



Briefing for the Public Petitions Committee

Petition Number: [PE01545](#)

Main Petitioner: Ann Maxwell on behalf of Muir Maxwell Trust

Subject: Residential care provision for the severely learning disabled

Calls on the Parliament to urge the Scottish Government to recognise residential care as a way severely learning disabled children, young people and adults can lead happy and fulfilled lives and provide the resources to local authorities to establish residential care options for families in Scotland.

Background

Dravet Syndrome

Whilst the petition relates to all those who have severe learning disabilities and complex needs, the Petitioner's son has Dravet Syndrome (DS).

Dravet Syndrome is a neurodevelopmental disorder beginning in infancy, characterised by intractable seizures. A major contributor to DS is believed to be due to a gene mutation, though it is rarely inherited. Nevertheless, much remains to be understood about the causes of DS and research is on-going. Estimates of the prevalence of this rare disorder range from 1:20,000 to 1:40,000 births, but the incidence may be found to be greater as the syndrome becomes better recognised and new genetic evidence is discovered. Currently, treatment for DS consists mainly of antiepileptic medications to help control seizures.¹

Duties and responsibilities of local authorities

The petition relates to children and young adults. There are a number of duties and responsibilities that local authorities have in relation to the assessment and delivery of community care services for adults and children. These are outlined in Appendix 1.

The basic duty that local authorities have is to provide services to meet the assessed needs of the individual. It may be that those needs are best met through residential accommodation and, if there is a service that can meet those needs in its area, then it could be assumed the local authority would arrange for that individual to be placed with that service. If there is no

¹ Dravet Syndrome UK. (Online) [What is Dravet Syndrome?](#)

appropriate residential service then the local authority may be prepared to arrange for the individual to go to another area, should appropriate accommodation be available.

However, it is also worth noting that the local authority may decide that the needs of the individual can be met at home with appropriate support being put in place. In such a situation an individual (or a parent on their behalf if it is a child) will be eligible for self-directed support (SDS) (see Appendix 1). This means that the individual will have greater control in directing how their care is provided. It is important to note the provisions of SDS do not, currently, relate to residential care. The Scottish Government has agreed to small-scale testing into two areas – Moray and East Renfrewshire – to consider what could be done concerning this in the future.

Data

There is a lack of detailed centrally held data concerning adults and children with profound and multiple learning disabilities (PMLD), although the Scottish Government estimates that there are approximately 2,600 people with PMLDs in Scotland².

In terms of residential care, the latest [statistics](#) on adult care homes (ISD Scotland, October 2014) shows that, as at March 2014, there were:

- 220 homes across all sectors for those with learning disabilities (representing a 5.6% decrease since 2013 and a 42.1% decrease since 2000)
- 2,028 registered places for adults with learning disabilities (representing a 4.6% decrease since 2013 and 43.6% decrease since 2000)
- a total of 1,821 adults with learning disabilities who were resident in care homes (representing a 2% decrease since 2013 and 44.7% decrease since 2000)

The data above reflects the general policy direction over the years of enabling people with learning disabilities to live as independently as possible in the community.

Scottish Government Action

In 2013, the Scottish Government published 'Keys to Life: Improving quality of life for people with learning disabilities'³. This is the national strategy for learning disabilities and followed on from 'The same as you?'⁴ which was instrumental in the closure of remaining long-stay hospitals for people with learning disabilities in Scotland.

² Scottish Government (2013) '[Keys to Life: Improving quality of life for people with learning disability](#)'. Edinburgh, Scottish Government.

³ Ibid

⁴ Scottish Executive (2000) '[The same as you?](#)' Edinburgh, Scottish Executive

The new strategy is focused on the health inequalities experienced by people with learning disabilities but it is underpinned by the principles of choice, control and independence. The strategy also contains the following recommendation:

“Recommendation 6: That by June 2014 COSLA, ADSW and NHS partners work with Scotland Excel⁵ to improve the quality and consistency of support for people with learning disabilities who have a long-term need for specialist residential care, by developing a national framework agreement for procurement. This should include a core service specification which focuses on outcomes for residents, the rates that will apply, and the arrangements that will be put in place to monitor and manage performance.”

This recommendation aims to ensure that specialist residential care services for adults with learning disabilities are commissioned in line with a national framework which improves the quality and consistency of support. However, an overarching requirement of the strategy is that the provision of new services should not be large scale or attempt to replicate long stay hospitals. The strategy is also based on a human rights approach and is ‘outcome focused’ in that it regards effective services as those that deliver the outcomes required by the individual.

Scottish Parliament Action

The Scottish Parliament has not carried out any work on this specific issue.

Jude Payne
Senior Research Specialist
25 February 2015.

⁵ Centre of procurement expertise for Scotland’s local government sector

Appendix 1: Duties on and responsibilities of local authorities as regards the assessment and delivery of community care services for adults and children

Children	Adults
<p>Duty to safeguard and promote the welfare of children (section 22 of the Children (Scotland) Act 1995)</p> <ul style="list-style-type: none"> • duty to safeguard and promote the welfare of children in their area who are in need. This remains a wide-ranging duty, with flexibility for the authority to take a range of steps to safeguard and promote welfare. • duty to promote the upbringing of such children by providing a range and level of services appropriate to the child's needs 	<p>Duty to promote social welfare (section 12 Social Work (Scotland) Act 1968)</p> <ul style="list-style-type: none"> • duty to promote social welfare by making available advice, guidance and assistance on such a scale as may be appropriate for their area (Section 12 of the 1968 Act). This remains a wide-ranging duty, with flexibility for the authority to take a range of steps to promote social welfare
<p>Duties in relation to children affected by disability (section 23 of the Children (Scotland) Act 1995)</p> <ul style="list-style-type: none"> • duty to ensure that services provided under Section 22 are designed to minimise the effect of any disability on disabled children and to minimise the effect on any child who is affected by the disability of any other person in his family • duty, where requested to do so by the child's parent or guardian, to carry out an assessment of the child or any other person in the child's family to determine the needs of the child • duty, when assessing the child's needs under Section 23 of the 1995 Act, to take account of the views of the parent or guardian of the child and the views of the carer. 	<p>Duty to assess needs and establish eligibility for services (section 12A of the Social Work (Scotland) Act 1968)</p> <ul style="list-style-type: none"> • duty to assess the needs of any adult (aged over 18 years of age) where it is indicated that the person may have community care needs • Following the assessment, have regard to the results and decide whether the needs of the person being assessed call for the provisions for such services • in order to qualify as a person in need the person must be in need of support arising out of infirmity, youth or age or require support arising from illness, mental disorder or disability.
<p>Duty to have regard to the general principles of collaboration, informed choice and involvement as part of the assessment and the provision of support (section 1 of the Social Care (Self-Directed Support) (Scotland) Act 2013). This means the local authority should when undertaking assessments and delivering on them:</p> <ul style="list-style-type: none"> • collaborate with the supported person (or their carer / parent) when they undertake the assessment and provide support • take steps to ensure that the person (or their carer / parent) makes informed choices as part of their assessment and in selecting their support options • take steps to involve the supported person (or their carer / parent) in their assessment and in selecting their support options 	
<p>Following the assessment and establishing eligibility, local authorities have a duty to offer four self-directed support options to the supported person (or their carer / parent)</p>	

on their behalf) (Social Care (Self-directed Support) (Scotland) Act 2013):

1. *Direct payments* - the local authority makes a direct payment to the supported person in order that the person can then use that payment to arrange their support
2. *Directing the available resource* – where the supported person chooses their support and the local authority makes arrangements for the support on behalf of the supported person
3. *Local authority arranged support* – where the local authority selects the appropriate support and makes arrangements for its provision by the local authority (can be viewed as the traditional model of social service delivery)
4. *A mix of the first three options*

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