



Members Meeting Minutes

Online via Zoom

Wednesday 22 March 2023

10.30am – 12.30pm

Present:

Tanith Muller – NaoS Chair / Parkinson's UK
Clair Cairns – Coalition of Carers
Beth Strachan – Child Brain Injury Trust
Charlotte Encombe – Compass
Colin – Headway Dundee and Angus
Emily Holmes – Neuro Hebrides
George Allan – Post Polio
Jonathan Sher – QNIS/HPBL
Jules – PSPA
Katie Rigg – MSA Trust
Mary Ramsey – Scottish Tremor Society
Ross Cunningham – Epilepsy Scotland
Emily Beard – Epilepsy Connections
Steve Portelly – FND Hope UK
Vicky Cahill – Alzheimer Scotland
Anna Telford – Epilepsy Scotland
Matt – Muscular Dystrophy UK
Ewan Dale – ME Association
Ron Culley – Quarriers
Stephanie Fraser – CP Scotland
Alistair Haw – Scottish Huntington's
Alice Struthers – NAOs
Lorna McGee – NAOs

Apologies:

Helen MacDonald – Lanarkshire Epilepsy
Olivia Bird – MyName'5Doddie
Shirley Maxwell – Epilepsy Connections

1	<p>Chair’s welcome and Scottish Government update (NACNC)</p> <p>The Scottish Government is currently in a period of uncertainty due to the new leadership campaign. We are likely to see some change coming in the coming months.</p> <p>The National Care Service has been paused at stage 1 until June 2023. The Minister for Mental Wellbeing and Social Care MSP Kevin Stewart has voiced confidence that it will proceed as planned in due course.</p> <p>The recent Scottish Government exercise to quantify numbers of those with neurological conditions has attracted a lot of interest within NAOs membership. Unfortunately, there are gaps in the SPIRE data (with only 12 out of 14 health boards to have submitted data), as well as potential differences with the coding of certain conditions or symptoms. Thank you to all NAOs charities who sent in their own neurological conditions prevalence estimates which you can see here.</p> <p>Further talks with Scottish Government indicate that further to publication of their data, a new coding system (SNO-MED) is to be introduced in Scotland, which should be easier for GPs to use. We have no clarity at this stage of the expected timeline for implementation of this new coding system.</p> <p>NAoS has made clear to Clinical Priorities Team that the issue of data and its accuracy are still very important in order to plan services.</p> <p>We have also raised our concerns following Audit Scotlands’ report: NHS in Scotland: 2022 which states “workforce capacity is the biggest risk to NHS recovery” and also notes that there “has been a 17 per cent rise in people who can't leave hospital because often the social care they need is not available.” The report raises issues with neurosurgery, which is one of the specialities with the highest proportions of in patient/day case treatment waits of over a year. with the highest proportions of patients waiting more than a year.</p> <p>We have recently joined a new workforce subgroup of the Redesign Programme Group which will look in more detail at specialist nurse provision.</p> <p>We are still awaiting news regarding round four of funding from Scottish Government and framework but expect to have more news on this in the next few weeks.</p>
2	<p>Presentation of the NAOs Carers Mapping Project</p> <p>Between January and March 2023, NAOs issued a survey to carers’ centres across Scotland as well as to our members.</p> <p>We were commissioned by the Scottish Government to engage with Carers Centres to understand what information and advice, as well as training, is given to people caring for those with a neurological condition at Carers’ Centres across Scotland. Separately, we wanted to see how our members work with carers centres as well as what services and information is provided to carers.</p>

Many thanks to those members who participated.

We can see there's already a lot of interaction between charities and unpaid carers, and carers' centres and charities. And it's good to see that there is an appetite for greater engagement between the sectors.

Whilst what we have discovered is reassuring, we note that much more can be done. Across Scotland, Carers' Centres are already highly likely to be referring carers to condition specific charities including neurological charities. General training and education rank highly on the list of their services. But we believe that more can be done to support people caring for those living with a neurological condition – for instance by increasing the neurological support training available.

Following this research, we have invited Carers' Centres to join NAOs as associate members, which allows us to work more closely together going forward. This will help us as we work through the recommendations in our report.

[Click here to see the presentation given at the meeting](#)

Actions

Our [Carers Centre Mapping](#) report sets out short, medium and long-term recommendations. We have started to implement the short-term recommendations. Capacity limits are such that we may not be able to deliver all the recommendations without further funding.

3 Coalition of Carers in Scotland – supporting carers of people with neurological conditions and opportunities for future collaboration.

We welcomed Claire Cairns from the [Coalition of Carers in Scotland](#)

Claire delivered a presentation "[Supporting carers of people with Neurological Conditions](#)"

Claire highlighted the very difficult times that unpaid carers have experienced since start of pandemic. Most carers' centres would advise that their services are still not operating a full capacity since the pandemic. This is mainly due to the increased demand on services which they cannot keep up with.

A recent internal survey indicated that many carers suffer with poor health, which has worsened since the pandemic.

Only an estimated 1 in 10 carers are involved with their local carers' centre. Many unpaid carers do not seek support from carers' centres. Certain stigma remains about being a carer, and many do not identify as one. However, this means that they could be missing out on financial and practical support.

	<p>All carers' centres are independent and get funding from their local authority, however most also need to fundraise in order to operate.</p> <p>Since the start of the pandemic, carers' centres have moved lots of services online with more use of social media and online events. This has been great to raise awareness and accessibility but has also seen demand grow.</p> <p>Most carers' centres have a programme of training for carers that they offer, for instance medication and manual handling.</p> <p>Lots of carers' centres choose to independently fundraise in order to be able to provide counselling. This means that counselling as a service is not widespread across all centres. Counselling has been in huge demand since the start of the pandemic with demand still high.</p> <p>Overall, there is a good flow of communication between Scottish Government and carers' centres. This is a positive change seen since the start of the pandemic.</p>
4	<p>Q&A</p> <ol style="list-style-type: none"> <p><i>1. Very interesting to hear about the great work underway to support those caring with people with dementia. A lot of political work is required to build those alliances and raises issues about caring for those with dementia, which in turn has led to dementia service being prioritised and provided. What can we learn as the Neurological Alliance to support other complex conditions?</i></p> <p>Yes, dementia is a good example, but in the carers movement we campaign for the rights of carers. Campaigns often focus on lived experience, that seems to be most successful when speaking with politicians. The voice of lived experience was involved at every level and was therefore included when thinking about a carer's strategy. Dementia has one of the highest numbers of referrals to carers' centres which is why it has been a big focus. Like a lot of policy work, it is in chipping away consistently that finally gets the message through.</p> <p><i>2. Is there a clear relationship between poor medical recognition or service provision and difficulties in getting recognition of caring needs? Within the neurological community there are several conditions that this will resonate with, where people are left unsupported.</i></p> <p>It is incredibly difficult to get social care support, particularly if you don't have a diagnosis. Now that we are coming out of the pandemic, our experience is that services are still not back to full capacity, and the need for social care support is greater than ever.</p> <p>We currently have far from a perfect system but there is some support out there and carers' centres want to provide it to anyone who needs it – so please reach out to your local centre if help is needed.</p>

3. *Comment - We can confirm that voice of lived experience has been so important in our campaigning at Alzheimer Scotland. We are constantly pushing for services and recognition.*
There is a distinction and difference between carers centres depending on their location within the country, and developing relationships generally happen at a local level.
4. *There are challenges trying to get support when nobody knows what you are dealing with. This doesn't just impact getting a diagnosis. Rare conditions are complicated and there is often a lack of understanding of the demands of care for that condition. How can we support families and individuals when there is a rare condition involved? Carers' centres are very person-centred organisations, but can you give us a practical example of what we can suggest to our members?*

There are plenty of overlaps and similarities between conditions and the experiences seen in carers' centres. For staff, there are training opportunities to learn about different conditions. The training expertise sits in the NAOs network; can NAOs charities offer training/insights to staff? Realistically, carers centres can't possibly know about all rare conditions unless someone has come through their door and then we can put procedures in place supporting staff to access training in order to upskill in this area.

Carers' centres also share good practice and support each other where a new situation arises that we need help with. This means that although we might not have specific experience with a situation or condition, we can learn how other centres have dealt with it. This is helpful with rarer conditions.

5. *Discussion held about how we can signpost between carers centres and specific charity organisations. Follow up research is required to see how this signposting could work and if it is effective.*
Carers centres are already overworked and have no spare capacity.

Our overall experience is that referrals to carers' centres are up by 50% in some areas. In other areas, referrals are up 200% (since the pandemic). This increase in referrals hasn't been matched with increased support and resources. Carers' centres will of course respond to anyone who comes through the door, but it can take more time.

During the pandemic there was an awareness campaign: 'phone the helpline' to get referred to a local carers' centre. The uptake numbers were low, but the uptake of those who registered for the vaccine and winter recovery fund were high. We learnt that to motivate people, they need to be given a tangible reason to get in touch with a carers' centre and for clarity over the services and support that they will be able to access there.

6. *How can we help the families and carers of those supporting someone living with a neurological condition? There are strong emotions involved with the change of a relationship and being identified as a 'carer' rather than a parent or partner.*

How do we help people overcome their discomfort in defining their role as 'a carer' against being that person's sibling, partner or parent.

Lots of people don't like being defined as a 'carer'. The language needs to be clear, for instance by asking the question: 'do you help to care for someone?' We can only help those who identify themselves as carers. We need to reach more unpaid carers as families could be missing out on vital support that they might need.

Claire was thanked for her presentation and for answering all our questions.

NAoS Chair noted that organisations can be very focused on the person with the condition but support for carers is starting to become a developing area of work for many of our organisations. Being able to hear from Claire today is a great help to that developing change.

5 **Neurodiversity Commissioner Bill – where do NAOs members stand on it?**

NAoS Chair introduced Ross Cunningham (Epilepsy Scotland) to the group. Ross is also a NAOs Trustee. Ross introduced a discussion regarding the number of commissioner roles on the horizon and whether there is a conflict between the roles of the [Disability Commissioner](#) and the [Autism, Learning Disability and Neurodiversity Commissioner](#).

At the beginning of 2021, [Enable](#) and [Scottish Autism](#), launched a campaign '[Our voice, our rights](#)' calling for a Commissioner for autistic people and for those with learning disabilities. Overall, this received cross party support, with many parties making a commitment to this campaign within their [2021 manifestos](#). Notably the SNP manifesto committed to legislating for a Commissioner as part of a new Autism, Learning Disability and Neurodiversity Bill.

In a [previous policy group meeting we heard from Jeremy Balfour](#) -who proposed the introduction of a Disability Commissioner role.

NAoS responded to the consultation about introducing a Disability Commissioner. You can read [our response here](#).

There remains the argument that a broad-ranging Disability Commissioner would be unable to support the specific needs of individual conditions. Potentially, commissioners with a narrower focus might be better able to manage those needs.

There is still a lack of detail around a future Disability Commissioner and how this role would operate.

The perspective from Epilepsy Scotland is that about 1 in 5 with epilepsy also have a learning disability. Other charities may also see an overlap with learning disabilities amongst the people they support.

There is value in having a Commissioner to support people with learning disabilities and epilepsy, however with the development of the Disability Commissioner, there are concerns that people might be passed between more than one Commissioner. Another concern is if the remit of a particular Commissioner is too large, it may lead to a dilution in the services that they can provide.

Both bills are in development and there are ample opportunities for the third sector to get involved in shaping them.

Subsequently to this members' meeting, NAOs has joined the organisational stakeholder list for the Autism, Neurodiversity and Learning Disability Commissioner bill.

Comments from other members:

A Disability Commissioner could cover all types of disability, not just physical disabilities. There are potential concerns that if the remit of a Commissioner is too big, this could lead to the Commissioner being unable to help with individual issues or the specific needs of individual conditions.

In terms of timing, we are not expecting the Autism, Learning Disability and Neurodiversity Bill to be introduced before this autumn (2023). We believe it could be compatible to have a Commissioner for Autism and Learning Difficulties alongside a Disability Commissioner. There will likely be some overlapping within their roles, but they would not necessarily be in competition with each other.

However, a drawback of these bills is that the appointment alone of these Commissioners is not going to solve the issues faced by disabled people in Scotland

Eight different Commissioner roles are currently being discussed:

1. Commissioner for Ethical Standards in Public Life in Scotland.
2. Scottish Biometrics Commissioner.
3. Scottish Commissioner for Children and Young People.
4. Scottish Human Rights Commission.
5. Scottish Information Commissioner.
6. Scottish Public Services Ombudsman.
7. Standards Commission for Scotland
8. Patient Safety Commissioner

	<p>Whilst NAOs cannot get involved with consultations on each of these Commissioners, our members may want to be involved individually as these commissioner roles take shape.</p> <p>Update: The Scottish Government has recently published research about Commissioner roles.</p>
6	<p>Summary of our Brain Awareness Week campaign</p> <p>This was the second year that NAOs ran a Brain Awareness Week campaign. This year it was a great success, with a social media reach of 450,000+. Thanks to all members who got involved with either designing the infographics or contributing to some of the key messages within them.</p> <p>We expect to start planning for BAW'24 from Nov '23. There will be many opportunities for our members to get involved from creating messaging and graphics and we look forward to working with you again.</p> <p>We would like to thank Ross Cunningham (Epilepsy Scotland) for creating the video that we included in our campaign – this was really popular on social media platforms, reaching much greater numbers than the individual posts. Thank you to all members who submitted a clip to make the video possible. You can watch it here.</p> <p>Twitter report attached</p> <p>Facebook.</p> <p>1st posts – very well received, 600+ reach, by end of the week only achieving 50-100 reach. The video had a reach of 700+, 50+ reactions and 18 shares over the course of the whole week, we reached over 3,000 accounts.</p> <p>We gained 15 new followers in Brain Awareness Week and had over 700 visits to our page.</p> <p>We reflected on feedback from members who did/did not get involved.</p> <p><i>Compass</i> – great success for minimal effort and no budget etc, Compass has a number of videos out at the moment with a treadmill and suits, rehab options. Want to promote this equipment.</p> <p><i>Epilepsy Scotland</i> – really good response. Suggestion of charities doing a video each month to share going forward. Could be a spotlight month and the charity submits a video to NAOs to share.</p> <p><i>Alzheimer Scotland</i> – social media campaign with Brain Health Scotland already planned for Brain Awareness Week. Focused on preventative measures. Brain pledge, 1 small change. No specific numbers at this point. Planning starts much earlier than NAOs did.</p> <p><i>ME Association</i> – good Facebook response of first graphic, over 9,000. Over the course of week, engagement dropped. Own graphic messaging stayed quite strong.</p> <p>Good week generally.</p>

	<p>The conclusion from the campaign was where the charities tailored the messaging to their condition, engagement seemed higher overall. The suggestion is that this is made a focus for future years' campaigns.</p>
7	<p>AORB NAoS visited Scottish Parliament with the Scottish Tremor Society last week. The Scottish Tremor Society and the National Tremor Foundation organised the event to raise awareness of the lack of NHS funding for focussed ultrasound in Scotland. It was a very well attended event, which the Minister for Women's Health, Public Health and Sport was also attended.</p>
8	<p>The next meeting date will be 24 May 2023, 10.30am – 12.30pm</p>