

SUMMER 2018

Share

Practice, Knowledge
and Innovation

Scottish
autism

Centre for
Practice
Innovation

CONTENTS



From the Spectrum: Writing my Blog

Page 5



Report: Positive Identification within the Autistic Community: it could Save a Life

Page 6-7



Conference Review: Autism, Anthropology and Lived Experience: An Interdisciplinary Symposium

Page 16-17

3 **Letter from the editor:**
Alan Somerville, Chief Executive Officer,
Scottish Autism

4 **News and Events:**
Round up of news and events

5 **From the Spectrum:** Writing my Blog.
By Emma Stanley

6-7 **Report:** Positive Identification within
the Autistic Community:
it could Save a Life. By Kirsty Monaghan,
Scottish Autism

8-9 **Case Study:** Autism in Progress.
By Lucy Chetty, Scottish Autism

10-11 **Opinion Piece:** Getting the
Questions Right. By Ken Aitken,
University of Glasgow

12-15 **Feature:** Is it Time to Think of Autism
as an Entity in its Own Right?
By Alan Somerville, Scottish Autism

16-17 **Conference Review:** Autism,
Anthropology and Lived Experience:
An Interdisciplinary Symposium.
By Alastair Clarkson, Scottish Autism

18 **Associates:**
Meet the Centre's Research
and Practice Associates

19 **50th Anniversary Conference**

Guest Editor



Alan Somerville
Chief Executive Officer,
Scottish Autism

The role of research in developing autism strategy in Scotland has become contentious. Some argue that it is beyond the remit of the groups currently working on the Scottish Strategy for Autism but most accept that there are a significant number of “known unknowns” and that shining a light on these would greatly assist in the development of policy.

Although the concept of personalisation is claimed right across the care sector, how do we ensure that this is more than lip service? Scottish Autism’s approach of deconstructing a person’s autism, principally through the identification and removal of the stressors which adversely affect that individual’s life, involves skills which cannot be deduced from first principles but only through the detailed observation and reflection on our autism practice.

Of even greater significance is the almost universal acknowledgement that autism represents something quite different from other conditions which in itself makes it a “special case” in the field of policy generation.

Dr Glenys Jones and Professor Tommy Mackay of Birmingham and Strathclyde Universities respectively justify autism’s special identity as follows: “The justification for making a special case for autism is that it is in fact a special case. The autism spectrum represents the major part of the group of conditions classified as ‘pervasive developmental disorders’ (American Psychiatric Association, 1994; World Health Organization, 1992). It is the very nature of its pervasiveness that

makes the autism spectrum different from other conditions, no matter how high their prevalence or how potentially debilitating their effects.”ⁱ

The very definition of “strategy” is a method or plan chosen to bring about a desired future, such as achievement of a goal or solution to a problem. The fact that the need for a strategy is acknowledged represents acceptance that either the technology, the knowledge or the material in some combination are not available to achieve the goal immediately. That means that they must be either developed or acquired.

A dichotomy of opinion has emerged between the participants in the development of the Scottish Strategy which can crudely be defined as a focus on short-term purely tactical focus versus a longer-term truly strategic focus. These views translate into the following positions:

- Those who believe that a sufficient amount is known about the organisation and delivery of services to plan provision effectively within existing state structures; and
- Those who believe that we need an infrastructure to accumulate data from practice-based research, combined with standardised systems of appraisal and assessment of interventions, so that future decision making and resource allocation can be improved.

Scottish Autism is very firmly in the second camp and Share magazine is one of many manifestations of our commitment to the principle of practice-based research.

REFERENCES

- ⁱ Jones, G., & Mackay, T. (2013). Promoting the vision of the Scottish Strategy for Autism. *Good Autism Practice Journal: The Scottish Perspective*, 14 (1), 4

NEWS

Shortlisted for the Scottish Social Services Awards

We are excited and honoured to be shortlisted in the upcoming Scottish Social Services Awards in two distinct categories. In the category of 'Thought Leadership' our Centre for Practice Innovation has been shortlisted for the work it carries out to harness and utilise the knowledge and experience of practitioners and the autistic people we support to inform and improve services.

In the category of 'Making Research and Evidence Real' our Practice Research Team has been shortlisted for their development of a programme of practice research. The team facilitate practitioners and supported autistic people to undertake research, evidencing the most enabling support and developing a reflective, critical approach to practice.

We are also delighted to support the Scottish Women's Autism Network (SWAN) who are shortlisted in the category of 'Head Above the Parapet'.

Makers

Our new Alloa based community hub, Makers, provides supported day and vocational placements for autistic people and individuals with learning disabilities aged 16 and over to develop the confidence they need to succeed in a workplace environment.

The hub also houses a community cafe which is open to the public Tuesday to Saturday 9.30am to 3.00pm. For more information visit: www.makersalloa.org

Autism in Context

From Neurodiversity to Neuroharmony

In July 2018, a new company in the field of sharing knowledge about autism will be launched: Autism in Context. It's the new company of Peter Vermeulen, lecturer, trainer and author of more than 15 books on autism. Through training and workshops, lectures, online support and publications, Autism in Context aims to increase the understanding of autism in different contexts: the context of the how the brain works and how people experience and understand the world, the context of the environment and how this environment can be made autism friendly, and – most importantly – the context of the most basic human need: happiness. With more than 30 years of experience, Peter Vermeulen wants to inspire everyone who is part of the context of an autistic person (parents, teachers, professionals, policy makers, etc.) to take autism a step further: from neurodiversity to neuroharmony.

For more information visit you can contact Peter at info@petervermeulen.be or info@autismincontext.be

EVENTS

Scottish autism

CELEBRATING 50 YEARS

50th Anniversary Conference

In celebration of our 50th anniversary, we are holding a two day conference in the Grand Central Hotel in Glasgow, with the aim of providing a platform for sharing visionary approaches to the development of autism practice.

Our programme will be influenced and informed by a contemporary view that embraces autism as a developmental difference and focuses on a capacity view of the individual. There will be a focus on novel practice related research that demonstrates the meaningful participation of, or that has been led by autistic individuals.

For more information visit:

www.scottishautismconference.org

NHS Scotland Event

18th – 19th June, Scottish Event Campus, Glasgow

We will be at this year's event with information and advice on autism

- Visit us at stand 41.

For more information visit: www.nhsscotlandevent.com

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

Writing My Blog



Emma Stanley

My name is Emma Stanley and I have Asperger's Syndrome. I post a monthly blog on the Scottish Autism website which I think helps me with my autism. I started my blog because I feel that there is not enough information about women with autism out there. My goal is to help other women with autism understand their condition and to help people without autism understand what it is like to be living as a woman with autism.

I also want to see more recognition for women and for support to be more tailored, especially in areas like relationships and friendships. I think women need different support to men with these kinds of things.

“I feel that posting my monthly blog has helped me cope with my condition and it has made me feel a lot happier.”

I feel that posting my monthly blog has helped me cope with my condition and it has made me feel a lot happier. It makes me feel that I have achieved something great and knowing that I may have helped other women (with or without autism) understand the condition more, is a very happy feeling. Writing the blog helps with my feelings of frustration. I can channel my feelings at the computer rather than people. It's hard to say what specifically makes me feel frustrated but it's a good outlet. Before the blog, I would rely on support staff but writing the blog makes me feel more in charge. I can write about what I want to, I am in control. I write things in my blog book then I use this to write the actual blog each month. I don't have a favourite thing to write about, I just like to get it all out there. It's a bit like a campaign, a campaign to say that autistic people should be treated like everyone else. In my blog I like to include things that I have achieved,

things that make me happy, how I am feeling in general life and how I feel I have coped that month.

I am generally a happy person. I love music, especially 80's music. Seeing my mum happy also makes me happy. She is the strongest person I know. The blog helps with my wellbeing, it helps me cope and I would encourage other autistic people to blog too.

Here is an excerpt from one of my recent blogs:

“I have been to see Bananarama in concert and it was the original line up!

We got to the Hydro and we were a bit early so we had a walk round, apparently next door the little muffins as I call them (little mix) were next door. We got in the wrong queue, we got in the VIP queue with the backstage passes for the meet and greet which we didn't have so he directed us to the other queue and we got in eventually and I bought myself a Bananarama hoodie which is lovely and warm. I bought myself a packet of crisps and a bottle of Diet Irn Bru, we got up to our level that our seats were on and then we had to sit outside for a while as they were still setting up. They did warn us that they had strobes in their lighting, but it was not too bad it was nice and soft and they had a backdrop of old videos of themselves which was good. It was almost a sell-out, there were a few empty seats, they were pleased to see us all and it was amazing to see how many middle-aged men were there dare I say it! I got a bit overwhelmed but once I got used to the crowd and the Bananas came on I really got into the music and started dancing...”



Read more of Emma's blogs at www.scottishautism.org/blog

Positive Identification within the Autistic Community: It could Save a Life



Kirsty Monaghan
Autism Practitioner,
Scottish Autism

Whilst studying for my Psychology degree at Dundee University, I worked for Scottish Autism in our Tayside support service. I specialised in research methodology for my postgraduate degree, and sought to use that opportunity to contribute to understanding the inequalities faced by the autistic community.

Every two hours, somebody in the UK will die by suicideⁱ. The prevalence of suicidal ideation in the autistic community is predicted to be nine times higher than the general populationⁱⁱ. Upon hearing about the high prevalence of suicidal ideation in the autistic community, I decided to dedicate my postgraduate project to understanding the processes that underlie this. The project found that the relationship between a person's autistic traits and desire to end their own life is mediated by the extent to which they identify with social groupsⁱⁱⁱ.

"If an individual has a higher level of autistic traits, they will also have less feelings of group identification. As a result, they experience more feelings of suicidal ideation."

We are part of many social groups; no matter how concrete or abstract that group may be. I am Scottish.

"Humans are social creatures. We have an inherent need to feel a sense of belonging in society, and this creates a feeling of purpose in the world."

Therefore, I am part of the social group, "Scottish people". I am also a vegetarian. Therefore, I am part of another social group, "vegetarians". If I was active enough to take up a sport, say football, I could be part of a more concrete social group, "The SA girl's

football club". In this sense, a social group is defined as any number of people who are all a member of that group due to one or more shared factors.

Group identification

However, claiming membership of a social group is only half the story. Group identification is a subjective experience which is not measured by the extent to which you physically see or speak to other members of the group. It is a person's own feelings of belongingness to a group of people with whom they have things in common. Research is indicating that strong identification with our social groups is good for our physical health^{iv}, mental health and wellbeing^v. In turn, it is believed to be a protective factor against developing suicidal thoughts^{vi}.

Indeed, an autistic individual is also part of many social groups. Autistic people also attend colleges, workplaces, recreational groups and clubs. They also have nationalities, religions and political identifications. In fact, they probably have just as many groups to identify with as a neurotypical person. Nonetheless, autistic individuals can feel dissimilar to others in society. Even though they share something in common with others in their groups, they may see too many differences between themselves and others in order to feel belongingness. In this regard, can an autistic person ever truly develop the subjective feelings of commonality and belonging that is needed to identify with social groups?

Moving forward

There is one social group that many autistic people can certainly find commonality with: the autistic community. Just like nationality, religion or gender, it is an abstract social identity that does not necessarily require contact with others in order to develop.

The Scottish Autism "Voice, Participation and Involvement" project is a great building block to initiating positive identity with the autistic community. It ascertains that autistic people should lead the way in defining how they want their community's voice to be heard, and empowers them to set their own terms in how they wish for their autism-specific groups to function. This, by far, is the most important first step for people to identify with the autistic community.

Initiatives such as the Scottish Women's Autism Network (SWAN) is another fantastic example of building identification within the autistic community. Girls find identification with other girls in many different forms. New mothers find themselves identifying with other mothers, and building supportive networks. Victims of gender-based crime find commonality through their experiences and support each other to find their strengths. Autistic women also experience gender-specific life events which connect them to others. By providing opportunities for autistic women to share these experiences with others, it can empower them to realise their strength and take pride in their autistic identity.

There are many other initiatives which are helping autistic people to find pride and comfort in their autistic identity. More autistic people are writing blogs on their experiences, and connecting with others online. There are also more initiatives set up by organisations like Scottish Autism to pave the way for the autistic voice to be heard and the identity to be embraced. For example, the Autism in Focus campaign where the autistic community shared their experience in a public exhibition (www.scottishautism.org/autisminfocus) on what they wished other people knew about autism and Right Click for Women and Girls, an online support programme which features interviews and presentations from autistic females.

I now work in Lothian support services, and I have had the opportunity to have a chat to some of our supported individuals about this area of research. Some people can relate to the concept of a lack of identification with groups they are already part of. They can also relate to how this may develop into feelings of isolation, lack of purpose, and thus, suicidal feelings.

Nonetheless, there are others in the community who do not agree. Some individuals state that they do not wish to identify with the autistic community, and feel that doing so would only aggravate their negative thoughts and feelings. It reminds them of the factors that have acted as an impediment to their life goals; they wish to detach themselves from the "autism" label as a result. They may find that other autistic people face difficulties in communication and interaction which are different to their own. In turn, they may feel unable to connect with others and function as part of that group. In this light, the celebration of neurodiversity becomes important. Autistic people can certainly find commonality, and thus, belongingness in a predominately neurotypical group of people – there simply needs to be less focus on group

member's differences, and more focus on their similarities and what brings them together.

At Scottish Autism there is a commitment to, and focus on, participatory action research. We still need to hear more thoughts from the autistic community on how they feel about building on their autistic identity, and whether or not they would like the neurotypical community (including researchers and professionals) to contribute to this.

Final thoughts

Understanding the processes that cause a person to develop suicidal thoughts is complex, and social isolation has traditionally been a prime focus. The shift of focus from 'social isolation' to 'group identification' helps us to understand that there is more to suicidal thoughts than merely seeing or speaking to other people. It is a personal and subjective experience of how people define themselves in the context of society, and when lost, can thwart our sense of purpose and belonging in the world. Most importantly, autistic people are at high risk of experiencing a lack of subjective group identification. So, if we can change the way the autistic identity is viewed and embraced – it could save a life.

REFERENCES

- i Samaritans. (2017). Suicide statistics report 2017. Retrieved from: https://www.samaritans.org/sites/default/files/kcfinder/files/Suicide_statistics_report_2017_Final.pdf
- ii Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry*, 1(2), 142-147.
- iii Monaghan, K., & Robertson, A. (2018). *Manuscript in preparation.*
- iv Sani, F. (2012). Group identification, social relationships, and health. *The social cure: Identity, health and well-being*, 21-37.
- v Sani, F., Herrera, M., Wakefield, J. R., Borch, O., & Gulyas, C. (2012). Comparing social contact and group identification as predictors of mental health. *British Journal of Social Psychology*, 51(4), 781-790.
- vi Van Orden, K. A., Witte, T. K., Cukrowicz, K. C., Braithwaite, S. R., Selby, E. A., & Joiner Jr, T. E. (2010). The interpersonal theory of suicide. *Psychological review*, 117(2), 575.

For updates on current research on suicide and autism, stay in touch with MHAutism at Coventry University: Website <http://mhautism.coventry.ac.uk/> and on twitter @MHAutism

Autism in Progress



Lucy Chetty
Head Teacher,
New Struan School

B Squared Ltd. has produced Autism Progress in association with Scottish Autism, Autism Wessex, and the North East Society. This tool aims to develop a deeper understanding of how an individual's autism affects them in order to best support their growth, development and understanding of self. At New Struan School, many of the young people we support are trying to learn more about who they are and understand what their barriers to effective learning experiences might be.

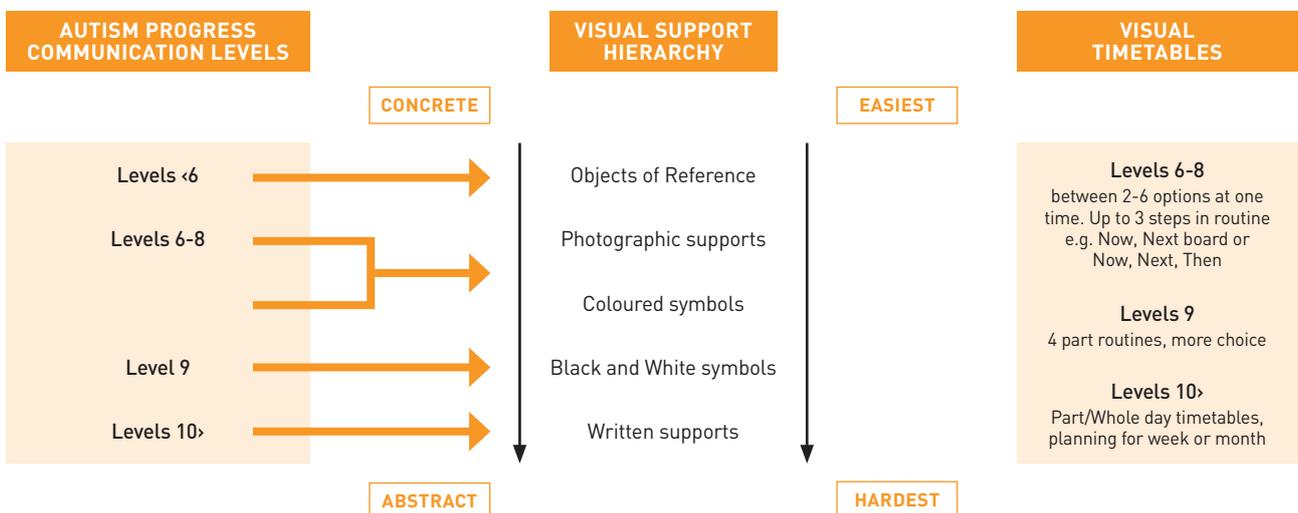
Autism Progress has descriptors within the following four areas; Communication, Social Interaction, Flexibility of Thought and Emotional Regulation. It is important to remember that whilst it uses a scale ranging from 1-17, within each area this is a framework, providing a canvas of what an individual can do and should not be understood as required levels to achieve.

Each descriptor within the four areas is evaluated using the following eight levels of engagement;

Encounter, Awareness, Attention and Response, Engagement, Participation, Involvement, Gaining Skills and Understanding, and Mastered. It is important that as a school we have a moderated understanding of what each of these levels look like for the individuals that we teach. In order to achieve this collective understanding we use the levels to evaluate learning across all contexts.

At New Struan School we work to complete the baseline assessment of an individual's profile within the first six months of joining the school. This process involves identifying which elements the person has mastered. From this point, and this starting level, we are then able to evaluate progress using all eight levels of engagement. Each level has a corresponding page that is filled with support strategies. These strategies can help to inform support plans and individualised education plans. It is important that we take time and build the learning experiences for each pupil using a strength based approach, taking the time to understand their aptitudes and unique developmental profile.

We have aligned the communication levels with the visual support hierarchy. This enables a consistent approach to both communication strategies and supports across the range of pupils within the school.



The teachers are able to use the strategies to reflect, perhaps generate interest, to find out more or look to new resources to investigate. We know that any learning community needs to focus on both how children like to learn along with what they are experiencing. The pupils we work with need their learning experiences to be motivating, meaningful and purposeful for them. The consistency of approach in strategies to support young people is critical, through Autism Progress the teacher and staff team are able to track, share and reflect upon how a young person is coping.

Listening and understanding the pupil voice should also inform the profiling process. Within New Struan School, some of our pupils are able to engage and reflect on their own autism profile; often they like to focus within the area of Emotional Regulation. Some of our young people can identify their emotional states and feelings. They may take a descriptor, such as 'they remember and describe how certain events made them feel' and have a conversation about this concept with a trusted member of staff.

RECEPTIVE

- Listens to, and can engage with, a range of music
- Responds to voices with background noise present
- Searches for a sound source that has ceased
- Shows an understanding of familiar objects, e.g. looking at/touching
- I** Sits calmly to listen to a story
- U** Turns a book around to look at pictures in different ways

Here we can see that one of our pupils has been assessed as engaging with Involvement and Understanding within level 7 of the Communication area. As we would expect with the profile of our young people they may sit across levels for a variety of areas within Autism Progress. Below is an extract of the same young person's expressive communication where we can see some Mastered levels of engagement at level 10. Using these descriptors the team around the

individual are able to fully understand the individual's profile, allowing them then to design experiences to support and enable their learning in a cohesive manner.

EXPRESSIVE

- M** Asks a simple "Why...?" question
- Communicates basic expectations to their friends, e.g. "You should share your toy with me"
- Communicates in a manner that can be understood by an unfamiliar person
- Describes a simple sequence of movements or actions
- M** Describes an object they have in their hand, giving more than one property
- Expresses what they are doing and gives a reason, using words, signs or symbols
- Expresses likes and dislikes clearly, giving simple reasons
- Participates in presentations or performances with some prompting but delivery is clear (words, signs or symbols)
- Responds to an adult when offered a selection of motivating items
- Responds with their own name in response to "Who wants ...?"
- M** States a preference, giving their reason

In order to effectively track and monitor incremental progress in a young person's education we need to use tools that can guide the gathering of the necessary information on their autism profile. Autism Progress supports staff to truly understand this picture so they can then efficiently support their access to the curriculum using a strength based approach.

Getting the Questions Right



Ken Aitken
Clinical Psychologist,
University of Glasgow

This article was written in an effort to stimulate more productive discussion and focus around the value and importance of autism research in Scotland. I want to make the case for a significant increase in autism research funding, and how to make it count.

Some suggestions are given on how we can improve the situation and why we should all become more involved in helping to make it better, stronger, more influential, and, most importantly, more useful.

Over recent years I have had many discussions with autistic people, their families, carers, clinicians, and teachers, and with many people actively engaged in various avenues of practice development and research into autism. I have heard many conflicting viewpoints, put with equally strong conviction. Sadly not everyone's fondly held belief can be correct. With the benefit of hindsight I want to offer my own perspective for discussion.

“As is happening elsewhere, applied research should command the greater share of resources and needs to be carried out well to help advance practice.”

Nothing I write here is intended to cause offence. I am not arguing for the Luddite position that we don't need to waste money on research because all our monies would be better spent on bolstering and improving our overstretched practical services. Neither do I want to suggest that most of the important questions have already been answered. Nor do I want to argue that decisions on research should be left to the many committees and experts who are trained in considering such things. Autism research is now more important than ever.

It will be the greatest use if we can identify the most helpful questions to ask. As is happening elsewhere, applied research should command the greater share of resources and needs to be carried out well to help advance practice. There continues to be a role for theoretical as well as applied research, but a theoretical understanding of autism is not going to emerge soon and needs to be informed by better practical understanding.

British research in this area, has to date, taken a fairly standard competitive academic approach: funding agencies accept bids for research monies, and the chances of being successful depend on a mix of things like how many bidders apply, how good the proposal is - whether it has a clear question, and if it can be answered using the proposed approach, if it is novel, whether it is realistic on the funding applied for, how well the group have completed previous pieces of work within a time frame, and how well rated the output from that research was. Unfortunately, a proposal can tick all of these boxes as a piece of research but have little or no practical application. Britain, unlike Germany, the USA and, to a lesser extent France, has failed to appreciate and value sufficiently the importance of applicable research. We have focused on how academically important it is, ignoring whether it will have any likely benefits.

There is a need to convince researchers to engage more actively with diagnosed individuals, carers and clinicians, to understand the important issues that affect them, how these relate to autism or associated issues, and how they can be better understood. This will only work if there is a Government commitment to fund such a changed agenda. Currently, University departments encourage their staff to conduct and publish academic research that will give them as good a ranking as possible for the next Research Excellence Framework - the mechanism that dictates the level of central funding they will receive.

To formulate meaningful research we have to support autistic people, carers, clinicians, service providers, commissioners, and Government departments to collaborate and become more involved in a collaborative process of focusing the agenda. In the

past, many of these voices were often ignored and a process of bridge building needs to be done to achieve this. This is a two-way process, and researchers are often as guilty of ignoring the views of others (both those on the spectrum and other researchers), as services and end users are of being unaware of the research. Research should try to answer questions people have that are important to them rather than operate in a vacuum.

“ There is a need to convince researchers to engage more actively with diagnosed individuals, carers and clinicians, to understand the important issues that affect them, how these relate to autism or associated issues, and how they can be better understood. ”

We need to encourage greater involvement in research itself, and ways to disseminate and implement relevant findings to inform practitioners and those affected and focus on improving quality of life for all on the spectrum. To know what we need to do to achieve this we need evidence, and to get the evidence we need research.

For that research to have the greatest impact we need agreed standards for carrying it out. We need to take on board some recent developments elsewhere in order to do this.

Prioritising – asking, ‘what do we need to know’ questions rather than funding research groups who decide what they should look at, kick-started the recent growth of autism research in the United States. Their Interagency Coordinating Committee (IACC) was set up to develop a research agenda, minimise needless replication, develop a common research approach, increase collaboration and improve dissemination of findings. It has a wide range of representation and sets the framework - what questions do we need answers to and how can we achieve this.

The US agenda is driven by a research framework that began by identifying where work was needed. Today the US spends about the same amount per person on autism services, but over 80 times as much on research, much of this on showing what works, looking into the best ways to provide practical help, and how to estimate level of need.

Despite the mountains of research already published on autism, far more remains to be discovered than we already know. We need compassionate, involved and informed approaches to focusing on the most important, useful and relevant issues. This will be a ‘work in progress’ for many years to come. More open discussion of what is needed and more active involvement in autism research should reap many benefits.

You can contact Ken Aitken for a more detailed version of this article at drken.aitken@btinternet.com

Is it Time to Think of Autism as an Entity in its own Right?



Alan Somerville
Chief Executive Officer,
Scottish Autism

Alan Somerville has been Chief Executive of Scottish Autism for nine years. In that time he has worked to modernise the organisation and has encouraged a culture of creativity and experimentation that has resulted in a wide range of organisational developments and improvements. Alan has also drawn on his business background to bring novel thinking to societal issues relating to autism. As his retirement date draws near, we have invited Alan to commit to record his perspective on how some of the persistent challenges we have faced at a service infrastructure level might be addressed.

John F Kennedy once said: *“The great enemy of the truth is very often not the lie - deliberate, contrived and dishonest - but the myth - persistent, persuasive and unrealistic.”* Autism is a phenomenon riddled with myths. These myths exist in the perception of the general public (many of whom still think of “Rainman”); in some parts of the health community who see it as mental illness; in local authorities, some of whom perceive it as purely a learning disability issue and others who see it inter alia as a behavioural issue (including criminality), as a consequence of a genetic difference, as a dietary phenomenon and many more. Just like everyone else the needs of an autistic person are dependent on the individual. In this article I will argue that autism’s unique characteristics make it an entity in its own right and one which can be particularly badly served by the existing processes and structures of the state.

Dr Glenys Jones and Professor Tommy Mackay of Birmingham and Strathclyde Universities respectively justify autism’s special identity as follows:

“The justification for making a special case for autism is that it is in fact a special case. The autism spectrum represents the major part of the group of conditions classified as ‘pervasive developmental disorders’ (American Psychiatric Association, 1994; World Health Organization, 1992). It is the very nature of its pervasiveness that makes the autism spectrum different from other conditions, no matter how high their prevalence or how potentially debilitating their effects.”ⁱ

Autism occurs as the result of significant atypical features in the way people develop. The most noticeable differences are in the areas of social communication, social interaction, and social imagination, and sensory and cognitive processing. This however is only to scratch the surface.

Autism is a so-called “spectrum condition” – this term implying a number of linked conditions. It is a multidimensional phenomenon, with great complexity generated by the possible permutations of co-existing conditions. In fact, autism rarely occurs alone and it is more common for autism to be accompanied by other conditions. Indeed in some instances it will be addressing the co-existing conditions that provides the key to an improved quality of life for the individual concerned.

Professor Chris Gillberg of the University of Göteborg also attests that the co-existence of disorders *“is the rule rather than the exception in child psychiatry and developmental medicine”*. This leads him to conclude that children may need to see specialists in multiple disciplines to understand the complexity of their presentation.

“There is no time to wait; something needs to be done, and that something is unlikely to be just in the area of speech and language, just in the area of autism or just in special education.”ⁱⁱ

The concept of a single spectrum is outdated. Just as it takes a minimum of three dimensions to define a regular three dimensional object, multiple spectra would be required to reflect all the dimensions of such a complex phenomenon as autism.

The various spectra are unlikely to be continuous, with certain combinations of conditions existing in “clusters” irregularly along the length of any particular spectrum. It seems likely that some form of generally accepted conceptual “map” of autism and its co-existing conditions would be useful, defining a topology of “autism space.”

The autism spectrum gives rise to a range of personal and professional perspectives. It is therefore important to acknowledge that it can be a challenge to find a common language that reflects the understanding, values and principles of the various groups who are invested in advancing our understanding and support of people of all ages across very diverse spectra.

Many people in the social care community, understandably, find the idea of “classifying” people undesirable, but, it can be argued, this is also a barrier to understanding in terms of resourcing an autism strategy. This difficulty has led to a reluctance to take a “segmenting” or classifying approach to people’s autism for fear that someone might be wrongly labelled and provided with the wrong services. In other cases it might be a barrier to the receipt of any support at all. This is a misconception, although in line with Kennedy’s myths it is certainly persistent and persuasive. It is not intended that these segmentations are used to prescribe services for autistic people rather; they are a framework for the planning and resourcing of services.

Agreeing a standard segmentation of autism would be strategically useful but falls foul of the cherished theories of the plethora of practitioners who will only use a classification based on their own research, even when the differences between the rival systems are insignificant - a phenomenon recognised and labelled by Sigmund Freud as “the narcissism of small differences.”

While much progress can be made in setting out services for autistic people in this way, it cannot be “one size fits all.” The spectrum is wide, ranging from people who require care all their lives, to people who are of very high intelligence but might require support

in social situations – e.g. for such activities as employment interviews. The saying “if you’ve met one person with autism, you’ve met one person with autism” is as true today as it ever was. In this complex environment it is more productive to address the specific requirements of the various spectra when planning services rather than treating the condition as a homogeneous whole.

The implication of this is that we must segment the autism spectrum in order to make sense of the services people require. Again I recognise that many people have deeply held misgivings about “labelling” people but reaffirm that service specification should always be uniquely personalised. This is a “mapping” for planning and understanding of different presentations of autism. It has no more direct implications for an individual than say the depiction of Australia in an atlas has on the actual shape of that continent.

Existing statistics on the autistic population are of limited value in isolation. They are often the result of studies commissioned by education, social care or health bodies and tend to record only the aspects of people’s autism which interfaces with that particular dimension. It seems quite possible that the majority of the adult autistic population does not present as a “problem” to any of the major organs of the state and therefore it is conceivable that a significant proportion of the total autism population does not appear anywhere in statistics gathered by any public agency.

It is equally likely that a significant number of people have been misdiagnosed and are receiving the wrong sort of support e.g. schizophrenia is often cited as a diagnosis which can wrongly be given to autistic people. In other cases individuals might be diagnosed with the dominant co-existing condition and their autism not mentioned.

Fairly sophisticated statistical analysis of available data would be required to identify these gaps and the inevitable double counting. This problem was addressed in the “Microsegmentation Project” funded by the Scottish Government and carried out

Is it Time to Think of Autism as an Entity in its own Right?



Tommy MacKay
Professor,
University of Strathclyde



Martin Knapp
Professor,
London School
of Economics

by Professor Tommy MacKay of the University of Strathclyde and Professor Martin Knapp of the London School of Economics. The origins of the project lay with Scottish Autism and it became the grant holder. The authors propose a microsegmentation matrix that takes account of a range of variables such as intellectual ability as well as additional factors likely to impact on quality of life.ⁱⁱⁱ

I now want to turn to the second theme of this essay, which concerns the way both practitioners and legislators address such a complex multidimensional phenomenon as autism.

Malcolm K. Sparrow is Professor of the Practice of Public Management at Harvard's John F. Kennedy School of Government. His thinking set out in his book *The Character of Harms: Operational Challenges in Control*, Cambridge University Press, 2008 led to the Scottish Government and Scottish Autism jointly funding a workshop in Edinburgh in December 2012 – "The Scottish Strategy for Autism: Structuring Services and Harm Reduction Work for the ASD Community."

Much of this theory is directed towards what Sparrow describes as "sabotaging harms." The word "harm" may seem inappropriate in the context of autism, but the theory is readily adaptable to many complex issues facing government organisations. First, consider the levels at which "harms" could be addressed. Autism is a phenomenon rare enough to be considered optional (for which I am arguing change), but common enough

to require organisational systems. Many agencies lack any apparatus for this and therefore assume that the issue is "covered" by existing functions and processes.

The result of this is that the majority of risk-control work is not organised around risk-concentrations (such as the unaddressed needs of people on the spectrum), but around functions, processes and agency structures.

This has several important implications. Imagine a concentration of risk/harms in the external world – in our case the entire needs of the autistic population. In response to this government creates a number of agencies to address this – most importantly health care, social services and education. The governing body now needs to decide what might be done, which Sparrow calls the *theory of operations*. Usually the general method of operations is set out in the governing/delivering body's policies or authorising legislation – but not always.

Often the *theory of operations* represents an entrenched tradition which has never been questioned. This is perfectly normal and understandable – governments, local or national, need to plan for the delivery of services and are required to show fairness and objectivity as well as being efficient and providing value for money. This general theory is perfectly adequate for most of the population.

However the challenges and issues associated with autism exist in the outside world and are *independent* of the structures local and central government put in place to address them. The core of the problem is that with something as complex and multidimensional as autism for a significant minority of individuals there is a misalignment between the "standard" processes the state has in place and the nature of their needs.

In reality this works on two different scales:

- 1: On the autistic population as a whole - recognising that autism is not a single specific issue but a series of "populations"; and
- 2: On the autistic individual recognising the complexity inherent in co-existing conditions, sensory issues and the presentation of their autism.

Therefore our conceptual concentration of risks in the real world could represent either the issues facing the entire autistic population or multiple issues faced by an individual with ASD.

The layers of complexity created by the various segments of the autism spectrum combined with a variety of co-existing conditions causes autism to straddle multiple functions – particularly health and social care. Functional organisation is important but not sufficient because it leaves no-one in charge of processes which straddle multiple functions. This is not to imply that there is some form of conflict between processes owners (e.g. health and social care), just a lack of consideration of the individual's interaction with the other process. The process owners may have markedly different views on how to proceed.

This can result in the individual being classified e.g. as a "patient" or as a "service user" according to where he/she comes to the attention of government services, and his/her other needs are not addressed.

The logical implication is that the issues are better focused on the individual than on the mainstream processes. Sparrow's analysis concludes "*that focusing on processes and focusing on problems produces two quite different patterns of thought and action.*"^{iv}

Addressing the various elements of a complex "harm" naturally produces a series of tailor-made interventions which are outside the normal policies and procedures of the state.

Conventional quality improvement policies in local government tend to focus on process improvement i.e. they are managerial tools for improving the agency's processes. By contrast a *problem-solving* approach is an operational way of working on external "harms".

The different segments and the different co-existing conditions (which are not the same thing) are what place autism into different service categories/ institutional structures. Any of these institutional structures *alone* is poorly adapted to catering for individuals who may present differently to education,

mental health services, social care or even the criminal justice system. This point at first appears a little counter-intuitive: that although autism in its own right needs specialist attention and services, the co-existing conditions and needs that usually come with it do not make those specialist services exclusive providers, but they function in a constellation of different services meeting the needs of individuals.

This suggests additional resources specifically to manage all the various requirements of complex individuals. This may seem impracticable in the current economic climate but the escapable costs incurred through the failure to address the needs of such complex individuals are very large indeed. It is important that all the agencies of the state recognise that for such a multidimensional phenomenon as autism, staff in all disciplines must acknowledge that they may only be seeing one facet of the individual's presentation and adopt an individual-focused approach (i.e. a problem-solving approach) if all the individual's needs are to be met and quality of life maximised. In this context autism might well prove to be a useful test-bed for the integration of health and social care.

A vital first step towards this goal and the dispelling of the myths which surround autism is the recognition of autism as an entity in its own right, with as soon as possible a clearly defined and universally recognised topology of autism space.

REFERENCES

- i S Jones, G., & Mackay, T. (2013). Promoting the vision of the Scottish Strategy for Autism. *Good Autism Practice Journal: The Scottish Perspective*, 14 (1), 4.
- ii Gillberg, C. (2010). The ESSENCE in child psychiatry: Early Symptomatic Syndromes Eliciting Neurodevelopmental Clinical Examinations. *Research in developmental disabilities*, 31(6), 1543-51.
- iii Mackay, T., Boyle, J., Connolly, M., Knapp, M., Immei, V., & Rehill, A. (2018). The Microsegmentation of the Autism Spectrum. Scottish Government. <http://www.gov.scot/Publications/2018/03/3640>
- iv Sparrow, M. *The Character of Harms: Operational Challenges in Control*. Cambridge: Cambridge University Press, 2008.

Autism, Anthropology and Lived Experience: An Interdisciplinary Symposium

Edinburgh Centre for Medical Anthropology (EdCMA) and Scottish Autism, 22 March 2018



Alastair Clarkson
Researcher in Residence,
Scottish Autism

When we practice ethical principles within services we bring values to our support relationships which help us meet the needs of autistic people throughout their life journey. When we believe that autism services exist in order to respect, interpret and respond to the lived experience of autistic people, it is likely we value the experience of others as we value our own.

In many professions and areas of research however, the autistic community continue to be described by the language and framework of medical 'disorder'. As this language characterises autistic people in terms of variation from social 'norms', there is a risk that less value is attributed to their lived experience.

Whilst some areas of autism research inform our contemporary understanding of autism the agenda of the medical model continues to prioritise, research investigations which focus overwhelmingly on causation and 'treatment'. This restrictive impact of this agenda means the influence of the positive factors, values and practices that we know are able to directly improve the quality of individual autistic people's lives remain largely unexplored. As a consequence, much of the knowledge and experience of staff and autistic persons is excluded from the majority of autism research studies.

In an effort to change this status quo, Scottish Autism set up the Centre for Practice Innovation (CPI) to focus on work with staff, autistic people and the wider research community which can promote the use of new methodologies and forms of evidence and share the innovative practice of staff. We believe that autistic people, families and the staff that support them are able to help the wider public and professional

community understand autism in a positive way – we identify autism as a diverse neurological and physical difference rather than a pathological condition needing to be 'cured' or fixed. By researching the qualitative experiences within autistic lives, Scottish Autism aim to support the autistic community to share the knowledge of their experience and communicate how best we can support them. With this goal in mind our Research Manager Dr Joe Long recently collaborated with Roslyn Malcolm, a social anthropology PhD student at the University of Edinburgh to host an interdisciplinary symposium, 'Autism, Anthropology and Lived Experience'. Joe's expertise in anthropological research has been central to the development of our practice research programs within Scottish Autism.

The event aimed to focus on the lived experience and the embodied worlds inhabited by autistic people - exploring the contribution that ethnographic and phenomenological research can make to autism studies in order to promote alternatives to medicalised autism research. Joe and Roslyn's opening joint presentation, 'Foundations, Applications and Future Directions' set the ground for the rest of the seminar. Providing an overview of the application of anthropology within autism research, Joe spoke about contemporary ways of understanding autism - seeing autism as a 'way of being in the world'. This view recognises autistic experience as part of a diverse way of being rather than a deficit measured against social norms. Relating changes in the application of anthropology from early colonial documentation to the exploration of self-understanding within groups, cultures and individuals, Joe discussed the advantages of a 'situated' approach to research which relies on participant observation and intersubjective analysis. With the use of these research methods, processes of meaning making can occur for both research subjects and researcher, allowing both staff and autistic subjects to achieve ownership in the production of knowledge alongside the researcher.

Roslyn spoke about some of her research findings which focus on the therapeutic use of horse-based

activities by children and adults on the autism spectrum. Her talk was highly practical and gave several key insights into some of the common misconceptions that surround phenomenological research analysis. Her practical experience demonstrated that the application of these research techniques can make a solid contribution to the autism research literature.

The seminar also included a written contribution from Pum Dunbar – an autistic researcher and artist. As Pum preferred not to present publically, Joe worked beforehand with Pum to support her contribution to the seminar. This is a key example of the attitude that the wider autism research community should aim to adopt when collaborating with autistic people. At Scottish Autism we believe that by supporting autistic people to become authors of their own experience we can ensure the autistic community can make the most unique, practical and valuable contribution to autism research - that of their own lived experience. Pum's work communicated to me that when we place value in the voice and experience of the autism community, we become open to a depth and breadth of autistic creativity and thought which is frequently overshadowed by a negative medical narrative.

Dr Damian Milton's talk, 'What is an aut-ethnography and what might one look like?' drew on a wide range of literature to examine the meaning of an autistic sense of self. His rich exploration of self and identity was particularly interesting as he presented his aut-ethnography against this influence of the medical model. Damian explored the elements that helped form his own self narrative over time and discussed the intersection and influence of social concepts of autism and disability on the development of his own autistic self-identity.

Dr Catriona Stewart from the Scottish Women's Autism Network (SWAN) and Scottish Autism spoke in depth about the application of phenomenological methods within her research - Catriona has done much to raise research awareness around the issues that autistic women face in society today. Her discussion of gender

and autism stereotyping was particularly powerful when she related accounts of the institutional and professional bias that many autistic women face when barriers such as residual sexism intersect with a lack of understanding within professionals. One powerful example given was when trained professionals frequently question the ability of autistic women to bring up their own children.

Dr Stephen Kapp from the University of Exeter then gave an inspiring account of autistic advocacy within the Neurodiversity movement - it was clear from his talk that the amount of work the autism community has needed to invest just to have their voice heard was disconcerting - however on a personal level this made me feel more determined to change societal perceptions and attitudes toward the autism community.

After lunch, invited speakers joined in an open discussion chaired by our Deputy CEO, Charlene Tait. Many interesting discussions took place during the afternoon, including the use of new methodologies to produce relevant, and personalised research evidence with the use of 'mixed methods'. In the final stages of the discussion, Dr Stewart raised a central point relating to the poor return of evidence within autism research which appeared to underpin much of the day's discussion. She identified that as the scope of the questions that researchers ask remain fundamentally determined by their own view of the world, researchers have an ethical responsibility to be mindful of the questions they ask when designing research studies. Most crucially Dr Stewart argued that researchers should be able to explain the reasons why their research questions are being asked and identify the projected benefits for autistic people. This point is of particular relevance to an autistic community whose central request to the wider academic autism research community is one which still remains largely still to be honoured - 'nothing about us, without us'.

Meet the Centre's Research and Practice Associates

Research Associates



Ken Aitken

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



Sue Fletcher-Watson

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



Karen Guldborg

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



Andrew Jahoda

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



Tommy MacKay

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



Richard Mills

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



Anna Robinson

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



David Simmons

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

Practice Associates



Debi Brown

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



Yvette Q. Getch

Yvette is Associate Professor at the University of South Alabama, 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

Scottish autism

CELEBRATING 50 YEARS

Innovation in Autism Practice: The Future is Calling

Grand Central Hotel, Glasgow, 8-9 November 2018



As part of our 50th anniversary celebrations we are holding a two day conference which aims to provide a platform for sharing new and visionary approaches to the development of autism practice.

Our programme will be influenced and informed by a contemporary view that embraces autism as a developmental difference and focuses on a capacity view of the individual. We want to engage with others who share our ambition to promote practice based evidence and recognise the value of the lived experience of autistic people.

- Day one of our conference will centre around the culture and context of practice
- Day two will look at innovation in practice

The conference will be of interest to Researchers, Practitioners, Autistic people, Parents, Carers, Commissioners and Policy Makers.

Find out more at www.scottishautismconference.org

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.



Contact us.

Centre for Practice Innovation
100 Smithfield Loan
Alloa
FK10 1NP

Tel: **01259 720 044**

Email: **CPI@scottishautism.org**

Company Limited by Guarantee
Registered in Scotland No. 81123
Scottish Autism is a charity registered
in Scotland, No. SC 009068

WWW.SCOTTISHAUTISM.ORG/CPI

Share Issue 7, Summer 2018
Published by Scottish Autism
Editors: Charlene Tait and Joseph Long
Issue Editor: Alan Somerville
ISSN 2515-2327 (Print)