

PE1545/N

Tuesday 5 January 2016

Submission to the Public Petitions Committee on PE1545

I am pleased to offer a further update on recent progress made around the issues raised in PE1545 and hope that the committee will find it useful when considering the direction of further scrutiny of the issues it raises.

As the letter that the committee received from the Scottish Government on 1 December indicated, I have been in direct touch with members of the civil service care rights and support team led by Jessica Mcpherson. We had a very positive meeting on Monday 7th December and are in the process of securing a date for a further meeting early in the New Year. Having initially been concerned that the Scottish Government was wholly and exclusively committed to care in community settings for people with PMLD, I am now confident that the solutions that I have been advocating in PE1545 are receiving serious consideration.

Specifically, I have received assurance that on-going work to improve the visibility of people with PMLD that was alluded to by Prof Sally-Ann Cooper in her letter to the committee dated 31 July 2015, will be added to by the appointment of a research fellow tasked with filling in the gaps in our knowledge of young people with PMLD, including their numbers and the range of their conditions. Completing this study is just one important piece of the jigsaw that, when finished, will allow us to judge what the needs are of people with PMLD. It has been a direct result of the light shone upon the issue since PE1545 began.

There is still further work to be done to ensure that every person with PMLD will be counted in future and have their needs met in full. There remains a degree of confusion which is evident in the letter the committee received from the Cabinet Secretary dated 1 December. It once again cited policy while avoiding the substance of the issues I raised originally. In response, I would stress that the carers of young people with PMLD know that existing policies designed to govern social work assessments and regulate post-18 transitions, are supposed to offer support and flexibility. That was never in doubt, but the problems they face, and which I have highlighted in previous evidence to the committee, still persist.

The fact remains that existing social work guidance and practice in this area is not fit for purpose, and I do not think it is good enough that delivery is just a matter for individual local authorities. The embrace of responsibility for better standards and best practice needs to start at the top and I would urge all relevant branches of the Scottish Government – including the Chief Social Work Adviser – to engage equally and meaningfully and provide leadership. At the very least, failure to do so risks leading to more incidences in which carers of severely learning disabled people do not feel they have the support or backing of their social workers. As the pressure they are under grows, so does the risk of tragedies that will only serve to compromise the good reputation that social workers in Scotland enjoy.

As I have said before, I think that one potential solution offered to some people with PMLD should be bespoke residential care of the sort provided to my son Muir by Donaldson's School. I stand by those comments and the letter received by the committee from Laura Battles has underlined to me the extent to which the learning disability support sector has been working in silos when it should be acting in unison. Clearly, and contrary to my previous understanding of its intent, the school will not be in a position to act as a model for future residential care in Scotland, meaning that the options for transitional care are more limited than ever. I am therefore relieved that Jessica Mcpherson's Scottish Government team have had the foresight to invite Young Epilepsy (YE), which runs a superb residential facility in Surrey, to attend a fact finding round-table session in Edinburgh in January to explore what – if any – facets of YE's bespoke care solutions might be applicable in a Scottish setting.

I brought PE1545 to the committee because of my frustration that the problems I and others identified when trying to access the levels of care for the most vulnerable were thwarted by policies that were held up as good examples of personalised care, but which in reality stemmed from a one-size-fits-all approach. The wholly positive and constructive attitude lately adopted by the government's care rights and support team is to be commended and has underlined to me the extent to which all branches of government, both national and local, will only succeed in supporting our most vulnerable people if prepared to challenge received wisdom and communicate properly with one another. My ultimate aim is not to overturn or disrupt a system that undoubtedly works well for the majority, but to refine our capacity to support a sizable yet extremely vulnerable minority.

I would therefore urge MSPs to build on the good work that has begun by continuing to provide the scrutiny that is needed to ensure that the issues underlying PE1545 are teased out fully by those with the power to effect lasting improvement.

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