

PE1577/C

Chris Hynd
Committee Assistant
Public Petitions Committee
The Scottish Parliament
Edinburgh
EH99 1SP

Petitions@Scottish.Parliament.uk

Your ref : PE01577

4 January 2016

Dear Mr Hynd,

Re: PE01577 – Adult Cerebral Palsy Services

I am responding to Capability Scotland's written submission dated the 8th of December 2015 and Jamie Hepburn's, Minister for Sport, Health Improvement and Mental Health written submission dated the 11th of December 2015.

Capability Scotland

I am pleased to see that Capability Scotland fully supports my petition. They agree with me that Cerebral Palsy (CP) should be recognised as a life long condition and have evidence to show that secondary aging is a major factor affecting physical performance and seeing an increase in pain and fatigue. Without maintenance physiotherapy adults with CP see deterioration in health and physical function which compounds their disability. Capability Scotland also state that adults with CP living in Scotland have unmet health needs. Resources are not currently meeting individual needs. The evidence supports my argument for a national clinical pathway for adults with Cerebral Palsy within the NHS.

Scottish Government

On reading the response from the Scottish Government, I am very disappointed and concerned that there is no mention of provision of services for adults with Cerebral Palsy, or a national clinical pathway within the NHS. £30,000 given to a charity is a token gesture that will do little to establish comprehensive national services. What evidence has shown is that the need is for access to trained professionals who understand the complexities of Cerebral Palsy and the needs of adults with the life long condition. After a nine month wait, I have now seen a NHS physiotherapist, the appointment consisted of a brief examination followed up with a printed sheet of exercises designed for non disabled patients and instructions for self management. This is not acceptable, but is the norm for NHS services. Mr Hepburn stated, "the

service provision for adults with Cerebral Palsy can sometimes be lacking". I would argue that service provision is non-existent. I would welcome the opportunity to work with the Strategic Planning and Clinical Priorities team, as I could give them an insight into the service users' experience and what life is like living with Cerebral Palsy. Furthermore, I would like the opportunity to meet with Jamie Hepburn to discuss these issues further.

Moving forward, I would like to see adequate funding within the NHS across Scotland for services for adults with Cerebral Palsy that is not constrained by a local health board or local authorities. Adults with this life-long condition need trained health professionals. Other complex neurological conditions have clear referral pathways. Adults with Cerebral Palsy need a pathway to be able to access support services, which at the moment do not exist.

Yours sincerely,

Rachael Wallace