

Cross-Party Group on Autism 20th March 2023, 12 until 2pm Minutes

Attendees:

MSP:

Alexander Burnett, MSP (Convener)
Daniel Johnson, MSP (Deputy Convener)
Stephanie Callaghan, MSP

Invited Guests/Speakers:

Kabie Brook, Autism Rights Group Highland (ARGH)
Debbie McColgan, Inspiring Scotland
Suzanne Kinross, Scottish Government
John Grafton
Gyll Curtis-Machin
Sonny Hallett, AMASE – provided a pre-recorded video of their presentation
Jill Ferguson, Scottish Autism
Dr. Mary Doherty, Autistic Doctors International

Secretariat:

Rob Holland, National Autistic Society Scotland
Suzi Martin, National Autistic Society Scotland
Stephen Caulfield, National Autistic Society Scotland
Charlene Tait, Scottish Autism
Mark McDonald, Scottish Autism
Marion McLaughlin, Autism Understanding Scotland

Non-MSP Group Members:

Andy Crosbie	Dorothy Barbour	Katy King
Andy Williams	Edward Fowler	Kirsten Mutch
Angie Ferguson	Ewan Carmichael	Laura Bilton
Aurora Constantine	Fiona Clarke	Lauren Murray
Ben Paechter	Fiona Riddoch	Lavinia Dowling
Billy Alexander	Fiona Culbert	Leanne McNeill
Bob Thomson	Fran Foreman	Leila Talmadge
Callum McCrosson	George Watts	Lesley Parker
Cath Purdie	Gideon Henner	Lesley-Anne Farm
Catherine Steedman	Gillian Shuttleworth	Leticia Martinez Garcia
Christine Jones	Hayley McMurray	Louise Moth
Christopher Fox	Helena Cundill	Lynda McLeod
Clare Kennedy	Jack MacLeod	Lyndsay Macadam
David Allott	Jacqueline Campbell	Margaret Smith
David Stewart	James Barbour	Maria Chan
David Nicholson	Jamie Kirk	Mark Halliwell
David Stewart	Jay Brownlee	Matt Barclay
David Anderson	Julie Cuzen	Maurice Frank
David Yeoman	Kate Monahan	Melea Press
Diana Barnard	Katie Forbes	Michelle Graham

Nicola Watson
Patricia Hewitt
Pauline Grigor
Rachel Birch
Ramon Hutchingson
Richard Ibbotson

Ryan Cuzen
Sean Macaskill
Shirley Moore
Sofia Akbar
Steve Billingham
Steve Kent

Susan Chambers
Susan Fullerton
Suzanne Kinross
Tom Wightman
William Rae

Convener's Welcome

Alexander Burnett, MSP, (AB) welcomed everyone, including MSPs, to the first CPG on Autism meeting of 2023.

The theme for this meeting is "Health".

Mark McDonald (MM) and Rob Holland (RH) approved the Minutes from the previous meeting, held in October 2022.

Feedback from 06/03 Accessibility Meeting (+ Questions)

Rob Holland (RH), Director, National Autistic Society Scotland

In prior CPG meetings, it was agreed that there should be an 'Accessibility Meeting' prior to a CPG. To date, there has been four such meetings. RH thanked all who have attended these meetings.

Two key points from the accessibility meeting were:

- Challenges of submitting questions in busy meetings.
 - The Secretariat will explore separate ways for members to submit their questions, including the possibility of pre-submitting questions ahead of the meeting.
- There have been requests for hybrid meetings.
 - Some prefer face-to-face, while others prefer virtual. The Secretariat will explore the possibility of hybrid meets and learn from other CPGs on how this has gone for them.

Meet the Members

Kabie Brook (KB), Chair, Autism Rights Group Highland (ARGH)

KB provided an overview of ARGH, including: its core principals; the different types of membership they offer, and to who; campaigns ARGH have contributed to; and the varying types of enquiries they receive nationally / internationally.

ARGH are keen to ensure that autistic voices are heard, and that others do not speak for them. ARGH will act as a voice for those who ask that they represent them.

ARGH hold Autistic Pride events in Inverness each year and hope this will continue in the future. ARGH hold other events through the year.

ARGH has links with national and international autism organisations and are currently working with Autistic Mutual Aid Society Edinburgh (AMASE) on a project at improving internal governance with Scottish Autism.

ARGH have also worked alongside AMASE on an event with the aim of creating more Autistic People's Organisations (APOs).

KB gave information about the current courses ARGH offer.

Update on the Scottish Government's Leadership Framework: Autism and Mental Health

Suzanne Kinross (SK), Autism Policy Manager, Scottish Government

Debbie McColgan (DM), Autism Fund Manager, Inspiring Scotland

John Grafton (JG), Autistic 'Driver'

Gyll Curtis-Machin (GCM), Autistic 'Driver'

SK gave an overview of the team and roles within the project.

The aim of the project is for the Scottish Government to work more closely with autistic people and people with learning disabilities to help guide autism policy.

DM gave an update on the process and time it took to decide where to focus and how to go forward, including identifying priority areas and creating a working model.

JG gave an overview of the 'Drivers' group, its aims, and priority areas. These priority areas were identified as GPs and 'Autism Informed Services'.

After identifying the key areas, the group has looked further into what needs to change and the resources required to establish change.

GCM provided information about the role played by the autistic 'Drivers', including: creating group Agenda, bringing their own lived experience, and acting as 'translators' for autistic experiences. They, alongside the other 'Drivers', have worked diligently as researchers to identify academic work, good practice and organisations who contribute to better understanding of autistic experiences.

Together, JG and GCM continued to explain their work and the people / organisations with whom they have worked, and what they hope to achieve going forward. Both bring a wealth of professional knowledge to the project.

Accessing Suitable Mental Healthcare as an Autistic Person

Sonny Hallett (SH), Co-Founder, Autistic Mutual Aid Society Edinburgh (AMASE)

SH introduced themselves and gave an overview of the report 'Too Complicated to Treat', which was produced in 2018 by AMASE.

The purpose of the report was to highlight the difficulty autistic individuals were having accessing mental health services, including being denied access altogether. SH then shared some statistics from the report including:

- 42% of people said they were not understood, listened to, or taken seriously by practitioners
- 26% said that they were denied mental health services as they were autistic

- 30% had 'problems' with inaccessible services
- 36% said practitioners had inadequate knowledge of autism
- 40% believed that there is nothing out there to help them
- 52% said that they have 'negative' experiences with a mental health service

Following their research, SH wanted to try to find solutions to these issues and began their journey as a counsellor.

SH feels that there has not been much in the way of improvement since the publication. SH recognises that there is pressure on mental health services from all communities, plus the pandemic, leaving many people feeling isolated and alone.

A positive of the pandemic was the ability to access mental health services remotely, which enabled autistic people, who had never been able to access the services, to do so for the first time. Many have remained online following the pandemic. SH feels there needs to be flexibility in the services: offering both online and in-person support for the differing needs of autistic people is the best way.

Many local mental health services have now shut down following the pandemic. These services tended to be more flexible, and may have been provided free of charge, or at low cost. The loss of such services has been felt throughout autistic community.

Autism and End of Life Care

Jill Ferguson (JF), Regional Manager, Scottish Autism

JF identified her, and Scottish Autism's, commitment to supporting autistic people in a 'whole life journey', with a real focus on supporting an aging autistic population.

Scottish Autism has been involved in projects to identify research priorities within the area of the changing needs of an aging population of autistic adults.

Scottish Autism developed residential accommodation for older autistic people, some of whom transitioned into residential care, owing to additional health needs. Founders House was designed to recognise the changing needs of older adults and those living with additional health and mobility challenges.

JF discussed the learning opportunities that arose in supporting an autistic individual throughout their lifetime, up to and including the person's death from cancer some years ago. It gave the team the opportunity to learn more about end-of-life care, share their experiences, and use these conversations as the basis of a practice resource on providing this care.

JF discussed key themes from an IRISS Insights about the value of storytelling.

JF talked about the collaborative work between Scottish Autism and Health and Social Care teams when delivering end-of-life care.

Planning ahead for end-of-life care is essential. Scottish Autism have held workshops to create support templates. Scottish Autism have had conversations with those that they support to discuss what is important to them, their views, and wishes

for end-of-life care. This information might not have been known if those conversations had not taken place.

Challenging Barriers to Healthcare for Autistic People

Dr Mary Doherty (MD), Anaesthetist; Founder, Autistic Doctors International

MD introduced herself, and shared her educational background and career path. MD also gave background to Autistic Doctors International (ADI), which is the organisation she founded in 2019.

ADI advocates for its own members, including doctors, medical students, and autistic people more widely. ADI work closely with several nursing colleges, the British Medical Association, and others to improve recognition of autism.

ADI provide workshops at events and training for many different health care settings.

ADI are involved in research to assist with improving the lives of autistic people. This work allows them to work with organisations and education settings within the U.K., as well as organisations internationally. They have developed a framework for meeting the needs of autistic people in healthcare, "Autistic Space".

MD shared some statistics around the mortality rates for autistic people and some of the health reasons for these statistics. MD also gave examples of statistics for autistic people accessing health settings.

Through her research, MD discovered a range accessibility issues for autistic people when accessing healthcare. MD gave examples of accessibility barriers. MD reiterated the need for training at all levels within healthcare services.

<https://www.magonlinelibrary.com/doi/full/10.12968/hmed.2023.0006>

Q&A

Question – What research has been done about the health of autistic people in relation to suffering strokes or heart attacks?

Taken by MD

At the moment, the team are specifically looking at mental health and that will continue for another year. Those resources produced can be adapted to other areas; however, we will focus on our current programme for now.

Question – The Leadership Framework Project has a focus on GPs, what is being done with other health care professional, such as dentists for instance?

Taken by JG

JG clarified that the group is currently focused on GPs as it is the first point of contact with health services for most autistic people.

Question – Is there a recruitment and training programme to deliver appropriate services?

Taken by SK

This falls under the National Care Service (NCS); however, the assets produced from the Leadership Framework Project will be looked at within GP training, as well as professional learning for specialists.

Question – For a long time, there has been a lot of talking, lots of planning but nothing ever seems to change on the ground. Regarding the NES Training Framework for training and recruitment, is there a timeframe or a date when this will happen?

Taken by SK

We will take this question to colleagues working in that area and will feed the response back via the Secretariat.

Question – Has there been any comparison between neurotypical and autistic people who have been diagnosed with life threatening conditions such as heart disease or cancer, as well as suicide rates? If this research hasn't taken place, are there any plans to do so?

Taken by MD

MD confirmed that there have been studies which showed cancer mortality is doubled in autistic people; that rates of suicide were x7 overall, including x13 with autistic women. MD provided statistics for other medical conditions and said she feels we really need to start looking at physical healthcare, as well as mental healthcare, as it is neglected.

Question – What can be done to ensure autistic people can access autism friendly exercise groups and opportunities for physical activity?

Taken by MD

All exercise is good, including solo physical exercise which some autistic people may prefer.

Question – How are health and mental health services integrated with other big institutions such as the education system and social work?

Taken by SK

They link in closely and meet regularly. Relationships have been established within government and across the relevant public bodies to ensure a flow of information.

Convener's Reply

AB thanked everyone for their attendance, and the speakers for sharing a great wealth of information.

The date of the next CPG meeting is 12 June, 5pm-7pm.

The date of the next accessibility meeting is 30 May.

Following this, the third meeting of the CPG in 2023 will be on 20 November.

Any Other Business (AOB)

There was no further Business discussed.

Written Contributions Made in the 'Zoom' Chat Function

Each of the entries below are verbatim lifts from the 'chat transcript', as provided by Zoom. Only those contributions marked with a 'C' at the time have been included in these Minutes, in keeping with what the Secretariat sets out in the provided pre-meet papers.

Consequently, the entries below may not 'flow' as a conversation; however, many are effective as stand-alone remarks.

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Chris: Q&A: Sorry I can't stay longer today but wanted to ask in Q&A about links between the work of this CPG and The Promise. Given that rates of neurodivergence/disability are much higher in the care experienced population how is this group being represented and included and agendas joined up.

Jay Brownlee, Parent, NT: My experience of getting mental health support is that everything is put down to her being autistic and yet no-one is willing to provide support BECAUSE she is autistic, So everyone recognises the likelihood of mental health being less good because she is autistic and yet this is the exact barrier to getting support.

George Watts: This is such a common experience. I'd argue that a great deal of poor autistic mental health isn't the result of being autistic per se but rather the result of stigma and misunderstanding from non-autistic people.

Jay Brownlee, Parent, NT: I also had an issue with getting my ASD diagnosed daughter referred for and ADHD assessment as my GP thought they were the same thing. I later found he was still using DSMIV as his frame of reference despite that being superseded in 2007!

Maurice Frank, ELAS: ELAS, Edinburgh's original support group, has for a long time had a model ethical code for emotional safety against arbitrary rejection, that all should follow. The medically known existence of rejection sensitivity makes it an abuse violating autistic mental health for any of our organizations to operate on a basis of choice who to reject, by liking your face, or to want that power.

Andy, NAS South Lanarkshire Branch: Also, there seems to be a big focus on GP's. What is being done with other healthcare professionals e.g. dentists?

Ramon Hutchingson: The Oliver McGowan training is mandated and a good example of this approach#. Secondly, the presentation outlining the increase in 'time imposed' brief therapeutic interventions evidences the paucity of both A.A.C., preferred communication approaches, and non-verbally based therapies such as EMDR, Psychomotor and Somatic Experiencing amongst many other alternatives for the ND community.

Fiona Clarke: That was a very important point about disabled people being assumed to lack capacity to make decisions, when in fact it is inadequate supported decision making and independent advocacy provisions that are the issue.

Steve Billingham: How many times do we need to hear “if we get this right for autistic people we get it right for everyone”? I’m not autistic myself but when will service providers get this simple truth?

Steve Billingham: Can we please get copies of the stats that Dr Doherty shared with us (or a link to them).

Fiona Culbert: It is not "fear" that prevents disclosure of autism in terms of judgement of parenting capacity. It is well documented fact.

George Watts: Yes it's a very realistic fear, not unfounded anxiety. Autistic parents need to somehow balance between appearing distressed enough to warrant getting any support but not so distressed that their ability to parent is called into question.

Susan Chambers, PASDA: Thank you Mary for a very clear summary. The figures for poor outcomes are shocking but not a surprise. I have been involved with Pasda for over 20 years and we have been campaigning for better services for autistic adults for most of that time. We feel as the main support for family members we are marginalised until we are needed in a crisis eg during the pandemic to provide the day to day mental health support. The question is how to make the changes and reduce barriers. Carers/parents need to be included in discussion if agreed by their family member.

Michelle: there should be some investigation into how many autistic students are out of education due to anxiety related absence. Many suffering from mental health issues

Melea Press: My experience in connections with NHS, CAMHS, and education with my 7yr old kid has been very un-linked up.

Sofia Akbar: I have a question. What research is being undertaken comparing the health outcomes of white and non-white autistics?

ENDS.