Steve Silberman, author of NeuroTribes: “I wanted to try to change the global conversation about autism”

Pietro Cirrincione: Autism-Europe’s first self-advocate vice-President

European Accessibility Act: Eliminating barriers across Europe

First National Strategy for Autism in Spain

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Dear friends,

Our 11th International Congress, “Happy Healthy and Empowered”, is approaching. The event will bring together the international autism community in order to share the latest developments in the field of autism. The slogan for the Congress reflects Autism-Europe’s aspirations as well as our main strands of activity, which will also be present throughout this edition.

Illustrating the notion of happiness, we have decided to feature an article on the book *NeuroTribes* by American author Steve Silberman, who recently won the Samuel Johnson Prize for having “injected a hopeful note into a conversation that’s normally dominated by despair”.

We will also share the example of Spain where a network dedicated to the quality of services for autistic people was recently created. Having access to a good quality of life is essential throughout one’s lifetime. Up until the very end of their lives, people with autism should be assured the greatest level of well-being possible, as this edition’s reflection on end-of-life care serves to testify.

This issue also explores the notion of “empowerment”, a dimension of our activities to which we at Autism-Europe are very much attached. As such, we are pleased to introduce to you the organisation’s first autistic Vice-President, Pietro Cirrincione, who is keen to provide a greater voice to self-advocates.

“Empowerment” also touches upon greater accessibility within society. Autism-Europe welcomes the recent proposal for a European Accessibility Act, and we hope that the accessibility needs of people with autism will be fully taken into account in the text.

We very much hope you enjoy reading this edition.

Yours sincerely,

Zsuzsanna Szilvásy
President

Aurélie Baranger
Director

Zsuzsanna Szilvásy

Aurélie Baranger
Determined, attentive and smiling, member of the Council of Administration since 2010, it is not the first time Pietro has visited the office of Autism-Europe, but it is clear that his level of engagement has not waned, on the contrary. Aware of his new position of responsibility, Autism-Europe’s new vice-President explains the importance of self-advocate representation at the European level.

“Being vice-President of Autism-Europe as a self-advocate is more than a responsibility for me: it’s a mission. The autism spectrum is vast, and it’s very positive that people with autism who can represent themselves are active within associations not only at a regional or national level, but also at the European level” he says.

Same direction, different routes

Pietro underlines the fact that Autism-Europe coordinates more than 85 autism associations in 25 different EU countries, but that there is not yet an organisation among them consisting exclusively of self-advocates. “In the field of autism there are several groups whose voices should be heard, and the way of enforcing the rights of people with autism varies depending on the point of view and experience of each of them. For example, some parents have a tendency to protect people on the spectrum, whereas self-advocates favour autonomy. We are all going in the same direction but the route is not always the same”

A life dedicated to autism

Pietro’s responsibilities in the field of autism go beyond his contribution to Autism-Europe. Since 2013, Pietro has been a member of the European Disability Forum’s “Communication and Information Technologies” experts group (EDF-FEPH). In Italy he is a delegate of the National Federation of Associations for the Protection of Persons with Autism and Asperger Syndrome (Fantasia), and Executive Committee Member within both the Gruppo Asperger Onlus and Gruppo Asperger Lazio Onlus associations. Alongside these activities, Pietro is an IT expert in Rome, as well as being a member of the Multimedia Exploration Laboratory (LEM), a cooperative run by people with Asperger syndrome.

Find out more about the structure of Autism-Europe: http://www.autismeurope.org/fr/qui-sommes-nous/notre-structure/

Engaging through sport

Pietro is also involved in several sports projects. In 2010, he took part in the Italian athletic project “Diamoci una mossa” (Let’s move!). In 2015 he helped create the Autistic Football Club, acting as President. This was an initiative by Giuliaparla Onlus, realised with the support of the Lazio Asperger Group. It is an inclusive team consisting of a group of players with autism, parents and educators. The goal of these two initiatives is to favour the social inclusion of children and adults with autism, through sport.
Steve Silberman, author of *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*

“I wanted to try to change the global conversation about autism”

Steve Silberman is an American writer based in San Francisco, where he is best known for his work with *Wired* magazine, a publication reporting on science and technology. His 2015 publication *NeuroTribes*, an investigation into autism, autistic people and the history of autism, has become the first popular science book to win the Samuel Johnson prize. He was praised by judges of the prestigious non-fiction award for “inject[ing] a hopeful note into a conversation that’s normally dominated by despair”.

NeuroTribes goes back to explore the earliest days of autism research. It chronicles the brave and lonely journey of autistic people and their families throughout recent history. Silberman’s work, exploring the way society’s approach towards autism has evolved over the decades and centuries, maps out a path for our society toward a more humane world in which people with disabilities and those who love them have access to the resources they need to live happier, healthier, more secure, and more meaningful lives.

In December 2015 Autism-Europe spoke to Steve Silberman to ask him some questions on his hugely successful publication, and about his thoughts on some of the issues at the heart of Autism-Europe and its members’ work.

You explain in the first chapter of *NeuroTribes* where your particular interest in autism stems from, but why do you feel it is so important to understand the history of autism?

The media was having loud, fervent conversations about autism, but it was always about autism and vaccines, and whether vaccines cause autism. And even if it wasn’t about vaccines, the comments sections would be dominated by arguments about vaccines.

Even really reputable publications like the New York Times, when writing about autism, would always say that the profound increase in diagnosis and estimates of prevalence that began in the 1990s, was a “mystery”: So I decided that the only way to figure out the answers to this mystery was to go back to even before the official beginning of autism history and try to figure out what was going on.

Did you want to change the insight people could have on the issue and try to steer the debate in another direction?

Yes, I was very touched by the journey of Craig and Shannon Rosa, the family in the chapter called “The Boy who Loves Green Straws”, because they are very smart people, and when their son Leo was diagnosed with autism they got the usual predictions of disaster both from clinicians and from the media, particularly because Leo was born at the height of the vaccines media hysteria. They were told his future was over. They became convinced that Leo had been made autistic by vaccines, and so initially went through a journey that many parents went through. They initially tried to cure Leo of autism using dietary interventions, it didn’t work.

Eventually Shannon and Craig decided that this is their son, and they must love and support him as he is. They stopped thinking in terms of cures and vaccines, and started thinking “what can we do to help him live up to his maximum potential, whatever that may be?”

We see from the bibliography of *NeuroTribes* that it constitutes a work of extensive research. Was there anything to come out of your studies that you were not expecting at all?

Yes it took my five years to do the research. I didn’t expect to find a living connection between Hans Asperger (the Austrian paediatrician, medical theorist, and medical professor whose work later fed into our understanding of autism as a spectrum) and Leo Kanner (the Austrian-American psychiatrist and physician known for first identifying autism in children), because every history of autism has maintained that the two discoveries were made independently. So that really surprised me. Basically what happened was I was reading an early tribute to Irwin Lazar (founder of the clinic in Vienna where Asperger worked), and I saw the name Georg Frankl. Then I was reading Leo Kanner’s unpublished autobiography and I saw the name Georg Frankl again.

I thought “where have I seen that name before?” And I realised it was the name in Leo Kanner’s landmark 1943 paper that was considered the discovery of autism. At first I thought it couldn’t possibly be the same person, but it turned out to be true. Through this link I managed to find a paper Georg
Frankl wrote after coming to America, on autistic people and their families. He talked about the “autistic continuum”, at a time when there was no concept of the autism spectrum (he wrote this in the 1950s at the University of Kansas). So it suggests the work in Asperger’s clinic fed into Kanner’s discovery, and that it did not happen completely independently.

Do you think the autistic community has been significant in shaping our world?

Very much so. I want to be careful, because I think a lot of the people that shaped the digital technology that we use today, they might not have had diagnosable autism, but they had autistic traits.

There was a book written in the 1980s about early Silicon Valley, called “Silicon Syndrome”. It was about relationship problems women had with their husbands who seemed to have very few friends and very narrow focus. In other words, silicon syndrome was a very good description of Asperger syndrome before the term was even invented.

In chapter 11 you go into the self-advocate movement, and talk about some examples of those who are the most well known in America. Here at Autism-Europe we value the participation of self-advocates. In your opinion, what do self-advocates bring to the movement for the rights of autistic people that those without autism cannot?

They provide us with an insider’s view of autism. They can tell you what it’s like to experience the world with an autistic brain. I am not saying that clinicians are not experts. Clinicians are experts at clinical descriptions of autism, but autistic people can provide us with an insider’s view of not only what autistic lives are like, but also what autistic people and their families really need. Autistic people [...] have been more focused on what we can do to help autistic people and their families now”.

Well I think it’s really important to include the voices of self-advocates in the media coverage on autism. For decades the conversation about autism in the news was basically behind the backs of autistic people, as if they had no opinion and, you know, couldn’t even speak. And so I think that having autistic voices in the media will help destigmatise the condition.

I also think another thing that would help autism acceptance is if we stopped using the word “epidemic” to describe the rise in prevalence. When you hear “epidemic” you think of plague, contagion, germs, disease... “epidemic” is a very stigmatising word. By using the word “epidemic” what you are actually promoting is autism stigma.

How was Neurotribes received by the autistic community?

I got the book of the year award from the Autistic Self-Advocacy Network, which is probably the most prominent organisation of self-advocates in America, so they liked it very much.

Are you planning on coming to Europe for any events in the near future?

I don’t have any scheduled but if any organisations want to host me, feel free (Steve laughs). But I don’t have anything planned right now. I mean I love coming. I’ve been to two National Autistic Society events. I went to the Professional Conference in Harrogate, and that was actually the first public event I did for the book. What was especially touching was that there were some people who are in the book that were actually there, like Judith Gould. It was a very emotional experience for me.
Spain approves its first National Strategy for Autism

The Spanish government recently adopted its first National Strategy for Autism, which aims to develop specific measures to improve quality of life, promote awareness and identify and respond to the needs of those living with autism. The document considers fifteen main strategic lines in terms of healthcare, education, employment and culture, among others.

In November 2015, Spain took a step forward in the recognition of the rights of people with autism. As a result of a historic demand by the Spanish autism community, the Council of Ministers unanimously adopted the "Spanish Strategy for ASD", which will serve as the "reference framework for defining national, regional and local policies and actions concerning people with autism", according to the Spanish Ministry of Health.

For the implementation of this Strategy, the Ministry has set a time limit of one year to draft an action plan, which will include concrete measures and actions to meet the objectives, the agents involved in their implementation, the timeline for each action, the necessary resources for developing interventions and methods for assessment and evaluation by means of indicators.

According to the third sector organisations that helped to draft the text, the need for the Strategy stems largely from the increasing numbers of people who, in recent years, have been diagnosed with autism. In 1975, the rate of diagnosis in Spain was merely one in 5,000. Today the figure is one in every 100 people. As such, there are currently around 450,000 people with autism in Spain. In addition, it is hoped that a nationwide strategy will help bridge the disparities across the country’s regions, namely with regards to care and treatment.

Miguel Ángel de Casas, President of Autismo España: "Autismo España appreciates the approval of the Spanish National Strategy for Autism, which requires the newly-elected government’s commitment to translate the Strategy into an action plan that considers specific actions and resources to improve the social inclusion, quality of live and protection of the rights of people with ASD. The adoption of this Strategy is a historic demand that lets us move forward to an effective enjoyment of the rights of people with ASD".

Ruth Vidriales, Technical Advisor to Autismo España: "This adoption is ‘good news’ for our collective, since it will contribute to increasing the visibility of the needs of people with ASD, as well as to reducing current inequalities in the way regions tackle these disorders".

Jesús García Llorente, Director of Autismo España: "This achievement is the result of a historic demand made by Autismo España, Confederación Española de Asociaciones de Padres y/o Tutores de Personas con Autismo (FESPAU) and the Federación ASPERGER. After being rejected by the Congress in 2010, in 2014 a Non Law Proposition was approved with the support of all political parties, which urged the government to draft the current National Strategy for Autism."

Alfonso Alonso, Spanish Health Minister: "For the first time in history, Spain has a strategy for ASD. It was the wish of the Council of Ministers (all the political groups voted unanimously), and a reiterated recommendation by both the WHO and the EU. Autism has a great impact not only on the development of the people affected, but also on their families. The prevalence of these disorders is highly significant. In Spain we consider it to be a public health issue."
The strategy in a nutshell

The guidelines and goals outlined in the Strategy focus on favouring independence, autonomy, full participation and integration, equality of accessibility, and non-discrimination. These guidelines are essential for improving social inclusion, quality of life and the protection of the rights of people with autism. In this regard, the Strategy has been constructed around 15 lines, each with defined goals for guiding the development of concrete measures within a year’s time.

Cross-cutting strategic lines

Four of these lines have a cross-cutting character. They are devoted to:

- **consciousness and awareness-raising**, in order to boost the inclusion of people with autism and promote a positive image of their real capacities;
- **accessibility**, which aims to reduce difficulties in understanding the information;
- **research**, favouring the coordination of resources, development, innovation and transfer of knowledge;
- and **training for professionals** who work alongside people with autism throughout their lives.

Specific strategic lines

The remaining eleven strategic lines deal with:

- **health**, with a number of proposals that favour the early detection of autism, access to diagnosis and to specialised integrated interventions, as well as to advice and care starting from the moment of diagnosis;
- **education**, with goals to promote school inclusion and academic success for pupils with autism. This will focus particularly on specialisation, innovation and an adaptation of schooling methods throughout their lives;
- **employment**, with measures for fostering orientation and services for employment facilitating employment in both the private and public sectors;
- and **social inclusion, participation and independent life**, favouring assistance integrated processes, specialised and multidisciplinary care, improving the associative network and autistic people’s access to community resources.

In addition, other proposals are foreseen for promoting justice and **furthering the rights of people with autism**. What is intended is to promote the protection of their rights in legal proceedings and in cases of abuse and violence. Lastly, other measures foresee the consolidation of the **quality, equity and sustainability** of facilitated support.

Drafting process

The first draft of this document was prepared jointly by the entities of the “Third Sector of Social Action”, representatives of persons with autism and their families, the Secretary of State for Social Services and Equality and the General Directorate of Policies concerning Support for Disabilities.

The first version of the document was sent to the ministries, regional administrations, the Spanish Federation of Municipalities and Provinces, the Spanish Committee of Representatives of People with Disabilities (FERMI, acronym in Spanish) and to the National Council of Disability, allowing each actor to make their own amendments. Numerous suggestions were then received and added, resulting in a great improvement on the first draft.

Throughout the drafting period, contacts were maintained with the main associations representing autistic people, welcoming and assessing remarks from their representatives, and seeking their agreement on the text to be adopted at the end of the process. These associations are: **Confederación Autismo España (CAE)**, **Confederación Española de Asociaciones de Padres y/o Tutores de Personas con Autismo (FESPAU)** and the **Federación Asperger España**.
Reference framework
With the approval of this strategy, the Spanish government has established a reference framework recognising the need to establish minimum parameters to avoid territorial disparities, especially at the regional level.

The strategic lines followed by this document use the United Nations Convention on the Rights of Persons with Disabilities as a reference point. In 2013, this convention led the Spanish government to approve the General Law for the Rights of Persons with Disabilities and their Social Inclusion (Royal Legislative Decree 1/2013, of 29 November). Furthermore, the objectives of the strategy are in line with the health plans coordinated by the Ministry of Health, Social Services and Equality.

Legislative measures for autism in Europe and abroad
Other European countries have also developed and implemented legislatives measures and specific strategies and action plans focusing on people with autism. This is, for example, the case in the United Kingdom, which has disposed of a legislative framework on autism since 2010 (Autism Act). This framework encourages the recognition of the needs of people with autism, namely in the area of adult life and healthcare, as well as the development of strategies for giving them answers (Think Autism. Fulfilling and Rewarding Lifes. The Strategy for adults with Autism in England). In April 2014, this strategy was updated, with 45 million pounds set aside for its effective development.

Several other countries have also developed strategies and action plans to raise awareness, promote identification and provide answers regarding the particular needs of people with autism during their lifetime, whilst at the same improving their quality of life and that of their families.

For more information, please see (ES): www.autismo.org.es

Social inclusion, participation and independent life are the axes of the Strategy

The main international actions developed concerning autism in the 21st century are the following:

2000: Nebraska (US), Autism Spectrum Disorders. Nebraska State Plan (Updated in 2001);
2008: New Zealand, Autism Spectrum Disorders Guidelines;
2008: Denmark, National Autism Plan;
2008: Hungary, National Autism Strategy (2008-2013);
2008: The Autistic Spectrum Strategic Plan for Wales (2018-2015);
2009: England and Wales, Autism Act;
2009: Victoria State (Australia), Autism State Plan;
2010: Massachusetts (US), Governor’s Special Commission Relative to Autism (Legislative Commission);
2011: Scotland, Scottish Strategy for Autism;
2013: Peru, Bill for the integral protection of persons with autism;
France fails to stop “exile” of people with disabilities to Belgium

Representatives of disabled persons in France have urged their national Parliament to take concrete steps to find support solutions for more than 6,500 French children and adults with disabilities, allowing them to live in France instead of promoting a forced “exile” to Belgium because of a lack of adequate support services in their own country.

Ryad, who is 19 years old and was given a late autism diagnosis, has been exiled in Belgium 200 km from his family since 2012. He never had support tailored to his needs. Esther, 20 years old, also has autism and has been exiled in Belgium since the age of 15. She splits her time between medical and educational institutions, and private monitoring at home.

Ryad and Esther are among more than 6,500 French citizens with disabilities who are currently being cared for in Belgian medical and social establishments, according to the French Ministry of Social Affairs, Health and Rights of Women. These departures can be explained in part by the lack of adequate solutions in France, especially for complex disabilities.

Last October, the French government began discussing the budgetary law on social security for the year 2016. An additional €15 million is set to be channelled into the national healthcare budget for persons with disabilities.

As one of the axes of this campaign, in October 2015 Unapei launched a petition to the French Parliament in order to stop the flow of forced exiles to Belgium and create new reception and support solutions in France. The disabled community warmly received the petition, which gathered around 10,500 signatures within the first three months, with a total of 15,000 needed in order for the petition to move from rhetoric to action.

Disability figures in France

- Today, over 6,500 French citizens with disabilities1 are sent to Belgium to receive care owing to the lack of available support services in their home country.
- Today, these policy choices are depriving France of at least 4,000 jobs and cost health insurance companies and the French départements2 at least €250 million3 per year.
- France still has more than 47,000 people with disabilities4 without any accompanying solution.

A campaign to stop disabled people being banished

Unapei, member of Autism-Europe and Inclusion Europe, warns that the foreseen €15 million is just a drop in the ocean compared to the €250 million that France puts into Belgian healthcare. As such, Unapei has released a dossier listing statistics about France’s mentally and physically disabled community and is carrying out a large-scale campaign calling for the adequate support of persons with intellectual disabilities in France in accordance with article 19 of the United Nations Convention on the Rights of Persons with Disabilities.

The United Nations Convention on the Rights of Persons with Disabilities, ratified in 2010, recognises the right for disabled people to choose their place of residence and with whom they wish to live. The Convention also requires states to offer them support solutions to meet their needs and expectations so that they are fully included in society.
European Accessibility Act to harmonise the accessibility of goods and services in the EU internal market

The European Commission has proposed a European Accessibility Act (EAA), which will set common accessibility requirements for certain key products and services that will help people with disabilities at the EU level to participate fully in society.

The proposal for a Directive aims to improve the functioning of the internal market, making it easier for companies to provide accessible products and services across borders. The products and services covered include ATMs and banking services, PCs, telephones and TV equipment, telephone and audiovisual services, transport, e-books and e-commerce.

Commissioner Marianne Thyssen commented: “Disability should not be a barrier to full participation in society, nor should the lack of EU common rules be a barrier to cross-border trade in accessible products and services. With this Act, we want to deepen the internal market and use its potential for the benefit of both companies and citizens with disabilities. In fact, we all may benefit from it”.

The publication of the EAA was followed by an eight-week consultation period in which Autism-Europe and its allies took part to voice their concerns. This consultation will be followed by a regular legislative procedure involving the European Parliament and the Council of the European Union.

A recommendation made by the United Nations

The UN Convention on the Rights of Persons with Disabilities contains accessibility obligations. It requires that its Parties, like the EU and the Member States, take the necessary measures, including legislation, to ensure accessibility.

In 2010, the EU ratified the UN Convention on the Rights of Persons with Disabilities (UNCPRD). It covers civil, political, economic, social and cultural rights, in all areas of life: from justice to transport, employment to information technology, and so on. Article 9 of the Convention contains the obligations for State Parties on accessibility to ensure persons with disabilities have access on an equal basis with others.

The European Accessibility Act is part of the European Union’s Disability Strategy 2010-2020, and will help to support the implementation of the United Nations Convention on the Rights of Persons with Disabilities throughout the EU. Without EU action, each Member State will continue to develop different laws as they implement their obligations, thus fragmenting the EU market more and more. The EU decided to take action to prevent such fragmentation and create more market opportunities for businesses. It is also anticipated that the EAA can reduce the cost of accessible products and services and have a positive impact on public budgets on the long-term, by reducing the dependency of older and disabled persons.

The publication of the proposal also follows the recommendations made by the UN Committee on the Rights of Persons with...
Disabilities earlier in September calling on the EU to adopt the EAA as a step towards better implementation of the Convention. In September 2015, the UN committee overseeing compliance with the UN Convention on the Rights of Persons with Disabilities (UNCRPD) recommended that: “the European Union take efficient measures for prompt adoption of an amended EAA that is aligned to the Convention”.

Around 80 million people in the European Union are affected by a disability to some degree. Due to an ageing population, this figure is expected to increase to 120 million by 2020.


Reactions

Aurélie Baranger, Autism-Europe (AE), Director:

“AE welcomes this long-awaited Directive that will have an influence on ensuring that innovative, affordable and accessible goods and services will be available for persons with disabilities in the EU internal market”. In the context of the consultation we have highlighted the following priorities:

• The need to have a broad definition of ‘accessibility’ that includes access to information and communications as well as sensory accessibility.

• Access to support services and accessible public information and communications, in alternative format, such as easy-to-read format and pictograms, especially on public transport, in public places, on the internet and for emergency services.

• Adoption of very clear and detailed accessibility requirements, in particular to respond to the needs of people with autism and/or with intellectual disabilities, to ensure an effective transposition of the Directive and a real harmonisation across the European Union.

Yannis Vardakastanis, European Disability Forum (EDF) President:

“We highly appreciate that Commissioner Thyssen has delivered on her commitment to publish the Act this year. For many years, the Act has been a top priority for EDF and its members through our Freedom of Movement campaign. In the coming weeks and months EDF and its members will work together with the EU institutions, partner organisations and other stakeholders to make this piece of legislation meaningful for 80 million people with disabilities in Europe”.

Magdi Birtha, Inclusion Europe, Policy Officer:

“Only a strong and legally enforcing document can ensure that accessibility is taken into account in all relevant EU legislations and policies. It was high time to make concrete steps to comply with the EU’s international obligations and put the provisions of the United Nations Convention on the Rights of Persons with Disabilities into practice to bring real change in the lives of 80 million European citizens”.

Around 80 million people in the European Union are affected by a disability to some degree. Due to an ageing population, this figure is expected to increase to 120 million by 2020.
Science and experience come together to improve the quality of life of people with autism in Spain

The “Network for Quality of Life” (Red para la Calidad de Vida in Spanish) is an initiative created by Autismo España to promote innovation regarding the support systems and the services provided by its partner entities for people with autism and their families. The network, currently made up of 15 professionals linked to 12 organisations located throughout Spain, consolidates stable networks of collaboration between allied organisations, and drives innovation in their development models.

The Network was created in 2011 due to the need to transform and adapt the support, programmes and services offered by the partner entities in light of current concepts, models, and planning based on the Quality of Life model. 73 family members of people with autism, 143 professionals and 60 people with autism have reported directly on their quality of life, and another 80 have participated indirectly in this working group by sending representatives. Over the course of the almost five years, the Network has designed a system of indicators that will allow stakeholders to objectify and contrast the impact of the support provided to ensure the quality of life of people with autism, as well as to promote innovation and continuous improvement in this field.

The network uses a qualitative and participatory research methodology, which seeks to combine the value of scientific methods with the experience of the professionals involved in Autismo España’s member associations. To this end it has also received the support of experts during the consultation process and time spent conducting social research. The Confederación Autismo España is committed to the development of support, programmes and services that incorporate advances in knowledge about autism, and a planning model based on measurements of quality of life.

This commitment underlines improvements in the quality of life of persons with autism as being the fundamental criterion for assessing the effectiveness of the interventions and support they receive. It also underlines how essential it is to progress towards models that support organisational development. Furthermore, it is essential that the factor of quality of life be incorporated transversely into all their actions, and that approaches be adapted in order to adequately respond to these requirements.

Objectives of the Network

- To inform people about the developments being made in research into the quality of life of people with autism and the implementation of good organisational practices.
- To advance knowledge about the perspective of autistic people on their quality of life, as well as the opinions of their families and professionals.
- To develop a consensus model on promoting the quality of life of people with autism, incorporating factors relevant to the people involved and the criteria to be met by services and support systems in order to favour this.
- To propose a system of objective indicators directed at services and entities whose activities focus on autism, allowing them to measure the positive impact they have on the quality of life of autistic people to those providing support.
- To support Autismo España’s member associations in implementing the system of indicators and in improving the processes to promote the quality of life of people with autism.
iCalidad, an app to boost innovation and continuous improvement

As a part of its aim to develop indicators to assess quality of life, the Network for Quality of Life is currently developing iCalidad (iQuality in English), an app for the promotion, innovation and continuous improvement of the quality of life of people on the spectrum over the age of 14, as well as their families.

iCalidad is a technological tool that will apply these indicators in incorporating a system of evidence-recording that the person with autism can fill in themselves, or that a significant other, such as a family member or a professional, can fill out on their behalf. Thanks to iCalidad, it is possible to have three different views when assessing the aspects that affect the quality of life of a particular person the most, and thus identify the actions necessary to optimise it.

The app is currently in the pilot stage, which is taking place within three of the entities of the Network (Autismo Burgos, Autismo Sevilla and Asociación Pauta) to test its validity and make improvements where necessary, such as the possibility of including an evaluation phase or to add extra indicators for children under 14. Once this pilot stage has been completed, the application will become available free of charge (at some point in 2016) to the rest of the Network’s entities so they too can implement it. In the medium/long-term, the objective is to make this app available for all those in the Network wishing to make use of it.

Guidelines of the Network

- Evaluating the subjective perception of autistic people’s quality of life and the factors that contribute to favouring it, taking into consideration the different points of view of:
  - people with autism
  - families
  - professionals
- Consensus on methods and strategies (derived from experience and practice) that incorporate the perspective of persons with autism in the consultation process and decisions affecting their lives, with special attention to those who have higher support needs.
- Design of indicators and tools to objectively assess the positive impact of support provided by the confederated entities with the aim of improving the quality of life of people with autism.

More information:
About the Network for Quality of Life: Ruth Vidriales, Technical Advisor to Autismo España: asesoramiento(at)autismo.org.es
About iCalidad (ES): http://www.autismo.org.es/proyectos/investigacion/calidad-de-vida

The network uses a qualitative and participatory research methodology, which has sought to combine the value of scientific methods with the experience of professionals.
Employment and inclusion of people with autism get a boost in Portugal

Inclusion and employment opportunities for people with autism in Portugal might be about to move up a gear. The Portuguese Federation of Autism (Portuguese acronym FPDA) recently created two new platforms and hosted a conference in Lisbon on upholding the right of people with autism to be supported in employment, as outlined in the United Nations Convention on the Rights of Persons with Disabilities.

In 2014, statistics from the Portuguese Institute for Employment and Professional Training (Portuguese acronym IEPF) showed that public investment in the area of vocational training and employment of disabled people was decreasing, while the global number of beneficiaries was increasing. Persons with disabilities were thus getting less support, as legislation introduced in 2009 reduced the hours of training programmes and the duration of support mechanisms available to facilitate their transition into the labour market. In parallel, EU statistics on income and living conditions (EU-SILC) show that employment rates are significantly lower for disabled people than for their non-disabled peers.

In light of this, the Portuguese Autism Federation (Portuguese acronym FPDA) is implementing two online platforms to disseminate examples of best practice and facilitate the inclusion of adults and young people with autism in the labour market:

**Autism and Employment platform**

The national socio-professional platform "Autism and Employment" addresses all adults and young people with autism who want to be made aware of employment offers. This innovative platform allows people to receive information by simply signing up. Registered applications are then made available online to businesses and organisations involved in the project. The platform is an effective and dynamic employment tool establishing a network between businesses, local associations and other regional and local organisations. As a requirement prior to registering, all candidates should have the support of a federated association of the FPDA or an association that is recognised by it.

**Inclusion platform**

The "Inclusion Platform" aims to familiarise young people on the autism spectrum with businesses, and social and recreational organisations, both while still in and once having left school. This search engine allows young people and their families to navigate a "ways and means" database. The platform counts on numerous examples of best practice from pioneering inclusive projects in the fields of the arts, sport, cooking, gardening, information technology or in the development of autonomy. Through the establishment of competence workshops that are connected to the community (businesses and cultural, sports, and social and recreational organisations), young persons with autism are being trained to perform tasks related to their interests and capacities.

30 voices for ensuring effective participation

Persons with autism, their families and business leaders were represented by participants at a conference held in Lisbon in October 2015 to promote work opportunities and employment for autistic people, discuss access to employment and share the recommended methodology to ensure effective participation, following a successful initiative launched on World Autism Awareness Day 2015 (April 2) in Portugal. FPDA board member, José Miguel Nogueira, stressed the importance of everyone having the right to work, highlighting not only its therapeutic potential but also its moral imperative.

Through different roundtable discussions, attendees were able to broaden their perspectives, exchange thoughts and share good practices and experience in the field of employment dynamics and the workplace, as well as volunteer work and other manner of occasional social engagements. People...
with autism who are still studying at high school or university, or who are currently unemployed, also had the opportunity to share their experiences and express their thoughts about their future.

The considerable role professionals play in the preparation for work experience or employment was also discussed. They can help candidates find offers that are suitable to their abilities and training, and help organisations recruit candidates that are, in turn, suitable for the job at hand. The panel addressed the role of families, healthcare technicians and work colleagues in preparing young people for their future jobs and their integration in the work place.

Developing autonomy to enable work place integration and inclusion

The Portuguese Association for Asperger’s Syndrome (Portuguese acronym APSA) is also developing an "Employment Programme", which seeks to develop social and functional autonomy competences so as to enable workplace integration and inclusion. Multidisciplinary teams of healthcare professionals assess each individual's functionality profile and intervene accordingly, working towards one of the programme’s five types of work experience: employment, paid internship, unpaid internship, training and community experience. APSA provides training to the host organisations’ employees and acts as a mediator throughout the entire process.

More information:
"Autism and Employment" platform: http://autismoetrabalho.fpda.pt
"Inclusion Platform": http://plataformainclusao.fpda.pt
APSA Employment Programme: http://www.apsa.org.pt/comunidade/empresas/programa-de-empregabilidade

Employment of disabled people in Portugal: Policies, facts and figures¹

- The number of people working in sheltered employment is low when compared to other European countries – the latest numbers show that in September 2014, 234 disabled people were employed in a sheltered workshop and 138 disabled people were employed in an enclave.

- The promotion of the professional integration of disabled people in the open labour market is also supported through an annual merit award that aims to honour and reward especially successful cases and a mandatory quota for external admissions to public services (Decree-Law 29/2001) of 5% when the application process involves ten or more places, one place when it involves between three and nine places, and preference to the candidate with disabilities of equal qualifications when the application involves one or two places.

- With regards to employment, the Portuguese National Reform Programme contains one measure related to disability (although not exclusively, as the measure of professional internships targets disadvantaged people in general, including people with disabilities, single-parent families, persons whose partners are also unemployed and victims of domestic violence).

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Invitation to Autism- Europe’s 2016 Annual General Assembly

Cagliari, Italy

In accordance with the statutes for our organisation, we are pleased to invite you to attend Autism- Europe's Annual General Assembly, which will take place in Cagliari, Italy on May 6-8, 2016.

Agenda:

- Presentation of the executive committee report
- Presentation of the activity report: 2015
- Presentation of the financial report: 2015
- Presentation of the work programme: 2016

An Autism-Europe Council of Administration meeting and a study visit will also take place in conjunction with the meeting.

The meetings will be hosted by the Association Diversamente Onlus

All the working documents related to these meetings will be emailed to registered participants at a later date.

For more information, please contact Autism-Europe’s Secretariat:
secretariat@autismeurope.org

¹ACADEMIC NETWORK OF EUROPEAN DISABILITY EXPERTS (ANED); ANED Country report on the European semester. 2014.

Casa Grande is a space to promote and support the social integration of people with Asperger’s Syndrome, favoring conditions for independence and a better life.
Equal rights for people with autism at the end of life

Michael Baron, a National Autistic Society founder, parent and former UK representative in Autism-Europe’s council of administration, whose son Timothy is 60, says of the concept of “a good death”: “At the age of 86, I want that for myself, but just as much I want that end of life conversation for people on the autism spectrum like my son.”

Michael Baron has just contributed to what he calls “necessary and timely” guidance on end of life care for people with autism or learning disabilities. The guidance from the British Institute of Learning Disability (BILD), titled “Peaceful, Pain Free and Dignified: palliative and end-of-life-care for people on the autism spectrum”, is unique due to its autism-specific focus and its step-by-step descriptions of how healthcare staff and social workers can offer better care.

“As his family, we don’t want the manner of Timothy’s death to be decided solely by others,” explains Michael Baron. “He may be disabled and lack legal capacity but nonetheless, a ‘good death’ involves meaningful conversations [between individuals, families and staff] that acknowledge the absence of legal rights but the enduring presence of human rights. Families should be consulted [throughout end of life care] and no decision should be made which has not already been discussed. That is the minimum human right to which someone is entitled.”

The UK is home to around 1.5 million people with learning disabilities, but the real figure, including the undiagnosed, may be higher. The British Institute of Learning Disabilities (BILD) says that by 2030, there will be a 30% increase in the number of adults with learning disabilities over 50 using social care (no figures exist for older autistic adults). This population faces health inequalities; the 2013 Department of Health-funded confidential inquiry into premature deaths of people with learning disabilities found that people die on average 16 years earlier than they should, because of poor diagnosis and treatment.

“We all wish for a pain free, peaceful and dignified end to our lives,” says Lesley Barcham, BILD’s ageing well project manager, “but for people with learning disabilities or autism, who may not be able to speak up for themselves, it can feel like this isn’t something they can control.”

The publication stresses how autism or a learning disability affects end-of-life care. People may have verbal and non-verbal communication difficulties, for example.

Some support exists – advice on helping bereaved people with learning disabilities and the voluntary PCPLD Network (Palliative Care for People with Learning Disabilities) connecting disability and palliative care professionals – but learning disability end-of-life care has a low profile. A recent European Association for Palliative Care taskforce report on people with intellectual disabilities, describes “a largely invisible population with hidden needs”, warning of “a risk that their needs are therefore not seen as a priority, or even as a problem”.

As pointed out by Jill Ferguson, co-author of the BILD’s practice guide mentioned above, there is a much wider question at stake. “It’s a much bigger issue about early diagnosis and early treatment planning for vulnerable individuals who struggle with self-advocacy […] People with a learning disability or autism should have access to the same care that the rest of us do”.

This article was published by Saba Salman in the blog “The social issue” on 2 December 2015

http://thesocialissue.com/

On this subject, a new guide for social care practitioners has been written by Autism-Europe member Scottish Autism, exploring the topic of end-of-life care for individuals on the autism spectrum. This practice guide, titled “Peaceful, Pain Free and Dignified: palliative and end of life care for people on the autism spectrum” by Jill Ferguson and Val Laurie, published by BILD, is designed to inform others who provide care and support for individuals with autism in the final stages of their lives.

The guide can be ordered from the BILD website: http://www.bild.org.uk/our-services/books/health-and-wellbeing/peaceful-painfree-and-dignified/
In just a few months, CUAA has established an office in Zagreb and employed three people. This has allowed CUAA to organise four national meetings in order to bring together its member organisations from all over Croatia. This action has helped the number of member organisations grow from eleven to close to fourteen, with several new members set to join soon. Furthermore, six education meetings have been held, attracting hundreds of participants. These developments have allowed CUAA to concentrate on reorganising and strengthening the position of people with autism in Croatia.

Over the past few years, the Union has been making a difference by developing new programmes and implementing new technologies, all with limited resources, and often with the help of volunteers. Parents provide insight and demonstrate their ability to operate as great advocates for their children, while young professionals can keep up to date with new funding opportunities and the development of new technologies. In this spirit, CUAA has already finalised two projects in which new ‘Information Technology’ was used.

Awareness-raising and education to promote inclusion
Since 2014, CUAA has organised six education sessions for both member organisations and all relevant stakeholders, to teach them about how to gain a better understanding of autism and how to approach people with autism. Professors from the University of Zagreb, employees of the Centre for Autism in Zagreb and doctors of medicine working in the field of autism were some of the experts who held sessions. Each conference welcomed around 300 attendees. Members of CUAA also ran a session for bus drivers in Zagreb and, since December 2015, future police officers have been given training on how to communicate effectively with autistic people.

Advocating towards policy-makers
Major breakthroughs have been made in the field of advocacy surrounding policy makers. CUAA is becoming a major partner connecting Ministries, Government offices, local departments, NGOs and other citizen groups all over the country. Some developments have already been made. For instance, Osijek, the fourth largest city in Croatia and administrative and industrial centre of the Slavonia region, is currently developing its own Centre for autism. The whole initiative was carried out by parents of children with autism, alongside members of CUAA.

Furthermore, the National foundation for development of the NGO sector has, in cooperation with the Ministry of Social Policy and Youth, developed a new model of sustainable funding for organisations that support people with disabilities. For the first time, Croatians are getting used to the idea of organising and bringing about change through representative organisations, rather than waiting for politicians to bring about the necessary changes.

Throughout 2014 and 2015 CUAA worked extensively on reaching out to the general public and informing them about autism. With this same aim, a new website was developed and activity on social networks was intensified, with the number of people following the Facebook page doubling during this period. CUAA also commemorated World Autism Awareness day on the 2 April, inviting seven major cities in Croatia to participate in lighting their buildings up blue.

Active at the European level
In June 2015, CUAA started lobbying for the European Parliament’s Written Declaration on Autism, drafted in cooperation with Autism-Europe and adopted in September 2015. In doing so, CUAA was the first national union of associations in Europe to acquire signatures from all its national Members of the European Parliament (MEP). This was also a great way for CUAA to make contact with Croatian MEPs, and we hope to continue this cooperation well into the future.

More information (In Croatian):
www.autizam-suzah.hr
Register now for Autism-Europe’s 11th International Congress!

The Congress, which will be hosted from the 16 to the 18 September 2016 in the International Convention Centre in Edinburgh, UK, is organised by the National Autistic Society in partnership with Autism-Europe.

In this eleventh edition of the Congress, submissions are linked to the overall theme: ‘Happy, healthy and empowered’. Autistic people, researchers, practitioners, teachers and other interested parties have submitted abstracts for presentations with the aim of exploring a broad range of perspectives, both theoretical and practical. Value will be placed on robust and well-evidenced knowledge, including academic research and professional, personal and collective experience within the three key topic areas. Here are some examples that outline the values and topics to be discussed at the Congress.

Yo Dunn PhD

Trainer and consultant in education, social care and health, specialised in autism

In 2014, inspectors visiting St Clement’s special school felt that the needs of autistic pupils were "not being well met". The school needed to "identify learning needs accurately and implement appropriate strategies to overcome barriers to learning, especially for children and young people with autism spectrum disorders.”

In 2015, inspectors highlighted "outstanding progress”, particularly for autistic pupils. “Children and young people now have much better learning experiences” and “[t]hose with autism feel less anxious as a result of the increased expertise of staff and more appropriate programmes of learning.”

This progress was achieved by:

- working collaboratively with staff to build a professional development culture
- embedding autism development within wider school improvement
- extending the change beyond school out into the community
- ensuring training and consultancy focused on practical strategies
- moving beyond one-off training to embed autism knowledge in classroom practice.

Highlights:

- reduction in the use of physical restraint to zero
- every child accessing their full curriculum entitlement with coherent pathways, progress tracking, appropriate differentiation and range of accreditation
- positive, inclusive, capability-focused school culture
- sensory profiles regularly reviewed and used to inform curriculum delivery
- staff empowered as skilled professionals able to match strategies to positive and achievable goals.

Gina Davies

Gina Davies, specialist speech and language therapist

Autism spectrum conditions in a young child are confusing. The things we use to build relationships and nurture communication just don’t work as expected. The apparent lack of interest in doing the things we do with young children just for the fun of it, such as sharing a game of peek-a-boo or tickles and chatting as we play, makes it difficult to keep a natural flow of social communication going. People get confused, anxieties set in and confidence begins to falter.

What is needed requires some knowledge of how an autistic child learns differently, how things that may seem counter-intuitive such as using visually supported communication when the parents want the child to talk actually build a successful way forward for the child. Intervention needs to provide a practical and doable way forward that creates shared good times, fun in shared interaction and communication that works for building connections and relationships. Yet when things get tough and worries seem overwhelming, having fun and staying playful is difficult, even though we know these feature strongly in the learning of typically developing children. There is a feeling that quality intervention should be serious and hard work. Early intervention can be all of these things but to work it must appeal to the child and their family. Intervention that is enjoyed gets done with the intensity needed to be effective! We can inspire curiosity and offer irresistible invitations to learn. Our aim is to engage the child and share the skills with families so they are woven into the fabric of everyday life. Our objective? Joyful learners fascinated by the world we live in.
About the Congress

Autism-Europe’s international congresses are dedicated to sharing advances in the practical and scientific knowledge of autism to as wide an audience as possible, including autistic people, researchers, professionals and parents.

Autism-Europe’s 11th International Congress will focus on the most recent developments in the field of autism, including diagnosis, early intervention, treatments, education, support, employment, rights and policies, as well as many more.

The Congress will also cover the evolution of knowledge, rights and services for people with autism, as well as providing insight into future developments in knowledge and technologies for those on the autism spectrum, which may soon become a part of everyday life.

The conference will be held at the Edinburgh International Conference Centre (EICC). Situated at the heart of Scotland’s elegant and historic capital, the EICC is one of the world’s most outstanding venues for conferences, conventions and exhibitions.

To find more about the Congress and book your tickets, please visit: www.autism.org.uk/autismeurope

Register now for early bird prices!

Benefit from a discount on congress registration before the 30 April 2016!

Artists with autism take part in Autism-Europe’s 11th International Congress: submit pictures of your artwork

Participants of “Ilustrautismo”, an international art exhibition showcasing the work of persons with autism, will have the opportunity to see their creations shown during Autism-Europe’s International Congress in Edinburgh.

Since 1997, Spanish association Autismo Burgos (Autism-Europe member) has organised “Ilustrautismo”, which aims is to stimulate creativity and artistic expression among autistic people. In this edition, only digital photos of the works will be shown, as opposed to the originals.

The objective is to arrange a virtual exhibition in June 2016 on the association’s website. The general public will have the opportunity to see the works and vote for them on the internet prior to the Exhibition in Edinburgh. The works will then be presented on a slide during the congress.

Participation forms and digital photos must be sent to Autismo Burgos before the 30 April 2016. Works (paintings) must be original and unpublished. The number of works is limited to one per participant.

For further information about the Exhibition rules and how to participate, please visit (EN-ES): http://www.autismoburgos.es/vii-exposicion-internac-ional-de-arte-para-personas-con-autismo/
50 years improving the lives of all affected by autism

In November 2015, the Autism Society of America officially marked five decades of being the voice of families and individuals on the autism spectrum in the USA. When the organisation was founded in New Jersey in 1965, the autism community was very different than it is today: the term “autism” was not widely known, and doctors often blamed the condition on “refrigerator mothers,” or parents who were cold and unloving to their children – a theory that we now know to be completely false.

In 1965, about 60 people, mostly parents, met for the first time to talk with other parents about autism. Most had spent years and a small fortune obtaining a diagnosis, only to learn that no further help was available. The group realised more than ever before the need to have a national organisation that would work to seek out education and care for people with autism, one that would work for adequate legislation, research and publicity for their unique challenges. It was following this meeting that the Autism Society (then called the National Society for Autistic Children) was born. Nowadays, its efforts are focused on meaningful participation and self-determination in all aspects of life for individuals on the autism spectrum and their families.

Americans with Disabilities Act – 25 Years Later

In July 1990, US President George H.W. Bush signed the Americans with Disabilities Act (ADA) into law to enforce the right of every individual to realise their maximum potential without barriers to basic services and supports. With the passage of ADA, people with disabilities were guaranteed the right to fair hiring practices; access to state and federal state services and programmes; and reasonable access to public accommodations and commercial facilities under the law.

The commemorative campaign’s official slogan, “Advancing Equal Access”, is fully in line with the Autism Society’s stated goal of improving the lives of all affected by autism. “Discrimination against any person is wrong and we must be willing to label incidents of bias and confront them at all cost,” states Scott Badesch, current President/CEO of the Autism Society.

Looking ahead

50 years after the creation of the Autism Society, technological advances and a myriad of therapeutic options have drastically altered the quality of life of those with autism. Nevertheless, more must be done to ensure every individual on the spectrum has a chance to find a quality job and sufficient housing. “We remain steadfast in our quest to guarantee every person with autism can access employment and be fully integrated into communities. From city hall to Capitol Hill, the Autism Society and our nationwide network of affiliates will continue to advocate for programmes and services to help those living with an autism diagnosis to shatter low expectations and reach new heights”, states Badesch.

More information:
www.autism-society.org

Autism Society key dates:

1965: Dr. Rimland, together with 60 others, form the National Society for Autistic Children (NSAC) (renamed the Autism Society of America in 1987).
1969: NSAC plays a key role in vital legislative efforts such as Section 504, the Developmental Disabilities Act and the Education for All Handicapped Act (now known as IDEA).
1970: NSAC establishes an Information & Referral department to distribute information about autism.
1976: 400 people attend the first NSAC National Conference in Washington D.C.
1978: Temple Grandin is the first member-elected person with autism to serve on the Autism Society Board of Directors.
1999: The Autism Society launches the autism puzzle ribbon to promote international autism awareness.
2004: The Autism Society launches Autism Source, an online referral database of autism-related services and supports.
2015: The Autism Society reaches over 120,000 members and supporters.
The APEPA celebrates its 40th birthday: an alternative view of autism in Francophone Belgium

The APEPA (Association of Parents for the flourishing of people with autism – French acronym), is a non-profit organisation covering the whole of Francophone Belgium. It is made up of a mixture of dynamic volunteers, parents and grandparents of autistic people, as well as professionals. Ever since it was created, it has aimed to lobby public authorities on behalf of parents, while at the same time listening to their concerns and offering advice.

For 40 years now members of the Administrative Council have ensured that a permanent phone-in service is available, and contributed to organising discussion groups for parents. They facilitate the creation of associations and provide guidance on the procedures to follow, supporting private initiatives.

What does the APEPA do?

For a long time the APEPA has collaborated effectively within different advisory bodies: in the Walloon Council of Disabled Persons, in the AWIPH (Walloon Agency for the Integration of Disabled Persons) which in 2016 will be integrated as a branch of the AVIQ (Agency for a Life of Quality), and in the High Council of Specialised Education. The APEPA has taken part in the elaboration of a number of opinions and recommendations within these bodies as well as in national working groups, including the High Council of Health and the KCE (Federal Centre of Healthcare Expertise).

The APEPA is also a founding member of Autism-Europe, and of the non-profit organisation Participate! It is a member of the Platform for the Declaration of Disability, the Platform for the Inclusion of Children with Disabilities and Chronic Illness in Schools, the JABS platform (Young People with Specific Learning Needs – French acronym) and the League of Health Service Users. It is also present within the Madras service for persons whose parents are no longer able to provide care for them (Service Madras pour l’après-parents). The APEPA represents families at the Dialogue of Three Associations that it is part of, alongside the non-profit organisation Participate! It is a member of the Platform for the Declaration of Disability, the Platform for the Inclusion of Children with Disabilities and Chronic Illness in Schools, the JABS platform (Young People with Specific Learning Needs – French acronym) and the League of Health Service Users. 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XI Autism-Europe INTERNATIONAL CONGRESS 2016

16 September – 18 September 2016
Edinburgh International Convention Centre, Edinburgh, UK

www.autism.org.uk/autismeurope

Accept difference. Not indifference.