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Our campaign: Autism and work. Together we can.

> Screening procedures for earlier diagnosis

Advocacy for autism with the EU institutions

Making tourism accessible in the EU

Staying safe on social media

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Edito



Dear friends,

In 2014, in partnership with the Institute for International Legal Studies of the Italian National Research Council, Autism-Europe has focused our work on the theme of autism and employment. During the year, two reports focusing on the practical, political and legal aspects of this theme were produced. The first, titled 'Autism and Work. Together we can' focuses on good practices in the field of employment for people with autism from Europe and across the globe. The second, titled 'Protecting the rights of people with autism in the fields of education and employment: International, European and national perspectives' provides insight into policies and legislation related to education and employment of people with autism. We hope that our members and readers will find these reports, as well as the highlights of our campaign on autism and employment which you will also find throughout this magazine, to be useful and inspiring sources of information.

The past year has also seen the election of 751 new representatives in the European Parliament and the appointment of the new members of the European Commission. Hence, we have taken the opportunity in this edition of LINK to highlight the role of the various political institutions of the European Union and the many ways that Autism-Europe works to influence them to reinforce the rights of people with autism.

As many of you know, much of Autism-Europe's work is based on the United Nations Convention on the Rights of Persons with Disabilities. In 2015, the implementation of the Convention in the European Union will be examined by the CRPD committee of the United Nations. Autism-Europe will be following this process closely and will keep you informed of the results.

Finally, we also extend an invitation to all of Autism-Europe's members to attend our next Annual General Assembly meeting which will be held in Barcelona on May 2, 2015.

We wish you all a wonderful new year and thank you for your continued support. As the new year begins, we also hope that it will bring positive news and developments for people with autism around the world!

Yours sincerely,

Zsuzsanna Szilvasy President Aurélie Baranger Director

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Our campaign: Autism and work. Together we can.

Since 2014, Autism-Europe has been running a campaign to raise awareness of the rights and abilities of people with autism in relation to employment. On these pages, we highlight the year's campaign activities.

The campaign in brief

Autism-Europe's 'Autism and work. Together we can.' campaign has aimed to raise awareness of the rights, abilities and needs of people with autism under Article 27 (Employment) of the United Nations Convention on the Rights of Persons with Disabilities.

The urgent needs of people with autism across Europe include:

- Education People with autism need access to lifelong education, adapted to their needs, higher education and vocational training;
- Jobs Studies show that between 76 and 90 per cent* of adults with autism are currently unemployed;
- **Recognition of their unique skills** People with autism can have unique skills that may be harnessed to produce a high quality of work, making them a valuable asset to their employers;
- Investment Education, training and employment initiatives for adults with autism are investments that require both public and private funding;
- Social inclusion People with autism often suffer from social exclusion. Education and employment can enable them to take more active roles in their communities, rather than being dependent on family and social support.

* Statistics from the National Autistic Society (United Kingdom), Autism Speaks (United States) & Specialisterne (multiple countries).

Autism-Europe releases new reports on autism and employment



Autism-Europe has released two reports on autism and employment, providing comprehensive information on this topic.

The first report, titled 'Autism and work. Together we can. A report on good practices in employment for people with autism from across Europe.', outlines good and emerging practices in the field of autism and employment. It provides a foundational guide for everyone working towards the goal of employment for people with autism,

including their families, autism professionals, employers and policy-makers.

The second report, titled 'Protecting the rights of people with autism in the fields of education and employment: International, European and national perspectives' published under the supervision of the Institute for International Legal Studies of the Italian National Research Council (CNR) provides insight into policies and legislation for autism.

More information:

www.autismeurope.org/publications/reports-and-good-practices



AUTISM AND WORK. TOGETHER WE CAN.

😳 World Autism Awareness Day | April 2





World Autism Awareness Day

On World Autism Awareness Day this year, Autism-Europe members conducted a common campaign to raise awareness across Europe about the potential and needs of adults with autism in the fields of employment and education.

At least 17 of Autism-Europe's member organisations from 13 countries participated in the campaign, using campaign materials prepared by Autism-Europe, such as press releases, feature articles, graphic banners, posters, images and social media contents.

The President of the European Parliament, Martin Schulz, expressed his support for Autism-Europe's campaign through Twitter, calling for innovative employment opportunities for people with autism. His support was followed by tweets in 21 languages from the European Parliament, helping us to raise awareness throughout Europe.

More information:

www.autismeurope.org/activities/worldautism-awareness-day/

Conference on autism and employment, Turin, Italy



Turin, Italy

In November 2014, Autism-Europe held a conference titled 'Promoting equal rights for people with autism in the field of employment and education', in Turin, Italy, which was attended by over 100 people.

The conference included presentations on the employment rights of people with autism under the United Nations Convention on the Rights of Persons with Disabilities, national plans and strategies for autism in the EU Member States, Autism-Europe's campaign and presentations of various initiatives for the employment of people with autism from across Europe. A special address was also given by a representative of the Italian Presidency of the European Union.

The conference was held in conjunction with Autism-Europe's regular Council of Administration meeting and a study visit to the premises of cosmetics company, L'Oréal, which has recently begun a programme to train and employ people with autism.

More information:

www.autismeurope.org/espace-membre/ member-meetings/

United Nations Convention on the Rights of Persons with Disabilities Article 27 – Work and employment



- States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities. States Parties shall safeguard and promote the realization of the right to work, including for those who acquire a disability during the course of employment, by taking appropriate steps, including through legislation, to, inter alia:
- a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions;
- b) Protect the rights of persons with disabilities, on an equal basis with others, to just and favourable conditions of work, including equal opportunities and equal remuneration for work of equal value, safe and healthy working conditions, including protection from harassment, and the redress of grievances;
- c) Ensure that persons with disabilities are able to exercise their labour and trade union rights on an equal basis with others;
- d) Enable persons with disabilities to have effective access to general technical and vocational guidance programmes, placement services and vocational and continuing training;
- e) Promote employment opportunities and career advan-

cement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment;

- f) Promote opportunities for self-employment, entrepreneurship, the development of cooperatives and starting one's own business;
- g) Employ persons with disabilities in the public sector;
- h) Promote the employment of persons with disabilities in the private sector through appropriate policies and measures, which may include affirmative action programmes, incentives and other measures;
- i) Ensure that reasonable accommodation is provided to persons with disabilities in the workplace;
- j) Promote the acquisition by persons with disabilities of work experience in the open labour market;
- k) Promote vocational and professional rehabilitation, job retention and return-to-work programmes for persons with disabilities.
- 2. States Parties shall ensure that persons with disabilities are not held in slavery or in servitude, and are protected, on an equal basis with others, from forced or compulsory labour.

Highlighting good practices in the field of autism and employment

A major aspect of Autism-Europe's campaign in 2014 has been to highlight good and emerging practices in the field of autism and employment. Here we highlight two case studies from Autism-Europe's report, titled 'Autism and work Together we can. A report on good practices in employment for people with autism from across Europe.', that provide inspiring examples for other organisations to follow.







Design and printing by people with autism

PASPARTA, Czech Republic

Autism-Europe's report, titled 'Autism and work. Together we can. A report on good practices in employment for people with autism from across Europe.', has been designed by people with autism working at PASPARTA in the Czech Republic.

PASPARTA Publishing is a social enterprise founded by the autism organisation, APLA Prague, in the Czech Republic. Its



objective is to offer employment opportunities to people with autism in an adapted environment where they can make use of their unique skills. PASPARTA publishes books on education, special needs education, sociology, law and other topics.

Changing attitudes and overcoming stigma

Kuwait Center for Autism, Kuwait



It is not only from Europe that we can find good practices emerging in the employment of people with autism. The Kuwait Center for Autism currently employs four adults with autism within its own services.

The staff who have autism work as library or teaching assistants within a training course for students with autism to learn vocational skills such as wood crafting, life skills, social studies and geography. They have gained the skills to work in their jobs as a result of participating in the Kuwait Center for Autism's vocational training programme.

The vocational training programme for was launched in 2000 with the aim to help people with autism prepare for, and find, suitable jobs. The programme has trained many young people already and there are currently 120 young people with autism participating in it, with the aim to start working in 2015.

The staff of the centre network with companies and other organisations in Kuwait to find suitable jobs for the young people with autism who complete the training.

The employees with autism provide positive role models for the students with autism, as well as demonstrating to other potential employers that people with autism can be very capable at work, thus helping to raise awareness and break down stigma associated with autism.

The Kuwait Center for Autism was created in 1998 and is the first centre for autism established in the Middle East region. Its main purpose is to raise awareness of autism and to offer a range of evidence-based educational services to people with autism.

More information :

www.autism2014.net/KuwaitCenterForAutismActivities.aspx

Social media in the Making social connections safely online

Social media sites, such as Facebook and Twitter, have grown in popularity in recent years and many people with autism, and their representative organisations, are becoming active on these sites. But these new forms of social interaction bring new challenges for people with autism of all ages. This article presents some tips for people with autism to stay safe and avoid problems like bullying when using social media.

Individuals with autism sometimes find the structure and non-face-to-face nature of interacting with others via the internet an appealing way to create and maintain social connections. Composing messages in writing allows people to edit and reconsider their comments and posts before sending them. In this way, social media can provide an avenue for self-expression and help those who are feeling isolated to connect with others. It can also provide a place to gather information about, and discuss, topics that are hard to discuss with others, such as mental and sexual health.

At the same time, this new way of connecting brings with it some new risks and challenges, such as sharing personal information that you don't want others to know, being vulnerable to bullying and spending too much time on the internet.

Reliability of information

When it comes to information on the internet, there is always a judgement to be made about whether what you are seeing or reading is true or can be trusted. These judgements are particularly difficult for people with autism who may not recognise the need to be critical and or may take information presented to them literally. People with autism will find it useful to remember:

- People can remain anonymous or create a different identity on the internet. Text, photos and even live video are not a guarantee of a person's identity.
- The contents people post on social media sites are not necessarily true or accurate.

Concepts of friendship

The use of the term 'friend' and the idea of friendship are used differently in the context of social media sites to how these terms are used in person. While friendship is a concept that can be different for everyone, people with autism who use social media sites should be aware of the general differences between online and offline interactions, and the risks associated with them.

- Some people online may not be honest and may lie about who they are.
- People that you have only met online and never in person are still strangers, regardless of how friendly they appear or how much information they have shared about themselves.
- It can be a good idea to only accept friend requests from people you know in person, however, for people with autism seeking to make new social connections online, if you do connect with 'friends' you don't know in person, remember that they might not be who they say they are.

Privacy

Most social media sites provide some measures to protect individual privacy, but information posted on these sites is no longer private. For people with autism, the consequences of loss of privacy may sometimes be less obvious than for others.

 Consider carefully which information you share and with whom you share it. Any information that you wouldn't give to a stranger on the street also shouldn't be given to someone you've only met online.





autism community

- Don't give out personal information such as your full name, home address, where you work, passwords or bank account details on social media sites.
- Information that has been shared on social media sites cannot always be withdrawn. Therefore, you should only post information that you are comfortable with other people (including people you don't know) seeing, now and in the future.
- Before posting pictures, captions and comments it is a good idea to consider whether these could have a negative impact on how others perceive you, for example how a potential employer might feel about you if they saw it.
- Consider carefully, whether, how and to whom you disclose the fact that you have autism. Many people with autism use the internet as a way to connect with other people who have autism, share their experiences and learn from each other, and in this context telling others you have autism may be a positive experience. In other contexts, however, you may find that disclosing your disability can have negative consequences. It can be useful to discuss the issue of disclosure with someone you trust in person before deciding when, where and how to share this information with others.
- Be aware that other people also have a right to privacy, therefore you should not share personal information about them on social media sites unless you have their permission.
- Consider using the privacy settings provided by social media sites to control who can see the content you post.
- Consider creating different 'friends lists' in order to share different information with different groups of people, such as friends, colleagues and others in the autism community.

Being bullied

People with autism are particularly vulnerable to bullying in person, and now also online. Cyberbullying on social networking sites can





include bullies posting hurtful comments, sending nasty or threatening messages, setting up hate groups or posting unflattering photos of a person with negative comments about it. All forms of bullying are very hurtful for victims, but bullying online can be particularly distressing as the victim may not know the identity of the perpetrator and portable technologies such as smartphones mean that bullying online is not isolated to a particular location; it follows the victim and becomes inescapable. Cyber bullying may lead to, or be accompanied by, bullying in person at school, at work or in public. It can cause significant emotional harm resulting in depression, anger, avoidance of school or work, violence and even suicide.

- Identify 'safe people' that a person with autism can contact if he or she experiences hurtful social interactions online.
- If bullying occurs online, don't reply or retaliate. Most of the time the person who is bullying is looking for a reaction. Instead, save the evidence and block the person who is harassing you from contacting you.
- Bullying behaviour can be reported on social media sites and or in person to relevant authorities such as teachers, employers or the police.
- Consider other actions such as asking the person responsible to remove the hurtful content down.
- In serious cases of bullying, find out what legal protections exist in your country. There may not be specific laws about cyberbullying, but most countries have laws that can apply in terms of harassing or threatening behaviour.
- A person who has been bullied needs support and reassurance that they have done the right thing by telling someone about the incident.
- While it may seem like the best way to avoid cyberbullying is to avoid social media sites, this can also lead to a person to miss out on the benefits of using social media.

Bage 7

Bullying or harassing others

Due to the nature of their disability, some people with autism find it difficult to determine appropriate social behaviours in different contexts. Occasionally, this can lead people with autism to contact others too much or in inappropriate ways. For some people with autism it is also useful to consider and avoid behaviours that others will experience as bullying or harassment, even though it may not be intended as such.

- Show respect for others through using polite language and avoiding swearing, even if you don't agree with a comment or opinion that someone else has posted.
- Contact others appropriately. This can include only contacting people online that you have met in person, only sending further messages after receiving replies, respecting other people's decisions if they say they don't want to be contacted frequently or at all.
- Avoiding pressure from others to engage in bullying behaviours. A study of young people with disabilities and social media in the United Kingdom found that cyberbullying sometimes took the form of bullies peer pressuring others to get involved in bullying someone online. This was often done on the promise of friendship or the fear or threat of isolation and exclusion from within a peer group¹.
- If bullying behaviours or harassment do occur, it is important to work with the person who has bullied or harassed others to help them to change their behaviour. A person with autism may have been bullied themself, and/or may have difficulty in understanding how their behaviour and actions have affected others.

Risk of sexual abuse

A rare, but particularly concerning risk for children and young people with autism who use social media sites is that they can be more vulnerable than others to paedophiles who seek victims online.

The term 'online grooming' is used to describe the process by which someone with a sexual interest in children will approach a child online, with the intention of developing a relationship with that child, to be able to meet them in person and intentionally cause harm. Young people with autism may not be aware that they are being groomed, as this may be less obvious to them than other problems online such as negative or bullying comments.

- Children and young people should be encouraged not to respond to contact online from unfamiliar people and to tell a trusted adult if they feel uncomfortable or worried about anyone they encounter online. They must also be aware that some adults may pose as children to engage in conversations.
- If a child or young person has been contacted online by an unfamiliar person who makes sexual or other inappropriate conversation or comments, it is imperative to tell someone in a position of relevant authority immediately.



Spending too much time on the internet

While spending too much time on the internet can be a risk for anyone who uses social media sites, for many people with autism who already have difficulty in organising their time, social media can be a particularly distracting activity.

• It can be a good idea to set a time limit for using social media each day to avoid losing track of time and forgetting about other things that are important.

While there are many factors for people with autism and their supporters to consider in relation to using social media, the benefits of social media should not be underestimated. Social media sites are opening up new avenues for people with autism to explore and connect socially online, from the comfort of their own computer. Used with some caution, these can be a positive way for people with autism to increase and deepen their social connections.

1 Anti-bullying Alliance (2014). Cyberbullying and children and young people with SEN and disabilities: guidance for teachers and other professionals. http://www.anti-bullyingalliance.org.uk



Accessible version of YouTube for people with learning disabilities



An accessible version of YouTube has been developed to enable people with learning disabilities to view videos on YouTube more independently.

ACCESS: YouTube' simplifies the design of the standard YouTube site, making it easier to search and play videos, and allowing the use of assistive technologies. Some contents of the standard YouTube site have also been removed, including advertisements, comments and links which can be particularly distracting for people with autism.

ACCESS: YouTube has been developed in the United Kingdom by Henshaws College and Jisc, a UK charity that promotes innovation in the UK education and research sector.

More information: http://accessyoutube.org.uk/

Award-winning social media campaign raises awareness of autism in Poland



The SYNAPSIS Foundation's recent 'Autism deceives the senses' campaign used YouTube, Facebook, television and radio to reach 1.6 million people.

The innovative campaign began with a well-known Polish actor, Bartek Topa, showing unusual and repetitive behaviours (like a person who has autism) while being interviewed on a television show. Then, Topa was also caught acting strangely in public places by people with amateur video cameras. These videos were posted to the internet. Nobody knew why he was acting like this; the public started to ask questions and gossip spread about what was happening to this famous actor.

Finally, Topa was interviewed again on the same television show, where he explained that he was just acting – like a person with autism.

In this second interview, and on an advertisement that SYNAPSIS Foundation placed on Polish television, Topa explained the symptoms of autism and why it is necessary for the public to have some understanding of this condition.

In addition to raising mass awareness of autism, the campaign also won a 'Grand Prix' award from the Golden Drum Festival that recognises innovative advertising campaigns in Poland.

Are you connected to Autism-Europe's social media sites?



Share updates with us via Facebook and Twitter: www.facebook.com/AE and www.twitter.com/AutismEurope

Watch videos from Autism-Europe on YouTube: www.youtube.com/user/AutismEurope2010

Connect with us on LinkedIn : www.linkedin.com/in/autismeurope

Accessible travel and tourism for people

Travelling can be a real challenge for people with autism and their families. Accessing information, using travel services and finding appropriate accommodation can be difficult and time-consuming. In this article we highlight some examples of tourism services that cater to people with autism, as well as the work Autism-Europe is doing in Brussels to advocate for more accessible travel and tourism across Europe.









Air travel initiatives

Some airlines and airports in the United Kingdom, Ireland and the United States are now providing visual guides and rehearsals for passengers with autism.

Rehearsals provide individuals with autism and their families the opportunity to practice buying tickets, checking in, walking though security lines and boarding a plane (that doesn't take off).

Visual guides, in the form of videos and booklets, can assist people with autism to become familiar with the airport; from how to get to the airport, how to get to the correct terminal, to understanding the processes of checking in, going through security, boarding a plane and picking up luggage upon arrival.

More information:

www.manchesterairport.co.uk

www.dublinairport.com

blue-horizons-autism

www.autismspeaks.org/site-wide/

Sea travel initiatives

Some cruise ships around the world are now ensuring that their services meet the needs of travellers with autism and some are now even certified as 'autism-friendly'.

An organisation called Autism on the Seas has developed this autism-friendly certification, in which ships must meet a range of the standards in relation to:

- staff training;
- pre-vacation planning services;
- priority check-in, boarding, use of facilities and disembarking;
- adapted activities;
- accessibility measures for all people with disabilities;
- catering for special dietary needs;
- continuous improvement based on guest feedback.

So far, the initiative has certified numerous cruise ships operated by Royal Caribbean, a Norwegian cruise line.

More information :

www.autismontheseas.com

Accommodation

The National Autistic Society has produced a list of accommodation and holiday services within the United Kingdom and other countries around Europe which have stated that their facilities are appropriate for people with autism. Some of the features of these accommodation services include:

- personalised assistance with special needs and requests;
- supportive and non-judgemental staff;
- calm environments;
- security fences and gates.

A holiday booking service in the United Kingdom called the Disabled Holiday Directory also offers comprehensive assistance in finding suitable accommodation and other holiday services for people with autism.

More information:

www.autism.org.uk www.disabledholidaydirectory.co.uk

Activities and tourist attractions

Crowds, noises and unfamiliar surroundings can make tourist activities and attractions especially stressful for people with autism. Some organisations are taking initiative to specifically accommodate the needs of people with autism.

Skiing4all, Austria

Skiing4all provides skiing and outdoor activity holidays aimed exclusively at children and adults with special needs, including autism, throughout the year.

with autism

Individual programmes are prepared for each participant, based on their specific needs and in collaboration with parents and carers. Skiing sessions are offered on a one-to-one basis by highly trained staff who are experienced in working with people with special needs, overseen by a psychologist.

The organisation's methods incorporate the principles of ABA therapy and the TEACCH framework. Daily activity sessions are evaluated in conjunction with parents and carers and the programmes aim to provide the following therapeutic benefits such as improvements in communication and social skills, improvements in psychomotor skills and increased self-confidence.

Other supports for people with autism include visual aids (PECS, timetables, social stories, reward charts), optional buddy support, sensory rooms and safe spaces. Whenever possible siblings or friends or people with autism can ski at the same location (with their own instructors), share breaks, lunches and other activities together.

More information:

www.skiing4all.com

Buckingham Palace, United Kingdom

Buckingham Palace, the royal palace of the United Kingdom, and several other royal attractions offer online visual information guides to assist visitors with autism to prepare for their visits. All visitors on the autism spectrum who need to bring an access companion with them are entitled to a complimentary ticket for that companion.

More information:

www.royalcollection.org.uk/visit



Buckingham Palace, UK

Advocating for accessible travel and tourism throughout the EU

The European Accessibility Act

The European Commission is currently working on a new European Accessibility Act, which aims to make goods and services more accessible to people with disabilities, including autism, across Europe.

The Act will make specific provisions on accessibility in areas including transport and electronic communication services.

The Act is part of the European Union's efforts to ensure the implementation of the United Nations Convention on the Rights of Persons with Disabilities.

Autism-Europe and the European Disability Forum have participated in the European Commission's consultation, providing details of what people with disabilities need in this new Act, including:

- a definition of 'accessibility' that includes access to information and communications;
- accessible public information and communications (in plain language with visual supports), especially on public transport, in public places, on the internet and for emergency services;
- access to education and lifelong learning;
- access to healthcare services and the provision of reasonable accommodation within them.

The European Day of People with Disabilities

To mark this day in 2013, the European Commission in collaboration with the European Disability Forum held the European Tourism Day and the Accessible Tourism in Europe joint conference in Brussels. This conference aimed to raise awareness of the right of people with disabilities, including people with autism, to have equal access to tourism services and destinations.

Some success stories and best practices in this field were also presented during the event, which was attended by Autism-Europe self-advocate, Pietro. The conference on accessible tourism was also part of the European Union's wider efforts to promote the mainstreaming of disability issues in line with the European Union Disability Strategy 2010-2020 and the United Nations Convention on the Rights of Persons with Disabilities.

The European Day of People with Disabilities 2013 was also opened by Autism-Europe's representative and vice President of the European Disability Forum, Donata Vivanti.

More information: www.ec.europa.eu/enterprise/newsroom/ cf/itemdetail.cfm?item_id=7052

Social inclusion through

Since 2010, the 'Let's get a move on' project in Italy has been increasing the social inclusion of children and adults with autism through sports.

Based in Rome, the project engages children and adults with autism who are in need of a low-level of support in athletics training and team sports like rugby, basketball and football.

An initiative of a sport psychologist and the Atletica Roma Acquacetosa sports club, the project operates with the support of the Gruppo Asperger onlus and CulturAutismo onlus.

Athletics and sports training

The project holds training sessions in an athletics stadium in Rome once a week, conducted by trained staff and a psychologist.

In the training sessions, the athletics and sports activities are adapted to meet the specific needs of the participants. The participants are divided into two groups according to their age, with each group including both males and females.

Developing physical and cognitive skills

All of the participants follow a structured programme in which activities are taught step-by-step using visual aids showing each body movement that is required for each athletic or sports task. This method is designed to give participants a clearer understanding, and to enable them to perform each movement and task with greater confidence.



Feedback is provided to participants in a positive and simple way to help participants to improve their skills, as well as to reinforce their sense of commitment and enjoyment.

The project aims to assist the participants to gain a wide range of basic motor skills and to help them to develop more complex coordination skills. In addition, the participants improve their cognitive skills such as attention maintenance, memory, teamwork and cooperation skills, the ability to assimilate information from different sensory channels, and the ability to solve tasks and problems by using appropriate strategies.

European sports competition for young people with autism

The 'Progetto Filippide' (Filippide project) is another project to promote sports activities among people with autism in Italy. This initiative also aims to foster the social inclusion of people with autism and other intellectual disabilities through sports.

'Progetto Filippide' is currently organising a sports competition aimed at young people with autism, which will be held in Rome, Italy, in November 2015. The 'European Competition for Autistic People' will include a swimming competition and the 'Run for Autism' race, consisting of a 2.5 kilometre walk and a 10 kilometre run.

The project is supported by the Municipality of Rome's Department of Social Policy and Department V Handicap Office (Comune di Roma – Assessorato alle Politiche sociali – V Dipartimento Ufficio Handicap).

More information: www.progettofilippide.it/ (Italian)

One of the participants in the 'Let's get a move on' project in action.

Developing communication skills

The project also aims to increase the communication skills of participants. Training sessions include activities designed to encourage participants to make verbal requests and respond to requests from team mates within sports games and activities. Participants are also encouraged to express their needs, desires and moods, as well as to hold conversations with one another.

They also learn relaxation techniques to assist them to better manage their emotional states and increase their tolerance for frustration. These techniques can also help to reduce the physical symptoms of emotional states such as anxiety, panic or physical stress.

Social interaction

Participants use the communications skills they develop to interact with each other and act as a team when playing team sports like rugby, basketball and football.

As a team, participants also take part in amateur sports events and competitions where they have the opportunity to meet people from other sports clubs. Some of the participants have even attended international sport events and related social activities, gaining experience in social interaction with unfamiliar people.

sports in Italy

Achievements

The number of participants is gradually increasing and the ones who train on a regular basis have experienced improvements in their cognitive and motor development, as well as improvements in their quality of life. These results are backed up by the positive feedback and comments received from their families and people close to them.

In future, the project is hoping to increase the number of participants and to be involved in more sports events and competitions.







Invitation to Autism-Europe's 2015 Annual General Assembly Barcelona, Spain

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 Barcelona, Spain on May 2, 2015.

Agenda:

- Presentation of the executive committee report
- Presentation of the activity report: 2014
- Presentation of the financial report: 2014
- Presentation of the work programme 2015

An Autism-Europe Council of Administration meeting and a study visit to a local organisation supporting people with autism will also take place in conjunction with the meeting.

The meetings will be hosted by Fundación Autismo Mas Casadevall.

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



During the past few decades, several autism screening tools have been created. These tools help medical professionals to identify children who have, or are most at risk of developing, an autism spectrum disorder (ASD) in order to refer them to autism specialists for further testing and diagnosis. When correctly applied, screening tools improve the diagnosis process and enable earlier access to interventions. However, underuse of autism screening tools is common amongst medical practitioners. In addition, the design of screening tools is not always optimal, resulting in a risk of misclassification. Both factors are causing delays in diagnosis. This can be improved through better designed screening tools, increased awareness of screening tools among professionals and guidelines and policies for how to use screening tools.

Screening tools, surveillance and diagnosis

Autism screening tools usually take the form of questionnaires to be completed by parents or observation grids to be completed by medical professionals. They are composed of questions that aim to identify symptoms in the core deficit areas of autism spectrum disorders. Screening tools constitute the first step in determining whether an individual has autism.

Two types of autism screening tools can be distinguished. Level I tools are designed to be used by primary care providers at set intervals, in the context of a routine developmental surveillance procedure. They aim to identify children at risk of ASD amongst the general population. Level II tools are designed to be used by specialists to further scrutinise possible symptoms of autism. They target children previously identified as being at risk of ASD, with an aim to differentiate them from those at risk of other developmental disorders.

It should be noted that screening, surveillance and diagnosis are distinct, but related, activities. The term 'surveillance' refers to a continuous and systematic process of data collection by parents and professionals who closely monitor a child's behaviours and progress. In that context, developmental surveillance is the tracking of a child's developmental pathway over time. Conversely, 'screening' provides a snapshot of the child's develop-

Seeking bet screening p

Sophie Carlier

While a diagnosis of autism can be made from around 18 months of age, throughout most of Europe the estimated average age of people receiving a diagnosis of autism is over 4 years. Screening tools to identify early signs of autism are key to earlier diagnosis, yet according to the findings of a study conducted in Belgium, many doctors and other practitioners are not using them.

ment at specific times. Screening aims to identify specific disorders through the application of standardised tests. 'Diagnosis' is the identification of a disorder, based on its signs and symptoms, according to professionally recognised criteria.

The early application of screening tools leads to earlier diagnosis and faster referrals to specialist services. However, families still face a considerable delay between their first concerns and the diagnosis. Indeed, research demonstrates that the majority of parents of a child with autism notice an unusual pattern of development as early as during the first or second year of life. Regardless of these warning signs, the estimated mean age at formal diagnosis exceeds 4 years in Europe. In the United States, where screening guidelines and policies exist, the average diagnosis of ASD was made around an estimated 53 months in 2010¹. The average age at the time of diagnosis in Europe and the United States is slowly lowering, yet there is certainly room for improvement.

Lack of awareness among professionals

A large proportion of family doctors are not aware of autism screening tools². Last year in Belgium, a specialist autism team from the Queen Fabiola Children's University Hospital in Brussels surveyed a sample of 100 general practitioners and a further 100 paediatricians³. None of the general practitioners showed any awareness of autism screening tools. Furthermore, they felt this issue had little to do with their daily practice. Amongst the sample of paediatricians, only four were aware of such tools' existence. However, none of them could name a specific tool.

In 2006, a study in the United States⁴ also found that only 8 per cent of primary care paediatricians reported conducting routine screening for ASD.

The lack of awareness of autism screening tools causes professionals to adopt a 'wait and see' attitude, minimising or dismissing parental concerns. Many professionals either do not detect possible ASD symptoms or make inappropriate referrals to other professionals who have no expertise in ASD. In these circumstances, it can take months or even years before someone

ter practices in autism rocedures

suspects an autism spectrum disorder and redirects the child to the right service, hence delaying diagnosis. The lack of autism screening by general practitioners also leads to children being referred to autism specialists inappropriately. For example, this happens when children who show difficulties in communication and social interaction, but no stereotyped behaviours, are referred to autism specialists. In this case, the specialists and families experience frustration at their time being wasted as they must be redirected to an appropriate specialist because the child does not fit the fundamental criteria for a diagnosis of autism. This problem can be avoided if autism screening is conducted by general practitioners and paediatricians.

Lack of familiarity with autism screening tools needs to be addressed through better informing general practitioners and paediatricians. Education about autism spectrum disorders during doctors' residency training should also be improved.

Design of screening tools

Level I autism screening tools aim to find people who could possibly have an ASD. They scan widely in order to miss as few suspected cases as possible (focusing on 'sensitivity'). This focus leads to a high rate of false positive results (the over inclusion of children who are not at risk of an ASD, though they may have another developmental and/or psychiatric disorder which includes some of the same social and communication deficits as ASD). False positive results cause parents avoidable anxiety and unnecessary assessment of the child for ASD. Considering the broad content of level I autism screening tools, these may also induce false negative results (the under detection of children truly at risk of ASD). This particularly applies to those children with milder presentation. In the case of false negative results, children and adults who do fit an ASD diagnosis remain undetected for longer periods, missing opportunities for intervention.

Level II autism screening tools aim to eliminate those who are not affected by ASD and have been incorrectly detected as such (focusing on 'specificity' rather than sensitivity). Despite having more detailed contents, their discriminant power is not always robust enough, leading to further detection problems.

Ideally, a test should be 100 per cent sensitive and 100 per cent specific. In reality, no screening tool is that accurate and there is always scope for detection errors. As a result of these psychometric deficits in the design of autism screening tools, no single tool is sufficient to decide whether a child needs a specific autism assessment. Similarly, negative autism screening results do not confirm that a child is free of any risk of having an ASD. Therefore, repeated screening is indispensable for children whose difficulties persist, even after a negative autism screening result.

Screening to improve practices in autism diagnosis

- Screening is not diagnosis; it helps to determine whether additional investigation is necessary before a diagnosis can be made;
- Repeated and combined screening procedures (level I and II) improve the accuracy of the results;
- Practical autism screening guidelines should be included within European health policies;
- Awareness campaigns need to be conducted in order to improve knowledge of autism screening tools among relevant professionals.



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Good practice screening procedures

Taking into account recommendations on good practices in autism screening by relevant professionals such as the American Academy of Neurology⁵ (supported by the American Academy of Pediatrics⁶), and the variety of detection tools that are currently available, effective autism screening could be conducted as follows:

Step 1

First autism screening (using a level I tool)

If a child fails to meet specific developmental milestones, autism screening should be performed by primary care providers (such as general practitioners and paediatricians), along with audiological assessment and screening for lead in case of pica behaviour (an unusual craving to eat substances that are not food).

Step 2

Second autism screening (using a level II tool)

If the first autism screening returns a positive result, the child should be thoroughly evaluated by a child specialist (such as a child neurologist or child psychiatrist), to determine the probability of autism rather than other developmental disorders. Simultaneously, the child should be referred to early intervention services, with the aim of beginning multidisciplinary intervention as soon as an ASD is suspected, rather than waiting for a formal diagnosis.

Step 3

Diagnosis

If the second autism screening returns a positive result, the child should be referred to a team of autism specialists for formal diagnostic testing.



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This article aims to provide useful information to our readers on the topic of autism screening. This article is not intended to promote any particular approach to, or model of, autism screening, nor does it reflect any particular policy position of Autism-Europe.

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3 Carlier, S. & Ducenne, L., [Study pending publication in 2015].

4 Dosreis, S., Weiner, C.L., Johnson, L., & Newschaffer, C.J. (2006). Autism spectrum disorder screening and management practices amongst general pediatric providers. Journal of Developmental and Behavioral Pediatrics, 27(2), pp.88-94. 5 Filipek, P., Accardo, P., Ashwal, S., Baranek, G., Cook, E., Dawson, G., Gordon, B., Gravel, J., Johnson, C., Kallen, R., Levy, S., Minshew, N., Ozonoff, S., Prizant, B., Rapin, I., Rogers, S., Stone, W., Teplin, S., Tuchman, R., & Volkmar, F. (2000). Practice parameter: Screening and diagnosis of autism. A report of the Quality Standards Committee of the American Academy of Neurology and the Child Neurology Society, Neurology, 55(4), pp.468-479. 6 Johnson, C.P & Myers, S.C. (2001). Developmental surveillance and screening of infants and young children, Pediatrics, 108(1), pp.192-195.

¹ Center for Disease Control and Prevention (2010). Prevalence of Autism Spectrum Disorders: Autism and developmental disabilities monitoring network [11 sites in the United States], MMWR surveillance summary, 63, p.1-21.

The European Union and autism advocacy

Following the election of new Members of the European Parliament (MEPs) in May 2014, in this article we present an overview of some of the institutions of the European Union. We outline how they make decisions and how Autism-Europe works to influence them in the interests of people with autism.

The European Union is composed of several institutions, that each play a different role in making and enforcing laws, policies and budgets. Autism-Europe works to influence each of them in different ways.

Setting the agenda – The European Council

The European Council is the EU's top political institution; it sets the EU's goals and the course for achieving them. It is composed of the presidents and/or prime ministers of each Member State, plus the presidents of the European Commission and the European Council.

>> Autism-Europe's members can lobby their national governments regarding issues that are relevant at the EU level.

Proposing and implementing laws – The European Commission

The European Commission is responsible for initiating and implementing laws, upholding the European Union's treaties and managing the day-to-day running of the EU, including the majority of the EU's budget and programs.

When proposing legislation, the Commission consults relevant stakeholders and national governments early in the decisionmaking process. National governments have the power to intervene when a legislative act is still a Commission proposal.

The Commission consists of 28 commissioners (one from each Member State) who are appointed by agreement among the Member States, subject to the approval of the European Parliament.

To create laws and manage the day-to-day running of the EU, the Commission employs around 23,000 staff, mainly in Brussels and Luxembourg, who work within departments called Directorates-General and Services.

The Commission is accountable to the European Parliament.

>> Autism-Europe responds to the structured consultations that the European Commission conducts with civil society organisations on policy matters relevant to people with autism. >> Autism-Europe receives some funding from the European Commission

Making decisions – The Council of the EU and the European Parliament

The budgets and most of the laws of the European Union are adopted through a co-decision procedure in which both the Council of the EU (representing national governments) and the European Parliament (representing European citizens through their directly elected MEPs), must agree on each proposed law and budget.

The Council of the EU (also known as the Council of Ministers) makes decisions by holding regular meetings which are attended by one minister from each of the EU's national governments, according to the subject matter (for example, agricultural ministers decide farm policy, foreign ministers are responsible for foreign policy). Each minister in the Council is empowered to commit to decisions on behalf of his or her Member State's government.

The European Parliament is comprised of 751 directly elected representatives from all 28 Member States. Each of these Members of the European Parliament (MEPs) are affiliated with Europe-wide political groups, according to their political beliefs and priorities. The Parliament holds its major debates at monthly plenary sessions, in Strasbourg, France, with additional sessions and preparatory work taking place in Brussels, Belgium.

>> Autism-Europe's Charter of Rights for Persons with Autism was adopted as a written declaration by the European Parliament in 1996.

>> Autism-Europe monitors European laws and policies while they are still in development, and where necessary we consult our members at the earliest possible stage of policy development.

Shared responsibilities between EU institutions and Member States

The European Union operates according to the principle of subsidiarity, which means that it only takes actions, such as creating new laws, if it is more effective than actions taken at

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national, regional or local level (except in the areas which fall within the exclusive competences of the EU). Thus, the European Union operates within a framework of shared competences between the EU institutions and Member States.

Exclusive EU competences: The EU may legislate and adopt binding laws regarding the customs union, the common commercial policy, competition rules and monetary policy for countries that use the euro as their currency. The role of Member States is therefore limited to applying these laws, unless the EU authorises them to adopt certain laws themselves.

Shared EU-Member State competences: The EU institutions and the Member States share competences in specified areas including economic, social, and territorial cohesion; the area of freedom, security, and justice; aspects of social policy; aspects of public health; aspects of research and technological development and space; agriculture and aspects of fisheries; the environment; internal market rules; consumer protection; transport; trans-European networks; energy; and aspects of development cooperation and humanitarian aid. The EU institutions and the Member States are authorised to adopt binding laws in these fields. However, Member States may exercise their competence only in so far as the EU has not exercised (or has decided not to exercise) its own competence.

Member State competences with support from the EU: Member States retain competences in areas related to the protection and improvement of human health; education, vocational training, youth and sport; civil protection; culture; tourism; industry; and administrative cooperation. Yet, in these areas, EU actions can support, coordinate, or supplement Member State activities. The EU can only intervenein these areas for these purposes.

The EU also coordinates economic and employment policy, and a common foreign and security policy; although these areas are managed separately from the above framework of competences.

Within this framework of shared responsibilities, most areas of law and policy that affect the lives of people with autism and

their families are competences of the Member States. Therefore, Autism-Europe's member associations advocate for changes to improve the lives of people with autism at the national level. Autism-Europe provides member associations with relevant information and support in the form of advice, newsletters, position papers, toolkits and forums for mutual learning and discussion.

There is scope for the European Union to provide more support for people with autism and their families, however, and Autism-Europe also advocates for action at the EU level.

>> Autism-Europe has also advocated for the European Union to:

 Collect standardised data on the prevalence and situation of people with autism across the EU;

• Harmonise diagnostic criteria and practices throughout the Member States;

 Create European standards for the provision of high quality, evidence-based support services for people with autism and their families;

• Promote the creation of high quality, evidence-based support services for people with autism and their families throughout the Member States;

• Promote the creation of evidence-based, individually tailored lifelong education for people with autism throughout the Member States;

• Fund high quality coordinated research that reflects a rights-focused approach to people with autism.

>> Autism-Europe produces reports, tool kits and other information resources, as well as facilitating the exchange of good practices among our members to promote a rights-based approach to social inclusion and appropriate care and education for people who have autism, at both EU and Member State levels.



Representing Autism-Europe before the European institutions: (above, left to right) Donata Vivanti, Aurélie Baranger and Pietro Cirrincione; and (above, right) Pietro Cirrincione.







President of the European Council, Donald Tusk (Poland), 2014 – 2017 (2.5-year term).



President of the European Commission, Jean-Claude Juncker (Luxembourg), 2014 – 2019 (5-year term).

Advocacy for autism and other disabilities in the EU

As most of the European institutions are based in Brussels, Autism-Europe and many other similar organisations work in Brussels to influence the European Union's law, policy and budget making processes.

To maximise our impact on these processes, Autism-Europe works in strategic coalitions with organisations that share common concerns and goals. These include the European Disability Forum (EDF), the Platform of European Social NGOs (the Social Platform) and the European Coalition for Community Living (ECCL).

In recent years, the main focus of Autism-Europe and other organisations that advocate for the rights of people with disabilities in Brussels has been to ensure that the United Nations Convention on the Rights of Persons with Disabilities is fully implemented throughout Europe.

The Convention outlines the specific rights of people with disabilities and it is a legally binding document for the States Parties that have ratified it, including the European Union, which ratified the Convention in 2010.

To implement the Convention within the framework of its competences, the European Union created the Disability Strategy 2010-2020, which provides an action plan for the EU to implement the Convention in eight priority areas including accessibility; participation; equality; employment; education and training; social protection; health and external action.

As part of the Disability Strategy 2010-2020, the European Commission is also currently drafting a new European Accessibility Act. The Act aims to make goods and services more accessible to people who have disabilities throughout Europe.



President of the European Parliament, Martin Schulz (Germany), 2014 – 2016 (2.5-year term).

European Parliament in Brussels, Belgium



Presidency of the Council of the EU, Laimdota Straujuma (Latvia), January - June 2015 (0.5 year term, rotating among Member States)

Autism-Europe has advocated for accessibility for people with autism within this new law, including:

- a definition of 'accessibility' that includes access to information and communications;
- accessible public information and communications (in plain language with visual supports), especially on public transport, in public places, on the internet and for emergency services;
- · access to education and lifelong learning;
- access tohealthcare services and the provision of reasonable accommodation within them.

>> Autism-Europe participated in the European Commission's consultations, providing details of what people with disabilities need in the Disability Strategy 2010-2020 and the European Accessibility Act.

>> Autism-Europe actively takes part in the monitoring of the implementation of the Convention, for example by drafting an alternative report.

>> Autism-Europe's former President, Donata Vivanti, is also Vice President of the European Disability Forum and participates for example in high-level meetings with the Presidents of the EU institutions on the implementation of the Convention.

>> Autism-Europe provides information to our members about the processes for, and progress towards, implementing the Convention within the EU.

>> Autism-Europe members advocate for their national governments to ensure the full implementation of the Convention in the Member States.



First report on the implementation of the UNCRPD in the European Union published



The European Union has published its first report on the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The report describes how the European Union has been implementing the UNCRPD

through legislation, policy actions and funding instruments. It addresses all the rights and obligations enshrined in the Convention across a wide range of policy fields. failing to include organisations of people with disabilities in the reporting process, for not addressing the diversity of people with disabilities, and for adopting a restrictive view of the EU's obligations in the implementation of the UNCRPD. In order to address these gaps, EDF is currently working on an alternative report in collaboration with other civil society organisations. Autism-Europe cooperates with EDF and is actively involved in the drafting of this alternative report, which is expected to be published in early 2015.

View the EU report: http://ec.europa.eu/justice/discrimination/files/swd_2014_182_en.pdf

The European Disability Forum (EDF) has criticised the report for

Autism-Europe representatives participate in autism awareness raising events in Morocco



Autism-Europe's Vice President, Evelyne Friedel, presented two training workshops on the implementation of the United Nations Convention on the Rights of Persons with Disabilities in Rabat, Morocco, in May, 2014.

The training workshops were organised by Collectif Autisme Maroc as part of a national campaign to raise awareness of autism in Morocco, titled 'Je suis différent comme toi' ('I am different like you'). The first training workshop was held in partnership with the Moroccan Conseil National des Droits de l'Homme (National Council for Human Rights), with participants coming from regions across Morocco. The second training workshop was held under the aegis of the Law University of Rabat with professors, students and representatives of autism advocacy organisations.

Autism-Europe representative and Vice President of the European Disability Forum, Donata Pagetti-Vivanti, also gave a presentation on autism and the United Nations Convention on the Rights of People with Disabilities at an international congress on autism in Rabat, Morocco, in April, 2014. The event, which was supported by the Moroccan Ministry for Solidarity, Women, Family and Social Development, involved discussions on how to increase opportunities for training and networking between Moroccan and European autism organisations.

More information: www.autismeurope.org/

Online video gaming event raises over 2,000 euros for Autism-Europe



An online video gaming marathon has raised over 2,000 euros in donations for Autism-Europe. The event, called 'Hajime', took place in August 2014 and involved participants playing online video games together over a period of 24 hours.

The event was broadcasted via Twitch, a popular streaming platform for gamers. During the 24-hour gaming session, onlookers made donations which allowed them to get their comments broadcasted on the Hajime event page, as well as to ask the players for special requests within the games.

Autism-Europe is very grateful to Forum Thalie, a French association promoting artistic activities, events and conferences, that organised this event.

More information: http://hajime.forum-thalie.fr/

New study reveals costs of autism in the United Kingdom



A new study found that autism costs the economy of the United Kingdom more than heart disease, cancer and stroke combined.

The study, led by the London School of Economics and Political Science, estimates that autism costs the United Kingdom at least £32 billion per year. This expenditure includes hospital services, home health care, special education facilities and respite care, as well as lost earnings for both people with autism and their parents. At the same time, however, autism

research in the United Kingdom receives far less funding than research into heart disease, cancer and stroke.

The conclusions of the study, published in the Journal of the American Medical Association Pediatrics in June 2014, highlight the need for government action such as more research funding, more effective interventions to treat autism and better coordination of services.

More information: www.lse.ac.uk/newsAndMedia/news/ archives/2014/06/Autism.aspx

Vocational training project for people with learning disabilities releases publication



The 'Count Me In' project has released a publication with examples of vocational training opportunities for people with disabilities in cultural organisations across Europe.

'Count Me In' is a European vocational education and training initiative to create tools for trainers of people with learning disabilities and educators in the arts and cultural sector in Europe, with the aim to assist them to promote social inclusion of people with disabilities in the labour market.

The publication features guidelines for vocational education and training professionals based on good practices from the Gaia Museum of Outsider Art in Denmark, the art workshops at Debajo del Sombrero in Spain, and other museums and arts organisations such as galleries, theatres, and music festivals.

Autism-Europe is a partner in the 'Count Me In' project, which is funded by the European Union's Leonardo da Vinci Programme.

More information: www.count-me-in.eu/

Open Book tool for people with autism to simplify text released



After three years in development, Open Book, a tool for people with autism to simplify text, has been released.

The tool has many features to make text more accessible for people with autism, including replacing long sentences with one or more shorter sentences, providing definitions of long and difficult words and expressions or replacing them with simpler ones, and adding images to aid understanding.

It also provides an interface for carers, in which they can provide extra assistance to help users with autism better understand the text. The Open Book tool is available in English, Spanish and Bulgarian, and aims to increase the social inclusion of people with autism by improving their access to written information and communications.

The tool has been produced by the FIRST (Flexible Interactive Reading Support Tool) Project, in which Autism-Europe was a partner. The project's team of experts worked with a large group of people who have autism to ensure that Open Book is designed and clinically tested to meet their needs.

More information: www.first-asd.eu & www.openbooktool.net

British Government launches 'Think Autism' funding programme

The British Government has announced the 'Think Autism' initiative to improve the quality of life of people with autism across England.

The government will invest £4.5 million in funding towards an innovation fund and a community-led awareness programme. The innovation fund will support the development of new services and the awareness programme will help to increase understanding of autism among professionals and the public.

'Think Autism' is the result of the Push for Action campaign launched by the National Autistic Society to turn the country's Autism Act 2009 into action. Push for Action has been calling on the national government and local authorities to make sure adults with autism across England receive the everyday support they need.

More information: www.autism.org.uk

Autism-Europe participates in a conference on accessibility of higher education for students with disabilities



The conference, titled 'MapAbility: strengthen the accessibility of higher education institutions to students with special needs', took place at the European Economic and Social Committee in Brussels in June, 2014.

At the conference, Autism-Europe's Director, Aurélie Baranger, discussed ways of increasing the participation of people with autism in higher education and the Erasmus exchange programme, with representatives of the Erasmus Student Network, the European Commission and other disability organisations from across Europe.

The first results of the MapAbility project which mapped the accessibility of higher education institutions across Europe for students with disabilities and special needs, including students with autism, were also presented at the conference.

More information: www.esn.org/content/mapability

Member Associations of Autism-Europe

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XI Autism-Europe International Congress

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