

PE1545/X**Petitioner submission of 30 May 2018****Response to Scottish Learning Disabilities Observatory (SLDO) submission of 17 April 2018**

SLDO's response to the committee confirms that they are not addressing the specific points raised in PE1545 but rather reporting on a work programme agreed with Scottish Government (the funder) and aligned to Government policy outlined in Keys to Life.

PE1545 has been addressed separately with a copy of SLDO's historic response dated 31.7.15. This response states that:

1. There are approximately 3,177 adults with profound learning disabilities in Scotland. (Keys to Life estimates 4,000)
2. In terms of care provision, there is a move away from institutionalised care for people with learning disabilities, in favour of person-centred care in the community. (PE1545 acknowledges this shift and argues that there is a still a place for residential care amongst these options.)
3. The response acknowledges that person-centred care is not the answer for all families and local authorities must provide a range of services, support and accommodation in order to provide choice. (PE1545 is asking for exactly this.)

SLDO's comprehensive programme of research which is still in progress, highlights a number of problems that we believe support the issues raised in PE1545 for some families.

1. Those with learning disabilities in Scotland receive poorer primary health care - we believe this is because doctors are not as accessible in the community as they are in a residential care setting where there is medical support on site. This is particularly relevant for profound epilepsies where the need for specialist epilepsy care is paramount. Much mention is made in the research of autism and also Down's syndrome and the comorbidities of these conditions, which in a large number of cases will include epilepsy - but there is barely any reference to epilepsy, although Keys to Life refers to 60% of those with profound learning disabilities having epilepsy.
2. Poor primary health care leads to lower general health ratings for people with learning disabilities - the day to day health care needs of this group are far greater than in the general population because of compromised immunity due to their health condition and possibly prescription medication. Minor ailments such as skin and eye conditions can be over looked or ignored because of the absence of immediate access to a doctor. These minor ailments badly need attention as they can be a sign of compromised general health, including mental health. Health issues in the profoundly learning disabled should not be considered in isolation but as part of a 'whole health' picture. This requires a

much higher level of medical care than that of the general population that for the most part, cannot be accessed by people with profound learning disabilities who are living in the community.

3. Mental health conditions are more prevalent amongst those with learning disabilities than in the general population - care in the community doesn't always meet the needs of those with profound learning disabilities, failing to consistently provide the right skill set to keep them safe and well and a lack of engagement in fulfilling activities that can lead to boredom and frustration. Mental health is therefore compromised and can lead to difficult behaviours. Families who are dependent on self-directed support to provide care themselves for their learning disabled child or young person often find that financial support to be inadequate and sometimes the care resource is unavailable. Many profoundly learning disabled people living at home, cared for by family members are therefore leading unfulfilled lives.
4. Clinicians need a heightened awareness of comorbidities in autism - this begs the question what about epilepsy? Understanding and awareness of comorbidities in epilepsy and autism and indeed all cases of profound learning disabilities is paramount for good physical and mental health; but only a specialist skill set will enable an understanding of the 'whole picture' in these patients, not generally available from within the community.
5. The impact on mental-health of maternal carers is an extremely important area of research in terms of PE1545. Mental health can be devastating and totally debilitating for maternal carers, particularly if their learning disabled child or young person is cared for at home or even in a local community setting. Many simply cannot cope and this in turn impacts on the health of the learning disabled off-spring.
6. Poor oral health. The importance of routine dental health care in this group is underestimated, many of whom are affected by their medication and /or poor oral or dental hygiene. Amongst the profoundly learning disabled dental treatment is more often required under sedation and therefore regular dental check-ups and easy access to specialist dental care is as vital as easy access to medical care. A residential setting where medical care is on site is better placed to provide this vital support in dental care. Those with learning disabilities are not necessarily able to communicate tooth pain. An undiagnosed abscess can lead to sickness, difficult behaviours and even death.
7. Antipsychotics are reportedly prescribed to those with learning disabilities at rates higher than rates of mental-health patients - this is most alarming and begs the question why? If we are treating behaviours that are the consequence of frustration or depression or general unhappiness then we are treating the symptoms and we are failing to address the underlying cause. Behaviours in profound learning disabilities are often a form of protest in the absence of the ability to express feelings and emotions and communicate in any other way. It is important to ensure that we are meeting the needs of the profoundly learning disabled person and that they are living a fulfilled life, often more easily facilitated by more structured residential care.

8. Hospital admissions are higher and mortality is 20-25 years earlier and 40% of deaths are due to amenable health care - amongst the profoundly learning disabled better access to primary health care and also specialist health care as described above is vital. This is not facilitated in the community to the same extent as residential care with medical provision on site.
9. About 20% of people with learning disabilities have autism. About 20% of people with autism have learning disabilities. Do those with comorbidities in autism and learning disabilities have different health needs? A reference to epilepsy is essential in this too and YES THEY DO HAVE DIFFERENT HEALTH AND SOCIAL CARE NEEDS, particularly if they have profound learning disabilities. But to this end there simply isn't enough choice.
10. Transition issues include poor physical and mental health in transition, including anxiety and challenging behaviour, limited appropriate options for post school activities and lack of support for families (including the absence of any residential care options as discussed in PE1514).
11. Issues with hate crimes - such issues raise the question of whether the profoundly learning disabled should live in the community or whether they should be cared for in a more protected environment, more compatible with their needs and one that shields them from a population that for the most part, cannot understand their health issues and may not be sensitive to their needs.
12. Physical multi morbidity can result in mental health issues for those with learning disabilities - in particular where the learning disabilities are profound, which in turn supports the argument in favour of protecting them from the general population who cannot be expected to understand their health issues and their resultant needs. A more appropriate environment can perhaps better support their mental health.
13. Ageing parent carers bring risks to the health of off-spring - what happens to a profoundly learning disabled adult cared for by an ageing parent who can no longer cope or who dies? At the best of times these grown up children can't cope with change, never mind in the event of a aged parent who has been their life-long carer dying. Better to establish that learning disabled person at an early stage in life in an independent setting where they will have the time and youth to adapt.

Whilst PE1545 is asking the committee to consider the issue of the absence of any residential accommodation in Scotland for the profoundly learning disabled, we accept that residential care would not be the preference of all parents but only of some. We also accept that residential care may not always be perfect and indeed, at times, may face some of the same challenges presented to local authorities in terms of providing care in the community. But whilst residential care may not necessarily be a 'perfect place' for those with profound learning disabilities, it should better meet their needs by providing a safe haven and where routine is their refuge, supported

by the right level of experienced staff, as well as round the clock medical and nursing support.

For parents who prefer this option, they believe they know what they are dealing with and do not trust that the alternative care in the community will be safer or that the extensive services required for their son or daughter will be available. These parents believe that not everyone can live well in the community, they also are concerned about their off-spring's long term future taking in to account their own inevitable mortality. They are seeking a sanctuary, a calm and perhaps semi-enclosed environment that enables leisurely walks and a connection with nature without exposure to risk or the population at large. They want recreational activities and structure and routine with dedicated staff and residential living in an appropriate environment that can also meet their specific health and social care needs. Ideally this place would be in reasonable proximity to their own homes to enable regular visits by family members. And they want a relationship with the care providers that will involve the family in every plan. Such a place for some families will resolve many of the issues raised by SLDO's on-going programme of research and which so far remain unresolved for too many Scottish families caring for a profoundly learning disabled.

This level of care is undoubtedly more costly which doubtless is a factor that has influenced the shift in favour of care in the community away from residential care but the financial consequences of inadequate care for the profoundly learning disabled are increasingly evident and should perhaps be an additional focus of research by SLDO on behalf of the funder, Scottish Government.