

**Disabled Children (Family Support) Bill**  
**Briefing and Explanatory Note**  
February 2007

**Summary**

The Disabled Children (Family Support) Bill will introduce a specific duty on local authorities and Primary Care Trusts to provide appropriate short breaks for families with disabled children who provide a substantial level of ongoing care. The Bill applies to England and Wales.

The Bill is being 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 campaign is delighted that Gary Streeter MP (Cons, Devon SW) has adopted the Bill, which will have its second reading on 23<sup>rd</sup> February 2007.

**The need for legislation**

Regular, reliable and appropriate short breaks are the key service priority for families with disabled children. The report from the recent Parliamentary Hearings on services for disabled children states that ‘the lack of short breaks was the biggest single cause of unhappiness with service provision’ in submissions from parents to the hearings.<sup>1</sup>

Short breaks are an essential service. They can be provided in a variety of ways, within the family home, through accessing community facilities or by the child staying overnight with another family or in a residential setting.

Families who get breaks describe them as essential in helping them to continue caring. Parents tell us how important short breaks are to sustain their caring role: *I am fortunate to finally receive respite. What a wonderful relief. One night a week we can be a normal family. Go to the cinema, pub or for a meal or just be. No strict routine, no bathtime, no struggle to medicate, no getting up four or five times in the night. Bliss.*

Yet the provision of short breaks across England and Wales is patchy and inadequate. Figures from CSCI show that only one in 13 disabled children receive a regular support service of any sort from their local authority.<sup>2</sup> A recent survey by Mencap for their Breaking Point campaign found that even for those families receiving breaks, one in three had experienced a cut in service in the past year.<sup>3</sup>

The consequence of this failure to provide sufficient short breaks is that in the same survey, 8 in 10 families caring for children described themselves as at or close to breaking point. One parent told the Parliamentary Hearings that: *I had to have a breakdown to get help. My children almost ended up in care...yet three hours a week help prevented this – what did that cost?*

<sup>1</sup> Parliamentary Hearings on Services for Disabled Children – Full Report, October 2006, p45

<sup>2</sup> Commission for Social Care Inspection (2005), Social Services Performance Assessment Framework Indicators, CSCI / ONS

<sup>3</sup> Mencap (2006), Breaking Point – Families still need a break, Mencap: London

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Disabled children are entitled to have their needs assessed and services provided under s17 of the Children Act 1989. Carers have a range of entitlement to assessments, services and support from the raft of carer's legislation passed since 1995 – although Mencap have found that half of all carers who have had a carer's assessment still receive no services.<sup>4</sup> However, as yet, 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.

This has led to unacceptable variations in service provision and has prevented families from accessing the breaks they need to continue to function. As a direct consequence of the shortage of short break services, rates of costly placements in residential care facilities for severely disabled children, often many miles from their family home, continue to rise. As one parent told the parliamentary hearings:  
*It doesn't take a rocket scientist to work out the savings if my authority provided me with one night a week respite – say £500 per week as opposed to £4,000 a week for a residential placement!*

The Disabled Children (Family Support) Bill remedies this gap in the legal framework for families with disabled children. It imposes specific duties on local authorities and health agencies to provide short breaks for families who provide a substantial level of care on a regular basis. Further, it amends the recent Childcare Act to require local authorities to secure a sufficient supply of short breaks in their area.

Finally and most importantly it requires the breaks offered to families to be of benefit for the child and their carers, to safeguard against the low quality breaks that some families are currently offered. The benefits of short breaks are well recognised by families:

*Respite for my daughter provides some social life with her peers outside of school and gives me time to spend with other children and recharge my mind and body. I need to be a mum, not just a carer.*

*Without respite, our son would not have a separate life from us other than when he is at school. It teaches him self reliance within a safe environment. Of course it gives us a life too!*

The Disabled Children (Family Support) Bill is being launched in the context of the ongoing HM Treasury / DfES review of services for disabled children. That review provides the opportunity for government to increase the level of resources available to local authorities to provide short breaks.

Families reach crisis point not because they are carers, but because they are forced to care without any support. With the right kind of short breaks, families will continue to support and care for their children. Disabled children deserve – and get – as much love and affection from their families as other children. The Disabled Children (Family Support) Bill creates the legal right to support for families to sustain their caring role – support which makes sense both morally and financially.

For further information on short breaks, see [www.mencap.org.uk/breakingpoint](http://www.mencap.org.uk/breakingpoint)

<sup>4</sup> Mencap (2006), Breaking Point – Families still need a break, Mencap: London

## **The Bill – Detailed Briefing**

### Clause 1 – Principles

This clause sets out three principles which inform the Bill:

- i) Carers for disabled children on an unpaid basis have a right to short breaks from their caring role on a regular basis. (Clause 1(2))
- ii) Local authorities and the National Health Service have a responsibility to provide high quality short breaks (or respite care) for the benefit of both disabled children and their carers. (Clause 1(3))
- iii) In any assessment by a local authority of the ability of a carer to provide care for a disabled child, provision must be made for regular and appropriate short breaks from a caring role for that person. (Clause 1(4))

### Clause 2 – Short Break Social Care Services

This clause amends section 17 of the Children Act 1989 to include a specific duty on local authorities to:

- assess the needs of the child and family for short break care, and;
- make arrangements for the provision for that child of a suitable level of short break care

### Clause 3 – Disabled Children with health needs

This clause ensures that disabled children who have a ‘material health care need’ receive short breaks that are appropriate to their health needs. ‘Material health care need’ is defined in clause 3(4) as a health care need which, in the opinion of the local Children’s Services Authority, either:

- impairs the ability of the Children’s Services Authority to arrange short break care, or;
- is a health care need that may require attention during a period of short break care

Where a disabled child has a material health care need, the Primary Care Trust where the child’s GP is registered has a specific duty, in partnership with the Children’s Services Authority, to:

- assess the child’s needs for short break care (clause 3(1))
- make arrangements for the provision of short breaks following the assessment (clause 3(2))

The clause requires the Primary Care Trust or Local Health Board and Children’s Services Authority to:

- advise carers of their entitlement to a carer’s assessment under the Carers (Recognition and Services) Act 1995 (clause 3(3)(a))
- take any carer’s assessment into account when assessing when a disabled child needs short break care (clause 3(3)(b))
- co-operate with each other to deliver the most effective package of short break care for each child (clause 3(3)(c))

### Clause 4 – Carers Assessments

This clause amends the Carers (Recognition and Services) Act 1995 to give carers a right to request that the Children’s Services Authority should assess their ability to provide and to continue to provide care for the child, as a precursor to assessing the

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child's needs for short break care under clause 3. If a carer makes such a request, the Primary Care Trust and Children's Services Authority must 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 need for short breaks is assessed. This would include (but not exclusively) carers who are themselves disabled or in poor health, one parent families and carers with multiple other caring responsibilities.

## Clause 5 – Amendment of Childcare Act 2006

This clause amends the Childcare Act 2006 to place a duty on Children's Services Authorities to ensure a sufficient supply of short break care to allow parents and carers of disabled children to sustain their caring responsibilities. The amendment is intended to give Children's Services Authorities the overarching responsibility for ensuring that sufficient short break services exist to allow them to meet their specific duties to each disabled child in their area.

## Clause 6 – Definition of disabled child

This clause amends the Children Act 1989 definition of disability, inserting the definition from the Disability Discrimination Act (DDA) 1995. The DDA definition is widely supported by disabled people and their families. By contrast, the existing Children Act definition (at s17(11)), is 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.

## Clause 7 – interpretation

This clause 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's 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 that child has a break from caring

## (Clauses 8 and 9 – procedural clauses)

## Clause 10 – Short title, commencement and extent

This clause specifies that if passed, the legislation should be cited as the Disabled Children's Short Breaks Act. It further states that the legislation applies to England and Wales.

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**For further information on the Disabled Children (Family Support) Bill and the Every Disabled Child Matters campaign, please contact:**

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