

## **PE1545/R**

The Muir Maxwell Trust Ltd submission of 25 April 2017

Further to the meeting of the Petitions Committee on 30 March 2017, our observations regarding progress are summarised below.

### **1. Timelines &. Meetings**

**1.1** An initial meeting in May 2013 with Cabinet Secretary for Health Alex Neil to discuss the issue of the absence of residential care in Scotland for the profoundly learning disabled, resulted in the above petition which was lodged on 3rd December 2014.

**1.2** The petition has been considered by the Committee on seven occasions and in that time we have been invited to attend three meetings with the Scottish Government's Care & Autism team. Additionally, a Government representative, Linda Allan, consultant nurse from this team attended a conference on the same issue, jointly organised by us and Holyrood. A Residential Care Development Session was also hosted by Scottish Government's Jess McPherson, Strategic Lead, Care, Support and Rights.

**1.3** The most recent meeting we were asked to attend with Jess McPherson was held in August 2016. The purpose of the meeting was to provide an update regarding progress. At the meeting Dr Anne MacDonald was invited to outline the work she is undertaking regarding out of area placements for people with complex needs, with the aim of presenting her findings, including recommendations, to Scottish Government in March 2018.

**1.4** Since then there have been no further updates.

### **2. Issues**

**2.1** Little tangible progress has been made since the petition was lodged in December 2014, although Scottish Government will report that there is work in progress which will be duly completed by March 2018 and presented to ministers, as was explained to us at our last meeting in August 2016.

**2.2** The work in progress referred to is only in line with recommendations 51 and 52 of Scottish Government's review of services 'The keys to Life' and aims to garner information from Local Authorities to establish the needs of those in out of area/out of country placements, details of the assessment process that resulted in that out of area/out of country placement and also how that placement can be better met in Scotland.

**2.3** The work in progress, though worthy, omits to address the issues raised by our petition and also ignores my own representations when I was invited to speak to the petition on its first consideration. A focus on out of area placements will not fill the gap in data relating to people in Scotland with profound and multiple learning disabilities. It is this serious lack of data that continues to lead to a failure in service delivery and an absence therefore of much needed residential care in Scotland.

A transcript from that day quotes me as saying "The Government relies on data provided by local authorities and social work ..... and I know first hand that both are failing to properly assess the needs of this group because of their lack of understanding of the profound disabilities and their lack of proper application of the assessment process."

**2.4** It seems that the work in progress that the Government refers to in fact fulfils no more than the policy requirements as outlined in "The Keys to Life", which is to bring those in out of area placements back to Scotland by June 2018 and bears little resemblance to the issues raised by our petition.

### **3. Epilepsy**

**3.1** It therefore appears necessary to consider once again the details of our original petition and my representation to the petition and the facts stated therein:

- a small minority of learning disabled people in Scotland are people with profound and multiple learning disabilities
- as a small minority, they are therefore overlooked and their Significant care needs are failing to be recognised or understood
- the Scottish Government's own policy review identifies that 66% of people with profound and multiple learning disabilities have epilepsy

### **4. Continued Health Care (CHC)**

**4.1** Epilepsy in the profoundly learning disabled is therefore a complex health need that requires to be elevated, with the provision of continued health care (CHC) but in Scotland care packages do not include a continued health care component, except for long stay hospitals for the mentally unwell or the elderly, whereas in England this is not the case.

**4.2** In England in the event of a care package with a continued health care component for a young person with profound and multiple learning disabilities, the assessment process is lead by health professionals and not by social care. The serious health needs of the profoundly learning disabled are therefore identified and given priority as well as funding and indeed, that gives recognition to a need for residential care and specialist health care services.

**4.3** In Scotland there are no residential care homes with specialist health care services, in particular epilepsy services for young people with profound and multiple learning disabilities, only care homes in the community which are unsuitable for young people with continued health care needs, especially comorbidities including epilepsy.

### **5. Conclusion**

**5.1** In the absence of continued health care in Scotland for adults with profound and multiple learning disabilities, the assessment process will continue to be flawed and care needs will not be identified or met. Social care services do not have the skill set to understand the complex health care needs and therefore fail to identify the essential funding requirements to meet these needs.

**5.2** We would urge Scottish Government to take the lead and recognise the desperate need for continued health care especially in complex epilepsy and in so doing, provide the vital support and funding by health for the profoundly learning disabled and their families who are struggling to cope. Not all will require or want residential care but it will evidence the need for such care and care standards will require to be high. Without continued health care Scottish Government will go on failing Scotland's profoundly learning disabled, especially those who also have epilepsy.