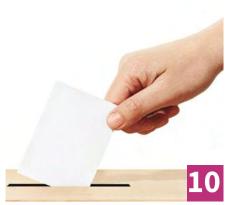


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More news at: www.autismeurope.org



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Cover: Jon Adams is a British artist and geologist who only discovered that he had Asperger's and dyslexia as an adult. Adams is the founder of the 'Flow Observatorium', creating safe places and attitudes for neuro-divergent artists and performers to show their work. Picture by Rosie Barners for Autism-Europe

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Dear friends,

In 2017, Autism-Europe members reflected on the future of the European Disability Strategy 2010-2020 and how policies can better address the remaining gaps and challenges to respond to the specific needs of autistic people, so as to ensure the full realisation of their rights in line with the UN Convention on the Rights of People with disabilities.

This reflection echoes the fact that over the last decade several EU countries and regions have adopted autism-specific policies. Currently, some Member States have national autism plans or strategies, while some have autism-specific legislation in place. For example, this is the case of Spain, which voted in a strategy in 2015, and which is mentioned in this edition. This strategy is articulated around 15 thematic lines, addressing a wide range of key issues from access to diagnosis, to life-long support, independent living and health.

For countries and regions with an autism plan or strategy, these seem to bring about a positive impact and change for people on the autism spectrum, even if they do not necessarily achieve all their objectives towards the full respect of the rights of autistic people.

At the same time, as evidenced by research conducted by Autism-Europe in 2016, EU Member States face a range of common challenges in the field of access to diagnosis, education, healthcare, lifelong services, employment, justice and social inclusion, etc., as regards autism.

AE thus considers that there would be a high-added value to adopt an EU strategy that would support harmonisation across the Member States, promote guidelines to respond to the needs of autistic people and foster the respect of their rights. An EU strategy can also assist Member States in developing their own, complementary, national strategies and could provide a platform for sharing good practices throughout the EU.

This idea is backed by the European Parliament, which also expressed strong support for an EU autism strategy, notably by adopting a Written Declaration in 2015, endorsed by 408 Members of the European Parliament (MEPs).

As you will discover in this edition, AE has recently presented its key recommendations for a European Strategy on autism in Madrid. We count on your support to bring home and relay to your national governments (that would ultimately have to endorse and vote such a strategy at the EU-level), the fact that it would be of high added value to improve the quality of life of autistic people and foster social cohesion in Europe.

Thank you for your continuous support,

Happy reading!



Zsuzsanna Szilvasy President



Aurélie Baranger Director



Spanish Ministry representative presents Spain's autism strategy to AE's Council of Administration

On October 21 and 22, 40 representatives from 15 European countries met in Madrid for Autism-Europe's second Council of Administration meeting of the year.

or the hosting organisation, Confederación Autismo España, it was a key opportunity to inform Autism-Europe (AE)'s member associations about Spain's new strategy for autism. Managing Director of Disability from the Spanish Ministry of Health, Borja Fanjul, was invited to introduce the Spanish Strategy for Autism Spectrum Disorders, approved in November 2015. Representatives from Autismo España then explained the strategic lines and general content of this legislative framework. Autism-Europe's President, Zsuzsanna Szilvasy, highlighted the importance of this strategy and the need to foster its implementation, considering it to be a model of good practice for advocacy at the European level.

The meeting included the participation

of Joaquín Fuentes (*Policlínica Gipuzkoa*, *Donostia* – San Sebastián, research consultant for Gautena) and Manuel Posada (*Instituto de Salud Carlos III - ISCIII*), who informed participants about the ASDEU programme, the activities of the European Society for Child and Adolescent Psychiatry (ESCAP) and about the foreseen updated edition of the AE publication "Persons with Autism Spectrum Disorders: Identification, Understanding, Intervention".

Highlights of the meetings included the presentation of AE's quadrennial strategy 2018-2021 and its work programme for 2018. Its priorities have been established following consultation with AE members and notably aim at supporting access to education, employment and a better public health response (including mental health) for autism as well as fostering the

participation of self-advocates. Members also engaged in an in-depth discussion about a planned framework guidance document on the quality of autism services.

On Friday 20, AE's Council of Administration members visited the National Museum of Decorative Arts in Madrid and enjoyed a guided tour delivered by Mickey Mondejar, a young autistic student, who works as a guide in the framework of an initiative supported by the Asociación Argadini.

On Sunday 22, a number of AE's Council of Administration members also attended a meeting with local self-advocates to discuss about the main issues and concerns of people on the autism spectrum in Spain, in order to better understand their needs and aspirations.

Key recommendations for a European Strategy on Autism

Recently, Autism-Europe unveiled its preliminary recommendations for a European Strategy for Autism based on a wide consultation and the results of its mapping of policies and legislation across the EU. They were presented in the framework of a high-level conference on the preliminary research results of the ASDEU programme.



n January 2018 Madrid played host to around one hundred decision-makers and key stakeholders who came together to discuss a range of key issues including prevalence, early detection, evidence-based intervention and access to care for the elderly.

The Institute of Rare Disease Research, part of the University Carlos III in Madrid, was the venue chosen for the final conference of the EU-funded ASDEU programme. It was an occasion for the programme partners – coming from fourteen different countries – to present the outcomes of their research. Those present included elected officials, representatives from national ministries and the European Institutions, autism advocacy groups and universities from 29 European countries.

ASDEU is a three-year programme funded by the European Commission's Directorate-General of Health and Food Safety (DG-SANTE) aiming to increase understanding of and improve responses to the needs of people on the autism spectrum. The scope of the ASDEU research was wide, looking into areas such as prevalence, the economic and social costs of autism, early diagnostic and evidence-based intervention, and effective care and support for adults and older people on the autism spectrum.

Of key interest to participants was the research into autism prevalence across the continent. Research was conducted at a national level in four European countries (Finland, Denmark, Iceland and Romania) and then focused on specific pilot areas in another eight countries (Spain, Austria, Poland, Ireland, Italy, France, Bulgaria and Portugal).



The research into autism prevalence

- Although research seemed to generally support the notion that 1% of the European population is on the autism spectrum, this figure varied from region to region. In Iceland initial figures seem to suggest a prevalence of 2.67%.
- Research looked at children aged from 7 to 9 in 2015.
- In Denmark, Finland, Iceland, and some areas of France, data from national or local registries were used. In other countries, prevalence was gaged using Teacher Nomination Forms (TNF) filled out by teachers, and Social Communication Questionnaires (SCQ) typically filled out by parents or guardians. The efficiency of respective methods was discussed during the conference.
- Increasing prevalence is shown to be a reality. It is shown that there are now more autism cases diagnosed during childhood and adolescence.

urvey-based research conducted as part of the project also shed light on service provision for adults on the autism spectrum. Responses suggested that there is still a long way to go for autistic people's needs to be sufficiently met.

Concrete analysis of all data compiled through research conducted in the ASDEU programme will be made available after the summer of 2018.

Autism-Europe's call for a holistic EU autism strategy

Within ASDEU, Autism-Europe is the leader of the Work Package on autism policies in the EU, which includes formulating recommendations for an EU public health plan for autism based on extensive research and stakeholder consultation. Autism-Europe's Director, Aurélie Baranger, thus presented the list of initial key recommendations for a holistic EU autism strategy.

Closing the conference, Antoni Montserrat, Senior advisor in the European Commission Directorate of Health and Food Safety,

welcomed the high relevance of Autism-Europe's recommendations and called on EU Member States representatives to support such an EU autism strategy at their governmental level.

In the lifetime of the ASDEU initiative, the European Parliament has also expressed strong support for an EU autism strategy, notably by adopting a Written Declaration in 2015 endorsed by 408 Members of the European Parliament (MEPs). In fact, several EU Member States have already seen the added value of adopting autism strategies at the national level, with two of the most recent being presented during the conference in Madrid.

Firstly, the Parliamentary Secretary for Persons with Disability and Active Ageing of the Maltese government, Hon. Decelis, presented the Malta's recently-adopted 'Persons within the Autism Spectrum (Empowerment) Act' and Maltese MEP Miriam Dalli was also featured via video and reiterated her support for a European strategy on autism. Representatives from the Spanish Ministry of Health, Javier Salgado and Paloma Casado Durández, also presented the health dimension of the Spanish Strategy for autism that was adopted in 2015.

Outline of AE recommendations for an autism strategy

Currently EU strategies in the field of public health only exist for a handful of conditions: cancer, Alzheimer and dementia, diabetes and rare diseases. They typically aim at reducing inequalities between EU countries by fostering cooperation, the exchange of expertise and benchmarking. They also promote a horizontal approach and branch out

into other policies areas to have a holistic approach to improve the quality of life.

Based on the common needs identified across Europe and taking into account the EU's competences, an EU strategy for autism could have the following scope of actions:

1

Encouraging Member States to adopt cross-sectoral national strategies or action plans to respond to the needs of autistic people, in line with the UN convention on the Rights of People with disabilities and international recommendations;

- Promoting coordination between

 Member States of all relevant policies in
 - 3

Producing guidelines to harmonise evidence-based practices and promote quality of support care and inclusion across Europe; Adopting principles of best practice and fostering exchange between Member States;

- Promoting training of professionals across sectors, and supporting them through the EU funds;
- Supporting research and networks or experts and partnering for progress across the EU;
- Supporting and involving representative NGOs throughout the process.

The following key areas have been identified and should be addressed by a future strategy:

- Screening and diagnosis
- Post-diagnosis support (including in the field of healthcare)
- Access to inclusive adapted education
- Access to individualised support and inclusion throughout one's lifetime (including access to employment)
- Support for families

- Training for professionals
- Independent living and community-based services
- Empowerment of autistic people and their families
- Legal capacity and access to justice
- Research to promote a better quality of life
- Awareness-raising

A more detailed version of the initial recommendations is available on Autism-Europe's website.



"Everything could be art, including my own experience and intimate being"

Jon Adams - Artist and geologist, self-advocate

Jon Adams is a British artist and geologist who only discovered that he had Asperger's and dyslexia as an adult. Today he is a Cultural Ambassador for the National Autistic Society (NAS), a champion for the Autism Mental Health project at Coventry University and an Associate Artist of the New Theatre Royal Portsmouth.

utistic digital artist, poet and neurodiversity campaigner, Jon Adams trained as a geologist and his work references his Asperger's, dyslexia and post-traumatic stress disorder. He is also a synesthete, meaning that he experiences synesthesia, a neurological condition in which stimulation of one sense leads to automatic, involuntary responses in a second sense, for example 'seeing or touching sounds'.

The artist's work explores sense and sensitivity through the 'hidden' and plays with perceptions of normal and the inaccessible. Adams is also the founder of the 'Flow Observatorium', creating safe places and attitudes for neurodivergent artists and performers to show their work, which is based at the New Theatre Royal, in his home town of Portsmouth (UK).

"I always wanted to be an artist but never went to art college because, when I was 10, a teacher had torn up a picture I had drawn, mocking me in front of the class because I had spelt my name wrong", remembers Adams. "I've always drawn, created or made ever since I can remember, but I was especially drawn to understanding the natural world. My early years were busy watching and challenging the world around me in an attempt to make sense of things, especially people. I had no idea then that this was through the lens of an autistic dyslexic person with the gift of synesthesia". Aged 22 after finishing his geology degree, one exhibition in London, a retrospective of the Danish artist Asger Jorn, rekindled Adams's desire to represent the world around him in alternative ways. He started working as a book illustrator soon after.

"My first milestone was being diagnosed as dyslexic in 1999. I started writing poetry in response to hearing 'you can't do this writing lark' and soon was both published and winning international competitions. One judge, the Poet Laureate at the time, took me aside at an exhibition and told me 'never to stop writing'. I understood that everything was, or could be, art, including your own experience and intimate being. This was a very liberating experience, and had been triggered by others who seemed to

Since 2013, many diagnoses of autism in the UK have also included a range of sensory issues, among them aversions to certain textures, sounds, smells and tastes, as well as a deep dislike of sudden noise. In Adams's case, these seem to blur into a complex kind of synaesthesia.

My first milestone was being diagnosed as dyslexic in 1999. I started writing poetry in response to hearing 'you can't do this writing lark'

22

think I was capable of more. This led to a realisation that I was a synaesthete, answering the questions of why I experience the world differently and why the world sometimes treats me differently, tells Adams.

"The world of people often seemed unfathomable and I always seemed to be an outsider by several degrees of difference. The way this 'difference' and 'ability' are not accepted or understood by the everyday person on the street soon leads to exclusion and mental health issues. In the arts world, I've learnt seeing the world differently and being Asperger's is a talent, a gift, not a disability. People tend to only see autism as a very negative thing.

"We need visible autistic role models given real opportunities as you do not change people's minds by telling them they have to. You change people's minds by example".

The Konfirm Project

Jon Adams was formally diagnosed at the age of 52, at an NHS clinic run as an offshoot of Cambridge University's Autism

Research Centre, after he was referred there by his GP. The initial spark had been a meeting with the centre's founder and director, Professor Simon Baron-Cohen, who asked Adams to work with him as resident artist at the Autism Research Centre in Cambridge.

This meeting led to 'Konfirm', a project funded by Wellcome Trust, a personal, artistic and scientific journey where Adams processed conversations, observations and experiments through his Asperger's filters. He worked with poetry, image and sound to illustrate how autistic people may have talents in systemising, breaking autism stereotypes and myths. He took the intrusive sounds of an MRI machine, split them into millions of fragments and reassembled them into coherent music. This was mixed with sea noise and synthesiser parts and has been used as a soundtrack for several films.

When this project highlighted that he was autistic, the world and his journey through it suddenly made sense. "It explained some of my social difficulties and the gifts I had with time, space and connecting. In a way I felt complete; not because I had a 'condition' as an excuse, but rather because I knew who I was and that I belonged to a 'tribe' of like-minded people. I didn't feel 'outside' anymore", he affirms.

Flow Observatorium

In early 2015, Adams set up Flow Observatorium, a national project recently granted initial funding by Arts Council England. The aim is to become a hub for neurodivergent artists, campaigning for recognition and providing support. Neurodivergence is about being 'wired differently' and experiencing the world through a 'differing way of thinking' from the 'neuronorm'. It's about celebrating an innate part of our wider neurodiversity and the talents it may bring, rather than looking at dyslexia or autism simply as being a deficit. Being different shouldn't hold you back; it's only people's stereotyped attitudes that do. At 'Flows' core is a concern that the next generations of autistic people do not have to suffer the setbacks of traditional misunderstandings of being autistic and will be able to work, live and play in a world they really belong to.



Adams was commissioned by UK Parliament to lead on the digital engagement arts project for the Magna Carta celebrations in 2015 because of his Asperger ability uniquely mapping social engagement. The project Democracy Street asked participants to look at the names of roads connected to democracy and suggest people who'd made a 'difference to society'.

Right to vote of persons uniolation of the UN Converged to the UN

The point of view of Evelyne Friedel Lawyer (Paris Bar) and Vice-President of Autism-Europe



t is important to distinguish the right to vote on the one hand, and the exercise of this right to vote on the other.

Naturally, one cannot exercise their right to vote if this right is taken away from them. Stripping an individual of their right to vote logically assumes that the person should not exercise this right.

In some European countries, such as in France, the right to vote is in fact not universal!

Let us take the example of France.

In France, our Constitution expressly retains universal suffrage, and not suffrage based on capacity. Since France has not retained the latter, there is therefore no basis on which to withdraw the right to vote based on considerations related to an individual's capacity!

Article 5 of our electoral code expressly allows for voting rights to be withdrawn from persons placed under guardianship. Before the law of 2007, which reformed the legal protection regimes, being placed under guardianship stripped an individual of the right to vote, although a judge could authorise this right on a case by case basis.

Since the law of 2007, the right to vote exists in principle, but a judge can withdraw it on a case by case basis if he or she considers that the person lacks lucidity! The judge bases his/her decision on a medical diagnosis! It is unacceptable, with regard to the fundamental rights of the person, to allow a doctor or a judge to remove the enjoyment of such a civil and political right. It is not up to the judge or any other person to remove this right based on the criteria of capacity, while our Constitution retains universal suffrage.

Our Constitution also recalls that international treaties are superior to laws.

Bur our law is not in line with the UN Convention on the Rights of Persons with Disabilities, which recognises that all people with disabilities are equal citizens. The withdrawal of the right to vote for people with disabilities, which is permitted by our electoral code, is therefore unconstitutional.

The withdrawal of the right to vote for people with disabilities is unconstitutional and violates the UN Convention

under legal protection: ention by the

How has the UN Convention changed the situation?

This Convention is revolutionary. With the exception of a few provisions in the European Social Charter of the Council of Europe, before the Convention there was no such text on the fundamental rights of persons with disabilities, let alone one with such an international reach.

Two articles of the UN Convention are particularly important on the subject of citizenship: Article 12 and Article 29. Article 12 recognises the legal personality of persons with disabilities. Being citizens on an equal basis with others, their voice must be heard. This article also recalls that every disabled person must have legal capacity. In the past, a person with a disability, benefiting from a legal protection measure, was considered to be an incapacitated adult. Today, the paradigm has changed. We start from the opposite principle. Every disabled person is considered capable and he or she must be allowed to actually exercise this legal capacity.

This exercise can be assisted and accompanied, but the person must not lose his or her legal capacity. The accompaniment provided for this exercise can naturally vary according to each person and each situation. Accompaniment can be total with respect to some disabled people with particularly high support needs but, in any situation, it is always the choice or the aspirations of the person that must be at the heart of the decisions taken.

Article 29 of the Convention concerns the exercise of political rights. This article deals with the right to vote and the right to be eligible to stand for election. Nothing in Article 29 allows for the withdrawal

It is always the choice or the aspirations of the person that must be at the heart of decisions made.

of the right to vote in any case whatsoever. France, when ratifying the Convention in 2010, stated: "With regard to Article 29 of the Convention, the exercise of the right to vote is a component of legal capacity that can only be restricted under the conditions and in the manner provided for in Article 12 of the Convention".

Article 12 does not directly or indirectly target any restriction on the legal capacity of the person. On the other hand, it requires States to provide accompanying measures for the exercising of rights. In its report submitted last March to the United Nations Committee on the Rights of Persons with Disabilities, the French Government recalls that Article 12 of the Convention requires that measures taken for the exercise of legal capacity comply with "international human rights law".

But France repeats its mistake and distorts the interpretation of the text. According to the Government, the reference "to international human rights law" allows for an interpretation of Article 12 in light of the International Covenant on Civil and Political Rights, of which article 25 provides for reasonable restrictions on the right to vote. The Government adds "it is a restriction that is all the more reasonable as it is never automatic, but decided on a case by case basis, according to the faculties of the person concerned and by a judge".

What do you think of this analysis?

This analysis is completely unacceptable for two reasons: Firstly, if Article 12 focuses on compliance with international law, it is only to ensure that States retain harmonised approaches in accordance with the provisions of the most advanced universal rights. These provisions have become increasingly demanding over the decades.

Secondly, the approach taken by France goes directly against the jurisprudence of the United Nations Human Committee on the Rights of Persons with Disabilities, against Hungary.

Right to vote of persons under legal protection (continuation and end)

This Committee recalls that under Article 12, States must recognise and respect the legal capacity of persons with disabilities on an equal basis with others in all areas, including political life, which implies the right to vote.

The Committee also stresses that by depriving certain people with disabilities of their right to vote on the grounds of intellectual disability, real or perceived, the State violates the Convention.

According to the Committee, the assessment of the fitness of individuals is discriminatory in nature. The State must therefore adopt laws that recognise, without any assessment of fitness, the right to vote for all persons with disabilities.

This is not the case in France. Article 5 of our electoral code must therefore be repealed.

States have a positive obligation to take the necessary measures to enable persons with disabilities to exercise their legal capacity

Guardians may be reluctant to vote "on behalf" of the person...

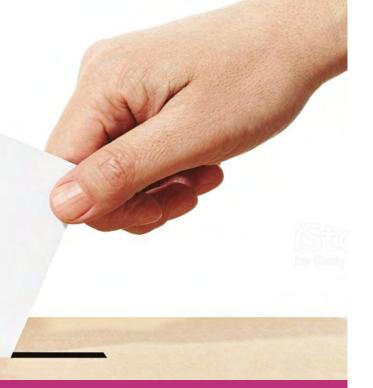
The Committee recalls that States have a positive obligation to take the necessary measures to enable persons with disabilities to exercise their legal capacity. As required by Article 12, the essential issue is to accompany the person in the expression of his or her choices, and not to decide for them on the basis of what is thought to be his or her interests.

Family guardianship or empowerment should be privileged in this respect. This could be a family member or a close friend who accompanies the person, has come to know his or her preferences and knows the mode of expression of his or her choices, including through alternative means of communication used by those with higher support needs.

Today, the guardian of an intellectually disabled person is given multiple proxies or authorisations in order to manage the daily and financial life of the person in their care, including his or her place of residence and bank accounts.

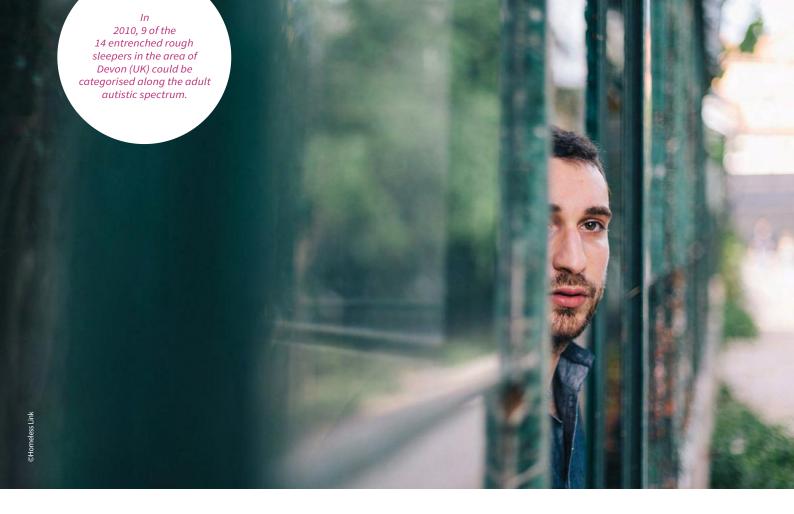
In what way would it be a bigger deal for the disabled person to have his or her guardian be responsible for delivering a proxy vote in order to exercise his or her right to vote, in accordance with the choices and aspirations known by this guardian? When the guardian is well chosen, depending on the proximity and the emotional ties with the disabled person, it is not clear why he or she would not be granted, in addition to all other proxies and authorisations, the right to express the decision of a person who remains a citizen, and whose vote must count!

Why deny a guardian the possibility of delivering a proxy vote when everyone finds it normal to ask their next-door neighbour to deliver their vote when they cannot go to the polling station?



Opinion of France's National Consultative Committee on Human Rights (Commission Nationale Consultative des Droits de l'Homme) on the right to vote for people with disabilities

On January 26, 2017, the National Consultative Committee on Human Rights unanimously adopted an opinion on the right to vote for people with disabilities - voting is a right, not a privilege. The Committee advocates that the right to vote should no longer be taken away from people with disabilities, including those with intellectual and psychological disabilities, and calls for election campaigns to be made accessible to all.



How can we support autistic homeless people?

"Factors that cause homelessness are well researched. Family breakdown, unemployment and poverty, housing that does not reflect individual need and lack of educational attainment; all issues linked to autism".

Liza Dresner, Director of the charity Resources for Autism since 2007, tells Autism-Europe about her experience working with homeless people on the autism spectrum. A social worker by profession, she is particularly interested in ensuring access to appropriate services for those who may find it difficult to navigate complex health and social care services due to poverty:

y interest in the link between autism and long term homelessness began when a London homelessness worker came to see me. He had a feeling that a long-term rough sleeper he knew of could be on the autistic spectrum. Not only did I agree with him that that was quite likely true of his client, but I realised how likely this was to be true of many entrenched,

long-term rough sleepers for reasons that will become clear.

Prevalence information is minimal to say the least. A small but significant research project undertaken by Pritchard in Devon in 2010 found that 9 of the 14 entrenched rough sleepers in the area could be categorised along the adult autistic spectrum and 7 of the 14 clients had actually been diagnosed with

autism. He concluded that this suggests that many homeless people with a long history of sleeping rough might be on the autistic spectrum (Pritchard 2010). The second piece of research took place in Wales in 2011 by Autism-Europe member the National Autistic Society and was followed up by a more extensive piece by Shelter Cymru in 2016. Both of these pieces of research appear to confirm Pritchard's hypothesis.

Autistic people are more at risk of becoming homeless

When you have a child with a lifelong condition, whose behaviour may bring criticism and judgement from your immediate and extended family as well as from school, social groups and shop assistants, the pressure on parents becomes enormous. A young person who may be becoming violent and controlling, with behaviours that are hard to understand and even harder to manage, both for the individual themselves and those around them, adds to that pressure. Statistically families with a disabled child are much more likely to separate. Where that disability manifests itself in the form of socially unacceptable behaviours, families are even more likely to fall apart.

For those with a profound learning disability and other co-conditions, there may be some help at hand. There certainly may be more acceptance and sympathy. For many others there is very little indeed. School exclusions are common and school refusal extremely frequent. There are no friends with floors to sleep on. The street beckons. Our young adults can become isolated, depressed and extremely controlling because control makes them feel safe and the street is somewhere they can be in control.

They can follow routines without irritating anyone, they can meet their own sensory needs by choosing where they are and when and they can sleep as little or as much as they like without disturbing anyone. They are not expected

to engage in meaningless small talk or to obey seemingly irrelevant social rules. It fits all the criteria someone with autism may feel they have for where they live.

The need for social workers to work differently

If we accept the premise that at least some entrenched rough sleepers are on the autistic spectrum, then we need to look differently at how we work with them. Even for those without a diagnosis, if nothing else has worked then there is nothing to be lost by making an assumption that they could well be on the autism spectrum and trying to work differently with all those where other approaches have failed. There is nothing in what I suggest that can be harmful. However, there is much in what I will suggest that goes against current practice regarding choices and personalisation. People with autism generally struggle with choices, usually preferring clear instructions and rules that make sense and are absolutes. No unnecessarily long discussions. No options. It is important to use as few words as possible and visuals rather than words. Allowing the person time to process what has been said or asked of them and sticking to those rules is essential. This includes keeping to time with appointments. Wherever possible you should have the same person to deal with. Staff should not be trying to make friends, but being clear that there is a job to do and that job is to get the individual inside. You should ensure that if you say you are going to do something, it is something you can actually do, not something you might be able to do.

Forget choice. If you accept what I have just said, then a choice has been made and that choice is to live outside, in whatever unsafe way they choose. It is untrue to start claiming that we are offering a choice. We are saying you must come indoors and there is no choice in that. If there are choices about where they go inside, then make sure there are no more than two options. However, my understanding is that often there is no choice. You must therefore be clear and say to the person that this is where they are going to be living, rather than asking them if they would like to be living there. Form filling and interviews have a major impact on our likely success or failure.

How much of a form is it really necessary to ask for? We, as in the 'authorities', ask the same questions over and over again, often when we know the answer. Fill in what can be done in advance and check if you already have the answer on your system. If you then have the answer before you it is unnecessary to ask again. It may be helpful to ask questions as you walk with the individual. Sitting in an office may be uncomfortable for someone used to walking and being outside. Use a Dictaphone if you have to ask questions and record answers as you walk (with permission of course). Sometimes our organisation's policies and procedures do not allow flexibility for difference. It is our job to change these policies and procedures to make the world work for those who are different.

The challenge of keeping a tenancy

What might the pitfalls be and how can they be avoided? If we assume our client is going to say yes to being housed in a shelter, then is there really a bed available where you have said, on that day, at that moment? How is the person in question going to get there? Furthermore, the person might say yes at the time you are speaking with them, but this might not be their response the following day or next week. You also need to consider whether staff in a hostel understood the same needs for alternative communication, for a not too enthusiastic welcome, for allowing silence and for understanding sensory issues. It is useless for staff working directly with people on the street to understand this and then not conveying it to hostel staff in advance and planning how a new resident is to be welcomed. Information must be shared to make a tenancy work.

If the person has a routine and route they like to walk to feel safe then we must make it clear that we encourage them to continue with that, but to extend the route to start and finish at the new place they sleep. If they collect and keep lots of objects they find in the street then we have to make explicit the rules around this. However we cannot say they must not hoard in this way, as this is a need

not a desire. We must pick our battles. What are the areas where we cannot be flexible, and in which areas could we allow for an adapted approach?

In some cases, you might know someone will never pay their service charge because they can't see what they are getting for their money, like they can when they buy a loaf of bread, for example. In such a case, what can we do to ensure that the service charge gets paid before it becomes an issue? Someone with autism needs to be told, clearly, that if they have a possession they value then they can keep it and it will be safe. They may well not ask but they need to know. They may well need visual interpretations of rules stuck on their wall. If rubbish has to be taken out for collection on Tuesday, then a picture of the rubbish, of Tuesday and of all Tuesdays may be necessary. But, by Tuesday do we mean just this Tuesday or every Tuesday and is Tuesday at midnight ok? Be explicit and break things down. And what if Tuesday is Christmas day or there is a strike or if the borough change the day bins are collected? A rule for a particular person should include that person's name, otherwise a rule is



interpreted as being for everyone and therefore the rule is not interpreted as being for them personally.

Thinking about how things can appear from an autistic perspective is not rocket science, but it does challenge much of what we are given as generalised good practice. I would argue that much of what is currently deemed good practice is designed in a deceptive way to hide what options are not there and present the existing options in ways that confuse and frustrate many of us. If we are to really make a difference to those who think differently then we have to think differently ourselves and challenge our own practice, especially when our own practice has repeatedly failed.

Resources for Autism is a charity established in 1996 that provides practical services for children and adults with autism and their families across Greater London and the West Midlands. They work with anyone with an autism diagnosis but their focus is on those whose behaviour may challenge other organisations.

The charity cooperates with Homeless Link, the national membership charity for organisations working directly with people who become homeless in England.



Zoe Carpenter, autistic advocate and a pioneer of the REIGN project

"The voice of experience is the most powerful tool for combating discrimination"

Zoe is a young autistic woman from the UK who is a survivor of child sexual exploitation. A talented advocate focusing on the vulnerability of autistic girls and children in relation to sexual exploitation, she is one of the pioneers of the REIGN project. This initiative contends that "the voice of experience is the most powerful tool for combating disability discrimination and abuse".

"I grew up wishing to meet other people like me, but I had no access to a community that understood the way I was or who did not see me as broken". With these words, Zoe explains to Autism-Europe her need to become a true advocate and cope with child sexual exploitation, as an autistic person who had experienced it herself: "I was outraged to discover that the vast majority of my female autistic friends had been sexually abused as children, and many have been involved in prostitution in order to survive, because they did not have the employment opportunities or friendship networks to support them".

Zoe started her work in the autistic community administrating online support groups and facilitating off-line meet-ups, both in women-only and mixed-gendered settings, including hosting autistic pride events in her city. She adds that connecting people together remains one of her favorite things to do within the autistic community. "I had started talking openly about my experiences growing up without the correct support or understanding and the effects that has had on my life opportunities and mental wellbeing. I did not want anyone else to feel isolated



REIGN team after delivering a workshop to the Greater Manchester Police Force.

or be failed in the same way, so along with facilitating the meet-ups, I started campaigning for autistic rights and acceptance, working alongside other autistic advocates and activists", she said.

The REIGN project

In 2016, Zoe joined three other young survivors of child sexual exploitation in Manchester (UK) in setting up REIGN. The REIGN project operates under RECLAIM, a charity which aims to identify and support young leaders from working class communities with different projects and programmes since 2007. "We want to be the people we needed when we were younger, then pass the baton on to the next group of strong survivors who wish to continue the work. We also want to improve laws and policies around child protection so that preventing child sexual exploitation becomes a priority across the UK and Europe", she explains.

REIGN offers training and consultancy to authorities and front-line services such as social workers, the police, schools and fostering agencies on how to identify and prevent child sexual exploitation. "I believe it is of particular importance that agencies hear directly from people with lived experience of these issues to improve their services in ways they would not consider, and to inform them of problems and prospective difficulties they would otherwise be unaware of", affirms Zoe. They also educate school children and campaign to raise awareness of child sexual exploitation and increase a sense of responsibility in the community.

REIGN targets all children, regardless of gender, background, race, class or disability. They are a diverse collective, all highly aware of the various intersections within child sexual exploitation, and they are determined to fix the flaws in the systems that failed them as children. "For me, the lack of understanding around my neurology played a major role in the abuse I suffered and prevented me from getting the support and protection I needed", she said.



One of the seven billboards from the REIGN campaign displayed around Manchester

Awareness and social inclusion to tackle abuse

In the specific case of autistic children, Zoe points out the fact that many symptoms of psychological trauma can be mistaken for traits of autism. "A child may constantly run away from a home where they are being abused, they may be aggressive, have regressive development, or be sexually inappropriate. These are all classical signs of an abused child but can be mistaken as simply relating to the child's autism and dismissed". Adults may assume their child will not be at risk of sexual exploitation because they believe they do not have the independence, competence or desire to engage in a sexual relationship. "This is often very far from the truth but the parents do not have a true insight into an autistic child's mind. This ignorance causes complacency in the protection of that child. Autistic adults can remember how they processed the world as children and are the best people to inform parents and professionals on the autistic experience".

An autistic child may also have less of an understanding of what is socially appropriate and lack a sense of danger or personal agency, causing them to not realise what is happening to them

is abuse. Thanks to REIGN, they are able to give personally informed strategies for developing that awareness in a child that will help them stay protected. "Many therapies for autism focus on training a child to be compliant to adults' demands in return for a reward. This is also how perpetrators groom their victims into sexual exploitation. Autistic children who have been through compliance-based behavior therapies are very easy targets because the work is already half done. These therapies often involve touching or restraining the child against their wishes until it becomes normalised. It is of vital importance that all children, but especially autistic children, are taught about body autonomy and the right to say no".

Zoe also highlights that "there is a general assumption that autistic people lack both sexuality and a desire to be loved or socially included. Children are often pulled into sexually exploitative situations because they want or need the love or acceptance an abuser may be offering. This is easier if the child isn't receiving that from other places, i.e., through friends at school".

Read more about REIGN on the RECLAIM website:

https://www.reclaim.org.uk/reign

REIGN Blog: http://reignreclaim.blogspot.co.uk/

"Identity-first Autistic" campaign

In 2015, Zoe launched the "Identity-first Autistic" campaign to raise awareness of the way the language used around autism and disability effects social attitudes, calling for the acceptance of identity-first language for autistic people. The campaign allows companies and organisations to pledge to the use of Identity-first language, as the majority of the autistic community in the UK prefers it. "I prefer to be called 'autistic', or 'an autistic person' and not 'a person with autism/on the autism spectrum'. We proclaim that 'autistic' is not a dirty word. It is integral to our being, and we can be proudly, and perfectly autistic – not a failed version of neurotypical", she clarifies.

More information: www.identityfirstautistic.org



The Catherine Graindor Teaching Unit for Autism in Rouen

France's new network for intensive early care

Annick Tabet: As part of the Third Autism Plan launched by the French Government, around 100 Preschool Teaching Units for Autism have been established or, as they are known in France, UEMs (*Unités d'Enseignements créées en école Maternelle*). France's Ministry for National Education is also planning to appoint a specialist educator to each of these new UEMs.

he Third Autism Plan (2013-2017) was presented in May 2013 by the Minister in charge of Persons with Disabilities. The French government has set aside 205 million euros to finance five areas of intervention: early diagnosis, lifelong support starting from childhood, support for families, research and training of those working with autistic people. These areas of action were selected collectively by associations, researchers, professionals and parliamentarians as part of a long-lasting collaborative effort.

The UEMs work by welcoming children aged three to six with the aim of developing early and intensive care for children with severe autism who have not developed verbal communication and have considerable behavioural problems. These children would not be able to attend mainstream schools, even with an assistant.

Identifying children who could benefit from the support of the UEMs is a collective task, organised by the Regional Health Agency, the Ministry for National Education, the local authority for the persons with disabilities and a local diagnostic team. The local authority for persons with disabilities then makes the final decision on the children referred to the UEMs. The work with each child lasts a maximum of three years but, if the

progress made by the child allows for it, they can have access to mainstream education during this time with the support of a classroom assistant.

There are currently 111 UEMs in operation; one per département (French administrative regional sub-entity), and several in the big cities, with a budget of 280 000 € per UEM as well as the appointment of a specialist teacher for each.

Spending at least 28 hours a week in the classroom, children are supervised by professionals who have been trained in autism and who have complementary skills: a specialised teacher assigned by the Ministry of National Education, a set of professionals (psychologist, speech therapist, psychomotor specialist, educators, etc.) belonging to a medico-social structure such as the Medico-Educational Institute (*Institut Médico Educatif -IME*) or a Specialised Home Education Service.

All educational and therapeutic interventions comply with the recommendations of good practice given by the French High Authority for Health. Educational, behavioural or developmental intervention programmes are co-produced by professionals from the Ministry of National Education, and the medico-social sector. These interventions are coordinated and supervised by an accredited external organisation.

When entering the classroom, each child is assessed using standardised tools. For each child, a personalised plan for enrollment is then established within the framework of the national education programmes. This is then complemented by a personalised plan of educational and therapeutic interventions. These plans are implemented during individual and collective work sessions, as well as during integration time with the other preschool children in settings such as the playground or the cantine.

The families of children attending the UEMs benefit from home-based parental guidance from professionals to help them better understand their child's way of working and the techniques that can be used to help them in their daily life. If needed, parents are given psychological support to deal with the impacts of the condition on their own wellbeing (stress, fatigue, guilt, isolation, depression, etc.).

Time to socialise with neuro-typical children

Each UEM welcomes seven children from the age of three into a class in a regular preschool. Autistic children attend school at the same time as other students in their age group.

The children in UEMs spend their playtime with the other children in the school. Other moments for collective inclusion are also organised, such as participation in school events and games. When students are able to, opportunities for individual inclusion

are also organised within the regular classes in the school, with the autistic child being given specific objectives to work on with the support of a specialised UEM educator. We should recall that the ultimate goal of the UEMs is to foster access to mainstream education after three years (or indeed during this process).

Encouraging outcomes

After three years, the outcome (although not yet official) of the UEMs set up across France is very encouraging: we have observed positive development in children, both on a neuro-developmental level and in terms of educational achievements, even if not all children were able to go on to join a mainstream preschool.

The elements that ensure the success of this type of facility are:

- participation of all stakeholders in initial training;
- coordination time, beyond time spent with the child, to exchange and ensure coherence of interventions;
- supervision by external professionals;
- good collaboration between families and professionals in the UEMs;
- a common desire between the Ministry for National Education, the Regional Health Agency, the medico-social sector and, above all, the consequential public budgets for the creation and operation of UEMs.

Invitation

Rotterdam, The Netherlands

to Autism-Europe's 2018 Annual General Assembly

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 Rotterdam, The Netherlands, on May 12 2018.

Agenda:

- Presentation of the Executive Committee report
- Presentation of the activity report: 2017
- Presentation of the financial report: 2017
- Presentation of the work programme: 2018

An Autism-Europe Council of Administration meeting and side activities will also be organised.

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

For more information, please contact Autism-Europe's Secretariat:

secretariat@autismeurope.org



Autism: the value of supported employment

The Situation after Graduation

Long before I joined Auticon, I had graduated from Edge Hill University (near Liverpool) with a Masters in Web Development. Even with a Distinction, I was struggling to find permanent work. Under the guidance of several people, I had refined my CV until few could find fault with it and then had uploaded it to most of the on-line job boards. Attention was paid to keeping an up-to-date LinkedIn profile and a personal website which showcased my skills. I was applying for vacancies, exploring opportunities for self-employment, and volunteering whenever possible.

Despite all of this effort, the goal of long term employment was proving surprisingly elusive. Occasionally, I was invited to an interview, but faced stiff competition from others with more of the sought after employment experience, or was sprung a technical test which I found difficult to complete with my level of knowledge. My age (I was in my fifties), was also counting against me.

Specialisterne and Specialists UK

In March 2014, I was invited to a conference run by the Department of Work and Pensions on how Jobcentre Plus, a service for

Thomas Madar,

Consultant with Auticon, an award-winning IT and compliance consulting business, whose consultants are all autistic.

finding employment in the UK, could be effective for people on the autistic spectrum. This took place at their headquarters in Central London. A number of employers were invited, and I took advantage of this invitation to broadcast my CV. As a result, I caught the interest of a representative of an agency run by Specialisterne, a Danish information technology company specialising in employing people on the autistic spectrum. In June, I was invited to attend a specially adapted telephone interview for a software testing contract with Ernst and Young in London. The special adaptation was that the agency representative listened in on the interview and so was able to give me feedback on my performance, and that all of the questions were fairly specific, requiring short answers. As a result, I performed very well and was offered the contract.

Two years of successful employment followed during which time Ernst and Young were well pleased with my work.

I was well supported. This consisted of weekly visits from my agency manager or a specially appointed job coach to discuss issues inside and outside of work. If there was an issue affecting my performance, then this was discussed with my Ernst and Young manager, and steps were taken to resolve it. There were no serious issues, though sometimes the area of the office allocated for my team became somewhat crowded. When this happened, I was allowed to move to a quieter area to continue my work. There were two serious incidents arising as a result of circumstances which were beyond my control, and which could have resulted in loss of employment or long term clerical work. In these cases, my supporters negotiated a return to interesting and fulfilling work with the Ernst and Young management.

In February 2015, work dried up for six weeks, and the termination of my contract was seriously considered. It was only through this sort of negotiation that this disaster was averted. A little later on, I was assigned a season of clerical work which made little use of my skills. Again, similar negotiation ensured that this was supplanted by work more appropriate to my skills.

From Specialists UK to Auticon

All good things come to an end, and so did my employment with Ernst and Young. At short notice, I was made redundant because of a new policy such that only middle and senior management roles would be based in the UK. By August (2016), I was again on the market. As 2016 turned into 2017, a person from my

church chanced upon the Auticon website and felt impelled to send me the link. In perusing this, I was gripped by how suitable working for this company would be for a person in my situation and delighted that they were expanding and looking for staff. However, I realised that competition was tough, and standards were high! Dare I risk the disappointment of my application being rejected? After some deliberation, I decided that an application was well worth the risk.

I was accepted for an interview, which led to a skills assessment. By a remarkable coincidence, Auticon had successfully negotiated for a contract with Experian in Nottingham, a firm factor which could have been an influence in my eventual recruitment. After an apprehensive wait, I was very pleased when an offer of employment with Auticon arrived in my in-box.

The Way Forward

My work with Experian has ended. While working there, I have received support in the form of regular visits or Skype meetings with a job coach to discuss issues inside and outside of work, and how they could be resolved. There have been no work-related issues, so discussion has centred on how to deal with challenges to my mental health such as a difficulty in attracting conversation and hence friendship from other people, and intrusive memories of being rejected and bullied at school and elsewhere. Left unchecked, these would have caused intense feelings of low self-esteem and damaging mood swings.

By now, I am used to a working life of working on contracts, sometimes hundreds of miles from home. This has been a feature of my employment since 2006. I look forward to continuing this work, secure in the knowledge that I will be well supported in an autism-friendly environment.

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