

The Muir Maxwell Trust

Wednesday 14 October 2015

Submission to the Public Petitions Committee

The committee will recall that the core purpose of PE1545 was to gain recognition for residential care as a way people with profound and multiple learning disabilities (PMLD) can lead happy and fulfilled lives and that I have been urging the Scottish Government to provide resources to local authorities to establish residential care options for families in Scotland. While there have been a number of welcome, positive developments since I last wrote to the committee, I am concerned that the actions being taken, while marking positive though tentative steps forward for the assessment of need for people with PMLD, will not deliver the fast response that is needed. I am pleased therefore to take this opportunity to update MSPs on recent events in the hope and expectation that members will be prepared to act as the catalyst for positive change that the issue requires at this stage.

As the letter to the committee from Linda Allan of the Scottish Government suggests, I have been contacted by civil servants from the Learning Disability policy team to discuss the implications of the petition. Indeed, there has been increased recognition from the Scottish Government and organisations like PAMIS and SCLD that the issues raised in PE1545 represent a significant barrier to attaining proper support for the most severely learning disabled people. In particular, there seems to be a new appreciation that the data held on people with PMLD in Scotland is inadequate, as are assessment methods used by local authority social work teams.

Moreover, I have witnessed the dawning of a recognition among the wider learning disability support community that the core point raised by PE1545 – that appropriate residential care needs to form part of the package of options for our most severely learning disabled people – is valid. There is presently an unmet need that must be addressed in Scotland.

Since the committee last discussed my petition, the issue of residential care, the appropriate assessment of people with PMLD and the collection of data on them, have been the subjects of a very successful day-long conference on 23 September organised by Holyrood Conferences in response to the issues originally raised in PE1545. The roster of speakers, which included myself, as well as representatives from PAMIS, Govan Law Centre, Donaldson's School, Barnardos, Learning Disability Alliance, the social work sector and SCLD, reflected a broad combination of expertise in learning disability-related policy. Overall, there was significant agreement that gaps in assessment and data on people with PMLD were a real barrier to effective, tailored care and that there needs to be enormous improvement.

Moreover, the letter that the committee has received from Professor Sally-Ann Cooper stating that she, "fully concur(s) with the statement that people with learning disabilities are present but not visible across Scotland's routinely collected health and social care statistics" confirms conclusively and authoritatively the view of a majority of conference speakers that there is a significant problem with data. Perhaps more significantly though, Professor Cooper's letter cuts to the heart of the need for person-centred care and the truth that, "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." As Professor Cooper notes, "it is important that people have choices". I, and families in a similar position, who lack those choices for our loved-ones in Scotland, could not agree more.

It is because such choice – the choice of a suitable adult residential care package for people with PMLD – is not available in Scotland that my son Muir moves this year to the dedicated Young Epilepsy (YE) residential care facility in Lingfield, Surrey. I am confident that the Lingfield centre, where Muir will receive the care he needs until the age of 25, is the only appropriate care choice that meets my son's needs in full. That doesn't make the choice an easy one, given the huge distance that will necessarily separate us, combined with the fact that when he turns 25 we will

once again have to consider transition to a new care arrangement that meets his needs. In seven years' time I will be back in an identical position, searching for a transition to a care arrangement that meets my vulnerable son's needs but which no public authority is willing to recognise or support in Scotland. Simply, we must be prepared to do more for people like Muir and the families across Scotland who face the same shortage of appropriate local transitional care that we do.

As I have told the committee previously, up to the age of 18 Muir has benefitted from first class residential care at Donaldson's School in Linlithgow. I appreciate that for some with learning disabilities, transfer to 'adult', community-based care packages makes complete sense, but a 'one size fits all' approach will not suffice for the most profoundly learning disabled people. I would urge the committee to appreciate that for Muir, and others too, only a residential setting like Donaldson's or Young Epilepsy in Lingfield makes sense. I am sure that a visit by MSPs to either facility would serve to cement their own understanding of the uniquely constructive settings provided to people with PMLD.

It makes absolutely no sense that there is an ongoing presumption that people with severe learning disabilities like Muir, who are thriving in a structured environment like Donaldson's School, should be treated any differently by public authorities just because they have reached an age threshold that for them is wholly arbitrary. If removed from such a setting, I fear that Muir's quality of life will diminish. His needs are complex and specific to him alone and they will not be met in a traditional community setting. He will be attending YE's centre in England only because similar support by public authorities here in Scotland is not available.

The sad irony is that I and the families in my situation know that a solution is at hand, though just out of reach. If a facility like Donaldson's School does a first class job for Scots with PMLD up to the age of 18, then there is little practical reason why its services cannot be expanded to accommodate over-18s if their needs align well with its service model. Having discussed this matter with senior staff at the school, I am confident that this is a matter of capacity-building that can be achieved with support from MSPs. That capacity building is more than a matter of increasing funding. In truth, there is existing infrastructural capacity at Donaldson's School for it to admit significantly more children to residential care, but the key barrier is that local authorities have been unwilling to refer families to the services it provides, with most referred as a result of tribunals rather than proactive individual needs-based assessment by social workers.

A change in culture is required. Families are hampered by a widespread lack of local authority understanding about the opportunities that residential care packages can provide. This is in part because the problems that hamper assessment of people with severe learning disabilities have contributed to a gap in understanding of levels of need. There also remains a concern among families that local authorities seek to avoid developing that understanding because they fear that the requirement to provide proper residential care will create a funding crisis. I would argue that by ignoring and failing to get a handle on the needs of the most severely learning disabled people, we are merely storing up problems for families that will cost society more in the future. People with PMLD and their families often need more support, but public authorities are choosing to ignore that need in many instances. Local authorities must adopt a more preventative approach or it will not be long before the pressure and isolation that many feel reaches a crisis point.

I would urge the committee to focus continued attention on three key areas.

- Firstly because of the strength of evidence emerging that local authorities are not assessing the needs of severely learning disabled people correctly or thoroughly enough, I would urge MSPs to ensure that steps are taken to fix the present assessment system as quickly as possible.
- Secondly, they should ensure that people with the most complex and severe learning disabilities are recognised as a category of people who should receive additional support, subject to rigorous assessment procedures.
- Finally, if it is the case that local authorities are worried about the impact on their budgets of providing proper residential care where needed, then I would ask MSPs to examine

how ring-fenced funding can be provided by the Scottish Government to help them with costs.

The problems that I have highlighted are not unique to Scotland. Indeed, the failure to assess and cater properly for the needs of severely learning disabled people throughout their lives is an international one that countries across the world are only beginning to address. The challenge here in Scotland is to recognise and address the issues at hand and create a system that is more ambitious for our most vulnerable learning disabled people and their families.

Yours sincerely,

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Founder
Muir Maxwell Trust