

## **PE1545/Z**

Petitioner submission of 20 July 2018

The need for residential care in Scotland for profoundly learning disabled children and young adults.

With respect to current members of this panel, the petition committee has been considering PE1545 for almost 4 years now and absolutely nothing constructive and supportive has resulted. Families seeking residential care in Scotland for their profoundly learning disabled child or young adult continue to be let down whilst the authorities fail to answer their own question about the numbers concerned.

In response to the committee's numerous letters, Scottish Government has failed to address the issues raised by the petition except to acknowledge that families should have the choice. Scottish Government has repeatedly deflected the matter to the Learning Disabilities Observatory (LDO) in an attempt to convince the petitioner that their research is relevant to the issues raised.

The Learning Disabilities Observatory, in their reply of 6th July 2018 to the committee, clearly state that their research is not focussed on the issues raised by PE1545 concerning those with profound learning disabilities and confirms that LDO's research was commissioned by Scottish Government to inform policy and practice, a fact that the petitioner has repeatedly highlighted but until now has not been acknowledged.

After nearly 4 years it is difficult to contain our anger and immense disappointment in Scottish Government's response to the petition. At the heart of the matter are real families who are struggling to cope, many of them at breaking point and their learning disabled children and siblings are suffering. We find Scottish Government's response delinquent, unkind and uncaring. Life for many of these families is untenable. Scottish Government's failure to address the desperate need for residential care in Scotland when it has been so clearly and vividly brought to their attention by PE1545, is unconscionable and unforgivable.

On Monday 16th July this year, the BBC broadcast a Panorama documentary about the UK's children with complex needs and the plight of families. The documentary emphasises the need to address long term care requirements as more and more children with severe and complex needs are surviving in to adulthood. The programme references numbers of approximately 118,000 in the U.K. at the severe and complex end of the disability spectrum - and this figure is rising.

In our response we respectfully ask the committee members to watch the documentary (link below) with a specific regard for the long term care needs of the children who feature, and 118,000 more children in the UK, approximately 10% of whom live in Scotland, who have severe and complex needs and will survive in to adulthood. In the absence of any long term residential care options with essential medical facilities in Scotland, how on earth do care for these most vulnerable children and young adults and ensure that they enjoy a worthwhile quality of life?

We cannot continue to ignore this voiceless minority whom authorities have failed to provide for adequately for decades. LDO's response confirms that there are no datasets in Scotland that include a marker for this group. Because we ignore them they are therefore invisible.

<https://www.bbc.co.uk/programmes/b0bc2ch6><sup>1</sup>

We would welcome a relevant debate in Scottish Parliament as a matter of urgency.

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<sup>1</sup> Please note, as at 20 July 2018, the link was available to watch for 12 months and will be unavailable after this date.