

SUMMER 2020

Share

Practice, Knowledge
and Innovation

Scottish
autism
WHERE AUTISTIC PEOPLE
ARE VALUED

**Centre for
Practice
Innovation**

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From the Editor



Dr Joe Long
Research Manager,
Scottish Autism

Since its inception *Share* magazine has sought to consider change and innovation in autism support practice. Yet even as the last issue was published, few of us at Scottish Autism could have envisaged the pace and scale at which we would have to change the way we work in 2020. As I write this editorial the country has been in lockdown for nine weeks owing to the Covid-19 pandemic. This has been a period of extreme anxiety and stress for many autistic people and those around them as regular services, routines and sources of social support have no longer been available.

The long term implications for support provision may not be clear for some time, but in this issue we include some immediate reflections on the challenges supported autistic people and those that support them have faced. Yet we also hope that the articles will provide some hope for the future – in the resilience shown by many in the autistic community, in the creativity with which practitioners have adapted their support provision, and in the possibilities offered by positive dialogue and policy change described by our guest contributors.

In this issue Alexander Edwards and Daniel Page, two autistic people supported by Scottish Autism, reflect on the particular challenges that they have faced during lockdown, and ways that they have found to cope. As Alexander recounts, disruption to routine can be particularly difficult for autistic people, particularly when those people are isolated from their friends and regular support staff.

From a different perspective, Meagan McConnachie and Katie Davies, two of our Senior Autism Practitioners, describe ways that services have sought to provide a semblance of continuity for supported people and to maintain social networks and communities.

The Covid-19 crisis has highlighted serious social inequalities and gaps in service provision in the UK. Policy-making after the crisis will not just be focused on preparing and dealing with pandemics, but on addressing these stark inequalities. In their contribution to the issue, Charlene Tait of Scottish Autism and Nick Ward of the National Autistic Society Scotland argue for the establishment of an Autism Commissioner for Scotland to advocate for the rights of autistic people. Moving forward through the crisis and adjusting to the world after lockdown will also require consensus and community-building among the autism community. Here, Jonathan Drury reports on Autism Dialogue – a method and organisation aimed at facilitating exchanges of perspective. Autism Dialogue has met growing demand through a shift online during the crisis, yet its possibilities go much further. In that spirit of dialogue we offer these reflections as part of a wider discussion on how policy and practice can respond to the needs of autistic people in times of crisis and beyond.

Time to Act?



Charlene Tait
Deputy Chief Executive,
Scottish Autism



Nick Ward
National Director,
National Autistic Society
Scotland

Prior to the Covid-19 health crisis, a small group of interested individuals together with Scottish Autism, National Autistic Society Scotland and Scottish Women's Autism Network (SWAN) had come together to consider "What next?" when the national autism strategy comes to an end in 2021. We wanted to put forward a positive vision of what support for the autistic community could look like in Scotland and convened an advisory group of autistic individuals and family members to help inform our thinking.

We concluded that we should collectively campaign for legislation that would see an Autism Commissioner for Scotland established. This would be a world first. Inspired by the Commissioner for Children and Young people, a rationale and remit were drafted, debated and refined.

We identified five key functions which we believed the Commissioner should have:

- **Promoting the rights of autistic people**
- **Consulting and involving autistic people and their families in the work of the commission**
- **Conducting formal investigations into social disadvantages or abuses of the rights of autistic people**
- **Investigating individual cases of abuses of rights**
- **Promoting good practice for the support and social inclusion of autistic people**

Our strategy was to influence all political parties, ahead of the 2021 Holyrood elections, to commit to establishing a Commissioner in their respective manifestos.

Then, along came Covid-19. This global crisis has led to social and political change on a scale and pace that is unprecedented. Rightly, the focus has been on saving lives and minimising the impact of the pandemic on our National Health Service. It has also redefined what is considered "essential" in our society and has shone a light on the pressures on our health and social care system that were, in part, factors that led to a strategy specific to autistic people and their families being launched in 2011.

Several weeks into the crisis, there are emerging discussions as to what the "new normal" will look like. Here, we set out reflections on what we can learn from the Covid-19 response and consider how our health, social care and legislative landscape could and should change for autistic people, their families and involved professionals after the crisis.

It is likely that it will take some time for the full societal impact of the Covid-19 crisis to be understood. However, the lockdown measures resulted in overnight change to how our lives are lived and how services are delivered. For the autistic people we support in our services and across Scotland, the effects of significant change, uncertainty and the resulting anxiety were immediately felt. The crisis magnified a range of issues already recognised as being challenging for autistic people and their families when accessing education, health (particularly mental health) services and social care systems. These include but are not limited to, concerns about adapted and augmentative communication, and autism knowledge, understanding and acceptance. The long term requires proactive, community based supports rather than crisis-driven, reactive responses to autistic needs that have typically been prioritised during times of austerity.

In addition to being service providers, Scottish Autism and National Autistic Society Scotland have a role to play in influencing government. Central to this is ensuring that the priorities of autistic people and their

families are understood and articulated in a way that resonates across a diverse community.

Prior to the Covid-19 crisis, one of the key forums for this was the Cross Party Group (CPG) on autism which gave a space for debate and discussion as to the impact and legacy of the Scottish Strategy for Autism. In particular it gave an opportunity for autistic people, their families and practitioners to express their views as to the real life impact of the many initiatives that have sprung from the strategy. In addition to meetings in parliament, the CPG travelled to Aberdeenshire and Dumfries and Galloway.

In order to enable as many voices to be heard as possible, National Autistic Society Scotland ran an online survey which had over 900 respondents. Unfortunately, the health crisis interrupted the planned dissemination of the Cross Party review of the strategy. It is hoped this will be published later in the year. However, the new context of Covid-19 and the Scottish Government's response to supporting the autistic community during this crisis, point to the potential for new ways of working to emerge. Some notable examples include funding initiatives aimed at reducing isolation, and providing support, guidance and practical resources to autistic people and their families. Weekly meetings with stakeholders across the sector have been important in ensuring there is a direct process for highlighting and addressing issues as they emerge. We have been able to expedite action to address issues, such as providing guidance to Police Scotland in their approach to autistic people.

In many respects we have seen a more proactive approach from the Scottish Government in terms of funding being made available for a wide range of initiatives. We know, however, all the challenges that existed before the crisis such as diagnosis, support and access to services are still being felt at local level. These have been exacerbated by social distancing and lockdown. It is therefore imperative that the post-crisis landscape looks different for autistic people and their families.

The issues that have emerged during the outbreak and the need to prioritise and mobilise resources make the case for an Autism Commissioner even stronger.

If such a role had existed already, we would have had in the heart of government a national point of contact, a central voice for the dissemination of good practice, and a way for concerns and challenges to be raised. Without this, National Autistic Society Scotland and Scottish Autism have to advocate from outside government for changes to decisions already made. This is always a more significant challenge.

So many of the issues that have affected the autistic community have come directly from a lack of understanding of autism. We know that we have made significant progress in raising awareness. People know that autism exists, but people still don't really understand it and the impact it can have on individuals and families. The Scottish Government is making progress with this, as are our two charities. An Autism Commissioner would really be able to spearhead this work in partnership with autistic people and their families.

We have also, regrettably, heard of a number of cases of care packages being withdrawn or significantly diminished during the crisis. A Commissioner would be able to work directly with Local Authorities on the issues facing them and work with them to ensure that autistic people and their families are getting adequate support. Perhaps most crucially, they would be able to take action where this wasn't happening.

There are significant challenges ahead for our community. The transition out of 'lockdown' will be just as challenging for many as the transition into it. Both Scottish Autism and National Autistic Society Scotland will be working to ensure that the needs of autistic people and their families are taken into account but we know in the 'new normal' we will be entering a time of even greater resource limitations. The rights of autistic people and their families are likely to come under greater strain. We believe that an Autism Commissioner would provide a bulwark against any such erosion and a platform to advocate for greater rights and resources, not fewer. It is our intention to launch a joint campaign to advocate for an Autism Commissioner and we hope you will support us.

The Power of Dialogue



Jonathan Drury FRSA
Founder of Autism Dialogue

Autism Dialogue is an inclusive, safe and confidential space that brings together members of the autism community including autistic people, parents, carers, practitioners and academics. Within the space there is an attempt to reach a common understanding and to experience everyone's point of view fully, equally and nonjudgmentally. The application of David Bohm's Professional Dialogue methodology allows multiple perspectives to co-exist in the same space of enquiry. This method of group communication has no agenda other than to explore the movement of thought and language in a spirit of generosity and care. Once parameters are set and trust is built, minds open and there is opportunity for deep reflection on important issues such as mental health, anxiety, isolation, stigma and social injustices, and some things are celebrated. Individuals participating come to understand what each other agree or disagree on, they build on each other's contributions and the group keeps moving forward together.



Professional Dialogue in Action

Photo: Jonathan Drury

A session might include autistic adults from all walks of life, a health commissioner, the parent of autistic children, an occupational therapist, a cognitive scientist and a school teacher. The dialogues are always rich and revealing and whilst it can sound esoteric for the uninitiated, dialogue is a very practical matter. Within the dialogic 'container', there is to be found emotional support and empowerment for individuals and increased cohesion for the autism community. This can lead to raised levels of understanding, tolerance and acceptance in wider society. We aim to train both community and organisational autism dialogue facilitators and convenors.

The Practice

The basic requirement for participating in Autism Dialogue is alignment with our overall aims and understanding of 'the four practices' of Dialogue. These are Voice (speaking your truth), Listening (to each other and oneself), Suspension (of judgement and assumption) and Respect (for each other and oneself). The facilitator's role is to support the balance of conversation initially and to eventually become obsolete as everyone aims to facilitate together a dialogue that flows. There is never an obligation to contribute. People are reminded where the door is, and to know that they can leave at any time. In the case of online dialogues, no one has to have their camera on. Usual conversational modes such as side conversations are put aside, as participants 'talk to the centre'. The pace is slow and an awareness of fairness in speaking time and processing time is nurtured. Silences are no longer 'awkward' and are utilised for processing a statement and experiencing thinking. Dialogues also have a convener who provides support for the facilitator, as well as 'housekeeping' of practicalities like timing, safeguarding and reminding of the practices.

History

The first ever Autism Dialogue session was instigated by Dr. Richard Smith at Sheffield Adult Autism Neurodevelopmental Service (SAANS), in September 2017. Richard had suggested I speak to Professor

Liz Milne at the University of Sheffield Autism Research Lab about my idea. Liz was coming to the end of a British Academy research project, providing a platform for autistic speakers, and warmed to the idea for an 'Autism Dialogue'. In the initial session we asked the question 'What are WE thinking?', and around a dozen autistic people, parents and academics attended.

The people that consequently gathered since then have been at the heart of Autism Dialogue's success. Early on there were only a handful of us sitting on sofas in the corner of a huge student union events hall. One week, one of the facilities staff had kindly prepared a ring of about 50 chairs under glaring spotlights that looked like the set for a psychological thriller!

After my diagnosis of Asperger's, I found group sharing circles at SAANS supportive, but they seemed to lack what Dialogue could offer. 'Bohm Dialogue' is based on the work of the renowned quantum scientist David Bohm and I felt it was possible to go much deeper into understanding autism with this method. Today SAANS and Sheffield NHS's Clinical Commissioning Group kindly invite users to attend the new online programme that we've convened in response to the Covid-19 crisis, funded by them to relieve pressure from services.

Early experiments with Autism Dialogue challenged my personal notions of disability, of power from within and from others, and the sensitive relationships I was building with people who I wanted to see as peers and friends.

Sometimes when I chose to share I would occasionally lead the conversation down an autistic-existential rabbit hole! I was to do some deep reflecting on my own boundaries so Autism Dialogue could have maximum impact in society. It's amazing to see friendships being formed and people undergoing transformations within the Dialogue space and in their lives.



David Bohm

I ran the monthly sessions as a volunteer for two years at the Quaker Meeting House in the centre of Sheffield, a perfect 'autism friendly' venue and held two annual conferences there.

Attendance and speakers from national organisations led to wider interest and talks are underway to develop schemes at organisational level. This has been made possible with ongoing support from the founders and fellow members at the Academy of Professional Dialogue. Jackie Elliott, a specialist in women leaders and team coaching has been instrumental in organising this year's programmes and extremely supportive as my usual session convener.

I gained Postgraduate Certificates in Autism and Coaching & Mentoring and last year I was invited by the Royal Society of Arts to become a Fellow 'for services to language and communication in the autism and neurodiversity communities'. I've spoken at a few conferences and I'm very grateful to Scottish Autism who have invited me to speak in Glasgow at their next conference.

Future

Participatory research in autism is evolving and, as a social enterprise with research aims, we hope our approach can help to narrow the research-to-practice gap. Professional Dialogue is being developed as a research methodology in and of itself among a growing network of practitioners.

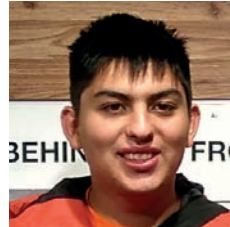
Disagreements are a part of human nature but we believe the rules of engagement in dialogue increases tolerance of difference. Because Dialogue is a tool for community cohesion, among other things, as we grow internationally, embracing online technology, we need to urgently address how autism differs across continents and cultures. In May we received an award from the Royal Society of Arts towards this focus, launching a new and exciting phase.

Dealing with Lockdown: Supported People's Perspectives



Daniel Page
Supported in
Scottish Autism's
Fife area services

My name is Daniel and I get support from Scottish Autism. I get staff 24/7 and I can do things independently. When staff told me about Coronavirus I was not happy as I could not get out to see friends or visit shops. It was hard staying in and finding things to keep me occupied. My mum phoned to ask if I would like to stay with her for a while until this Coronavirus is over with. I said that I would like to stay with family. In my spare time all I really do is use my laptop and DVDs. To keep safe I wear gloves going to the local shops, and always wash my hands at home. I keep in touch with my friends and staff: I use the telephone and WhatsApp on my laptop so I can still see people. I am concerned how long Coronavirus will go on, until it is completely over with, so I can see all my friends.



Alexander Edwards
Supported in
Scottish Autism's
Lothian area services

Lockdown has affected my life in several ways. I haven't been able to go to college for the last two months. I haven't been able to go to the Day Centre where I get my support, or go on buses. I haven't been able to go to the One Stop Shop that I go to, to see friends, or go to a community project. I miss doing all the things I would usually do. I have found staying at home stressful. It is difficult for autistic people because a lot of us rely on routine.

I have tried to keep myself busy. I spend a lot of time doing crosswords and Sudoku, playing Patience, and tidying the garden. I've been getting virtual support online, and I've spoken to staff at the One Stop Shop online too. I've been using Skype and even used Zoom on one occasion. I also took part in a virtual art club that Scottish Autism were running. I liked seeing people I hadn't seen in a while. Having virtual support gives me something to do and someone to speak to. We spend a lot of time chatting and we've also been playing games online. We're planning on doing some baking. I've been to stay at Respite Support which was one positive – I'm going again next week. They looked after me well and I had a nice short break. It was great to see new people.

This situation is something I could never have imagined happening before. I am looking forward to it being over, which I think is going to happen soon.

Adapting Autism Services during the Covid Crisis: Art Opportunities, Alloa



Meagan McConnachie
Senior Autism Practitioner,
Scottish Autism.

During these difficult times, it has been important to try and support our individuals to the best of our ability. The closure of Scottish Autism's Day Opportunities as a result of Covid-19 has meant that the team within Art Opportunities has had to be creative in the way we deliver support. For those individuals supported within our residential, home support and outreach services this has meant providing vocational support within the home. In allocating staff, we have ensured that the practitioners are supporting individuals they are familiar and have positive relationships with. We have aimed to keep a consistent approach to make everyone feel as safe and secure as possible, as well as trying to maintain some semblance of normality during this period of change and disruption.



Peter creates a rainbow and shares his message

For some of our supported people this has meant recreating timetables similar to their day service provision. Some chose to have their pictorial timetables from Art Opportunities displayed within their homes and have kept the structure of sessions they would normally take part in the same. This involved taking

supplies such as textile pieces, pens, paper and Hama beads home with them and staff supporting them with these activities. We have tried to ensure that our creative themes (currently mini-beasts) has remained the focus. One of our team, Kimberley, has also supported the men within one residential service to complete NHS rainbows to be displayed in their windows. Another team member, Claire, has continued to run musical theatre sessions within one supported person's home, this is a very important part of this person's timetable and to still have the opportunity to take part in this has meant a great deal to her.

For those individuals we have been unable to support at home, the team are staying in regular contact with them and their family. It has been important to check in with how people are coping with changes and to ensure they still feel supported. Before the temporary closure of Day Opportunities some were given art supplies to take home with them so that their families could try and keep some form of structure within their day. More recently the team have begun to issue daily art challenges via email. These are simple tasks with instructions to follow and templates where necessary. Some of these tasks have been making super hero masks, paper aeroplane challenges, and making hand-print family trees. Working this way has allowed us to broaden our community: with not only local services getting involved, but also supported people in Orkney which has been really nice to see. Participants have taken pictures of their completed work so they can then share with each other and the team. Our staff team have also set weekly musical theatre and baking tasks for those who are missing out on the Musical Theatre group and the local Cottipot café (a café for those we support and their family members). We are also hoping to have Skype Musical Theatre sessions with individuals; if this proves to be successful we will look into opening the opportunity up to others so they can get a face-to-face experience.

Adapting Autism Services during the Covid Crisis: Lothian Outreach Service



Katie Davies
Senior Autism Practitioner,
Scottish Autism

There is no doubt that Covid-19 has flipped the world of support services on its head. How we deliver support to those who need it has had to change radically and quickly. Whilst this is a stressful, terrible time for many, it has also afforded an opportunity for creativity.

Lothian Outreach services have diversified since the beginning of the Covid-19 pandemic. Whereas the standard provision of services previously comprised 1:1, face-to-face community or home support, many of our supported individuals have now seen the introduction of virtual services. For some people, virtual support runs alongside face-to-face support sessions. For others, it has replaced face-to-face support altogether.

Virtual services for our supported people vary from a text or WhatsApp conversation, to a phone call or a video chat depending on the needs and wants of the individual. What has been particularly interesting in the development of virtual support services is that despite the fairly limited methods of communication (phone, message or video call), each service seems to have developed their own ways of embracing the technology. Whilst one supported individual may simply enjoy a cup of tea and a catch up over video call or a phone call, another has been teaching their support staff how to use complex drawing programmes on their computer by sharing their screen and talking them through it. Others are watching YouTube videos together. Some are baking together, with support staff and the supported individual choosing a recipe to work on together from their own homes over video chat. Others are getting

help with their college work by sharing their work over a shared screen. Some are having yoga sessions, crafting sessions or drawing sessions with their staff over video calls.

The creativity from the teams has been impressive at this time. They've shared resources that allow supported individuals and staff to take virtual tours of museums and zoos. They've shared games and apps that supported individuals can play or use with their support. And, whilst supporting the emotional needs of autistic individuals, practical support continues with staff able to prompt, for example, going for a shower after the next YouTube video or cleaning up the kitchen before baking. We are even exploring the idea of virtual social groups with the opening of our Virtual Art Club. We are still in the early stages of developing this group (and hopefully others) but we are excited to see where we go from here.

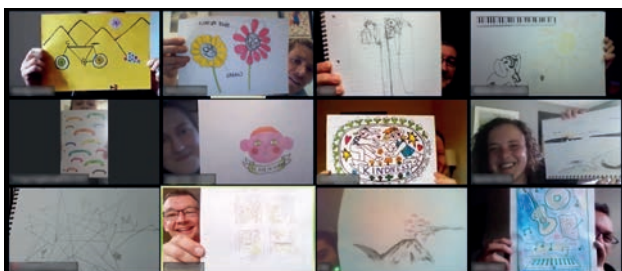
"The supported individual decided with her team that each virtual support session will centre around one planned shared activity. This could be yoga or crafts for example. Both the supported individual and the staff member will then partake in the activity together which removes the pressure of holding a conversation for three hours. The person I support felt more comfortable with that and expressed that they enjoy the virtual support a lot more."

Gabriele, Support Worker

Getting virtual support right for the individual (or group), has been key and not always easy. Some supported individuals have chosen not to receive virtual support at all. Others, have not enjoyed the type of virtual support that they have received. A video chat for three hours can be very daunting if there is no clear outcome or purpose for it. For some, therefore, it has been a case of trial and error and working with the individual to find creative ways to address what works for them.

“Some have really excelled and taken the virtual support in their stride, engaging more than they would in face-to-face interactions with staff. It has the added benefit that they can tailor their support to what they want to watch or do or share. The ability to screen share has really benefited all parties involved meaning that we can do a range of activities e.g. watch each other play games, videos, music, art all while chatting to each other. One of my supported people really enjoys it and is constantly looking for new ways to engage with staff. It’s so good to have them looking out new apps to use and have them teach us!”

Amy, Support Worker



Artworks created by the Virtual Art Club

“As the delivery methods of support sessions change and some supported individuals choose to pause their support, more and more staff are also asked to work from home at this time. This has been a steep learning curve for many as new technologies become an integral part of staff member’s working lives. One clear benefit of this change, however, is how these technologies have afforded much closer team working than ever before. As a Lothian Outreach team member, the majority (if not the entirety) of your working week involves lone working. There is no crossover of staff between shifts and you can go weeks without bumping into a colleague. With shifts occurring across the city at all sorts of times and on all days of the week, trying to find a suitable place and time for the entire team to meet for keyworker meetings or team meetings is nigh on impossible. Using the technologies that we have for video chatting and sharing documents and files has

allowed the team to pull together and have regular contact with one another. Whilst we may have had access to these technologies and programmes pre-Covid-19, we had never used them to their full potential – in ways we may never have learned had it not been for necessity at this time. I have found the transition from working out in the community every day to working from home quite challenging as I am so used to being out and about with the individuals I support. However, there have been many positives to take from this experience that I hope we can carry forward in the future. For example, it has been great to have scheduled meetings every week via Microsoft Teams and talk to my colleagues about the services we work in and have the chance to discuss ways to make changes/improve these services during these difficult times but also when normality resumes. Working in outreach can make it difficult to catch up with everyone in your team so this has been great!”

Katie, Support Worker

There is no doubt that this has been, and continues to be, a difficult time period for supported individuals and staff, full of uncertainty and transitions. But I for one, am excited to see how our services will develop as a direct result of this period of time. There is no doubt in my mind that virtual support will continue to be a useful tool both for collaborative team working, but perhaps more excitingly, for supporting individuals.

For a supported person’s perspective on the shift to virtual support, see Alexander Edwards’ contribution to this edition of Share (page 8).

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 a Lecturer in Autism as well as the Autism Masters Director at the University of Strathclyde. She is a Psychologist and practicing Experiential Therapist researching autism and mental health.



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.



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 an MSc and a PhD in Psychology and Pedagogical Sciences. He has worked with autistic people and their families for more than 30 years and is the Founder and Director of Autism in Context. Peter can be found teaching, training and presenting all over the globe. In his work he focuses on many different topics, but in particular: autistic thinking (autism as context blindness), sensory issues in autism, psycho-education in autism (relationships, sexuality and coping with the diagnosis) and happiness & wellbeing in autism.

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

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

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