

Cross-Party Group on Autism

23 September 2024, 2pm-4pm

Minute

Present

MSPs

Alexander Burnett (Convener)
Annie Wells

Invited guests

Professor Jill Stavert
Professor Colin MacKay
Andrew Jarvie

Non-MSP Group Members

Secretariat

Suzi Martin, National Autistic Society Scotland
Alexandra West, National Autistic Society Scotland
Mark McDonald, Scottish Autism
Jean Foggarty-English, Scottish Autism
Marion McLaughlin, APO Representative

Non-MSP Attendees (names are drawn from the Zoom attendee list, so surnames are only presented where these were present within usernames):

NAS Scotland
Jill Stavert
Colin McKay
Andrew Jarvie
Marion Aurora
James Muir CENTRAL ADVOCACY PARTNERS
Maurice ELAS
Susan Chambers Pasda
Siobhan McCaffery
Donna
Dorothy
Jean Foggarty English
David Anderson East Ayrshire NASWUT Vice President Scotland

Robyn
Leo Bollins
Laura
Trish Collins
Naomi Nyamudoka (Be. Herd and Be. Counselling)
Tom Wightman
Andy Williams - Central Advocacy Partners
Sean Macaskill AKD
Anna Nicholson
Louise Storie (Louise)
Lesley Farm - The Autistic Collective ER
Kabie (they/them) ARGH
Jess C
Mark McDonald - Scottish Autism
George Watts
Richard Ibbotson
Stephen Caulfield The Donaldson Trust (S Caulfield, The Donaldson Trust)
David Taylor
Cherie Morgan
Dorothy Barbour
Joe Long (Scottish Autism)
Dawn Brown (SCDC)
June Deasy
Mary Doherty
Sally Cavers (she/her) | Inspiring Scotland (Autism Team
Autismenquiries@inspiringscotland.org.uk)
Fiona Clarke
Sam Nicholson
Fergus (they/them)/AMASE (AMASE Account)
Gideon Henner (he/him) / AMASE
Jessica Costello - Inspiring Scotland
Rodger
Kyrine Wood
Louise Carson - HOPE for Autism
Michelle
Lauren Miller
Ross Wight
Melea Press
Dorry McLaughlin
Carrie Watts
Jill Ferguson
Kate's iPhone
Sofia - SEMA
John Grafton

Carmen Murray - SG
Sophie MacLagan
Jacqueline Campbell
Fergus (they/them)/AMASE
Matt Barclay
Jamie

Apologies

None.

Agenda item 1 – Convenor’s Welcome

The Convenor welcomed attendees to the CPG and thanked everyone for attending.

The theme for the meeting was ‘Mental Health Law Reform’.

The Minutes from the previous meeting (held in April 2024) was approved as read, with no objections.

The Convenor stated that some topics mentioned in the meeting might be distressing including restraint, seclusion and compulsory psychiatric treatment.

Two speakers sent their apologies - Leo Starrs-Cunningham and Cara Rose Cameron from the Scottish Government Mental Health & Capacity Law Team which have given us a written submission which will be read out on their behalf.

This meeting was online only.

Agenda item 2 – Meet the Member

Autistic Mutual Aid Society Edinburgh (AMASE)

Gideon Henner, Secretary, stated that AMASE was founded in 2017 and has an autistic management committee.

AMASE offer two types of membership – Full (autistic adults aged 16 and over in Edinburgh, Lothians and Fife, whether or not they have been formally assessed) and Associate (for autistic adults based elsewhere).

AMASE support the local community, regular online events & groups. One-off online or in-person events, as well as a discord server, and a monthly newsletter.

AMASE looks to the future; resuming activities that are currently on hold, rebuilding capacities, and regaining funding.

Edinburgh and Lothian Aspergers Society (ELAS)

Maurice explained that ELAS first began in 2002 and was called Lothian Autistic Society which they then branched out to different areas.

ELAS continues to have in person meetings that grew to a weekly Google group, and a Facebook page.

ELAS has also organised a series of group holidays ranging from 2-4 days.

Membership to join ELAS is easy and is done by taking part or following online via Facebook or Google.

ELAS will support members by letter writing e.g. for benefits or service exclusion.

Agenda item 3 – Speakers

Scottish Mental Health Law Review

Prof. Jill Stavert and Prof. Colin Mackay

Prof. Jill Stavert explained that the Scottish Mental Health Law Review is misleading as it also includes reviewing adults with incapacity and adults protection law. The recommendations of the Review relate to these three pieces of legislation

The law should be reformed and there should be a stronger rights protection for people with mental and intellectual disabilities.

Prof. Stavert referenced the importance of the UNCRPD (UN convention on rights of persons with disabilities) within the context of the Review. The UNCRPD is not yet incorporated into Scots Law.

Prof. Colin Mackay spoke about economic, social and cultural rights which is a fundamental change to the scope of Mental Health Law. Reducing coercion was seen as another important aspect, including regulating detention and people being physically restrained or forced to take medication etc.

The Government have said this package reform will take several years and needs to be tied in with the development of other things e.g. the Human Rights Bill, the development of the national care service, and the Learning Disabilities, Autism and Neurodivergence (LDAN) Bill.

Rome Review

Trigger warning: suicide

A video from Leo Stars-Cunningham was played on his behalf

Leo spoke about his one-time friend who took his own life. He met his friend 15-20 years ago at a gathering of fellow autistics.

Leo spoke about his friend's hopes and aspirations. He also spoke about his friend's experience of having his support cut, which resulted in his mental health deteriorating. Eventually Leo's friend took his own life.

Leo said that the system had failed his friend at multiple points.

Leo was part of the Rome review as an advisor. Leo said that five years later we remain in the same place with the same problems. Leo said that the changes the community needs are:

- more support on their terms
- more humanity in a system that should be helping people
- listening more to people with lived experience.

Engagement and Participation Officer at the Mental Welfare Commission

Andrew Jarvie

The Commission is effectively the watchdog for mental health in Scotland and is an independent organisation set up by Parliament.

They carry out hospital visits and inspections and carry out investigations where things have gone seriously wrong. They also respond to mental health legislation consultations as well as having an advice line.

Andrew spoke about the LDAN Bill. He said:

- There are potential problems with specified conditions within the Bill, as this would potentially lead to a number of exclusions.
- Staff training should be mandatory.
- People with lived experience need to be involved in designing the services that they use.

Autism and ADHD are the most researched conditions in the world, yet Andrew has seen poor evidence of that translating into knowledge at a diagnostic or clinical level.

Andrew mentioned missed diagnosis which is a major theme that he has picked up repeatedly.

Increasingly, people are reporting that GPs are refusing to make a referral for an autism assessment. Despite this, 86% of people in Scotland on Neurodevelopmental Assessment Service waiting lists who are eventually seen do receive a positive diagnosis.

Scottish Government, Mental Health and Capacity Law Team

Update on Mental Health & Capacity Law reform which was distributed to the attendees and read by Suzi Martin.

Agenda item 4 – Q&A; and comments

These comments were all made in the chat during presentations and addressed during the Q&A.

Commented [SM1]: You're missing a question here

Q: Re the recommendations and the difference between primary and secondary legislation requirements.

Reply – Prof. Stavert.

The vast majority of recommendations from the SMH Law Review require a practice structure, resource allocation, and culture change in order to bring about the desired changes.

They are moving away from a focus on legislation on coercive matters and towards supporting someone's needs.

As for keeping people's voice at the centre of any decision, this can mean assessing whether something is in fact restricting a person's autonomy. Putting this down to culture change, this can ultimately be achieved without legislation.

Q: Why was the removal of autism from the Mental Health Act not recommended by the Scott Review after being so clearly endorsed by the Rome Review?

Reply – Prof. MacKay.

Acknowledged the argument for taking autism out of the Mental Health Act. However, with regard to people's human rights being upheld, it is not helpful to distinguish between diagnoses or have different laws for different diagnoses.

Recognises that a change of law will take a long-time and might have to deal with the existing Mental Health Act for a while yet.

He also pointed out difficulties in finding an alternative to having autism in the Mental Health Act, arguing that the people may be detained under the Adults with Incapacity Act, which would mean people would actually have fewer safeguards and fewer protections than if detained under the Mental Health Act.

Q: What and how was considered within the review – for example, anti-racism and intersectionality? How do you propose hearing the voices and experiences of autistic young people who are currently in-patient settings or a past experience of inpatient admissions? How can you make sure it's truly safe for those young people and young adults to have their say directly?

Reply – Prof. Stavert.

Acknowledged that some groups are doubly stigmatised and discriminated against under the law and this must be taken into consideration.

However, better data is needed to work out where exactly this is happening. Stated that one size does not fit all.

Reply – Prof. MacKay.

With regard to children's issues, there is a need to develop collective advocacy both for adults and children.

Q: What are the main challenges facing autistic people in wards?

Reply – Andrew Jarvie.

One of the biggest challenges to be staff trying to differentiate between what is autism and what is a mental health condition. There is room for clinical staff to improve their knowledge and understanding of autism.

Q: How do we address the significant number of consultant psychiatrists whose training specialty is personality disorders? If someone is not trained or specialised in neurodevelopment differences, how are they able to look through an autism ADHD lens?

Reply – Andrew Jarvie.

Step 1 is identifying it. Step 2 is asking how to we go about bridging the knowledge gap.

There is value in lived experience, for example, by bringing autistic people into design processes and showing people what actually works - because even beginning to explain to someone a very different view of the medical world is incredibly difficult.

Q: Is there any plan for widening the work of the Mental Welfare Commission to include ordinary neuro different people who is deteriorating in mental health to a degree which means hospitalisation or suicide, due to a lack of consideration and adjustment by the workplace?

Reply – Andrew Jarvie.

The remit of the Mental Welfare Commission has to be anyone or any setting that comes under any mental health legislation – so that technically includes people on waiting lists who are not getting receipt of services.

Uprooting all legislation is not needed to begin making a difference.

Q: What can be done under existing frameworks? How long will things take with law reform and what is happening now to strengthen protection rights for people?

Reply – Prof. MacKay.

Law reform can take a long time. For instance, the SMH Law Review took three years to produce a report and two years to produce a limited delivery plan. Furthermore, it took 19 years in Northern Ireland to reform mental capacity and mental health law- which still hasn't been fully brought into effect.

He also explained that all that's really needed for change is a commitment from the government. However, many changes can be made without this, such as improving the way services are organized and giving lived experience a greater voice.

Q: Is it a missed opportunity that the LDAN consultation paper proposes zero immediate actions?

Reply – Prof. Stavert.

The LDAN Bill consultation is an opportunity to state what you want the Bill to achieve.

With regards to the SMH Law Review, the main question is what support does a particular person, regardless of diagnosis and condition, need? But for the LDAN Bill, it's about ensuring that the appropriate support is available and is covered by a piece of legislation, as well as bringing about culture change.

Reply – Andrew Jarvie.

Reforming everything is not necessary in order to do better.

The Mental Welfare Commission has used its budget increase to hire extra staff, and it is now involved in 25% more cases this year – even though its legal duties haven't changed.

Argued that, with mental health law reform, it's about prioritising the biggest, most important things instead of trying to get things done as quickly as possible.

Agenda item 5 – AOB

School building design

Off the back of the last CPG meeting, the Convenor presented some of the work being

done regarding new build schools (the noise and environment for autistic children).

He suggested representatives of the CPG meet with Scottish Futures Trust

He, Marion McLaughlin & Suzi Martin met with them last week and discussed a number of issues around how school building designs impact autistic children.

He will follow up with Aberdeenshire Council then might ask groups on this call to get in touch with local authorities where they are to again ask similar questions. One of the concerns was with 32 local authorities all doing their own thing. The Convener is also going to write to the Architecture and Design Scotland and the Royal Institute of British Architects.

There are a number of upcoming events related to this work, such as Learning Places Scotland Conference and the Scottish Future Trust's Learning Meetings which could provide another opportunity for discussion.

LDAN Bill

The CPG received a letter from a Maree Todd MSP regarding the LDAN Bill which will be shared after this meeting. The Convener expressed that disappointment would be an understatement and a lot of people have already expressed that view. The Convener proposed writing to the minister to invite her to come and respond to the group in some format.

Scottish Human Rights Commission

Fiona Clarke wanted to speak about the Scottish Human Rights Commission's response to the Scottish Government coming home implementation plan.

Fiona mentioned that she was on the Project Group and wanted to let the CPG know that within the next few weeks the Scottish Human Rights Commission will be publishing research and their report and recommendations after a project that looked at people living in institutions. She asked everyone to keep a look out for this and please share amongst networks and media etc.

The SHRC is also going to publish a tool that everyone can use to measure the extent of institutionalisation for different living options and different situations for people. Fiona explained that this is a tool that can be used by everyone.

Agenda item 5 – Convener's reply

The Convener thanked speakers and everyone for attending and commented that he is just waiting for another date and time to be confirmed for the next CPG so will get this out to everyone shortly. He noted it will also be the AGM and the topic will be 'The Autistic Employment Gap', which will be a hybrid meeting.