

PE1545/T

Petitioner submission of 16 October 2017

Response to Scottish Government's submission to the Petition Committee of 13 June 2017

1. The work of Dr Anne MacDonald

The Scottish Governments's reply to the Committee regarding the points raised in our earlier submission of April 2017 is exactly as predicted.

They said "As the Committee will be aware Dr Anne MacDonald's project commenced during May 2016 and will end March 2018."

As stated in our submission of April 2017 it is our view that the work in progress referred to is only in line with recommendations 51 and 52 of Scottish Government's review of services 'Keys to Life' the aim of which is to bring those in out of area placements back to Scotland and to have relevant data, gathered from Integration Joint Boards and a proposed solution/recommendations by 2018.

We stand by our opinion that this work fails to address the serious issues raised by our petition and in no way addresses the gap in data relating to people in Scotland, with profound and multiple learning disabilities, including the children, in order to properly meet their needs and the needs of their families.

Our opinion appears to be supported by Scottish Government's reference to "Themes that are emerging to date include solutions to improving the discharge of people with learning disabilities with complex needs, focussing particularly on suitable accommodation." Though their statement is most confusing.

2. The work of Integration Joint Boards (IJBs)

We are aware of one Integration Joint Board which is attempting to make some form of longer term provision in Scotland for adults with more complex needs but the focus of this provision thus far, is solely on accommodation (in keeping with the above statement) and does not address the supporting environment and services that will be essential to meet the profound needs of the group that we are referring to and enable a fulfilled life for them. Consultation with stakeholders, especially customers (families) will be vital, for such a project to be successful and a regard for the children and young people also coming behind will be necessary to ensure such a facility can accommodate all of its potential customers. Accurate data gathering is therefore fundamental for the success of such a project. Substantial funding will also be required - the needs of this group cannot be met with a restricted budget.

The work of Scottish Learning Disability Observatory (SLDO)

Scottish Government has referred to work they have commissioned to address the data visibility of people with learning disabilities in Scotland, including projects by SDLO. However, the focus of this work and its relevance is particularly alarming, being largely around the prescription, and effect, including mortality of antipsychotic drugs - the definition of which is below.

"Antipsychotics, also known as neuroleptic or major tranquillisers, are a class of medication primarily used to manage psychosis, principally in schizophrenia and bipolar disorder."

As antipsychotic medication, including its prescription and consequences is the major focus of SLDO's research, explained in Scottish Government's submission to the Committee of June 13 2017, it is quite clear that we are talking about a very different group of profoundly learning disabled adults and children in Scotland who would for the most part, not be receiving a prescription for such a horrific form of medication.

Our petition (PE1545) is about identifying children and young people who have profound and multiple learning disabilities, and who will thrive in high end, supported residential care that will enable them to live safely in a protected environment, with a significant ratio of appropriately skilled carers to customers, enabling happy and fulfilled lives and peace of mind for families.

Summary

It is now two years since the submission of PE1545 and we are not only disappointed but also deeply frustrated by the lack of progress and in particular, the continued lack of understanding of the needs of this small group of children and young adults in Scotland with profound and multiple learning disabilities.

We are of the view that actions must now speak louder than words. In adulthood this extremely vulnerable group may not be able to give any one their vote but nevertheless, we have a moral obligation to look after them properly and we must start doing that right now.

We need action, we need substantial funding and we need a clear plan.