

PE1545/S

Scottish Government's submission of 13 June 2017

Following the Committee's consideration of the above Petition on 11 May 2017 you wrote asking for an update on the preliminary results of phase one of the project plan currently underway by Dr Anne MacDonald.

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

Thus far 26 of the Integration Joint Boards (IJB's) have now returned information with 5 currently being followed up. Analysis of the data is underway.

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. In addition to data collection and analysis, meetings have been held with representatives from a number of IJB's to discuss local issues and to ascertain their views on potential solutions.

These discussions are at an early stage and further consultation is required with the sector as well as a range of other stakeholders before any recommendations can be made in terms of strategic direction to support for people with learning disabilities with complex needs.

You also asked for a response to the concerns raised by the petitioner in her submission dated 25 April 2017 that the above project will not address the gap in knowledge about people with profound and multiple learning disabilities.

Dr Anne MacDonald's project is specifically focussing on out of area placements and NHS provision in Scotland for adults with learning disabilities with complex needs. In addition to this work the Scottish Government has commissioned a range of work streams to address the data visibility of people with learning disabilities in Scotland including the work of the Scottish Learning Disability Observatory (SLDO)

A number of projects are underway by SLDO which will fill the gap in data relating to people in Scotland with Profound and Multiple Learning Disabilities (PMLD) These include the Scotland's Census, 2011 and the ScotExed Scottish Pupil Census projects (specifically focussing on children and young people with learning disabilities) This project will look at :

1. Trends, geographic variation, and cumulative frequency in antipsychotic prescribing
2. Educational outcomes (e.g. absence, truancy, exclusion), and relationship to antipsychotic drugs.
- 3 Birth, maternal, obstetric and early lifestyle factors relationships to antipsychotics .
4. Rates of diabetes, ADHD, epilepsy, depression and asthma, and cancer, and prescribing patterns.
5. Frequency and duration of hospital admissions for all causes, for ambulatory care-sensitive conditions, injuries, accidents and falls, and specialities.
6. Standardised mortality ratio, and relationship with antipsychotic drugs.
7. Cause-specific mortality rates.

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