

Policy Group Meeting Summary

19 April 2023

Attendees:

Jennifer Hall, Chair, Alzheimer Scotland
Keith Park, MS Society
Thomas Mulvey, MS Society
Mary Ramsay, Scottish Tremor Society
Tanith Muller, Parkinson's UK Scotland
Gillian Robinson – Compass Therapy Centre
Sam Fitzgerald, MSA Trust
Vicki Cahill, Alzheimer Scotland
Alison Philipps, Scottish Centre for Children with Motor Impairments
Julia Brown, PSPA
Colette McDiarmid, MND Scotland
Avril McClean, Action for ME
Ross Cunningham, Epilepsy Scotland
Jonathan Sher, QNIS
George Allan, SPPS
Lyla Scott, SPPS
Alice Struthers – NAOs
Lorna McGee – NAOs

Apologies:

Carol Cochrane – Brainstrust
Ewan Dale – ME Association

AGENDA ITEMS

1. Chair's welcome - Jennifer Hall – Alzheimer Scotland

Our Chair for the meeting, Jenn Hall, introduced herself and welcomed everyone to the meeting. As the focus for the meeting is the NAOs response to the mobility component of the ADP consultation, Jenn asked people to raise their hands if they had already submitted a response on behalf of their own organisation and again to raise hands if they were present today to hear what NAOs was putting into the joint response.

2. Action points from previous meetings

Jenn confirmed there were no action points outstanding from the previous meeting chaired by George Allan from the Scottish Post Polio Network in January. However, the question of multiple disability commissioners which was part of the January Policy Group discussion, arose again amongst the NAOs executive in March, partly to understand which one will be most relevant for people with disabilities caused by a neurological condition. We followed

up with the Scottish Government to see how they understood the inter-relations to sit between the Disability Commissioner bill (led by Jeremy Balfour MSP – Cons) and the Learning Disabilities, Autism, and Neurodiversity Commissioner bill – proposed by various autism groups and ENABLE Scotland, and put into the 2021 SNP Manifesto. The Scottish Government has now committed to delivering a Learning Disabilities, Autism and Neurodiversity Bill before 2025.

The Clinical Priorities team confirmed that they are looking at how the Learning Disabilities, Autism and Neurodiversity Commissioner bill progresses, to see how the different commissioners might inter-relate. The Learning Disabilities, Autism and Neurodiversity bill remains a priority for Scottish Government and there will be a consultation later on this year about this bill. Furthermore, the SG are going to commission research into existing commissioners to help understand all the advantages (and disadvantages) of having such posts.

Action: NAOs to investigate getting a seat at the table on the Learning Disability, Autism and Neurodiversity bill stakeholder group.

3. Adult Disability Payment consultation response from NAOs (deadline 25 April)

Keith Park (Policy, Public Affairs and Campaigns Manager at the MS Society Scotland) provided some background about the mobility component review of Adult Disability Payment. Scottish Government is now in charge of Adult Disability Payment, which was rolled out at the end of last year (2022). As part of the consultation on ADP, the Scottish Government promised to do a review within a year of full roll out. However, as there was a furore around the moving around component of ADP, the SG agreed to review this part earlier and this is the part we are discussing today.

The purpose of today's conversation is to give feedback to inform the NAOs response. The analysts of the responses will be looking for key themes at each question, so repetition is key.

There are three main sections to the current review:

1. Moving around component – how far can you walk – this is otherwise known as the '20 metre rule'

In the first section, NAOs calls for the Scottish Government to drop the 20 metre rule altogether and instead to ask if people can move any distance aided or unaided, without any negative consequence. Reflecting that this is a big ask, in the interim, NAOs asks that the questions on the form are adapted, giving more space to allow people to reflect on their own specific circumstances and explain what the impact of walking 20 metres to them is.

We point out that moving 20 metres on a flat, even surface in a controlled environment does not in any way reflect normal life, or that being able to move 20 metres might not reflect a normal walking gait that is safe and balanced. We used an example provided by the MSA Trust about balance being a key issue for people which contributes to falls, and this isn't adequately reflected on the ADP form.

2. Planning and following journeys activity

In the planning journeys section, we call for better definitions of 'familiar' and 'unfamiliar' and whether taking public transport is part of taking a journey. We point out the link between cognitive and physical fatigue and how the ability to remain safely on a journey where fatigue is increasing, or where something unpredictable happens, cannot be assumed.

We talk about bladder issues and difficulties getting out and about when dealing with this. And we talk about the impact of post-journey fatigue which is not picked up by the form.

3. Fluctuating conditions and how these impact mobility

The fluctuating conditions eligibility criteria are impossible to understand and the jargon used doesn't help. The way it is written doesn't assess the person's need for support, and it's impossible for someone with a fluctuating condition to know when that condition is going to have an impact.

4. Later sections

Question 12 needs some input. Disability benefits are designed to support people with their costs, irrespective of whether they are feeling better or worse on that day. To mitigate the additional costs, you need to look at what the costs on a worst day might be. Currently the form doesn't look at the costs as they should be.

We think it's better to talk about a worst day, rather than talking about 50% of the time. That said, people can't tell whether they are having a worst day until that day is over. They will be hoping for the best whilst planning for the worst.

For question 18, which is about affordability and deliverability, we talk about how social security costs must be taken in conjunction with housing, employment and other costs.

Rather than being asked to limit our views on how to build a genuinely useful social security system, the SG is trying to limit our input to something they can affordably deliver. This isn't a review of the Scottish budget and so we shouldn't focus on what the SG can afford. We are being asked to help them redesign a better social security system – it is up to them to see how they can afford and deliver it.

Parkinson's UK – bladder and bowel issues go across all aspects of the moving around criteria and might be better moved to other areas of the form.

Action -flag up bladder and bowel issues across other parts of the form.

Scottish Tremor Society – The steady closure of public toilets has a big impact on people with bladder and bowel issues and needs to be stopped.

A more focussed discussion looked at members' views of passporting which comes up at the end of the consultation, at q19.

In their submission, the MS Society will say that no reserved benefits as it stands should be impacted by the enhanced rate of ADP, other than the Motability scheme. However, this shouldn't be a reason to block change in this area. This is caveated that if wholesale changes are made, that people shouldn't lose out because of this. The UK Govt white paper does change things a bit, but that won't happen until after the next election, so there's the chance for the SG to get ahead of the game.

Alzheimer Scotland – raise the issue about how Scottish disability benefits came into play – when they came to the responsibility of SSS, they needed to be done on a 'like for like' basis. The challenge is the UK govt may take the decision that ADP is too far removed from PIP, which removes the automatic entitlements to additional premiums and payments. So there has to be either a mutual agreement arranged with the UK Govt DWP or there has to be a mutual agreement around how people who are Scottish claimants are bale to access the additional premiums. In terms of passporting, which is a complex measure, those who receive disability benefits could be disadvantaged from claiming the reserved benefits such as universal credit, so the passporting question has to be addressed in a way that doesn't disadvantage Scottish claimants in terms of accessing wider financial funds.

MS Society – agree with this, but DWP are aware of this issue and are willing to negotiate with SSS, so we shouldn't limit what we're asking for and should ask for this benefit to be the best that it can for Scottish claimants. Similarly, deliverability and affordability shouldn't be in this consultation. These caveats are there to make a case for not changing things.

Action: reflect strong views from membership that we shouldn't be limited but also reflect the reality that people shouldn't be disadvantaged in terms of accessing UK benefits. There is potential overlap between reserved and devolved benefits and we need to look at how this will be delivered and how to avoid disadvantaged people in the process.

Additional points – we need to raise the layout and length of the form as an issue, as it is 100 pages long and the mobility component falls towards the end. This will be hard for anyone with focus or memory issues to get through and answer fully. The photographs used are difficult to understand as they require good depth perception which impacts both those with an without neurological conditions. The photographs showing an empty car park are also very unrealistic – no-one goes on a journey which is only on smooth ground, and more emphasis needs to be made on how that is unrealistic.

NAoS submitted our response on 24 April - [click here to see it.](#)

4. New cabinet responsibilities

Michael Matheson is the new Cabinet Secretary for NHS Recovery, Health & Social Care
Jenni Minto is the new Minister for Public Health and Women’s Health
Maree Todd is the new Minister for Social Care, Mental Wellbeing and Sport
Natalie Don is the new Minister for Children & Young People and “Keeping the Promise”
Shirley Ann Somerville is the new Cabinet Secretary for Social Justice

The Labour team has also had a reshuffle in response to the SNP changes above:

Jackie Baillie – overall responsibility for Health and Social Care and likely to take the lead on the National Care Service
Paul O Kane – Social Security
Carol Mochan – Women’s Health and Public Health
Paul Sweeney – Mental Health and Veterans Issues

Action: NAOs to send welcome letters to Ministers and their Shadows with a brief that falls under our concerns (including CYP) along with a copy of the 1 in 6 report – we can explain how our report fits with their specific remit.

5. A.O.B

Nothing was raised here.

6. Next meeting date: Wednesday 7th June, 11am -12pm

If you haven’t chaired a policy group meeting yet and would like to do so, please get in touch with Alice (info@scottishneurological.org.uk)