

Thank you for your letter dated 11 June 2019 regarding the Committee's consideration of the above Petition on 6 June 2019 and the evidence it heard from me at its meeting on 10 January 2019. You asked for an update on the progress of this work.

At the evidence session, I offered to meet with the petitioner Mrs Maxwell OBE to discuss the concerns raised in her petition. I am happy to report that I will be meeting Mrs Maxwell and her representatives from Epilepsy Scotland on 4 September.

The Committee may be interested to note that on the 25th of June the Minister for Mental Health wrote out to the Health and Social Care Partnerships (H&SCP) asking for detail on their actions following the Coming Home report's recommendations. My officials are currently reviewing all the responses and following up on those yet to respond. However, early analysis is encouraging with evidence that H&SCP are developing risk registers for those at risk of being placed out of area. This should ensure better monitoring of those individuals, and mean that regular reviews take place, with anticipatory care put in place nearer to home. H&SCP are also looking at their commissioning processes, planning a variety of housing solutions and developing more person centred services. The next steps for this work are being led by Dr Anne MacDonald who is planning a joint commissioner and provider event in the autumn. This will bring commissioners and service providers across Scotland together to explore the issue and learn from examples of good practice.

At the Committee hearing in January, I made an undertaking to look into research into the needs of children and young people with profound learning disabilities. As the Committee will be aware, there is no marker for this group in routinely collected data. The main reason for the lack of a marker is that there is no one diagnostic category for "profound" learning disabilities. There are various conditions, which may have a profound impact on an individual's capacity and/or functioning. Following a desk-based research exercise, my officials have found that there are no internationally agreed definitions relating to either diagnosis or categorisation of this group.

Various definitions related to "Profound and Multiple Learning Disabilities" exist and in the context of Scottish Learning Disabilities policy, we currently use the MENCAP definition which relates to the level of support that a person requires. The support provided to each child or young person will be person specific and based on an assessment of their need. The recording of this assessment is made on an individual basis and is highly personalised and not amenable to extraction for quantitative research purposes. The only possibility might be a qualitative research study looking at the needs of a sample of young people. This would be difficult to organise given the nature of the group, and would likely only highlight that need is highly individual. Therefore I have reflected that this research into the needs of children and young people with profound learning disabilities may be of little value, costly, and would not answer the questions the committee have posed about the national or regional level of need for residential care for this group of vulnerable people.

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

I hope this provides a helpful update on this work.