

## **PE1545/CC**

Petitioner submission of 6 November 2019

In response to Cabinet Secretary's (Health & Sport) response of 11 September 2019

It is disappointing to reiterate yet again how little progress has been made in the consideration of PE1545 in pursuit of high quality residential care for children and young adults in Scotland with profound learning disabilities. It seems that we are eternally bogged down in the answer to the original question posed by the Petition's Committee about the number of people who might require this service and now also, semantics around the definition of those people that might make up this group.

Suffice to say the Cabinet Minister's response of 11 September, which was shared with the Petitioner on 21 October, is out of context. The meeting with the Petitioner that she refers to took place on 4 September and was also attended by representatives of Epilepsy Scotland, a charitable body that supports PE1545, Dr Anne Macdonald of the "Coming Home" report and other members of the Cabinet Minister's office. Please note that those in attendance from Epilepsy Scotland are not the Petitioner's representatives.

At the 4 September meeting the Cabinet Minister reported details of the Minister for Mental Health's communication with Health & Social Care Partnerships (H&SCP) regarding actions following the Coming Home report. She referenced a review of 'commissioning processes', planning for 'housing solutions' and more 'person centred services', all of which we have heard before. Significantly, amongst these actions there was no mention of residential care services as pursued by PE1545. Dr Anne Macdonald also confirmed that residential services with supporting medical care is not part of that remit. We therefore fail to see how a proposed event in the autumn, bringing together commissioners and service providers from just Scotland, to look at examples of good practice, will result in a meaningful discussion about essential residential care needs when there is nothing in Scotland and therefore no experience of this good practice across this group. Indeed, there remains an unnatural and unhelpful prejudice against this kind of provision which we now see as more vital than ever before, as evidenced by the shocking headlines about the autistic young lady Beth, who has been in a cell in a mental health hospital now for three years - the tip of the iceberg in terms of those who are not receiving appropriate care in the UK, including many Scots in out-of-area placements.

In terms of semantics, does it really matter whether we refer to the group in question as children and young people who have profound learning disabilities or who have profound and multiple learning disabilities? By the Cabinet Minister's own admission we still do not know who they are. The Cabinet Minister states that support of those in this group is 'person specific' and 'based on need' and concludes that "this assessment is made on an individual basis and is highly personalised and therefore not amenable to extraction for quantitative research purposes." The people in this group, no matter how we refer to them, continue to be invisible. At the same time we know their needs are not being met, a failure that is the result of poor assessment of need and inadequate resource, skill-set and support, resulting in many out-of-area placements as well as neglecting to support those families struggling at home and also in the community.

The Cabinet Minister's response of 11 September to PE1545 concludes "I have reflected that this research in to the needs of children and young people with profound learning disabilities may be of little value, costly and would not answer the questions (of the Committee)." This statement directly contradicts the discussion at the meeting of 4th September when the Cabinet Minister stated this research was vital to enable her to present a meaningful case to Scottish Parliament for a Scottish residential care facility with medical support. Further, she charged the representatives of the cabinet office in attendance at the meeting, to work together with Epilepsy Scotland to identify the group in question - whom, for the purpose of PE1545, can be described as children and young people who have profound and multiple disabilities, if that is going to be helpful.

We can only presume that the Cabinet Minister did not write her own response to the Petition's Committee and the response of 11 September we are reviewing is the hand of a civil servant who was not in attendance at the meeting of 4 September. Suffice to say after more than 5 years, this remains a shocking state of affairs. Whilst there has been some acknowledgment that there must be more choice for 'this group', including residential care with supporting medical services, Scottish Government has made absolutely no attempt to deliver on that service need and worse still is guilty of ensuring that this seriously vulnerable group we continue to advocate for against all odds, remains invisible.

Our most vulnerable citizens in Scottish society are made to be invisible at the hand of Scottish Government. This seems to be the preference - an absolutely damning indictment that we hope someone with good conscience in Scottish Government will face up to and address with real and urgent action and no more filibustering.