders such as Mira Pekeć Knežević, Ombudswomen for People with Disabilities, Melani Marković, representative of UNICEF and dean Antonija Žižak and professor Jasmina Frey Škrinja, from the Faculty of Education and Rehabilitation of the University of Zagreb.

Ombudswomen Mira Pekeć pointed out that shortcomings in Croatia as regards the full respect of the rights of people on the autism spectrum were highlighted in a special report that was accepted by the Croatian Parliament in 2015. This report took into account recommendations addressed to state bodies with the expert assistance of UNICEF and the cooperation of all three responsible ministries (the Ministry of Health, Science and Education and Demography, Family, Youth and Social Policy). With the support of UNICEF, a national framework for early screening with adequate guidelines was also adopted in 2016 and should now be implemented on the ground. In April 2017, a new Disability Strategy Framework was released and Autism-Europe hopes it will fully take into account the needs of people on the autism spectrum. These needs pertain to access to diagnosis and early intervention, support for autistic adults, and the training of professionals.

AE extends its sincerest thanks to the Croatian Society for Autism for their efforts in order to make the meetings successful and enjoyable for everyone involved.

See all the pictures from these meetings on AE's Facebook page:
www.facebook.com/autismeurope.AE/

On this trip, participants had also the opportunity to take part in a visit of a community-based house in Mostari, organised by Udruga za autizam – Zagreb (member organisation of the Croatian Society for Autism). Our Hosts: Marka, Marija, Damir, Janka, Željka and Igor (adults on the autism spectrum who have been living in Mostari for six years) were joined by their parents, support workers and female vocal group *Ive* and warmly welcomed us to explain their activities. On their way, AE members also visited one community-based apartment managed by the same organisation and three others managed by *Centar za Autizam*.

Alistair de Gaetano, autistic self-advocate

Everything about us, without us


©Alistair de Gaetano

Alistair de Gaetano at the UN

Alistair de Gaetano is an autistic self-advocate from Malta, who is also currently an Advisor to the Junior Ministry for Disability Rights locally, having represented it as Vice-Chair of the Council of the EU's Working Party on Social Questions discussing the *European Accessibility Act,* during Malta's EU Presidency.

Having previously been part of the effort that brought about Malta's Persons within the Autism Spectrum (*Empowerment*) Act, during his time at Trinity College Dublin where he read for a PhD on autism rights, he most recently attended the UN's 10th Conference of States Parties (COSP 10) to the CRPD, representing Malta.

The following is Alistair's personal account of his impressions and opinions following COSP 10, and in no way purports to constitute an official position of the views of the Government of Malta.

It was interesting to be back at COSP, but it was also a strange and interesting feeling to sit 'on the other side' of the fence this time round. My first time was through the International Disability Alliance, when I had also attended the CRPD Civil Society Forum that takes place the day before COSP, as a panellist discussing the experience of different NGOs working together to deliver an official submission to the United Nations.

The theme of that submission paper was 'Leave No One Behind', tying in with last year's official COSP theme, and paving the way for lobbying for better inclusion of persons with disabilities in the first-ever High-Level Political Forum on Sustainable Development, held between 11 and 20 July 2016.

And it was this theme which resonated so firmly for me this year. I once again met many NGO activists on whose 'side' I was last year. And while I also met with colleagues from other countries who are endorsing a more progressive agenda in their national capitals, I also once again saw the great divide between States Parties on the one hand, and civil society on the other.

Last year, I felt empowered because I was part of a 'bloc' - yes, we were in the minority, fighting for change, to get States Parties to realise, endorse and prioritise concepts in line with the human rights model of disability. This time round, I was glad to be among those representing the 'executors' of policy - and I was also so glad to meet colleagues from other States Parties, who shared similar sentiments as to the way forward, and who also were implementing such sentiments.

But I also felt very lonely. Because these colleagues only represented a small 'avant-garde' within the current order, and otherwise, I could feel a deep chasm between civil society and States Parties – In the words of activists during COSP, a chasm representing 'Everything About Us, Without Us'. Having been 'on the other side' – and still being an activist, since I represented the Government in a consultancy role at COSP, but not formally being a State employee – I had the benefit of having seen the mirror image on both sides, and could tell that something was missing, going both by issues being (or not being) addressed, and by sentiment.

States Parties spoke of how they strived to bring their policies and legislation in line with the UN CRPD. However, some of these States Parties then also refused to engage with civil society, even when approached by activists from their same countries during COSP, and to engage with the CRPD Committee, the human rights mechanism set up by the States Parties themselves when adopting the Convention in 2006, in order to provide guidance and oversight in this regard.

Part of the reason for this deep divide is lack of willingness. Disabled persons cost money, and we are still a minority group that doesn't carry with it enough votes or economic importance, in certain countries. But in other countries it is, rather, a genuine lack of knowledge about and sensitisation to disability matters and, most importantly, to the lived experiences of disabled persons.

I experienced this first-hand, but in a much more positive manner, on the 4 and 5 of July of this year in Amman, Jordan. My colleague and myself were invited as international disability experts from Malta, together with a Belgian colleague, to address the fledgling International Group of Experts on Disabilities (IGED) of the UN's Economic and Social Commission for Western Asia (ESCWA). Here, we found a number of member states from the region yearning to learn, to discuss, and to find ways forward in which to implement disability policies, improve practices, and bring their legislation and institutions in line with the UN CRPD, and eventually also the Paris Principles.

So there is hope. There is definitely hope. One gentleman also described how, in his country, a training on disability was organised for government officials. Having participated in a sensitisation exercise, their Social Affairs Minister was so shocked, that he went back to the drawing board, and worked on a coordinated approach to policy reforms, in line with what he had gleaned from this training.

I am sure – and I would like to err on the side of caution and believe – that there are more States Parties whose authorities have not carried out similar CRPD-compliant reforms yet, simply because they find themselves in the same situation as the government of this particular State Party, prior to the sensitisation exercise. I am glad that my country, Malta, is working towards change in the area, and progressing in leaps and bounds. However, it is important to address the reticence in certain States Parties who still insist on evaluating issues of 'disproportionate burden', or on conducting cost-benefit analyses, before implementing disability-specific reforms.

Disabled persons are human beings with the same rights as everybody else. We are entitled to equal access to the same rights, and necessary accommodations if these serve as the only means to guarantee us such rights – but then again, only when design of products, services or the environment cannot be made equally accessible to all.

> *"Putting a price on our rights is disgusting. Would you do this with women's (or any other group's) rights? Fundamental rights are non-negotiable."*

And as a disability community – and as to our specific community, composed of both autistic persons themselves, as well as families and allies of persons on the autism spectrum – we are duty-bound to keep up the fight, in order to bridge this gap. Awareness leading to acceptance, inclusion and empowerment where there is a receptive audience – in line with the Maltese model – both from the bottom up, as well as from the top down.

And also standing up firmly to authorities where they insist on breaching the CRPD and our fundamental rights – as Autism-Europe has unashamedly done in the past in front of the Council of Europe's Committee for Social Rights, and which we should be ready to do again at any moment, up until the point where understanding and dialogue is possible, as the appropriate vehicle allowing the cause of our equality to be taken forward.

What is the COSP conference?

Every year, the State Parties to the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) meet at the UN headquarters in New York. The meeting is called the ‘Conference of States Parties to the CRPD’ – in short COSP- and its purpose is to consider any matter with regard to the implementation of the CRPD. Leading experts in the field are calling for greater recognition of a range of human rights and fundamental freedoms for persons with disabilities while focusing on helping the most vulnerable among them.

This year the 10th session of the COSP took place from 13 to 15 June 2017 under the theme: ‘The second decade of the CRPD: inclusion and full participation of persons with disabilities and their representative organisations in the implementation of the Convention’.

10th Conference of States Parties to the Convention on the Rights of Persons with Disabilities

UN Headquarters, 13 - 15 June 2017

#COSP10 www.un.org/disabilities enable@un.org

AE website revamped

In line with the main objective of its 2017 campaign “Break barriers together for autism. Let’s build an accessible society”, Autism-Europe (AE) launches its upgraded website aiming at getting more autistic people involved in its activities. The revamp includes a parallel website in easy-to-read language with pictograms, and a private forum for autistic people.

In response to the needs of people on the autism spectrum, AE has modernised its website, including different accessibility solutions for people with sensory disabilities. It notably features a parallel website entirely written and designed in easy-to-read format with pictograms, in order to increase accessibility for people with learning disabilities (together with a regular e-newsletter in the same format). The website has been developed with the content management system (CMS) Wordpress, which adheres to the WCAG 2.0 guidelines, meaning it covers a wide range of recommendations for making web content more accessible.

On top of this, a private forum for autistic people is now available. This forum is open to any interested person on the autism spectrum (member of AE or not), after having filled out a brief registration form to monitor the platform.

In addition to these improvements, the new website also includes other new functionalities such as a global reference map for locating AE’s members and useful and autism-friendly services and/or places throughout Europe (to be constantly enriched), a calendar of events, and an extranet for AE’s members.

Innovative approaches to sex education for persons with disabilities

On the 31 May 2017, Autism-Europe welcomed participants to a conference in Brussels on sex education for persons with disabilities, in the framework of the TRASE project funded by the European Commission's Erasmus+ programme. The conference explored the often overlooked importance of sex education for the wellbeing of persons with intellectual disabilities, and provided a practical insight into how to ensure effective learning.

The TRASE project, standing for "Training in Sexual Education for Persons with Disabilities", began in January 2016. It came about as a response to a noted lack of trained professionals in Europe offering adapted sex education classes to persons with learning disabilities. As such, not only does the project develop a training programme for parents and professionals willing to fill this void, but it also produces a range of adapted, free and ready-to-use learning tools, activities and games to facilitate sex education teaching for people with a range of learning requirements.

The TRASE conference on the 31 May saw members of the project consortium, made up of organisations from Belgium, Luxemburg, the UK, Germany, Austria, Portugal and Lithuania, lead a number of workshops to test the newly-developed learning tools, and discuss the topic of sex education for persons with learning disabilities. Two keynote speakers also fed into the discussion. The first of whom was specialist in the field Professor Michel Mercier from the University of Namur; the second was Izabela Fornalik, an experienced sex education practitioner and writer from Poland.

2017 marks the 10-year anniversary of the United Nations Convention on the Rights of Persons with Disabilities. Although the Convention makes specific reference to disabled people's rights to "found a family", "freely decide on the number and spacing of children" and "retain their fertility on an equal basis with others", as well as to "free and informed consent" when providing healthcare, including reproductive health, throughout Europe forced sterilisation and coerced abortions are nevertheless too often considered an acceptable way of dealing with the lack of available sex education for people with learning disabilities.

You can find out more about the TRASE project, the partners involved, and of course gain access to the free TRASE tools by visiting the project website at: http://www.traseproject.com/


©Autism-Europe

Final conference of the TRASE project in Brussels.


©Autism-Europe

Images of the workshops held at the final conference in Brussels.

Among the tools on show at the conference were:

- **The TRASE Dice Game:** an ice-breaking activity in which students answer questions and discuss different themes about sexuality and relationships according the dice they throw;
- **The TRASE Decision-Making game:** an online game where players are presented with a number of scenarios and asked to choose the best way to react in each situation;
- **The TRASE Word Bank:** An easy-to-read, illustrated encyclopedia of key vocabulary to help students understand the human body, sexuality and relationships;
- **The TRASE Dolls:** anatomically realistic dolls to help explore the human body and sexual intercourse in a non-threatening and easy-to-understand way;
- **The TRASE Board Game**: A board game containing questions on sexuality, which can be adapted by level of intimacy, depending on the target user and their level of comfort discussing the topic.


©CIP

Dr. McManmon conducting an Equine Therapy session with CIP students in Massachusetts, USA

“I am truly the first CIP graduate”

Dr. Michael McManmon, Ed.D. – Founder of the College Internship Program (CIP), self-advocate and member of a large family with several people on the autism spectrum

During his 42 years of experience with students with learning differences and Asperger’s Syndrome, Dr. McManmon has worked on curriculum development, staff training, programme evaluation, and administering community-based programming. He has a unique perspective as he himself was diagnosed with Asperger’s syndrome at the age of 51 and grew up in a large family with several individuals on the spectrum. He has six children and 17 grandchildren, and is an avid artist, swimmer, gardener and traveller.

In 1984 he founded the College Internship Program (CIP), a post-secondary programme that supports young adults with Asperger’s syndrome, autism with lower support needs, ADHD, and other learning differences as they make their transition towards college and starting their careers. With five centres across the USA, CIP is described as one of the most comprehensive programmes in the world for assisting young adults with learning differences to succeed in college, employment, and independent living. “I set up CIP to be a community-based apartment living programme for individuals being let out of institutions so that they could learn to live normally in a community with the additional services they needed”, Dr. McManmon proudly explained.

Autism-Europe: For you, what is the main evolution to occur since the programme began in 1984? Has the profile of the people you support changed over time?

Dr. Michael McManmon: The main evolution since we started would be the tremendous growth in our knowledge and curriculum over the last fifteen years (…). When we started, we were dealing with multiply disabled individuals who had severe psychological problems. It was very intensive. After the first ten years, we moved slowly over to students with learning differences and some had some autistic features. We did not have a name for them, they just exhibited more repetitive and perseverative behaviours and had more cognitive rigidity. Around 2003, we started to identify individuals with Asperger’s syndrome and high functioning autism separately from our learning differenced students.

AE: You grew up in a large family with several people on the autism spectrum, so you have also come to understand autism from the point of view of a relative. What is the role of the family and relatives in the success of CIP students?

MM: In my family of origin, my parents became overwhelmed and did not know how to cope. During the 50’s and 60’s in the U.S. people hid problems and pretended that they were not occurring. I watched my older siblings make huge mistakes and my parents suffer through this with them without the support they all needed. It was a chicken and egg sort of problem. What came first the “untreated learning differences” or the “mental problems and addictions?” That is a whole book that is being written by me for the last ten years.

The family’s role switches when a student enters CIP. Before CIP the parents were highly involved in decision making and direct services with a student. They now switch to the role of “Facilitators”. In this role, they pay the bill, insure the staffing is good, and are supportive. The student takes over control, so that they can stand on their own two feet. CIP helps them bridge the gap.

AE: On the CIP website, we can read the following: "During the era of deinstitutionalization, I read Wolfensburger's Normalization Theory while studying for my Doctorate in Special Education and wanted to implement it in a community-based program where students could experience living in normal living conditions".

From your experience, what is the current situation in the USA regarding deinstitutionalisation and community-based programmes? What are the main challenges you are facing?

MM: Most services in the U.S. are community-based and most institutions have been closed. The main challenges are public funding for those who cannot afford the private options. Core basic services are spotty at best in most areas. Private services are very innovative and state of the art, but you need resources to access them.

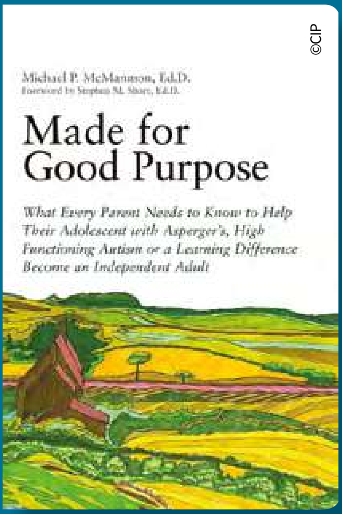
AE: The CIP programme focuses on real-life skills in areas of social thinking, executive functioning, sensory processing and wellness to prepare students for independent living. At a glance, what can you recommend to those young adults with Asperger's Syndrome to master their executive functioning in order to correctly achieve independent living? How can they avoid anxiety and forgetfulness, for example?

MM: Anxiety and depression are almost co-morbid with a diagnosis on the spectrum (the chicken and egg again). We have found that a good sensory diet, including fun and exercise, along with a good sleep regimen and eating healthy foods is the magic formula for wellness.

Executive functioning: Obviously, if you are not doing the above, your executive functioning is going to be thrown off also. But there are at least thirty two areas of executive functioning to look at and assess with each student. Most people just think of "organisational skills" but it is much, much, more. Everything from being able to gauge or size up the demands of a task to estimating time or retrieving information. Doing the proper assessments will help a student to find the specific areas to concentrate on to remediate.

AE: Could you cite some examples of good practices from Europe related to the transition towards independent living?

MM: I think the independent living part is the easiest in many ways and in most countries they can get a handle on it. For example, in Denmark they have programmes for long term independent living for adults that are clustered in apartments, with a lot of autonomy for their clients.



©CIP

Made for Good Purpose: *What Every Parent Needs to Know to Help Their Adolescent with Asperger's, High Functioning Autism or a Learning Difference Become an Independent Adult.*

Filled with practical advice and useful techniques, this book helps parents support their child with Asperger's Syndrome to make the transition from an adolescent to a happy, confident, and engaged adult. With this essential guide, young "Aspies" can achieve independence and learn life-long skills for succeeding in college, work, relationships, and more.

Dr. McManon is also the author of Mploy, a Job Readiness Workbook scheduled for publication later this year by Jessica Kingsley Publishers.

AE: You were diagnosed with Asperger's Syndrome at age 51. What were the biggest challenges you faced before receiving the diagnosis?

MM: My social thinking abilities were limited. I was successful in being able to do enough to run a business, get married and have children, but beyond that it was very limited. My diagnosis opened my world and helped me to understand myself and once the lid was off, I just took off. My special interest became learning all I could about all the facets of our curriculum. I am a "poster boy" for late diagnosis. I just started to apply the curriculum in each area to myself and then write it up so that it was more useful for our students. I am truly the first CIP graduate.

I have been able to navigate the world now, have a real relationship with my children, and daily I try new foods and activities and just add on to my repertoire.

AE: In an interview with the Internet Special Education Resources (ISER), you affirmed: "I now have children who have a human being for a father instead of a «human doing.» How has learning that you are on the autism spectrum changed your life?

MM: Now that my cognitive rigidity is dispersing I am open to new ideas and can work with others in groups as a colleague. I can learn new social skills, I have a self-modulator between my brain and my mouth. I can emotionally self-regulate through swimming, sleep and eating well. My fear has dispersed and I will try new things and new ways of doing things. I am determined to be as "normal" as possible, while I know I have superior areas of functioning at the same time.

I like spending "time" with others and just being with them.

AE: Do you have a message for other autistic people who are diagnosed later in life?

MM: Don't let fear rule your life, it's too short and you have so much to contribute to the world. It's time to jump out of the box and explore and experience. Build the supports you need around you and try new things constantly. You will see the benefits once you engage (I still mourn all the decades I refused to try Indian food and Naan bread!).

More information about CIP: www.cipworldwide.org

Video games marathon "Hajime" supports Autism-Europe

The second edition of the Hajime video game charity marathon raised € 1,600 for Autism-Europe. The event, which was broadcast non-stop on the Twitch streaming platform, was held in Lomme, France, on 29 and 30 April 2017.

As for the first edition of «Hajime» back in 2014, the marathon lasted more than 24 hours, including relays between different players. Participants also accepted specific challenges in order to raise extra money.

In the name of Autism-Europe, we would like to sincerely thank all the organisers, participants and donors for this entertaining initiative in support of Autism-Europe!

More information:
www.marathon-hajime.fr

How to support the activities of Autism-Europe

Autism-Europe is an international non-profit association located in Brussels, Belgium. We accept and encourage donations and fundraising to support our activities. You can help us in a variety of ways and help make things happen, for example:

- Organise your own event and donate part of the profits to Autism-Europe (as was the case for the Hajime marathon);
- Participate in a local race, ask your friends to sponsor you, and run on behalf of Autism-Europe;
- Ask your friends and family to make a donation to Autism-Europe on your behalf, such as a birthday or Christmas gift;
- Offer Autism-Europe a portion of your company's profits for a day, a week, or even longer, and so on.

Autism-Europe has suscribed to the Association for Ethical Fundraising (AERF)

Keith Stuart at Microsoft's #Book-Talk event in Brussels

Keith Stuart, parent of a child with autism and author of "A Boy Made of Blocks"

"I wanted to communicate to other parents who may feel really alone"

Autism-Europe interviewed author and Games Editor for The Guardian newspaper Keith Stuart about his book "A Boy Made of Blocks", a touching and humorous account of one father's journey to get to know and understand his autistic son through the medium of video games.

The novel tells the story of Alex, the father of eight-year-old Sam who is on the autism spectrum. When we meet Alex he is not only struggling to forge a relationship with his increasingly withdrawn son, but is also battling with problems in his marriage, at work, as well as overcoming a recurrent trauma that originated from his own childhood. An unlikely saviour comes his way in the form of the video game Minecraft, opening a window to what his son thinks and feels, giving Alex a new sense of direction in life and a newfound respect for what his son is capable of.

Autism-Europe: Tell us a bit more about the "A Boy Made of Blocks"

Keith Stuart: "A Boy Made of Blocks" is the story of a father, Alex, who is estranged from his family. He has had to leave his home and his wife Jody and his autistic son Sam and he has to build a relationship with his son from outside the family home. So they get together online and play Minecraft together and it is through Minecraft that they build a relationship and an understanding and he learns that his son is a creative and interesting young boy.

AE: Why did you decide to write this book?

KS: I was actually asked to write this book after I'd written some journalism about my son Zack who is on the autism spectrum. I wrote about how Minecraft had been a really helpful influence in his life. The big publishing company "Little, Brown" asked me to write a book about that story but a fiction book. So that's how "A Boy made of Blocks" came about.

AE: What can parents learn from this book?

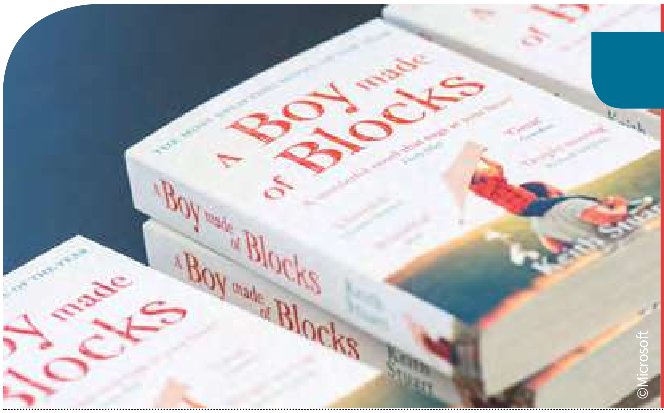
KS: When I started writing "A Boy Made of Blocks" there are lots of experiences I had as the parent of an autistic son that I wanted to communicate to other parents who may have children on the autism spectrum and who may feel really alone. So I wanted to present lots of things that can happen to families where there is an autistic child to tell people essentially, not to give them advice, but just to tell them that they're not alone.

So this is very much a story about what it's like to have autism in your family and the fact that sometimes people don't understand it and that is really difficult. All I wanted to do really was tell people that these are things that there's people going through all over the world and you are not alone and do not despair.

AE: Have you had any feedback from the autism community?

KS: I have had some really lovely positive feedback from autism charities but also from people on the autism spectrum or people who have relatives on the autism spectrum.

I actually got a letter from the parents of an old University friend of mine a couple of months ago and they wrote to me to tell me that they have one of their grandchildren is on the autism spectrum and they found it quite difficult to know how to deal with her and what to do. But apparently they read my book and they just felt it gave them a really good insight into autism and some of the things you need to take into consideration, and they wrote me this lovely letter to say thank you for helping them understand their granddaughter better, which was amazing!



The book deals with multiple issues faced by children on the autism spectrum and their parents.

It touches upon things such as judgement from passers-by, common misconceptions about the condition, the off-base categorisation of people as "high-functioning" or "low-functioning", difficulties at school, the desire for autonomy, difficult life transitions, family strains, and the well-intended but often misinformed advice given by other parents who are less familiar with autism.

“The world hurts; All sounds happen all the time”

Sensory Spectacle help you to understand how sensory processing disorder can impact people’s lives and how we can support their needs.

Sensory processing is something we all have to do to interpret and respond to our environment, it is a personalised processing system which means that we all interpret our surroundings differently.

For example I may love the smell of someone’s perfume, whereas my mum may not. These are sensory preferences which we form over time based on past experiences of processing sensations.

For some people processing the sensory information in their environment can be difficult. Sensory processing disorder (SPD) is when someone may find it difficult to organise and respond to the sensations which their brain is receiving from their senses.

This could mean that someone is hearing all the sounds in their environment and their brain is finding it difficult to filter out the unnecessary sounds so they are all of the same importance. Some people have described this to be like all the sounds are at full volume.

We may recognise people coping with this by covering their ears, wearing head phones, ear wax or removing themselves from that environment.

SPD can relate to any of the sensory systems and can present in a few ways. There can be difficulties modulating information – we may recognise the terms ‘seeking’ and ‘avoiding’ sensations. It could be someone has difficulties discriminating where sensations have come from – locating where sounds have travelled from in a room. Another way can be motor-based difficulties which will impact moving through spaces etc.

Research states that over 75% of autistic people have SPD. All of the work Sensory Spectacle is based on descriptions and quotes from people who have SPD.

Sensory Spectacle educate about and create awareness of SPD. We do this through creating experiential learning environments to help you experience for yourself how it might feel to have a SPD.

We believe it is important for you to be able to recognise characteristics relating to SPD, like rocking, flapping hands, chewing clothes, eating a select diet and understand what they mean and how you can support these characteristics.

Our most recent training experience is our Sensory Dining room, this helps you to identify how SPD can impact meal times and how we can support sensory needs. During this training you are served a 3 course tasting menu to help you experience some difficulties for yourself.

We run workshops for parents, professionals and students to help teach about SPD and how to begin supporting their needs. These are our FEEL IT and DO IT workshops. I travel worldwide creating awareness, running workshops and speaking at conferences. It is vital that more people are able to identify and support people with SPD so that we can support them to reach their potential. SPD can also be closely related to people with ADHD, Dyspraxia and learning difficulties as well as Autism spectrum conditions.

Becky Lyddon
Sensory Spectacle Founder
www.sensoryspectacle.co.uk

To make an enquiry or booking email us at hello@sensoryspectacle.co.uk

Experiential learning about sensory processing difficulties

Sensory Spectacle creates experiential learning environments to help people experience for themselves how it might feel to have SPD. It is important to fully recognise the characteristics linked to SPD, like rocking, flapping hands, chewing clothes, following a select diet, as well as understanding what they mean and what kind of support is needed. This unique approach to learning about sensory processing difficulties revolves around their experiential installations. Each one was created by to help people experience how it might feel for you to have a specific sensory processing difficulty.

Furthermore Sensory Spectacle runs workshops for parents, professionals and students to help teach about SPD and how to begin supporting their needs. These are their FEEL IT and DO IT workshops. Becky Lyddon travels worldwide creating awareness, running workshops and speaking at conferences. It is vital that more people are able to identify and support people with SPD so that they can in turn be supported to reach their potential. SPD can also be closely related to people with ADHD, Dyspraxia and learning difficulties as well as Autism spectrum conditions.

Some of the Sensory Spectacle’s recent work has been with The Autism Show, BBC, Queensmill School (London, UK), Flo Longhorn, The Space Centre, Jo Grace, Special Yoga Foundation, Young Epilepsy or The National Autistic Society. Sensory Spectacle works worldwide and has supported schools in Mumbai (India), Kampala (Uganda), Dubai (the United Arab Emirates) or Amsterdam (The Netherlands).

Some recent films about autism not to be missed

USA

Life Animated

Year : 2016
Genres : Documentary, Animation, Drama
IMDb rate: 7,5/10

This film covers the life of Owen and how he manages to acquire new skills with the help of Disney and his family to the point of starting living independently. However, on his path to adulthood, Owen soon learns as well that there is more to real life than what Disney can illustrate in animation. The film was nominated for the Academy Award for Best Documentary Feature in 2017.

USA

Atypical

Year : 2016
Genres : Series, Comedy, Drama
IMDb rate : 8,4/10

Atypical is a coming-of-age dark comedy television series created and written by Robia Rashid for Netflix. It focuses on the life of Sam Gardner, an 18 year old with autism, who announces to his family that he wants to start dating. The series has received a positive reaction since its release this year, albeit with certain critics claiming it sometimes falls into a stereotypical and/or textbook portrayal of autism. It has nevertheless achieved quite resounding popularity, and makes a commendable effort to bring across the challenges that autism presents when it comes to dating.

FRANCE

Dernières nouvelles du cosmos

Year : 2016
Genres : Documentary
IMDb rate: 7,0/10

Now almost 30 years old, Hélène is the author of powerful texts with corrosive humour. A visionary, her telepathic poetry tells us about her world and ours. She accompanies a director who adapts her work to the theater, she talks with a mathematician... However, Hélène, cannot talk or hold a pen. She has never learned to read or write. It is at 20 years old that her mother discovers that she can communicate by arranging laminated letters on a sheet of paper. This is just one of the many mysteries of this autistic girl, nicknamed Babouillec...

USA

Asperger's Are Us

Year : 2016
Genres : Documentary, Comedy, Drama
IMDb rate: 6,7/10

This documentary gives an inside look into the lives and dynamics of the Asperger's Are Us comedy troupe, four American friends on the autism spectrum who have bonded through humour. The film follows the comedians as they write, rehearse, and perform their most challenging and entertaining performance ever. They will prepare for one final, ambitious show before going their separate ways.

Pictures from Up to Bottom: Frame from the film "Life Animated"
Frame from the TV series "Atypical"
Frame from the film "Dernières nouvelles du cosmos"
Frame from the documentary "Asperger's Are Us"

20 years “reaching dreams” with autistic people in Seville

***Autismo Sevilla* is a Spanish non-profit organisation created in 1978 by a group of parents of children with autism to improve the quality of life of autistic people and their families through responsible, ethical and excellence-guided management. In 2015 alone, Autismo Sevilla provided services to more than 700 people in Seville (Spain) and there are now 110 qualified professional working with and for people with autism.**

A*utismo Sevilla* shares many strategic priorities with Autism-Europe, in line with the United Nations Convention on the Rights of Persons with Disabilities, including long-term concerns about appropriate attention and support, education, employment, well-being, ageing, the care crisis and the role of the families. As part of their multiple areas of activity, they offer services such as:

- Early intervention
- Educational inclusion
- Information and social awareness
- Independence and self-determination
- Employment and housing
- Cultural activities and sports
- Social participation and advocacy
- Community services

An Integral Resource Reference Centre for autism

Nowadays, Autismo Sevilla has a broader knowledge about autism thanks to experience acquired over the years by all the organisations and professionals who work within its network. Nevertheless, more than 20 years ago, the situation was very different. There was almost a total lack of understanding about disability, a lack of specialised resources for assisting people on the autism spectrum, and not a single professional was capable of providing diagnoses and interventions. It was at that moment that a group of parents joined forces in Seville, motivated by the need to provide their children with specific resources in order to cover their needs, which until that moment did not even exist.

This pioneering group of fathers and mothers developed, thanks to a huge effort, the gradual and enormous process of mobilisation, resources acquisition and implementation of different projects in the South of Spain. Over the years, these efforts have been rewarded by the institution’s growing strength.

Two decades later, and their dream has come true: they have become an Integral Resource Reference Centre for autism. Today, Autismo Sevilla is the only institution in the province specialising in autism, establishing a network of specialised services from the earliest ages (diagnosis and evaluation of children from the age of 18 months, early Intervention, leisure activities and respite care…), to educational care (Center of Special Education for Autism, a cabinet of psychological intervention, pioneer projects into educational inclusion in mainstream schools…) and adulthood (day care centre, training for employment and training for independent living for people with lower support needs…).

Beyond all these services, in the past 20 years the institution has become an autism reference Centre in Spain where families and professionals from different fields and other institutions can find advice and information, as well as specialised training and care. One of their main challenges is to achieve the full social inclusion of autistic people in society. In order to achieve this, it is essential to have an adequate understanding of autism, and for society to offer the opportunities needed for participation on an equal basis.

Currently, Autismo Sevilla also manages various projects, co-funded by the local, regional and national government, for the care of around 800 people with autism (80% of them are below the age of 30). Last year, they started working on European projects in the framework of the Erasmus + Programme and, for the next year, are hoping to seek out other funding opportunities.

Autismo Sevilla is an affiliated member of Autism-Europe.
More information:
www.autismosevilla.org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Three-day International Congress “Reaching Dreams” to celebrate the 20th anniversary

On the occasion of the 20th anniversary of the creation of Autismo Sevilla’s Integral Resource Centre, the association is organising a number of different commemorative events. The key event will be a three-day International Congress titled “Reaching Dreams” running from November 30 to December 2 2017. More than 25 speakers will come from all over the world to share their experience, good practices and research in the field autism. A number of autism professionals have already confirmed their participation, such us Hilde de Clercq, Peter Vermeulen, Connie Kasari and Katie Marie Brady, in addition to other speakers from Spain such as Amaia Hervás, Margarita Cañadas, Rubén Palomo or Isabel Paula, among others.

Alberto Brunetti, president of Il domani dell'autismo, applying to become a member of Autism-Europe.

Empowering autistic people for a brighter tomorrow in La Spezia

***Il domani dell'autismo* Foundation ("The future of autism" in English) was created in 2013 at the initiative of a group of parents from La Spezia (Italy), aiming at leading their autistic children towards a semi-independent life to ensure them a serene future and a better tomorrow.**

The basic focus of the Foundation consists of "taking a global approach" towards assisting autistic people and their families, ensuring there is a balanced and constant exchange of information and support. To reach its main objectives, the Foundation:

- Encourages social inclusion and integration;
- Enhances the potential skills and capabilities of autistic people;
- Fosters employment;
- Enhances individual abilities through suitable theoretical/ practical training, tailored to promote a semi-independent life in the framework of the project "Living Life".

The Foundation works closely with other associations acting in the region of Liguria, such as ANGSA La Spezia, in order to facilitate and support the transition of autistic people from school-age into adulthood.

The Foundation also promotes activities for improving the employability of people with autism in the catering industry (hotels, bars and restaurants) and food production facilities. It is through these kinds of projects that the Foundation hopes to fulfill one of its priorities: to enable autistic people to reach a sufficient level of autonomy (to the greatest extent possible) and empower them to live a full and satisfactory life after their parents have passed away.

In collaboration with local, regional and national authorities, the Foundation is actively working on the basis of a complex project, which will culminated with the construction and management of an important centre. It is foreseen that that centre will include a semi-residential complex for people with autism, together with a small section offering accommodation, it will also include a bar, as well as facilities for producing pasta and bread. This centre will be managed by trained autistic people with the support of skilled tutors.

Fondazione Il domain dell'autismo is an affiliated member of Autism-Europe.

More information: https://www.facebook.com/Fondazione-Il-Domani-dellAutismo-1460638740854861/

The adventure of walking the Camino

Since 2015, one of the initiatives taken each year by the Foundation has been to walk the Camino de Santiago. On the 17 July 2017, together with members of ANGSA La Spezia, a group of young people with autism, their relatives and friends (and, for the first time, an autistic girl) embarked on this week-long adventure from Bergamo, pursuing 130km of the of the Camino's "English way" (from Ferrol to Santiago de Compostela), one of the long trails that pilgrims have undertaken since the Middle Ages. "If walking is good for one's health, in our case it is mainly good for the spirit, relieving anxiety, removing stereotypes and coping with challenging behavior", explained Alberto Brunetti, President of the Foundation.

"When we walked the Camino for the first time" said Brunetti "we faced the experience with a bit of fear, because of the unforeseeable events and the changing conditions that our children with uncontrollable anxiety and challenging behaviour had to face every day. Fortunately, and apart from some rare episodes, the adventure ended positively and allowed those young people to grow. We never found ourselves in uncomfortable or difficult situations . Actually, the Camino has proven to be a blessing for our children. In just a few days we have seen their autonomy and abilities increased, quickly adapting to changes in routine. For this reason, this experience has become almost obligatory and it has been incorporated into our annual programme of activities. It provides our children with the ability to become aware of new realities and come into contact with people and places with very different characteristics than they are accustomed to facing in their daily lives.

Group of young people with autism upon their arrival in Santiago

Member Associations of Autism-Europe

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(national associations of people with autism and parents)

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