

PE1545/F

**Submission to the Public Petitions Committee
Ann Maxwell
Founder, Muir Maxwell Trust
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Executive Summary

On behalf of the Muir Maxwell Trust, I am pleased to offer supplementary evidence on the responses received so far to PE1545. Many of those responses underline the key points that I originally presented to the committee in March.

In summary, I would stress the following key points:

- a) Families often face huge obstacles obtaining standards of care that meet the individual needs of people with profound and multiple learning disabilities (PMLD) in Scotland, meaning that they are left isolated and struggle to get the right support.
- b) Every person with PMLD has specific needs and there is widespread confusion over a working definition of PMLD among support service providers.
- c) It therefore takes appropriate, rigorous assessment methodology for providers of support services to establish the profile and needs of people with PMLD and in what setting they can best be met.
- d) This can be a challenge at the best of times, but we know that current models of assessment are simply not fit for purpose. As a result, we do not have an accurate idea of how many people with PMLD there are in Scotland. All stakeholders agree that sufficient data in this area isn't collected.
- e) And because people with PMLD consistently aren't recognised properly during assessment, their needs effectively become invisible. Public sector providers of support services don't assess them effectively, so their numbers aren't counted and their complex needs don't get addressed.
- f) That means families often have to fight – and face repeated denials – before they are granted access to the right treatment and services, like residential care, that they know will help their severely disabled loved-one to thrive.
- g) The situation is worsened because families that fight for and win care for PMLD young people routinely have the goalposts moved when that young person turns 18, even though the condition they have hasn't changed and the care their families need to provide remains the same.
- h) This, combined with the fact that Scotland has no appropriate residential care facilities for over-18s with PMLD, routinely leaves families bereft of adequate support.
- i) At the moment, it seems to families that the deck of support for people with PMLD is stacked against them, with decisions about care based on misguided and ill-advised policy or simply on the basis that it is too expensive to do more for them.
- j) From childhood, and into adulthood, these are the most vulnerable people in Scotland. Families are desperate for help and it's becoming a national scandal that service provision does not meet their needs and their needs are not recognised.

1. The problem of assessing needs

I am grateful that the written responses the committee has received underline the need for urgent change. The Scottish Government's written response to the committee suggests that it is "*reasonably*" confident that current datasets capture PMLD accurately. The reason that it expresses such qualified confidence is because, as the Scottish Consortium for Learning Disabilities (SCLD), which is responsible for collating data on people with learning disabilities notes, "*...there is a lack of detailed centrally held data concerning adults and children with PMLD, in particular about their needs and circumstances. SCLD would agree with [the petitioner's] statement. People with learning disabilities are present but not visible across a number of health and social care datasets.*" This cuts to the heart of the problem. As long as detailed information on the needs and circumstances of people with PMLD is "*not visible*" on the datasets held by health and social care authorities, then their needs will continue to be neither recognised nor met.

The SCLD and Scottish Government responses cite figures on the numbers of adults with learning disabilities who live in residential care since 2009, saying there are about 2,000. Yet, we know that those records do not gauge true demand. Many more families would choose residential care for a family member if something suitable was available and if local authorities were to fund it. Additionally, these statistics exclude children in residential care and children who have been denied residential care by local authorities.

They miss the people with PMLD, and their families, who charities like the Muir Maxwell Trust know are currently falling between the cracks in the system.

2. How the current system treats families

While families find that the system of disability assessment fails to recognise the scale of their needs, the result is that the care offered by social workers is insufficient. All the 'official' statistics and social work policies that are in place are only of use if they address the particular challenges inherent in caring for people with PMLD. All too often they fall short.

Since addressing the committee in March, I reached out to families that have reported problems accessing the services they need to care for people with PMLD from childhood through to adulthood. While some were unwilling to risk negative reactions from care service providers by speaking out, I am grateful for the opportunity to include the following testimonies, which are reflective of experiences throughout Scotland.

Case Study: John's mum*

"My son, John, who just turned 18 and has Dravet's syndrome, had a good neurologist in Ninewells Hospital who was able to obtain the treatments that we needed to manage his condition. However, we recently moved to an area under a different health board where John was transferred to local adult services. They told us that this health board's neurology department refused to take him on as they didn't want to have to pay for the cost of his medication, Stiripentol (STP). Then, just one week before he ran out of STP, Ninewells stepped back in to continue

John's care.

A year later, because he had passed the age of 18, John was referred once more to our local health board. This time, the neurology team said they wouldn't treat John, because they don't take on 'special needs' patients. So, John was assigned to the Special Needs Team, but when I spoke to a practitioner about his medication, we were referred right back to neurology! At this point, I lost faith in the NHS and asked our GP to see if he could find any experienced neurologist out-with the area who could give us the medication John needs.

"All this reminds us of years of cruel frustration. When John was younger we spent five gruelling, stressful years trying to get local social services to provide appropriate care in a residential school setting. That was at a point when things became too much for the family and John's dad suffered a nervous breakdown. Still John's social worker said he was just "a bit disabled" and that residential care wasn't needed. We learned later that in truth there was a money-saving policy not to send any child out of the local area, and so John was written off with inadequate care.

"A is severely disabled, and his family, including his 5-year old sister, need all the help we can get, but fast forward to the present day and nothing's changed. We know what good treatment and care looks like and where we can get it, but the people who are supposed to help us are no help at all. I'm furious, but feel isolated and hugely frustrated. I constantly worry what the future holds for the whole family if John doesn't get the right long-term care for his severe and rare medical condition."

Case Study: David's parents*

"Our son David will be 30 next month. This is a milestone which we thought he would never reach. David started to have seizures aged five months. He had many life-threatening, damaging seizures in infancy, the cause of which was only finally identified in 2006 as Dravet Syndrome. Sadly, as a result, David is severely cognitively impaired and functions at the level of an 18 month - two year old child. He still has regular and varied seizures which have an increased impact as he gets older. His condition became ever more complex with the onset of Scoliosis in his early twenties.

"David attended Camphill Schools in Aberdeen until age 18. We will never forget the terrible realisation that there were virtually no available options for him post-school. It quickly became apparent that the more complex and challenging the young person is, the fewer the options are available. We considered ourselves very fortunate to have David accepted for a local day centre run by Real Life Options - it was the only organisation which would consider taking him on! David still goes there between 10am and 4pm, Monday to Friday, when he is well enough, but the service provider say they may not be able to meet his needs if he continues to regress. Then the only option will be home-based care which will deprive David of much-enjoyed social contact and will make it very difficult for his mother to have much needed respite.

“Our great fear now is what happens if we become ill and are unable to keep up 24 hour care for David indefinitely. We are getting older and David’s dad has a heart problem. Last year we were only able to have a total of three nights away while David was looked after by carers at home. Otherwise the caring burden is relentless. We are very fearful for the future.”

***Note: names have been changed**

3. Common misunderstandings about people with PMLD

Unfortunately, Learning Disability Alliance Scotland’s (LDAS) characterisation of people with PMLD echoes common misunderstandings of this group that are based on the inadequacy of current datasets. By no means do all have severely limited understanding, while many have good unaided mobility. PMLD, combined with mobility, presents a huge problem to families in the care and management of a relative.

Furthermore, the “*severely limited understanding*” cited by LDAS doesn’t rule out some relevant and sometimes considerable understanding and also, importantly, age-appropriate emotions. Commonly, the level of understanding is different in every person. Only family members and long-term carers really have an insight into understanding. In the experience of many families, the tendency to base decisions on care packages on commonly-held misconceptions, rather than a deep understanding of each person’s needs, means that those needs don’t get addressed properly.

The Scottish Government’s response to the committee rightly acknowledged that Keys to life recommends that alternative models of provision, like residential care, are available “*where for a few supported independent living is not an option.*” I am acutely concerned that this significantly underplays demand for such services. Firstly, it cannot be accurately determined whether only “*a few*” need such services because, as the government acknowledges, data on people with PMLD is vague at best. More crucially though, it seems clear to many families that even when it is clear that a person with PMLD needs alternative residential provision, local authorities usually aren’t prepared to entertain the possibility of making it available, in spite of the clear recommendations in Keys to life.

4. The role of social workers

It has become clear that establishing who fits into the PMLD group is not an easy task, because of the complexity of needs combined with a consistent failure by social workers to improve the situation. As I told the committee in March, I had to fight hard before my local authority would carry out a Section 23 Assessment for my son Muir and our family so that his complex needs were met. Others lack the time, energy and will to fight like I did, but in truth we shouldn’t have to fight. Upon reflection, I am exceptionally disappointed that the cursory summary of training and policy provided to the Committee by the Chief Social Work Adviser (CSWA) does not actually reference the specific points that I raised, and would urge him to engage more fully with families on this matter, and at least try to understand the points being discussed.

As LDAS confirms, when dealing with social workers *“families describe being 'left on the clip board'.....It doesn't take much to see how the quality of service might vary or deteriorate under such circumstances.”* That being the case, families consistently remain worried that social workers lack the wherewithal or training to assess their needs properly. In truth, remedying the issue goes beyond training, and will not be fixed until there is wider recognition that there is an urgent problem. Similarly, the response from Scotland Excel which makes no comment on my petition, suggests that more considered action from the Scottish Government is needed before the situation will improve.

5. Further barriers to better understanding of PMLD

At the moment, the key data sets for people with learning disabilities in Scotland, eSAY (electronic Same As You), rely on returns completed by local authorities. My point to the CSWA and others is these are inaccurately compiled and therefore not fit for purpose. LDAS notes that there is a current proposal to link up local authority, health board data and GP records to create *“a more comprehensive data base that can track health and other outcomes for people with learning disabilities”*, but it has been confirmed to me that this will not address the issue. Indeed, through private correspondence I have been informed that this research project, under its current remit and funding, will still not identify the needs of the most profoundly disabled, predominantly because that information is not available anywhere for researchers to draw upon. I would urge the committee to write to Sally-Ann Cooper, Professor of Learning Disabilities at Glasgow University, for more insights into the scope of the work she is undertaking on this.

6. Appropriate care settings

When I lodged PE1545, I did so because my son Muir, and other severely learning disabled Scots, are faced with an uncertain future because their specific needs are not met into adulthood. For six years Muir has thrived in a dedicated residential care setting, Donaldson's College. I had to fight a long battle before he won a funded place there, but now that Muir is entering adulthood, there is no similar facility in Scotland that he can attend. LDAS's submission to the committee included a statement from PAMIS stating that *“There are some excellent examples of successful tenancies for people with PMLD that can be shared with the committee and with Mrs Maxwell. Our families have asked to be fully consulted and involved in final decisions regarding community living/supported accommodation.”* I have no doubt that this is the case, but I would stress the simple truth that not everyone with PMLD can live a fulfilled life in community living or supported accommodation. Some need more stimulus and support than such arrangements have to offer. We are not all the same and some of us need different things, whether or not it aligns with established policy.

As I indicated to the Committee in March, I am not advocating a return to old models of hospital care, and I acknowledge that community/supported living is suitable and desirable in many cases. I would urge MSPs to acknowledge that in some of the most complex instances we must go further, and that sophisticated, specialist residential care is the only reasonable option for some people with PMLD.

7. Conclusions

Since I spoke to the committee, I have engaged directly with a wide range of stakeholder groups, including third sector groups SCLD, PAMIS, Mindroom and Speur-Ghlan, as well as academic specialists at the universities of Glasgow and Edinburgh. They have been unanimous in agreeing that the relevant data needed to assess Scotland's population of people with PMLD simply does not currently exist. We do not have an acceptable grasp of the numbers or profiles of our most vulnerable disabled people and until that situation is addressed, we cannot be confident that care services will address their needs.

Urgent change is required and we must now have an urgent review of the way that the needs of people with PMLD are assessed, so that this data can be rigorously gathered, interpreted and used to improve the lives of people with PMLD and their families. Moreover, these families must be given confidence that they will have a right to access the services that support their needs, including specialist residential care options, if that improves their quality of life. Innovative models of care like that run by Young Epilepsy in England offer responses to the needs of people with PMLD beyond the age of 18 which would be of enormous benefit to Scottish families if replicated here. It cannot be right that family members have to be sent hundreds of miles from home to get the care they deserve.

I would urge the Public Petitions Committee to pursue these matters in detail with the Scottish Government and relevant public agencies, to make sure that in future the families of people with PMLD let down by the system receive the support they deserve. The Muir Maxwell Trust would be happy to work with them to share information on data collection and residential care options until these issues are addressed fully.

Ann Maxwell
The Muir Maxwell Trust