**Summary of Policy Group Meeting**

**24 August 2022**

**Attendees**

Carol Cochrane, Chair, brainstrust Scotland
Mary Ramsay, Scotttish Tremor Society

Ewan Dale, ME Association

Keith Park, MS Society

Colette McDiarmid, MND Scotland

Thomas Mulvey, MS Society

Sue Millman, Ataxia UK

Iain McWhirter, Revive MS Support

Olivia Bird, My Name5 Doddie

Anna Telfer, Epilepsy Scotland

Anna Hunter, Cerebral Palsy Scotland

Helen MacDonald, Lanarkshire Epilepsy

Laura Pultney, MS trust

Tanith Muller, Parkinson’s UK Scotland

Alice Struthers, NAoS

Kirstyn Cameron, Epilepsy Scotland

Iona Campbell, Spina Bifida Hydrocephalus Scotland

**Guests**

Pam Duncan Glancy

**Apologies**

Jonathan Sher

Stephanie Fraser

AGENDA ITEMS

1. Chair’s welcome

Our Chair for the meeting, Carol Cochrane, Support Specialist and Volunteer Manager, welcomed attendees and asked people to explain briefly what they were hoping to get out of the meeting.

1. Action points from previous meetings – follow up

We are pleased to report that there are no outstanding actions from the policy group. Further to our June members’ meeting where we collected anecdotal information from members about gender inequalities in neurological conditions, we sent a letter to the

Minister for Health, Women’s Health and Sport, Maree Todd MSP. In this letter we outlined our concerns that the promised appointments in each health board of a Women’s Health Champion and a Women’s Health Lead, do not appear to have occurred, that there was no budget set aside for the creation of the promised Women’s Health Research Fund which hasn’t been set up, the systematic problem of clinical research and diagnostic advice being based on male patients and more generally about the higher likelihood of women with neurological conditions being misdiagnosed as having a mood disorder or menopause. We will update the group with the Minister’s response once we have received it.

1. Pam Duncan Glancy MSP: Introduction to the Proposed Disabled Children and Young People (Transitions to Adulthood) (Scotland) bill followed by a Q&A

*This is not intended to be a verbatim account of PDGs contribution, rather it notes the broad sense of what was said.*

Following a brief introduction, Pam explained that the bill is aimed at giving young disabled people a fighting chance as currently too many disabled people are being left behind, particularly once they leave school. Disabled people are six times more likely not to be in education or training – a statistic that has worsened through the pandemic. There is a significant gap between disabled and non-disabled people getting their Highers. Although at 16 there is no difference in the aspirations of disabled and non-disabled people, 44% of disabled people are unemployed compared with 16% of the general population.

That period between 16 years old and 26 years old is a critical period for the bill to address in order to reduce this inequality. Part of the problem is the time involved in project managing care, ensuring that different groups talk to each other on the person’s behalf as well as managing appointments. The bill makes it a statutory requirement for a new body to co-ordinate the different professionals involved in a disabled person’s care, freeing that person up to spend their time on their education, training and career.

The bill is now at stage 1 and is being considered by the Education, Children and Young People Committee. As there will be a significant budget attached (over £500k), it is also being looked at by the Finance Committee. All support is appreciated, as are improvements or amendments to the bill. The costs have been carefully looked at, but if members consider any additional costs that need to be added, please let Pam’s office know.

There are three parts to the bill, which is designed to give extra support to disabled children and young people to help them transition to adulthood. The bill does this by streamlining the transitions process and making government ministers accountable for a transitions strategy.

The three parts are:

1. To make it a statutory duty to ensure young disabled people experience a positive transition via the creation of a national strategy.
2. To make it a duty for local authorities to have a transitions plan in place for young disabled people aged 14 at the latest, through to 26. Taking it to 26 also ties in with care leavers legislation.
3. A duty to report annually on implementation and progress of the National Transitions Strategy

Pam Duncan Glancy MSP is working closely with Jackie Baillie MSP (the Scottish Labour party spokesperson) to ensure it also aligns with the new National Care Service, and with Mark Griffiths MSP to look at how the bill will impact on housing.

Following this intro, there was a Q&A.

Sue Millman (Ataxia UK): is there anything missing from the draft bill?

Pam Duncan Glancy MSP: We are open to suggestions including looking at the age the bill covers (14 – 26), who has the rights to a transitions plan and building in obligations on local authorities to give referrals to access work, although this last point may be left as secondary legislation.

Kirstyn Cameron (Epilepsy Scotland): What structures and support are in place for young people with disabilities who need support but whose disabilities are not so severe that they have a team in place to support them?

Pam Duncan Glancy MSP: This is harder to get right. We need to make it easier for schools to recognise disabilities including learning disabilities. Hidden impairments are not always properly monitored and also people don’t always recognise themselves as disabled, meaning it’s harder for them to be targeted for support. Under the Equalities Act, disabilities are defined as:  **i**[**f you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities**.](https://www.gov.uk/definition-of-disability-under-equality-act-2010#:~:text=You're%20disabled%20under%20the,t%20apply%20to%20Northern%20Ireland.)However looking at recent exam results from SQA (Scottish Qualifications Authority), there were more people listed as having an additional support need than as having a disability. This in itself is problematic and we anticipate a push-back from schools and families if we tell people with additional support needs that they are disabled.

The two biggest open issues that the bill faces, are who will be responsible for delivering transitions plans (a co-ordinating role, or a body?) and who will be considered under the bill.

Mary Ramsay, Scotttish Tremor Society: Primary school aged children should be considered in this bill. It is hard to diagnose ASN such as dyslexia in primary schools but it is routinely picked up in secondary schools. However, by the time the child gets to secondary school, their interest in school may have diminished if their dyslexia hasn’t been picked up at an earlier stage.

Pam Duncan Glancy MSP: This comes down to who has rights under this legislation from the point of diagnosis. At the point by which someone is recognised to have a disability, the person will be covered by law to be given a transitions plan. It could be at primary school, it could be at secondary school, but the latest we want young people to be identified is by the age of 14.

Iona Campbell, SBHS: How would the bill ensure the care and support is person-centred and relevant to the experiences of the individual, when there is a range in age and cognitive abilities between each condition?

Pam Duncan Glancy MSP: The guidance would deal with this. It will create a big change for schools where those responsible for pastoral care are guidance teachers. COSLA (the Convention of Scottish Local Authorities) are worried guidance teachers are already busy enough. We need more posts in place with additional funding. We need more training for everyone responsible under the bill. We don’t expect everyone to be an expert on every disability, but people need more training. We could consider an amendment to the bill to bring the third sector in to support this.

Sue Millman (Ataxia UK): The third sector is better off independent and not responsible to government. Thought needs to go in before putting the third sector in this position, not least for making people responsible for actions like this, and then cutting funding.

Pam Duncan Glancy MSP: This was meant more in line with putting something in statute that means local authorities need to engage with the third sector.

If anyone has any thoughts on how to improve the bill, amendments that should be considered, or any questions, you can contact Pam on:

pam.duncan-glancy.msp@parliament.scot

If people want to tweet about it or mention the bill on social media, Pam’s team are using the hashtag #fightingchance - it would be appreciated if this could be included in any posts.

End of Q&A

1. Horizon Scanning (consultation responses, Parliamentary activity of interest etc)
2. Mental Health Strategy Consultation (closes 9 September 2022)

**Action raised: Ewan Dale to look at this with Alice to see if we can put a response together**

1. NCS bill call for evidence (closes 2 September 2022)

The MS Society and Cerebral Palsy Scotland are submitting a response**. Action: Alice to look at their responses and see if we can do a response of our own.**

1. Others?
2. A.O.B

Sue Millman (Ataxia UK) - The Rare Disease Framework has been delayed – having expected publication to be in February 2022. We are keeping an eye out for it.

Thomas Mulvey (MS Society) updated the group on the lobbying work that we are doing. At the joint epilepsy / MS Cross Party Group in June, there were only 4 MSPs present so we created a plan which aims to culminate in a Parliamentary debate this side of Christmas.

We are working with health spokespeople and having round table meetings over the next few weeks.

Once all the meeting dates have been agreed, Thomas will share them with anyone interested in being involved. The focus of these meetings is on our 1 in 6 report, looking at the lack of prevalence data, the impact on mental wellbeing and the lack of mental health provision in Scotland.

Iona Campbell (SBHS): Our charity has recently created a transitions board game which is particularly useful for the 12 – 14 year age group. If anyone would like a physical copy of this game, please get in touch with iona.campbell@sbhscotland.org.uk

1. Next meeting date: 2 November, 11 – 12pm. If you would like to Chair this meeting, please get in touch with Alice.