



The Scottish Parliament
Pàrlamaid na h-Alba

PUBLIC PETITION NO.

PE01545

Name of petitioner

Ann Maxwell on behalf of Muir Maxwell Trust

Petition title

Residential care provision for the severely learning disabled

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to recognise residential care as a way severely learning disabled children, young people and adults can lead happy and fulfilled lives and provide the resources to local authorities to establish residential care options for families in Scotland.

Action taken to resolve issues of concern before submitting the petition

I met with Cabinet Secretary for Health Alex Neil to discuss this issue in May 2013 but no Scottish Government action was taken forward as a result. I later sent him an open letter calling for more residential care options in Scotland but, again, the Scottish Government didn't commit to taking a fresh look at this issue.

In addition, I have brought up the issue of long-term residential care in formal written evidence submissions to Scottish Parliament consultations and have raised the issue in the local and national media.

As the lack of suitable residential care options is a problem affecting the whole of the UK, I also met with UK Minister of State for Care and Support Norman Lamb MP to bring the issue to his attention.

Petition background information

The profoundly learning disabled have a range of complex physical and mental disabilities which leave them in need of 24 hour-a-day care and with no hope of living independently.

The Scottish Government has placed a great emphasis on ensuring the disabled can live independently within the community, but for those with profound learning disabilities, even supported living in community settings is simply not appropriate.

Right across the UK, it is recognised that access to appropriate residential care for profoundly learning disabled children is an issue, especially for those leaving school and unable to pursue further education or employment.

The normal world in which we live is not a world in which the profoundly learning disabled can relate to; indeed, they must be protected from it while at the same time being given the opportunity to live a happy and fulfilled life. The fear of many is that the profoundly learning disabled will be forced to live unseen behind closed doors with families who may struggle to cope with their needs or who may have to put up with an endless stream of visiting carers.

There are many loving mums and dads who give up everything for their children but for some, the condition their child may suffer from is so extreme that the only way they can hope to lead a happy and fulfilled life is in the specialised environment offered by residential care.

Right now, there are no suitable long-term residential care options for families in Scotland. My own son Muir suffers from Dravet Syndrome, which has left him with a range of complex physical and mental disabilities. He needs residential care, but the only suitable facility for him is in Surrey, in the very south of England.

The reason for the lack of long-term adult residential care in Scotland is because the Scottish Government currently measures the demand for long-term residential care in part on the current number of children and young people currently in residential care. This is a wholly flawed way of measuring demand and fails to capture the true need that currently exists in Scotland.

Moreover, the Scottish Government have admitted that the statistics they hold are not fit for purpose and are far too generalised to form a meaningful basis for any policy decisions regarding profoundly the profoundly learning disabled. It will be 2015/16 before this data on disabilities is reassessed, meaning families will have even longer to wait before policy catches up with their needs.

In addition, many parents believe they can cope or are wrongly stigmatised for putting their children into what may be perceived by others as 'institutions'. Add to this the fact that the needs of profoundly learning disabled children can evolve greatly as they get older and many parents don't realise they need residential care until it is too late.

The Scottish Government should not wish to limit the profoundly learning disabled's interaction with the world to a succession of visiting carers and a few hours respite away from home each week.

More community care is not the answer for this group. Scotland needs long-term residential care options for this vulnerable group and the Scottish Government should provide the funding in which to make this a reality.

Unique web address

<http://www.scottish.parliament.uk/GettingInvolved/Petitions/PE01545>

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1

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