

## **Petition 1545: Response of the Scottish Consortium for Learning Disability**

### **Introduction**

The Scottish Consortium for Learning Disability (SCLD) has been asked to provide a response to the Scottish Parliament's Public Petitions Committee on a petition concerning residential care for people with severe learning disabilities. The petition calls 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.*

The Committee considered the petition on 3rd March 2015. At that meeting, the Committee agreed to seek the view of the Scottish Consortium for Learning Disability on the petition and the issues raised by the petitioner in her oral evidence.

### **Background**

SCLD was established in 2001 as a result of a recommendation of the Scottish Government's previous learning disability strategy, *The Same as You?* SCLD is an independent organisation currently constituted as a SCIO (Scottish Charitable Incorporated Organisation). Its primary source of funding is from the Scottish Government via the Care, Support and Rights division of the Population Health Improvement Directorate.

SCLD is not an open membership organisation as such and does not have fee paying members. However, the constitution of the SCIO is owned by 12 'member organisations' including nine learning disability charities and three universities. Its board of trustees is comprised primarily of nominated trustees from those 12 organisations.

### **SCLD's role**

SCLD's main role since its establishment has been to undertake research, policy and practice development, training and public engagement. It does not provide care services to people with learning disability services and their families but does work closely with them to deliver its work using a coproduction model. Neither is it a campaigning or lobbying organisation. Rather it seeks to be a critical friend to the Scottish Government and other stakeholders providing evidence informed advice and information.

SCLD's current priorities are focused on supporting the Scottish Government to drive the delivery of *The keys to life*, the current learning disability strategy which was launched in 2013 in addition to continuing with the delivery of a number of ongoing programmes of work.

A key focus in relation to *The keys to life* is to assist the Scottish Government with communications and engagement concerning the strategy. One of our long standing programmes of work is the development of Learning Disability Statistics Scotland, a national dataset commissioned by the Scottish Government about adults with learning disabilities known to Scottish local authorities. We are currently in discussion with the Scottish Government about our priorities for 2015/16. There are parallel discussions taking place between the Scottish Government with the Scottish Learning Disabilities Observatory about its role and purpose.

## Discussions with the Muir Maxwell Trust

Although SCLD is not an open membership organisation we are always pleased to work with learning disability stakeholders and others who have a role to play in improving the quality of life for people with learning disabilities and family carers across Scotland. This includes non departmental public bodies, universities, local authorities, health boards, integrated joint boards and national and local charities.

Since the Committee met, the petitioner contacted SCLD to seek to understand more about our role and how we might work together. We have had a lengthy initial discussion with the petitioner, one of the outcomes of which was to arrange a mutual introduction to PAMIS, one of our member organisations whose specific focus is profound and multiple learning disability. We are in the process of arranging a tripartite meeting with PAMIS and the Muir Maxwell Trust to explore this further.

## Data from LDSS

LDSS has collected information on the numbers of adults with learning disabilities who live in residential care since 2009. Our analysis shows the total number of adults in residential care has been around 2,000 since this time with exact figures shown below.

Number of adults with learning disabilities who live in registered care accommodation

	2009	2010	2011	2012	2013
Registered adult care homes	2,364	2,403	2,305	1,866	2,001
Registered child care accommodation	21	33	30	29	26
Total	2,385	2,436	2,335	1,895	2,027

Source: eSAY 2009-13

The smaller reported number of people living in registered adult care homes in 2012 is partly attributable to Inverclyde Council misreporting accommodation data for 47 people. This means the published figure for registered adult care homes in 2012 is underreported by 47.

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. SCLD would agree with this statement. People with learning disabilities are present but not visible across a number of health and social care datasets.

We are currently working closely with colleagues at the Scottish Government to address this gap in evidence 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 data 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.

Based on the information that we do have, it is worth commenting on the extent to which data can tell us whether the policy direction in *The keys to life* is being achieved. As the SPICe briefing states in relation to care home data, the policy direction is as far as possible to enable people with learning disabilities to live independently in the community.

Because LDSS collects information about people who are known to local authorities it is biased towards the identification of adults with learning disabilities with higher support needs. Although severity of learning disability is not a variable which is specifically included, we can be reasonably confident that we are capturing PMLD more accurately as a category than any other by virtue of the methodology. This is because there is also an in built bias in the methodology towards the inclusion of those with formal support packages, which would include care home residents. As the above data shows the size of this population has remained relatively stable over the last five years.

## **Response from PAMIS**

Given its specific focus on a population group relevant to the petitioner's specific concerns, we asked PAMIS to provide a response to the issues raised.

PAMIS – Promoting A More Inclusive Society - is a registered charity that works solely with people with profound and multiple learning disabilities and their family carers.

Established in 1992 the principal aim of *PAMIS* is to support people with PMLD and their families to be full and active members of their communities. This is carried out through a range of services and projects including:

- a dedicated Family Support Service, with Directors in Tayside, Grampian, South Lanarkshire, Fife and Greater Glasgow and Clyde.
- additional intensive support to family carers through the difficult and often stressful period of transition from children to adult services through the Futures Project.
- leisure projects to promote accessible leisure activities for people with profound and multiple disabilities –
- engagement in a wide range of consultations and campaigns.

- the Information and Library Service based at the head office in Dundee and provides specialist advice and information on all areas concerning complex disabilities. There is also an extensive library which lends resources across Scotland.

PAMIS is committed to ensuring that:

- people with PMLD are valued both as individuals and in the contribution they make to the community
- people with PMLD should receive all the support needed to realise their full potential
- people with PMLD have a right to a full life shaped by personal choice, abilities and needs and that this underlies all provision and policy affecting their lives
- the knowledge and experience of family carers is recognised, and that their views are fully taken into account in service development

We as an organisation have been supported by the Scottish Government to lead on specific pieces of work within the Keys to Life; for example the changing places toilet campaign that ensures that people with PMLD are not excluded from community activities because of lack of appropriate facilities. This has been supported not only by the Scottish Government learning disability team but also the Transport Scotland directorate.

Although we acknowledge that there is a lack of awareness of the complex needs of people with PMLD and their family carers we as an organisation have found the team at the Scottish government to be responsive and inclusive of this group. We agree that it is often at a local council level that there are issue regarding resources. Packages of support can be extremely resource intensive and expensive and within the areas we are working we have had to provide input to support family carers to negotiate, and in many cases strongly advocate to get the support they need.

We provide support for approximately 652 people with PMLD and their family carers across all five areas. This includes supporting families when their sons or daughters move from the family home. We have recently been supporting a group of family carers who are requesting individual tenancies so that their sons and daughters can live in their own homes with the appropriate support and equipment rather than the suggested residential unit for 4 people. There are some excellent examples of successful tenancies for people with PMLD that can be shared with the committee and with Mrs Maxwell. Our families have asked to be fully consulted and involved in final decisions regarding community living/supported accommodation.

We acknowledge that people with PMLD should be given the same choices as other people and that for some of them living with other people that they have not chosen to live with is wholly inappropriate and a breach of their human rights. However there should be options, different choices of accommodation, and an opportunity for people with PMLD to have their voice heard.

In relation to training we agree that it is important for all health and social care practitioners to have experience of supporting people with PMLD and their family carers. Only after this experience and education can they truly understand the complexities of this group of people and the extensive caring role of the family carers. Again there are some excellent examples of this and PAMIS is proud to be supporting family carers to educate social work, nursing, medic and allied health professions students and is also currently exploring an interprofessional education practice placement opportunity for health, social care and education students. NHS Education for Scotland is supporting further roll out of the models used as are the Scottish universities and Scottish Council for Voluntary Organisations.

PAMIS is also establishing a project for schools and university students to get involved with people with PMLD and their family carers in order to support the next generation of care staff as well as to build community involvement. This will include specific support and training.

We would welcome further debate and discussion on the complex needs of people with PMLD and how we can work collectively to ensure that the voice of people with PMLD and their family carers is heard and acknowledged specifically in relation to supporting appropriate community living. We are keen that we speak about living in the community as an option as we are aware of many families who would not want their sons or daughters living in even small residential units.

We would also welcome the opportunity to work within other areas of Scotland and will pursue further funding to enable this to happen.

### **Opportunities for policy development**

In this response we have sought to refer to key elements of the current policy and evidence known to us. In our discussions with the petitioner we have recognised that the subset of the learning disabled population that the petition refers to has specific needs and that there would be value in taking steps to understand those needs more clearly. This could be in the form of consultation and research in the first instance.

We would recommend that steps are taken to undertake that work with the involvement of PAMIS.

**Chris Creegan**

Chief Executive

Scottish Consortium for Learning Disability

7<sup>th</sup> April 2015