Cross Party Group on Autism

20th September 2021 at 2.00 pm via Zoom

Minutes

Attendees:
Alexander Burnett, MSP (Chair)
Daniel Johnson MSP
Finlay Carson MSP
Jean Foggarty (Minutes)
Rory Paterson, NAS
Anna Kynaston, Scot Govt
Jacqueline Cameron, Scot Govt
Suzanne Kinross, Scot Govt
Kabie Brook, ARGH
Annie Wells MSP
Stephanie Callaghan MSP
Rob Holland, NAS
Jason Henderson NAS
Lucy Mulvagh, ALLIANCE
Fiona Clarke
Rodger Watt, Scot Govt
Fergus Murray, AMASE
David Nicholson
Aurora Constantin
Billy Alexander
William Rae
Jill Rattray
Carolyn Kennedy
Anne White
Pauline Grigor
Rachel Birch
Ruth Young
Billy Alexander
Karen Delaney
Jay Brownlee
Richard Ibbotson
Dr. Claire Evans-Williams
Pete Mathews
Sheila Mackay
Linda Singer
Kirsten Mutch
Tracey McFall
Helena Cundill
Jocelyn Peace
Louise Moth
Anna Nicholson
Marion McLaughlin
Paul White
Annette Masson
Stephanie Bain
Dr. Catherine Compton
Wendy Ferguson
Jerry Edwards
Callum McCrosson
Carolyn Kennedy
Gill Shuttleworth
Dawn Ranson
Kate Monaghan
Lorene Amet
Angie Ferguson
David Campbell
Jenny Rae
Rebecca Marshall
Andy Williams
Michelle Graham
John Greenwell
Angus Nelson
Susan Chambers
Jasmine Ghibli
Frances Holborn
Dr Catriona Stewart
Rachael Davis
Maria Chan
Catherine Steedman
Anita Patel
Stephanie Snedden
Dorry McLaughlin
Tom Wrightman

1 Welcome & Introductions

Alex Burnett MSP welcomed everyone to the meeting – stating it was the first meeting of the new Parliament & that the CPG on Autism is one of the best attended Cross Party Groups. AB also confirmed the chat function could be used for questions & comments and no photos or screenshots should be taken.

Apologies were confirmed from Oliver Mundell MSP, Cath Purdie & Charlene Tait.

2 AGM/Re-registration of CPG

AB noted that those on the Cross Party Group distribution list had received the information already regarding the process, before confirming the proposed purpose of the group as "To raise awareness and promote the interests of autistic people, their families and carers, and to act as an influencer of government policy". AB also confirmed that the proposed Office Bearers were himself & Annie Wells as Co-Conveners, with Scottish Autism & National Autistic Society Scotland continuing as the Joint Secretariat. Annie Wells MSP formally proposed this, with Daniel Johnson MSP seconding.

AB then acknowledged the MSPs membership of the CPG in the new Parliament – Jeremy Balfour MSP; Stephanie Callaghan MSP; Finlay Carson MSP; Daniel Johnson MSP; Fulton McGregor MSP; Carol Mochan MSP; Oliver Mundell MSP & Mark Ruskell MSP, as well as Alexander Burnett MSP & Annie Wells MSP. Additions to the non-MSP membership were confirmed as Eddie Fowler, Sheila Mackay, and Education Scotland.

Daniel Johnson MSP raised a query regarding Education Scotland's membership & possible conflict with their role as a government agency. AB stated he would report back on this. A number of other organisations in attendance expressed an interest in joining the secretariat of the CPG and AB confirmed that this will be explored in the future.

3 Scottish Government Update: Working with Autistic People and People with a Learning Disability

Jacqueline Campbell introduced Rodger Watt, Team Leader, and Suzanne Kinross, Lead Policy Officer on Autism, before giving an update on the recent engagements.

JC confirmed that there are three Ministers with an interest in this area – Kevin Stewart MSP, Minister for Mental Wellbeing & Social Care; Clare Haughey, Minister for Children & Young People; and Christina McKelvie, Minister for Equalities & Older People. They will work between all three Ministers depending on the issues are arising.

JC gave an update on a new approach involving people with lived-experience that had been developed between the Scottish Government, stakeholders, autistic people & people with a learning disability. Open discussions have taken place during the pandemic & work has been done to respond quickly. The Scottish Government had sought to develop solutions to make a difference in everyday life & bring together policies at a national level, and an agreement had been reached to fund Autistic People's Forums regarding what life is like now & what is needed. Separate discussions will take place with people with a learning disability, and with parents & carers. These discussions will be regional & open, with the first session on mental health. Once the three groups come together there will be groups from the public, third & private sectors who will help to implement solutions.

The first session is set to take place at the end of the year before bringing the wider group together in earlier 2022.

4 A National Care Service for Scotland

The Scottish Government has set out proposals on the National Care Service in Scotland & the consultation is currently open with a deadline of 2nd November 2021 (consultation available at: https://www.gov.scot/publications/national-care-service-scotland-consultation/). Anna Kynaston, Deputy Director for the NCS Division, gave an overview of the discussions regarding the National Care service & signalled a desire to hear views on the social care in Scotland & how it needs to improve.

The priority of the consultation is to engage with as many people as possible, both those accessing services & those working within the systems, to ensure proposals, changes and ideas are improved with front-line and first-hand experiences. There is ongoing work on the proposals & an independent review – it is recognised that change is needed as there is a huge implementation gap between people in receipt of community help & social care services, and how services are delivered. High-level proposals include bringing forward a National Care Service for Scotland that would be responsible directly to Scottish Ministers, with a responsibility for National Care standards, quality & complaints. This delivery must be managed at a local level – Community Health & Care Boards who will be responsible for the commissioning & delivering of the services. It is recommended that local authorities are represented on these boards alongside professionals & members of the community to enhance that local approach.

Timescales are tight & AB will keep the CPG updated of these & next stages of the process.

5 Living life to its full potential: the future of social care in Scotland

Lucy Mulvagh, Director of Policy & Communications at the ALLIANCE, addressed the Scottish Government on its social care proposals & the Alliances' member responses to the consultation document so far. LM explained that Covid-19 has impacted all aspects of our lives, including the pre-existing issues within social care in Scotland & the Alliance has called for a radically different approach. Several elements are based on the recommendations of the Independent Review of Adult Social Care. Alliance have several actions that they think are crucial of the creation of the NCS & will be highlighting these both through the consultation process & in a briefing.

The main points this will be addressing are: supported decision-making, equality & human rights, and investment in social care. The final point made by LM was around human-rights budgeting - public resources are still limited & consultation proposals will be assessed for value for money to make sure the maximum impact is achieved from that investment.

6 Doing Better, Together

Fiona Clark introduced herself as an autistic individual who works to improve the lives of autistic people & their families. FC focused on human rights in social care & the need to work together to do better, highlighting a lack of the right type of support. Good models of practice were recognised but FC also stated that there is a lack of accountability at national & local levels, which requires a system redesign.

FC stated that all autistic people & their families will need support at some stage, and so it is vital to remove barriers, misconceptions & stigmas. It was also stated that the National Care Service consultation itself is far too complex, making it inaccessible for lots of autistic people. Scotland needs a system with a collaborate approach across all areas, and a move from person-centred to person-led.

Any reformed system will require rights-based approaches & transparent processes, with active & meaningful participation of those who use such services at every level. People with lived experience are the experts on their needs & the NCS provides a huge opportunity to work together & do better.

7. Discussion – National Care Service

AB stated that the discussion part of the meeting was an opportunity to make this a listening exercise for those from the Scottish Government in attendance, and a chance for attendees to have their say.

Tracy McFall commented on the importance of a National Care Service built around families, which come with a range of complexities rather than individual needs & reiterated that the focus should be on families. AK responded that there was a firm belief that moving forward we need to take that holistic approach & asked TM to tell the Scottish Government more on ‘the how’ as she will have more experience in this area.

Dawn Ranson stated that the National Care Service consultation isn't appropriate. DR felt that questions are leading, being pushed into a direction without actually being about real consultation. DR stated that Derek Feeley asked for radical change in social care. DR explained she is autistic & is self-employed helping people go through the SDS community broker. AK stated that the Scottish Government are seeking commentary exactly like that from

DR & explained that the consultation proposals are a strawman designed to start the conversation.

Susan Chambers agreed with DR regarding the restructure. SC commented that consultations, strategies & frameworks do not mean very much unless you have somebody driving & committed to the policies. SC stated that the Government has a poor record on policies & that we are still waiting on the independent report which was carried out by Blake Stevenson on the Autism Strategy which was meant to be published. Rodger Watt, via the chat, flagged that the evaluation was due to be published shortly.

AB agreed with the point made regarding policies not being followed up. AB asked if there is anybody on the CPG that has questions on various policies & where they are at or if they have not been delivered. These will be questions for Parliament – anyone who has concerns can wait till a CPG meeting contact your MSP & ask them to raise them on your behalf.

LM commented that SC has made an important point regarding accountability. It is an issue that comes up again & again. The ALLIANCE are keen that equality and rights are embedded in the system. What gets put into this legislation is essential & have to try & get more things right in the first place.

AB explained that the consultation will only be the first stage of such a bill, there are other opportunities as it progresses through parliament for amendments & lobbying on particular points. The more that can be included in the early consultation stage, the easier it is to refer back. There will be other opportunities to raise these points as a bill progresses through parliament.

AB confirmed that Aberdeenshire Council has started on their strategy. AB also confirmed that he had met with NAS & COSLA recently due to ongoing casework involving autistic children. Rob Holland commented that NAS met with COSLA to discuss various topics, and will be raising issues with the COSLA Children & Young People Board in the coming months.

FC stated that autistic children are dealing with hostile environments & their rights are not being met. Everyone - including local authorities and the Government - needs to do stuff now to raise the bar, not wait for a few years down the line. AB highlighted the often lack of consistency between local authority areas. SC agree with FC’s comments, stating the need to improve the life of autistic children in schools as very little has changed in 20 years.

It was raised that autistic people are not necessarily used to the format of discussion used for parliamentary groups such as the CPG, with formal language often being used which can be difficult to grasp. It was suggested that a better way to prepare autistic people for these discussions could be explored. AB acknowledged some of the issues around the way in which CPGs are conducted.

8. Response from the Co-Convener

AB apologised for some of the jargon used during the meeting, particularly during the AGM & re-registration process, and stressed that the parliamentary language is usually kept to a minimum. AB suggested making contributions to the NCS consultation as detailed as possible. AB thanked the speakers & attendees.

9. Date & Topic of Next Meeting

To be advised.

10. AOB

Chat Function Contributions

Kabie: I think you need to address secretariat addition requests
Fergus Murray: AMASE and ARGH have informed the NAS and Scottish that we would like to be added to the secretariat for this CPG. Susan Chambers has just stated that Pasda would also like to be added.
Dr Catriona Stewart OBE SWAN: It would be a good idea at these meetings to have a couple of people who take on checking the text chat.
Dr Catriona Stewart OBE SWAN: Several of us have had our hands up for some time, too, so it would be good to have that kind of support for the chair as well.
Dr Catriona Stewart OBE SWAN: The secretariat should be shared between the national charities, and others, especially those led by lived experience. So that would be PASDA, AMASE, ARGH, SWAN, Triple A's and AUScotland.
Dr Catriona Stewart OBE SWAN: But it probably could get too unwieldy…
Richard ibbotson: There is also "Spectrum Voices' a new (ish) APO
TraceyMcFall, Partners in Advocacy: INLUDES CHILDREN AND YOUNG PEOPLE AFFECTED BY A RANGE OF DIFFERENT ADVERSITY INCLUDING AUTISM - THERE MAY BE SOME LEARNING WE CAN TAKE FROM THIS
Fergus Murray: We just need some autistic representation - specifically, representative DPOs - in the secretariat, for oversight, and accountability to the main community affected. As per the UN CRPD Article 4.3 and General Comment 7.
Dawn Ranson: Am very concerned having read the Easy Read Version that the NCS Consultation not only isn't particularly Easy Read and that it is leading people in a certain direction. I am an autistic person, who works in the Social Care profession. My concern is it is very different from the recommendations in the Independent Review of Adult Social Care. Very poor consultion.
Fergus Murray: I don't think insisting that anything people want minuted should start with a C is helpful or accessible. There should be parity of esteem for different modes of communication.
Dr Catriona Stewart OBE SWAN: I didn't know that; I'd like everything I've put in chat to be minuted please. I'll use C going forwards.
Dawn Ranson: Can you tell us how many actual people with Autism are on the Secretariat?
Jay Brownlee (NT): as with many aspects of care for my autistic children the issue is often just accessing services. My eldest has been waiting 9 months so far for a children disabilities social worker so cannot access services yet as she has not been assessed for a care plan. and that doesn't take into account the 6 years between me asking for help and her receiving a diagnosis as the CWD team couldn't even place her on the waiting list till she was diagnosed.
Sheila Mackay: I live in Perth & Kinross and we seem to have few specialist care providers. There are also issues with lack of capacity and so even when needs of people with autism are identified, they can't be met.
Pauline Grigor- Borders Additional Needs Group: The third sector provide vast amounts of support but dont have the resources, integration or alignment - Early Intervention is critical to our community. Lived voice must have a say and be engaged in Strategy
PAUL WHITE: Would the Community H and SC Boards replace Health Boards as well? Duplication of the responsible bodies has led to divisions in care and excessive bureaucracy!!
Fergus Murray: There need to not just be openly autistic people on the secretariat, but also people who are accountable to the autistic community, which is to say DPOs (as per the CRPD, as above).
Marion McLaughlin OSSAberdeen: Agree, having the APOs in Scotland consulting with each other on this sounds sensible too
Dawn Ranson: Seems to me the Consultation has be written with the decisions already made.

Dr Catriona Stewart OBE SWAN: Yes, not sure we need to take on more responsibilities right now either at SWAN; if AMASE/ARGH happy to represent autistic folk then perhaps they could consult with OSS Aberdeen, Triple As and SWAN in between CPG meetings to check in if there's anything we want to bring to any agenda etc. Happy to discuss in any case.
susan chambers: Thanks Lucy. HR are essential but who will drive the implementation?
davidmartinnicholson: Great presentation Lucy. Excellent to hear that the Alliance is putting Human Rights at the very heart of their response.
Kabie: National Autistic Task Force Guide to Quality Care for Autistic People: https://nationalautistictaskforce.org.uk/wp-content/uploads/RC791_NAT_Guide_to_Quality_Online.pdf
Kabie: human rights breaches such as PBS (ABA)
Dawn Ranson: That was the best presentation I have heard from anyone in a long time. Not much is said about SDS and Independent Support especially in relation to autistic people.
Anna Nicholson: Congratulations to Fiona on such a clear and important presentation.
davidmartinnicholson: Well done on a superb presentation Fiona.
Kabie: Great presentation Fiona, thanks
Dawn Ranson: how many people with autism are part of the Secretariat
susan chambers: Thanks Fiona. Not all autistic people can express themselves easily even if they have speech. They also need someone who can interpret for them often parents/carers..
Anna Nicholson: In relation to what Susan said, this forum is sadly inaccessible for many Autistic people. Many of us find it difficult to process speech quickly, and need more time to respond than would be possible in this format.
Anna Nicholson: What was meant by 'early intervention' being key in this context? Often when talking about Autistic people, this is ABA or PBS, which is not appropriate. Societal/structural change is far more important then 'intervention' in many individual cases.
Richard ibbotson: Access to a range of informed advocacy is essential but it not equally accessible for all.
Billy Alexander (Grampain Autistic Society): essential whole family approach to adult social care,, aligning with The Promise and care review
Anna Nicholson: Families are important, but not everyone lives in families.
jillrattray: It's essential that families are only involved to the extent the autistic person wants them involved.
Fergus Murray: regarding the idea of 'early intervention', this recent chapter from two Edinburgh academics and an autistic researcher is excellent and well worth reading. https://osf.io/zrfyp/
Fiona Clarke:
were disabled people or others with lived experience involved to co-produce the consultation? The questions would seem that no.
susan chambers:
Sometimes families are the "problem" but not always. There are skilled people required to know when the autistic individual is expressing their views.
Fergus Murray: key passage from that chapter: 'While "intervention"refers to strategies intended to bring about a behavioural or other change in an autistic person, "support" generally refers to an external change or accommodation that can benefit autistic people. Although both may have their place to varying degrees for autistic children, there is currently a disproportionate emphasis on "interventions" and a lack of "supports". '
Anna Nicholson: Support, not intervention, is what we need, in those terms, Fergus.
jillrattray: When we're looking at care of autistic people, and neurodivergent people in general we need to be looking at what care is. Too often it's do you need someone to do x, y & z for you, not what assistance do you need to do x, y & z.

Dr Catriona Stewart OBE SWAN: The evidence to support this trope of 'early intervention' is flimsy at best; the most likely thing is that for some families, being informed at an early stage of their children's lives can be really helpful all round. For others, it just isn't. The prevailing narrative of autism that tells people their children/they won't be able to access their human rights ie employment, social inclusion, have relationships or families is the worst thing, damaging in itself and a disaster for teenagers who are just facing the prospect of an adult life they can't imagine our picture themselves in anyway.
Dr Catriona Stewart OBE SWAN: I get tired of hearing about all the ways in which autistic people need support/supported. All people need supports of varying kinds what we need is inclusion and for our human rights to be made accessible.
Tom Wightman (Pasda): We can get funding from SDS, but where do you go to get the services that are needed. They don't exist, so money can't buy them.
Anita Patel (Independant): Agree with your statement Dr Stewart. ASD brings a 'spiky' profile, individuals have differing needs
Dr Catriona Stewart OBE SWAN: Thanks Anita and that's a good point.
Sheila Mackay: I agree Susan. As another parent who's been around a while, there are so many great plans and strategies sound great but so little implementation and action.
michelle G: Michelle Graham, Scottish Advisor on PDA Society Enquiry Line - Listening to Autistic Adults, Children & Carers throughout Scotland, I feel that we are underestimating the level of crisis & the lack of dignity / respect given by LA's. We need support and change to happen quickly to lesson the level of burnout & stress being experienced. I welcome the consultations but I also worry about actions becoming reality.
Sheila Mackay: Where are we at with mandatory autism awareness training for all health and social care staff? If staff are unaware, they are unlikely to understand needs.
Dawn Ranson: Alex Burnett - never heard anything when I offered my views for Aberdeenshire strategy.
Anna Nicholson: Telling autistic children to deal with a hostile environment because 'that's the real world', as Fiona says, is no better than telling wheelchair users to get used to steps 'because that's the real world'. (Ideally that wouldn't be the case.)
Anita Patel (Independant): Schooling Counselling should be available to every child in Scotland in school over 10 years old. The co morbid conditions that may be experienced could be supported through the school counsellor
Dawn Ranson: Could we have the text of the chat forwarded with the minutes as some useful contacts there.
Dawn Ranson: Female autism can be very different and needs to be highlighted too.
Pauline Grigor- Borders Additional Needs Group: Should their be a reference steering group of Autistic people that is supported to promote engagment
susan chambers:
agree with Paultine's proposal but it will only capture a few people. At least it is something.