PE1545/AA
Petitioner submission of 29 January 2019

The Meeting
The Petitioner (Ann Maxwell OBE) is grateful to this Committee for bringing PE1545 to the attention of the Cabinet Minister for Health and Sport and in particular to those committee members who presented questions to the Minister on behalf of the Petitioner. She notes the robust discussion that followed and is satisfied that this occurred in a public forum making all that was said a matter of record. Given the progress that has been made in terms of tabling the serious issues that the petition raises, she respectfully requests that continued discussion of these matters should be in the same public forum and would welcome the support of Shadow Ministers, Epilepsy Scotland and the CPG.

The views of other families
Much consideration has been given by the Petitioner to all that was said in the discussion. She is sensitive to the fact that the subject matter and some of the associated language is not necessarily familiar to all participants and the desire to understand the issues raised was tangible. Again, respectfully, she would add that unless you are living the life she refers to, it is beyond most people's comprehension as what the challenges are. But she is not a lone voice, as evidenced by her open letter on the same subject sent to the then Cabinet Minister for Health, Alex Neil, signed by a number of parents and published in the Scotsman on Friday 11th October 2013 (copy attached) https://www.scotsman.com/news/opinion/your-say/care-about-care-1-3136537 The Petitioner's concerns are also echoed in Dr Anne Macdonald's report 'Coming Home' https://hub.careinspectorate.com/media/834185/report-on-out-of-area-placements-and-delayed-discharge-for-people-with-learning.pdf, which the Minister refers to, and is reflected in the views of families referred to therein.

Policy
Continued reference to policy is a place to hide behind mantras and platitudes that have served to silence the needs of this vulnerable group and their few advocates. The Petitioner knows the Scottish Government's policy on matters of social care for the learning disabled. She has read 'Same as You' and "Keys to Life". She has also read Dr Anne MacDonald's report, 'Coming Home' which highlights some alarming facts about those in out-of-area-placements and in the Petitioner's opinion, speaks in support of her own request for a need for high quality residential care in Scotland. She is aware of the divergence of opinion with other charitable organisations and some policy advisors, their stance often being not necessarily helpful to the cause. It is the Petitioner's view and also those families whom she represents, that it is 'policy' that continues to fail this small and invisible group. She notes the Minister's comments about Enable and Sense Scotland, just two of a number of charitable organisations who influence Government policy and who remind us "it is vital to resist any temptation to revert to multi-bed residential units" and in the Minister's own words "we must not return to the large scale institutions of the 1980's" - a stance the Petitioner supports, but nonetheless a mantra that in itself has resulted in stigmatising all discussion around any form of residential care for this group.

Single tenancy arrangements
The Minister mentions Beeswing in Dumfries & Galloway, Teviot Court in Midlothian and new homes by Moray Council - all the result of personalised care packages, enabling some individuals with severe and complex needs to live successfully in their own homes with their own tenancy agreements - but definitely not all which is reflected in the analysis in the 'Coming Home' report.

The Petitioner is familiar with these arrangements and indeed was approached by Midlothian planning department about a Teviot Court tenancy for her own son when the idea of single tenancy agreements was first conceived. Despite her son's severe and complex health needs in the form of a catastrophic epilepsy syndrome - it was anticipated he could live an independent life with minimal support. Indeed, it was referred to in that meeting with the planner as his 'human right.' Whilst single tenancy arrangements work for some they are beyond the coping mechanism of others, including the local authorities' ability to cope with the complex needs of a few in this setting, her own son being a good example - now instead a residential student at St Pier's College, at Young Epilepsy in Lingfield, Surrey.

Dr Anne MacDonald in her report advises there are those for whom independent life is not possible within community settings, stating that "there are implications for the support of (some) individuals....., as it is less usual for additional staff to be readily available within ordinary social care settings and care providers are not usually funded to make these potentially large numbers of extra staff available on a flexible basis." She goes on to say "community provision for people with learning disabilities and challenging behaviours is not meeting the needs of this client group and is the primary reason for people either going out-of-area or in to hospital." Of those in out-of- area-placements, 80% of whom have challenging behaviour, a large percentage have come from supported living arrangements and the rest have come from family homes where the family can no-longer cope.

Dr Anne MacDonald's report
The Petitioner, like others, welcomes Dr Anne MacDonald's report. 'Coming Home' provides an insight in to the number of out-of-area-placements and the reasons for some of those placements, with the exception of Glasgow City Council who notably failed to provide any data. Significantly the report does not fill the data-gap on the wider group we are referring to who have severe and complex needs, omitting those who remain in-area in Scotland, most likely at home with their own families or in failing supported living arrangements, and also importantly the children under the age of 16 years.

The report confirms the consequence of the absence of suitable residential care in Scotland, resulting in many 'inappropriate' placements for adults with severe and complex needs who reach a place of crisis when their families or carers can no-longer support them. The citing of reasons/issues such as behaviour problems (over 80%), generally regarded as an expression of unmet need, and mental health problems (1 in 5) by local authorities in their feed-back and the use of anti-psychotic medication is particularly alarming. Both issues are the consequence of long-term inadequate care and would constitute a symptom masking a serious underlying health need which should be recognised as the primary health care need. We suspect epilepsy features

much more than is reflected in the local authority feedback. Indeed, in more than 1/5th of cases the reason for the out-of area-area-placement was unanswered by respondents. The potential of the high incidence of epilepsy is a huge concern which the Petitioner has raised with Epilepsy Scotland who act as Convener for the Cross Party Group on Epilepsy and has asked them to get involved.

Dr Anne MacDonald's report acknowledges the complexity of those in her 'priority to return' group in out-of-area-placements (approximately 109, with another 32 unanswered and 80 whose status had not been agreed) and advises that in terms of repatriation the needs cannot be met by the introduction of a single service but rather a "transformational systems change" that will require all stakeholders to come together. This in itself is a problem, Glasgow City Council's lack of contribution to this data gathering process being an example. The report acknowledges the absence of appropriate services in Scotland to care for the complex needs of this group and the lack of skill-set (and an ever widening gap in skill-set particularly in the area of Positive Behaviour Support). So the prospect of those in out-of-area-placements returning home any time soon is unlikely and in the meantime, another generation of 'the same' unrecognised and therefore unmet needs is coming along behind, exacerbating the problem and adding to the on-going financial burden for Local Authorities. The requirement for a transformational systems change is now vital and urgent, something Dr Anne MacDonald refers to as "fundamentally a human rights issue and must be addressed with the urgency that context indicates."

Early Intervention

One commendable observation in Dr Anne MacDonald's report is the need for early-intervention and early assessment of the children to address the issues in their infancy and potentially avoid many of the problems in crisis that are resulting in admission in adulthood to 'care-take' problems that are the symptom of other issues that have never been properly or appropriately addressed. She highlights "the need for earlier intervention with young people with learning disabilities who are at risk of developing challenging behaviour."

The Petitioner would respectfully remind Scottish Government of Nicola Sturgeon's promise to her as Minister for Health in 2012 to 'personally' look in to the issue of the absence of comprehensive Section 23 Assessments under the Children (Scotland) Act 1995, which was failing and continues to fail the children with severe and complex needs and their families. Indeed, the Petitioner highlighted to Ms Sturgeon that Section 23 Assessments should be the passport that children with severe and complex needs require to whole-life quality care, also providing the gap in data that has been acknowledged via this petition. Ms Sturgeon's response in 2012 was to reassure the Petitioner that Scottish Government's GIRFEC approach would strengthen the Section 23 Assessment process for children - but it has not. (See attached email correspondence with the Cabinet Office.)

Epilepsy

The Petitioner notes that in the 35 minute discussion with the Minister epilepsy was mentioned just once and only in the context of the work of the Petitioner's own charity. Autism was mentioned on numerous occasions, though it is recognised that autism and epilepsy often exist together. Dementia was also mentioned. Scottish

Government's own policy document Keys to Life estimates that 66% of those with severe and complex needs in Scotland have epilepsy. Severe epilepsy causes significant communication difficulties and leads to a high risk of behaviour problems. This fact is one the Petitioner has made mention of many times. Epilepsy in those with severe and complex needs is often an overriding health need. The Petitioner argues that an overriding 'health' need, which should be identified in the early years, is potentially a key bench mark that policy is ignoring for those with severe and complex needs, recognising in particular, the complexities of severe epilepsy or an epilepsy syndrome.

The Petitioner is hopeful that the Minister for Health and Sport will acknowledge this catastrophic oversight and make it an immediate priority that this bench mark is applied as early as possible in the assessment process (ideally a Section 23 Assessment beginning in childhood) in order to identify the invisible group we are referring to and provide the essential data we are all seeking in order to avoid unmet need that leads to care-in-crisis.

What does good residential care look like?

In Scotland the institutional hospitals of the 1980's have closed and 'policy' now expects the residents they once cared for to live instead supported within the community. But sadly it is a fact that many are socially isolated, desperately struggling and those families who have given up their own lives to provide the care are struggling too.

In England, though the situation is still desperate in terms of a lack of provision, at least there is some provision, some of it new and also a few of the original hospitals which have adapted and evolved and continue as refurbished and vibrant centres, providing a community in which to thrive, despite profound health needs which are provided for by on-site medical support. The residents do not live in the local community but their spacious centres are supported by local communities. Their overriding health needs come first and these needs dictate the social care needs which are inevitably skilled and labour intensive because of the complications of health - in the case of epilepsy often profound and irreversible neurological damage. But the quality of care is good and life-long and the care in crisis that we see when families or carers can no longer cope does not happen to these residents, though a few may find themselves in these extremely worthy 'out-of-area- placements ' due to the absence of any suitable provision in Scotland. They lead fulfilled lives, in appropriate spacious accommodation, with activities that support their care needs including intensive levels of socialisation, sensory and purposeful activities, in open spaces and around water, with animals, with flora and fauna, with arts and with crafts, with books and with music. They are immersed in all of this whilst importantly their epilepsy and other significant health needs (co-morbidities) are provided for too and the burden on families and the State is relieved.

Dr Anne MacDonald's report refers to 705 from Scotland in out-of-area-placements. The report acknowledges that a small number of these have been successfully placed, more than likely in the centres referenced, and they are not considered to be in need of urgent repatriation, though a suitable facility in Scotland would be most welcome. Interestingly, most of the centres in England referred to below specialise in epilepsy

and were once hospitals supporting those who had epilepsy. Some now also support autism. In total they successfully care for approximately 600 adults and 200 children - not nearly enough as almost all of these centres have a waiting list. What they have achieved is not only inspired but continually evolving in order to provide "the right support in the right setting."

When PE1545 was first presented in December 2014 Professor Sally-Ann Cooper was consulted by Scottish Government on the issues raised and she responded in August 2015 as follows;

"Local Authorities need to be able to provide or commission a range of services, supports, and accommodations to suit every person with learning disabilities in their area. Some people flourish in settings where there is space, structure, and routine. Larger group settings, due to scale, may be able to offer a wider range of activities that perhaps are not available or accessible in the local community. It is important that people have choices."
Sally-Ann Cooper
Professor of Learning Disabilities & Honorary Consultant Psychiatrist Deputy Director – Institute of Health and Wellbeing

Conclusion
The choice the Professor refers to does not exist in Scotland. The Government needs to address this now and build a suitable facility if necessary, recognising that further delays will result in ever escalating costs. Without suitable accommodation and appropriately trained staff, it is inevitable that policy will continue to fail this group, leading to the "crisis management and resulting in multiple placement breakdowns and hospital admissions and other difficult experiences" referred to.

Dr Anne MacDonald is correct in her conclusion that the reasons for out-of-area-placements are "multifaceted and complex" and recommends that "a transformational change approach is required to address the issue throughout the sector." She describes transformational change as "a change of attitude and culture, a new belief in what is possible, resulting in significant changes in structures and systems." In the discussion of 10th January the Minister stated that "Scottish Government agrees with and intends to implement the report's recommendations" but so far little progress has been made because she says "it is complicated." This is a worry, the Petitioner's own evidence highlighting at least 7 years of zero progress on this issue, despite the involvement of a number of Ministers and numerous Ministerial pledges.

The Petitioner believes that change should begin with a broader policy that recognises the need for choice, including the availability in Scotland of more suitably trained staff, in high quality residential care settings, that are primarily health lead, because service users are not all the same and what constitutes a human right for one person, in the context of their specific needs and a fulfilled quality of life, may be different for another.

It is therefore incumbent on Scottish Government to change policy and mandate all stakeholders to come together and appropriately support this very small group of young adults with severe and complex needs, as well as their families, identifying and meeting the needs with the right accommodation and skill-set and providing the choice

referred to. Otherwise what Dr Anne MacDonald refers to as 'inappropriate' out-of-area-placements will inevitably continue and at ever greater cost to Scottish Government and potentially breaching the human rights of this vulnerable group.

David Lewis Centre (120 residents) https://www.davidlewis.org.uk/
Home From Home Care (90 residents) https://www.homefromhomecare.com/
The Meath Epilepsy Centre (80 residents) https://www.meath.org.uk/
The Epilepsy Society (90 residents) https://www.epilepsysociety.org.uk/care
Young Epilepsy (200 residents, including children) https://www.youngepilepsy.org.uk/
St Elizabeth's (100 residents) http://www.stelizabeths.org.uk/
Independence Homes (80 residents) http://independencehomes.co.uk/