

# Link



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English Edition

## Autism - Europe

- European Days of Autism, 2011
- Legal capacity and the UN Convention
- New technologies: Advocating for accessibility
- Hiking in the alps with autism
- Passwerk cooperative - employment in technology



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# Editorial



Dear members,

In this issue we are passing the baton between two presidents, and we are pleased to introduce you to the members of the new Executive Committee of Autism-Europe, with representatives from all over Europe.



We look forward to working together to advance the rights of people with autism in Europe. We would also like to seize this opportunity to invite you to the Annual General Assembly of Autism-Europe and its related activities on May 4-6 2012, in Istanbul, Turkey. It will be a good opportunity to meet and network with other AE members.



We are delighted that the membership of Autism-Europe keeps growing. In this issue, you will find information about some of our new members from Denmark, Iceland and Italy.

The dynamism of our membership is reflected by the success of the last European Days of Autism, held across Europe in October, and with the Autism-Europe Council of Administration members in Prague, Czech Republic. The European Days of Autism 2012 will take place this October, in Lyon, France, and will be devoted to the issue of ageing. Indeed, 2012 is the European Year for Active

Ageing and Intergenerational Solidarity, and we think it is crucial to raise awareness of the specific challenges faced by elderly people with autism. We also recommend that our members echo this call to action across Europe.

Of course, World Autism Awareness Day on April 2, 2012, is the other important date for autism awareness in our yearly calendar. Once more, we are looking forward to working together to achieve more visibility for people with autism and to sharing with you the activities and events held on this occasion, in our next issue.

Information and communications technologies (ICT) are featured prominently in this issue. As many of you are aware, ICT devices can help improve accessibility and inclusion for people with autism. In the framework of the preparation of a European Accessibility Act by the European Commission, Autism-Europe has been advocating to make sure that issues related to communication are thoroughly taken into account when tackling accessibility barriers for people with disabilities. In that context, we are therefore glad to introduce to you various new ICT research projects in which Autism-Europe is now involved, and which aim at improving inclusion of people with autism. ICT is also an area of employment where people with autism can use their specific skills. The cooperative, Passwerk, is a good example of how people with autism can be included in the workplace and make full use of their potential.

We hope you will enjoy reading this edition, and look forward to receiving your comments and contributions to this magazine, which is intended to be a platform for exchanging experiences among AE members.

**Zsuzsanna Szilvasy** (President),  
**Evelyne Friedel** (former president and Vice-President),  
**Aurelie Baranger** (Director)

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Cover : 'In the library' artwork by Yolanda Manrique Pereira of Fundacion Menela (Vigo, Spain). This artwork won second prize in the fourth International Art Exhibition of People with Autism, organised by Autismo Burgos and Autism-Europe in Oslo, Norway, in 2007.

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## New leadership for Autism-Europe (2012-2015)

In 2012, Autism-Europe has a new President and Executive Committee who will lead the organisation through the next four years. New President, Zsuzsanna Szilvasy, will be accompanied by a committee that aims to reflect Europe's diversity, with most geographic regions of Europe represented. The new committee members bring a wealth of experience in advocacy for people with autism from across Europe.

### The new Executive Committee

#### President

Zsuzsanna Szilvasy, Hungary



Zsuzsanna has been involved in autism organisations, both in Hungary and at the European level, for the past seven years. Zsuzsanna was the president of the Hungarian Autistic Society for four years and has played a key role in advocating for the rights of people with autism

in Hungary, as well as providing advice to organisations and families about their rights and best practices.

She has been a member of the Autism-Europe Executive Committee since 2008.

Zsuzsanna currently works as manager of the Autism Help Centre in Hungary, a residential complex that also provides education for children and employment for adults with autism. She is also currently the Vice President of the Hungarian Autistic Society and is playing a central role in the organisation of the next Autism-Europe International congress that will be held in Budapest, Hungary, in 2013.

In addition to her work for Autism, Zsuzsanna is also the mother of a teenage boy with high-functioning autism.

#### Vice President

Evelyne Friedel, France



Evelyne has more than ten years of experience in advocacy for people with autism, both in France and at the European level. Her experience includes winning a collective complaint before the Council of Europe in 2002, in which France was found to have failed to fulfil its

educational obligations to people with autism.

Since 2005, Evelyne has played an important role in the national French association for the management of services and facilities for people with autism (AFG).

She has been a member of the Autism-Europe Executive Committee since 2003, and held the role of president from 2008 to 2011.

In addition to her voluntary work for autism, Evelyne is also the mother of a teenage boy with low-functioning autism and a partner of international law firm, Taylor Wessing, where she practices in European law.

## Vice President

**Harald Neerland, Norway**



Harald has more than ten years of experience in advocacy for people with autism in Norway. He has served as a board member of the Norwegian Autism Society for the past ten years, including two terms as president and one term as vice president. His roles

have also included representing people with Autism on government committees and projects. He is currently the chairman of the advisory group for the National Autism Centre at Oslo University Hospital.

Harald is a new member of the Autism-Europe Executive Committee.

In addition to his voluntary work for autism, Harald is also the father of a teenage girl with low-functioning autism and works as an engineering manager for an international manufacturer of oil and gas production equipment.

## Treasurer

**Claude Schmit, Luxembourg**



Claude has 20 years of experience in advocacy for people with autism. Since 1993, he has played significant roles as a board member and in the management of finances for several autism organisations in Luxembourg, including

Autism Luxembourg and the Association of parents of people with Autism, Luxembourg (APPAAL). He is currently also the president of Autism Foundation Luxembourg, a parents' association that he co-founded in 1996.

Claude has been a member of the Autism-Europe Executive Committee for 15 years.

In addition to his voluntary work for autism, Claude is also the father of an adult son with low-functioning autism and teaches engineering subjects at a high school.

## Secretary

**Maria Wroniszewska, Poland**



Maria has more than 20 years of experience in advocacy for people with autism. Maria has played a key role in improving the laws and services for people with autism in Poland. She has advised government departments and non-government

organisations, provided specialised training sessions, consulted with families and coordinated advocacy efforts with other autism organisations in Poland, including as a volunteer for 15 years. She is currently a staff member of SYNAPSIS Foundation, where she manages programs for employment and social integration of adults with autism.

Maria is a new member of the Autism-Europe Executive Committee.

In addition to her work for Autism, Maria is also the mother of an adult son with low-functioning autism.

## Many thanks to our former executive committee members

Autism-Europe would like to express our utmost gratitude for the dedication shown by outgoing committee members, Donata Vivanti and Michel Favre.

### Donata Vivanti

Donata has given endless support for the rights of people with autism for many years, through her roles in Autism-Europe and other organisations. Donata was a member of the Autism-Europe Executive Committee for 16 years. She held the role of president of Autism-Europe from 2000 to 2007, and vice president from 2008 to 2011. Donata also played an instrumental role as co-president of the organising committee for the ninth Autism-Europe International Congress that was held in Catania, Italy, in 2010. In addition, Donata has also represented Autism-Europe in her role as Vice President of the European Disability Forum (EDF - the umbrella organisation for all people with disabilities in Europe) since 2005. She will remain active in her role in EDF as well as in her role as Vice President of the Italian federation for autism, FANTASIA.

### Michel Favre

Michel has also been involved in advocacy for people with autism for many years. Michel was a vice president and member of the Autism-Europe Executive Committee from 2008 to 2011. He was also a member of scientific program committee for the last Autism-Europe International Congress in Italy. He is currently the President of French organisation, Pro Aid Autisme, and will play an active role in the next Autism-Europe International Congress that will be held in Budapest, Hungary.

# European Days of Autism, 2011

The 'European Days of Autism' have been held annually since 2007 to raise awareness about autism spectrum disorders (ASDs) and issues faced by people who have autism. The initiative also aims to foster cooperation among Autism organisations in Europe, because together we can achieve more.

In 2011, the European Days of Autism were marked by a range of events across Europe throughout the month of October, including conferences, exhibitions, concerts, fundraising events and high level meetings to engage government officials in support for autism.

Many organisations also took the opportunity to highlight the inequality of austerity measures being imposed on people with disabilities throughout Europe as part of the financial crisis. Autism-Europe has also echoed these concerns in the media.

## Autism-Europe members in Prague, Czech Republic

Forty representatives of Autism-Europe member organisations from around Europe went to Prague, Czech Republic, to participate in events to share knowledge and best practices. Events organised by Czech host organisation, APLA, included a high-level conference for a large audience of people with autism, families and professionals, and a roundtable discussion in which young adults with Asperger's syndrome talked about their experiences in education and employment.

Co-host, Autistik, organised a study visit to a community-based residential centre for adults with Autism. Autism-Europe's Council of Administration meeting was also held in Prague during the European Days of Autism.

## Belgium

APEPA, autism association for the Wallonia



\*1

region of Belgium, worked with other disability organisations to call on the government for greater action on the rights of people with autism.

The organisation also received a cheque from Miss Belgium as a result of fundraising activities that aimed to assist in supporting people with autism during the ongoing financial crisis.

## Hungary

The Hungarian Autistic Society spent the month of October lobbying their government for better support for autism in the context of the financial crisis.

They also held a conference for their own 'Autism Day' in November, which was attended by people living with autism, their family members and professionals.

## Luxembourg

APPAAL, a parents association in Luxembourg, published and distributed its annual report to all the hospitals in Luxembourg.



\*2



\*3

Images:

\*1 - Autism-Europe members in Prague, Czech Republic

\*2 - The conference organised by APLA

\*3 - Autism-Europe Council of Administration members at the study visit organised by Autistik





## Portugal

The Portuguese Federation for Autism celebrated its 40th anniversary at the same time as the European Days of Autism. Events included a music festival, an exhibition, a workshop and a seminar.

## Romania

Autism Romania also celebrated its anniversary – of 10 years – during the European Days of Autism, with a fundraising concert. The concert raised money for two projects; the development of a multipurpose centre for rehabilitation and social inclusion of young people with autism, and for an autism art and occupational therapy club.

Autism Romania also highlighted their concerns over austerity measures being imposed on people with disabilities as part of the ongoing financial crisis.

## Slovenia

In Ljubljana, the Center va Avtizem held their third 'Festival of Autism'. As part of the festival, the final conference was held for their 'ACE' project; a project to assist adults with autism from across Europe to establish friendships across borders.

The project also involved partner organisations from the United Kingdom, Romania and Estonia, as well as Autism-Europe, and it was funded by the European Commission.

## Spain

Autismo Burgos held an event to launch their new 'Azahar' software program. The program assists people with autism in communication, leisure and planning.

The software was developed with partner organisations from Spain and funded by the Orange Foundation. More information: [www.proyectoazahar.org](http://www.proyectoazahar.org)

## Ukraine

In the Ukraine, Child with a Future, an autism organisation, organised a high-level round table event called 'Autism exists in the Ukraine' to raise awareness and discuss the most urgent needs of people with autism with policy makers.

The event marked the first time representatives of the government ministries of health, labour and social policy had sat down together with doctors, international experts, parents and representatives of autism organisations. The meeting marked the beginning of greater cooperation around the issues faced by people with autism.

Images :

- \* 1/2 - Roumania  
Autism Romania staff and young people with autism at the concert
- \* 3 - Hongrie  
Autism-Europe President, Zsuzsanna Szilvasy, speaking at the conference
- \* 4 - Ukraine  
Participants at the round table event
- \* 5 - Espagne  
Autismo Burgos President, Simona Palacios
- \* 6 - Belgique  
APEPA team; Freddy, Michèle and Alice

# Legal capacity of people with autism

While the UN Convention outlines the legal rights of all people with disabilities, what happens when a person with low-functioning autism is not able to exercise these rights because they cannot speak, understand or communicate at the level required to discuss rights and legal matters? Lawyer, Evelyne Friedel, explains.

It is well known that autism covers a wide spectrum. This means that autism can affect individuals who are severely intellectually impaired as well as those who have an above average IQ level. Irrespective of their level of ability, all people with autism have the same rights and these rights must be applied and adhered to, effectively.

It is crucial to take into account the level of a person's impairment when legal rights, legal representation and assistance are at stake.

Legal rights, legal representation and assistance are notions to be understood and interpreted in light of Article 12 of the UN Convention on the Rights of Persons with Disabilities. Article 12 of the UN Convention reaffirms **equal recognition before the law** for all people with disabilities and underlines that they have an inalienable right to exercise their **legal capacity on an equal basis with others**.

The UN Convention adds that people with disabilities who need assistance in taking decisions shall be provided with a system of supported decision-making. The concept of supported decision-making is new to most jurisdictions, and should lead to the reform of guardianship systems.





### Article 12 of the UN Convention on the Rights of Persons with Disabilities:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that **persons with disabilities enjoy legal capacity on an equal basis** with others in all aspects of life.
3. States Parties shall take **appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.**
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for **appropriate and effective safeguards** to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.



## 1 - Equal recognition before the law and legal capacity

In accordance with the notion of 'equal recognition before the law', people with disabilities, including autism, have their status recognised in the legal order like all citizens. The notion of equal recognition enables them to hold, exercise and benefit from, equal and inalienable rights; irrespective of the nature and degree of their disability.

'Legal capacity' is a stronger notion, meaning that people with autism can not only effectively exercise and benefit from their rights, but also have the capacity to act.

## 2 - Support in exercising legal capacity

People with disabilities – autism in particular – might need support for exercising their legal capacity. To ensure the effectiveness of rights and the ability to exercise legal capacity, the UN Convention provides that people with disabilities have the right to receive support.

However, **maintaining the full legal capacity of an individual with a disability must always be at the centre** of the process when someone is supporting a person with a disability to make a decision or is delegated to make a decision on behalf of a person with a disability. Therefore, and in light of the UN Convention, due diligence must be applied in order to act in the best interests of the supported person.

Supported decision-making must always start from the **presumption of full and equal legal capacity** of people with disabilities, including those with severe and profound levels of disability.

The **concept of incapacity must be rejected**, and the degree of assistance must be tailored to the needs and abilities of a person, bearing in mind also that the degree of support required can vary from one situation to another for the same person. The assistance or support measures provided must be proportional to the degree of disability, and respect the right to self-determination as much as possible.

The role of a support person may vary from providing assistance with day-to-day matters with legal implications to support in formal legal representation. The specific support tasks totally depend on the wishes and the needs of the person with a disability.

A higher level of support may be needed for some adults with autism and severe intellectual disabilities who are unable to evaluate the consequences and implications of some of their actions (or inactions). Even



when an individual requires a high level of support in most, or all, areas of life including support in decision-making, States must take appropriate measures to ensure that the legal capacity of the individual is nevertheless enjoyed on an equal basis with others.

Regarding people with autism, the support in exercising legal capacity must not only be based on a personal knowledge of the individual, but also on the **knowledge of alternative and augmentative communication methods**.

The ability of some people with severe or profound disabilities to receive, process and send normal communication signals, like language or gestures for example, may be very limited or virtually absent. Some people with autism use verbal language in a non-functional way or need communication devices or specific techniques to relay their wishes.

In such contexts, States should recognise that all forms of communication are valid and the way people communicate should not be a reason to question their decision-making ability. States should therefore promote model projects and research into how supported decision-making can be implemented for people with severe disabilities and/or complex needs, such as people with autism.

## 3 - Selection of support people and prevention of conflicts

Support people should be **selected by the individual with a disability or his/her family, whenever possible**. It might be an advantage if the support person has known the individual personally for a significant period of time. In any case, the person with a disability should have the possibility to build a relationship of trust with his/her support person.

There should also be the possibility to assign several support people to one individual, particularly for people with severe and profound intellectual disabilities where a group of support people who know the individual in different capacities may better match all the support needs of a person.

In order to avoid conflicts of interest between a person with autism and their supporter, support people should never be linked to a psychiatric facility, governmental authority or a service provider on whom the person with a disability is dependent for some other purpose (for example, housing, education or health services).

In case any conflict arises, and to ensure accountability of support people, administrative procedures that are easily accessible for the supported person and their family should exist or be established.

#### 4 - Appropriate and effective safeguards

The UN Convention requires that **appropriate and effective safeguards be put in place to prevent exploitation and abuse in the exercise of legal capacity** by people with disabilities. This is particularly necessary for people with autism who need a high level of support in all areas of life and require such safeguards at all times.

The UN Convention adds that safeguards should be **proportional and tailored to the person's circumstances**. This means that safeguards must be higher for people with a more severe degree of disability or with high support needs, such as many people with autism. Safeguards must also be higher when major decisions regarding the life of the person are being made.

Safeguards might include: a procedure for careful assessment of the actual need for support, periodical re-examination of the support measures adopted and a mechanism for people with disabilities or their family members to make an appeal to change a decision that has been made. The safeguards must be separate from

the support mechanisms, as they should protect the person with a disability from any exploitation or abuse by supporters.

In addition, while maintaining their right to take decisions, **people with disabilities should also be protected from personal harm**. People with disabilities may take decisions which are not in their best interest, for example, giving money to others for unjustified reasons, purchasing goods that they cannot afford, or resigning from his/her employment. Support people therefore have a duty to inform the supported individual by all possible and appropriate means about the consequences of any important decision. States should also permit the cancellation of contracts in cases where a person was intentionally exploited or abused.

#### 5 - Other mainstream mechanisms

Allowing the cancellation of contracts in cases where a person was exploited or abused means that the supported decision-making system is not the sole measure to be put in place to protect people with disabilities.

**Mainstream mechanisms** such as consumer protection and information, rights of medical patients, and rights of employees, **should also be made more accessible and inclusive**.

States should ensure that these existing legal mechanisms for protecting citizens' rights in various areas of life are accessible to people with disabilities, accommodate their needs and take their interests into account.



# The emerging world of technology for autism

As any parent or person with autism knows, difficulties with information and communication present major barriers to everyday life. On these pages, we describe Autism-Europe's recent advocacy work at the European level in relation to accessible information and communications technologies (ICT) and we explore some exciting new software programs that are being developed for accessibility and inclusion.

## Advocating for accessible communications

Autism-Europe is currently advocating for more accessible information and communications for people with autism through consultations with the European Commission over the new European Accessibility Act. This new Act will contain measures to improve the accessibility of goods and services across Europe for people with disabilities. It could therefore have a great impact on increasing inclusion of people with autism throughout Europe.

Autism-Europe, along with the European Disability Forum, has highlighted to the European Commission that communication and accessibility of communications are major issues for people with autism. Barriers in communication affect their access to public transport, education, health services, workplaces, public offices and social activities. Communication barriers also hinder their access to information in general, including information on the internet and information about emergency services. There is currently a shortage of accessible texts in simple language and visual supports, as well a lack of assistance for people with autism in relation to communication. Autism-Europe therefore called for a thorough understanding of the needs of people with autism and measures in the new Act that will meet their needs.

'Accessibility' is defined under Article 9 of the United Nations Convention on the Rights of Persons with Disabilities (to which the EU is a party, along with its member states) as meaning that people with disabilities have access, on an equal basis with others, to the physical environment, transportation, information and communications (including via technologies), as well as other facilities and services.

## New possibilities from technology

Nowadays, accessibility can also be achieved with the support of information and communications technologies (commonly referred to as ICT). Technological devices and computer software can even offer the kind of predictability and structure that people with autism spectrum disorders tend to prefer. In fact, new employment opportunities are even being developed in the computer industry for some people with autism due to their unique systemisation skills that can be an advantage in this field (for example, see the article on Passwerk Cooperative on pages 14 and 15).

Autism-Europe has become involved in several projects which utilise technology for people on the spectrum. In the last edition of LINK, we reported on a project that used Facebook to help adults with autism develop friendships. We have also recently begun work with technology partners on two new software projects that are described on the next page...

Stay tuned! Upcoming editions of LINK magazine will feature more updates, information and discussion about new technologies for people with autism...

## Conference

### Technology and Autism: Tools, Trends and Testimonials

Valencia, Spain, July 6-8, 2012

This conference will present the latest research in the field of autism and technology, including demonstrations of new products. It will also provide an opportunity for parents and people with autism to come together with researchers and software developers and network, give feedback and participate in a forum to discuss the future of the field.

The conference is co-sponsored by Fundación Orange, Fundación Adapta and Autism Speaks.

Registration costs have been kept low (people with autism €60, parents €100 and professionals €140). Registrations are due by July 1, 2012, and discounts are available for those who register early.

More information can be found at: [www.itasd.org](http://www.itasd.org)



# Software of the future for people



The following software programs will soon be available for people with autism...

## 'Open Book' software to simplify text and documents

The Open Book program will translate documents and text into a simplified format that is easier for people with autism to read and understand. As people with autism often have difficulties in understanding long sentences, complicated concepts, metaphors and other expressions, the software aims to assist in making information more accessible. The software will also provide images to aid understanding of words and concepts, and allow users to personalise the translations to their own level of reading and comprehension ability.

This program is being developed by the 'FIRST' project as part of a European Community-funded research project. As a partner in this project, Autism-Europe will work with universities, technology companies and other autism organisations\* from around Europe to develop the software over the next three years. The software is expected to be available in English, Spanish and Bulgarian in late 2014.

More information on the FIRST project can be found at: [www.first-asd.eu](http://www.first-asd.eu)



## 'ASC-Inclusion' games to help children understand and express emotions

ASC-Inclusion interactive computer games will help children with autism to understand and express emotions through facial expressions, tone-of-voice and body gestures.



This software is being developed by the 'ASC-Inclusion' project. Autism-Europe is also a partner in this European Community-funded research project which also involves universities, technology companies and other autism organisations\* from around Europe. The games will be developed over the next three years and are expected to be available in English, German, Hebrew, Italian and Swedish in late 2014.

More information on the ASC-Inclusion project can be found at: [www.asc-inclusion.eu](http://www.asc-inclusion.eu)



## 'iSpectrum' software to help adults gain skills for employment

Another new educational computer game that is being developed for people with autism is the iSpectrum program, which will assist adults to gain skills for employment.



Currently getting close to completion, iSpectrum will enable people with autism to participate in virtual work environments in the fields of retail, office administration and gardening (which are common vocational fields of employment for people with autism).

The 'serious game' is being developed with advice from professionals in the field of autism, employers and people with autism who will use it. It aims to promote the understanding of social relations, conversation skills and dealing with abstract concepts in relation to getting a job and working with other people.

The game is being developed by a research consortium of companies and universities from around Europe and is funded by the European Commission's Leonardo Lifelong Learning Programme.

The game will be available in English, German, Italian and Bulgarian and will be accompanied by an online training course for practitioners in the field of autism. The game and training course will be available online in April and will be free to use during the software development project, which lasts until the end of 2012.

More information on the iSpectrum project can be found at: [www.ispectrum.eu](http://www.ispectrum.eu)

\* The other partner organisations of the FIRST project are: the University of Wolver-



Images: from the iSpectrum software program.

# le with autism

hampton (UK), Kodar Ltd (Bulgaria), Central and North West London NHS Foundation Trust (UK), iWeb Technologies Ltd (UK), Deletrea, s.l.p. (Spain), Universidad de Jaen (Spain), Parallel World Sdruzhenie (Bulgaria) and Universidad de Alicante (Spain).

\* The other partner organisations of the ASC-Inclusion project are: Technische Universität München (Germany), the University of Cambridge (UK), Bar-Ilan University (Israel), Comedia (Israel), Università degli Studi di Genova (Italy) and Karolinska Institutet (Sweden).



The research leading to the ASC-Inclusion and Open Book software programs has received funding from the European Community's Seventh Framework Programme (FP7, 2007-2013), under grant agreement numbers 289021 and 287607. The research lead-

ing to the iSpectrum software product has received funding from European Commission's Leonardo Lifelong Learning Programme.



## Invitation to the 2012 Autism-Europe Annual General Assembly

**Istanbul, Turkey**  
**May 5, 2012**

In accordance with the statutes of our organisation, we are pleased to invite you to attend the Autism-Europe Annual General Assembly, which will take place in Istanbul, Turkey, in the afternoon of Saturday May 5, 2012.

### Agenda of the meeting:

- Presentation of the executive committee report;
- Presentation of the activity report 2011;
- Presentation of the financial report 2011;
- Presentation of the work programme 2012.

The meeting will be followed by the Autism-Europe Extraordinary General Assembly

Evening: social dinner

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

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

### Additional events:

#### Roundtable discussion & study visit

On Friday 4 May, a round table with members of the Turkish Asperger association and a study visit of a school will be organised by our Turkish member, Todev.

#### Autism-Europe Council of Administration meeting

The Autism-Europe Council of Administration meeting will also take place, in the morning, on Saturday May 5 and Sunday May 6, 2012.



Image : The Blue Mosque, Istanbul. Photograph by Daniel Bouwmeester

# Belgian cooperative employs the unique skills of people with high functioning autism

**Passwerk, a cooperative launched in 2008 in Antwerp, combines business with social responsibility to train, employ and coach adults with autism in computer software testing.**

Passwerk was inspired by Specialisterne, a similar organisation in Denmark. At Passwerk, after individuals have been carefully recruited for the software testing jobs (such as functional testing, and in particular, regression testing), the employees are offered committed professional development. Passwerk adjusts as an employer to meet their abilities, strengths and competencies, offering a well adapted workplace. Not only does Passwerk offer vocational skills development, but employees are also coached in developing the necessary social skills to function appropriately in a work environment more generally. It is central to Passwerk's mission that employees are empowered and supported to fully participate and integrate in contemporary society.

Passwerk's IT testing services are then offered to a variety of customers. Passwerk explicitly profiles itself as a company with trained test engineers who have autism, and go out on location, to customers' offices to conduct their work.

## Passwerk staff testing access gates in Brussels metro stations

In 2011, four Passwerk staff members completed a project for the Brussels department of public transport – STIB – testing software and electronic chips for the access gates in metro stations around Brussels. Kris Lauwers, STIB Deputy Managing Director, was impressed by the speed and efficiency of their work, saying he considers this initiative as “relevant both at societal and economic levels”. The STIB is now considering further collaboration with Passwerk.

## Governance

Passwerk CVBA (a limited liability cooperative) receives sponsorship from a variety of businesses, to varying degrees. There are currently three groups of shareholders in the company: IT companies (A shareholders), autism organisations (B shareholders) and other shareholders (D shareholders).

An Advisory Board to the company was set up in April 2009, to allow Passwerk to stay in touch with clients and top managers in the field, and respond to the changing needs of their market. Some Advisory Board members come from major banks and businesses (full list of Board members can be found on the Passwerk website).

## Major values of the cooperative

**Care for people** – Diversity is acknowledged and utilised in the company. Individuality is utilised for the good of the cooperative and its customers. Each employee is judged on their own abilities and the employer seeks to adapt to these. Communication styles and training are adapted to allow each employee to reach their potential. The wider social environment is also respected.

**Care for business performance** – When employees feel good, they perform better. With personalised training and development plans, employees are able to achieve excellent professional outcomes.

**Care for development** – There is an emphasis not only on professional development of employees, but also social and personal development. Again, the methodology used to achieve this is tailored to the individual.



\*1



\*2

## More about the services offered

Passwerk offers functional ICT testing (including installation and regression testing) and non-functional testing (such as performance and usability testing). Test engineers are all given basic training with a view to gaining ISTQB certification. Further professional training is then offered; adapted to the learning styles of the employees.

## Why might a customer be interested in using this service?

People with autism have a tendency towards being thorough, precise and accurate in their work. Sources suggest that there are high numbers of people with autism who show high functioning abilities. Passwerk employees are rigorously recruited with interviews, competency tests, assessments and consultations. Passwerk does not use employees with autism to arouse feelings of charity or sympathy in customers, instead it is out of a conviction that these people have attributes that are incredibly valuable to this field. Employees work in an environment specifically designed to bring out their best qualities and commitment. Therefore, customers using Passwerk can gain both a highly professional and accurate software testing service, along with the added bonus of a social commitment.

Where the limitations associated with an employee's autism preclude them from being able to carry out a given task, then other employees contribute. Passwerk employs 'job coaches' who step in at such times and work closely with the employees who have autism. There is one job coach for every seven employees. They act as an extension of the Passwerk employees; a first point of contact for both employees and customers.

IT companies sometimes find it difficult to place Passwerk within the spheres of their social responsibility and their economic framework, as the two concepts are often viewed and treated as being so fundamentally different. For this reason, Passwerk works in the 'convergence market'. This means that Passwerk combines both business and social dimensions and offers this as an added value to its customers. This is a revamped concept for socially responsible organisations (SROs). Passwerk represents a careful and sustainable business and hopes to inspire other organisations to start on a similar path of employing people with disabilities.

To find out more, and for contact details, go to [www.passwerk.be](http://www.passwerk.be)

The name 'Passwerk' was chosen as it comes from the Dutch abbreviation 'ASS' for autism spectrum disorder. The logo was designed by Bart Van Roy, who has autism. The 'A' resembles a door that a person is looking through, representing the opportunity Passwerk offers its employees. The horizon symbolises future prospects and wider opportunities offered to these employees.



\*3

Images:  
 \*1 - Passwerk staff at work in a Brussels metro station  
 \*2/3 - Passwerk staff at work in the office

# In the Alps with autism

**Bettina Bönsch, Autism Germany**

**Last year, a small group of Germans with autism challenged themselves with a week-long hike in the Austrian Alps.**

In early summer 2011, Autism Germany organised a hiking week in the Austrian Alps. The destination was a small mountain village in the Hohe Tauern National Park. Spending time in the mountains makes some quite exceptional experiences possible: getting close to the mountains and the mountain air, clear water, cliffs, alpine plants, minerals, pastures, agriculture and... facing your own challenges while hiking. There were lots of practical things to organise - Which paths guarantee safe hiking? How fit are the hikers? Can they all cope with a tunnel or a cable car ride? When is each mountain hut open? What do we do if it rains for a long period of time?

Several of the hikers wrote a great deal about their experiences. Let me introduce them to you:

- Sabine Gaevert, who lives in a small town in Thüringen and was given the trip as a 40th birthday present from her friends and colleagues;

- Jan-Henning Schoch, who has worked for 20 years in the parks and gardens department of his home town and is an ambitious endurance sportsman; and

- Christopher Wagner, who is particularly interested in geography, and works in a workshop for people with disabilities.

## The following report is taken from their diaries...

The starting point was in Munich - everyone arrived punctually, with excitement written on their faces. Some already knew each other from earlier trips, some came alone and others were accompanied by a parent. Jan-Henning wrote:

"I travelled on the 29th of May to Munich and arrived in the service pavilion [of the central railway station] in the early afternoon, one hour before the arranged meeting time. From there, we travelled to the village of Mallnitz [by minibus]. As we entered into the Alps region I was fascinated by the sight of the impressive mountain scenery with glaciers and mountain streams. However, as a habitual early riser, I did have some difficulty changing my sleeping habits. The next morning, we started with a walk to discover the local area. We saw mountain plants, clear mountain springs with rare fish, and free roaming cows."





Indeed, on the first day of our trip we had the most wonderful weather. We enjoyed a light walk through the valley to acclimatise and a nature trail nearby seemed like the perfect opportunity. As we walked, we also marvelled at the moss-covered boulders, uprooted trees, rare flowers, mountain springs and waterfalls and an ice cave.

Our second destination was partly covered in snow, but the sun was shining and we could make a trip into the mountains. Sabine reported:

"We drove to Maltatal. We had to drive around lots of bends. We saw lots of mountains on the way; we were 2000 metres up. We drove through tunnels. There were lots of bends driving up from the valley, up and down.... There weren't any forests up high; no trees. We were in the bright sunshine all day... After a break we looked at the Osnabrücker Hütte [a historic hut]. It opened on the 1st of June. We had to wade through water. We met hikers on the way. We drank coffee and ate apple strudel. We saw gentian flowers and wonderfully varied rock formations, as well as Kärnten's biggest waterfall."

After that, it seemed wise to have a break from hiking. Christopher wrote:

"On the third day, Wednesday, we went by train to Spittal, where we spent almost the whole time in the local museum. We watched simulated flights over the alps on a big screen and panoramas of the Kärnten area on the floor. We had to put pumps [textile footwear] on, then we could see 3D pictures of Kärnten and an exhibit of the lifestyle and work of the local people in the 19th century. We got leaflets from there. At the end we had cake and tea or coffee, and juice. The cake speciality, with nuts, was from the local area. Then back again with the train."

The fourth day left many of us with the impression: "hiking uphill is exhausting!" However our efforts were well repaid with views of the valley and some lovely Kaiserschmarrn [a traditional dessert]. Christopher's report is more down to earth:

"On Thursday, the only day without a bus trip, we spent two hours in an inn for lunch. Two hours there and two hours back. I was so tired that I had to lie down until supper."

The request for the last day's activity came from one member of the group and was as short as it was clear: "train ride!". Said, done. The Risseck-Bahn [a cable railway] took us up 2200 meters in cable railway cars. With butterflies in their stomachs, everyone really enjoyed the view. Sabine wrote:

"We rode almost one hour with the train. At first we wanted to go for a hike. After a few metres it began to rain heavily. We escaped to a nearby inn, where we had food and hot drinks to warm up. After that we did go for a hike. There were lots of stones that invited us to build little mountains, and we had a wonderful view over the valley and of the clouds that were climbing out of it."

The heavy rain wasn't forecasted, but it can happen very suddenly in the mountains. Whilst at the inn we all crowded around the fire and warmed ourselves with tea. And, somehow, such experiences are all an integral part of hiking in the mountains! Then, all too soon, we were packing our cases, writing our last diary entries, and saying goodbye to the mountains.



The next day, we all loaded ourselves into the minibus after breakfast. Jan-Henning summarised the week:

"I personally had limited freedom within the context of my wishes (limited time on the mountains and long distance walks), however, as part of the group I had many experiences and much proficient communication [about autism and lifestyle]... I could largely remove most of my stereotypes and compulsions. So, I hope that other trips of this type will be possible".

So all that is left for me to say is thank you to our hosts... 'til next time!

More information:  
[www.autismus.de](http://www.autismus.de)

# GAUTENA

## GAUTENA's new housing and temporary accommodation service in San Sebastián

After four years in the making, GAUTENA, one of our member associations based in the Gipuzkoa province of the Basque Country (Spain), opened a new housing service for adults with Autism in early 2011.

The housing service is based in a large detached house built on a 1,516m<sup>2</sup> plot of land granted by the San Sebastián City Council. It is located in a nice, low-density residential area. The building is divided into two independent dwellings, each with room for six residents.

In total, the building has three floors and a total covered surface area of 1,113 m<sup>2</sup>. The lower-ground floor measures 496 m<sup>2</sup> and houses the garage, laundry room, warehouses and staff changing rooms and toilets. The ground floor, where the two dwellings are located, measures 415 m<sup>2</sup>. Each dwelling has a kitchen, dining room, sitting room, two bathrooms and six bedrooms, as well as large south-facing porches. Finally, the top floor measures 202 m<sup>2</sup> and contains two large rooms used as recreation and workshop areas for the residents, as well as a utility room and an office for the service coordinator.

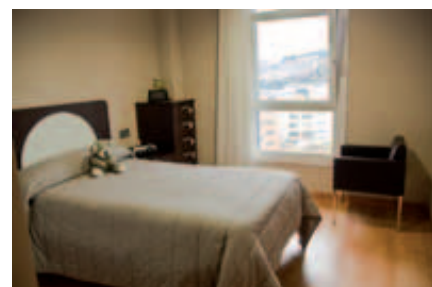
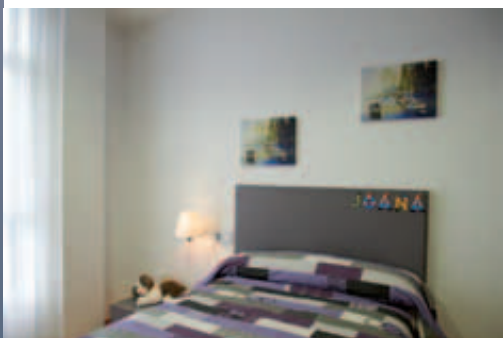
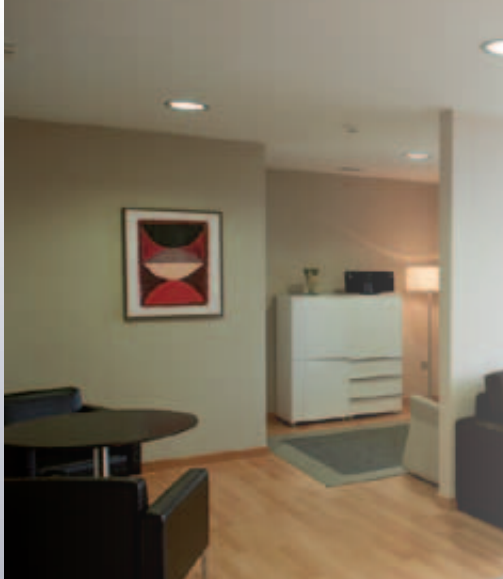
The building is also located close to a day centre for people with Autism which is likely to benefit some residents.

The new housing service, including all the furniture, equipment and fittings, cost 1.9 million euros. The Gipuzkoa Provincial Council's Social Policy Department funded 75 per cent of the cost, while the remaining 25 per cent was covered by the Kutxa bank's social works fund. In addition, the ONCE Foundation also collaborated in the purchase of the equipment.

Thanks to this service, GAUTENA has increased its offer of sheltered housing places to 69 people, and has also estab-

lished a special service providing temporary accommodation to six people. The aim of this service is to provide temporary accommodation throughout the year for a number of different purposes, including weekend stays, weekday stays, interventions during crises and mid-term stays. This service is expected to benefit around 100 families.

For more information, visit:  
[www.gautena.org](http://www.gautena.org)  
and [www.donostia.org](http://www.donostia.org)





# Creating a sustainable community life for adults with autism in Italy

**In just three years, Fondazione Oltre Il Labirinto Onlus has evolved from one parent's concern for his son's future to the creation of a sustainable village for adults with autism in the Italian province of Veneto.**

It all began when the organisation's founder, Mario Paganessi, realised that there was no clear strategy for the future of children with autism in his region. He met with a small group of other parents and together they established a foundation to make services available for their children, both now and in the future when their parents are unable to care for them anymore.

The foundation's current project – its greatest vision – is a housing project for adults with autism called 'Villaggio Monica Migotto'. This project, however, goes beyond the scope of most supported housing projects for adults with autism. In fact, it is more of a whole village than just housing. It will provide housing for 15 adults with autism, as well as employment and training activities.

The activities that will provide employment for the residents will include a working farm, food store, market, bakery, restaurant, bicycle hire and a campervan parking area for tourists. Some adults with autism will be able to fully earn their own living, while others (due to the severity of their autism) will make a modest contribution to their personal needs. These enterprises will also make the village financially sustainable.

The foundation is determined to ensure that the village will not be a 'golden ghetto'. The residents will regularly interact with two local communities, in Pederobba and Cavaso del Tomba, including while they are at work in the village's commercial activities.

Villaggio Monica Migotto is named after one of the founding members of the organisation, a mother of a child with autism who died recently after a long illness.

The village is currently under construction. The first building opened in 2010 and the rest of the village is expected to be completed in 2014.

## Other services

Fondazione Oltre Il Labirinto Onlus (in partnership with other Italian autism organisations) also provides a wide range of services for children with autism and their families. These include a home-based education program for parents, independent living skills training for adults with autism, a program using iPads for communication and education, the 'Superability' course (a comprehensive approach to education for people with autism to develop skills in independent living), swimming lessons and other water-based recreation activities, excursion days in aquatic theme parks and Summer camps. Training



courses are also provided for professionals, including ABA therapy and specialised swimming teacher training.

The foundation's members include local autism associations as well as parents, relatives and friends of people with autism. The board is comprised mainly of parents, experts in the field of autism and representatives of other autism associations.



More information:  
[www.oltreilabirinto.it](http://www.oltreilabirinto.it)

**This organisation is now an affiliated member of Autism-Europe**



Images:

\* 1 - Fondazione Oltre Il Labirinto Onlus activities

\* 2 - The first completed building at Villaggio Monica Migotto

\* 3 - The first completed building at Villaggio Monica Migotto

# Lifelong approaches to

## The Icelandic Autistic Society

**The Icelandic Autistic Society (IAS) - called Umsjónarfélag einhverfra in Icelandic – has improved support for people with autism throughout the country, and now even provides training and employment.**

Since the Society was established in 1977 by parents and carers to get better schools and homes for their autistic children, much has been accomplished. The Society has made all possible efforts to protect the rights of, and improve services for, people with autism across Iceland.

In the 1990s, the Society's work led to the appointment of a committee to discuss the future of services by the Icelandic Ministry of Social Affairs. The committee, which included two representatives from the Icelandic Autistic Society, completed its work in 1996 to provide better diagnostic services, better housing and improved school services (in both mainstream classes and special classes).

Last year, the Icelandic Autistic Society - along with 7 members of the Society - founded the company 'Specialisterne ses'. Specialisterne is a software testing company that trains and employs people with autism spectrum disorders (ASD). It is based on the model of a Danish software testing company (also called Specialisterne, see our article in LINK n° 52), launched by a man named Thorkil Sonne, which trains and employs adults with autism. The Icelandic Specialisterne aims to train between 14 and 18 individuals with autism each year and to seek jobs for them in the open market or within the company.

The Society now has 660 members (including parents and relatives, people with ASD and professionals), and their goals are:

- to ensure the rights of individuals with ASD in our society are upheld;
- to ensure that they are provided with adequate services, such as diagnosis, education, employment, housing, hobbies and various other forms of support.

The Society provides 7 support groups for parents that meet once a month across the country, as well as groups for teenagers and adults with Autism.

There are also Summer programs for teenagers with autism, in which groups of 10 to 12 teenagers meet with four tutors who run activities such as visits to companies, making short films, cooking lunch together, going swimming and climbing.

During Winter a series of free lectures are given by professionals in the field of autism who inform parents and other professionals about topics relevant to autism such as the school system from kindergarten to college, standards for housing and services, pharmaceutical treatments and sensory issues, among others. and so forth.

The Society is governed by a board of five people, of which the chairman is always a parent and the majority of board members must be parents or relatives of individuals with autism.



The Icelandic Autistic Society is also an active member of the Organization of Disabled in Iceland and the National Association for Intellectual Disabilities.

More information:  
[www.einhverfa.is](http://www.einhverfa.is)

Images:

\*1 - The Board of Umsjónarfélag einhverfra (the Icelandic Autistic Society) (left to right): Sigríður Sigurjónsdóttir, Eva Hrönn Steindórsdóttir (leader of the board), Guðrún Ólafsdóttir, Ásgeir Sverrisson and Ari Ingólfsson.

\*2 - Hjörtur Grétarsson, former leader of our Board who began the Specialisterne company in Iceland and Eva Hrönn Steindórsdóttir, current leader of our Board, with Thorkil Sonne, founder of Specialisterne in Denmark, at the opening of Specialisterne in Iceland on April 2, 2011.

**This organisation is now a full member of Autism-Europe.**



# Autism

## The Danish Autism Society

As the Danish Autism Society (Landsforeningen Autisme) enters its 50th year, their whole-of-life approach to supporting people with autism may provide inspiration to other autism organisations around the world.

Founded by parents in 1962, the organisation began by removing children with autism (then a newly recognised and rarely diagnosed condition) from institutions and providing them with appropriate housing. As the original children have grown older and require different forms of assistance, the Society has grown up with them. In order to provide lifelong support, the Society worked with the National Board of Social Services to create a 'National Autism Plan' which was published in 2008.

The Plan adopts a lifelong approach, providing guidelines for best practices in diagnosis, care and treatment for people with autism in all stages of life from infants to the elderly.

Today, the Danish Autism Society now supports more than 8,000 families in a range of programs and 600 children and teenagers in youth-specific programs. The Danish Autism Society continues to facilitate and create new housing, schools and residential centers for people with autism, always holding a position on the board of the new institution to ensure that best practices, based on ethics and evidence, are adopted.

The Society recently ran a special project to provide 16 low income families with a much needed five-day holiday over Christmas. The children received Christmas presents, food was prepared for them and activities were provided. Those who attended had the option to socialise with other families or just spend quality time with their own family group.

The Society's 'Girl project' provides a social club for teenage girls with autism, in which they meet once a week to learn social strategies and do creative activities with a team of highly skilled volunteers. Last Spring, the Danish Autism Society's royal patron, Princess Marie, visited the girls in the project.

Her Royal Highness took the time to talk to each of the girls, ensuring that each girl felt special. After the visit, one of the girls said: "It was really cool having Princess Marie visit us, in some way it tells me that I am worth something; that I am important too."

A new national 'Girl Network' will also be launched in 2012 to bring teenage girls with autism together to talk with, and learn from, older women and mothers. The network will be internet-based and participants will also have the opportunity to meet in person twice per year at conference-style events where they will also hear talks from prominent women and experts on autism.

The Danish Autism Society also runs courses all over Denmark for parents, siblings, grandparents, professionals and volunteers. It holds an annual conference called SIKON, for more than 1200 parents and professionals from around the world. Every third year, an international science conference called 'Meeting of Minds' is also held, in conjunction with the Danish Social Ministry and the Collaboration of Special Schools.

For more information go to:  
[www.autismeforening.dk](http://www.autismeforening.dk)  
 and or contact:  
[heidi@autismeforening.dk](mailto:heidi@autismeforening.dk)

Images:

\*1 - Participants in the 'Girl project'

\*2 - Princess Marie visits the Girl Project and one of the girls had made her a gift: a blue Manga cat.

\*3/4 - Participants in the 'Girl project' with Princess Marie



This organisation is now a full member of Autism-Europe.

# MEMBER ASSOCIATIONS OF AUTISM-EUROPE

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(national associations of parents of people with autism)

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