

PE1545/DD

Scottish Government submission of 6 January 2020

Thank you for your letter dated 12 December 2019 regarding the Committee's consideration of the above Petition on 5 December 2019 and the evidence it heard from me at its meeting on 10 January 2019. You asked for clarification on the research discussed at the meeting and information about the joint commissioner and provider event.

In your letter you ask for confirmation that I have met with Mrs Maxwell. I can confirm I met with Mrs Maxwell, Dr Anne MacDonald and representatives from Epilepsy Scotland on 4 September and that the meeting helped clarify the petitioners key concerns about the needs of families of people with complex needs, especially those with epilepsy.

In your letter you asked for clarification on the research discussed previously. The meeting on 4 September clarified the request for research on the number of people with learning disabilities and epilepsy rather than the need for research on the number of people with profound learning disabilities. All in attendance at the meeting agreed the need for better data. The Scottish Government is committed to improving data on people with learning disabilities, including those with epilepsy.

Epilepsy Scotland explained that there is no national picture on the number of people living with a diagnosis of epilepsy, nor the level of severity of the condition. There are a number of reasons for this. It is extremely difficult to ensure consistency of data collection and definitions about "complex care needs" as this term can be applied to a variety of conditions and situations. Also, person centred care planning looks at the person's needs rather than their diagnosis. This means that services are commissioned looking at what people need, however this makes ascertaining a definitive number of people with complex needs and epilepsy challenging. Additionally, epilepsy is a spectrum condition which means that depending on the severity people's needs will vary greatly.

Following the meeting with the petitioner, the Scottish Government are working with Epilepsy Scotland and Learning Disability Nurses to determine what further work can be undertaken to understand the national picture on epilepsy and learning disabilities. We will work together to try to identify the number of people with learning disabilities who also have epilepsy.

Since the publication of the Coming Home report there have been multiple Health and Social Care Providers areas who have or will introduce risk registers for people with learning disabilities. These risk registers will identify the group of people being supported who are at risk of not having their needs fully met. This will allow plans to be put into place in the case that they are not able to be properly supported where they are.

The joint commissioner and provider event took place on 9 December. While the focus on the event was not specifically on those with complex needs and epilepsy, we know from Dr Anne MacDonald's report that within the group who are out of area there are people with profound learning disabilities and epilepsy. The event was focused on solutions which were person centred rather than one specific model of

care. The event also provided the opportunity for commissioners and providers to detail what resources they require to better meet the need of people with learning disabilities. Once this has information has been analysed it will provide useful information if there is an unmet need for residential services with supporting medical care.

Please be assured that this works remains a priority for the Scottish Government.

I hope this provides a helpful update on this work.