

**PE1577/K**

**Scottish Government Letter of 25 August 2017**

Thank you for your letter of 31 May 2017 on behalf of the Public Petitions Committee (PPC) regarding their consideration of petition PE1577 (*Calling on the Scottish Parliament to urge the Scottish Government to develop and provide funding for a clinical pathway and services for adults with cerebral palsy*). Please accept my apologies for the delay in responding.

It may help if I start by outlining two key pieces of work which are currently underway that will impact on the management and treatment of Cerebral Palsy (CP) going forward.

The Clinical Standards for Neurological Health Services (2009) are currently under review by Healthcare Improvement Scotland (HIS). HIS has been working with neurological stakeholders on a Short Life Working Group, tasked with deciding the future of the standards. The SLWG has recommended that the standards should be revised – with a small suite of generic neurological standards being proposed to replace the existing standards. It is proposed that HIS will publish a refreshed suite of generic standards by August 2018. This change in focus to more general neurological standards has been welcomed by Bobath Scotland as conditions like CP did not feature in the 2009 standards.

In addition The National Institute for Health and Care Excellence (NICE) are taking forward guidance for the management and treatment of CP in adults in NHS England. This is due to be published in 2019 and we will want to consider the impact of this refreshed guidance thereafter.

Given these two strands of work currently underway, we are not minded to develop national guidance on CP in adults at this point.

With regards to the request for information relating to a mapping exercise undertaken by Capability Scotland, while this work was not commissioned by the Scottish Government, we were made aware of this exercise through discussions with Bobath Scotland who took it into account as they developed their project proposal. Scottish Government do not hold this information.

Bobath Scotland's findings from the pilot project are summarised below:

- A need to raise knowledge and awareness with all members of staff within Integrated Joint Boards (IJBs) and Integrated Authorities (IAs) of the management of CP, to enable greater empowerment of those with CP to be in control of their condition and to help access existing services.
- Reviews must be regularised to avoid missing changing requirements of those with CP – this can occur almost accidentally because of the sometimes slow deterioration some experience, and an assumption by staff that needs have not changed.
- The multi faceted way the condition manifests itself dictates that services need to be person-centred and developed from a user-led perspective. Proscriptive guidance and approaches risk services becoming less nimble and adaptable to changing and varying needs of patients, with potentially negative consequences and poorer outcomes for those with CP.

We believe that driving change involving local service users and local multi-disciplinary teams is the best approach. As CP can manifest in a variety of ways, with different levels of

impact on individuals, treatment and management therefore relies on a range of providers across Health and Social Care - and this means local bespoke pathways work better to meet the needs of individuals. As such, we believe testing new approaches at a local level is the best way to develop person-centred services and local pathways.

With the integration of Health and Social Care, some of the needs of people with CP will fall to JBs and IAs as they are responsible for commissioning local services across the partner agencies. Therefore, it is important that the Bobath Scotland work continues to engage with JBs/Health and Social Care Partnerships and takes account of the new landscape.

As that work progresses, we believe there may be an opportunity to develop information that captures some national principles that can be applied in relation to provision of local services. As this work is being developed from the 'ground up', we believe this will lead to the development of better, user-led, information and guidance. Therefore, we intend to continue working closely with Bobath Scotland on the project work they are taking forward - seeking to expand the project work around the country and share learning with Boards and JBs/Health and Social Care Partnerships.

On the specific issue of transition, members may wish to note that the Scottish Government is in the early stages of developing a 'Framework to Support Disabled Children, Young People and their Families'. This will be framed around three priority outcomes relating to information and rights; accessibility of services; and transitions. An extensive consultation period will commence later this year, with a final framework published in late summer 2018.

The format and development of the Framework is currently being considered in conjunction with our Disabled Children and Young People Advisory Group (DCYPAG), and will sit under the overarching Fairer Scotland for Disabled People Delivery Plan published in December last year.

Members may also want to be aware of the Government's ongoing support for young disabled people through the Independent Living Fund (ILF). On top of the existing £47.2 million of support (transferred from UK Government) for existing Scottish ILF users, Ministers have committed an extra £5 million per year to open a new scheme of ILF support.

This new ILF scheme will be a broad discretionary fund to support disabled people to live independently. Within its first phase, this will be focused on supporting young disabled people, aged between 16 and 21, who are at an important transitional stage in their lives. This supports the Scottish Government's Disability Delivery Plan, which includes actions to tackle the inequalities and barriers faced by disabled young people, including overcoming social isolation, improving lives at points of transition, and improving outcomes.

Further information about the scheme can be found here:

<http://www.gov.scot/Topics/Health/Support-Social-Care/Independent-Living/ScottishIndependentLivingFund>

I hope the information in this letter is helpful to the PPC.