

Share

Practice, Knowledge
and Innovation

AUTUMN/WINTER 2017



Scottish
autism

Centre for
Practice
Innovation

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Guest Editor



Dr. David R. Simmons
School of Psychology,
University of Glasgow

I write this editorial in my office during Fresher's Week at the University of Glasgow. As I write, the gentle tapping on my laptop keyboard is accompanied by the deafening throbbing beats from an outdoor sound system, set up just across the road to entice new students to this year's street food festival. Needless to say, this makes concentrating on what I am doing much more difficult.

This sort of noise is an example of what we call "sensory stress." Most of us are bothered by such things: the flickering from a faulty fluorescent light, the hammering noises from a nearby building site, the stench of fresh paint from the decorators next door. However, for many people with autism these sensory stressors can be unbearable, and lead to panic attacks, "meltdowns" or simply make the draw of a nice quiet, dark bedroom that much more appealing.

When I first started doing research on autism 15 years ago, I was surprised at the lack of interest in sensory and perceptual aspects of autism, coming as I did from a background in basic research on visual perception. The neglect of this topic was all the more surprising given that most of the autistic individuals that I knew were affected by sensory stress, and/or other issues related to sensory or perceptual processing, in one way or another. Since 2002, there has been an explosion of research on this topic, culminating in the inclusion of sensory "reactivity" in the revised diagnostic guidelines of the American Psychiatric

Association in 2013. There are numerous books and research papers, themed sessions at conferences and a number of research groups throughout the world focusing on precisely what is going on.

This edition of Share presents a range of views about sensory and perceptual aspects of autism. I am pleased that we have three first-person accounts from autistic individuals, along with parallel accounts from parents. The features and reports from research colleagues illustrate some of the work we are doing on how better to measure sensory stress, and how better to ameliorate sensory stress in different challenging environments like classrooms and airports.

Ultimately, all of these projects are works in progress: the future involves further research on how best to characterise sensory difficulties, especially in less verbal individuals; how best to help autistics cope with the sensory stressors that can't be controlled; and how best to persuade the general public that sensory stress is a real issue, not just for autistics, but for a significant number of the population, meaning that all requests for environmental adjustments should be heard sympathetically.

For updates and news on this topic, follow me on Twitter: [@DrDavidRSimmons](https://twitter.com/DrDavidRSimmons)

Sensory and Perceptual Aspects of Autism: Personal perspectives



Susanna Henderson

4:02pm on Thursday 7th April 2016, I was diagnosed with Asperger's Syndrome. Then I went home. I probably had pasta for dinner. The point is, there was no support. Even a year and a half later I still want to tear off my skin and renounce my ownership when I overhear an autistic joke. The head of Learning Support asked if I wanted to meet another pupil with autism. One Wednesday afternoon, I was introduced to Felicity. I'd seen her walking around the school, head down and hands in her pockets. Towards the end of our introduction, the teacher told us about a book whose cover included a big green M. Then the girl said something.

"M isn't even a green letter."

My eyes lit up. "Do you see colours for letters too?"

We peeked out of our shy shells to see someone actually understand what we were saying – while the teacher looked at us, startled.

A couple of months later, we exchanged numbers while I tried frantically to remember her name and not just its colours. We met up to walk around the local park and got banana milkshakes. We talked about autism, philosophy, and pigeons. And the rest is history.

Ordinal-linguistic synaesthesia is the attribution of traits, and grapheme-colour is the association of colour with numbers and letters. For me, eight and E are red, but H, I, J, and K all blend together in a murky purple-y/green grey (probably because they're a clique). Felicity and I both see completely unique alphabets. We only agree four is blue. She describes it as seeing a photo in black and white, but knowing the colours that should be there (e.g. brown hair, red bricks). We read in black and white, but think in technicolour.

Object-personification synaesthesia is the involuntary assignment of human traits to inanimate objects. Feelings of guilt and treachery come from binning anything. I can't leave the house with odd socks in case the other sock of the pair feels lonely. I have gone out with another T-shirt in my bag because the two were bought as a pair. I have grown out of clothes I rarely wore due to the extensive planning involved in making sure they were worn for the same length of time at the same places. But I'm working on it. I have a selection of socks just for mixing and matching... but don't expect me to leave the house with them.

Growing up, I developed a funhouse mirror/copy and paste method of communicating. In Japan, people have two personas; their public and private. I consider myself to have another layer. Between my public and private mannerisms, I have my mask. Masking is a common term when talking about autism, as it tends to be the reason many are diagnosed with Asperger's later in life; it's easier to hide. Since personas are not linear, it's hard to tell where one stops and another starts – but isn't that the point? Maybe it takes longer for people with autism to have those barriers broken because of the fear they won't like the person you actually are underneath. In the first two layers, so much relies on copying dialect, body-language, and interests; literally acting like the person we think we're expected to be. As layers are broken down, and I feel comfortable enough to tell someone which specific episode of Doctor Who I'm referencing, that person can choose to continue or to walk away. I play the part of someone who can be liked, for fear my final layer isn't desirable.



Visual representation of how Susanna sees letters and numbers.



Felicity Barrett

When I found out I had Asperger's I felt relieved that I finally knew what had been wrong all throughout primary school.

When I started primary school is when I first remember having to interact with people and make friends and feeling like I was speaking a different language to everyone else.

Because of my Meares-Irlen Syndromeⁱ I did quite poorly in primary school and I came to think I was stupid.

I was unhappy and misbehaved because of it and also because of boredom. I got into fights and didn't do work and spoke back to teachers because I would rather they think I was a trouble maker than simply stupid.

When I started secondary school, I had tinted glasses and medication to help with my insomnia but still thought I wasn't academically clever.

In S3 I started to realise I was good at the sciences but I was still in the lowest maths class and thought I was terrible at it because of the focus on arithmetic which I had failed to properly learn during primary school due to my inability to read.

“Because of my Meares-Irlen Syndrome I did quite poorly in primary school and I came to think I was stupid.”

During course choice, I decided I wanted to be a vet and I needed three sciences for that and in order to do the sciences I had to take Nat 5 maths. My teachers tried to dissuade me but my parents supported me

“In S3 I started to realise I was good at the sciences but I was still in the lowest maths class.”

and the school set up some tutoring to advance my maths abilities.

I now have an A in Higher Maths, Physics, Biology and Chemistry.

Becoming more engaged in school had its issues. I now had teachers talking to me all the time and my usual tactic of agreeing to whatever in order to end the conversation didn't work as I now actually cared about what I did in school. Whenever I disagreed with them they would question me about it and my Post Traumatic Stress Disorder (PTSD) caused me to panic and run away from school.

“I now have an A in Higher Maths, Physics, Biology and Chemistry.”

In primary school I had a number of unpleasant experiences with teachers which cumulatively caused me to develop a pathological fear of them.

Visual representation of how Felicity sees letters and numbers.

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- ⁱ Meares-Irlen Syndrome is a condition similar to dyslexia but where reading is dramatically improved by using coloured spectacles or overlays.

Sensory and Perceptual Aspects of Autism: A parent's perspective



Ute Barrett

Background

My daughter Felicity, who shares her own experiences in this issue of Share, was diagnosed with Asperger's Syndrome when she was almost eleven years old. She had been diagnosed with Early Onset (Childhood) Insomnia six months previously and with Meares-Irlen Syndrome (visual stress) when she was 8 years old. After her Meares-Irlen diagnosis she was put on the CAMHS 'Early Intervention Team' waiting list for further assessment for two years, this is the reason why her ASD diagnosis was delayed. She was diagnosed with PTSD last year, caused by her experiences in primary school.

Every parent of an autistic child will agree with me when I say that to speak of "an ongoing battle" for understanding from others is quite an understatement, especially as her issues are so well hidden from anyone she meets. No, you cannot tell that Felicity has autism and sensory processing difficulties to contend with just by looking at her. This is one of the many barriers regarding her situation.

Another of those barriers was my own understanding of what her world is like, and how fundamentally it differs from mine. When Felicity was in primary school we spent an hour on her reading homework every evening. It was an incredibly fraught affair. She was our first child and I thought this was normal. Attending parents' evenings I realised we were supposed to be spending ten minutes on reading homework. Her teachers were concerned and questioned her academic skills. She was just one of those children who had to work harder, constantly had to catch up and just wasn't as advanced as her peers. My husband and I were very surprised to hear this but put in the work to improve things. We even

got extra reading books for all the holidays. When other children ran around the beach, Felicity sat learning to read. One day I realised that she could recognise and read the word 'and' on one page but not the next. She would read a whole paragraph or page of a reading book fluently but would be incapable of reading the next page, despite it containing some of the words of the previous page. I became exasperated and asked her 'Why can you read the word 'and' on page three but not on page four?'. She looked at the words closely and then looked up at me. 'You mean, when you look at the letters they don't change?' I looked at her with disbelief and said: 'Well, no, obviously not!' She looked back at me and said two words which changed our lives: 'No way!!!!'

It was like a light bulb had gone on over my head, a real Eureka moment. In that one instant I realised that my own child, and by extrapolation anyone in the world, perceived reality very differently from the way I did. Previously I had literally no idea that this was even possible I had difficulty identifying and even seeing the problems Felicity encountered every day. She told us many years later that what she did in school was listen very carefully to the other children reading parts of the book, memorised what they read, and then, instead of actually reading the words, she just recounted that particular paragraph by heart. She developed amazing compensation strategies, which have now turned her into an incredibly skilled problem-solver. I applaud her for that and I feel many employers are missing out on some of the incredible skills autistic people develop.

Raising awareness of sensory and perceptual issues with school and other institutions.

The school's understanding and ability to find and implement solutions to Felicity's issues were greatly hampered over the last 11 years by the fact that there seemed to be very little awareness among most teachers in primary and secondary schools.

When one looks at Felicity's history it stands out that she 'slipped through the net'. Her needs were not recognised in school, except by one support teacher who mentioned Meares-Irlen Syndrome to me for the first time after I had been spending three years discussing with the

deputy head every fortnight why Felicity kicked the teachers and had not completed work in class. Had I not been one of those persistent parents who kept denying that her child was just a troublemaker in a language the deputy head could understand – what then? There must be many children and young people out there who have nobody advocating for them. They must turn into the many women in their 40s who are just being diagnosed now. Raising awareness is a must within our school system because there is too little of it. Every young autistic person encounters different issues in school because their sensory and perceptual experiences differ so widely, as Susanna's and Felicity's personal accounts show.

Addressing sensory and perceptual issues – working towards finding solutions.

Both Susanna and Felicity had never met another girl with Asperger's Syndrome. They were completely isolated. Unfortunately, the nature of their condition does not necessarily make them want to seek the company of others because of all the corresponding possible pitfalls in terms of social communication, interaction and imagination, so it is actually really difficult for them to find someone who is 'like them', a kindred spirit, someone they recognise as being 'the same' and not 'the other'. This is something so fundamental to human beings and their sense of belonging that one can only imagine how lonely it must be for so many people on the spectrum. Susanna described this final experience of recognition so movingly in her account of meeting Felicity – they share the same perceptual world.

It was almost certainly the best thing that has ever happened to Felicity.

I think in order to move forward and make our schools completely inclusive we need to put strategies in place, such as procedures which make it clear to teachers that they need to be facilitators for young people on the spectrum. Schools need to understand that they need to lead a very close dialogue with the students themselves and listen very carefully to their individual needs and then implement individual solutions consistently – it is not a question of 'one size fits all'.

Some possible solutions:

- Most people with ASD have a very large private space around them, which needs to be respected.
- If someone is experiencing a "meltdown" it is important not to approach them – a notion that is often difficult for those in caring professions where the natural response is to go up to the person and protect them.
- Teachers and students need to agree on what to do before a "meltdown" happens, such as a gesture from the student – Felicity closes her eyes and puts her hands over her ears when she is getting too near sensory overload. All teachers need to be reliably informed of these agreed procedures. They will almost certainly differ from student to student.
- It should be compulsory for teachers to be taught how to support students with autism as part of their Continuous Professional Development or teaching degree. After all, they are the ones looking after and being in contact with our young people for many years – they are actually in the position to catch young people with autism, so they – unlike Felicity and many others – do not fall through the net.

I would like to leave the last word to Felicity and her friend Susanna. Their advice is: 'Most importantly, understanding and awareness are key.'

To read Ute's article in full please go to www.scottishautism.org/share

Sensory and Perceptual Aspects of Autism: A researcher's perspective

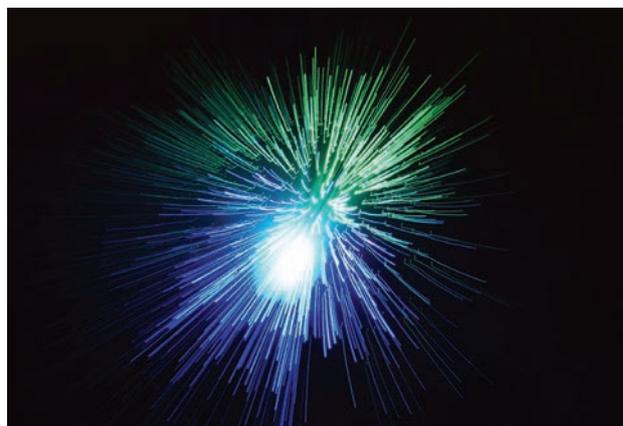


Dr. Ashley Robertson
Research Associate,
Coventry University

Sensory processing in autism has fascinated me since childhood. I have a family member who is autistic, and I have always been interested in how he perceives the world. Growing up, he enjoyed looking at bright lights, and refused to eat foods that weren't solid. Therefore, I wanted to know more about his experiences (as well as those of other autistic people), and how they might differ from those of people without autism. This interest has driven what I have chosen to study, and has impacted on my chosen career.

During my undergraduate degree in Psychology at the University of Glasgow, I began considering a research career in autism. I approached Dr. David Simmons during my third year and started researching sensory reactivity in autism in my undergraduate final year project. During my degree, I worked at both Scottish Autism and the National Autistic Society as a support worker for autistic adults. This was a valuable experience, which gave me further insight into sensory responsiveness in autism, and the impact that this could have on quality of life. I was interested in how many of the adults I worked with appeared to be both hyper- (over-sensitive) and hypo-reactive (under-sensitive) to sensory stimuli, and that this was often in the same sense!

“Growing up, he enjoyed looking at bright lights, and refused to eat foods that weren't solid. Therefore, I wanted to know more about his experiences.”



I continued my research into sensory responsiveness throughout my postgraduate degrees (which were also at Glasgow). After my undergraduate project, in which I asked parents about the sensory responsiveness of their children with autism, I felt that it was important to gain first-hand information about sensory experiences. For this reason, my supervisor and I designed the Glasgow Sensory Questionnaire, which is a self-report measure of sensory reactivity. It covers both hyper- and hypo-reactivity in all the “classic” five senses (vision, hearing, touch, smell and taste) plus balance, and the internal sense of our own body, which is known as “proprioception”.

“I hoped that, by learning more about this, we could help people take steps to make their own environments more pleasant and enjoyable.”

As previously mentioned, I have a strong interest in learning more about the sensory experiences of autistic people, from the perspective of those with a diagnosis themselves. For this reason, I chose to hold focus groups with autistic adults and children, in order to hear about how they perceived sensory stimuli, and the impact it had on their lives. I was particularly interested in hearing about the things they had found that helped them to deal with the negative aspects of

hyper- and hypo-responsiveness. I hoped that, by learning more about this, we could help people take steps to make their own environments more pleasant and enjoyable. We found that unpredictability and a lack of control exacerbated the difficulties experienced around sensory stimuli. Therefore, reducing uncertainty and increasing control appears to improve the ability to tolerate difficult sensory environments.

“Many of the participants I saw told me that being over-sensitive to stimuli could elevate their anxiety, especially if there was little they could do to change it.”

After completing my PhD, I started a postdoctoral position, where I began researching mental ill health in autism. While working in this area, I was struck by how important sensory reactivity seemed to be for mental health – especially anxiety. Many of the participants I saw told me that being over-sensitive



to stimuli could elevate their anxiety, especially if there was little they could do to change it. Furthermore, they discussed how it could impact on their experiences of receiving help from professionals – if the clock in the room ticked loudly, and the lights were very bright, this reportedly impacted on the ability of the individual to engage with therapy.

After this post, I began working at the University of Dundee. I was fortunate to work with some very enthusiastic students that were particularly interested in sensory reactivity in autism. Like me, they had worked as support workers, and noticed that the autistic people they supported either experienced difficulties with, or were fascinated by, sensory stimuli. One of my students held a focus group with teachers, in order to explore the sensory experiences of autistic children with additional support needs. Interestingly, the school were very aware of the importance of sensory issues in this population, and had adapted the school environment in order to minimise any difficulties for the children. My other student was very interested by some recent research by Dr. Jacqui Rodgers and Dr. Mikle South, in which they reported a link between sensory processing and anxiety. She found a similar relationship in adults with autism, supporting their results.

“I am particularly interested in improving ways of measuring sensory processing in autism.”

I have recently started a new position at Coventry University, where I will conduct research into sensory reactivity in autism, as well as mental health and suicidality in autism. I am particularly interested in improving ways of measuring sensory processing in autism, as well as investigating how autistic people, and those that work with or support them, can improve sensory environments. As mentioned previously, there appears to be a link between mental health and sensory reactivity in autism, and therefore I plan to explore how they impact on each other, as well as independently.

To read more about Ashley’s research go to:
<https://pureportal.coventry.ac.uk/en/persons/ashley-robertson>

Too Noisy to Learn?

The Impact of Sensory Stress in the Primary Classroom



Sally Bell, Niamh Stack, David Simmons
(School of Psychology, University of Glasgow)

This summer we have been working within the School of Psychology at the University of Glasgow on a project, funded in the British Psychological Society's (BPS) Undergraduate Research Assistant Scheme called, "Too Noisy to Learn? The Impact of Sensory Stress in the Primary Classroom".

The idea stems from research into autism and the well-recognised fact that individuals with a clinical diagnosis of Autism Spectrum Disorders (ASDs) are likely to have hyper- or hypo-sensitivity to certain sensory stimuli – heightened or weakened reactions to things like everyday sounds, smells, fabric textures or lighting. These sensory difficulties are thought to contribute to some of the more widely known social aspects of autism as individuals may avoid frequenting specific environments due to the stimuli around them. Moreover, research into sensory perception has led to the addition of sensory problems to the revised diagnostic criteria for Autism Spectrum Disorder in the American Psychiatric Association's diagnostic manual – the DSM-5. Therefore, if sensory intolerances are contributing to the difficulty of a social situation, then methods to ameliorate these are incredibly important to determine.

Sensory stress is the term used to describe stimuli in the environment that may evoke adverse reactions. These might include fluorescent lights, strong perfumes or loud noises. In more recent years it has been recognised that high susceptibility to sensory stressors may not be limited to those with an ASD diagnosis, with up to 30% of the general population experiencing

noticeable sensory intolerancesⁱ. Studies have shown a strong link between sensory processing difficulties and autistic trait level. Higher levels of autistic traits are not just confined to those with a diagnosis of autism, but are relatively widespread throughout the general population.

These traits can be quantified by an Autism Spectrum Quotient (AQ) score. The AQ test was developed by Simon Baron-Cohen and his colleagues in 2001ⁱⁱ. It is a 50-question instrument measuring different behavioural and personality traits associated with autism. We used the parent report version for our study where parents answer the questions regarding their childⁱⁱⁱ.

An individual may have a high Autism Quotient score regardless of the presence or need for an ASD diagnosis – this just shows that they present a high level of traits associated with autism. Therefore, our working theory is that the higher Autism Quotient score an individual has, the more susceptible they are to be affected by sensory stressors in the environment. This led us to question how much impact the sensory environment of a primary school classroom can have on a child's learning. If we can apply the growing knowledge on sensory stress and environments to an early educational setting would we be able to lift a potential barrier that may be holding back some children's education? A specific additional focus is the link between "giftedness" and high autistic trait levels that has been identified in the literature^{iv}.

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There were three main components within the study: the sensory audit, the parent packs, and the sensory workshops. The sensory audit, developed by Ashley Robertson & David Simmons^v, is a method to objectively measure specific aspects of the sensory environment. The audit focuses on three senses: visual, auditory and olfactory (i.e. vision, sound and smell). This is achieved by using a combination of cameras, recording equipment, sound and light meters and human inspection. In each school, specific areas were identified to audit to ensure a large representation of the school. For example, two or three classrooms would be selected in different parts of the building and communal rooms such as canteens, P.E halls and toilets. Any other particular rooms of interest would also be picked, for example one school had specific sensory rooms which were chosen to be audited.



Visual Audit Equipment



Visual Audit in Action



Auditory Recording Equipment

The workshops were designed to cater to a range of ages and abilities. As we are conducting these workshops with children in Primary 1 to Primary 7 (aged from 4 to 12 years), in both a local primary school and a specific school for pupils with additional support needs, it was important to ensure that activities were easily altered and suited to a large ability range. Our workshops focus on four sensory modalities – vision, audition, olfaction (smell) and touch. The activities range from mind mapping activities to discuss the school environment to a fun feely box and messy activities. From recording the workshops we are able to analyse what the children discuss and pick up on any particular factors that persist as stressful or annoying in their schools.

This project is ongoing and there are many steps to be taken in further research. Plans involve analysing the images obtained using recently developed software from collaborating laboratories as well as looking at acoustic profiles of particularly problematic sounds. In the case of the olfactory audit we will concentrate on how best to standardise the data and look for general trends. With all of the sensory audit data we shall try to compare precise sensory stressors in specific schools with the particular things that the children complain about in our workshops. The long term aim for this area of research is to work collaboratively towards ways of ameliorating sensory stress in primary schools to give all children a fair chance to work in the best possible environment, and subsequently extend the technique to other groups of people and environments.

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Making Access Possible



Glyn Morris

Friendly Access is an organisation devoted to inclusion for people with hidden disabilities. Here Founder and Chief Executive Glyn Morris shares some of the organisation's history and current projects.

In order to explain where Friendly Access came from and how it started, I need to take you back to the very beginning.

We're a regular family: two kids, two dogs, four cats, and a passion for life. Our eldest, Gregor, now 18 and towering above me in height, has been the inspiration behind every direction life throws at me. I am jealous of his outlook as he lives in the present and is always happy. Gregor was diagnosed with neuronal migration disorder and epilepsy aged 3. He does not communicate verbally, is balance-impaired and has autism. He is my constant reality check on life.

We involve Gregor in mostly everything we do as a family. In 2011, during a theatre visit to London, we were asked to leave just 10 minutes into the performance. Apparently, the low audible sounds he was making didn't agree with the sound engineer. It was a badly handled and upsetting decision by the theatre and even our neighbouring audience members looked on in disbelief. Obviously, this was wrong and our attention turned to how we could fix this. Through sheer determination we won over the theatre industry and the first major autism-friendly performance in the UK, *The Lion King*, was held in London and Edinburgh in 2012. From autism-friendly to relaxed to inclusive, it seems like we're heading in the right direction.

There are around 12 million disabled people living in the UK. There is no disabled register as such; these stats are based on the DWP records, so only reflects the point where a disability impacts someone's life to trigger support. 12 million is 19% of the UK's

population, of which 57% live with a mobility impairment. It's therefore a fair assumption that the other 43% of disabled people are living with a hidden disability or condition.

Friendly Access was granted charitable status in 2014 and has always been on a mission to make Scotland a more accessible and inclusive place, especially for those living with hidden disabilities and conditions. Last month saw the introduction of our very own autistic-led training team - one of our core objectives being delivered.

September 2017 saw the launch of our SurfABLE Scotland project. This is Scotland's first adaptive and inclusive surf school and a follow-on to our hugely successful autism surf school which started 18 months ago. We wanted to cater for everyone regardless of disability or condition. Every individual should have a choice and the right to experience adventure.



The SurfABLE Scotland Project

Whilst a person's disability cannot necessarily be changed, the environment often can. Too often the environment is the disabling factor in someone's experience. There are variables within any environment which are beyond our control. These can be unexpected sensory experiences which can impact on an individual with debilitating effect.

Many individuals have extreme difficulties with heightened noise or crowded situations, and these sensory stressors can act as barriers, stopping those individuals from doing what most may think are everyday activities. These individuals will include many autistic people.

When we venture into new or unfamiliar environments, it can be a stressful experience for most of us. The impact for individuals living with acute sensory hypersensitivity, mental health conditions and heightened anxiety issues, is to be placed at an unfair disadvantage compared to their peers. This can often lead to social isolation.

In order to meet some of these challenges Friendly Access has joined forces with experts in Virtual Reality in the School of Simulation and Visualisation at The Glasgow School of Art and tech start-up, Crag3D to create an innovative application to help support individuals living with hidden disabilities and conditions.

The team are harnessing the potential of Virtual Reality (VR) to create an interactive and immersive experience to support people living with hidden disabilities such as autism, learning disabilities and mental health conditions. Through virtual familiarisation with an environment, individuals can anticipate and build resilience to stressors before they experience that environment. As my colleague Ian Taylor of Crag3D put it: *“Creating an immersive experience can help individuals become accustomed to an environment which they have previously feared, before they get there”*. The project is funded by the European Social Fund and the Scottish Government’s Social Innovation Fund.

“Creating an immersive experience can help individuals become accustomed to an environment which they have previously feared, before they get there.”

As part of the project, Friendly Access has partnered with Aberdeen International Airport (where we have already delivered environmental and awareness training to staff).



Early development screenshots, modelled on Aberdeen Airport Check In & Boarding Area

Aberdeen Airport is a complex environment, which makes it a perfect place to base our study and establish our proof of concept. However, we aren’t planning to work solely within airport environments and have already made tracks to cater for other scenarios. As Dr Matthieu Poyade of Glasgow School of Art explained: *“Our aspiration is that it will give individuals increased confidence and to feel safe in some of the most challenging environments they visit.”*

Our demo Android app will be available to download free of charge from late November 2017.

Further details can be found at friendlyaccess.org. Versions will also be available for a VR immersive experience using any affordable VR headset.

Four years have passed since Friendly Access was created and now technology offers new possibilities to fulfil our vision. It is a truly exciting time. The future for individuals living with hidden disabilities and mental health conditions looks brighter as we use technology to work towards a more inclusive, more accessible Scotland.

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A personal account of the impact of sport and exercise



Ryan Cuzen

Life before training at my athletics clubs would be spent in my bedroom by myself. I just wanted to draw and play with Lego. I wasn't active and didn't do anything. I found gym too difficult to deal with. I didn't enjoy or look forward to these lessons. After my experiences in mainstream primary school, being fit and healthy meant nothing.

Eventually I was moved to a new school. One day my amazing teacher at the time decided to enter me into the final of the P7 running competition. She knew going through the heats would be too stressful for me and the Head Teacher agreed that I could just run in the final. I did well in the finals, finishing second.

I started secondary school the following August. A short time after, a swimming instructor and a PE teacher my mum spoke to suggested I join an athletics club for people with disabilities.

I went along to Red Star Athletics in October 2009. I met Janice, the head coach, who was lovely, but initially I couldn't join in. I would play in the long jump sandpit (I loved playing in sand, it was calming for me) as joining in scared me, as did speaking to new people and learning something new with strangers. Thinking back, I still felt lost from the time I had been in mainstream school. Being in groups was too much. However, my mum kept taking me to the track every week.

“Thinking back, I still felt lost from the time I had been in mainstream school. Being in groups was too much. However, my mum kept taking me to the track every week.”

One night in February 2010 I finally got up the courage to join in and train with athletes in a small group, not a full session. It was a start. When I began training, it was demanding and stressful, being around people, always being afraid of saying the wrong thing. Having conversations with people wasn't easy and getting jokes didn't work for me. As we kept going I slowly began talking with the other members of the club. This was a stepping stone for improving my social skills as this was something I was lacking in and I am always trying to get better at. Social conversation can be difficult but the people at the club started to get to know me and it helped. I was also getting active.

“Social conversation can be difficult but the people at the club started to get to know me and it helped.”

My new-found interest in sport grew, as my mum found something new I could try: skiing lessons. We had problems, but then new things do bring a whole lot of challenges for me and my ASD mind. However, eventually, after many weeks of going and trying without success, a Disability Snowsport UK instructor took over the lessons. He got it. He understood me, how it wasn't just straight forward for me. My journey of learning to ski then began. This led to more one-to-one lessons and the amazing experience of freedom in a one-to-one lesson with my instructor in the Cairngorm Mountains. I also, again with mum's support and persistence, joined Temple swimming club, a club for kids and young people with disabilities.

Eventually I found myself competing in athletics for my club Red Star Athletics, swimming with Temple Swimming Club and competing in both swimming and athletics in Regional and National competitions. I found competing physically and mentally challenging often when I didn't win, blaming myself for not doing well enough.



“Eventually I found myself competing in athletics for my club Red Star Athletics, swimming with Temple Swimming Club and competing in both swimming and athletics in Regional and National competitions.”

My mum deciding to join me and get fit herself has helped me. She gets why fitness is important to me mentally, as well as keeping me healthy for life and competing. She now helps to train me. Who'd have thought my mum would be my personal trainer! She also makes sure I eat well and we do training sessions together. I like that we can have some fun sessions as well as my personal training sessions. We still manage a laugh. I'm usually better with jokes. She says I helped her. I know we both helped each other change our lives through fitness. Her support in all I do with sport and fitness has meant I have been able to access opportunities I'd never have thought possible.

“I know we both helped each other change our lives through fitness.”

Sport has helped me to learn about working as part of a team, through Red Star AC, Victoria Park AC, Temple Swimming Club, being part of the Scotland West Teams for swimming and athletics, learning that it's not just about winning, it's about taking part, working on improving constantly, using skills you learn both in your sport and in life. Being on the autistic spectrum means stress and anxieties are part of everyday life for me. Sport and fitness help me to escape from them.

When I'm training with mum, at an athletics track, skiing on a slope or doing lengths in a swimming pool it allows me to switch off and take my mind off my worries for that time. I feel a sense of freedom and a chance to break free of the strings of life for a short time. I believe that sports and being active has had a positive impact on my life. I'm a work in progress, probably always will be, but sport and being active has helped me see how I should take every opportunity in life and how small changes in lifestyle can have great results.

“I feel a sense of freedom and a chance to break free of the strings of life for a short time.”

I hope to encourage other children and young people like me with disabilities to try to use exercise and sport to help them socialise with each other, try something new with the bonus of getting fit and active at the same time. They may even find a sport they enjoy and one day be competing like me at the Special Olympics.

Ryan's mum Julie shares her account on the impact of sports and exercise online at www.scottishautism.org/share

Little fish crosses the big pond to the International Meeting for Autism Research 2017



Maggi Laurie
1st year PhD student
at Development
Autism Research
Technology Group,
University of Edinburgh

The International Society for Autism Research (INSAR) is a network of academics and researchers, who meet annually to share cutting-edge findings with other autism researchers. In May this year the meeting (IMFAR)ⁱ was held in San Francisco, California, and I was very fortunate to attend for the first time.

The IMFAR conference is huge, with a jam-packed schedule from 7am until 7pm, and more presentations and discussions than it is physically possible to attend. There are poster sessions and clusters of short talks around specific themes, as well as keynote speakers and special interest groups. The special interest groups (SIGs) are seminars focused around new or controversial research themes. This year's SIG themes included ageing, safety on public transport, participation in brain imaging research, and suicidality.

Keynote speakers this year included Professors Pat Levitt, Connie Kasari and Ami Klin, who each gave wonderful speeches about their recent research findings. Levitt discussed the influence of brain circuits and genetics on individual differences in children with autism and other diagnoses. Kasari presented the effect of peer-implemented (rather than teacher or therapist-implemented) support in mainstream classrooms for autistic pupils. Klin (in a beautifully illustrated joint talk with collaborator Dr. Warren Jones) talked about development of social attention in children with and without autism and asked whether, by investigating what infants look at, scientists can predict which children will later receive a diagnosis of autism.

My area of research is technology, so I was straight up at the technology demonstration to play with all the

shiny gadgets! There was a good mix of both technology applications (e.g. using technology to reduce sensory overload or support pretend play) and design (i.e. developing new technologies which have been designed by autistic people). There were lots of novel technologies (such as robotics), which will be interesting to follow over the years as these technologies are developed and evaluated in classrooms, at home and in the community.

Whilst IMFAR was an incredible experience, and I got a lot out of attending, there are a few things I would like to see changed in future meetings. The organisation INSAR do make efforts to engage with the autistic community, but I think they can showcase this more to the attendees, and invite autistic and community speakers to host discussions. In an ideal world, I think all conferences about autism should have a language policy (informed by autistic people), interaction cards, and be hosted in autism-friendly venues (whilst 2017 was an improvement on 2016 from reports, it still was not great). Whilst this may be too idealistic to achieve in time for the next conference, I am uplifted by the discussions I had with colleagues and friends about what changes could make the next meeting more community-friendly.

In all, I am grateful for the opportunity to attend IMFAR and I had many insightful conversations with delegates about my research and related topics, including theories of autism, early development, and outcome measures. The biggest thing that I left IMFAR thinking about is how to feedback these discussions to the autistic community (although twitter was very good for doing this remotely) and other stakeholders, such as teachers, parents and therapists (and I like to think it begins with this article). As a PhD student, the frontline for me is attending an international conference and trying to network with my academic idols, but for the community, the priority is bridging the gap between community and research at all levels.

To see the full IMFAR program (free) and for information about future meetings, go to <http://www.autism-insar.org/ii>.

Shaping Participatory Autism Research



Joseph Long
Research Manager,
Scottish Autism

Between 2015 and 2017 the Economic and Social Research Council funded a UK-wide series of seminars aimed at improving meaningful autistic participation in autism research. The seminars followed the publication of *A Future Made Together* in 2013, a report that highlighted a need for better involvement of autistic people and their families in setting the priorities of autism research. In response, the *Shaping Autism Research* seminars brought together autistic people, parents and families, practitioners and researchers in order to discuss how autism research could be made more collaborative and inclusive.

Seminar themes included Adult and Children's services, autism practice, participatory research, and wellbeing. Scottish Autism's research team took part in three of the series seminars. We shared our work on practice-focused research at the Edinburgh seminar, which focused on autism practice. At the London seminar on wellbeing the team presented on inclusive survey methods for autistic people. We also took part in final seminar dedicated to pulling together the findings from the series.

The seminars marked an important shift towards collaborative and participatory approaches to research in the field of autism. Outputs from the seminars will be disseminated over the coming months. So far participants have produced a guide to participatory research for early career researchers and are collating examples of best practice to share on the series website. You can read about the series, view video and slides from presentations, and comment on discussions at www.shapingautismresearch.co.uk.

The collaborative approach promoted by the seminars is central to the work of the Participatory Autism Research Collective (PARC), a community seeking to share knowledge and good practice relating to the meaningful involvement of autistic people in research. More information can be found at <https://participatoryautismresearch.wordpress.com>.

Initially based in London, PARC are now hosting events around the UK and hope to begin activities in Scotland in the very near future, watch the PARC website for more details.

REFERENCES

- i Since its inception, INSAR's annual meeting has been called "IMFAR" (the International Meeting for Autism Research), but next year will be re-branded as the "INSAR Annual Meeting"
- ii The next INSAR Annual Meeting will be in Rotterdam, the Netherlands in May 2018.

NEWS

Creating Capacity – Support for Adult Siblings

Siblings Australia has been working in the area of sibling support, both for young and adult siblings, for nearly 19 years. In 2016 it was supported to carry out a project to improve the resources available to adult siblings, especially given that the disability sector has undergone some major changes in recent times. The project discusses implications for the disability sector and also makes some recommendations for recognising and supporting siblings more effectively. To read the report please go to www.siblingsaustralia.org.au/Final-Report-SDF-Aug-2017.pdf

Keyhole Training

Scottish Autism was granted Scottish Government funding to pilot the delivery of Keyhole training to 25 Early Years staff. The Keyhole Early Intervention Programme is a holistic approach for young children to enhance their development from a young age. The training was initially developed and delivered by Autism NI in Northern Ireland and the University of Ulster facilitated evaluation of the project. It is being delivered for the first time in Scotland in November 2017.

Success at the Scottish Awards for Business Excellence

Scottish Autism was delighted to receive three accolades at this year's Quality Scotland Awards for Business Excellence. As well as the overarching 4 Star Recognised for Excellence (R4E) Award, the organisation picked up the Good Practice Award for Harnessing Creativity and Innovation. This is bestowed upon organisations which grow their reputation on a national and international basis through innovative practices and recognised a number of initiatives undertaken within the Centre for Practice Innovation. David Harkins, Quality and Risk Manager, also received the Quality Scotland Ambassador for Excellence Award.

EVENTS



Knowledge Share

Scottish Autism's Knowledge Share seminars are taking place in Orkney and Fife. Upcoming in Orkney on 31st of October is a Seminar on Voice Participation & Involvement. Our Relationships and Sexual Health seminar takes place in Fife on 30th of January and in Orkney on 27th of February 2018.

For more information about Knowledge Share and other Scottish Autism events please visit: www.scottishautism.org

Centre for Practice Innovation Annual Seminar – Sharing Knowledge, Enriching Lives

The Centre's Annual Seminar takes place at New Struan School in Alloa on Tuesday 24th of October. Presentations are being delivered by Joe Long, Research Manager, on 'Developing a Culture of Participation' and Charlene Tait, Director of Autism Practice and Research, on 'Values into Practice – Outcomes of Organisational Learning'.

Autism Network Scotland

Autism Network Scotland provides reliable and impartial information that connects and communicates with individuals on the autistic spectrum, their families and carers, and practitioners working in the field of autism.

For forthcoming events across Scotland, please visit: www.autismnetworkscotland.org.uk

Meet the Centre's Research and Practice Associates

Research Associates



Ken Aitken

Ken is a practicing Clinical Psychologist. He has been Chair of the Research Subgroup of the Scottish Autism Strategy and an active member of the main Strategy Group since its inception.



Sue Fletcher-Watson

Sue is a Developmental Psychologist with an interest in using research methods from psychology to address questions with clinical, educational and societal impact.



Karen Guldborg

Karen is a Senior Lecturer in Autism Studies at the University of Birmingham as well as Director of the Autism Centre for Education and Research (ACER) and a Senior Fellow of the Higher Education Academy.



Andrew Jahoda

Andrew is Professor of Learning Disabilities in the Institute of Health and Wellbeing at the University of Glasgow.



Tommy MacKay

Tommy is one of the UK's leading psychologists who works across the fields of educational and child psychology, health psychology, clinical neuropsychology, psychotherapy, teaching and research.



Richard Mills

Richard is the Research Director of Research Autism, London and Research Fellow at the University of Bath. He is also a Senior Research Fellow at Bond University, Queensland, Australia, consultant at the ARC Singapore and an Associate of the Tizard Centre at the University of Kent and AT-Autism. Richard is an editor of *Autism, the International Journal of Research and Practice and Advances in Autism*.



Anna Robinson

Anna is an Emotion-Focused Therapist, and is the Autism Courses Leader for the MEd in Autism programme at the University of Strathclyde.



David Simmons

David is a Lecturer of Psychology at the University of Glasgow.

Practice Associates



Debi Brown

Debi was diagnosed with Asperger's Syndrome as an adult and has since written and published two books about autism: 'Are you Eating an Orange?' and 'The Aspie Girl's Guide to Being Safe with Men'.



Yvette Q. Getch

Yvette is Associate Professor, Department of Diversity and Community Studies at Western Kentucky University Bowling Green, Kentucky, and part-time Associate Professor, Department of Counseling and Human Development Services, the University of Georgia Athens, Ga.



Michael McCreadie

Michael is a Health Psychologist with a specialist knowledge and experience in Neuro-Developmental conditions and Acquired Brain Injury.



Kate Strohm

Kate Strohm is the Founder and Director of Siblings Australia, the only organisation in Australia focused on the needs of siblings of children living with disability/chronic illness.



Peter Vermeulen

Peter has a MSc and a PhD in Psychology and Educational Sciences. He has worked with people with autism and their families for more than 25 years and is currently Co-Director of Autisme Centraal, a training and education centre for Autism Spectrum Disorders in Belgium.

To find out more about the Centre's Research and Practice Associates, please visit our website: www.scottishautism.org/cpi

The Centre for Practice Innovation provides a focus for practitioners, researchers and organisations to come together and collaborate, share knowledge and ideas and shape innovative autism practice.



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