**Policy Group Meeting**

**18 May 2022**

**Attendees**

Stephanie Fraser, CP Scotland, Chair

Iain McWhirter, MND Scotland

Jonathan Sher, QNIS

Charlotte Encombe, Compass

Shirley Maxwell, Epilepsy Connections

Anna Telfer, Epilepsy Scotland

Beth Strachan, CBIT

Carol Cochrane, Brainstrust

Ewan Dale, ME Association

Michaela Regan, MDUK

Stoo Brown, Action for ME

Sue Millman, Ataxia UK

Susan Webster, MND Scotland

Thomas Mulvey, MS Society

Gillian Robinson, Compass

Tanith Muller, Parkinson’s UK

Jane Haley, MND Scotland

**Apologies**

Colin Robertson, Headway Dundee & Angus

Helen MacDonald, Lanarkshire Epilepsy

Rachel Maitland, MND Scotland

Morna Simpkins, MS Society

Andy Wynd, Spina Bifida UK

Leanne Creighton, Sue Ryder UK

Anna Hunter, CP Scotland

Colette McDiarmid, MND Scotland

Summary of the meeting

AGENDA ITEMS

1. Chair’s welcome

Our Chair for the meeting, Stephanie Fraser, CEO of Cerebral Palsy Scotland welcomed attendees and asked everyone to explain briefly what they were hoping to get out of the meeting.

1. Action points from previous meetings – follow up

The Minister for Mental Health and Social Care, Kevin Stewart MSP has agreed to speak at our AGM on the 21st September.

The outstanding action is for the NAoS to write to the Minister for Health, Women’s Health and Sport, Maree Todd MSP to raise concerns about conditions in women, an area which is often misunderstood and misdiagnosed. We have collected valuable anecdotal information from members at our recent Members’ meeting, which will be used to inform the letter.

**Action: Alice and Jonathan to work together on this letter**

1. Can we identify principles for good transitions for people with neurological conditions?

The focus of the meeting today was on transitions. The Neurological Framework for Action specifically acknowledges transitions as being an area that needs investment and improvement. Cerebral Palsy Scotland, NHS Ayrshire and Arran, ARC Scotland and the University of Dundee were funded to do a collaborative project on transitions in round one, and their paper on literature review on transitions was sent to all members prior to the meeting.

In this paper, the definition of transitions was explained as:

*“Transitions can be defined as an ongoing process of psychological, social and educational adaptations due to changes in context, interpersonal relationships and/or identity. This can be simultaneously exciting and worrying for an individual and others in their lives and may require ongoing additional support”.*

However, this broad definition of transitions is often lost as it is mainly thought of and acted upon in reference to clinical transitions from child to adult services only. The meeting agreed that all interpersonal areas were important.

Given that neurological conditions are life-long and people will therefore experience many times of transition, the question was put to members of the meeting, as to whether NAoS should concentrate on children to adult services transitions as the most important one to get right or whether members representing conditions that this was less relevant or felt that there were other life stages that should be a focus as well for the NAoS.

Shirley Maxwell (Epilepsy Connections) In epilepsy the focus for transitions is on child-adult services and this already has challenges in implementation. Using the wider definition is a new way to leverage community support for the kind of services that charities provide. Pathways that are already in place for child-adult services tend to be medical pathways and therefore refer to a medical transition.

Beth Strachan (CBIT) Child-adult transition is important and medical care is important. However, for children with brain injury, a key non-medical transition is that of the parents who go from having a child without a brain injury to having a child with a brain injury and parents have to find their own pathway for that transition.

Stephanie Fraser (Chair, CP Scotland) Another important transition is for families where elderly parents need to support an adult child to go to independent living.

Tanith Muller (Parkinson’s UK) First of all we need to look where people need support around transitions – which includes a wider scope than just child to adult services. But child to adult services are genuinely problematic. Secondly, we are already concerned how siloed the NHS and council services are by condition, severity and age and if we stop emphasising the need to de-silo, we risk the responsibility for transition being lost altogether.

Sue Millman (Ataxia UK) The word ‘transition’ is widely known to be the point where people move from child to adult services. It may not be helpful to re-define it although it is true that all other transitions are problematic and shouldn’t be restricted to medical care. Could the term ‘continuity of care’ be applied to all other transitions and leave ‘transitions’ to child to adult services? The problem is that statutory services have singularly failed to manage child-adult services. Continuity of care works well at accredited centres where staff go to both child and adult centres to create a link.

Jonathan Sher (QNIS) Transition assumes both things exist – which is not the case in many instances. There are 172,000 people with Fetal Alcohol Spectrum Disorder (FASD) in Scotland, but less than 1% have been diagnosed as such. So for these people, they are transitioning from nothing to nothing, as no support exists for FASD.

Secondly, misdiagnosis is a real issue. FASD frequently gets misdiagnosed as ADHD or autism. We need to transition from misunderstanding to understanding correctly what people have.

Thirdly, many transitions are not medical but are very important. Young people with FASD can get in trouble with the law, ending up with custodial sentences, but they are never diagnosed or dealt with.

Stephanie Fraser (Chair, Cerebral Palsy Scotland) One of the reasons services fail is because it is a shared responsibility between the NHS, education services, and social services to deal with children and therefore no one in adult services takes responsibility. Pathways exist for certain conditions such as epilepsy as there are consultants for epilepsy in both child and adult services. But there are many neurological conditions where adult services don’t exist.

Adult services need to get involved in transition from child to adult services for us to get it right.

Mary Ramsay (Scotttish Tremor Society) There is a lack of knowledge of conditions by both the medical profession and education authorities.

Stephanie Fraser (Chair, Cerebral Palsy Scotland) [Pam Duncan-Glancy’s](https://www.parliament.scot/bills-and-laws/bills/disabled-children-and-young-people-transitions-to-adulthood-scotland-bill-session-6/overview) Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill refers only to child to adult transitions. The concern is that unless adult services exist, this bill will not make a difference.

Anna Telfer (Epilepsy Scotland) SIGN clearly sets out a pathway from child to adult services in epilepsy, but there is variability between health boards. There are some epilepsy specialist nurses in some Health Boards and not in others.

[Healthcare Improvement Scotland General Standards for Care and Support for people with Neurological Conditions](https://www.healthcareimprovementscotland.org/our_work/standards_and_guidelines/stnds/neurological_care_standards.aspx), which should be the minimum care that people could be expected to receive, also mentions transitions.

Stoo Brown (ME Action) Reflecting on the absence of services in the ME world, everyone ends up with their GP. Other conditions are served by neurologists so are less dependent on GPs. GP services are overstretched.

Stephanie Fraser (Chair, Cerebral Palsy Scotland) In conclusion, points agreed in the discussion were:

* It is valid to look at whole-life transitions, but child to adult transitions are failing people currently so, in campaigning terns, it is worth NAoS concentrating on that.
* We have concerns how siloed the NHS is by age and impairment. It would be better to focus on where people need support.
* Succession planning is another critical issue, amongst both primary and secondary care across all conditions.
* The importance of continuity of care needs to be emphasised and the challenge is that so many people are reliant on primary care which is currently under enormous pressure.
* Good transitions assume both services exist and for many the reason child to adult and other transitions don’t happen is because the services don’t exist.

**Actions:** The NAoS and member organisations will keep a watching brief on the progress of Pam Duncan Glancy’s bill in case there are further opportunities arising there.

1. Social Care Package Alliance- Michaela Regan, MDUK

MDUK are keen to bring together a group of charities to look at key barriers to accessing care and support for those that require it across Scotland, particularly in light of the proposed development of the National Care Service. MDUK plan to produce a report with key recommendations and overarching themes from the perspective of complex care conditions which will go to Parliament for engagement with key policy makers.

The ask of charities interested in working as part of the alliance will be to attend meetings, provide feedback, keep the group informed of matters of interest and support the promotion of any surveys and fieldwork that the group engages with.

Please can interested parties contact Michaela on m.regan@musculardystrophyuk.org to find out more and get involved.

1. Current Consultation Responses
* Health and Social Care for older people – closes on 19 June

We have held two meetings and the third will be on:

[Monday 30 May 1.30 – 3pm](https://us06web.zoom.us/j/85397856453)

* ABI call for evidence

 We have had an even split of opinion between members with half thinking the ABI strategy should focus on ABI only and half saying it should include other related neurological conditions. NAoS therefore advises that individual members submit their own responses and please send us a copy so we can see what charities are saying.

* Carers’ Assistance - closed 23 May

 Apologies to those who were ready to dial into the meeting on Wednesday which was cancelled due to a perceived lack of interest. NAoS does not have capacity to respond to this consultation but please share your submissions with us.

* Any others?

 Jeremy Balfour MSP’s [Disability Commissioner Consultation](https://www.parliament.scot/bills-and-laws/proposals-for-bills/proposed-disability-for-scotland-commissioner-bill) – closes 3 August. Can members interested in working on a NAoS submission contact Alice please.

1. A.O.B

No other business was mentioned.

1. The next meeting date is the 24 August 2022, 11-12pm via Zoom. If you would like to Chair this meeting, please get in touch with Alice.