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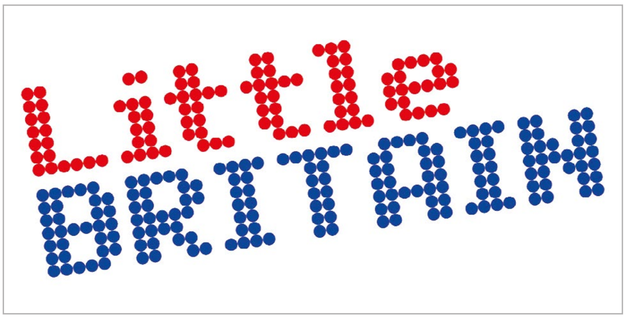

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Guest editor

Dr Catriona Stewart
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There were two key reasons for choosing Women and Girls as a focus for this issue. One is to celebrate our Right Click resource for Women and Girls, launched this year. Within it, as well as interviews and demonstrations, lists of resources and links, there are presentations on the research carried out for the programme with an overview of what is currently understood within this area. I go into this briefly in the coming pages.

The other reason is that this is a population needing attention. Despite increasing awareness that they exist, there is still very little research and even less in the way of specific resources or support. The Right Click programme is just a start, although a very positive one.

Focusing on a specific group - women and girls - within the autism community has given us the underpinning theme for this issue. But it's unusual in another way; having sent out the guidelines to the people I thought would offer insight into some of the issues we wanted to cover, what stands out for me is that even when not written as a personal account, most of the articles that came back contain some description of the author's personal experiences. And more than that, each and every one has embedded within it a passionate plea for change or, in at least two cases, determination to be that change.

There is a personal account from mother of two, Dr Shirley Smith, who has been, as she describes herself 'waitress, student, computer programmer, traveller, web designer, doctor, writer, conference organiser...' (and more!). Author of 'From Here to Maternity', Lana Grant discusses some of the complexities of being a mother who is on the autistic spectrum. Alina Spence discusses issues arising within the educational setting. Dr Claire Evans-Williams' case-study on real-life 'Julia' gives us a poignantly descriptive look at one young girl's strategies developed and employed to cope in her daily life, or at least to hide her daily struggles.

Dr Dinah Murray, autism pioneer and advocate, with numerous academic and literary achievements over decades, writes from her personal experience of life, offering advice to her younger self and in doing so, gives us insight into some of the ways in which she has learned to negotiate and make sense of the world as an autistic adult. Emma Kirkby is a determined and able young woman who describes her experiences as a school girl diagnosed with Asperger's Syndrome.

Many thanks to all the contributors.

If you have ideas, experience or knowledge to share for our next edition, please contact the Centre for Practice Innovation by emailing **CPI@scottishautism.org**

Information and Inspiration: creating the Right Click online resource for women and girls.

Dr Catriona Stewart
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Right Click for Women and Girls was developed to provide support, information and inspiration for autistic women and girls, their parents and carers and the professionals who may be involved in diagnosis or ongoing support. Supported by the Scottish Government through their Scottish Strategy for Autism funding, Phase 1 was completed in May 2016. Work on phase 2 has now begun.

The development team consisted of Charlene Tait, Director of Autism Practice and Research at Scottish Autism and myself who was commissioned as academic advisor to the project. The idea for the programme arose during the Scottish Strategy Autism research seminar series at Strathclyde University in 2014 when I presented on my PhD research that focused on girls with Asperger's Syndrome and anxiety, completed in 2011[i]. Underpinning that earlier study was the goal of making this previously invisible population visible, about giving them a voice and then listening. Conceived as a practical resource underpinned by research, the programme has been built around themes and issues identified through a number of routes, the rationale for which and methods involved are outlined below.

What is being increasingly recognised, is how little is known about women, girls and autism[ii][iii]. What has also emerged over the last few years is a range of issues affecting women and girls and their parents and carers - as well as the practitioners working with them - with little recognition, support or practical resources in place for them. Information, then, was one goal of this Right Click programme, gathering information, adding to the knowledge-base, highlighting areas of importance where perhaps more research can be done, resources focused.

The other goal, defined as 'inspiration', is a response to emerging evidence about the effects of diagnosis of autism or Asperger's Syndrome, for people of all ages, but in particular young people. This has raised increasing concerns about the issues of stigma and narratives of negativity around autism and how these impact on self-esteem, confidence, life-choices, individual and personal outcomes[iv][v].

What was core to this project was that it should be grounded in the experiences of autistic women and that what was developed would be cogent, supportive, life-enhancing. It is certainly about increasing knowledge and disseminating information, but more, presenting a positive, outcome-oriented resource.

The project involved autistic women and girls from the start; grounded in earlier research the areas covered within the Right Click online survey we created arose out of many interviews and group discussions held over a period of years starting with earlier research work carried out by the team, and my involvement with SWAN: Scottish Women's Autism Network. These areas have been expanded on and developed throughout the Right Click project and continue to be so.

When considering methods, there are always questions to be answered before embarking on any research. 'Evidence-base' is a much used term, often bandied about by researchers, medics and the media, and usually taken to mean 'true' or 'real'. What should always be asked and often is not, is what kind of evidence does that mean and whose reality does it reflect? How was that evidence gathered? What does it tell us and how can it be applied to benefit those being researched?

Quantitative and qualitative methods of research should complement each other: one tells us about the whats, the whos, the how manys, the numerical means and statistical probabilities; the other tells us about the whys and the hows, describes the complexities, gives us insight into the lived reality for individuals and can point us towards new areas for exploration.

The Right Click programme for women and girls used a mixture of methods. Firstly, a survey was developed, which was an online 28 item questionnaire snowballed out via various networks, including SWAN, and autistic individuals with large personal networks.
The questions were made up of a combination of demographics e.g. age, diagnostic status, numbers of children if any, and any diagnosis for them, ethnic background. There were multiple choice questions and there were also open-ended/self-report items.
The survey was disseminated in two waves, the first gathered 39 responses from women and parents of girls; the second was targeted at autistic women only and received 35 responses. I also ran a number of focus groups with women, autistic women who are mothers and two schoolgirl groups; these were all recorded, anonymised and transcribed.

What was created was a wealth of numerical and rich text data, with a combination of quantitative data analysis (thanks to Bonnie Auyeung[vi] of Edinburgh University for invaluable input here) and qualitative thematic analysis. The quantitative survey data largely serves to identify some of the challenges, the problems and areas of concern currently involved in being a woman or girl on the autism spectrum.

These are crucially important as a start in highlighting where there should be further research and most importantly, resources allocated. For example, difficulties in accessing health care for women, across the board, but specifically antenatal services, challenges in the experiences of giving birth and anxieties around post-natal support were all identified.

What the qualitative data, on the other hand, has served to illuminate, is the 'whole picture' aspect of autism in women and girls, that each and every individual has strengths and challenges; needs and assets; individual personalities, humour, determination, love for their children (where they are mothers), insight, aspirations and achievements as well as difficulties.

The clearest emerging picture is of a population who, because they have been largely, perhaps not 'hidden', but certainly under-recognised, first and foremost need much greater awareness of their needs and crucially, not just awareness but understanding and support.
In every area identified, the key message was one of need for increased knowledge in professionals e.g. in diagnosis, health care, education. Also better understanding and acceptance within the community at large, for example, in employment, accessing public spaces and activities, parents' and other community groups, social services.

There is much to be proud of in the Right Click programme for women and girls. It is innovative and unique in a number of ways: interviews with and presentations by autistic individuals such as Debi Brown, Lana Grant, Dr Dinah Murray, Sarah Hendrickx, Dr Wenn Lawson and Lynne Moffat; the way it address some of the more prosaic but so important and often problematic aspects of daily life for young people on the spectrum (and many older ones too). Personal grooming, sexual health, general health, food and nutrition, are all areas that are covered.
Year one of the project has made a start on some of these things; in year two there will be much more.

More research is under way, there will be more practical skills items included and more interviews.
There are plans for a range of new areas identified over the course of the first year; there will be more on younger women and girls for example. Built into this resource is a process of ongoing review and assessment and it will continue to be built around input from autistic women and girls who are the source of such inspiration!

RESOURCES AND LINKS

i Stewart C. (2012) 'Where can we be what we are?': the experiences of girls with Asperger syndrome and their mothers. Good Autism Practice GAP,13,1, pp 40-48.

ii Van Wijngaarden-Cremers, PJM et al J Autism Dev Disord (2014) 44:627–635

iii Westman Andersson, G., Gillberg, C. & Miniscalco C. (2014). Pre-school children with suspected autism spectrum disorders: Do girls and boys have the same profiles? Research in Developmental Disabilities Volume 34, Issue 1, January 2013.

iv Snow (2013) Beyond Visions of Repair: Evoking a parlance of capacity and competence in research on Asperger Syndrome and Schooling.

v Humphrey, N. & Lewis, S. 2008 `Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. Autism, 2008; 12; 23.

vi School of Philosophy, Psychology and Language Sciences, Edinburgh University.

I was working as a waitress in a cocktail bar[i]...

Dr Shirley Smith (nee Moore)

...not quite, but at 15 years old, I followed a friend into a Saturday job waitressing for wedding receptions. The owner was a dragon (not literally) and most people lasted in the job for 3 weeks. I lasted 3 years! The work was routine with a defined structure, I wasn't expected to speak to the guests other than "excuse me", "may I clear your plate" etc. I followed instructions, worked hard and did not waste time gossiping in the corridors. So I mostly managed to avoid the dragon's fire. I didn't particularly enjoy the job, but it was easy money.

I always wanted to be a doctor. I would be glued to TV medical documentaries and dramas and I loved hospitals! However, executive functioning challenges meant I was not able to access the work experience and other extracurricular activities required for medical school. Nor did I have the confidence or communication skills to sell myself to interview panels of authority figures. I liked maths and physics so I read engineering at university, which had the advantage of not requiring a high level of social skills!

I didn't work while studying. I did not have a wild social life to support and I managed with a grant. My mother, however, was less than impressed when I spent holidays in my room reading. "Why don't you get a job?" If only it were that simple! The possibilities and anxieties were too overwhelming and I didn't know where to start. My mother found me some work once, picking apples - I was the worst picker the farmer had ever had (so she told my mother)! Why? I was left in an orchard with no instructions. So I picked apples... but only ones that I would want to eat. I examined every apple rejecting those with the slightest blemish! Apparently I should have picked everything, I would have filled more boxes and actually covered my bus fare!

I underachieved at university. I couldn't concentrate during lectures or tutorials so had to teach myself. I would put in 110% to the subjects I was keen on, but neglect others. I once failed a paper spectacularly but got 98% on the re-sit. It wasn't an academic problem but an executive functioning and sensory one. My peers moved onto large city companies. I stayed in the "safe" world of academia for an M.Sc. in medical engineering.

I graduated with distinction, but was stuck. I didn't know how to transfer my intellectual skills to a "proper job". Fear of failure, appearing stupid, not fitting in and the prospect of commuting kept me from applying for industry positions. In hindsight my social communication, social imagination and sensory difficulties were evident here, but I covered them up, ashamed and embarrassed that I couldn't be like everyone else.

> “I didn't know how to transfer my intellectual skills to a "proper job".”

Eventually I secured an IT post within a medical school; my future boss saw something that would fit in well with his small team of computer "geeks". This was a good job, I got to write code, work flexible hours, cycle to work, dress casually AND work in a hospital! My boss believed that most work-related meetings should take place in the pub; the anxiolytic effects of beer helped me to contribute to team discussions in a way that I was unable to do in a more sober environment!

While I was initially happy here, I became plagued by thoughts that something was missing, that I should be aiming for "greater things". After taking time out to travel and "find myself" I was lucky enough to be in the right place at the right time and 10 years after I first went to university I convinced a medical admissions panel that I could be a doctor.

I thought being 10 years older than my peers would be advantageous socially and emotionally, but during the very first lecture I felt I had made a terrible mistake. Fellow students were chatting to their neighbours and making new friends while I smiled uncomfortably at random people and rustled through my papers[ii].
I eventually settled in, mostly enjoying medical school and graduating in the top 5%. Lectures were still hard. Group work was challenging. Clinical work was terrifying! While I loved talking to patients 1:1, examining them and putting together the diagnostic clues, being observed doing so could leave me almost paralysed with fear. I developed my doctor persona by watching and imitating fellow students, but never became comfortable in the role, having to hide my neurodiversity in order to fit in.

> “I developed my doctor persona by watching and imitating fellow students, but never became comfortable in the role, having to hide my neurodiversity in order to fit in.”

I spent the following 10 years as a hospital doctor. I never expected it to be easy, but with an undiagnosed autism spectrum condition it eventually proved untenable and I was finally dismissed following long term sick leave with stress and anxiety.

As a junior doctor, I was really “in at the deep end”. Medical school did not prepare me for the realities of working in the NHS with its financial and staff shortages, bullying culture and unrealistic expectations. I had to learn on the job, I couldn’t retire to my room to read about every condition or procedure I came across ; it was “see one, do one, teach one”, not “see one, research everything about it, finally have the confidence to do one 3 weeks later”! Constant interruptions with “more urgent” tasks were frustrating and exhausting.

Most doctors express the desire to throw their bleep out of the window - I had the urge to follow it. Hours, roles and teams changed daily in some jobs where I never felt like I belonged anywhere or really knew what was expected of me. There was little continuity of care and I felt like a ping-pong ball! My peers seemed happy to manage multiple patients and an ever increasing jobs list, whereas I struggled to think about more than one thing at a time and became overwhelmed easily. I had difficulty prioritising and I found it very difficult to ask for help as I couldn’t explain why I wasn’t coping like everyone else. I was thorough, but inefficient. My attention to detail was seen as being slow, my unwillingness to “just sign this” (without double checking it) or cover last-minute rota gaps meant I wasn’t a team player, and my reluctance to undertake tasks I hadn’t fully mastered meant I was under-confident.

In retrospect I can see why I had problems and where reasonable adjustments may have saved my career. I may have made different choices and had different opportunities had my ASD been known about and taken into account. I have references and comments, from my time as a doctor, praising my teamwork, multitasking, ability to work under pressure etc. However, I have also had comments saying I was unable to do any of these things! It is clear I worked best in small, supportive teams in more rural hospitals where my role was clearly defined, but did not cope well with a busy university hospital where I was a nameless cog in sensory nightmare!

> “I may have made different choices and had different opportunities had my ASD been known about and taken into account.”

Now twenty five years on, I don’t have the world at my feet. Success hasn’t been so easy for me. I’m exhausted from all these years of forcing my square peg into a round hole. I do believe my perfect job is out there. Hopefully with my new-found insights and acceptance of my differences and support needs it won’t be too long until I find it!

RESOURCES AND LINKS

[i] “Don’t you Want Me” by the Human League was a hit while growing up in the eighties!

[ii] Smartphones had not been invented yet!

Autistic Mothers... really?

Lana Grant

Advisor and Advocate

This morning I read another headline on social media about the frustrating lack of diagnosis of autistic girls. These headlines have been around since 2010. Every year, we are encouraged to believe things are improving with regard to recognising and addressing autism in females. They are - but not quickly enough.

I was an autistic girl. I was not diagnosed until I was an autistic woman aged 38. By that time I was also an autistic mother. My diagnosis followed that of one of my (male) children. Since then I have worked hard to raise awareness of the presentation of autism in females. Through the course of this work I have encountered many mothers who present as being autistic, are self-identifying as autistic or are actually diagnosed.

Many of these women are living with a (mis?)diagnosis of anxiety, depression, bi-polar disorder and other mental health conditions. Many of these women are also in relationships, working and raising families. Most of the women I speak with are doing this feeling isolated and different. This is wrong.

> “As autistic mothers we need a peer group.”

As autistic mothers we need a peer group. I have recently set up a group on Facebook called ‘Mums on The Spectrum[i]’. I expected to have a group with about 10 members. We have recently welcomed our 42nd member. The reason for establishing this group was to offer a safe forum for autistic mothers to discuss their lows and also their highs. Many have autistic children but the group is not a place to discuss them, there are many other groups for that. This is a safe group where we can talk about things in a safe space with peers who understand. We can discuss balancing our needs with those of our families, we can discuss our frustration about employment issues and interactions with professionals. We can also talk about our hopes, worries and fears and we don’t judge[ii].

Motherhood is tough. Autistic motherhood is really tough. It is also massively rewarding. Someone recently asked me if I felt guilty that I had passed my autistic genes onto my children (I have three children on the spectrum). On that day my answer was no. However, ask me on another day and my answer may well be different. That doesn’t mean I shouldn’t be a mother because I’m autistic and I was quick to point this out to the person who asked me the question (an autistic woman who was considering motherhood). It means that sometimes I may need some extra support and understanding. This can only come with early diagnosis of our girls and empowering them with the knowledge that they can do anything they want to, in some respects, because of their autism, not despite it. Autism may bring with it focus, attention to detail, problem-solving abilities, logic and often a great deal of determination.

> “Autism may bring with it focus, attention to detail, problem-solving abilities, logic and often a great deal of determination.”

Motherhood throws you into situations that can be difficult and unavoidable. From the ante-natal groups to the school gates, we are placed in situations that we may find uncomfortable. Before my diagnosis I raced through motherhood with anxiety levels that eventually propelled me to a breakdown. Through this time I visited the GP many times to ask for help. I was sent away with patronising smiles and told that it was just part of motherhood.

Yes, motherhood is stressful, life is stressful, but it shouldn’t send you to the depths of depression that I was experiencing. So I began a relay between medics who implied that I was struggling because I was defective. Sensitive and anxious were used as belittling, pejorative terms, meant for people unable to quite cope with life because there was something wrong with them. Only when I received my diagnosis did I realise what had been the key issue and problem all along. Lack of awareness of my autism, certainly but more importantly perhaps, lack of appropriate support.

> “What I urge in my work is that professionals recognise autistic mothers, our assets, our challenges, our needs.”

It is hard balancing our needs as mothers with our families' needs but because of the perfectionism – and our natural feelings of love and responsibility we feel for our children - we are prone to, we push ourselves, often feeling we are not good enough because of our self-imposed standards. Would this be different had I known about my diagnosis earlier? Yes, I think it probably would.

Many of the women I speak with have had involvement from professionals within the area of health and social care. For many undiagnosed autistic women their mothering may not fall into the usual patterns and presentations expected by professionals. Some women may be able to carry out the basic caregiving for their children, such as feeding and cleaning but they may not demonstrate overt physical affection or social interaction and play with their young. Others may be overly attentive to their children to the point of obsessiveness. Many are physically affectionate, however, and many may have a mix of qualities and presentations relating to their autism.

I have worked with mothers where there have been mutterings from professionals about Fabricated Illness Syndrome (FID) and in some cases children have been removed from the home following serious allegations and poorly informed or prejudiced professional judgments. These mothers face a long battle, with little understanding or support, to get their children back. They may be accused of being hysterical and inappropriate during court proceedings, because their autism is neither recognised nor understood or accommodated. Sensory issues, high arousal and emotional liability are seen as pathological, rather than a natural response by an autistic person to high levels of stress and often combative situations. When they ask for diagnosis they may be dismissed as 'attention seeking' because “women are not autistic”.

As a professional myself I am committed to the safeguarding of children and young people and this should always be the top priority. However, what I urge in my work is that professionals recognise autistic mothers, our assets, our challenges, our needs. We exist. We have individual presentations as do all autistics, male and female, but we do exist. Autistic girls grow up and may become mothers. We owe it to all the girls to recognise they exist and ensure that they are supported. For all of its messiness – and life is messy in many ways, for everyone – life and motherhood can hold positive, wonderful experiences. Autistic women can and do make wonderful mothers – quirky, eccentric, perhaps, but loving and capable. We need to stop ignoring autistic mothers and help them to become empowered to do what they want, just like other mothers, to be the best mothers for their children they can be.

> “Autistic women can and do make wonderful mothers – quirky, eccentric, perhaps, but loving and capable.”

Having worked within the field of autism for nearly 20 years, Lana Grant is a specialist advisor and advocate for people with autism and their families.

RESOURCES AND LINKS

i **https://www.facebook.com/groups/mumsonthespectrum/**

ii SWAN: Scottish Women's Autism Network runs a Facebook page at **https://www.facebook.com/swans.scotland/** SWAN's core group includes a number of mothers and many of the 1000+ 'likers' of the page are also mothers.

Recalibrating the Radar: Girls and Autism, an Educational Perspective

Alina Spence
Outreach Teacher

Girls with autism are often described as 'flying under the radar.' The implication being that they are not in the correct range for detection. It might be more accurate to say that the girls are in the correct range for detection, but that the radar does not always detect them because it is looking for something else - a more overtly observable male presentation of autism. This stems from the fact that most historical and contemporary research into defining and diagnosing ASD through behavioural analysis has been done by the study of a predominantly male ASD population, even since the original studies by Kanner[i] and Asperger[ii iii], resulting in girls (who display more introverted ASD behaviours) having been historically overlooked.

In recent years there has been more discussion and research in psychology and other areas about gender differences in autism presentation. This difference is crucial when considering how girls with autism present and prosper in educational settings.

In my role as Outreach Teacher for high school pupils with communication difficulties, there are 21 female pupils in my caseload of 83 pupils. This accurately reflects the statistical ratio of one female in every four people diagnosed with autism. One of the key reasons for this difference in incidence of ASD in females is often considered that autism in girls looks different to autism in boys and is hence underdiagnosed. It has been suggested that the current diagnostic criteria for ASD do not fit the female presentation of autism[iv].

The special interests of autistic girls, although very intense, tend to be similar to the interests of their neuro-typical female peers and are therefore sometimes not as observable. It is also thought that girls are more able to 'mask' their autism, in an effort to fit in, by using imitation to learn appropriate social behaviour. This repression of their true self could be the reason mental ill health, such as anxiety and depression, is more common among autistic females.

Emotional literacy forms a large part of my work with pupils, ranging from simply being able to identify common emotions, to anger management, mindfulness and relaxation techniques. The most common support I am asked to provide for high school girls is in the area of managing anxiety. Their anxiety stems from various sources, such as feeling overloaded by the demands of the curriculum, worry about academic performance, feelings of difference and striving for perfection. Effort to meet these demands and attempting to portray a veneer of coping can be exhausting for young women, leading to chronic anxiety and depression.

Discussion with female pupils with autism and their parents, along with my own experiences of working within several educational establishments, have identified the following areas of practice which support girls with autism to learn and develop in school.

Sharing information with open lines of communication is crucial - from an extended transition process between primary and secondary school with regular transition meetings involving parents and all relevant staff, to the use of case conferences involving all class teachers – it is important that school, home, educational psychologists and other agencies share any information that can help to support a pupil, and that this continues from nursery to post-school transition. This is in addition to the more traditional ways such as school reports and parent evenings.

Developing relationships

Relationships between pupils and teachers, Learning Support departments, parents and carers, and so on, are important to ensure that there is a support structure in place for pupils. Parents should feel able to call to speak to their child's Key Person or Pastoral

Support teacher; school staff should keep lines of communication open regarding successes and difficulties; and pupils should feel that they can trust teachers in order to share any challenges they are experiencing. As anxiety and depression are common for females with ASD, teachers will be able to identify any changes in a pupil's mood or appearance once they have developed a good relationship with a pupil.
A home-school diary is an excellent way of allowing parents and school staff to communicate as needed, as is a brief chat during handover time before and after school, or a quick telephone call.

Knowledge and understanding of autism in women and girls

It's important that educators and other adults working or involved with girls with ASD have good knowledge of ASD in women and girls, and awareness of how autism, including high functioning autism, can present in girls, so that they can adopt and develop teaching and pastoral styles which are suited to the very individual pupils in their care. This also enables adults to be in a better position to identify female pupils who may have difficulties with social communication, which could lead to better assessment and diagnosis.
Teachers may have a personal or professional interest in this, or may wish to learn this as a development area in their CLPL (Career Long Professional Development). It could even be considered as compulsory training for all teaching staff.

Diversity education

Teenagers as a whole shy away from difference as they feel a lot of pressure to conform, and it can be a difficult time to stand out from the crowd.
Diversity education as part of the whole-school health and wellbeing curriculum is important to encourage acceptance and celebration of difference. There can be opportunities for this in Personal, Social and Health Education and in whole-school or year group assemblies, covering topics such as religious, cultural and neuro-diversity. Mainstream pupils may be aware of the terms dyslexia, ADHD, ASD etc., but they may not have much understanding of these additional support needs, including the way ASD presents in girls.
We should not be in a situation wherein a peer told a pupil with Asperger Syndrome that, "I thought it only happened in boys." Celebrations of diversity around, for example, World Autism Awareness Week can help to increase visibility and understanding of ASD, although embedding a culture of celebration of diversity in schools would have greater impact.

Peer support

Peer support can help to alleviate the common feeling among autistic people of 'being different'. This can lead to feelings of alienation, and a struggle to enjoy successful long-lasting friendships and relationships. Girls who react to situations or problems in a non-typical way can find themselves 'falling out' with peers and struggling to repair broken relationships. It's therefore important that they feel they have somewhere they can go where they know that being 'different' is a strength, and where there is not the perceived pressure to conform within a neuro-typical community. Social groups for young people with ASD are relatively common, but it is also helpful to specifically engage young women and girls with autism in a group setting. This is a place to feel welcome and to discuss specific challenges associated with being a young woman on the autism spectrum. Luckily, these are becoming more accessible in some areas, and will hopefully continue to grow.

Young women and girls with ASD make up a significant proportion of the school, and wider, community, and this proportion will likely continue to increase with our developing understanding of the way autism presents among the genders, ensuring that girls and women with autism are diagnosed correctly. Continued development of neuro-diversity awareness will hopefully ensure that these women are not flying under the radar for much longer.

RESOURCES AND LINKS

i Leo Kanner who is accredited with being the first to define autism in children in 1943 in his seminal paper: Kanner L. Autistic disturbances of affective contact. Nervous Child 2, 217-250 (1943)

ii Asperger H; tr; annot. Frith U (1991) [1944] "'Autistic psychopathy' in childhood". In Frith U. Autism and Asperger syndrome. Cambridge University Press. pp. 37–92. ISBN 0-521-38608-X

iii Wing L (1998). "The history of Asperger syndrome". In Schopler E, Mesibov GB, Kunce LJ. Asperger syndrome or high-functioning autism?. New York: Plenum press. pp. 11–25. ISBN 0-306-45746-6.

iv https://spectrumnews.org/features/webinars/webinar-the-female-autism-conundrum/

The robots of Little Britain: Julia's story

Dr Claire Evans-Williams
B.A.(Hons) D.Clin.Psy.
Autism Academy International

It is fascinating how our minds can transport us back in time to recall a single event or person from our past. This happened to me recently whilst watching a repeat of the hit comedy show "Little Britain". One of the show's best-loved characters 'Vicky Pollard' depicted a defiant and anti-social adolescent, repeatedly getting into trouble with teachers, police officers, and friends. She represents an amalgamation of British adolescent stereotypes, and the humour lies in her naïve attempts to fool others into believing elaborate versions of the "truth". She is perhaps best remembered for the line "yeah…but…no…but…", which she used in the hope of buying extra time to dream-up an excuse for her (mis-) behaviour.

While I cannot claim to have known a real-life version of Vicky Pollard, I began to think about a close companion I have known since secondary school. Julia (as I will refer to her) seemed to share similarities with the Little Britain character. Stripping away the humour and mischief of Vicky Pollard, I could see subtleties of Julia's attempts to strategise social communication and interaction. I recognised the stalling tactics to buy processing time ("yeah…but…no…but…"); the meticulously learned postures (closely analysing others' body language); the focus on self-interest topics and minimal verbal inter-exchange (a safe topic of conversation was self-directed); the over-pronounced facial expressions (an actor at work); and the naivety (the hope of creating a believable and likeable interaction).

Julia did not know she was autistic then: she knew she was different but didn't understand why. Outwardly, she resembled the other girls at school; she studied their clothes and makeup, kept a record of phrases deemed "cool", and practiced the subtleties of socially accepted body-language. In essence, Julia was an expert at mimicry, a master of disguise. Secondary school heightened the necessity for this activity as any hint of being different (i.e. intellectual or a "teachers' pet") was not acceptable to her peers, and Julia would be considered an outcast. However, in a moment of reflection it has occurred to me that all teenage girls must think, feel, and act this way, do they not?

The art of robotic mimicking

Unlike others of a similar age, for Julia getting ready for school in the morning was not straightforward. Overnight, she may have "recharged her batteries", but each morning brought a process of learning through grieving, which meant saying a reluctant goodbye to her true self. Quiet respite and relaxation in a cosy bed were disrupted by the ritual of practicing the "game plan" she had evolved to help her make it through the day ahead. A series of quick-fire questions whizzed through her head, for example, "Should I act like this or that", followed by "yeah…but…no…but". By the time Julia left for school, she had already depleted her recharged energy stores.

To achieve success, Julia had devised what she refers to as a protective, robot armour that mirrored the culture, attitudes, and environment in which she was immersed. She was the designer, architect, and programmer of the armour, which she constantly adapted to achieve the version of the girl she believed she had to portray.

Throughout the day, however, the armour became an increasing burden until it was too much for her to bear, leading to exhaustion and a total "shutdown" of her mind and body. On occasion, the armour would fail her prematurely resulting in an overwhelming surge of anxiety, frustration, and sometimes anger - a "meltdown". By bedtime, Julia was an overloaded version of her self, longing to escape from the world. Home often seemed like the only place Julia could be free of the robot armour: her bedroom was sacrosanct, essential to her recovery and preparation for the following day.

Over time, Julia became increasingly aware that her "mastery" of disguise was failing her. Mimicking others and camouflaging her difficulties impeded her ability to cope with the extreme fatigue and sadness of daily life. In addition to juggling the challenges of social communication and interaction, she worked hard to block out the constant buzz of noise in the school corridors, the glare of the fluorescent lights in the classroom, and the physical sensations that accompanied a constant presence of anxiety.

However, as secondary school had required that she be someone else, it became increasingly difficult for Julia to shed the robot armour. She now believed that in order to be her true self she would have to take a huge risk: confronting her fear of opening-up to a judgemental world, and ultimately her fear of rejection. Most importantly, she was afraid to ask: "why am I different"?

Confronting *the* difficult questions

Julia only became aware of her difficulties when she realised her robot armour was both protective and harmful. It became apparent that even the toughest armour would erode under challenging conditions, which for Julia resulted in shutdowns and meltdowns. It was only when this erosion occurred, however, that she had an opportunity to ask "why am I different?" and "why must I wear this robot armour every day?".

When I speak to others about Julia, she is described as "funny", "brave", and a little "outspoken". Thus, following her formal autism diagnosis in late 2015, at the age of 34, it was a surprise to even her closest friends to learn that Julia's outward performance did not reflect her true self. On reflection, Julia is now able to express her need to have received support when she was a teenager, and has become aware of her difficult questions.

Unfortunately, however, there is often a long journey before girls and women are able to ask themselves their difficult questions. To begin with, there may be a degree of self-focus and the potential to get stuck on feeling different. There may even be a degree of repression of this self-awareness through strategies of active ignoring and denial. Indeed, to acknowledge and ultimately accept uniqueness and difference can be fraught with a fear so deeply unsettling that the pretence of strength, independence, and resilience (and the associated toll it takes) may seem like the only viable coping mechanism.

A plea to the "robots" of Little Britain...

To the girls and women who put on their robot armour everyday, and have thoughts of "yeah...I need to smile and laugh...but no...I don't understand the joke " or "yeah...that plan to act normal sounds good...but no... what if it comes across as robotic" please ask yourself the difficult questions. Most importantly, share your struggles (the thoughts, feelings, and questions) with people you trust in whatever way you can, whether through talking or written notes. Do not deal with the burden alone, there are people that can help.

A plea from the "robots" of Little Britain...

To those entrusted with such an approach, please think carefully about the message being communicated to you. While it is important not to over-medicalise/pathologise individuals just because they are different, it is equally important to recognise that there are many females living an autistic life without a diagnosis. Through a process of learning many autistic girls and women have developed a range of skills and abilities to help them cope with the challenges of our world, but are staggering under the weight of these survival strategies. Like Julia, they live in a drought of their own uniqueness because of their perceived need to be veiled in robot armour in order to be accepted and included in society. Let us hear their story. Let us help them bear that burden. Let us help free them of it.

Dr Claire Evans-Williams is a Clinical Psychologist in adult mental health services, with a passion for the specialty of adult autism. She is the founder of Autism Academy International, an organisation committed to the provision of accessible diagnostic assessment and therapeutic support within the autistic adult community.

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Advice to younger self

Dr Dinah Murray
Independent researcher
and campaigner

About Dr Dinah Murray

Dinah Murray is an independent researcher and campaigner, former tutor for Birmingham University's distance learning courses on autism (adults) and former support worker for people with varied learning disabilities, including autism. Her work has been published in journals, in books and online; she has presented at numerous conferences (world-wide), including several years of Autscape, an annual conference-cum-retreat run by and for autistic people. She contributed to Autism and Intellectual Disability in Adults Volume 1: Author(s): Ed Milton, D and Martin Dr N pub. Pavilion 2016 and is currently working on a partnership app development project with ARGH and another 'NownThen' picture sharing android app with autistic app engineer, James Bayliss.
Her autism-related research interests have included: medication and its impact on quality of life; information technology for people who don't use speech; the ethics of autism research; the nature of the human being, with a particular focus on interests. Dr Murray has been assessed as on the autism spectrum, and if growing up today would certainly have attracted an autism diagnosis.

Dr Murray contributed to the Scottish Autism Right Click programme for women and girls; video recordings of her interviews are available through the programme. One of them was on the subject of what advice she would give to her younger self if she was able to, on which theme she writes here.

Try acting as if what other people see as important matters to you too...

...or better, work at understanding why they seem to find it so important and recognise its point. For example, people do not automatically know how you feel. So making the gestures which seem trivial and unnecessary to you can be vital in a way that means they are actively hurt by their absence. If you care about someone, then train yourself to give and receive hugs with them if that is their desire; maybe you can learn to enjoy that and also to regulate the strength and length of the hug so it is minimally challenging for you.

People do not know that you are glad or sad unless you send out certain signals.

They do not know, for example, if you have appreciated them; all people like to feel our efforts are appreciated (universal). So, learn the value of sending out signals that will be picked up by others, i.e. will secure some understanding. Without these, we cannot begin to work each other out. Everybody has 'mind myopia' - only charlatans pretend they can 'read' other people's minds: they cannot, they are just working on clues and filling in gaps, often wrongly.

Everybody has highly personal context selection - it is automatic and follows from the current play of interests in each person.

It is an adaptive selection for each individual and it rarely perfectly overlaps - watching sport or performing art, singing and dancing together, appreciating beauty and shared pleasure may come closest. Therefore, complete understanding of people by each other is not an option except moment by moment.

So when misunderstandings inevitably occur remember it is not as though the whole world has turned upside down... put constant readiness for incomplete mutual understanding into your processing kit and learn to work with it.

Learn to surf the turbulence instead of being thrown off balance and instantly opting out; when thrown off balance, climb back and try again.

Face the need for painful and difficult discussions, do not always try to avoid these. This is where the deep learning happens, in this difficult, dangerous zone. Don't let cowardice stop you although the pain of failure is acute. That's not a good reason, there will always be a potential for pain and there are no effective ways to avoid it completely. Learn to fail gracefully.

What is more, one actually can get used to things.

To take some quotidian examples: one day you will like rice pudding and porridge, one day you will be able to enjoy them; one day you will be able to reach into tepid greasy water with bits swirling through, without retching; one day you may even learn to like figs or eat a peach without peeling it.

Other examples could be about other sorts of feeling, including purely physical sensations and what we experience as emotions. These tend towards the all or nothing for us, as do all features of our personality.

Some negative emotions can be so extreme that they 'freeze' one with terror: remember, no feelings last, "everything passes, everything changes" (so said Bob Dylan, Buddha) and feelings change faster than almost anything. A requirement also follows from that to actively appreciate what you love experiencing, to relish it as a blessing, be surprised by joy, over and over again.

Do not be afraid to speak out or speak up. It's good to learn to ponder your words and get a feel for their impact before you speak but much pain is inadvertently caused, however hard anyone tries. Other people's emotional state, though it may briefly tune in with yours, is usually more affected by what's been happening for them personally than by any feeling they may have about how you are feeling; it's guesswork deeply coloured by their personal immediate history that you do not know and probably cannot guess.

Society really does need stroppy people. We are all embedded in massive and pervasive power structures they don't explain in school. All except for a few, usually very rich, people, have little or no power over large questions about how to lead their lives. In our society, people are not encouraged necessarily to be orientated towards cooperation. There are all sorts of things, such as market forces, that influence and sometimes warp people's values or interact with them. Not all people feel the same duties to each other as you do; don't be surprised.

Go on expecting the best from people, but with a trace of caution: they will almost never do exactly what they say, and their memories are almost always patchy and unreliable. We each just have to carry on doing our faulty best.

Remember: nobody's perfect! – including you.

Before writing this homily, in my 30s, social difficulties had forced me into a crisis which required me to become capable of duplicity, and discovering this capacity in myself was horrifying and fascinating in equal parts. Did I become more 'normal' as a result? Yes, I think so.

Homily

Ask 'Is that so?' of every claim you make
Prefer the grimmest truth to glittering fake

If you imagine you're the centre of the show,
Forget it! No-one else thinks so.

Control the urge to say and see and do
Exclusively what pleases you.

Don't laud the beauty of a good intent,
Unless it's turned to deeds by effort spent.

Don't say, Oh Yes it must be done, and mop your brow.
If something's to be done, then do it now

And now you've made these sentiments so neat,
Why not go off and have a little treat?

XI Autism-Europe Congress 2016

Andrew Sloan
Support Worker,
New Struan School

Having previously completed an undergraduate degree in psychology and a post graduate degree in child development, I felt extremely fortunate to attend the Autism Europe international conference in Edinburgh recently.

Whilst working at New Struan School it can be quite easy to feel a little isolated from the rest of the autism community. So initially sitting in the opening address with over 1700 people all motivated by and involved with autism was a little mind-blowing. With so many speakers and posters there was a vast amount of knowledge to be shared across the weekend.

One such talk was concerned with the misdiagnosis of deaf children (Helen Philips and Jenny Sweetman). Researchers believe that many of the behaviors presented in both ASD and deafness are somewhat similar and this could suggest that some deaf children are also on the spectrum. They do however point out that many of the tools that are used to diagnose children with an ASD are not accessible to deaf children. With the introduction of more suitable tools for diagnosing autism in children with hearing impairments researchers believe that more children with hearing impairments would meet the criteria for a diagnosis and therefore be eligible for support and services that are more suited to their needs. Although this would seem to be a common sense approach for researchers it would seem that this has been a relatively recent strand of research.

Working at New Struan and given my own research interests, the symposium on education and autism stood out on the programme. Speakers discussed topics ranging from strategies for supporting autistic children within a mainstream set up, to ways to move from failing autistic pupils to outstanding pupil process.

Dr Yo Dunn presented about the progress made by a special school that was classed as having a weakness in ASD provision to a point where staff are now seeing many of their autistic pupils gaining recognised SQA awards. The basis of the improvement lay in empowering and also providing staff with more training to allow them to feel more comfortable in supporting the pupils within the school, but also providing similar training to parents. The biggest factor in their improvement in supporting the pupils was three days of direct classroom supervision to allow the researchers to aid in the development of support plans for the pupils and also to observe the staff and their practice.

L-R: Charlene Tait, Director of Autism Practice and Research and Catriona Stewart, Autism Advisor

This allowed the researchers to provide advice to staff in how to better support their pupils to achieve their potential. The biggest change made within the school was to reduce the number of restraints needed. This was done by better educating staff so that they feel confident and better equipped in a challenging situation but also by reducing the barriers to learning and enjoyment for the pupils and teaching better communication to staff. These changes have successfully lead to a drop in restraint now that any form of restraint can be seen by staff as failure to effectively manage a situation or understand a young person's needs.

Overall the conference was a very enjoyable and informative experience. My overall feeling coming away from it is that although we are moving in the right direction, what we know about autism feels very small relative to what still remains to be learned. More importantly the differences between what researchers are doing, what policy makers are attempting to do and what parents and service users need are still a million miles apart.

NEWS

Centre for Applied Autism Research

The new Centre for Applied Autism Research (CAAR) at the University of Bath was officially opened by Professor Dame Uta Frith in July this year. CAAR aims to understand autism through world-class research; to translate theory into practical applications; to fully include the community within research; and to offer an educational and research resource for autism. Research Fellow Richard Mills confirmed that one of the first projects will be a study of cyber crime and autism.

Danish Right Click

On 13th September our colleagues in Aarhaus, Denmark launched the Danish Version of our Right Click online support programme. The resource, "Autism Insight" is the latest outcome of our strengthening relationship with Ruth Lhem and her team. Over the last few years this has proved a productive collaboration for all involved. It is such a pleasure to work with like minded people and we are delighted that the Right Click model is being adapted and used to benefit families in Denmark.

Launch event for Autism Insight

'This is Me' - School Refusers Project

Scottish Autism has received funding from the Scottish Government Autism Innovation Fund to work in partnership with North Lanarkshire Council to support pupils within this local authority area who are at risk of school refusal, or are recorded as a school refuser. The project, called 'This is Me', aims to help prevent exclusion of these pupils from mainstream schooling.

EVENTS

Autism West Midlands: Exploring Autism Interventions

Autism West Midlands 5th Annual Conference will take place on Monday 28th November 2016 at the Queen Elizabeth Hospital, Birmingham from 9am - 4pm. The theme for the conference is 'Exploring Autism Interventions'. The keynote speaker is Bo Elven, author of 'No Fighting, No Biting, No Screaming'. Delegates will also hear from Dr Sue Fletcher-Watson from the University of Edinburgh and Dr Elisabeth Hurley.

Topics covered on the day will include:

- Self-control and challenging behaviour with Bo Hejlskov Elvén
- Autism and technology with Sue Fletcher-Watson
- Key principles for choosing an autism intervention with Elisabeth Hurley
- A parent's experience with Lisa Roberts

For more information and to register visit
www.autismwestmidlands.org.uk/conferences

AT-Autism: Behaviours that Challenge

AT-Autism is hosting a half day seminar on 14th December at the Royal Society of Medicine, London from 1:30-5:30pm. The seminar will present on and discuss how the recent National Institute for Health and Care Excellence (NICE) Guidance will impact on policy and practice. The keynote presentation will be given by Professor Glynis Murphy from the Tizard Centre at the University of Kent at Canterbury. She will provide an overview of the guidance and outline priorities and some of the key challenges for the field. The seminar will be chaired by Richard Mills, Research Director, Research Autism, and include a presentation from Dr Michael McCreadie.

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

Autism and Me

Emma Kirby

Hello! My name is Emma and I have Asperger's Syndrome. Before I go on to talk about my Asperger's, I would like to tell you a little about myself. I am 15 years old but going to be 16 soon. I am in 4th year at Eastwood High School. I love science (space) and maths. My favourite colour is blue and I have a mum called Linda, a dad called Michael and a brother called Andrew who all have Asperger's too.

I was diagnosed when I was four but never really understood at the time and when I was eight, I knew I had Asperger's, just didn't know what it was. In primary school people would ask if that meant I had 'behavioural problems' as I did get into a lot of temper tantrums. Then I did a split placement at Carlibar[i] which helped me control my temper a lot better and I met children who also had a diagnosis of Asperger's Syndrome.

Before I started high school, I went to a group run by the Autistic Outreach Teacher who is based in another secondary school in East Renfrewshire, where I met people who were going to my high school who also had Asperger's (all boys). This was great as it introduced me to people who are like me and it gave us a chance to get to know the staff at the support base, which made the transition smoother.

When I was going into 3rd year and picking my subjects, I picked all three sciences. Science and maths are my favourite subjects because they make sense to me and I'm not a big fan of English as there can be multiple answers to particular questions but in maths and science (especially physics) they all have one definitive answer which makes sense to me. I also picked geography, because it was like another science, health and food tech, because that is food science and P.E Nat5 because I had to make P.E worth my while (but it still isn't).

The reason that I became interested in Science in the first place was space. As I recall, I was four and remember seeing a space poster in my brother's room, since then I have been interested in space. I went to the Kennedy Space Centre a few years ago and loved it. During the winter, my dad and I frequently go to the Coats Observatory in Paisley when it's a clear night (which is a rarity!). I was part of my school's Astronomy Club in 1st year and the Science Club in 1st and 2nd year.

I recently went to Space School for a week ran by ISSET (International Space School Educational Trust). It was a great experience as I got to meet people who are also interested in space. During the week, we got talks from people who specialised in muscles and how space affects them, someone who was a specialist in contact lenses and again, how space affects them and a talk from astronaut Michael Foale who told us of his time during the shuttle missions and his time at the Mir and International Space Station.

At the end of 4th year, the physics department at Eastwood High School puts on a trip to the LHC (Large Hadron Collider) in Cern. I really want to go but it would be my first time away from my family (even though it's a couple of nights) but I try to not let my anxiety get the better of me as I wouldn't want to miss out on a trip of a lifetime.

I have a basic outline of what I want to do when I leave school; I want to do a degree in Physics at Strathclyde University and then maybe a post-graduate qualification in Astronomy at Glasgow University. The reason I want to do this is to keep my options open as I might change my mind about astronomy and might find that I like something else, or I might even want to do something that's not physics related for example, food science or a degree in maths.

I'm not a social butterfly as I like to have a limited number of friends (3) and I prefer to spend time with my family instead. I don't tend to make the effort to see my friends during the summer or any holiday, or at the weekend even though they are nice people. I have a little saying "school friends are for school". I don't like being in social situations as I don't understand some jokes and find it hard to detect sarcasm. In my 1st year at high school, a couple of girls I sat next to in Geography would test me with really obvious sarcasm to the not so obvious and would laugh as I find it hard to detect any.

Another thing is I can be really blunt at times but I try not to be. When I'm joking around with someone, I may have to tell them that I was joking because sometimes I can be really harsh but I don't mean it in a cruel sense.

Despite having Asperger's Syndrome, I don't let it control my every action, thought or sense of ability as I am just as good as everyone else. I don't let people tell me I'm different and therefore shouldn't do certain things. I refuse to conform to what society expects for my age, i.e. hair, make-up, clothes, these things are not important to me.

I am my own person and no-one can change that.

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[i] Carlibar Communications Centre, Barrhead, Glasgow

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 Guldberg

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 seven years ago 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.

Scottish autism | **Centre** for **Practice Innovation**

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