

AUTUMN/WINTER 2020

# Share

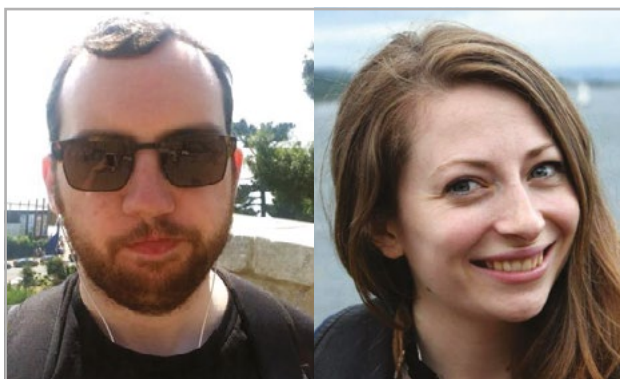
Practice, Knowledge  
and Innovation



Scottish  
autism | Centre for  
Practice  
Innovation

WHERE AUTISTIC PEOPLE  
ARE VALUED

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**Cover photo:** George pictured with Lucy Chetty, Head Teacher at New Struan School in Alloa. George is now supported in our adult services and Lucy is moving on to pastures new. We thank Lucy for being a wonderful Head Teacher and wish her all the best. Photo credit: Tina Norris

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# From the Editor



**Dr Joe Long**  
Research and Policy Lead,  
Scottish Autism

Welcome to the Autumn 2020 edition of *Share* magazine, produced in what continue to be unsettling and difficult times for many of us as the Covid-19 pandemic continues.

In the last edition we documented service responses to lockdown and our proposal for an Autism and Learning Disability Commissioner in Scotland. A commissioner would ensure that we do not return to 'business as usual' after the pandemic but begin to address some of the shortfalls in service provision that autistic people experience. Those debates and discussions continue. Since then the Scottish Government have announced a comprehensive review of social care. In this issue our Chief Executive, Dorry McLaughlin, and myself share some of Scottish Autism's suggestions for improving social care provision for autistic people. These include more joined-up commissioning of services across the lifespan and investment in a professionalised, skilled workforce.

As we look to build back better, *Share* magazine continues its mission to showcase research and practice innovation that can inform improved autism services.

We are delighted that the Scottish Government has invested in provision for better post diagnostic support and Caroline Hearst and Laura Crane's contribution evidences the value of autistic-led, peer support for newly diagnosed autistic adults.

Jack Howe's article on the University experiences of autistic students combines first-person reflections with research undertaken together with Dr Eilidh Cage, now at the University of Stirling. The research shows that many autistic students find university life extremely challenging and too often drop out. Yet the article makes some important suggestions for more proactive support of autistic students. As universities face the challenge of re-shaping how they operate, the importance of inclusive, accessible learning environments is more salient than ever.

In our culturally diverse society it is important that we ensure our practice is appropriate to support people of all backgrounds and Bérengère Digard's illuminating article on autism and bilingualism provides some important pointers for supporting autistic people from migrant communities or who have mixed cultural heritage.

Scottish Autism's Centre for Practice Innovation is lucky to have such a broad network of colleagues and friends that contribute to *Share*. While few of us have had the chance to meet in person in 2020, the strength of these networks has been vital to continue the business of exchanging ideas, advocating for good practice and pushing for policy to better meet the rights of autistic people. We thank you all for your continued support and engagement.

# Exploring Being Autistic

## An Autistic-Led Programme for Supporting Newly Identified or Diagnosed Autistic Adults



**Caroline Hearst**  
Autism Educator,  
Autism Matters



**Laura Crane**  
Deputy Director,  
Centre for Research in  
Autism and Education  
(CRAE)

“Where to from here?” That’s the question often asked when adults discover that they’re autistic. With growing awareness of autism, and a broadening of the autism diagnostic criteria, more people are receiving an autism diagnosis in adulthood than ever before. This can bring mixed feelings. After years of not ‘fitting in’, many autistic adults report relief (and even elation) in finally having an explanation for their feelings of difference<sup>i</sup>. For others, this information may come as a complete surprise: perhaps stemming from an assessment for another condition (e.g. mental health problems) or following their children receiving an autism diagnosis<sup>ii</sup>. In either case, identification or diagnosis can be an important gateway to supports and services<sup>ii</sup>.

Appropriate support can be a lifeline for autistic people, as the diagnostic process can be extremely challenging; for example, raising personal and emotional experiences from the past, but not providing the time or space for these to be worked through<sup>ii</sup>. Many autistic adults are dissatisfied with the help and support received post-diagnosis, with many receiving none at all<sup>ii,iii</sup>.

Post-diagnostic support for autistic adults tends to be provided by non-autistic professionals. This is often experienced as a series of lessons on what is wrong with the autistic person with instructions as to how to change to appear more “normal”. There is growing recognition that this approach may be both counterproductive and harmful<sup>iv</sup>. There is also

evidence suggesting there are benefits of peer-support for autistic people<sup>v</sup>. Advantages of peer support over professional support include greater empathy (given the shared lived experience of autism), gaining hope from seeing peers with the same diagnosis successfully navigating a (largely) neurotypical world, and a greater understanding of autism and how it may present in others. Whilst autistic-led peer support and education may not replace the need for some professional services, it can serve as a useful process for newly diagnosed/identified autistic adults.

*Exploring Being Autistic* is a ten-week autistic-led programme that was designed by one of the authors (Caroline Hearst) for autistic adults recently identified or diagnosed as autistic. Within a peer group context, it aims to enable people diagnosed or self-identified as autistic to:

- Learn about autism and discover if/how it affects them personally;
- Process an emotional response to identification/diagnosis;
- Consider the pros and cons of disclosing that they are autistic;
- Develop strategies to capitalise on the strengths and mitigate the challenges associated with autism;
- Socialise with peers.

An outline of the ten weekly sessions is presented in the table on page 5.

We carried out an initial evaluation of the programme with 16 autistic adults, who took part in one of two iterations of the programme. All 16 adults completed questionnaires before taking part in the programme, and then spoke with a researcher (Laura Crane) immediately after the programme and again six months later.

The results of our evaluation showed that the *Exploring Being Autistic* programme was well-received, with participants benefiting greatly, in many different ways. Specifically, they told us how they liked the autistic-led nature of the programme, developed a real sense of unity within the diverse group of attendees,

Week	Topic	Content
1	Introduction and establishing ground rules	The structure of the group. Overview of contents. Introductions. Sharing autism histories
2	Diagnosis/ Identification of Autism—what does it mean for you?	Initial feelings about autism. Is the label limiting or liberating? Disclosure in different contexts
3	Introduction and establishing ground rules	Factual vs social communication. Implicit and explicit rules. Non-verbal communication
4	Improving social communication	Locating and moderating emotions. Face theory. Empathy. Social skills vs social connection
5	Sensory issues	Stimming. Hyper and hypo sensitivities. Emotional sensitivity
6	Executive function	What gets in the way of moving from motivation to action? Strategies. Time keeping
7	Attention and disparate ability profiles	Attention shifting, mono attention, special interests. Spiky ability profiles
8	Flexibility	Dealing with change. Use of routines. Perfectionism. Boundaries
9	Anxiety, depression and mental health	The relationship between autism and mental health. Benefits and pitfalls of disclosure
10	Where to from here?	Consolidation. Autism and the law. Planning for the future. Course evaluation

and were able to use what they'd learnt to foster a positive, practical outlook on autism. Quotes from attendees are presented in the table below.

Key finding	Quotes from attendees
Appreciation of the Autistic-Led Nature of the Programme	"We are reaching a stage where we need autistic-led information, groups, support groups and workshops because, particularly with adults, it just doesn't work any other way. There's a certain feeling of imposition if someone is not on the same wavelength as you, so I think it's important that [autistic-led groups] happen and just keep going forward"
Unity in Diversity	"I like the fact it's mixed, I like the fact it's male and female, I like the fact there's a mix of age groups because there's some younger people and some older people—I think that's really key...you need to see it in all areas, because that's the nature of the whole thing itself—it doesn't just pick. If you had ten people like me in a room, we wouldn't learn anything...I think that was very important"
Developing a Positive and Practical Outlook on Autism	"It was a case of self-discovery, to be honest ... to actually go through the programme and go, oh my god, this is why that's happened and this is why I'm like this, it has just changed my whole outlook on life and to the point where I can make sense of things now."

Whilst our participants were complimentary about the skills and expertise of the facilitator, it was encouraging that many of the positive aspects noted by attendees were in relation to both the structure and general principles of the programme (e.g. the positive nature of the syllabus, the diversity of group members); all of which could be taken forward by other (trained) autistic facilitators in the future.

Key recommendations for future programmes include:

- Ensuring that peer-support programmes are autistic led;
- Accepting a range of group members, including those that self-identify as autistic;
- Providing material on practical tips and solutions to challenges group members face;
- Enabling ongoing support after the programme finishes.

For print version use the following:

You can read more about *Exploring Being Autistic* by Laura Crane, Caroline Hearst, Maria Ashworth, Jade Davies, and Elisabeth L. Hill. 'Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme' in *Journal of Autism and Developmental Disorders*, April 2020.

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# University Challenged

## Why are autistic people at higher risk of dropping out of university?



**Jack Howes**  
Philanthropy Manager for  
a leading autism charity,  
an autistic writer and  
researcher



**In collaboration with  
Dr Eilidh Cage**  
Lecturer in Psychology,  
University of Stirling

University is supposed to be a happy and rewarding time, with opportunities to learn, meet new people and form lasting relationships. However, the reality can be very different. One survey of over 37,000 students found almost 10% considered self-harming often or all the time<sup>i</sup>. Rates of anxiety, stress, requests for counselling services and suicides rise by the year<sup>ii</sup>. Given that around half of young people now go to university<sup>iii</sup>, such statistics are highly concerning.

For autistic people, their experiences as a collective are often worse and they are seemingly at higher risk of dropping out of university<sup>iv</sup>.

In the autumn of 2011, as a hopelessly naive 18-year-old whose life experiences extended to being miserable at school and playing *Football Manager* at home, I went to university to study History. After one term of crippling loneliness, reclusiveness and awkwardness, I left, never to return and receiving an autism diagnosis six months later. Last year, when my good friend and collaborator Dr Eilidh Cage suggested researching the experiences of autistic people who drop out of university<sup>v</sup>, I couldn't have been happier to help.

Based on a previous online survey<sup>vi</sup>, we devised questions for interviews on autistic people's experiences of dropping out of university. We undertook fourteen in-depth interviews with autistic people who had studied across the UK. After scrutinising the

interviews, we identified patterns and shared experiences in the interviewees' testimonies. Common themes from the interviews were organised into three broad categories - systemic issues, challenges within universities themselves and life after dropping out.

Looking into systemic issues, several of our interviewees, like myself, were only diagnosed as autistic after leaving university. Many felt that with an earlier diagnosis their time at university could have been more productive and enjoyable. Late diagnoses linked to a lack of understanding and acceptance of autistic people. One of our interviewees told us that every healthcare professional she had seen about a diagnosis had told her: *'You're not a boy, you can't have autism'*. At university, the lack of understanding meant our interviewees felt uncomfortable and they received insufficient or inadequate help with their studies.

Socialising proved a huge problem for our respondents. They often felt like outsiders, excluded from the lifestyles of their neurotypical counterparts. To quote one interviewee:

*"I just couldn't fit in, the whole time I was there I was always just on the outside looking in at everyone else having the time of their lives... I just wondered when that was ever going to happen to me."*

Feeling like an outsider is a common problem for autistic people. University, where many students are outwardly socialising and making friends, can induce greater feelings of loneliness. One point made by our interviewees was that other students "crowdsourced" their understanding and helped one another. Our interviewees therefore missed out educationally because of their outsider status.

Such problems can culminate in mental health problems, which we know autistic people are at higher risk of experiencing<sup>vii</sup>. In our research, one interviewee described how her PTSD became so bad at university she would not lock her bedroom door at night in case she couldn't get out. In many cases, our respondents were already experiencing mental health difficulties and university added to them.

These are all issues endemic in the autistic community, requiring radical societal change. We also identified several problems exclusive to universities which can be directly tackled.

The first of these was the sheer shock of moving to university. Living away from home for the first time (if applicable), in an environment with much noise and movement, proved overwhelming. Our correspondents were left with few places to retreat and recuperate.

High expectations from a personal and academic perspective also proved suffocating, with interviewees feeling unprepared for life at university. Without structure to their work, difficulties quickly became apparent:

*“What I found difficult was the amount of independent study and the fact we were supposed to be doing so much of it ourselves.”*

These problems led to increasing disengagement. Our correspondents were left floundering, struggling to meet deadlines and performing below their potential. This, combined with the other identified issues, led to gradual, rather than sudden, disengagement:

*“As time went on my motivation dropped, to the point where I basically got nothing of substance completed at all towards my final year dissertation”.*

Contributing to all this was an absence of proactive support for autistic students. One interviewee described how:

*“The head of the course, he wasn’t very polite, he was quite derogatory actually. And he was basically saying ‘can’t you bloody manage this’. There was absolutely no one at any point who said to me ‘are you struggling?’ or ‘can we help you with something?’”*

For our interviewees, they were left with little choice but to drop out of university. After leaving, many looked back at their time at university and felt like failures. Some had since been able to process what had happened, and looking back, they felt autistic people in similar situations had to do what was right for them:

*“Don’t blame yourself if it does happen – there are so many reasons university doesn’t work out for someone, and some of them are very fixable with time, experience, and more support. Lots of autistic people end up doing a lot better as mature students.”*

These findings present the question of what could be done to help autistic students and reduce the risk of dropping out. We believe the following would be hugely

beneficial:

- Improved autism understanding and acceptance from non-autistic staff and students, perhaps through training.
- A sensory environment which is designed to suit and understand the needs of autistic students.
- Increased mental health support which is suitable for autistic people.
- Greater structure in academic work, with adaptations so students can learn at their own pace and course materials shared in advance.
- More time before starting university to get acclimatised, perhaps through transitional programmes.
- Proactively identifying and helping students who may be becoming disengaged, with staff becoming trusted confidantes of autistic students, not dismissive of their struggles.

We all have a right to study, learn, earn a degree and live happily. Autistic students have been denied that. This needs to change.

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# When Autism Meets Bilingualism



**Dr Bérengère Digard**  
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Bilingualism, the knowledge of more than one language, is a skill shared by half the world's population. Bilingual people come in many shapes and sizes: their experience depends on the number of languages they know, how fluent they are in these languages, when they learned them, and how they use them. In reality, the perfectly balanced bilingual who grew up with two languages is the exception rather than the rule.

Like all the things we learn and do, being bilingual changes the way our minds and brains work. For example, it changes the way we manage several pieces of information at once, and it changes the way we understand and relate to other people. However there are several ways to be bilingual, and each way to be bilingual comes with a slightly different "bilingual effect" on the mind. For example, as I live in Scotland, I use English most of the time and I only use French when talking with my family in France: my languages rarely meet. If I were to move to Montréal, I would be switching between French and English all the time. This little difference is enough to lead to completely different "bilingualism effects" on the mind.

There is still a lot to be discovered about the way bilingualism shapes the mind and the brain. Moreover, almost all of what we know on this topic, we have learned from the experiences of non-autistic people. But what about autistic people? Do they experience the same "bilingualism effects", or is bilingualism a burden for the autistic mind, just as people used to believe it was a burden for non-autistic children? For example, does bilingualism slow down language development for autistic children?

Research on bilingualism in autism is only just starting, but it is much needed. Indeed, in bilingual families this tiny field of research has largely been focused on the language used to communicate with the autistic family member. Because we know so little, bilingual parents often worry about maintaining bilingualism with their autistic child, who may have difficulties with the development of language. Because of the lack of research, practitioners often advise parents to keep only the majority language (such as English in Scotland), as services and therapies will only be provided in this language. These concerns and recommendations can make sense, but unfortunately growing up monolingual in a bilingual family can make the autistic person feel particularly isolated. Moreover, if bilingualism is so beneficial for non-autistic people, in terms of both mind mechanisms and life opportunities, why not encourage language learning for autistic people too, especially if they come from a bilingual family?

Researchers are trying to answer these questions. However, before looking into the autistic bilingual mind, at the beginning of my PhD I wanted to explore the experience of autistic bilingual people themselves. In research and in the media only autistic children from bilingual families and autistic polyglot savants are presented. But these two profiles are not the only ways for autistic people to be bilingual. My first study, now published in *Autism* journal, is the first to describe the great diversity of the autistic bilingual population, which is as rich and varied as the non-autistic bilingual population. Any language journey you can imagine can be the story of an autistic person, just like it can be the story of a non-autistic person.

Most studies in the field focus on the development of autistic bilingual children's language. These studies show that autistic bilingual children do have a small delay in language development compared to autistic monolingual children, just like what is seen for non-autistic children. Of course, this delay due to bilingualism can be worrying for parents, but just like



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non-autistic children, research suggests that autistic bilingual children soon catch up with their monolingual peers. However, more research is still needed, on non-verbal autistic children from bilingual families, or the best way to support the learning of several languages for autistic children.

What about other mind mechanisms? There is very little research available on how bilingualism shapes the autistic mind, but the field is growing. My own doctoral research focused on a social mechanism called perspective-taking, the ability to take someone else's point of view, understanding what they think or feel. Autistic people can sometimes have difficulties with perspective-taking, and several therapies aim to explicitly teach autistic people how to do perspective-taking. My goal was to figure out whether this particular skill was shaped by bilingualism, and if so, which aspect of bilingualism (such as the age when one started learning a second language, or how fluent they are in their second language) was causing this effect. I also wanted to see whether the relationship between bilingualism and perspective-taking was the same for autistic and non-autistic people.

Thanks to the help of autistic and non-autistic bilingual adults, I managed to answer these questions. I have discovered that perspective-taking abilities were indeed shaped by bilingualism, and that for this particular skill, the most important aspect of bilingualism was the age when the person started to learn a second language: the younger people had learned their second language, the better they were at perspective-taking, regardless of other individual differences like general intelligence or other mental abilities. Remarkably, this relationship between bilingualism and perspective-taking was the same between autistic and non-autistic people. This is an important result: it means that when it comes to perspective-taking skills, bilingualism is as beneficial for autistic people as it is for non-autistic people. It also means that bilingual autistic children can learn perspective-taking "implicitly", simply by being in a

bilingual environment. Importantly, this effect of bilingualism in childhood is long-lasting, and can still be visible in adulthood. Where does this leave us? Of course, none of this means that bilingualism should be forced upon all autistic people. After all, we know that bilingualism is beneficial for non-autistic children, but not all non-autistic children are forced to learn a second language from birth! Instead, this result means that bilingualism does not seem to be a burden for the development of the mental abilities of autistic people, and that bilingual parents should not worry about speaking their mother tongues with their autistic child. It also means that autistic people who are keen to learn languages should be encouraged, as it can only be beneficial.

Indeed, bilingualism does not only shape the mind, but also the life of people. In my first study, aimed at understanding the profiles of autistic bilinguals, I asked the respondents to tell me about how, according to them, being both autistic and bilingual had shaped their life. They explained how learning languages had brought them so much more than just languages. It had helped them to better understand themselves and others; it had increased their self-confidence; it had given them travel, education and job opportunities; it had brought them closer to the worldwide autistic community. In other words, bilingualism can open up the world to autistic people, just as it does for others.

# Reforming Social Care in Scotland

## First Thoughts



**Dorry McLaughlin**  
Chief Executive,  
Scottish Autism



**Dr Joe Long**  
Research and Policy Lead,  
Scottish Autism

The Covid-19 pandemic has shone a stark light on social care in the UK. However, the Scottish Government's review of adult social care offers us an opportunity to shape and improve services for autistic people. Here we highlight some key issues that we think the review should consider.

Social care is not just about services for people at one given stage in their lives. It should be about supporting people throughout their lives. This is especially important for autistic people and those with intellectual disabilities. We need all agencies, including health and social care, to consider and plan for a person's whole life journey so that transitions do not become 'cliff edges' where services fall away or appear as traumatic points in a person's life. We can and should invest to prevent crises that do not need to happen.

To achieve this requires a shared understanding and a holistic view of a person's life and aspirations by health, social care, education and other services. Supported autistic people need to be involved in creating this shared understanding and be at the heart of shaping decisions about their lives from the outset. The integration of health and social care has not seen budgets shared. Professional silos have not been broken down and health services remain the dominant partner. Joined-up service commissioning and provision will only come when this happens. A starting point would be a single gateway into services. This will be vital in

ensuring that those autistic people who do not have an intellectual disability or acute mental health difficulty do not fall through the gaps in service provision.

Quality support can only be achieved if the workforce supporting autistic people have appropriate skills and knowledge coupled with professional values and standing. Generic, tick-box qualifications such as the SVQ do not provide such knowledge or skill.

Investment is needed in a professional, properly rewarded workforce who choose social care as a vocation as well as a career; investment in the skills and career development of practitioners; and funded time to train and learn. A professionalised model for service provision includes resources for the generation and exchange of practice knowledge. These are not optional extras but fundamental to the provision of quality services, innovative and evidence-informed support, and continuous improvement in all aspects of support for autistic people.

Importantly social care should continue to embrace the diversity and specialism offered in the third sector. This includes specialist autism providers as brokers of autism knowledge, and autistic-led organisations able to offer a community of lived experience, expertise and peer support.

Above all, health and social care services should take a human-rights based approach to supporting autistic people. Crucially, government, public services and social care providers should be held accountable for upholding and promoting human rights. To this end we are proposing an Autism and Learning Disability Commissioner for Scotland to close the current accountability gap.

We have seen countless reviews and legislation passed- now is the time and opportunity for real, systemic change.

We offer these proposals as starting points for a dialogue about social care reform and look forward to hearing ideas from our wider community.

## NEWS



### Scottish Government Launch National Campaign

In October the Scottish Government launched a new national campaign with the aim to provide the general public with a clearer understanding of autism and to be more accepting of the different qualities and attributes of autistic people, whilst debunking myths.

Developed with autistic people, the campaign is in response to the Scottish Government Consultation on The Scottish Strategy for Autism, which highlighted the stigma and discrimination that autistic people can face.

Learn more at [www.differentminds.scot](http://www.differentminds.scot)

### Research Funding Success

We are delighted to announce new research funding for Scottish Autism's Centre for Practice Innovation. The Centre has been awarded seed funding from The John and Lorna Wing Foundation for research that will work towards a relational understanding of autism support. The funding will support a partnership with the University of Strathclyde to investigate what constitutes enabling interaction between practitioners and supported autistic people.

### New Post Diagnostic Support Service

Scottish Autism is leading on a pilot to deliver a new National Post Diagnostic Support Service. This collaborative initiative, delivered in partnership with the National Autistic Society Scotland and Autism Initiatives, will provide a wide range of information and support to autistic people of all ages as well as their parents and families following diagnosis.

Funded by the Scottish Government, the service will ensure families are better informed and empowered. It will also support autistic individuals to understand and embrace their identity whilst giving them and their families the opportunity to connect with peers. This service will launch later in the year and we will shortly be sharing more details of how people can access it.

Learn more at [www.scottishautism.org/news](http://www.scottishautism.org/news)

### New Research Collaboration

We are delighted to announce that Medical Research Scotland have awarded a collaborative PhD Studentship to the Salvesen Mindroom Research Centre at University of Edinburgh and the Centre for Practice Innovation at Scottish Autism in order to undertake groundbreaking new research on autistic communication.

Learn more at [www.scottishautism.org/news](http://www.scottishautism.org/news)

## EVENTS



### Advice Line Plus

Scottish Autism received funding from The Scottish Government to allow us to provide much needed reassurance, guidance and support to autistic people and their families across Scotland during these uncertain and challenging times. As part of this, in April we began to offer online events such as our Autism Advice Q&A sessions. We have been delighted with the response and engagement we have received and continue to offer a range of virtual events until government guidance allows in-person events to resume. To keep up to date with our latest online events please sign up for our events e-news at [www.scottishautism.org/contact/enewsletter-sign](http://www.scottishautism.org/contact/enewsletter-sign) or follow us on Facebook or Twitter.

### Impact through Diversity - Strathclyde Autism Course Conference

Strathclyde University's School of Education is holding a 21st Anniversary Conference to celebrate the impact of their Autism programme on 21st November. On Tuesday 24th and Thursday 26th November, the university will also hold two Keynote Evening Webinars. All three sessions will take place online via Zoom. The conference will be opened on Day 1 by Sir Jim MacDonald, Principal.

Find out more and register your interest here: [www.bit.ly/21stAnniversaryStrathclyde](http://www.bit.ly/21stAnniversaryStrathclyde)

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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