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Share

Practice, Knowledge and Innovation

Scottish
autism

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Centre for
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Letter from the editor



Sue Fletcher-Watson
Developmental
Psychologist,
University of Edinburgh

If there is a theme running through this issue of Share magazine, perhaps we might label it “**autism: but not as you know it.**”

In these pages we hear about how parenting a child on the spectrum may be experienced in the black and minority ethnic communities of Scotland. We learn about autistic people engaged in productive employment, supported by family and friends, innovative practices and new technologies. We consider how to support students with autism in our higher and further education system – and how these supports may benefit the entire student body. Rather than focusing on the communication difficulties often emphasised in discussions about autism, we consider autistic people as enhanced communicators – understanding or speaking more than one language, and the benefits that might entail. Finally, one autistic person’s account of his participation in the Shaping Autism Research seminar series shows us how a journey through negative school and early adult experiences can nevertheless arrive at a point of personal happiness, and leadership in the Autistic community.

A frequent topic of discussion on social (and mainstream) media lately has been around the use of language such as

‘high-functioning’ or, conversely, ‘severely-affected’ to describe individuals on the autism spectrum. These simplistic additional labels do very little to provide meaningful information about specific people, or even groups. Instead, descriptors such as ‘high-functioning’ risk denying autistic people the understanding and accommodations they may need or want – at all times or in particular circumstances. Such people may be thrust into situations without due regard for how they may be affected, especially if they are working hard to mask their inner distress. On the other hand, ‘low-functioning’ and other similar terms imply that autistic people have little to offer – they require special attention and as such can’t be expected to advocate for themselves let alone contribute to their community.

The stories and research shared in this magazine clearly refute both of these misconceptions of autism. I would struggle to describe any of the autistic people featured in this magazine using the simplistic terminology of ‘function’. Yes, these articles showcase how autistic people encounter challenges – sometimes in domains which may be very familiar to neurotypical readers, sometimes in areas which seem more particular to the autistic experience. But they also recount the personal achievements and fulfilling relationships, which are central to all our lives. I hope you agree that this issue of Share magazine offers diversity of experience, inspiration, and hope for the way in which our concepts of autism may become more enriched and nuanced as awareness and acceptance spreads through society.

NEWS

Autism Europe Congress Success

Scottish Autism has had nine posters and presentations accepted for the Autism Europe Congress in Edinburgh in September. The presentations come from services across the organisation and are authored by a range of practitioners, service users, and organisational partners. Topics range from post-diagnostic support to running social enterprises, developing resources for women and girls to creative arts and drama. We look forward to sharing experiences with professionals from across Europe and to learning from all the other presentations and keynotes at the conference.

Uncertain Futures project begins work

Scottish Autism has partnered with our colleagues at Research Autism to support research into planning for the future and dealing with uncertainties for autistic adults. The work is undertaken by a team from Newcastle University led by Dr Jacqui Rodgers and includes autistic individuals and parents on the research team. We welcomed the team to Scottish Autism in April to run preliminary focus groups in order to establish the needs and aspirations of adults in dealing with future uncertainties.

Project to support school non-attendance receives funding

Scottish Autism and North Lanarkshire Council's education department have received funding to provide intensive support for autistic young people that currently refuse to attend school, or are at risk of non-attendance. Autism Advisors will work with Home and School Partnership Officers to improve autism profiling and better understand reasons for non-attendance before creating individual programmes of support. The research team at Scottish Autism will work to capture and evaluate the experience of the project.

Online Support Programme for Women and Girls

Funded by the Scottish Government, Scottish Autism will shortly be launching a new online support programme for women and girls. The programme provides valuable information addressing key health and wellbeing challenges, as well as providing practical advice on a range of issues. We have engaged with women and girls from the autism community and we have drawn on the expertise of a network of professionals to develop a range of videos and other support materials.

EVENTS

INSAR 2016 Summer Institute: Familial Aspects of Autism

The International Society for Autism Research (INSAR) is hosting a free series of six weekly online seminars on selected topics related to familial aspects of autism. The seminars will run every Thursday from June 23rd to July 28th, and will cover a variety of topics on autism and the family, from sex differences to family interventions, to the broader autism phenotype.

The presentations are designed for students, post-doctoral fellows, and other early-career investigators interested in autism research. Clinicians and established researchers who want to get a snapshot of the current state of science in topics outside their area of expertise may also find these sessions of value.

Visit www.autism-insar.org for more program details. Registration is free and available worldwide.

XI Autism-Europe International Congress

The Autism-Europe Congress will take place on 16-18 September 2016 in the city of Edinburgh.

The theme of the 2016 Congress is 'Happy, Healthy and Empowered'. The Congress will focus on the most recent developments across the field of autism, including causes, genetics, diagnosis, early intervention, treatments, education, support, employment, rights and policies, and many more. It will also cover the evolution of knowledge, rights and services for autistic people, as well as providing insight into future developments in knowledge and technologies for autistic people that may soon become a part of everyday life.

Autism-Europe's international congresses are dedicated to sharing advances in practical and scientific knowledge about autism to as wide an audience as possible, including researchers, professionals, parents and self-advocates.

For more information and to register visit www.autism.org.uk/professionals/conferences/xi-congress.aspx

Scottish Learning Festival 21 and 22 September

The Scottish Exhibition and Conference Centre (SECC) Glasgow

For more information visit: www.educationscotland.gov.uk/slf/

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

How can we support black and minority ethnic parents of children with autism?



**Shubhanna
Hussain-Ahmed**
Parent Carer

When our youngest child was diagnosed with Autism Spectrum Disorder at the age of 3, one of the greatest difficulties my husband and I faced was not around accepting his diagnosis, nor was it about the uncertainty of a future that lay ahead of us. Instead, our biggest difficulty was finding a way to explain what our child was going through to members of our family, many of whom did not speak or understand English.

I would like to think that I am a fairly fluent Urdu and Punjabi speaker, but even I found it hard to articulate what autism, delayed development, sensory overload and learning disability was to my non-English speaking parents and extended family. Even Google, my oracle for all of life's big questions, had no answers for me this time.

There were no resources or experts who could advise us on how best to explain the needs of a child with autism to non-English speaking families. We needed our families and members of our community to understand that our child was not suffering from an illness, that there wasn't a cure for his "condition", that a home remedy was most probably not going to help, and that sacrificing a goat was definitely not an option. It was then that we came to a realisation that what was needed was not an Urdu translation of the medical model of autism. Instead, we needed our families to understand that our child's view of the world was a little different, that he would learn at his own pace, that certain noises and textures were too overwhelming for him, that his quirky routines made him feel safe and, that there was a possibility that he may never be able to hold a conversation in Punjabi, Urdu, or English.

It has not been easy, but almost 4 years on now, and our son has made some amazing progress since

he was first diagnosed. Our immediate family are now much more aware of our child's needs through watching how we interact with our son and advocate for his needs. We feel blessed that we are surrounded by family and friends that provide a supportive non-judgemental environment which has enabled our little boy to grow and develop without any fear of being different.

Outside of our immediate family however, I feel that there is still a lack of understanding about autism. This is quite apparent, particularly when I look around the South Asian community in this country, where disability is still viewed as a stigma. There are families out there who will overlook the missed developmental milestones, ignore the advice from concerned health professionals, and insist that their child be educated in a mainstream school, despite the fact that they are obviously struggling in a busy classroom environment and would benefit from some additional support. As a community, we need to stop seeing disabilities as less than. Getting a diagnosis for your child will not make him or her any less able. In fact, a diagnosis will probably open up opportunities for your child to be supported and for them to reach their full potential. If we as parents are not prepared to put the needs of our child first and advocate for them, then it is highly unlikely that we will see the change in attitudes towards disabilities, which is so desperately needed in our society.



Bilingualism in Autism: Harmful or Beneficial?



Sarah Hampton
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Direct research into how speaking or hearing more than one language affects the development of children with autism is scarce. This means that families have little information to help them when deciding whether or not to raise their child with autism bilingually – a pressing question for the increasing number of families in our community who speak multiple languages. More evidence that asks whether this “bilingual exposure” (i.e. hearing more than one language) might be harmful or beneficial to children on the spectrum is needed. As a foundation for this, we recently conducted a study at the University of Edinburgh exploring how 17 bilingual parents of children with autism (from a wide variety of language backgrounds) make choices about the languages their child heard and spoke. Based on the results of this study, and on the (limited) other published work in the area, the potential advantages and disadvantages of bilingualism for children with autism are outlined below.

What reasons are there not to raise a child with autism bilingually?

Many parents of children with autism in our study had concerns that exposing their child to more than one language would cause confusion and increase language delays. As a result, parents often dramatically reduced their child’s exposure to a second language after diagnosis. For instance, one parent commented, ‘I’m scared of putting in too much confusion, and he doesn’t understand anything at all. So, that’s why I just said, right OK, English and that’s it.’ Some parents reported that they were also advised by professionals to provide an English-only environment for their child.

“I’m scared of putting in too much confusion, and he doesn’t understand anything at all. So, that’s why I just said, right OK, English and that’s it.”

Unsurprisingly, for parents in our study, concerns about bilingualism were strongly related to their child’s speaking ability. Parents of more verbally able children tended to express more positive views of bilingualism, whereas those of children with limited speech showed greater concerns: ‘for any kid that’s like David or worse, when it comes to communication, no, I don’t think it’s a good idea to try several languages. It’s hard enough with the single one.’

Several parents in our study also felt that bilingualism would be a burden for the family as a whole. They told us that they needed to ‘keep things simple’ for their child and that maintaining two languages whilst doing so would be too much of a challenge for them. Speaking a second language other than English was also made challenging due to a lack of bilingual interventions and resources: ‘all his interventions were in English, so it made sense for us to reinforce that, rather than try and introduce another word’.

What reasons are there to raise a child with autism bilingually?

The idea that bilingualism is damaging for language learning in children with autism, while widespread, is not supported by the few studies conducted so far. Research has found no differences in vocabulary, communication skills and age of early language milestones when comparing children with autism exposed to either one or two languagesⁱ. There is also evidence that children with autism can manage vocabulary in more than one languageⁱⁱ.

It is even possible that some of the ways that bilingualism helps typical children could also apply in autism. Bilingual children without autism tend to do better than monolinguals in some social and communication skills as well as flexible thinking^{iii/iv}. And in fact, one study showed that bilingual autistic children used more gestures to communicate than those exposed to one language^v.

This idea that bilingualism might yield benefits for those with autism was reflected in our study too.

“ Maybe it’s a safe way of explaining that different people have different rules, different languages have different rules, and it’s OK. ”

Parents mentioned communication and flexibility as skills that could be enhanced by bilingualism. For instance, ‘Maybe it’s a safe way of explaining that different people have different rules, different languages have different rules, and it’s OK.’ and ‘I think the main, positive thing of being exposed to two languages is that he’ll go a bit further to make himself understood.’

Bilingualism may also contribute to emotional wellbeing and identity for children with autism. For many parents in our study, speaking a minority language (i.e. not English) was associated with expressions of affection, communication with the extended family and links to cultural identity: ‘especially when he wants to express his fondness to me he deliberately chooses Russian words’ and ‘the native languages are much closer to home, family, community, so that’s very important that I’m speaking to him in that language because I feel much closer to him.’

In addition, some parents said that speaking only English with their child could be restricting, as they did not want to pass on grammatical mistakes: ‘Sometimes I would like to say something to her and sometimes I stop, because I’m worried to say things incorrectly, so that she learn things incorrectly’. Exposure to the home language of their parents, then, might mean high quality emotional and linguistic input for children on the spectrum.

All in all, the (admittedly limited) research suggests bilingual exposure is not a problem for those with autism, though parents and professionals continue to have concerns. There are also some potential benefits, including cognitive advantages and high quality linguistic and social input. There is still a long way to go to establish a solid evidence base to help families make the right decision for them. Our findings point to the importance of considering not just language and learning consequences of bilingualism, but also factors such as family relationships and community integration, in future research.

READ MORE ABOUT THIS STUDY AT

<http://www.dart.ed.ac.uk/research/bilingualism-and-autism/> and get information on bilingualism at <http://www.bilingualism-matters.ppls.ed.ac.uk/>

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Technology and I



Jamie + Lion
Senior Accessibility
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This article, is about the how I live my life and how technology underpins everything I do. But first, a timeline.

Eighteen months ago I was just about to get the job of my dreams after 2 years struggling through a difficult job. I lived with my boyfriend in Harrow, London. He looked after me while he studied and I paid the bills.

Twelve months ago I was sleeping in a bath of hot water most nights as that was the only effective pain-relief for the extreme pain I was feeling lots of the time. My boyfriend had left, my friends were looking after me as best they could.

Six months ago, I had an operation. A surgeon removed the gallbladder causing pain equivalent to childbirth and I believed I would “return to normal”.

That is not what happened.

Masks are Dangerous

I got ill because I was taught that appearing normal was more important than being happy or myself. Any time I was “more normal” it was seen as an achievement. It was made clear to me, autistic things were bad. The end result is I pushed myself too hard for too long.

Luckily, my friends (who saw me at my most spaced out and autistic) didn’t mind. They liked both sides of me.

I was open about being autistic, but I didn’t really accept it. I thought of it as something I could “beat” with enough effort.

In the interest of appearing normal I exhausted myself and hit burn out. So much so, rather than fix everything, the operation just triggered a collapse and loss of skills.

“ Luckily, losing my speech from time to time has happened to me since I was a kid. So I already had the Porloquo4text app installed on my phone. ”

After my operation, my “bad day” became my everyday. My mask was gone. I lost everything from speech to toileting and the ability to go outside alone.

I needed way more support than I could access at my home on the other side of London. The only option was for me to move and a week later, I had a new home close to my friends’ house. I was going to try and live independently.

Independence and Autonomy

I use to think independence meant “doing everything myself” but I quickly learned if I wanted to stay working I needed to focus my energy there.

Independence does not mean “doing everything myself”, independence is more nuanced, to me it really means gaining autonomy.

Autonomy means I captain the ship and set the direction, the speed and the destinations. For example, autonomy is more about being able to make decisions and change things I am unhappy with, than being able to do every task myself.

I tried doing everything myself, and that didn’t work. So I now focus on using my energy to do the important things (maintain a job, recover speech, etc) and I accept help for everything else.

However, to do this I must be able to communicate.

Talking Apps

I can think of words, but most of the time I cannot say them. They just won’t come out and the harder I force it, the less they come. I get some words, the words which fall out. I have 5 common ones. Washing Machine, Crumbs, Cake and Calgon, but they rarely make for deep conversations.

I needed a way to communicate.

Luckily, losing my speech from time to time has happened to me since I was a kid. So I already had the Porloquo4text app installed on my phone.

It converts what I type into spoken words for others to hear.

This technology is instrumental to my life. Not just in the form of communication but also confidence. I struggle with anxiety, and losing my speech entirely had made it worse.

Knowing I have a voice in my pocket if it is needed gives me the confidence to leave my flat alone. I don't walk far, I have just two short walks everyday, but that's 100% more than I could manage 6 months ago.

Communication is an essential starting point. Next comes finding and using appropriate support.

Meet the Babysitter

Six months ago, we quickly understood that I'd need more support than my friends could provide.

In theory social services should have helped, but in reality, they have spent 6 months denying my needs and generally being unhelpful. In the end, I borrowed money from friends to fund my care, selling my home to repay them.

Finding care is really difficult, most care agencies won't reply to emails, disclose pricing or give any indication of their experience with autism.

In the end, I used a website aimed at parents looking for babysitters! The website (findababysitter.com) allowed me to post a "job" and then see who replied.

In the job advert I explained the situation and my needs and I had about a dozen replies. This is the second time I have successfully found support via the babysitter website.

We got extremely lucky, a member of staff from one of the special schools replied and offered to help. She is an expert in autism having spent 20 years helping autistic people of all ages.

She's turned out to be an amazing person. Her experience has proved invaluable and with her support I am making good progress.

The way we do it is not typical. On purpose, she does not "support" me when she visits in the evening. She looks after me. This is all facilitated with technology.

When she arrives she writes a schedule on a whiteboard and sends me a photo. I am extremely shy with others in my home, so I tend to hide in my bedroom all evening. When I get the photo, I agree the schedule. That's the handover. From that point on I have agreed for her to take control a bit and guide me through the evening routine.

The same messaging technology I use with the babysitter, I also use with my friends, who maintain a chat room dedicated to supporting me. I always have somewhere where I can ask questions or call for help.

This all acts as a foundation so I can work and contribute to the world.

Employment

Technology is not just a tool, it's also my job. I work for the BBC where I have an amazing line manager who has really helped me to understand "disability" and acceptance.

My job at the BBC is to work with digital teams to ensure our apps and websites work for everyone. I have code on almost every BBC page and am involved with all the major projects from iPlayer to Cbeebies. I've even had my code run on the International Space Station.

Technology enables me to work, I work remotely 4 days a week using email, Slack and other text based tools.

Technology fits my strengths. I find building websites or designing gearboxes much easier than crossing roads. Roads are unpredictable, high risk and fast. Code just does exactly what I tell it to do (even if I didn't mean it).

The Future

I am learning that to accept the autism I must accept that it sets boundaries; but a boundary is not the same as a limit.

Using technology I have started to develop a support network which is capable, robust and sustainable. There is still much to do but this time around I am working with my autism and not trying to "defeat it". I no longer see "passing for" neurotypical as a sensible or productive aim.

Technology underpins all of what I do. Without it I would have no employment or support, no friends and no communication. Technology empowers me and breathes autonomy into my life.

Suggestions for Teaching University Students with Autism Spectrum Disorder.



**Yvette Q. Getch,
Ph.D., CRC**
Associate Professor,
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As the number of students with autism increase, they are making up a larger portion of students with disabilities on university and further education college campuses. Some researchers estimate that 1 or 2% of the higher education population has autismⁱ. Unfortunately, students with autism may find it difficult to be successful in the university classroom. For example, they may find it challenging to navigate the social and academic nuances of universities. Additionally, some students with autism tend to be rigid with routines and resist changeⁱⁱ, which is harder to maintain in the flexible (relative to high school) environment of the university campus. Furthermore, problems sustaining social interactions and building appropriate peer-based relationshipsⁱⁱⁱ may result in feelings of isolation and non-connectedness.

As a college professor, I believe that accessible and safe learning environments help facilitate learning. I resonated with what Kabie Brooks stated in the Autumn 2015 edition of SHARE Magazine, "All events should be accessible and inclusive; an event shouldn't have to focus on a particular group of people to make an effort not to exclude." Learning environments and college events should be accessible for ALL students but unfortunately staff rarely have training on how to create such an environment. Of course we must recognise that students with autism are not all the same. However, there are some basic things professors and instructors can do to increase the success of students with autism. I will share some of the things that I have found that improve the learning environment in my college classroom.

The importance of the sensory environment

While many instructors may think about the physical accessibility of the classroom, they may neglect the sensory environment. One of the most impactful conversations I had with a student with ASD who was struggling in a classroom was the reason they shared for their struggle. "I can't pay attention in that class... The florescent light is flickering and buzzing. I can't hear past the buzz and it is almost impossible for me to concentrate..." The solution to this problem proved simple. The student and I called building maintenance, put in a request, and they repaired the problem. While not all situations are this simple, creating a sensory environment that is more conducive to learning is important. Checking out the classroom ahead of time to note accessibility issues and facilitating a discussion the first day of class about sensory distractions can alleviate many issues for students with autism, and other disabilities.

Sharing advance information

Send out your syllabi early to students and invite students with disabilities to meet with you before the class begins. If possible, arrange the meeting in classroom where the class will be held. For many students with autism, navigating their way to class and examining the classroom may alleviate some anxiety and help pinpoint accessibility or sensory issues that need to be addressed before the first day of lessons.

Classroom discussions

Prepare students in your class and set expectations of behavior that demonstrates respect. The class syllabus is a great place to start. Include specific language about what is expected when communicating with others, especially if class discussion is going to take place. Set aside time during your first class to talk about what it means to have a safe environment and encourage students to chime in. Describe how students can disagree while being respectful of differing opinions. Lead by example.

Monitor discussion groups to ensure they are supportive of differences. Sometimes rotating membership is helpful – you might also assign roles during small group discussions allowing students to take turns being the observer or scribe. Take into account the sensory needs of individuals. A small room with multiple discussions occurring simultaneously can be overwhelming for some students.

Also remember that some students find it difficult to engage in classroom discussions. If reluctant to speak, they might try using notecards for questions or discussion points. Alternatively, if a student is monopolising the conversation, intervene by using a directive approach such as “let others weigh in on the topic and then I’ll come back to you.”

Create a sense of community

I like to encourage students to get to know one another. I find that structured activities work best and that giving prior notice and explaining these activities ahead of time helps reduce anxiety for students. When students discover other students with similar interests it can create a common bond that can be utilised to create more comfortable groups and connections both inside and outside the classroom.

Making oneself available to students by e-mail, phone, and in-person gives them the option of interacting with you in the manner that is most comfortable and effective. Try to communicate frequently with students in a variety of ways and check for understanding of assignments and instructions.

Provide supportive instruction and teaching

All classes are different even if the content is similar. Using different modalities while teaching increases the likelihood that all students will be able to learn the material. However, be aware that too much visual or auditory input can be overwhelming or confusing for many students. Hands on activities can include group work, projects, field trips, etc. If you have prepared well and met with your students who have accommodation needs, these activities are more likely to meet their needs.

Students with autism may experience extreme anxiety over class presentations. I learned to tweak presentation assignment requirements and allow the students to embed video clips and/or voice overs so they are not required to stand in front of the class and deliver a presentation in person. These presentations were so effective and creative that I now provide that option to all students in my classes.

Responding to problems

If a student falls behind or misses assignments, be proactive and follow up with them. Share resources available on your campus and in your community if you sense they are struggling. For example, most university campuses have writing labs, tutoring services, counselling, and other supports for students. Because students with autism may have difficulty with organisation and communication with others, pro-actively making them aware of support services can facilitate success. If we do not recognise student struggles early, students may get so far behind that they become overwhelmed, overly stressed, and that can lead to failure.

Students with ASD are a part of the diverse college learning community. They bring unique perspectives as well as unique challenges. The best way to know what supports or needs students have is to ask the student. As a college professor, I credit much of the improvement in my teaching to what I have learned from students with autism and other neurodiversity. I have learned to become much more aware of accessibility in regard to sensory stimuli and executive functioning issues. The suggestions provided in this article are based on my own and other faculty members’ experiences, comments and feedback from students with autism, and information gleaned from the literature. My hope is that these suggestions will provide a foundation of supports and strategies to create learning environments that promote engagement, acceptance, and learning for all students but especially for students with autism.

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Practice innovation and employment: The case of Cafe Kudos.



Alastair Clarkson
Researcher in Residence,
Scottish Autism

Despite a growth in public awareness of autism, misinformation and myths about autism are still common. One frequent misconception is that people with autism lack the abilities and social skills required for the demands of the workplace. This contrasts with Scottish Autism's 'capacity view' which focuses on the skills, strengths and abilities that autistic people have. For example, a very good attention to detail and tendency to stick to routines and timetables can make people on the spectrum highly punctual, accurate and reliable employees. Autistic people may also excel at understanding rule based systems and protocols and show excellent memory and recall. However a lack of awareness of these skills among employers, combined with limited opportunities for people on the spectrum, results in significantly lower rates of employment for autistic people¹.

The process of developing and fostering employment skills can be complex and challenging, requiring new ways of working. Such "practice innovation" has always taken place in Scottish Autism, as services and staff adapt to changes in need. The Centre for Practice Innovation (CPI) now provides a hub for the sharing of novel, good practice throughout Scottish Autism – for example we are training support staff to carry out research to capture and share ways of working. But what does 'practice innovation' look like and how does it occur within our services? This article considers one example which illustrates this key concept in relation to employment.

Practice innovation in Cafe Kudos – a social enterprise project.

Practice innovation started here as a reaction to an ideal – in 2004 local managers and staff in our south west services drew inspiration from a growing agenda for inclusion and developed a vision to place work opportunity and independent living firmly at the heart of service users' lives. Researching local vocational opportunities, they developed a plan for independent living services to link with the design of a new vocational opportunity.

This service became Cafe Kudos, which opened in 2004 to provide training for work within a 'not for profit' community enterprise scheme. Managed by a small, specialist team of staff, the cafe enables service users to safely develop their skills and confidence in a working business. Cafe Kudos is operated by a kitchen co-ordinator, a Cafe assistant and two support workers employed by Scottish Autism. Currently 9 service users attend and work on different days.

To create opportunities at Kudos that work for each service user requires assessment and adaptation. As with other services, this means having a personalised programme of support to provide consistency and structure for each individual. As Cafe Kudos is a unique service, staff and management were required to apply their knowledge of autism to this new setting and needed to develop innovative techniques to meet the variety of challenges that autistic staff faced in this complex business environment.

Here, adaptation has been key to success. Use of visual menus and customer order forms tailored to each service user means their specific learning and communication style is accommodated when serving the public. Staff are trained to provide support that lowers stress levels and helps to manage anxiety. Monitoring service user progress is vital in making task transitions and learning within the work environment happen as smoothly as possible.

Social stories and visual aids help staff clarify key expectations and learning points. Setting realistic targets and regular reviews with support staff, ensures each individual working in the cafe can safely build on their level of confidence and develop at their own pace.

Achieving Qualifications

Accessing work experience in a safe environment teaches valuable practical skills which can enhance the self-esteem of service users, as they see first-hand the value of their work. Whilst the opportunity to learn new skills and train for work in a real business environment means access to qualifications in Food Preparation and Cookery or Food and Drink Service, being included in the local community in a meaningful way also appears to matter a great deal to staff. Ewan Dunn started working in Cafe Kudos nine years ago just after it first opened: "I really enjoy feeling part of the community. I like socialising with the staff, customers and my peers. I have developed many skills working in the cafe such as money handling, food preparation, shopping, baking and customer service."

When visiting the cafe, I was struck by the enthusiasm of the staff. Employees were positive and took great pride in their work. When speaking to local residents in the Cafe, admiration for the autistic staff was a common theme. Parents have also shared in the benefits provided by the Cafe, as the skills and self confidence gained within this environment appear to transfer to other settings. Lesley, mother of Donald, who receives support at Kudos spoke about the positive impact: "The work of the staff there has enabled our son to cope with travelling to London by train for his twentieth birthday, with his dad and me, to stay overnight, sightsee and go on the Tube! We are so proud of what he has achieved and for the input of the staff in Lanark."

For management who have steered this project from its origins, the value of the service is more than clear – Gillian Smith, Service Manager at Cafe Kudos spoke recently at the 10th anniversary of the service. "Over the years we have supported many individuals, offering them the opportunity to develop their skills and confidence. Watching many of them grow and build their self-esteem has been a hugely rewarding experience. The cafe has become an important part of the local community and we would like to say a huge thank you to everyone who has supported us."

The Value of Practice Innovation

Practice innovation embodied in Cafe Kudos has enabled development of communication support strategies; vocational skills and qualifications and has fostered self advocacy and independence. The cafe has created bonds with local residents, community groups and charities, – people who have experienced the valuable contribution that individuals on the autism spectrum can make in their local community.

Services such as Cafe Kudos demonstrate to others that our service users have a valuable contribution to make to society. This makes real a belief that people with an autism spectrum condition should enjoy the same opportunities and experiences as others do, in order to enable them to lead happy and fulfilled lives. The innovation in practice highlighted here started from small beginnings – an awareness of what needs to change for the better, the sharing of this idea with others, and a program of work directed with passion and commitment to make these ideas a reality.

“ I really enjoy feeling part of the community. I like socialising with the staff, customers and my peers. I have developed many skills working in the cafe such as money handling, food preparation, shopping, baking and customer service. ”



Cafe Kudos offers individuals opportunities to develop new skills.

RESOURCES AND LINKS

- i Scottish Government, S.A.H. (2014). The Scottish Strategy for Autism Progress Report – Foundation Stage (2 Years) [Scottish Government, St. Andrew's House, Regent Road, Edinburgh EH1 3DG Tel: 0131 556 8400 ceuf@scotland.gsi.gov.uk].

Reflections on the Public Services Seminar



Jules Akers
Bananas In The Piano
Consultancy

This was a (so far) unique opportunity to inform the direction of research and the general debate on autism at a time when many of the established priorities are being vigorously challenged. As such I felt very privileged to be included. This also turned out to be another opportunity: to tell my story. Few of us get such a forum and I was determined that this chance would not be squandered.

The organisers could not have been more helpful; arranging the hotel, meeting me at the station, consulting an authentic autism group on environmental requirements and generally fostering a welcoming atmosphere. Then the colour badge system indicating willingness to interact. Or not. There was also a clear attitude of equality and inclusion: for example, the young women handing out seminar credentials turned out, on the second day, to be post-doctoral researchers and gave fascinating presentations of their own.

Speaking of credentials, I am a registered mental health nurse and qualified health and social care lecturer and have both looked after autistic people and taught prospective members of the caring professions about the condition. I am in the first year of a doctorate researching an autoethnographic study of autism advocacy and have just started a training consultancy. I have raised two autistic children (and two who are not) and, perhaps most significantly, I am autistic. But back to the event. There was a healthy mix of autistic people, parents, advocates, researchers and professionals (pretty high end – Lead Nurse for Wales among the attendees) and many occupying multiple positions.

The formal seminar took three forms: single and paired presentations, panel discussions and small pre-allocated groups. Not surprisingly the single/paired presentations were focused on the Academic / research community. These were the easiest to deal with as a passive observer and it was an appropriate start to the event to hear Patricia Howlin provide a historical review of autism awareness, epidemiology and the growth of autism as a research subject. Then the panel discussions: these took on a different character and presented the seminar with its main element of controversy and in some ways showed where the fault lines in research and practice exist. Nothing nasty of course, all professional and civilised but the dissonance is there. This was most apparent in the 2nd panel (discussing creative approaches in the context of austerity): it seems there are some who would pursue the current priorities but with a less ambitious outlook and some who are urging an

emphasis on nonmedicalised support and acceptance. It was a fascinating and mature exchange and my bet is that is going to be repeated many times at similar events. Then the preallocated small groups. Tough to deal with as an autistic person as they were the most intimate and least structured elements of the seminar but the atmosphere was always convivial and respectful. My knowledge base was very limited in these sessions but I felt my contribution was valued.

And the final thing (not chronologically, it was actually one of the first items in the seminar). It was, as I said before, a welcome opportunity to tell my story through the lens of my autism. Half a century in ten minutes is a bit of a challenge but I managed to cover the difficulties for my parents raising a 'different' child in impoverished circumstances, the sequence of disasters that constituted my school years and the inevitable falling out into long term unemployment and periodic homelessness – inevitable due to the new "Triad of Impairments" (No qualifications, no life skills, no self worth) handed to me in my formative years.

But most importantly I did not want my contribution to be a 'tragic tale': my life is OK now, better than most on the spectrum; I am not a tragic person. I came to help find solutions and I offered the following:

1. Support for breadwinners – give young 'stay-at-homes' a break and involve the 'stay-at-works' too. Raising an autistic child is no different to any other in that it is a team effort.
2. Schools to look out for the kids retreating to the shadows. Model interventions on their needs not the system's.
3. Treat autism bullying and discrimination like homophobia or racism – address the bullies' behaviour not the victims'.
4. Make autism a higher diagnostic option. I was not diagnosed until I was 50! I would not have been homeless if I had been diagnosed at school.
5. Promote research into intimate relationships which involve autistic and 'neurotypical' people.
6. Employment support both to find and stay in employment. It gives you skills, confidence and an income – A Triad of Empowerment!

Final final thing: it was a privilege to share a platform with Sarah, Dani and Alex (the young adults) and to hear about the amazing work they are doing. With people like them fighting our corner we will not hear middle aged autistic people telling the same story as me in the future.

Final final final thing: top scan! (Mancunian for "nice food". The caterers did us proud.)

You can read more about Jules' story here <http://www.alexlowery.co.uk/routes-to-autistic-homelessness-and-routes-away/>

and about the seminar series here:

<http://www.shapingautismresearch.co.uk/>

Meet the Centre's Research and Practice Associates

Research Associates



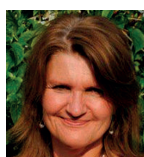
Ken Aitken

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 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.



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