



31.7.15

Ms Sigrid Robinson,  
Assistant Clerk,  
Public Petitions Committee,  
Room T3.40,  
The Scottish parliament,  
Edinburgh,  
EH99 1SP.

Dear Ms Robinson

**Re: Consideration of petition PE1545**

Thank you for writing to me regarding my views on this petition.

Mrs Maxwell's letter very powerfully describes the dedication that many families have for their loved family member with profound learning disabilities, and the stress, disappointments and battles faced over years whilst trying to secure the best resources, care and support for their child. Given the extensive needs of people with profound and multiple learning disabilities, their families have to work with many professionals and services over time. The families know their child best, and typically what is in their best interests.

I fully concur with the statement that people with learning disabilities are present but not visible across Scotland's routinely collected health and social care statistics. This is something the Care, Support & Rights Division of the Scottish Government are currently trying to address, and the new Scottish Learning Disabilities Observatory has started work on this. However, with regards to people with profound and multiple learning disabilities, this information is even harder to identify as it is not collected at local levels across Scotland. Probably the best estimate of the number of adults with profound and multiple learning disabilities comes from research conducted in Greater Glasgow and Clyde, and an assumption that there is a similar prevalence across Scotland. This suggests that there are 3,177 adults with profound learning disabilities in Scotland, or 6/10,000 general adult population.

However, the number of people with learning disabilities does not address the key point that Mrs Maxwell makes, as every person is an individual with different needs, wants, and likes. This is equally as true for people with profound and multiple learning disabilities as it is for everyone else. Across the globe, most high income countries have moved away from institutionalised care for people with learning disabilities, adopting the value-based policies and practices that person-centred care in the community is the best way forward. In the UK, the hospital scandals in the 1980s and 1990s also hastened this move, and Scottish policy has driven it. Many people have benefitted from the opportunities that come with having one's own single or shared tenancy, with the support they need, and integration into and participation within their local communities. This includes individuals with some of the most profound learning disabilities and with multiple and in some cases severe health conditions. But one size does not fit all, and

Local Authorities needs to be able to provide or commission a range of services, supports, and accommodations to suit every person with learning disabilities in their area. Some people flourish in settings where there is space, structure, and routine. Larger group settings, due to scale, may be able to offer a wider range of activities that perhaps are not available or accessible in the local community. It is important that people have choices.

Yours sincerely,

Sally-Ann Cooper

**Professor of Learning Disabilities & Honorary Consultant Psychiatrist**  
**Deputy Director – Institute of Health and Wellbeing**