



## For the consideration by the Petitions Committee: P-04-442

### Guarantee good support close to home for disabled children and their families

#### **P-04-442 : Guarantee good support close to home for disabled children and their families**

We, the undersigned, call on the Welsh Government to guarantee good support close to home for disabled children and their families. In order to achieve this, we call on the National Assembly for Wales to urge the Welsh Government to make sure the new Educational (Wales) Bill includes a 'Provide Local' principle in the Bill that will:

- ensure inclusive and accessible services in the local area, and
- put a duty on local agencies to introduce new inclusive and accessible services if they don't exist, through better planning, partnership and the involvement of local parents.

**Petition raised by:** Scope Cymru

**Date petition first considered by Committee:** 4 December 2012

**Number of signatures:** 2,415

#### **Why this is needed**

##### **There is a critical shortage of services for disabled children and their families**

Many of the parents Scope Cymru talk to want to use services that most families take for granted such as: childcare to support their child's development and so that parents can work; short breaks that enable a disabled child or young person to enjoy a leisure activity; or the right educational setting that supports their child to learn and reach their potential.

However Scope Cymru's research<sup>1</sup> has found that many of these families with disabled children and children with SEN are struggling from a lack of help and support in their local area.

- 64% said that the services that they and their children need are not available in their local area.

As a result, families tell us that getting the support they need is an enormous battle, and many are forced to travel outside of their local area – sometimes considerable distances – to get the help that their children need.

- The average distance travelled by families accessing services is over 4000 miles a year, or 80 miles a week.
- Four in ten disabled children live in poverty in the UK<sup>2</sup>, with direct extra costs such as travel directly contributing to this<sup>3</sup>.
- Families in Wales who access short breaks services will travel for an average of 289 miles or 18 hours a year getting to and from these services.
- Only one in ten families (11%) said they could access all the services they need locally.

<sup>1</sup> Unpublished: 61 parents and carers of disabled children took part in our survey during August 2012. The sample covered a good range of geographical regions and types of area, as well as impairment type. The most common impairments were learning, understanding or concentrating (74%), social or behavioural (67%) and intellectual delay (67%). Respondents were mostly female (92%) and in the lower income brackets (12% £0 – 9,999, 29% £10 – 19,999, 27% £20 – 29,999).

<sup>2</sup> The Children's society (2011) 4 in every 10 Disabled Children Living in Poverty; <http://www.childrensociety.org.uk/news-views/press-release/four-ten-disabled-children-are-living-poverty>

<sup>3</sup> Contact a family (2012) Counting the Costs, <http://www.cafamily.org.uk/professionals/research/reducing-poverty/>

Some families have told us that they have no choice but to struggle on without any help, while others are faced with the difficult decision to send their children away from home so that they can receive appropriate support.

### **The lack of support is pushing families to breaking point**

Scope Cymru's research found that the lack of support for disabled children and their families in their local area is pushing them to breaking point.

- 67% said that the shortage of local services caused them anxiety and stress.
- 39% said that the shortage of services impacted on their working life.
- Half said that they miss out on family activities such as days out or birthdays as a result.
- 31% said it put pressure on their relationship with their partner.
- 21% said that it puts financial pressure on their family.

### **How can the Welsh Assembly address this problem?**

#### **The Education (Wales) Bill**

The Welsh Government has recognised the need to improve the experience of young people with 'additional needs' and plans to introduce the Education (Wales) Bill to improve provision, largely through creating integrated 'Individual Development Plans' which will replace Statements of Special Educational Need.

The decision by the Welsh Government to delay the legislative reform in order to "work through the proposals with key partners" is welcome and is an opportunity for the Welsh Government to ensure that the Bill sufficiently meets the needs of disabled children, young people and their families.

Scope Cymru welcomes a number of measures contained in the consultation on the Bill, including:

- The intention to create an integrated, person centred approach which will look at the holistic needs of a young person, rather than just their educational needs, and create partnerships between health, social services and education.
- Plans to create regional consortia and 'Support Panels' to look at joint strategic planning and commissioning processes, including duties on agencies to collaborate on additional needs.
- The intention within the consultation that needs should be met "wherever possible within their local community"<sup>4</sup>.

However, the current proposals risk failing to improve the provision of local services for families with disabled children for the following reasons:

- Scope Cymru is concerned that, even when working in collaboration, Local Authorities will only offer what they are already planning to do, with no duty to make vital universal services inclusive or deliver the services that families with disabled children need.
- That despite the intention in the consultation to meet needs in the community, there is no duty or guidance to ensure that this is the case. The consultation already highlights that consortia could fund placements "in, or out of, the consortium area"<sup>5</sup>

### **The Welsh Government must introduce a 'Provide Local Principle' in Education (Wales) Bill**

Scope Cymru's petition '*P-04-442 : Guarantee good support close to home for disabled children and their families*' is therefore calling on the Welsh Government to introduce a 'Provide Local Principle' in the Education (Wales) Bill. The principle will ensure that:

1. Services in a local area are inclusive and accessible.
2. Where services for disabled children do not currently exist, local authorities must guarantee their delivery.

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<sup>4</sup> Welsh Government, Forward in partnership for children and young people with additional needs - Proposals for reform of the legislative framework for special educational needs, June 2012

<sup>5</sup> Ibid.

3. Disabled children and families will be included as partners throughout the commissioning process, ensuring that local authorities do not waste resources by providing services that disabled children and their families do not need.

Accessible services are not just those which contain wheelchair ramps. For example an inclusive and accessible school will be able to meet the whole educational need of the pupil, which can be very complex, involving support workers, an adapted curriculum or specialist technology. The lack of an accessible school can mean young people have to travel to a specialist school, which may be further from their home.

The types of services that would be included under the 'Provide Local Principle' are those amenities that provide a public service, such as childcare or playgroups, schools and colleges, day centre's or children's centres, leisure services such as sports centres, swimming pools and short breaks and healthcare services such as GPs clinics, health Centre's and hospitals.

### **What difference will this make to disabled children and their families?**

The introduction of the 'Provide Local Principle' would make a real difference to the services available to families with disabled children. Specifically, it would mean that:

- Families with disabled children are able to use more universal services locally, because they will be inclusive and accessible;
- Families with disabled children will not have to battle for the support they need from services; and
- Families with disabled children will not need to travel so far from where they live to access them.

### **These duties would ensure that local agencies consider the wider needs of children and families when making decisions on services and ensure families are able to access inclusive, accessible local services-**

When services that are provided within a local area are not deemed to be sufficient for disabled children, young people and their families, local agencies would be under an enhanced duty to re-assess local service provision until it is deemed sufficient by consulted parties and local family representatives. This would require supporting guidance to be produced by the Welsh Government to detail how local authorities should determine whether the services they are providing are sufficient, as well as the requirements on how they should consult with local family representatives.

We believe by adding this principle, forthcoming legislation and resulting framework for those with additional needs will better meet the aims of the Welsh Government of creating an inclusive system, with fewer barriers to inclusion and more individuals being enabled to access services in their communities.

### **About Scope Cymru**

Scope Cymru works with disabled people and their families at every stage of their lives. From offering day to day support and information, to challenging assumptions about disability and influencing decision makers - everything we do is about creating real and lasting change.