

PE1545/GG

Petitioner submission of 23 November 2020

The response to my questions addressed to the Health Minister but answered by the Mental Health Minister, makes disappointing reading and blatantly ignores my efforts of the last seven years to unpick Government policy and evidence the vital need for high quality residential care as a choice for some families caring for a profoundly learning disabled relative. In the course of the Petition, whilst the Scottish Government has done nothing to address the gaping hole in care provision highlighted by me, it has acknowledged the need for that choice. The Minister for Mental Health would now appear to be denying that need.

It is clear from the Minister's response that they have not reviewed the correspondence of the last seven years and are therefore unaware of the evidence that has already been presented and the support that has been given from numerous sectors (including organisations like PAMIS) to my argument. In effect the Minister's response is a rewind to the very beginning, once again raising long ago beaten down policy such as Keys to Life and The Same as You and many other opinions once considered worthy but very clearly discredited in the course of this long drawn out and deeply frustrating debate.

To have to reply to the Minister's response point by point would be an insulting revisit of all that has already been discussed - but by way of summary the following points should be noted;

1. I am not asking for state hospital provision in Scotland, although in the absence of such inappropriate provision I am aware that some people from Scotland are referred to England for such care when social services finally run out of more suitable options - as evidenced in the Coming Home report which the Minister refers to.
2. The Scottish Government has already conceded the need for high quality residential care provision of the kind I am asking for which presently does not exist in Scotland. It has also been agreed that the numbers are small, though the actual numbers that might require this quality of residential care continues to elude the Government.
3. I am quite clear that everyone's care needs are different and it is a matter of choice for some families who would prefer residential care on a scale that can properly meet the needs, including behaviours and medical needs, without defaulting to state hospital provision or a residential care model that is inadequate to meet the needs.
4. From personal experience I am acutely aware of the challenges for some families to look after a learning disabled relative at home and the glaring absence of suitable provision and support based on all of Scottish Government's current models and policies.
5. One of the most significant points made by Dr Anne MacDonald's Coming Home Report is that behavioural challenges are a symptom of unmet need. Through

behaviours the learning disabled speak and if they have been committed to an inappropriate mental health institution in England it is because Scotland is getting their care wrong.

6. The small group the Petition refers to have complex health needs as well as complex care needs, especially severe epilepsy and other syndromes. Autism features too, often in addition. These are known as co-morbidities and that is what makes the care needs of this small group so complex.

And now I write as a mother of a profoundly learning disabled child who is highly complex and whose needs are extremely challenging and at times impossible for me and my family to meet. Based on the Scottish Government's current policy and inadequate local provision, left unfulfilled I have no doubt my child would be in a horrible place but thankfully they live in a Centre in England where they lead a rich and rewarding life with access to wonderful facilities and supported by an extensive and highly skilled care team of staff including medical and mental health professionals. As a mother I can lay claim to decades of experience of caring for a learning disabled relative, real hands-on life experience that flies in the face of Scottish Government's policies. Who are these policymakers who think they know what they are talking about? They do not - and they insult us by thinking that they do and furthermore, by failing to listen to us.

PE1545 is a very important petition that must be properly addressed. Minister's and policymakers must stop 'dancing round their handbags' pretending to understand the vital needs of this small group and talking down to families like me and mine. It's time to listen and do something constructive or the scandal of their failure to even acknowledge the existence of this group will go on and history will eventually bring shame on them.