

PE1545/E

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Ms Sigrid Robinson
Assistant Clerk
Public Petitions Committee
Scottish Parliament
T3.40
Edinburgh
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Dear Sigrid

CONSIDERATION OF PETITION [PE1545](#)

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.

Following the Committee's consideration of the above petition on 03 March 2015; you wrote seeking my views on the issues raised by the Committee specifically:

- What data does the Government collect on the number of adults in Scotland who have severe learning disabilities and who would benefit from residential care?
- What assessment has been made of the need for residential care facilities for the severely learning disabled adults in Scotland?

Policy

The keys to life strategy for people with learning disabilities is based on a human right's approach and the right of people with learning disabilities to live in the community and to have a family life. People with learning disabilities including those with PMLD should be given the same choices as other people to decide where to live. For most people with learning disabilities living with other people that they have not chosen to live with is inappropriate and a breach of their human rights. Many of our stakeholders People First, PAMIS and Learning Disability Alliance would support this statement. However, there needs to be options available, different choices of accommodation, and an opportunity for people with learning disabilities including those with PMLD to have their say and for their choice to

be respected. Families want and have a right to be fully consulted and involved in decisions regarding community living/supported accommodation.

The key to effective services is to ensure that people are provided with the outcomes that they need at the right time and in the right place. Statutory bodies have legal obligations to provide the services needed locally and should follow 10 strategic outcomes when commissioning these services. The first outcome to help people with learning disabilities have positive outcomes is to ensure people have choice and control in their daily lives and are supported to live independently as they can.

An overarching requirement will be that any new provision of services should not be large scale or attempt to replicate long stay hospital provision. Implementation of recommendation 6 in the keys to life aims to ensure that specialist residential care for adults with learning disabilities are commissioned in line with a national framework which improves the quality and consistency of support.

There is no change in policy direction in the keys to life. The national policy is for people to be supported to live in the community. The framework however provides specifications on core services that focus on outcomes for the residents.

People with learning disabilities with more complex support needs require responsive local services to support the families and carers of people with more complex support needs. Community based services and specialist teams for people with learning disabilities are becoming more responsive to meeting complex care needs at home however there remains a challenge to strengthen local capacity and competence around meeting complex needs and enhancing the quality of life for people with learning disabilities and complex needs.

The keys to life also recommends that alternative models of provision are available by developing housing with support to improve outcomes for individuals and their families. The residential model is recognised as a model of provision where for a few supported independent living is not an option. Family carers know their relative best and the input is crucial to any decisions being made. Any package of care being considered must be person-centred in order to successfully meet the needs of people with learning disabilities, including those with PMLD.

Link to Scotland Excel – Care national framework <http://www.scotland-excel.org.uk/home/KnowledgeBank/News/CareHomesAdultsServiceSpecs.aspx>

Data

The Committee will be aware that the Scottish Consortium for Learning Disability (SCLD) is a strategic delivery partner in relation to *The keys to life* the national strategy for people with learning disabilities. SCLD assist the Scottish Government with communications and engagement on the implementation of the strategy. An established programme of work since the strategy's publication is the development of Learning Disability Statistics Scotland (LDSS), a national dataset commissioned by the Scottish Government about adults with learning disabilities known to Scottish local authorities. Data from LDSS confirms that the number of adults in residential care in Scotland with learning disabilities is about 2,000.

The Scottish Government is reasonably confident that the LDSS data is capturing Profound and Multiple Learning Disabilities (PMLD) accurately and the data shows that adults with learning disabilities in residential care has remained relatively stable at around 2000 over the last five years. However, there is expected to be an increase in the demand in services for

children born with severe and complex LD with exceptional medical comorbidities, surviving into adulthood as a consequence of medical advances.

The petitioner notes that there is a lack of detailed centrally held data concerning adults and children with profound and multiple learning disabilities, in particular about their needs and circumstances. The Scottish Government agrees with this statement. People with learning disabilities are present but not visible across a number of health and social care datasets.

However, a key focus in *the keys to life* is to address this gap in evidence and data through further data collection and linkage. Understanding the needs and demographic of this population and how those can be embedded in the provision of services is essential to the implementation of evidence informed policy and practice. Further research is required not only on those already known to existing datasets, but also on the population hidden within current collections to ensure the needs of people with profound and multiple disabilities are met. The establishment of the Scottish Learning Disability Observatory at Glasgow University aims to address this gap by working closely with SCLD, delivery partners and NHS Boards across Scotland.

Assessment of need

Statutory bodies have legal obligations to provide the services needed locally. We do however, recognise that the subset of the learning disabled population that the petition refers to has specific needs and that there would be value in undertaking some national work to understand those needs more clearly. This could be in the form of consultation and research in the first instance through the work of the Learning Disability Observatory. Should the committee agree we would commit to undertake that work with the involvement of PAMIS and other learning disability stakeholders.

I hope this response will be of assistance to the Committee in its continuing consideration of the Petition.

Yours sincerely

Annette Pyle
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Scottish Government