

## **PE1577/L**

Petitioner's submission of 4 October 2017

Unfortunately, I find the Scottish Government reply inadequate. It is the same repetitive rhetoric that they have used in all their replies to my petition. I am saddened to learn that the Scottish Government are not minded to implement a pathway that will provide continuity of care across all health boards in Scotland for adults with cerebral palsy. I am very concerned that health boards/IJB's will not implement support at a local level as they have limited resources, and budgets are being cut throughout Scotland. Care and support from the NHS for adults with cerebral palsy is unlikely to be a priority for health boards unless there is a national focus.

I am a regular user of NHS services and my care is not coordinated by a key healthcare professional. The clinicians will treat a specific problem and not take a holistic view of my condition. I agree that the services need to be person centred and the condition is multifaceted, but that could be said about other neurological conditions such as Multiple Sclerosis and Parkinson's Disease. Patients with MS and Parkinson's have a consultant and/or a specialist nurse to support the patient by giving advice, and discussing treatments and services available for the patient. On the other hand, I do not have regular reviews with key healthcare professionals with expertise to discuss my condition.

I would argue that prescriptive guidance is needed in order to make healthcare professionals aware of cerebral palsy in adulthood. Furthermore, guidance can be used as a template, and an experienced clinician should be able to adapt the guidance in order to meet the individual patient's needs. Patient centred care is best practice and should be the norm throughout the NHS and its services. Patient centred care can be provided within the framework of a national pathway. Such care is not a new concept. Not every patient will respond to the same treatment, therefore the Consultant will have to try another drug or treatment. After all, that is why there are specialist secondary NHS services. There needs to be a pathway /guidance issued to GP's in order for the GP to know which service or consultant to refer to.

Moreover, I appreciate that a person with cerebral palsy will have needs that are relevant to social care providers and also needs that fall within the remit of the health service. But that is also true of other neurological conditions. My petition has focused on the medical NHS services that are needed by adults with cerebral palsy because that is where the gap is. A person with cerebral palsy may need specialist neurological medication and pain relief that will need regular reviews due to secondary ageing. They may also need access to specialist physiotherapy and treatments such as hydrotherapy, Botox injections and muscle lengthening operations as well as any secondary conditions they may develop as a consequence of cerebral palsy. Local authority help from social care may be required, but in my experience in Perth and Kinross I have managed to access social care support and had a positive experience with that. The care I receive from the NHS is patchy and piecemeal at best. Adults with cerebral palsy deserve to access support and treatment from the NHS that is high quality and meets their specialist needs. If the

Scottish government localise the service then the danger is that it will become a postcode lottery. There needs to be the same access to high quality specialist care across all health boards in Scotland.

Although I welcome that NICE clinical guidelines are going to be published in 2019 - which will be helpful - and that transition guidelines are going to be published next year, but surely this could be an opportunity for the Scottish Government to provide progressive leadership rather than waiting passively for two years for those guidelines to appear.

I would remind you that there is in fact no transition from child to adult services because there are no relevant specialist services for adults, resulting in many of them falling through the cracks; the transitions framework will not help them. While the Bobath Pilot scheme is helpful from an evidential point of view, it is just a pilot project. At the time of writing, Bobath Scotland have not received any more government funding to expand the project. I fail to see how this project will develop specialist services on the NHS, although it may develop allied health professional support such as physio-, occupational therapy and social care support, which is positive. However, it does not address the specialist medical support that is needed by an adult with cerebral palsy. The Independent Living Fund is not relevant to my petition as it can only be accessed by 16-21-year olds.

I am concerned that the Scottish Government have not been in contact with me regarding the issues raised in my petition since the start of the year. The Health Minister, Aileen Campbell, made a commitment to continue to work with me. This has not happened and I have not had any direct communication from the clinical priorities team either. I am concerned about this because the Scottish Government want to develop services 'from the ground up' and use the 'lived experiences' of adults with cerebral palsy. I appreciate that they are working with Bobath Scotland, but they are not in direct regular communication with me. I would like the PPC to raise this with the Scottish Government and their officials.