**Policy Group Meeting Summary**

**9 March 2022**

**Attendees:**

Sue Millman, Ataxia UK, Chair

Andrew Montgomery, Social Security Scotland

Francesca Pacitti, Social Security Scotland

George Allan, Scottish Post-Polio Network

Carol Cochrane, Brainstrust

Jonathan She, QNIS

Ben Peter, Scottish Huntington’s Association

Shirley Maxwell, Epilepsy Connections

Gillian Robinson, MS Therapy Centre Edinburgh

Jonathan Marc-Gillan, MS Therapy Centre Edinburgh

Claire Winchester, MS Trust

Keith Park, MS Society Scotland

Colette McDiarmid, MND Scotland

Dr Jane Haley, MND Scotland

Anna Telfer, Epilepsy Scotland

Jules Brown, PSPA

Leigh-Ann Little, The Oxygen Works

Ewan Dale, ME Association

Alice Struthers - NAoS

Charlotte Sarrau - NAoS

**Apologies:**

Gerard Anderson, CBIT

Karen Garrott, Stroke Association

Jacqueline Munro, MDUK

Andy Wynd, SBHS

Rachel Maitland, MND Scotland

Stephanie Fraser, Cerebral Palsy Scotland

Michelle Keenan, Edinburgh Headway

Anna Hunter, CP Scotland

Victoria Wareham, Dystonia UK

Paula MacGillivray, MS Society

Jean Beaumont, Myaware

Summary of the Meeting

1. Chair’s welcome

Our Chair for the meeting, Sue Millman (Ataxia UK) welcomed the guests from Social Security Scotland and then each member of the group introduced themselves and summarised what they were looking to get out of the meeting.

1. Action points from previous meetings – follow up

We are up to date on all action points bar one, which was a suggestion made at the previous policy group meeting and was then reinforced by members at the Members’ Meeting in February. NAoS is to write to the Health Minister Maree Todd MSP about the Women’s Health Plan which doesn’t mention neurology. This could be an opportunity to flag up any distinctive ways that women are affected by neurological conditions that are not addressed by the framework for action.

Action – Jonathan Sher (QNIS) has agreed to take this forward with Alice

Awaiting info – We haven’t yet had a response to our invitation to Kevin Stewart MSP to come and speak to NAoS members at a future Members’ Event, but we will update with news as and when we hear more.

1. Social Security Scotland – update from Andrew Montgomery, National Engagement Lead

Andrew introduced himself and his colleague Francesca Pacitti from Social Security Scotland (SSS). As National Engagement Lead, Andrew is responsible for signposting and referrals and is looking at ways that charities can refer into SSS. SSS have created a [charter](https://www.socialsecurity.gov.scot/about/our-charter) which sets out what people can expect from the Scottish Government and SSS. As part of the charter, SSS commits to creating a service which will help individuals access everything they are entitled to. Signposting and referrals are ways in which SSS can ensure people get access to organisations which could improve their wellbeing or financial circumstances. Andrew and Francesca will be working with policy colleagues involved in the Scottish Government’s income maximisation policy, benefit take-up strategy and Child Poverty Action Plan to ensure that signposting and referrals are built into policies under development.

There are two main projects underway:

1. The Advocacy Project, which started in February 2022 and is being managed via [VoiceAbility](https://www.voiceability.org/support-and-help/support-to-access-benefits-in-scotland), provides access to independent advocacy services to disabled people applying for a SSS benefit. When an individual requests an advocate, SSS will make a referral to VoiceAbility. SSS will look to test this referral pathway to determine whether the referral process is a good and manageable journey for people or not.
2. The Local Delivery service, delivered by SSS, provides advice regarding SSS benefits and supports people in their application. This service taps into the wider support and advice organisation network within the local area, allowing Local Delivery to signpost individuals to organisations in the area that may be able to provide additional support and assistance.

In addition to working with policy, Andrew and Francesca will be looking at a number of achievable deliverables, such as benefits calculators, directories and referral partnerships. In order to establish these referral partnerships work around creating data sharing agreements and potential partnership agreements will be undertaken.

Adult Disability Payment (ADP) pilot is launching this month in Western Isles, Dundee, Perth & Kinross with roadshows that people can attend. While SSS are actively recruiting practitioners from a variety of backgrounds and skill sets, additional work around upskilling is being considered ahead of the ADP national roll out this autumn. Local delivery colleagues would also look to benefit from this upskilling, allowing for condition specific adjustments to be taken into consideration before any client appointments.

Following this introduction, members of the group had an opportunity to ask questions.

Q1 (Sue Millman, Ataxia UK) How do charities get onto the referral list?

A: This is still being looked at. The first priority is getting the data sharing agreement finalised and we need to ensure that SSS is referring for the correct support at the right time. It is not yet well understood when the right time is – at which stage in the application process this should happen, and whether timing is different for different conditions.

Q2: (Shirley Maxwell, Epilepsy Connections) What is the plan to upskill staff so they have a good understanding across all neurological (and other) conditions? Would 3rd Sector patient information leaflets be useful and what is the budget for this?

A: Discussions are being held with the practitioner lead about the upskilling programme. Currently we’re assessing the skills gap amongst SSS staff and we will engage with organisations to fill the gap. It would be helpful to have access to materials already produced by charities to provide a basic understanding of neurological conditions. A budget for upskilling SSS staff has not been confirmed, it will be part of an employees’ continuous professional development. We want to make sure people have a broad-based understanding of different conditions.

Q3: Ben Peter (SHA) What is the role of advocates in the referral process? Do advocates recognise the limitations to the advocacy they are able to give the applicant?

A: The advocacy project is separate to SSS, and all advocates will be 100% independent of SSS, and Voiceability will be making the agreement to support people. With the rollout of Adult Disability Payment we would expect the requirement for advocacy to increase and accordingly the referral numbers will increase too.

Q4: Ewan Dale (ME Association) Will there be a conflict between involvement in the advocacy side and reassessment schedules?

A: No, SSS and the advocacy service provided by VoiceAbility are two separate functions. The advocate is independent from SSS and is there to support the interests of the individual. While an advocate does not act on the individual’s behalf, they do take instruction from them and ensure that the individual is fully involved in decisions that are made. Where a person requests an advocate, SSS will refer them to VoiceAbility. An individual can request the support of an advocate at any time during their application process, including during any redetermination or appeal.

Q5: Jonathan Sher (QNIS) Have the implications of 1.5m people in the UK with long covid (LCV) been considered?

A: It is a challenge as numbers are unknown and modelling hasn’t been done to look at numbers transferring to people wanting to apply for benefits. In terms of eligibility criteria, it depends on how much the LCV impacts on a persons’ care and mobility needs as with any other illness. We may need to revisit this and add in some operational guidance.

Q6: Jonathan Sher (QNIS) A note that the 2004 Additional Support for Learning Act now has nearly 20 years’ experience as an information service, mediation service, advocacy and in tribunals. Worth looking to them for how they deal with people requiring advocacy and assistance.

A: Yes, we don’t want to reinvent the wheel, engaging with them is a good idea.

Q7: Keith Park (MS Society) The national roll out of ADP is in August, so what is the timescale for upskilling SSS staff? Some decisions from the pilot will be taken now of people who haven’t had this additional training and it would be counter-intuitive to do that training after the pilot has ended.

A: Recruitment of SSS staff will cover people from all different backgrounds and knowledge gaps will be identified in the recruitment process. Any gaps of knowledge identified in the pilot phase will be addressed. SSS is committed to making the most robust and accurate decisions from the beginning and staff need to know the key questions they need to look out for.

Summary of Q&A from Sue Millman (Ataxia UK, Chair)

It has been refreshing to hear what the Scottish Government are saying about social security. Organisations like ours have welcomed the initiatives and programmes being developed in partnership. But, for the voluntary sector to take on these roles, and partner with governments, we need resources to facilitate this. All charities are operating with limited capabilities and yet we want to be able to support SSS in the way you want us to.

A: We understand funding challenges facing third sector organisations currently. Ideally we’d be able to see a direct causal link between involvement from charities, increased referral rates and successful benefits applications. This would give charities the details they need to make the case for extra funding in due course. However, this is a long-term approach and in the meantime, I’ll raise this with the policy team. We would seek to have regular meetings with organisations in order to understand their capacity.

1. Future Consultation Responses

We discussed the fact that the response from an organisation carries the same weight as a response from an individual, and that can lead to nuances being lost and headline stats published that don’t actually reflect the views of people. One strategy would be for NAoS to build a collective response that is submitted but it is then shared with members who can tweak it to fit their views before submitting it as their own response. This would force SG officials to count every point made. The cons of this approach is the management burden involved, asking member organisations to then approach their communities for feedback before submission. This is onerous and not possible for some organisations operating on a limited capacity. Also, larger organisations may like to do their own responses to consultations, and timing of the suggested approach above may be difficult.

There are three consultations coming up:

1. [Health & Social Care strategy for older people – closes 31 March](https://consult.gov.scot/healthcare-quality-and-improvement/health-and-social-care-strategy/)
2. [Scottish Carer’s Assistance Consultation](https://www.gov.scot/publications/scottish-carers-assistance-consultation/)
3. [Inquiry into health inequalities](https://yourviews.parliament.scot/health/health_inequalities/)

Actions: a subgroup is needed to work on a NAoS response for these consultations.

1. Forthcoming Covid announcements - Scotland

The UK Government is restricting access to free covid tests. It could therefore be difficult for the Scottish Government to continue to supply free tests to everyone. People with immune and certain neurological conditions will be compromised.

Action: The MS Society will share a ‘write to your MP’ templated letter with NAoS to share with members who may like to take action on this for their communities.

1. A.O.B

The Scottish Government has brought forward the ‘moving around’ component of the ADP, to end 2022 (from 2023). The final timeframe hasn’t been announced.

MSPs attending the cross-party group (CPG) on MS will gather evidence to feed into the programme.

No Actions

1. Next meeting date: 18 May 2022, 11-12pm via Zoom. If you would like to Chair this meeting, please get in touch with Alice.