AUTUMN/WINTER 2015

Share

Practice, Knowledge and Innovation

Scottish autism

Centre for Practice Innovation

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Letter from the editor

Joe Long
Research Manager,
Scottish Autism

As Scottish Autism's Centre for Practice Innovation nears its first anniversary I am happy to bring you a second issue of our Share magazine. The articles we present here provide exactly the blend of discussions that we hoped our Centre would facilitate: the sharing of practice initiatives from within our services; input and knowledge from our Centre Research and Practice Associates; and reports, voices and opinions from the wider autism and research communities. All reflect our desire to grow channels of communication with the wider world through the Centre, and Share is a big part of that. We were delighted to receive positive feedback after our first issue and hope that members of our community will enjoy the thought-provoking articles presented here.

If a theme emerges from this collection it is the importance of inclusion and partnership working with the autism and autistic communities, for researchers and practitioners alike. Several of the articles here challenge us to think carefully about how we can be better at this. Kabie Brook's opinion piece on inclusion and accessibility for autism conferences provides practical pointers as well as stressing the imperative of accessibility. Kabie's input into the recent government-funded seminar on the future of autism research in Edinburgh illustrates how practicable many of these measures are, and the seminar is reviewed by Michael McCreadie on page 5. Lorcan Kenny's report of a project on the language and terminology of autism urges us to think through the implications of the language we use, while Richard Mills and Damian Milton's reflections on a mentoring programme conceived of, and steered by, the autistic community provides inspiring reading. Richard has been a friend of Scottish Autism for many years and we are delighted that he has accepted our invitation to join the Centre for Practice Innovation as an associate, providing us with insights from his wealth of experience with Research Autism and formerly the National Autistic Society. I am pleased that we have voices from our own practice community included here too: David Harkins and Vicky McMillan report on the incorporation of the ATLASS approach to support people within our autism services, and Jemma Byrne reflects on the journey from being a student learning about autism to a practitioner in our services.

We look forward to sharing more of the Centre's work as we grow and broaden our collaboration and partnership working. In this spirit, future issues of Share will be guest edited by our Research and Practice Associates, and we are excited at the prospect of what they will bring to the magazine.

Look out for the next issue in Spring 2016, and please do get in touch if you have ideas, experience, or knowledge to share.

NEWS

Scottish Autism announce new partnership with Good Autism Practice (GAP) Journal

Scottish Autism is delighted to announce a new partnership with the Good Autism Practice (GAP) Journal, a collaborative publication currently produced by the British Institute of Learning Disabilities (BILD), the University of Birmingham and Autism West Midlands, published by BILD.

The GAP journal is dedicated to promoting good practice with children and adults living with autism. Initially launched in 2000, the GAP Journal is published bi-annually in May and October. The publication is edited by highly respected academics and practitioners specialising in autism and aimed at a wide audience including people who live with the condition and their families, as well as health, education and social services professionals. Scottish Autism will join the existing partners on the journal's management group as a co-opted member. The charity will share its experiences as an autism service provider in order to encourage and promote the journal's mission to publish work that reflects on, and informs good autism practice.

For more information, please visit:
www.bild.org.uk/gap

Cybercrime and autism

An original paper has been published in *Advances in Autism* concerning this fascinating and important topic, which came to the public attention via the case of a British man with Asperger's Syndrome, Gary McKinnon, who was threatened with extradition to the USA for hacking into USA military establishments. The paper discusses research that was undertaken with law enforcement agencies worldwide to explore concerns of those agencies of an over-representation of autistic individuals in cybercrime.

Ledingham, R., & Mills, R. (2015). A preliminary study of autism and cybercrime in the context of international law enforcement. *Advances in Autism*, 1(1), 2-11.

Pet dogs and autism

A partnership between the University of Lincoln, the charity Dogs for the Disabled and the National Autistic Society, looked to explore the effects of pet dogs in families with a child on the autism spectrum.

Wright, H. F., Hall, S., Hames, A., Hardiman, J., Mills, R., Mills, D. S., & PAWS Team. (2015). Acquiring a pet dog significantly reduces stress of primary carers for children with autism spectrum disorder: a prospective case control study. *Journal of Autism and Developmental Disorders*, 1-10.

www.link.springer.com/article/10.1007/s10803-015-2418-5

EVENTS

Knowledge Share Seminars

Scottish Autism's Knowledge Share Seminars are taking place in Renfrewshire, Falkirk and the Borders. Topics for discussion include; Thinking about Independence and Relationships and Sexual Health.

For more information about Knowledge Share and other Scottish Autism events, please visit:

www.scottishautism.org

Looking Forward, Looking Back: The Janus View of Autism

Research Autism will be holding this international conference, at Prince Philip House, London on 25-26 November 2015.

It will be the charity's most significant conference to date, featuring several world-renowned speakers. The event will seek to review progress in the field of autism over the past decade, as well a tribute to Dr Lorna Wing, a founding trustee of Research Autism, who sadly died last year.

Lorna was a pioneer in autism research, and her original ideas have been critical to our understanding of autism. The conference title is derived from Janus the Roman god of doors who is depicted as looking back as well as forwards. The Janus view was a favourite concept of Lorna's as it was her firm belief that in looking forward we should not forget the past to understand the essence of autism and to avoid repeating past errors.

Speakers include Thomas Bourgeron, Kabie Brook, Christopher Gillberg, Judith Gould, Francesca Happe, Declan Murphy, Digby Tantam and Peter Vermeulen. The conference will be chaired by Richard Mills and Jeremy Parr.

For more information, please visit:

www.researchautism.net/about-us-research-autism/research-autism-events/research-events/looking-forward-looking-back

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

Can we change the future of autism research in the UK?

Michael McCreadie
Health Psychologist

In 2013 a report, *A Future Made Together*, was published which aimed to provide an overview of research into autism in the UK. The report found that greater investment in UK autism research was required in those areas that matter to autistic people, their families and those who work with them. Only a small percentage of funding is currently focused on researching autism services, for example. Since its publication the authors secured funding from the UK Economic and Social Research Council to bring together people from the autistic community, researchers and practitioners in five seminars across the UK.

The first of these seminars took place at the University of Edinburgh on 11 and 12 June 2015. Panel forums provided a mix of people, representing these communities to discuss specific themes and frame questions that were then explored in smaller groups. These groups allowed participants to enter into direct discourse with people they would not usually have access to in their day-to-day work. Questions emerging included: who are the autism community? How is the research question set? How are the findings of research disseminated to practitioners and who translates this into practice?

As a result of this discussion a number of important observations were made:

- The most robust research is generally carried out by academic institutions who see this as part of their day-to-day role and can dedicate resource to it.
- Academic institutions receive funding primarily through grant applications.
- The bodies that offer grants may not share the same research interests as either the autistic community or the services.
- The autistic community is diverse and so further effort is required to engage more people from across the community with regards to research.
- While professional researchers attempt to use robust methodology, the uptake of findings by practitioners is mixed.

Perhaps what the two days highlighted the most is that autism is a 'nexus' term, and so research should reflect this. It was also noted that while there is value in highly robust research involving randomised control trials, useful evidence can take many forms.

Following the event, I have further reflected on the question of funding, agendas, the research question, and the role of services. As a practitioner, I split my time between my clinic where I see people with autism who have elected for help with the difficulties they face, and services that support people directly. Services are in a unique position to listen to the autistic community and respond to the sometimes unique but often shared difficulties that people are confronted with. However, services have been placed under significant pressure by austerity cuts resulting in the curtailing of activity other than direct care. *A Future Made Together* highlights the lack of funding for autism research focused on services. I wonder if directing some funding to services to engage in research partnerships with academic institutions may bridge the way to influencing research questions.

To finish on a personal note: during the summation of the two days I posed a question to a fellow practitioner psychologist. As it is expected of practitioner psychologists that we engage in research as part of our competency framework are we then not in a unique position to encourage, carry out and research in the services in which we work? The answer must surely be in the affirmative.

RESOURCES AND LINKS

A report from the seminar can be found online at:
www.shapingautismresearch.co.uk/

Is a person "autistic" or do they "have autism"?

Insights from the UK autism community

Lorcan Kenny
CRAE Communication and Research Officer

Consider for a moment the difference between the phrases 'somebody who showed strength' and 'somebody who is strong'. The first phrase describes strength as a noun and leads us to think of it as something transitory, something that is likely to change across time, and which may relate to only one aspect of who a person is. On the other hand, when the adjective 'strong' is applied we are more likely to consider this a stable characteristic, something relatively unchangeable that may permeate into many aspects of a person's life.

This is an example of how the language we use shapes the thoughts we have. We, therefore, have a responsibility to be considered in our choice of words when we describe people. This is particularly true when describing disabilities in general and autism specifically. The words we choose play a role in shaping the way we, as a society, think about, understand and accept both autism and autistic people.

It is for these very reasons that the National Autistic Society conducted a survey of 3,470 people to better understand the terms they prefer to use to describe autism. The survey gathered the perspectives of autistic people, their parents, extended family members or friends and professionals who work in the field, such as researchers and clinicians. The survey was undertaken and analysed by a team of researchers, and the results have been published in the journal *Autism*.

The take home message from this survey is that there is no single term that was universally accepted across all groups or even within each group. Some terms, however, did stand out for some of the groups – with some striking disagreements.

One notable difference, for example, was the finding that more than 60% of autistic respondents endorsed the use of the word 'autistic' compared with less than 40% of professionals who work in the field. Almost half of the professionals who responded, on the other hand, endorsed the term 'person with autism' compared with only 28% of autistic participants.

> "The words we choose play a role in shaping the way we, as a society, think about, understand and accept both autism and autistic people."

One example of why some people prefer 'identity-first language' (e.g. an autistic person) was given by one autistic participant, who said:

> "Separating the person from their autism is damaging, as it reinforces opinions about autism being a 'thing' that can be removed, something that may be unpleasant and unwanted, and something that is not just another aspect of a whole, complete and perfect individual human being. Describing oneself as autistic is an extremely important and positive assertion about oneself, it means that one feels complete and whole as one is."

The reasons behind many professionals' inclination towards 'person-first language' (e.g. person with autism) were typified by one professional, who responded by saying:

> "We need to describe the individual and the ASD as separate entities with the emphasis on the individual and not the disorder."

It is difficult to argue that the professional's preferences are stemming from anything other than good intentions and a general set of guidelines about how to describe disability that has been instilled into them throughout their training.

Nevertheless, the results of the survey show that many autistic people do not feel person-first language represents the way they think and feel about their autism. Instead, many autistic people report preferring the adjective form of the word 'autistic' because it might make people more likely to think of their autism as a stable, relatively unchangeable characteristic that is a central aspect of their identity. This description allows for autism to be framed in a positive light and encourages us to view it as a difference rather than necessarily always thinking of it as a deficit. This, according to many autistic respondents, is more in line with what autism meant to them.

> "Many autistic people do not feel person-first language represents the way they think and feel about their autism."

To some of our respondents, the debate surrounding the use of positive language obscured other issues they felt were important. While respondents appreciated the positive ways in which autism affects people's lives, many parents highlighted the potential danger that emphasising this may pose, diminishing the difficulties experienced by the people who are most disabled by their autism. One parent said:

> "While it is good to celebrate autism and to find positive ways of talking about it, there is concern from parents of the most severely disabled children that their high level of need could become lost in this process."

One area that received agreement across all groups who completed the survey was the dislike for the terms 'high-functioning autism' and 'low-functioning autism' which many people found too simplistic to describe the full range of abilities and needs that they often aimed to capture. One parent of an autistic child reported:

> "If you are viewed as high-functioning your needs are often dismissed, if you are viewed as low functioning then your strengths are often dismissed."

Another contentious issue was the idea of autism being a spectrum upon which everyone is located to some degree. Professionals and family members were more likely to report using this type of description than autistic people themselves, some of whom were concerned that it trivialised the very real difficulties faced by those who are actually autistic.

All of us need to listen to these concerns.

There is no single way to describe autism, nor will there ever be. The terms people favour often centre on their beliefs of what autism is. When somebody is being described, they have the right to be described with words that fit their beliefs and when somebody is describing another they have a responsibility to respect that. With that in mind, professionals need to choose their words carefully, with the person being described in mind and to be willing to be flexible in different contexts and with different people.

"In describing someone who's autistic as 'a person with autism/person who has autism/(or worst of all) person who suffers from autism' you imply that autism is separate from a person, and behind their autism is a 'normal' person."

Image courtesy of CRAE

RESOURCES AND LINKS

Download the full research report 'Which terms should be used to describe autism? Perspectives from the UK autism community', from the *Autism* journal website **http://aut.sagepub.com/content/early/2015/06/10/1362361315588200.full**

Accessibility and Inclusion at Autism Conferences

Kabie Brook
Co-Founder and
Chairperson of Autism
Rights Group Highlands

It is widely accepted that cars require headlights. These can be seen as an aid, an accommodation, or an adaption to a perfectly useable vehicle to enable use at night. This is needed because our vision is reduced in the dark. Because the majority of people who use cars need this adaptation, it is seen as a necessity rather than a 'special' requirement. We need to start looking at society, in general, that way: adaptions that increase accessibility are necessary because if we exclude some we damage the whole.

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. Currently, though, even when an event has a focus on autism it is unlikely to get things right for autistic people wanting to attend. Maybe some thought will have been given to accessibility, but because this rarely includes appropriate input from autistic people the result can fall well short of what is required.

> “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.”

Organisers often don't know what makes an event accessible. Sometimes there is the opinion that if someone is able to travel to the event and wants to attend such an event there's no need to adapt environments – that this autistic person must be used to living in the 'real world'. This is just a lack of knowledge about what it's like to live as a minority in our society. It's quite reasonable for people not to know, but if those people are working with autistic people or running an event, then they need to do some work to find out.

Different autistic people require different things. Just remember that individual requirements will still need to be listened to and accommodated; autistic people don't just fall out of textbooks and if you only consider us as a list of 'symptoms' or 'traits' rather than as fully-rounded humans then you'll get things wrong. But there are some basics that improve access in general.

The first thing to consider is the venue location, choose somewhere easily accessible by public transport, with good parking, away from heavy passing traffic noise and other loud noises (e.g. avoiding flight paths) and make sure to visit, don't rely on a description from the website. Particular things to consider are natural lighting, ventilation, lingering smells (including kitchen smells), acoustics and decor; it doesn't need to be bland but avoid anything too fussy. For example, I recently saw an autism conference taking place in a room with a ceiling that resembled a psychedelic light show, pretty to look at but unsuitable as a conference venue.

Ensure that the rooms you book have surplus seating so that people don't have to squash together and leave plenty of space without seating at the sides and back of the room to allow people to move freely or stand during the event. At autistic-led events the need to move around, perhaps to leave and return is widely recognised, this needs to be accepted at other events too.

If having discussion groups, remember more than one group in a room can make it impossible to follow the discussion and join in; you will need separate rooms. Also provide a separate quiet lunch and break room and a 'no-queue' lunch option. You could also offer packed lunches for those people wanting to eat away from the building.

Going somewhere new is stressful, the more prepared we can be the lower the stress and thus the more able we are to attend. Having good quality well-laid out information available in advance reduces stress. This is something that if done well everyone will thank you for.

Include a running order with timings, maps and photos of the building and its location, public transport details, any workshop questions and advance copies of all written material. That sounds a lot when written together but it's about making materials widely available sooner.

Another idea is to provide details of what food will be available; break times and meal times can be stressful. These are all ways of making the day more predictable that gives a feel of familiarity to an event that if left as an unknown can make it harder to attend.

Minimising noise in large crowds is almost impossible, so it is worth reminding people of this in advance. This ensures that they are prepared and know how to escape the noise when necessary. Quiet areas should be available throughout the day; this includes a space for quiet dining and other breaks. In this space, a 'no-interaction' table is useful, a place where people can relax without needing to engage with others. Remind people that attending with earplugs, headphones, ear defenders, dark glasses, stim toys (non-light-up and silent), is welcome.

It's important to remember that autistic people have been running our own events for decades. The first Autreat was held in 1996, and Autscape, a UK autistic-led conference and retreat, started in 2006. Both of these have been an inspiration for work on creating autistic spaces and have acted as catalysts for autistic community development.

For example, widely used within autistic spaces (and increasingly by others too) are interaction badges. The interaction badge system was developed by and for autistic people (initially for Autreat), but is now widely used at all kinds of conferences and events. The badges allow people to take control of their own interaction in a way that often isn't possible in our day-to-day lives. Each person who would like to use the badges is given a set of four cards that fit into a plastic wallet: white for 'I can manage my own interaction'; red for 'please do not initiate with me'; yellow signals that only people with prior permission can initiate; and green that invites initiation. This provides a solution for those who really want to engage but find it hard to approach people and start the conversation.

Interaction badges are now widely used at conferences and events.

Other notable adaptations often seen in autistic community settings include: the waving of hands rather than clapping; requests for attendees to wear low or non-perfumed products and to avoid strong perfume or aftershaves; and instructions not to wear clanking or dangly jewellery that makes a noise. Requests for small changes make a big difference in comfort for many of the attendees.

Including a range of autistic people on planning committees and as paid consultants can help to steer an event in the right direction. Event content should include nonverbal workshops or activities that do not rely upon traditional verbal discussion. Consider alternative ways to have presentations such as more use of posters, video presentations, artwork and written work. Different ways of hearing people and including their views are also needed.

Including autistic speakers is essential. Many are professionals and experts in their chosen field. We have more to offer than 'experience talks' but are often only booked to enact examples of our 'autisticness'. Our community is a lively and beautiful mix of individuals and this is often not acknowledged.

> "Our community is a lively and beautiful mix of individuals and this is often not acknowledged."

If you are organising an event, the main questions to ask yourself are: 1) What worth does an autism conference have without including autistic people? 2) Do you see the autistic community solely through a non-autistic lens, and if so, how can you change that?

RESOURCES AND LINKS

Autism Rights Group Highland: **www.arghighland.co.uk**

Autistic Self Advocacy Network (ASAN): **www.autisticadvocacy.org**

Autreat: **www.autreat.com/autreat.htm**

Autscape: **www.autscape.org**

You can also read a view on interaction badges here: **www.quarridors.tumblr.com/post/52220250123/a-photograph-description-below-of-my-interaction**

If it's good enough for Cherie Blair...

The Cygnet life-coaching and mentoring programme for Adults with autism

Richard Mills

Research Director of Research Autism, and Research Fellow at the University of Bath

Damian Milton

Joint Head of Autism Knowledge and Expertise at NAS and Research Assistant at London South Bank University. Damian is on the autism spectrum and father to a teenager on the spectrum

In 2009, Research Autism organised and conducted a Collaborative Autism Research Forum entitled *Successful Futures for Adults with Autism*. At this meeting adults with a diagnosis of autism were invited to talk about the systems of support that were available to them or that they would find helpful.

There was a consensus among this group that the existing forms of social support were not meeting their needs. Whereas social groups enjoyed a mixed response, the majority of those attending expressed particularly negative feelings about befriending as something that had not been helpful to them. Some said it had been their parent's idea. Others reported that befrienders had either lost interest or moved away. One young woman was distressed to discover that her befriender was paid expenses. Problems with matching meant either no befrienders were found or they were paired with people with whom they had little in common. A view was expressed that friendships around shared interests were perfectly achievable for many autistic people but that a befriending arrangement often lacked this and seemed fairly meaningless for both parties. Participants were at pains to point out that for some autistic people befriending might work well – just not for them. What was needed, it was suggested, was a life coach or mentor working on a time-limited basis to help achieve specific goals or address specific points of concern. As one delegate put it 'Cherie Blair has one –why not me?'

Following the meeting a group of adults, all with a diagnosis of autism or Asperger Syndrome, met to scope the project. The group came up with the name 'Cygnet' and were quite specific as to what it should and should not be. Their vision included a training programme for mentors and a manual of 'how to do it'. It was also felt to be important that autistic people could themselves mentor other autistic people.

People should have the choice. It was acknowledged that circumstances would differ from individual to individual: one person might want to understand a 'neurotypical' perspective on a social situation, another might want to learn how an autistic person coped with a particular challenge and what had worked for them.

There was agreement that whatever was put in place would be systematically evaluated and a pilot would be developed. If successful, the scheme could be made more generally available and paid for by the individual, either through benefits or earnings. If unsuccessful the scheme could be thrown in the bin or modified.

The group provided a steer on how the programme would operate:

> "Young people and adults with autism frequently fail to reach their academic and social potential or get into difficulties because they do not understand how others think or behave. Consequently, they do not know how to successfully manage their relationships with them. This is a result of the core difficulties of autism which include severe communication or language problems and which are frequently compounded by a lack of confidence, anxiety, physical and or mental health problems and differences in sensory processing."

They described the type of service that they felt was needed as follows:

> "Life-coaching or mentoring services that will help the young person with autism navigate and understand the world through sharing first-hand knowledge and experience of the world and a joint approach to problem solving. It differs from befriending and advocacy in that it would be time-limited and goal-directed – a professional service."

The group believed that a mentoring programme would be a 'low-cost, socially valid' service that would have significant benefits for the physical and mental health and wellbeing of adults with autism. Importantly, they felt that it would reduce the demands on their families, and the need for other forms of health-based support or social care.

Our initial research found that although models of mentoring did exist, they were either not 'autism-friendly', or were not sufficiently well-described or consistent in their design or application. We found that often the term mentoring is conflated with befriending or advocacy. Such schemes as were described appeared unstructured, open-ended and lacking in focus. None had been systematically evaluated. We concluded from this preliminary review that there was no existing model that was suitable for use with autistic people. In some cases we felt that mentors and mentees were in fact made vulnerable.

> "This project is designed to offer goal-directed and time-limited mentoring to 12 adults with a diagnosis of autism. Mentors will be recruited and include autistic adults."

An open call went out for academic institutions to establish and evaluate the impact of the scheme. Professor Simon Baron-Cohen, Director of Cambridge University's Autism Research Centre, and Dr Nicola Martin, Head of the Education Research Centre at London South Bank University (LSBU), were successful.

Funding and ethical approval were secured to enable the project to launch in 2014. The project is supported and overseen by Richard Mills and Simon Baron-Cohen. The programme is delivered by two Research Assistants at LSBU on a job-share basis. One, Damian Milton, is himself on the autism spectrum. The interview panel contained two autistic members and the advisory panel also comprises three autistic members.

This project is designed to offer goal-directed and time-limited mentoring to 12 adults with a diagnosis of autism. Mentors will be recruited and include autistic adults. They will be vetted, trained and matched with those requiring a mentor. Each participant will receive half a day's mentoring per week over a six-month period, reflecting the view of those consulted that a short period of mentoring would be more effective for them. Six months will also be attractive to those who fund and commission services and who might have been deterred by an open-ended commitment.

Evaluation and outcomes

Evaluation is essential to facilitate accurate replication and dissemination of the scheme, as well as informing future research. Evaluation will be undertaken firstly using measures determined on an individual basis. For example, if an outcome specified by the participant is to get a job, this will be recorded as an outcome measure for that person. Other outcome measures might include reducing personal stress, handling criticism, managing conflict, joining a club or society, undertaking a course or leisure pursuit, or living independently. Goal setting will be through negotiation, and follow-up decided on an individual basis.

Secondly, changes in participants' wellbeing will also be measured using an extensively validated tool, the Personal Wellbeing Index, developed by Robert Cummins and the International Wellbeing Group at Deakin University in Melbourne. This measure has been standardised and shown to be useful in assessing quality of life in autistic and non-autistic populations, and in allowing intra-country and international comparisons to be made.

Outcomes will be measured against the situation each participant was in at the starting point of the project (pre-intervention) thus using the participants as their own controls. Their progress will be assessed at the end of the mentoring period, and again six months after the intervention ends. The team will be recording and analysing qualitative data from post-mentoring interviews and reflective logs, and triangulating that with the quantitative data to look for potential indicators as to why people either felt they benefited or didn't.

At the end of the pilot we will have put in place, and evaluated, an intervention that was designed by the autistic and wider autism community. Moreover, we will have evidence as to whether this model is helpful, how it can be applied, and how it can be replicated. If mentoring proves to be successful, the output will be a model of low-cost 'autism-friendly' support that is acceptable to, and accessible by, the autistic community. Through the development of a manual and training, the model will be able to be replicated and rolled out nationally through new community support arrangements and personal budgets; throughout universities where transition difficulties can be critical; and throughout the UK corporate community, where success or failure of adults on the autism spectrum often depends on this type of intervention.

RESOURCES AND LINKS

For more information about Research Autism, visit:
www.researchautism.net

Changing Cultures of Practice

Bringing the ATLASS approach to Scottish Autism's services

David Harkins
Quality & Risk Manager,
Scottish Autism

Vicky McMillan
Senior Learning &
Development Manager,
Scottish Autism

Since 2013 practitioners from Scottish Autism have been training in the ATLASS (Autism Training with Low Arousal Support Services) approach to supporting people with autism. As the organisation looks to embed the approach into everyday practice, David Harkins and Vicky McMillan of Scottish Autism, provide a background for those that are unfamiliar with ATLASS. We also reflect on experiences of the approach in practice and our plans for incorporating ATLASS into our work across the organisation.

What is ATLASS?

The ATLASS model was developed by psychologists from the Studio 3 organisation including Michael McCreadie, who is also a Practice Associate of Scottish Autism's Centre for Practice Innovation. ATLASS entails a holistic approach to autism support that focuses on the wellbeing and happiness of the individuals in our services. The programme recognises the impact of stress on wellbeing, so rather than focusing on 'challenging behaviour' as something to be treated on its own, ATLASS-trained practitioners focus on stress reduction in service environments, positive interactions between staff and those they support, and the importance of health and exercise for wellbeing. The approach is holistic, recognises that stress is transactional and that reducing stress among parents and practitioners helps provide a positive environment for the individuals that we support: positive interactions and relationships benefit everyone. This helps us move on from focusing solely on the individual and adapting 'their behaviour' to reflect on our practice in a way that empowers us all. The ATLASS model examines the spiritual, mental, environment, social, physical, and emotional wellbeing of individuals both individually and collectively.

The ATLASS training gives practitioners some key learning points in developing low stress support. These included an understanding of the physiology of stress, why it occurs, and how exercise and positive experiences can counter the effects. Participants are guided through a better understanding of autism, sensory perception, analysing the stress transaction, coping strategies for stress as well as insights into their own practice that include change talk and motivation, the use of mindfulness and reflection in autism practice, and on happiness and wellbeing as focuses of practice. The training includes numerous practical insights into identifying causes of stress in environments and interactions, and practitioners are mentored through the process of developing stress reduction programmes for individuals.

> "ATLASS entails a holistic approach to autism support that focuses on the wellbeing and happiness of the individuals in our services."

ATLASS in practice

One of the stress reduction programmes undertaken by the initial ATLASS cohort was provided by the staff team for 'Emma'. Emma is an autistic woman in her mid-40s who lives in one of Scottish Autism's supported living services, as well as attending our day resources. Emma has often displayed high levels of anxiety manifested in self-harm and verbal and physical attacks on staff.

In collaboration with Emma and her team, the ATLASS-trained practitioner identified where the particular stressors in Emma's life lay. Key factors included having her routines, or her thought processes disturbed; transition from one activity to another (particularly if activities do not have clear beginnings or endings); and changes to the environment (particularly increases in noise). The team also noticed that staff were communicating with Emma in different ways to one another and were not always alert to environmental stressors that may impede Emma's processing.

> "The ATLASS stress reduction plan gives an opportunity for staff and the people they support to identify stressors and wellbeing activities collectively."

The stress reduction plan has therefore involved supporting Emma to recognise her own signs of stress (through visual aids and references), validating the principle she can leave noisy or stressful environments if she needs to, and teaching relaxation skills such as breathing. Support staff have also worked on their mindfulness to be alert to environmental stressors and to be conscious of the way that they communicate with Emma. This includes important changes like giving Emma full attention (rather than multi-tasking while supporting Emma) ensuring that they always say Emma's name when addressing her, ensuring that the environment is calm and quiet, and providing clear markers to begin and end activities. Emma also enjoys using pet names that she has created for herself. Although this may have been unusual to some people, staff were encouraged to use these terms of address, which Emma finds meaningful and fun.

The ATLASS practitioner also worked with Emma to identify things that she liked doing. Although practitioners were sensitive to the possibility of sensory overload, Emma emphasised that she enjoys pampering and aromatherapy which she is given regular opportunities to do. The team also looked at increasing other activities that aid Emma's wellbeing and health such as extending her swimming sessions. Emma enjoys dancing at home and in her day service, and so Emma has also joined a Zumba class that she enjoys.

Many of these kinds of practice changes will be intuitive to some autism practitioners, or resonate with their existing practice ethos. Others, however, may still look at 'challenging behaviour' in isolation, and think about reacting to those situations as they arise rather than understanding holistically what may cause stress or aid wellbeing. The ATLASS stress reduction plan gives an opportunity for staff and the people they support to identify stressors and wellbeing activities collectively and, through encouraging mindful practice and interactions, encourages practitioners to be conscious of their own communication and the service environment.

Changing practice collectively

Two cohorts of practitioners (a total of 20 staff) have now been through the ATLASS training, the first in 2013-14, the second in 2015. The training comprises nine days in all with participants undertaking case studies between sessions and keeping a reflective learning log throughout the process. The first cohort has gone on to undertake a masterclass at Studio 3's base in Warwickshire, which allows them to train others in ATLASS. Masterclass participants have formed a working group to plan how to roll out the approach across Scottish Autism. Members of the working group have delivered workshops at our annual staff conference and to all the practice staff at New Struan School. The approach has been incorporated into many elements of Scottish Autism's learning and development programmes including mandatory training. ATLASS themes are also influencing the redesign of the organisation's support plans and will be threaded throughout the new documents.

We have been helped by our partnership with the Heimdal organisation in Denmark who are also moving to an ATLASS model of support. Our Danish colleagues have shared valuable insights into their own experience of ATLASS and we have undertaken reciprocal visits to compare our approaches and learn from each other through a process of peer sharing and support.

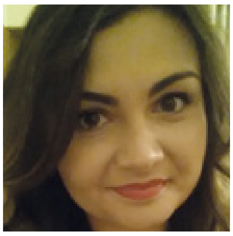
All trained practitioners agree that ATLASS represents a significant shift in thinking. Making the approach work will require changes to our cultures of practice, but the benefits for all of us will be significant if we inculcate a focus on happiness and wellbeing across Scottish Autism's services.

Some members of Scottish Autism's ATLASS team.

RESOURCES AND LINKS

For more information on the ATLASS approach please visit: **www.studio3.org**

Autism: from theory to practice



Jemma Byrne
Support Worker,
Scottish Autism

> "The first thing I learned as a Support Worker is that autism in itself and the individuals living with the condition cannot be defined by books."

I completed my degree in psychology in July 2014, and by mid-August I had started as a Support Worker with Scottish Autism in the West of Scotland services.

In preparation for my interview I equipped myself with knowledge about the organisation, including the mission statement: 'to enable people living with autism in Scotland through the whole life journey', and drew upon my experiences at university.

I believed myself to be well-informed about autism. As part of my studies I had enjoyed learning about the condition as an independent module and was fortunate enough to have been involved in a research project with Scottish Autism's Research Manager, Joe Long. I, therefore, felt I was clued-up and that my learning experience could contribute greatly to my role. Certainly these factors did help theoretically, but it was outside the lecture hall and away from researching on the computer that the real learning experience began.

I remember thinking nervously on my first day of the job, 'yeah I know what autism is' and reassuring myself, 'you know what to expect, you've read the books'.

Well, the first thing I learned as a Support Worker is that autism in itself and the individuals living with the condition cannot be defined by books. Autism cannot be merely classified by the infamous triad of impairment since the manifestation of the condition is so unique. Yes, we need a theory about what autism is in order to explain it generically, but it certainly cannot be generally defined. Thinking about all the individuals that I've met who receive support from Scottish Autism, there is not one like the other. Each has their own personality, pattern of challenges, and successes that makes them individual and consequently no day is ever the same and certainly never boring!

I feel fortunate that I am able to now draw upon my practical experience of autism and reflect on how it feeds into my theoretical experience. For example, the Theory of Mind hypothesis, surmises that individuals with autism have a limited concept of other people's thoughts and feelings. However, the individuals I've worked with have demonstrated otherwise and regularly consider how their choices impact on others.

Furthermore, a lot of the empirical research out there, especially on sensory processing, has mainly validated and explained the biological causes of what we as practitioners see on a daily basis: light and noise sensitivity, difficulty with fine motor skills and issues with proprioception and spatial awareness. Where the difficulty lies, however, is going beyond recognising these issues and working towards supporting the individual in managing them. This is where I recognise a gap between being a researcher and being a practitioner. Research findings of particular support methods are not likely to apply to all individuals with autism. And this is where more person-centred research would greatly inform the person-centred support we provide.

This job has been very challenging at times and one of the most harrowing aspects has been supporting those with self-injurious behaviour. I feel that, surprisingly, this is something that isn't widely covered in academic courses and doesn't appear to be a focus of the research or academic textbooks that I had read as a student. I feel it certainly should be more prominent in the literature since I would like to understand more about its occurrence and how best to support individuals living with this.

My time working with Scottish Autism has been greatly rewarding and beneficial. Overcoming different challenges every day has furthered my own personal development. Looking back I wish I'd been working as a Support Worker during my studies too, as it would certainly have brought me a greater, holistic understanding of autism.

Meet the Centre's Research and Practice Associates

Research Associates

Ken Aitken

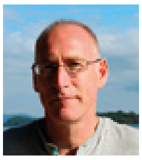
Ken is a practicing Clinical Psychologist. He has been Chair of the Research Subgroup of the Scottish Autism Strategy and an active member of the main Strategy Group since its inception.

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.

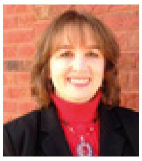
David Simmons

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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