



RESEARCH PAPER 07/15  
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# ***The Disabled Children (Family Support) Bill***

**Bill 20 of 2006-07**

This Bill is sponsored by Gary Streeter, Conservative MP for South West Devon. It is due to have its second reading on Friday 23 February 2007. The Bill makes provision for carers of disabled children to be assessed and provided with short breaks. It places duties on local authorities and the National Health Service in respect of disabled children and their carers.

Manjit Gheera

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## Summary of main points

The Bill is a Private Member's Bill sponsored by Gary Streeter MP and has cross-party support. The Bill has been drafted and promoted by the Every Disabled Child Matters campaign, run by four national organisations working with disabled children - Contact a Family, the Council for Disabled Children, Mencap and the Special Education Consortium.

The Bill proposes to change the current law by imposing specific duties on local authorities and the National Health Service to provide short breaks for families with disabled children. The Bill would also amend the *Childcare Act 2006* to ensure that local authorities secure the provision of childcare for parents in order to sustain their caring responsibilities for a disabled child.

The Bill would apply to England and Wales.



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# I Policy background to the provision of short breaks

## A. Current provision for short breaks

Short breaks provide opportunities for disabled and other vulnerable children and young people to spend time away from their primary carers. Short breaks are sometimes referred to as 'respite care'. An inevitable consequence of a short break provision for a disabled child is that it also gives the child's carer a break from caring responsibilities.

Short breaks can occur during the day, evening, overnight or over a weekend and can take place in the child's own home or in an outside setting. The following describes the main types of short break services that may be used:

**Family-based overnight short breaks** are short breaks in the home of approved carers (either short break or contract carers<sup>1</sup>) that include one or more overnight stays and can include activities in the community.

**Day care** is care that takes place on any day of the week and can include evenings but not overnight stays. Care is provided in the carer's home and may include activities outside the home. Carers are either approved as short break foster carers or are registered childminders.

**Sitting** is care that takes place in the child's own home on any day of the week. The sitter should be employed by a registered agency or by the parents through direct payments.<sup>2</sup> Alternatively, the sitter may be a registered childminder.

**Overnight sitting** is the same as sitting but includes overnight care. Parents may or may not be present.

**Befriending** is a one-to-one relationship that enables a child or young person to access a range of community or leisure activities. Befriending services are run by voluntary organisations, which provide specialist training to volunteers.

**Community and leisure activities** refer to a range of organised group activities such as play schemes and after school clubs. These may be specifically organised for disabled children or include their non-disabled peers or siblings.<sup>3</sup>

**Residential care homes and hospitals** can provide longer breaks, not exceeding 28 days, in a residential setting.

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<sup>1</sup> Contract carers are paid carers who have been approved by the local authority. They are usually foster carers but can also have other caring experience.

<sup>2</sup> See p8 for an explanation of direct payments

<sup>3</sup> Shared Care Network, *Creative responses to Changing Needs? Fourth National Survey of Short Break Services for Disabled Children in UK*, 2006 (in press)

A survey by the Shared Care Network, based on responses from 120 short break schemes found that:

- 78% of schemes were managed in the statutory sector and 22% in the voluntary sector;
- 44% of schemes offering more than three services were managed in the voluntary sector;
- 81 schemes (72% of schemes overall) included carers who offered day care only;
- Since 1999, short breaks offered by contract carers have increased from 7% to 25%;
- Since 1999 sitting services within short break schemes have decreased from 45% to 25%;
- Since 1999 befriending services within short break schemes have decreased from 32% to 17%.

## **B. Policy Developments**

In recent years, a number of policy initiatives have influenced short break services. The main changes have been:

### **1. Direct Payments**

Direct payments were first introduced in 1997 for disabled people over the age of 16. They are aimed at increasing individuals' independence and choice by giving them control over the way the services they receive are delivered. They are cash payments from the local council which can be used, by the service user, to buy services from an organisation or employ somebody to provide assistance. Direct payments were extended to older people in 2000 and to parents and carers of disabled children in 2001.<sup>4</sup> Since April 2003, local authorities have been under a duty to give direct payments instead of services, where requested by parents, and where children are eligible for services following an assessment of need.<sup>5</sup>

Direct payments can be used by parents of disabled children to pay for short breaks that have been arranged independently of social services.

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<sup>4</sup> Under the *Carers and Disabled Children Act 2000* (England) and the *Community Care Services for Carers and Children's Services (Direct Payments) (Wales) Regulations 2004* (No 1748)

<sup>5</sup> *Community Care, Services for Carers and Children's Services (Direct Payments) (England) Regulations 2003* (No 762) and the *Community Care, Services for Carers and Children's Services (Direct Payments) (Wales) Regulations 2004* (No 1748)



## 2. The Children's National Service Framework

*The National Service Framework for Children, Young People and Maternity Services* (Children's National Service Framework or NSF) is a 10 year programme intended to stimulate long-term and sustained improvement in children's health. It sets national standards aiming to ensure fair, high quality and integrated health and social care from pregnancy, right through to adulthood. Standard 8 of the NSF for England and Chapter 5 of the Welsh NSF focus on disabled children.

Standard 8 of the NSF for England provides:

### **Disabled Children and Young People and Those with Complex Health Needs**

Children and young people who are disabled or who have complex health needs receive co-ordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.<sup>6</sup>

In regard to short breaks, Standard 8 provides that local authorities and Primary Care Trusts ensure:

All children and their families who are assessed as having needs that can be met by short term breaks are offered without undue delay a range of services from which to choose. This includes home and community-based breaks as well as family-based and residential breaks and access to childcare and sitting services.<sup>7</sup>

The standards in Chapter 5 of the Welsh NSF<sup>8</sup> are:

### CHILD AND FAMILY CENTRED SERVICES

Disabled children, with their families from all communities, are fully supported to participate in valued childhood experiences and have access to the same range of opportunities, life experiences, and mainstream and community services and facilities as other children and their families.

### ACCESS TO SERVICES

All disabled children and their families receive accessible information about, and equitable and prompt access to, high quality co-ordinated services appropriate to their assessed needs.

### QUALITY OF SERVICES

Disabled children are provided with appropriate high quality, timely services in an environment that is suited to their needs, age and stage of development. Well co-ordinated multi-agency services are delivered to address all types of need.

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<sup>6</sup> Department for Education and Skills and the Department of Health, *The National Service Framework for Children, Young People and Maternity Services – Disabled Children and Young People and those with Complex Health Needs*, September 2004. <http://www.dh.gov.uk/assetRoot/04/09/05/56/04090556.pdf>

<sup>7</sup> *Ibid.*, p29

<sup>8</sup> Welsh Assembly Government, *The National Service Framework for Children, Young People and Maternity Services*, February 2006. <http://www.wales.nhs.uk/sites3/home.cfm?orgid=441>

### TRANSITIONS

Young people who require continuing services, such as those who are disabled or chronically ill, young people with persistent mental illness or disorders, vulnerable young people and their families and carers, and care leavers, are offered a range of co-ordinated multi-agency services, according to assessed need, in order to make effective transitions from childhood to adulthood.

The provision of short breaks is referred to as a 'key action' for organisations responsible for the delivery of the standards.<sup>9</sup>

### 3. Every Child Matters

The Government's Every Child Matters programme is a strategy for change in children's services. The Government's aim is for every child, whatever their background or their circumstances, to have the support they need to:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

As part of the programme, the Government has committed to increasing funding for short breaks through the Carer's Grant:

Short-term breaks are one of parents' most frequently reported unmet needs. Short-term breaks should promote the welfare of children by providing them with positive experiences including social activities that enable friendships to form. Good short-term breaks can also reduce marital stress and breakdowns in families.

We are increasing funding for short breaks through yearly increases in the Carer's Grant. This is leading to increases in services for parents of disabled children. The Carer's Grant is worth £185m in 2005-06. Approximately 20% of it is spent on children's services, including carers of disabled children.<sup>10</sup>

The grant is paid to local councils to support them in providing breaks and other services for carers. The Carer's Grant allocation has increased annually since its introduction in 1999 from £20million to £185million in 2005-06. The allocations for 2006-07 and 2007-08 will remain at £185million for each period.<sup>11</sup>

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<sup>9</sup> *Ibid.*, Chapter 5

<sup>10</sup> <http://www.everychildmatters.gov.uk/socialcare/disabledchildren/support/>

<sup>11</sup> Local Authority Social Services Letter LASSL 2006(1), 28 November 2006.

#### 4. Improving the Life Chances of Disabled People

In 2005, the Prime Minister's Strategy Unit published its report, *Improving the Life Chances of Disabled People*,<sup>12</sup> with the aim of identifying and recommending policies which will remove barriers and improve outcomes for disabled people. In relation to short break provision the report states:

**Support with caring:** all parents need a break from caring sometimes. Parents of disabled children can find this difficult if family or friends are unable to help, or if there is a shortage of daycare provision for their child. But around one-third of parents with disabled children wait over a year for a short break service. And families with very young children, children with complex needs "challenging" behaviour and Autistic Spectrum Disorders, as well as those from minority ethnic communities, are less likely to have short breaks.<sup>13</sup>

One of the key recommendations of the report is:

Improving support for families with young disabled children by ensuring families of disabled children benefit from childcare and early education provided to all children; meeting the extra needs of families with disabled children; and ensuring services are centred on disabled children and their families, not on processes and funding streams.<sup>14</sup>

### C. The statutory framework for supporting families

There are provisions in the current law to support disabled children and their families. Under Section 17 of the *Children Act 1989*, local authorities are under a duty to provide specific support services for children in need and their families. The definition of children in need includes disabled children.<sup>15</sup> The Department of Health has issued guidance in the form of the *Framework for the Assessment of Children in Need and their Families*<sup>16</sup> to ensure a consistent approach to the assessment process. With regard to disabled children and short break services, the Framework requires local authorities to assess children and their families within a given time-scale following the request for services.

Carers who provide a substantial amount of care for a disabled child that has been assessed under section 17 of the *Children Act 1989* are also entitled to request the local authority to assess their ability to provide care. Where a local authority receives such a request from a carer, it must carry out an assessment. These provisions are contained in the *Carers (Recognition and Services) Act 1995*.

The *Carers and Disabled Children Act 2000* provides similar rights to assessments for persons with parental responsibility who are providing or, intending to provide care, for a

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<sup>12</sup> Prime Ministers Strategy Unit, *Improving the Life Chances of Disabled People*, January 2005

<sup>13</sup> *Ibid.*, p111-112

<sup>14</sup> *Ibid.*, Executive summary

<sup>15</sup> Section 17(10)(c) of the *Children Act 1989*

<sup>16</sup> Department of Health, June 2000

disabled child. Under section 6A of the 2000 Act, local authorities must inform carers that they may be entitled to a carer's assessment.<sup>17</sup> This provision was inserted into the Act by the *Carers (Equal Opportunities) Act 2004*.

Although both the *Carers (Recognition and Services) Act 1995* and the *Carers and Disabled Children Act 2000* place duties on local authorities to assess a carer's ability to provide care, neither Act requires a local authority to provide the carer with services following an assessment.

## II Recent Research

### 1. Parliamentary hearings on services for disabled children

In July 2006, HM Treasury and the Department for Education and Skills jointly announced a review of children's services, designed to make recommendations to the 2007 Comprehensive Spending Review. One of the three strands of the children's review focused specifically on services for disabled children.

A cross-party panel of MPs was established to hold hearings on services for disabled children. The panel held three public hearings, following the life-cycle of a disabled child and focussing on:

- early years services
- family support and children's services
- transition to adulthood.

The panel heard evidence from Ministers in the Department for Education and Skills, HM Treasury, the Department of Health, and the Department for Communities and Local Government. Oral presentations were given by Sir Al Aynsley-Green, the Children's Commissioner for England; the Local Government Association; parents; and from a disabled young person.

The hearings were supported by four national organisations working with disabled children and their families – Contact a Family, the Council for Disabled Children, Mencap and the Special Education Consortium – and also Children Now magazine.

In addition to the hearings, written submissions were received from disabled children and young people, parents, professionals and other stakeholders.

Despite policy developments in the area, the panel found a high level of dissatisfaction with the current services that disabled children and their families receive. 52% of the written submissions to the hearings from parents described services provided by education, health and social services as 'poor'.<sup>18</sup> In its report, *Parliamentary hearings on services for disabled children*,<sup>19</sup> the panel states:

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<sup>17</sup> Inserted by section 1(2) of the *Carers (Equal Opportunities) Act 2004*.

<sup>18</sup> *Parliamentary hearings on services for disabled children* October 2006, p31

<sup>19</sup> *Ibid.*

Parents of disabled children need support to help them understand and meet their child's needs. However, too many parents receive no support at all, while others feel that rather than support, public agencies are suspicious and doubt their ability to care for their children.<sup>20</sup>

It was also clear from the evidence that the failure to consistently deliver appropriate services at the right time was causing huge distress to disabled children and their families. One parent submitted:

You have to be at breaking point for help. My child is severely disabled; she meets all the criteria, yet I had to have a breakdown to get help. My children almost ended up in care. That is costly for the council, yet three hours a week help prevented this – what did that cost?<sup>21</sup>

Parents and disabled people told the panel that they wanted services for disabled children and their families to be available as a right.

The report looked specifically at short break provision which it viewed as a key service priority for both parents and disabled children. The panel reported that:

The lack of short breaks was the single biggest cause of unhappiness with service provision in submissions to our hearings, mentioned unprompted by three in ten submissions from parents. ... The Children's Trust's submission described respite care provision in general for disabled children as 'grossly inadequate'.<sup>22</sup>

The report stressed that the provision of short breaks benefit not just disabled children and their families. Local authorities can also benefit from long term savings to their residential care budgets as a result of providing adequate short break services.<sup>23</sup>

The panel made the following recommendations in relation to short break provision:<sup>24</sup>

- Families with disabled children should have a statutory minimum entitlement to short break services, set to reflect the level of their child's needs and that of the family.
- Local authorities should target funding at providing a flexible menu of short breaks, as a proven preventative measure to further costs later. A multi-agency approach should be taken to funding and commissioning short breaks, recognising the potentials savings to a range of services.

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<sup>20</sup> *Ibid.*, p27

<sup>21</sup> *Ibid.*, p45

<sup>22</sup> *Ibid.*, p45

<sup>23</sup> *Parliamentary hearings on services for disabled children*, October 2006, p46

<sup>24</sup> *Ibid.*

## 2. Statistics

According to figures from the Commission for Social Care and Inspection, only one in 13 disabled children receive a regular support service from their local authority.<sup>25</sup> Further research from the learning disability charity, Mencap, found that, despite the influx of carer's legislation enacted since 1995, half of all carers who have had a carer's assessment still receive no services.<sup>26</sup>

Mencap's 2006 survey of 353 families with caring responsibilities for children with severe or profound learning disabilities found that:<sup>27, 28</sup>

- 8 out of 10 families had reached or come close to breaking point because of lack of short break services;
- 7 out of 10 families provided more than 15 hours of care every day;
- 5 out of 10 families always provided care during the night;
- 7 out of 10 family carers who were in poor physical mental health said it was because of the amount of care they provided;
- 9 out of 10 family carers who were in poor mental health said it is because of the amount of care they provided;
- 6 out of 10 families did not get a short break that fully met their needs;
- 1 in 3 families had experienced a cut in their short break services in the last year.

## III Every Disabled Child Matters

In 2006, four organisations working with disabled children and their families - Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium – launched the Every Disabled Child Matters (EDCM) campaign. The aim of the campaign is to ensure that the Government's Every Child Matters programme applies to all children, including those that are disabled. The campaign's website explains the purpose of EDCM:

Disabled children, young people and their families have been left out for too long. **Every Disabled Child Matters (EDCM)** is the campaign to put this right. We want

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<sup>25</sup> Commission for Social Care and Inspection, *Social Services Performance Assessment Framework Indicators*, 2005

<sup>26</sup> Mencap, *Breaking Point –families still need a break*, September 2006

<sup>27</sup> Mencap, *Breaking Point –families still need a break*, September 2006

<sup>28</sup> The figures are for families of disabled children only and have been adjusted from those in the Mencap report (as published) which include both children and adults.

all disabled children and their families to have the right to the services and support they need to live ordinary lives.<sup>29</sup>

[...]

The government says that Every Child Matters – so why aren't disabled children getting their rights?

- Only 1 in 13 families get support from social services
- Disabled children are 13 times more likely to be excluded from school
- 8 out of 10 families with disabled children say that they are at breaking point<sup>30</sup>

The campaign states that there is no clear entitlement to legally enforceable short breaks for families with disabled children, nor are there specific duties on local authorities or health agencies to provide breaks. In order to remedy this apparent gap in the legal framework for families with disabled children, the EDCM campaign has launched the *Disabled Children (Family Support) Bill*, a Private Members Bill, which has been adopted by Gary Streeter MP. An Early Day Motion<sup>31</sup> tabled by Brooks Newmark MP in November 2006, supporting the EDCM campaign and the Bill, has attracted cross-party support. A brief explanation of the clauses in the Bill is set out in the next section of this paper.

## IV The Disabled Children (Family Support) Bill

Clause 1 sets out three principles which inform the Bill. They are:

- Unpaid carers for disabled children should have a right to regular short breaks from their caring role (clause 1(2)).
- Local authorities and the National Health Service should have a responsibility to provide high quality short breaks for the benefit of both disabled children and their carers (clause 1(3)).
- Regular and appropriate short breaks should form part of the local authority assessment of the carer to provide care for a disabled child (clause 1(4)).

Clause 2 would amend section 17 of the *Children Act 1989* under which services for children in need, their families and others are provided. The amendment would place a specific duty on local authorities to assess the needs of disabled children and their families for short breaks and then make arrangements for a suitable level of short break care. When making those arrangements, the local authority would be required to act in accordance with the three principles set out in clause 1.

Clause 3 of the Bill requires that disabled children who have a 'material health care need' are assessed for short break care by the relevant NHS body and the relevant children

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<sup>29</sup> [http://www.edcm.org.uk/Page.asp?originx\\_157qn\\_74514704196194n42n\\_2006911575g](http://www.edcm.org.uk/Page.asp?originx_157qn_74514704196194n42n_2006911575g)

<sup>30</sup> [http://www.edcm.org.uk/Page.asp?originx\\_4477mp\\_745666790499s14a\\_2006971819c](http://www.edcm.org.uk/Page.asp?originx_4477mp_745666790499s14a_2006971819c)

<sup>31</sup> EDM 321. <http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=31943&SESSION=885>

services authority. If, following an assessment, the NHS body and the children services authority were satisfied that the child requires short break care, they would be required to make arrangements to provide that care.

A health care need is defined in clause 3(4) as 'material', if, in the opinion of a relevant children services authority, it either:

- impairs the ability of that authority to arrange short break care; or
- is a health care need that may require attention during a period of short break care.

The clause would require the relevant NHS body and the children services authority to:

- advise carers that they may be entitled to a carer's assessment under the *Carers (Recognition and Services) Act 1995*;
- take into account any assessment of the carer made under the *Carers (Recognition and Services) Act 1995*; and
- co-operate with each other to deliver the most effective package of short break care for each child.

Clause 4 would amend the *Carers (Recognition and Services) Act 1995* to give carers a right to request that the children services authority should assess their ability to provide and to continue to provide care for the disabled child, as a precursor to assessing the child's needs for short break care under clause 3. If a carer makes such a request, the relevant NHS body and the children services authority would have to take into account the result of the assessment of the carer in determining whether the child needs short break care.

This clause is designed to ensure that any specific barriers to caring experienced by the carer or carers of a particular child are recognised when the family's needs for short breaks are assessed. This would include carers who are themselves disabled or in poor health, one parent families and carers with multiple caring responsibilities.<sup>32</sup>

Clause 5 would amend the *Childcare Act 2006* to place a duty on the relevant local authority to secure the provision of childcare to allow parents to sustain their caring responsibilities for a disabled child. The amendment would place a duty on the relevant local authority to secure sufficient short break services for parents of disabled children.

Clause 6 would amend the *Children Act 1989* definition<sup>33</sup> of a disabled child by inserting the definition from section 1 of the *Disability Discrimination Act 1995*. The 1989 Act definition is viewed as outdated and has been used to exclude certain groups of disabled children, such as those with Asperger syndrome or high-functioning autism, from social care services and support.<sup>34</sup> Rather than categorising the type of disability, the 1995 Act

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<sup>32</sup> Every Disabled Child Matters, *Disabled Children (Family Support) Bill briefing note*, December 2006

<sup>33</sup> Section 17(11) of the *Children Act 1989*

<sup>34</sup> Every Disabled Child Matters, *Disabled Children (Family Support) Bill briefing note*, December 2006



definition focuses on the effects of a disability on a person's ability to carry out day to day activities.

Clause 7 of the Bill defines certain key terms used in the Bill, particularly:

**Carer** – a person with parental responsibility for a disabled child within the meaning of section 6 of the *Carers and Disabled Children Act 2000*.

**Children services authority** – a local authority as defined in section 63(1) of the *Children Act 2004*.

**Short break care** – a service provided to the disabled child in order that the person with parental responsibility for the child has a break from caring.

Clauses 8 and 9 are procedural clauses.

Clause 10 states that, if enacted, the legislation will be cited as the *Disabled Children (Family Support) Act 2007* and will apply to England and Wales.

## V Key publications

Ad hoc Parliamentary Committee, *Parliamentary hearings on services for disabled children*, October 2006.

[http://www.edcm.org.uk/pdfs/parl\\_hearings\\_reportamended.pdf](http://www.edcm.org.uk/pdfs/parl_hearings_reportamended.pdf)

Commission for Social Care and Inspection, *Social Services Performance Assessment Framework Indicators*, 2005.

Department for Education and Skills and the Department of Health, *The National Service Framework for Children, Young People and Maternity Services – Disabled Children and Young People and those with Complex Health Needs*, September 2004.

<http://www.dh.gov.uk/assetRoot/04/09/05/56/04090556.pdf>

Department of Health, *Framework for the Assessment of Children in Need and their Families*, June 2000.

<http://www.dh.gov.uk/assetRoot/04/01/44/30/04014430.pdf>

Mencap, *Breaking Point – families still need a break*, September 2006.

[http://www.mencap.org.uk/download/campaigns/breakingpoint/national\\_report.pdf](http://www.mencap.org.uk/download/campaigns/breakingpoint/national_report.pdf)

Prime Ministers Strategy Unit, *Improving the Life Chances of Disabled People*, January 2005.

[http://www.cabinetoffice.gov.uk/strategy/work\\_areas/disability/](http://www.cabinetoffice.gov.uk/strategy/work_areas/disability/)

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*Disabled Children (Family Support) Bill*, 13 December 2006, Bill 20

[http://www.publications.parliament.uk/pa/pabills/200607/disabled\\_children\\_family\\_support.htm](http://www.publications.parliament.uk/pa/pabills/200607/disabled_children_family_support.htm)