

PE1545/FF

Minister for Mental Health submission of 12 November 2020

Thank you for your letter dated 23 October 2020, to Jeane Freeman, Cabinet Secretary for Health and Sport, regarding the Committee's consideration of the above Petition on 10 September 2020. I am responding on her behalf as Learning Disabilities is within my portfolio. You asked the questions raised by the Petitioner and I welcome the opportunity to respond on behalf of the Scottish Government.

The Petitioner asked if I agree there are children and young adults with learning disabilities who have more profound needs, including medical needs, that require a high quality residential care setting with on-site medical support.

The Scottish Government are very clear that children and adults with profound and multiple learning disabilities and other medical needs may choose to receive support in a high-quality residential establishment but this should not be seen as a requirement for everyone with high levels of need. We know of children and young people who lead rich and fulfilling lives whilst living at home, attending school or indeed living in residential schools.

The 'keys to life' and 'the same as you' take a person-centred approach to supporting people with learning disabilities, however severe their condition may be. This approach is based on the UNCRPD and social model of disability with a drive to ensure that people are not viewed entirely through the prism of any medical conditions they may have. We know that the medical model can have significant unintended consequences in limiting the life experience of people with learning/intellectual disabilities and it is important to ensure that any medical issues someone may have are only considered as part of their experience, not all of it.

On a local level the numbers of people, who require nursing/medical support are so small that a regional model would be necessary, however this is totally contrary to Scottish Government policy ambitions as it would necessitate the removal of someone from their community. We know that nursing/medical support can still be provided appropriately and safely to people in their own homes (or their family home) from highly trained nursing/medical support staff such as District Nurses, Community Learning Disability Nurses, and/or Allied Health Professionals. People with the most complex medical conditions are still able to be supported in their own home and we have examples of this, however the choice should always remain with the individual and their family as to what model of support they receive.

The Scottish Government work with a range of partners to ensure that children, young people and adults with profound and multiple learning disabilities live a rich and fulfilling life. Our partnership with the organisation PAMIS (Promoting a More Inclusive Society) is central to this work and is again based on the understanding that everyone's needs are different.

Regarding the question if I agree there is a lack of residential care provision in Scotland for those with more profound learning disabilities and medical needs, the Coming Home report did not identify a significant number of people with complex health needs who were out-of-area due to requiring medical residential care. The most common reason was around behavioural challenge, rather than complex health

issues. The Scottish Government did not conclude that there is a lack of provision for the reason of medical needs.

The letter states that the petitioner is concerned that 'the fundamental aim of the petition does not appear to be fully understood by the Scottish Government'. The Scottish Government understands the petitioner's aim, but has not agreed with their aim.

The petitioner has sought to set up multiple-occupancy large-scale residential settings, with medical care as a key component of the approach. This is regarded as at odds with the government's focus on person-centred support for people with learning disabilities, which avoids the use of large institutional settings, and which uses a social model of support as its primary focus, rather than a medical model.

We understand that some people leave both their home area and Scotland to find appropriate accommodation. However, this should not be viewed as the norm and should only ever be the case when all other suitable possibilities have been exhausted. Again, we are aware of many people with profound and multiple learning disabilities who live happy and fulfilling lives in their own home with support, whether that be in family homes, in residential care homes or in other accommodation services based in their own home areas or in other parts of Scotland. Organisations such as TRFS, Cornerstone, Capability Scotland, PAMIS, Sense Scotland, ENABLE Scotland and others work tirelessly to ensure that this is the case. For many people with multiple and profound learning disabilities. These housing options are supported by a wide range of professionals both internal to the organisations but also from the NHS and local HSCPs to ensure that individuals have their health and wellbeing looked after in order that they may gain the maximum benefit from their home environment.

The Petitioner asked if I agree there has been a failure by the Scottish Government to progress the issues raised by this petition and in turn, that the Government has failed the severely learning disabled and their families.

The Scottish Government is committed to ensure that the needs of people with profound and multiple learning disabilities are accurately reflected in national policy and local implementation. For example, the Coming Home Report identified and investigated the needs of a small group of people who were living in out of area residential placements which neither they nor their family had chosen for them and which were failing to meet their needs. For many, these placements were in England. The recommendations in the report included, "identify suitable housing options for this group and link commissioning plans with housing plans locally". Scottish Government, working with Scottish Commission for People with Learning Disabilities, worked with commissioners and providers to explore solution to improve the housing options for people with learning disabilities. More recently, a Short-Life Working group has been established, along with COSLA, to develop solutions for the cohort of delayed discharges with learning disabilities or enduring mental health problems for people who remain in hospital. This group is also considering funding options and will publish their short term recommendations by the end of November. The remit of the group is to identify and describe the processes and finances required to avoid inappropriate admission to hospital, and to support the discharge from hospital of people with learning disabilities or enduring mental health difficulties,

who are currently ready for discharge, but whose discharge is delayed. One of the aims of the group is to improve the person centred commissioning of services so that people's needs are met. This group is due to report by January 2021 with any wider and additional findings being fed in to the Social Care Review.

Regarding the question if I am aware of the successful models of residential care for the severely learning disabled, in England which are in very high demand, the Scottish Government's focus has to be on the successful models of care for people with profound and multiple learning disabilities in Scotland. This work is to increase the options that people with learning disabilities and their families have about where and how they are supported, including whether this is on their own or with other people. However, we are aware of the disappointingly regular reports of failing residential and hospital specialist services in England and we are also aware of the Transforming Care agenda and the Care Quality Commissions ongoing programme of work to highlight and address these concerns. It could be argued that high demand is a result of these facilities offering a 'quick fix' or easy option, we do recognise it takes time to establish local service provision for this highly complex group.

The Petitioner asked if I can confirm when the provision of residential care can be expected for the severely learning disabled in Scotland.

We are aware of the many existing establishments which provide excellent care (as assessed by the Care Inspectorate) throughout Scotland.

As of 30 September 2020 there were 155 care homes for adults with learning disabilities. The caveat to this would be that other types of care homes may also have a learning disability unit but are not specifically registered just for learning disabilities, so would not show in these figures.

However, that is not to say that more accommodation options are not required and Scottish Government is working with COSLA and a wide range of partners to consider these can best be developed based on people's needs. The work following the Coming Home report, the Short Life Working Group on Delayed Discharge and the Independent Review of Adult Social Care all have this aim central to them given many of the issues are cross cutting.

I hope this helps answer the Petitioner's questions and clarifies the position of the Scottish Government, including the commitment to severely disabled people and that they are cared for to the highest standard and in a person centred way.