



Autism-Europe's 11th International Congress:
More than 1,700 attendees in Edinburgh

**Florian Van Acker, Belgian athlete with autism
and Paralympic Champion in Rio 2016:**

"My motto, 'never give up' is as relevant to sport
as it is to life in general"

Liz Pellicano: Building a participatory framework
for autism

Tracey Francis: Life after school - keeping on track

Mobile homes to empower autistic people
in Denmark



For Diversity



Against Discrimination



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Edito



Dear friends,

To be "Happy, healthy and empowered", this is our wish to you all for the year 2017. It was also the motto of Autism-Europe's International Congress, held in Edinburgh in September 2016.



The 11th international congress was a great success, welcoming more than 1,700 participants from 60 countries. It was an opportunity for autistic people, families, professionals and researchers to get together for three days to discuss an array of different topics and issues in order to promote a better quality of life for people on the autism spectrum.

This event, in keeping with Autism-Europe's mission, sought to ensure that the voices of autistic people and self-advocates were heard loud and clear. The term "Empowered" in particular echoes the motto of the disability movement: "Nothing about us, without us". It is essential that people with autism are heard, not least in the field of research, as Prof. Liz Pellicano from the CRAE points out. It is also important that no voice be forgotten, as Evelyne Friedel, Vice-President of AE, reminds us, underlining that that all people with autism must be represented and have their needs taken fully into account, including those requiring a very high level of support.

Promoting the exchange of good practices and new ideas to improve the lives of people with autism is another of Autism-Europe's missions. In this edition you will learn about an innovative system of mobile homes for people with autism initiated in Denmark, which facilitates better access to community living. Tracey Francis, for her part, embarked upon a tour of Europe looking for solutions to overcome the lack of support available to young people during the transition from school to the world of work. Here she offers us a sample of practices she observed in the various countries she visited. Facilitating access to employment is also the focus of a new campaign being run by the National Autistic Society (UK) that we will be presenting to you in this edition.

Finally, as the new year gets under way, two young people with Asperger syndrome, Florian Van Acker and David Nicholson, provide us with their messages of optimism. Here they share with us their dreams and aspirations, as well as shedding light on how they overcome everyday obstacles.

We very much hope you enjoy reading this edition. The team at Autism-Europe wishes you a very happy 2017 and thanks you warmly for your continued support.

Zsuzsanna Szilvasy
President

Aurélie Baranger
Director

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Florian Van Acker, a 19-year-old Belgian athlete with autism, became Paralympic table tennis Champion in Class 11 (Intellectual Disability) during the Rio 2016 Olympic Games. Photo from Luc Dequick (Belgian Paralympic Committee) for Autism-Europe.

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Overview of the Plenary Room

More than 1,700 self-advocates, parents, professionals, carers and other interested parties gather in Edinburgh for Autism-Europe's 11th International Congress

Situated at the heart of Scotland's elegant and historic capital city, the Edinburgh International Conference Centre hosted the eleventh edition of Autism-Europe's International Congress, which this year carried the motto "Happy, Healthy and Empowered".

From the 16 to the 18 of September, the Congress welcomed over 1,700 delegates from more than 60 countries. The triennial event, organised this year by the National Autistic Society in partnership with Autism-Europe, is dedicated to sharing advances in practical and scientific knowledge about autism to as wide an audience as possible.

The event focused on the most recent developments across the field of autism, including early intervention, health, education, support, employment and policies. It also covered access to rights and services for autistic people and provided insight into future developments.

Renowned speakers came from all over the world to lead plenary discussions and workshops. Speakers such as Virginia Bovell, Gunilla Gerland, Bo Hejlskov Elvén, Roy Richard Grinker, Dr Wenn Lawson, Professor Tommy Mackay, Professor Liz Pellicano, Dr Peter Vermeulen, Fred R Volkmar, M.D., Irving B. Harris, Gina Davies, Dr Wendy Keay-Bright and Diederik Weve all took centre

stage in the plenary room of the Conference Center to discuss their areas of expertise. Beyond the plenary room, five other spaces were provided to hold different kinds of sessions such as oral poster presentations, discussion groups, symposia, film screenings or cultural performances.

In its eleventh edition, participants submitted abstracts with the aim of exploring a broad range of perspectives, both theoretical and practical. In total over 600 abstracts were received.

As part of the congress, an online exhibition of art by people with autism was showcased by *Autismo Burgos*, in which prizes were awarded to the best artworks selected via an online vote.

This year the JiM Foundation (Poland) offered grants to fund thirty places at Autism-Europe's 11th International Congress. Fifteen of the grants were awarded to professionals who work with autistic people (therapists, academic, support workers, teachers and so on) and the rest were awarded to parents, family members and students as well as autistic individuals.



The Congress in figures

- **3**-day event
- **11th** edition
- **>1,750** delegates
- **61** countries represented
- **40** plenary and workshop speakers
- **52** stands
- **377** posters
- **>790** abstracts submitted
- **30** delegates attending with a JiM Foundation grant
- **6** conference rooms and **1** quiet room

Congress participants

Autistic Europe Fringe: Talks and Comedy

The Autistic Europe Fringe was run in parallel with the Congress by and for autistic people and funded by the Scottish Government. Everyone was welcome to attend the gathering, but were reminded to be aware and respectful of the fact that this was an autistic space.

Panelist Dr Larry Arnold, Caroline Hearst, Martijn Dekker and Dr Damian Milton preceded Guerrilla Aspies, the Show version of the Book with Paul Wady.

Furthermore, Autistic Europe Fringe were running an autistic “escape” space in a yurt a short walk from the Conference Centre. There was space to relax, meet other autistic people, join in daily discussions and learn about autistic-led projects.

Following conversations online

#AECongress16 was the hashtag chosen to follow the Congress' news on social media. A hashtag is simply a way for people to search for posts that have a common topic. The # is a hash symbol, hence the term hash tag or, more commonly now, hashtag.

By using this tool on the social media network Twitter:

- more than **250 different users** could be heard and joined discussions online;
- more than **500 messages** about the Congress were posted;
- around **374,000** different users received messages (posts and/or tweets) about the topics covered;
- and messages containing this hashtag were displayed more than **1,207,000 times**.
- It resulted in the #AECongress16 hashtag trending in the UK, i.e. being amongst the most visible and popular on the social network

These analytics are from the 13 September 2016 to 29 September 2016 period. Source: Keyhole

More information: : www.autismeurope.org

Some feedback from the organisers and participants:



ZSUZSANNA SZILVASY
AUTISM-EUROPE'S PRESIDENT:

"Happy, healthy and empowered are the themes of this year's Congress. But they are not just the themes. When met altogether they bring a profound sense of life to persons with autism. You are healthy, when all your therapeutical and health needs are met. You are empowered when society accepts you and you have the right to express your own colorful personality. When all these needs are met, then you can be happy. And this is what I wish to every autistic person in the world."



KATE LAIRD
CONGRESS ORGANISER FOR THE
NATIONAL AUTISTIC SOCIETY:

"I am absolutely overwhelmed by the interest from delegates. So many people attending and the atmosphere has just been fantastic. We are having a really great time."



DR. LAURIE SPERRY
SPEAKER. PARTICIPANT AT THE PANEL
DISCUSSION "PATHWAYS IN AND OUT
OF PROBLEMATIC SEXUAL BEHAVIOR IN
AUTISM":

"I am delighted to be at the Autism-Europe International Congress on autism. This Congress affords us an opportunity as scholars, family members, care providers to discuss important issues that are so pressing in the field of autism. It allows us to come together and acknowledge each other's expertise and learn from each other. And what a wonderful conference!"



MONIQUE POST
NVA <DELEGATE. REPRESENTATIVE OF
NEDERLANDSE VERENIGING AUTISM AT
AUTISM-EUROPE AND SELF-ADVOCATE:

"This is my first Autism-Europe Conference and, as a "newbie" here, as a professional, but also as a person with a diagnosis I've found it really interesting so far. The interesting thing is that there's more participation in this conference of people with autism. So rather than talking about it is more towards talking with."



RON FORTUNA
DELEGATE. DIRECTOR OF TARGET
AUTISM:

"I've had a really enjoyable time at this international conference. It has been really interesting to see what the other countries are doing watching and looking at the posters, listening to the oral poster presentations, having opportunities to actually mix and meet other people from other countries and to see exciting speakers."



HARALD NEERLAND
MEMBER OF THE AUTISM-EUROPE'S
EXECUTIVE COMMITTEE:

"The Congress was good, it had a lot of interesting topics. If I was to miss something it would probably be more towards the lower-functioning part of the spectrum. I found a lot of interesting things in the stands of the exhibition area and there were some very interesting posters also. So all in all, I thought it was a very good conference."



SUNČICA PETROVIĆ
DELEGATE. INTERNATIONAL RELATIONS
AND PROJECT COORDINATOR FOR THE
SERBIAN SOCIETY OF AUTISM:

"It is a pleasure to be at yet another Autism-Europe Congress. My first congress was in Budapest three years ago, but here in Edinburgh we have a pleasure as a full member of Autism-Europe also to network with all these lovely people and from around the world. So yes, we are looking forward to yet another one."



CAROL POVEY
DIRECTOR OF THE CENTRE FOR AUTISM
AT THE NATIONAL AUTISTIC SOCIETY:

"Zsuzsanna Szilvasy at the beginning of the Congress said that she wanted everyone to put aside their labels, statutes and regard each other as friends. It has been amazing over the last few days to see everyone doing that! I think it is been a real feeling of respect and appreciation of each other, so I really do appreciate that."



Making decisions, Transforming Lives: Building a participatory framework for autism

Liz Pellicano, Professor of Autism Education, Director of the Centre for Research in Autism and Education (CRAE) at the Institute of Education, University College London and keynote speaker at the 11th Autism-Europe International Congress.

What is going on today?

People should have a say in the decisions that affect their lives. Yet autistic people and their family members often feel left out of these decisions. Be it the nature of autism research that is conducted, the kind of schools that are available to them or the services provided in the community, autistic people report again and again that they feel excluded from the places where decisions get made. Our ambition at the CRAE is to help to change this.

Our work in this regard really began 5 years ago, with a project called A Future Made Together, funded by the UK charity Research Autism. CRAE's previous director, Tony Charman, and I conducted the most comprehensive review of UK research into autism ever undertaken, with the goal of finding out what autistic people made of it. We looked at how much had been spent on autism research in the UK between 2007 and 2011 and what it had been spent on and we consulted more than 1,700 autistic people, their families, practitioners and researchers to understand what they thought of current autism research in the UK and, importantly, where they thought the funds towards autism research should be prioritised in the future.

The findings were stark. While autistic people and family members were impressed by the amount of work that goes into autism research, they were not convinced that research had made a real difference to their lives. One woman said: "I fill in all these questionnaires and do everything I can to help ... but when it comes down to it, it's not real life. It's always missing the next step. It's great you've done this research ... but now do something with it."

Many people shared this view. Research doesn't seem to help a young autistic person learn to catch the train by themselves or to keep themselves safe. It doesn't say how to get autistic adults into jobs and keep them there. And it doesn't often say how education should work or other social services be provided. Our participants wanted to see research that led to real, measurable and impactful changes.

There were clear reasons for this response. Our analysis showed that the majority of autism research in the UK focuses heavily on "basic science" – neural and cognitive systems, genetics and other risk factors – rather than on research targeting the immediate circumstances in which autistic people find themselves, on services, treatments and interventions and education. In fact, our report showed that only 5% of UK research funding between 2007 and 2011 went towards identifying effective services for autistic people and their families (Pellicano, Dinsmore, & Charman, 2013, 2014a). This is not to say autistic people and parents didn't value the need for basic, scientific research, but simply wanted to see a more balanced profile.

This is also a problem for those responsible for commissioning local autism services, who would all gain much more support if they were able to draw on new research that was specifically designed in order to help them make evidence-based decisions on education, health and social care.

What can we do?

It is for these reasons, that I have been arguing that we need to change the fundamental questions with which we begin our work in autism. Rather, than asking what “causes” autism, we should begin by asking how we can ensure that autistic people have the same opportunities as everyone else, and how we can make sure that the services and supports they do receive are the very best and most effective possible.

There is no doubt that we must continue to develop our world-leading skills in key areas of autism science, of course. But we also need greater investment in currently under-researched areas – like education and service provision – and under-served populations – like autistic adults, autistic girls and women and those who have limited spoken communication.

In order to work out which new areas need the greatest investment, we ought to be listening to autistic people themselves about what they want from research. According to our findings, autistic people, their family members, and even practitioners are rarely involved in the decision-making processes that shape research and its application (Pellicano, Dinsmore, & Charman, 2014b). Researchers need to listen in order to appreciate what it is like to be autistic, to care for someone who is autistic, or to work with someone who is autistic. And we need to understand the most effective ways of eliciting the views and perspectives of autistic people - particularly those who do not use spoken communication - to ensure that they have more control over their own lives.

What are the chances of this happening today?

Fortunately, in the few years since we launched our initial project, we have already seen some significant shifts in this direction.

Academic researchers do appear to have shifted their attention away from a sole focus on underlying bio-medical or psychological phenomenon to a wider range of everyday and social concerns. Renowned autism scientists like Francesca Happé are now beginning work on the impact of autism on older people, for example, and are asking how we might be able to support autistic people as they move through their lives. Practitioners too are beginning new innovations and seeking out researchers to help them provide a more solid evidence-base to help them analyse their work. At CRAE, for example, we have begun work recently with a number of schools experimenting with a number of imaginatively different ways of combining an inclusive ethos with the specialist support and guidance that autistic students often need.

Also, there appears to be evidence that the broader public debate is also shifting in this direction, something indicated by the widespread and positive attention given to books like Steve Silberman's *Neurotribes* and Andrew Solomon's *Far From the Tree*. The success of organisations such as the Autistic Self-Advocacy Network in the United States has also ensured that the voices of autistic people are more loudly heard when key decisions are being made that will significantly affect their future.

It was especially encouraging, therefore, to see that people on the spectrum were critically involved in Autism-Europe's latest International Congress – both in the design of the event, and in the selection of content. Half of the scientific committee was made up of self-advocates, ensuring that the selected topics would be relevant to people on the autism spectrum. And presentations by autistic people, including the sharing of personal experiences, were also encouraged.



Not only was the research agenda of the Congress focused on the needs of autistic people, but the venue itself was also made accessible with the help of an autistic consultant who visited the venue and advised organisers as to which adaptations needed to be made.

Furthermore, speakers were also encouraged to use acceptable terms when talking about autism, based on the preferences of self-advocates and the autism community (Kenny et al., 2016). In this way, the congress organisers really embraced the motto “nothing about us, without us” – an ethos not only key to the disability movement but also fully in line with the approach that we advocate at CRAE.

There is, however, still a long way to go. We know that the challenges autistic people often face remain severe, whether with regard to social support or employment or mental health. And we know that not enough is yet done by some of the major institutions who could help to make a difference, be they universities, funding bodies, governments or others. That's why we need to continue to put pressure where we can to encourage every new autism initiative to involve autistic people in its design and to directly address the everyday concerns that autistic people face. It will be a long and sometimes hard road to bring about such change, but it is essential that we all keep going along the way.

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- See crae.ioe.ac.uk and www.shapingautismresearch.co.uk for more details and contact Liz Pellicano on l.pellicano@ucl.ac.uk



Miller: "I was walking with the group to the local village, Zitsa, to collect mail and supplies when Tasos stopped, raised his hand above his head and stared at me. It was the only time he made eye contact in three days."

The faces of the Greek financial crisis

In June 2015, documentary photographer Graham Miller spent several days living at the Eleni Gyra home for adults with autism in Greece to assess the impact of the financial crisis on disabled people. He found a community where, despite not being paid for periods of up to six months, support workers continued to give the highest standards of care.

In summer 2015, at the height of the financial crisis, Scottish documentary photographer Graham Miller travelled to Greece with his camera to capture the ravages of the economic situation with regards to people with disabilities. 27km from the city of Ioannina, Miller found the doors of the Eleni Gyra centre open to him. Aged between 27 and 43 years old, most of the residents are non-verbal autistic people and are often also affected by other conditions. One of the residents, for example, is also blind and deaf. The Greek Society for the Protection of Autistic People (GSPAP), member of Autism-Europe and responsible for the running of the Eleni Gyra centre, allowed Miller to live on the premises and, for several days, he photographed what he saw.

Miller affirmed that, during his stay there, he never tried to make assumptions. "I prefer to see with my own eyes and then communicate that to the world in an unbiased way thereby allowing others to make their own judgements. I did, however, assume that the financial crisis would affect those who were less able to care for themselves more deeply and that's not what I found", said Miller. However,

it is only due to the support of the local community and the dedication of the staff.

The role of the GSPAP in Greece

The Greek Society for the Protection of Autistic People (GSPAP), member of Autism-Europe, is a nationwide non-profit organisation aiming to uphold the rights of people with autism.

Since 1992, the GSPAP has been working throughout Greece to raise awareness about autism, support the families of autistic people and foster the establishment of public services and facilities by the national and local authorities.

Together with the Eleni Gyra centre, as of 2008 the GSPAP has also been running the Seirios centre, a day centre for adults with autism in Gerakas, in East Attica. There, people that need a significant level of support have access to education in an adapted and supportive environment which helps them to cope with to fulfill their own needs.

All services provided by the GSPAP are in accordance with the United Nations

Convention on the Rights of Persons with Disabilities, ensuring that they are entirely tailor-made and affordable for their users.

"Autism: Heart of angels", exhibited in Edinburgh

The photography exhibition resulting from the Miller's work in Greece was recently presented in the form of 14 striking light boxes during the 11th Autism Europe Congress in Edinburgh. Miller is currently working on a project with the National Autistic Society in Scotland and aims to continue working in new projects linked to autism in the future.



This photo exhibition was shown during Autism-Europe's 11th International Congress in Edinburgh



The house is located in Zitsa, a traditional Greek village in the mountains above Ioannina.



The Eleni Gyra center

The Eleni Gyra centre is the first educational and welfare centre for adults with autism in Greece, established in 2000. The house is located in Zitsa, a traditional Greek village in the mountains above Ioannina. The house itself was donated to the GSPAP by a local man, in memory of his wife, who had passed away.

The objective of this full-time centre is not only to provide care and attention, but equally pleasant, high-quality, and homelike living and entertainment. It offers the means for its 12 residents to receive appropriate and lifelong learning in order to make the most of their abilities, improve capacity building, develop skills regarding self-care, communication and socialisation, promote self-advocacy and support decision making.

The financial crisis in Greece has affected funding, and resulted in significant cuts across the health and social care sectors. The locals are supportive of the community, regularly donating food and other supplies.

Graham Miller

Graham Miller is a Scottish-based documentary photographer. He graduated with distinction from LCC University of the Arts in 2013 with an MA in Photojournalism and Documentary Photography. He is a member of the Greek-based photography collective M55Reports.

His work is focused on challenging stigma in relation to disability and has been featured in the international press, via newspapers and magazines such as *Stern* (Germany) and *The Guardian* (UK).

He has also been featured in a number of solo exhibitions, and has been a regular contributor and panellist at the Scottish Mental Health Arts and Film Festival. In 2013 he published the book *Six Percent: Down's Syndrome: My Photographs their Stories*, which sold over 500 copies.

More information about the GSPAP : www.autismgreece.gr

More information about Graham Miller : www.photohonesty.org

David Nicholson: Self-advocate, autism consultant and musician

“When I got formally diagnosed, I felt a strong sense of relief”

David Nicholson, who delighted participants at Autism-Europe's 11th International Congress with a violin performance, is a twenty seven-year-old self-advocate who has managed to combine his two passions: politics and music.



A violinist since the age of 11, and diagnosed since he was 19, David Nicholson affirms that “music has no doubt at all helped me in coping with having Asperger Syndrome”. “Through music and playing my violin I am able to express myself and to release my emotions. It helps me to communicate how I’m feeling. If I’m feeling sad or anxious I can turn to my instrument and play some slow airs which in turn helps to release the anxiety and sadness. I feel better afterwards”.

Despite having difficulties socialising and communicating, he has taken his own advice of “embrac[ing] being autistic” and has successfully landed jobs both in the UK and the Scottish Parliaments, as well as in other governmental bodies and with political parties. In the field of autism, David has also worked for associations like the National Autistic Society, Ambitious about Autism or Inclusion Scotland.

Autism-Europe: We read the following sentence on your blog: “I do not and never will regret having Asperger Syndrome. It

A message to your autistic peers

My main message to my peers on the autism spectrum would be to always be true to yourselves, celebrate being different and embrace being autistic. Dare to dream big and, despite what others may think, fight on and be the success that you can be.

is part of who I am”. To what extent did your life change after being diagnosed? What does it mean for you to be a person on the autism spectrum?

David Nicholson : When I got formally diagnosed in 2008 I felt a strong sense of relief. It made things official and I knew that I truly was on the autism spectrum. It did not change my life drastically but I knew that with a diagnosis I would be in better position to access support if I required it.

I take great pride in being autistic despite the challenges that the condition brings to me. It is who I am and forms a large part of my identity. It allows me to focus on what I love in life: music, politics and the countryside. I am determined that having Asperger Syndrome will not be a barrier to me achieving what I want to achieve in life including standing for Parliament as a Conservative candidate, finding a lady and getting married, having kids etc. There will be challenges ahead but with a strong fighting spirit I will make sure that any barriers will be smashed down.

AE: What challenges do you face in your daily life as a person on the autism spectrum?

DN: The main challenges that I face at the present moment in time is anxiety and social isolation. I do not have many friends where I come from in Fife (a county in the East of Scotland) and my good friends are scattered around the rest of Scotland and the UK. That means I do not have a very good social life. That has resulted in me sometimes trying to be someone I’m not in order to fit in. That was a mistake and never again will I change who I am in order to either a) fit in or b) impress people. It is essential not only for me but for others on the autism spectrum to be true to themselves regardless of what other people think in the community and elsewhere. In order to combat the anxiety and loneliness I have recently joined a local music group in Fife where I am meeting new people and that is helping my confidence and reducing my anxiety.

AE: As a self-advocate and autism consultant, what are your professional challenges and objectives in the field of autism?

DN: As a self-advocate my main challenge is to ensure that no area of society is excluding people on the autism spectrum. Be it from education through to sports and politics, society must be accessible and inclusive to my peers and I who are on the spectrum. I think society would be greatly enriched if people on the autism spectrum were given the chance to show off their abilities and talents in a wide variety of fields including law, science, music and technology.

It is important that Governments, autism self-advocates, families, the voluntary sector and others come together to try and work in partnership to ensure that society is as autism friendly as possible, where each and every person on the spectrum has the support that they need and to ensure that they have the opportunity to be as successful as they can be in any area that they have an interest in. I passionately believe that people on the autism spectrum have to have more opportunities to express themselves and to have their voices heard by those in positions of influence and power. My peers’ voices deserve to be heard and acted upon.



Evelyne Friedel

As much indifference as there are differences



Evelyne Friedel is a French lawyer admitted to the Paris Bar in 1992. She has a Doctor of Laws degree (University of Paris), and a Master of Laws (LLM) (Georgetown University Law Center – Washington D.C.). Since 2008, she is Partner of Taylor Wessing. She is vice-president of Autism-Europe (former president 2008-2012). Evelyne was president of *Autisme France* for several years. She also founded *AFG Autisme* in 2005 with her husband. In addition to her voluntary work for autism, Evelyne is also the mother of a teenage boy with autism who is in need of a high-level of support.

It is frequent to hear how people with autism are different due to their genius, their rare intelligence, their unusual skills and abilities, and to underline that they are like the rest of us with that extra something, so almost like the rest of us.

I have been defending their rights for 15 years now and was at the origin of the case won against France in 2003 by the Council of Europe, which resulted in the implementation of the national plans for autism.

Although much remains to be done, the fact is that certain progress has been made. At the same time, over the last 15 years we have witnessed a dramatic increase in the prevalence rate of autism. The official figure at the time was 1 in 1.000 (INSERM, 2002). Today we have reached a level of 1 in 100, i.e. 10 times higher, which means 660,000 persons with autism in France, compared with 66,000 previously.

The situation is more complex than that. Better diagnosis, advances in research, new classifications from the WHO and new definitions of developmental disorders are the reason for this, not an epidemic.

Today, many brilliant artists, researchers, philosophers etc. whose outstanding intelligence we boast of could fall within the scope of this wide spectrum of autistic disorders. Is it really necessary to label them all as having a disability? This is a significant question. Are we talking about disability or rather social interaction difficulties that often lessen at adulthood?

The autism spectrum is thus broadening, ranging from people who are actually superiorly intelligent, though they present communication difficulties, to the most vulnerable who are non-verbal and suffer from severe mental disabilities, totally dependent even for the simplest daily activities and showing behavioral disorders (self-injury etc.).

I was President of *Autisme France* and Autism-Europe, and am still Vice-President of the latter. I am also a founding and active member of *AFG Autism*. However, today I am merely speaking in my personal capacity and want to say just how the defense of those who are most vulnerable is, in my opinion, more essential than ever.

" In fact, constantly hearing only the voices of those who have this superior intelligence, this independence, and can integrate despite their difficulties, we end up forgetting the very existence of the most vulnerable. "

For several years now, the emphasis has been on autistic genius!

Worse still, some communications use the term "severe autism" to present intermediate cases, thereby totally detracting from and denying the most serious cases!

In its Decision of 2003, the Council of Europe stressed that people with autism were victims of discrimination not only compared to ordinary people, but also compared to other people with disabilities.

" I fear today that those most severely affected by autism, who still only make up 1 in 1,000 of the population, will be forgotten, or even "excluded" by the majority which is able to talk, learn and work. "

Let us not forget the children who will always need specialised services or establishments in spite of the comments aimed at their closure or suggesting that everyone can go to a mainstream school. This is not true! Those children most severely affected by autism will never learn how to read, write, or count and once they become adults they will still not know how to hold their cutlery or perform daily activities such as washing themselves, dressing etc. They will always need round-the-clock supervision and care. All this in spite of the best educational strategies selected.

Once they become adults, these people will not be able to work, not even to do repetitive tasks. The remarks made implying they can all work are false.

It therefore remains essential to pursue the development of suitable structures, of human and family scale, still compliant with the necessity to de-institutionalise.

So it is important to remain "the voice" of these children and adults who are non-verbal, rendered invisible today, and who are simply not "almost like the rest of us".

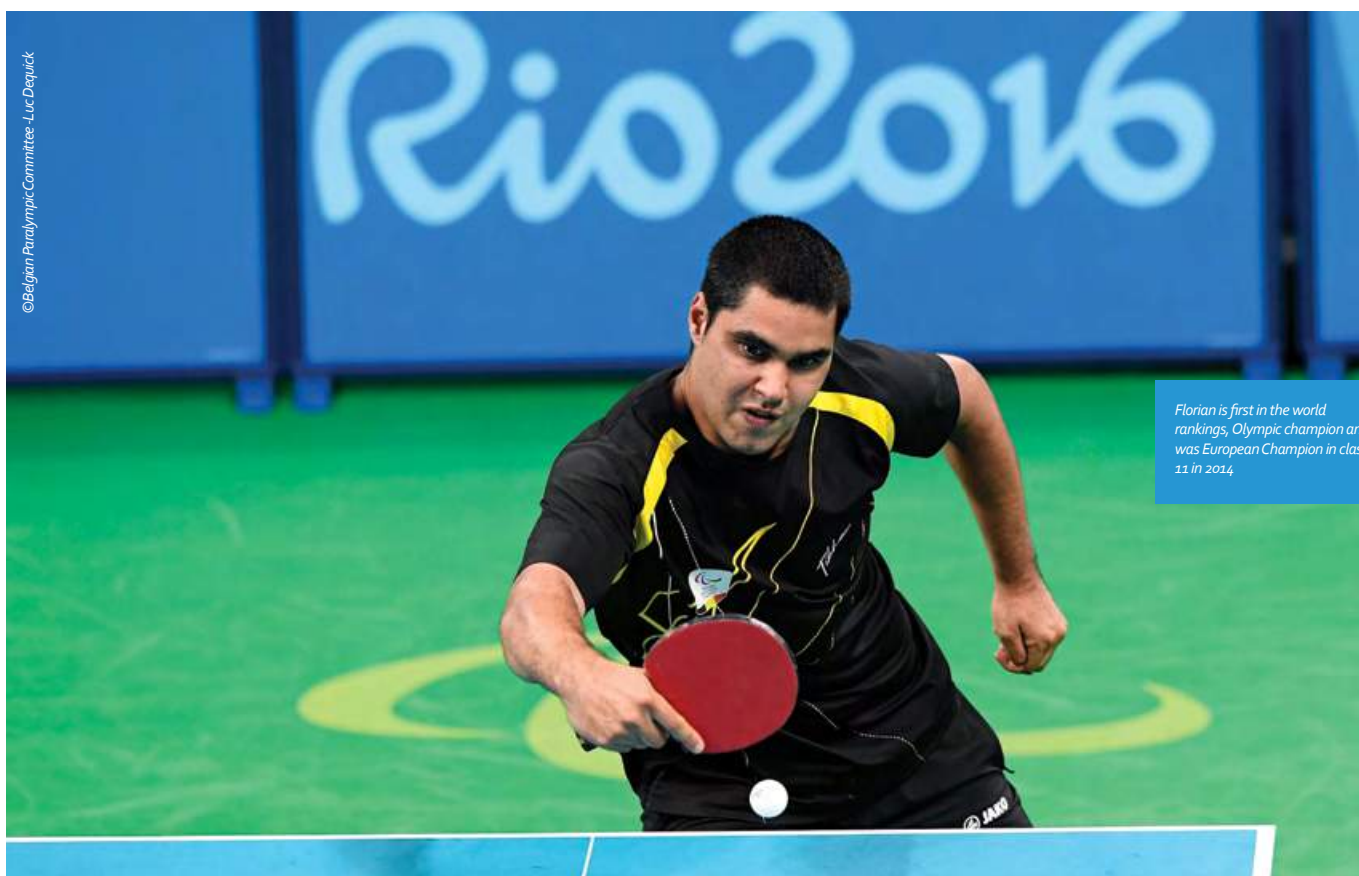
Never deny their existence, never deny the reality, continue to defend their rights, respond to their very special needs, precisely so they may be integrated, without confusion, in full respect of their dignity and ALL THEIR DIFFERENCES!

I conclude here with the utterly true remarks made by Kari Steindal in 2004 "A society that can cope with autism can deal with all forms of disability". The autism referred to here is not that which the media or the majority of us like to present.

Florian Van Acker – Olympic and world table tennis champion with autism

“Remain realistic, continue, and don’t give up!”

At the age of 19, Florian Van Acker, an athlete with autism, has already carried Belgium to the highest level of table tennis worldwide. Number 1 in the world rankings, he became Paralympic Champion in Class 11 (Intellectual Disability) during the Rio 2016 Olympic Games. In 2015, he became European Champion in Class 11 and in 2014 he made his debut in the World Championships, taking home a bronze medal.



Florian is first in the world rankings, Olympic champion and was European Champion in class 11 in 2014

Autism-Europe: What does it mean for you to have won a Paralympic gold medal in Rio?

Florian van Acker: It's a dream come true, that's what it means to me. It's an incredible feeling, like the excitement of a child the day before the start of the summer holidays.

AE: Tell us about your experience in Rio.

FvA: I went to Rio a week before the Paralympics, to gradually get used to my environment, the Olympic Village, my room, and so on. It is not easy for a person with autism to get out of his usual environment, especially in a stressful context. I had time to discover the venue where we were

going to play and train. During my second week there, I mainly rested. I ate and went to bed at fixed times.

AE: What is your experience as a player in the "ordinary circuit"?

FvA: It's very positive, but it was not easy at first. Because of my autism and my slight mental handicap, it is not always easy for me to join a group of people who don't know me.

They do not see that I have a disability. I have been playing table tennis for 9 years now in a standard category. It is thanks to the help and patience of William, a friend and member of the Board of Directors at my first club who taught me to play table

tennis and who believed in my abilities, that I have been able to gain confidence and recognition.

AE: What sports do you practice and why is table tennis your favourite?

FvA: For the time being I only play table tennis and, to relax, I go cycling as well. I also like horseback riding. I did it a lot in the past but I stopped for lack of time and for fear of falling and hurting my hands.

I also did judo and played basketball, but the rules were too complicated so I stopped. Basketball was especially difficult because it is a team sport that constantly requires you to take account of the other people in the game. In table tennis there is

only me, and I am the only one responsible. Although it may sound strange, I also like the fact that the ball goes back and forth, always with the same effect, like a pattern it repeats.

AE: What does being autistic mean for you?

FvA: With age, I understand better who I am and what I am like. I know that I am not always easy, but I am able to talk about it and I do not consider myself inferior to others, merely different. Thanks to my success in the world of sport, I feel equal to others. If someone does not accept me or is unpleasant towards me because they do not know me, in this case my mind is made up about them, and I decide to have nothing more to do with them. I stick with those who remain by my side. It is not always easy and sometimes I lose my temper.

AE: What are the difficulties you come across as an autistic person?

FvA: Trying to overcome the chaos and pressure I sometimes feel by concentrating on sport and taking myself off to my room to listen to some quiet music; hoping that there will not be too many changes to the day's plans and, if so, learning to accept that some things are not possible or are inevitable.

AE: Has sport helped you to cope with your autism?

FvA: Thanks to sport I am calmer and I have more confidence in my abilities.

AE: What things do you enjoy doing when you are not practicing sport?

FvA: Listening to music and watching films

AE: What new challenges have you set yourself?

FvA: To win the 2018 World Championships in my category. I already have the bronze medal, now I hope to win a gold. I would then have the first-place medal at the Paralympic Games, the World Championships and the European Championships.

AE: Do you have a message for other autistic people out there?

FvA: First and foremost, believe in yourself and those who support you, help you and believe in you, especially your parents who know you the best, but also your friends and all those who want what's best for you. People with autism very easily recognise people who have good intentions and those who don't.

My motto, "never give up" is as relevant to sport as it is to life in general.

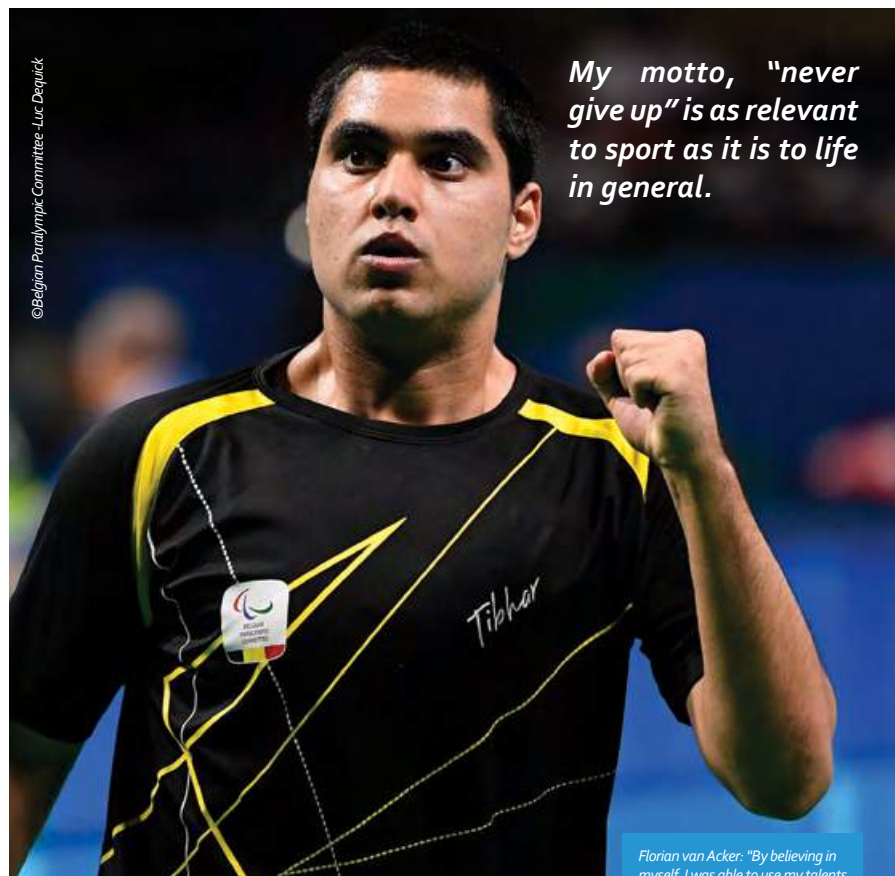


Florian with his parents Eric et Dora Van Acker-Debedts in Rio

Florian is the adopted son of the Belgian couple Eric and Dora Van Acker-Debedts. Florian was abandoned shortly after his birth in Romania. He spent the first years after his birth in an orphanage and a transitional foster family. Florian was 3 and a half years old when he arrived in Belgium.

Dora Debedts recounts her experience in an interview with *Sporta Magazine*: "He was active, impulsive, agitated. At first we thought that this agitation and tension was due to his stay at the orphanage. At the beginning, we had not considered other possible reasons, especially knowing that at the age of two Florian could not yet walk, ate no solid food, and spent most of his time in a small bed.

Later, my husband and I thought that his dynamism was linked to his thirst for discovery or an emotional need. We assumed that his IQ, slightly below average, was either hereditary or due to the neglect and lack of love that he suffered at the very beginning of his life. (...) Due to his intellectual or cognitive impairment, he is limited in his communication, autonomy and social interaction. At school, if something did not interest him, he would close his book, and that was it, full stop. He agreed to make a little effort only if he liked his teacher. Fortunately, this evolved positively over the years."



My motto, "never give up" is as relevant to sport as it is to life in general.

Florian van Acker: "By believing in myself, I was able to use my talents and improve myself. So I gained more confidence in myself and all this has brought me more serenity."

Tracey Francis

Life after school - keeping on track

You're on the right train but half way to the destination it stops: the rest of your journey is on foot, somewhere you've never been and without directions. What are the chances of losing your way? Probably quite high.

That's exactly where too many autistic young people find themselves when school ends. The age at which children's services hand over to adult agencies varies, but it's fair to say no country so far appears to have solved the problem of transferring support seamlessly and effectively. Yet where support is lacking, it can be the equivalent of the train terminating before its passengers reach the station.

There are three categories of "destination" for school leavers – further or higher education; first employment or training; or neither of these. But actually they aren't destinations at all: they're staging posts on a journey that should take someone in a direction they want to go. That requires preparation and planning to begin well before the school leaving date. And for many young people with autism, clear pathways and robust support structures are a must.

For those who know what they want and have the right qualifications, identifying next steps can be more straightforward. But for those who leave school with qualifications that don't match their ability, haven't yet developed the social skills for employment or training, struggle with mental health issues such as anxiety or depression, or can't visualise what next steps might entail, things are more problematic. A different kind of support is needed to make sure they don't lose ground in terms of motivation, aspiration and social integration.

Having nothing in place can have an immediate impact, according to Štěpán Hejzlár, head of social rehabilitation at NAUTIS, the national institute of autism for the Czech Republic.

"Often when clients enter our service, they have been out of the school system for a few years and they've lost ground in that time," he says. "Their habits – getting up at 7.00, being on time, being in contact with other people as they did in school – have changed. For some it's an uphill task because they've had that gap."

For many young people, transition to adulthood is second only to the first few years of life in significance and impact on future outcomes: yet it receives only a fraction of the attention and finance available to early-years services. The time is right for a serious debate about how money already in the system should be allocated to make the biggest difference.

As a social worker in Norway put it: "In primary they have assistance all the time. In secondary it gets less and less, and disappears. And when you should manage by yourself you have no one to lean on. Maybe they don't need all those assistants when they are seven. Maybe they should put them in at the end of the education system instead."

There is an urgent need to identify who within adult services should take responsibility for developing and implementing a support plan once a young person has left school. This is especially important for young people who do not go straight into education or employment: without clear assessment of their individual needs, and a plan to address these, temporary obstacles are much more likely to become entrenched barriers.

All the available evidence is that many able young people with autism will not automatically find their way into employment appropriate to their abilities and needs without support. Improving experiences at this stage, while the brain is still developing, behaviours are changing and momentum from school remains, can be the key to ensuring they have the same chances as their peers to achieve personal independence, find work and integrate in their communities. Fail now, and many find doors begin to close that may never reopen.

For more information, or to download the report, visit
www.lifeontheedgeofthecliff.com



Tracey Francis received a Travel Fellowship from the Winston Churchill Memorial Trust to research post school experiences of young people with Asperger's Syndrome, ADHD and Tourette's Syndrome in Italy, Norway and the Czech Republic. Her report includes examples of excellent practice from the three countries, along with recommendations based on interviews with fifty young people with one or more of these conditions and/or their families.

Getting to work: employability and therapy go hand in hand at Casa di Ventignano



Casa di Ventignano is a specialist centre for autism in Tuscany based on a unique collaboration between the regional healthcare body in Empoli, and a social cooperative. *Autismo Toscana* helped develop the project. It's a day-care facility for children and young people aged from 8 to 25, focusing on health and social habilitation, and complementing support work in mainstream education for those of school age and within the local community for those who are older.

Students experience adventure, community living and new challenges at Norway's folk high schools



that the formal system doesn't or can't provide, to anyone who wants it - remains the same. More than 10% of all school leavers enrol every year.

Each school is an independent, not for profit enterprise. Many specialise in outdoor activities, others in theatre, music, technology, water sports, and opportunities including work experience and trips abroad. There are no

Italy - Casa di Ventignano

Casa di Ventignano is a specialist centre for autism in Tuscany based on a unique collaboration between the regional healthcare body in Empoli, and a social cooperative. *Autismo Toscana* helped develop the project.

It's a day-care facility for children and young

The seamless progression allows maximum flexibility and continuity of support to meet individual needs.

The team is led by neuropsychiatrist Cinzia Pieraccini and includes psychologists, speech therapists, educators and social healthcare operators working alongside music and art therapists, pedagogues and specialised technical staff who manage the market garden in the grounds of the old farmhouse. Individual programmes incorporate life skills and therapy alongside practical work-based learning, all under the supervision of mental health professionals.

At present this is the only publicly-funded centre of its kind in Italy, and a clear example of what is possible with coordinated and creative partnership working.

Norway - Folk high schools

Folkehøgskoler or folk high schools, are an example of a post school option that offers the chance to develop new or essential skills as part of a small, supportive community. They have been part of the Norwegian tradition for 150 years but the premise - offering learning

entry requirements and no formal teaching programme.

The appeal is clear: with no leaving qualifications in the balance, the pressure is off. Many relish the chance to develop practical skills and abilities that haven't been part of their academic training. For students with additional support needs they are an opportunity to be part of a learning community that focuses on what you can do, not what you can't. Sometimes it's the first chance these students have had to be valued by their peers on completely equal terms.

Folkehøgskoler are a bridge between school and the adult world for those who aren't ready to make the leap themselves. Students apply for funding as part of their higher education entitlement, making them widely accessible. All are residential – a small, informal but structured environment that creates the perfect setting for learning essential life skills, social responsibility, and respect and value for others.

Prague theatre group DramAS develops essential skills for life and work



available alongside their help into work programmes.

Štěpán Hejzlar, head of social rehabilitation and supported employment, believes effective support

Czech Republic - a holistic approach

Creating leisure and free time opportunities is an essential part of the work undertaken by the social rehabilitation team at NAUTIS, the national institute for autism, with a readers' club, yoga, music therapy, an art workshop, cooking classes and more

has to address the needs of the whole person.

One example is a dating agency in collaboration with organisations whose client groups share similar characteristics and inclusion difficulties.

This is a direct response to need, as he explains: "Clients come to my office to find a job, but within 30 minutes they switch topics and say they are lonely and can't find relationships. Having friends, a girlfriend or a boyfriend, feeling respected in society – it's one of the most important things in life. If they can overcome loneliness, for me that would be the best result of our work."



One of the "AT home" mobile homes being put in place

Mobile homes to empower autistic people in Denmark

Twenty six mobile homes have been developed in Central Denmark (Midtjylland in Danish) aiming at being relocatable in order to meet the requirements of people with autism. Offering flexibility in terms of size, and built with high quality and environmentally-friendly materials, this new concept has been developed by the service provider Special Area Autism (*Specialområde Autisme*) for autistic people facing housing challenges. From July to October 2016, twenty three people have been benefiting from this new type of housing.

The right to live as independently as possible is one of the requirements of many adults with autism aiming at being fully empowered and included in the wider community. With this in mind, the service provider Special Area Autism, located in Central Denmark, has developed a new housing concept based on the rethinking of the physical framework, where experience and knowledge of autism-friendly construction come together.

The "AT Home" project consists of twenty-six small, modern houses that can be moved and settled wherever their future inhabitants want to live (albeit with some regulations and practical issues that restrain to a certain extent the spots where the house can be placed). The project's name – being a shortened version of "Apart Together Home" – is derived from the

notion of making people feel "at home" and at the same time giving them the opportunity of belonging to the wider community.

This housing concept breaks with the convention that dictates how autistic people should live in society, one which often leaves them marginalised. Through designing for diversity, autistic people can live together in a clustered and inclusive community, yet apart, allowing them to maintain their own privacy.

For instance, there are some young people who find it very hard to leave the family home. In such cases, the "AT home" unit can be set up in the parents' garden. Thus, they can move away from their parents in a very smooth way and, once she/he is familiar with the new house, it can be

moved to where the person may want to live her/his adult life.

Lars Hinge is one of the beneficiaries of the initiative. He lives in Tørring, a small town in Central Denmark, and calls his new home his "penthouse apartment" because he finds it very exclusive. "It is very good. My stress has been reduced and there is not so much space to keep clean", he says remembering that he used to live in a very big apartment. "It is nice that it has a glass door, so I can see who is standing in front it. Now it is easier to get in touch with the staff". His "AT home" has been placed on the premises of a group home, where some of his friends live, and where there are staff working for the most part of the day. His former apartment was situated around a kilometer from the group home.

The impact for the autism community

Lars Aarup Jensen, area manager of Central Denmark's Special Area of Autism, explains that the project stems from the premise that the physical setting and environment is crucial for the well-being and development of people with autism. "If you don't have a secure dwelling where you feel at home, your well-being and your chances to develop are challenged", Jensen says.

"We were very much inspired by a quote from the famous Danish painter Asger Jorn who said: Let us start with what the framework is needed! Let us recreate human life, and let the elastic framework be moulded by developments in the manifestations of this life so that living shapes the framework instead of the framework intruding on and shaping life. This is a noble and urgent challenge", Jensen continues.

"We were attracted by Asger Jorn's idea of establishing an elastic framework as the best possible way of supporting autistic people. We needed a new housing model based on this concept in our region".

"We will be Denmark's best, most innovative and specialised region in the area of autism" affirmed the Regional Council Chairman Bent Hansen when Central Denmark's group home containing the mobile homes was opened.

Heidi Thamestrup, president of the Danish National Association for Autism (Autism-Europe member), believes that "this is a unique opportunity". "Moving can be a huge and confusing change as well as a stress factor for people with autism. With mobile

houses we can move home while preserving a safe environment. For instance, you can move the autistic person closer to help or training", says Thamestrup. "The region of Central Denmark understands what autism is all about. There is an interest in making autistic people part of society instead of trying to fit autism into the existing offer. It contributes to good inclusion for people on the autism spectrum", she points out.

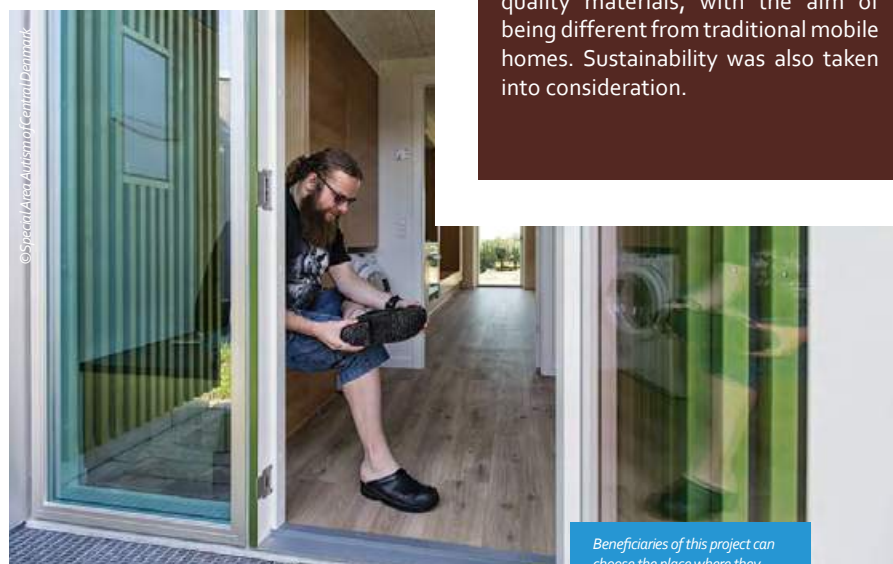


View of the outside and the inside of an "AT home" dwelling.

What are these homes like?

These small, modern mobile homes have been designed by architects striving for quality, with a sense of great aesthetics and specially designed solutions for people living with autism. Built using environmentally-friendly materials, they are also flexible in terms of size.

The houses are made using good quality materials, with the aim of being different from traditional mobile homes. Sustainability was also taken into consideration.



Beneficiaries of this project can choose the place where they want to settle their "AT home".

Inclusiveness and active citizenship for all

According to Jensen "the most important thing is that the concept is on the right path". Jensen explains that that path makes reference to the United Nations Convention on the Rights of Persons with Disabilities, especially Article 19, which underlines that:

"States Parties to this convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community".

"Communities are very interested in this concept because, in my opinion, there is a general understanding of what we need in order to be more flexible in terms of housing. We want persons with autism to be part of society and not remain on the sideline", Jensen concludes.

Specialist Area Autism's mission is to provide and develop the ultimate conditions for well being, development and change for adults with autism. They provide the following services designed for adults who have been diagnosed with autism: Group homes, intensive life skills courses for individuals, supervised living, education and employment. One of its departments also provides: advice, consultancy, research and education in autism for residential social workers

More information:

www.sau.rm.dk/om-os/about-us

"I'm not unemployable, I'm autistic"



Image and quote taken from the film "Could you stand the rejection?"

As a second stage of its successful campaign Too Much Information (TMI), the National Autistic Society (NAS) presents the video "Could you stand the rejection?", aiming at closing the employment gap for people with autism, since just 16% of autistic adults are in full-time paid employment in the UK.

"Employers don't see my abilities. They see my autism. They see a problem. And that makes them quick to judge me, to dismiss me. Simply because they don't understand me." These are some of the thoughts featuring in the video created by the NAS to launch the second stage of the TMI campaign, the UK's biggest ever campaign aimed at improving public understanding of autism. This video shows what job interviews can be like for an autistic person.

"Autistic people and their families have told us that understanding in the workplace is one of their top priorities for change. So, in this next phase of the campaign, we turn to autism and employment", states Mark Lever, NAS Chief Executive. "Work will not be appropriate for everyone on the autism spectrum, but our latest survey of autistic adults and their families showed that the vast majority want to work", he added.

The day before World Autism Awareness Day (April 2) 2016, the NAS released the campaign's first video. The video puts the viewers in the shoes of a child with autism experiencing sensory overload to make them understand the overwhelming impact it can have on a person with autism, with reactions that could be interpreted as bad or disruptive behaviour.

Call for Government action

The Government has just launched a consultation on disability, health and work, which is open until the 17 February 2017. They want to understand how to improve the system so that more disabled people who want to work are able to do so. The NAS insists that it is important for them to hear from people living with autism to make sure that the specific needs of autistic people don't get ignored in this. The Government will use this information to inform their "green paper" – a document with ideas for how to support more disabled people into work. It is possible to respond to this consultation via the NAS website.

In accordance with this consultation and the data reported by the NAS, a call for action in the framework of the TMI campaign for the Government has been made.

The NAS addresses the need for leadership from the Government – a new programme to promote the potential of autistic people and an end-to-end pathway to work, which includes specialist help. Employers can also make a huge difference by learning about the adjustments that autistic adults may need.

With the right information, employers can reduce the overload of too much information that autistic people may experience at work. They can offer internships and apprenticeships and work with the NAS and other autism experts to become Autism Friendly Employers. Working together, the UK Government, devolved governments, local government, third sector and employers, can make sure we understand autism, the person and what to do to tackle the autism employment gap once and for all.

Only 16% of autistic adults are in full-time paid employment in the UK



For nearly a decade, the full-time employment rate of autistic adults has stagnated in the UK. A survey carried out by the NAS in 2007 indicated that just 15% of autistic people were in full-time paid work. Shockingly, in this year's survey, the figure was just 16% for full time employment and 32% for autistic people in "some kind of paid employment".

The British Government has made a very welcome pledge to halve the disability employment gap by the end of this Parliament's mandate, meaning that they have to shift the disability employment rate from 47% to 64%. But the autism employment gap is even wider. For the number of autistic people in work to reach 64%, the Government will need to commit to doubling the number of autistic people in employment by 2020.

The NAS is currently asking people to sign a petition via its website, calling on the Government to double the number of autistic people in work by 2020. In December 2016, 2,760 signatures were still needed to reach the 30,000 mark.

The European Day of Persons with Disabilities celebrates 10 years of the UN CRPD

The conference specifically celebrated the 10th anniversary of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Presentations and discussions focused, in an interactive way, on the progress that has been made in the EU to promote the rights of persons with disabilities, based on the UN Convention.

Since 1992, the International Day of Persons with Disabilities (IDPD) has been celebrated annually on 3 December around the world. At the European level, the European Commission and the European Disability Forum (EDF) mark this date with the annual "European Day of Persons with Disabilities" conference. This year's conference took place on 29-30 November 2016 in Brussels with the theme: "Marking 10 years since the adoption of the UN Convention on the Rights of Persons with Disabilities".

The objectives of 2016 conference included assessing the current status of the UN CRPD and Sustainable Development Goals (SDGs), and laying the foundation for a future of greater inclusion for persons with disabilities.



Group photo of the representatives of the cities awarded for improving accessibility for elderly and disabled citizens.

UN Sustainable Development Goals (SDGs) and disability

In September 2015, the General Assembly of the United Nations adopted the 2030 Agenda for Sustainable Development that includes 17 Sustainable Development Goals (SDGs). Building on the principle of "leaving no one behind", the Agenda emphasises a holistic approach to achieving sustainable development for all. The SDGs explicitly include disability and persons with disabilities in the parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and the monitoring of the SDGs.

The UN CRPD has been ratified by almost all the 28 Member States of the EU, the only exception is Ireland (which has signed but not yet ratified). According to Article 9 of the Convention, disabled persons should be enabled to live "independently and participate fully in all aspects of life". As reported by Eurostat, 80 million EU citizens are affected by some kind of disability, a number which is projected to increase to 120 million by 2020 considering the rising elderly population.

Chester, European Access City 2017

The 7th edition of the Access City Award ceremony, a European prize for cities improving accessibility for elderly and disabled citizens, also took place during the conference. Ms Marianne Thyssen, Commissioner for Employment, Social Affairs, Skills and Labour Mobility, announced the winner. Chester (UK) was chosen out of 43 cities from 21 EU countries for "how it has made the historic center fully accessible, and for recognising and illustrating that it makes economic sense to invest in accessibility". Rotterdam (The Netherlands), Jūrmala (Latvia), Lugo (Spain), Skellefteå (Sweden), Alessandria (Italy) and Funchal (Portugal) were also awarded for improving accessibility for the elderly and disabled citizens.

More information: <http://ec.europa.eu/social/main.jsp?langId=en&catId=1137&eventsId=1152&furtherEvents=yes>



Pietro Cirrincione's intervention during the European Day of People with Disabilities event.

Pietro Cirrincione, Autism-Europe's vice president and self-advocate, addressed participants with a statement during the panel about accessibility and freedom of movement within the EU: "(...) Ten years after the Convention, the accessibility needs of other types of disabilities (cognitive and sensory disabilities) are still poorly understood, for example the autism spectrum, relational disabilities, intellectual disabilities, learning disabilities, and others. It's time to let everyone know about our accessibility needs that are, for example, having information available in easy-to-read format, and accompanied by pictures and symbols, simplified structures and processes to avoid cognitive overload, and the training of staff in public services to deal with those who have difficulties in communication and social interaction. So I ask for the help of everyone".

As an example of accessibility for people with autism in Chester, 137 staff members of the Chester zoo have attended autism awareness training delivered by Cheshire Autism and Autism Together. The training is rolling out to further staff during the course of 2016 with the aim of further improving the zoo's offer as an autistic friendly visitor attraction. Furthermore, the designer outlet Cheshire Oaks, a shopping complex just outside of central Chester, have also signed up to become more autism-friendly.

Daley:

an assistant to perform daily activities

Daley, an assistive software solution that allows carers to set up and plan daily activities for the people they are supporting, was proudly presented during Autism-Europe's 11th International Congress as a product of close cooperation between multiple international organisations and some volunteers.

Daley is a new, user-friendly, technological solution that assists the individual in performing daily activities by providing step-by-step guidance, using images, text and audio. It is aimed at people of all ages with special needs (who have difficulties planning and performing daily activities) and who require assistance from another person. Thus, people with autism, Down syndrome, Alzheimer's or any other form of dementia, and people recovering from different types of brain injuries caused by accidents or strokes, among others, can benefit from this technology.

The service offered by Daley can be used by an individual needing assistance themselves, as well as their carer. The carer can be a relative or friend of the individual with special needs, a doctor, nurse, or even an organisation that has people under its supervision.

How does it work?

The service consists of two parts: the online dashboard for the carers and the mobile app for the person that requires special care.

1. Online dashboard

The carer can access Daley through its website using a computer or any mobile device, and log in on their personal dashboard. There, they can programme the person's tasks for the day, week, or even the entire month, with the option to modify them at any time. They can configure the order of the activities and the duration of each step for one or more persons, for instance. Moreover, they can establish an action for the "panic" button. This action can be calling, texting, or sending an email message to a dedicated person (the carer or a relative of the individual) directly from the Daley app.

2. Mobile app

The activities programmed by the carer in the online dashboard are sent to the individual's Daley mobile application. When it is time to perform an activity, the app will notify the individual through an alert or notification. This will prompt them to open the scheduled activity in the Daley mobile app, which will automatically show every step to follow in order to complete the activity. Each step will be carefully explained using voice, text, and images. Daley also indicates the maximum amount of time the individual should take for each step and allows them to repeat the instruction of each step, if necessary. Once all the steps in the activity have been completed, the Daley app will return to the calendar to show the scheduled tasks for that day or week. When the application is closed, it will remain inactive until it is time for a new activity.

Daley is currently available for use in its initial phase. The Daley team and its network of motivated collaborators are constantly improving and further developing the assistive solution. This is due to the fact that the whole project is being run as a non-profit platform, operating with a limited budget. For this reason, they rely solely on volunteers and personal donations.



Daley benefits

- Higher level of independence (compared to traditional printouts) for individuals who need assistance in performing their daily tasks;
- Replacing bulky printouts by explaining daily routines with an interactive, and easy-to-use, digital solution;
- Single dashboard access for carers, providing a clear overview of daily activity planning and management;
- Real-time monitoring and planning of the daily routine for multiple individuals;
- Remote digital assistance solution for families, professionals, and organisations.



Members of the Daley team

How was Daley born?

Daley was created and developed by Almisa Solutions, a company founded in 2015. Close friends of the founders asked them at that time to help their autistic teenage son in performing his daily activities by creating a software that can provide him with step-by-step guidance for each activity. Alongside the Serbian Society of Autism, the Daley team brings together a group of likeminded psychologists, schools, institutes, and other specialists in different fields, as well as a network of students and professional experts. All of them are now working very closely together in building, promoting, maintaining, and further developing Daley.

To send your ideas, comments, or suggestions to contact@daley.help

More information: www.daley.help

Invitation

to Autism-Europe's 2017 Annual General Assembly

Zagreb, Croatia

In accordance with the statutes for our organisation, we are pleased to invite you to attend Autism-Europe's Annual General Assembly, which will take place in Zagreb, Croatia on May 6 2017.

Agenda:

- Presentation of the executive committee report
- Presentation of the activity report: 2016
- Presentation of the financial report: 2016
- Presentation of the work programme: 2017

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

The meetings will be hosted by the Croatian Society for Autism.

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

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

Take part

in the launch of our next WAAD campaign!

- **Are you a self-advocate, parent of a person on the autism spectrum, professional, carer or any other interested party?**
- **Do you want to help us to spread awareness of autism?**

Be part of the first stage of our World Autism Awareness Day campaign 2017 and let people know what they can do to reduce the accessibility barriers faced by people with autism!

1. **Grab** a white banner or a piece of paper (the bigger the better)
2. **Clearly write** on the banner: "A barrier to accessibility for me is..." and complete the sentence with a short message explaining your own thoughts/needs. You can write this in your own language if you prefer.
3. **Take** a selfie or record a video of you holding the banner with your message.
4. **Then film or photograph** yourself breaking through the banner, or ripping it in two, to remove your "barrier" for autism.
5. **Send us** your video and/or pictures to communication@autismeurope.org and share it on social media with the hashtag **#AutismDay2017**

Before launching the campaign "Break barriers for autism" on April 2, Autism-Europe will release a video. This video will be circulated in the following months as a campaign teaser to generate interest and make people understand what the main topics are surrounding the promotion of accessibility for people with autism.

More information: <http://www.autismeurope.org/activities/world-autism-awareness-day/autism-awareness-day>



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