



Breaking Point —

families still need a break

A report on the continuing problem of caring without a break for children and adults with severe and profound learning disabilities

MENCAP
Understanding learning disability



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The Breaking Point Survey— families still need a break

The survey was carried out between May and July 2006. Three hundred and fifty-three families, from six areas in England and from throughout Northern Ireland, took part.

Northern Ireland

The term “local authority” is used throughout this report. In Northern Ireland this should be read as “health and social services trusts”.

Terminology

The term “short breaks” is used throughout this report. Short breaks used to be referred to as “respite care”.

The report uses the phrase “children and adults with severe or profound learning disabilities”. By this we mean children and adults with the most severe form of learning disability who may also have physical, sensory and communication impairments. Some may have complex health needs.

Acknowledgements

Mencap would like to thank:

- Conor, Duke, Guy, Harry, Jodie, Lorraine, Matthew and Natasha and their families for sharing their stories
- all the families who participated in the Breaking Point Survey 2006
- all those who helped us to reach families willing to take part.

A message from Mandy

Mandy's story in 2003 prompted Mencap to write Breaking Point and to call for urgent improvements in short break services for families caring for children and adults with severe and profound learning disabilities.

Mandy was forced to breaking point. Today, things are different for her family. But they should not have been pushed to breaking point before things changed.

“ When I reached breaking point I could see no future, no way I could go on. I was pushed to breaking point when we had our short break services cut and were left to fend for ourselves. Those were the darkest days of our family's life and I never ever want to go back there. It shouldn't have happened. We should not have been pushed that far.

I got involved with the Breaking Point campaign to speak up for other families – to stop it happening to them. I'm outraged that now, three years on, this report has had to be written because families are still not getting the short breaks they need to help them to carry on, to stay together and to enjoy their family life. No family should be left without short breaks.

Life for our family today is so different to how it was then. Social services now provide services so that we can share Natasha's care. Our life is completely different. I have regular breaks and I can be the kind of mum I wanted to be to both Natasha and my two other children. I'm now also a self-employed businesswoman.

We love Natasha, but with no support Natasha always had to come first, no matter what, and this was affecting the whole family, such as being able to spend enough time with my son Daniel and our other daughter Hannah. ”

Daniel says:

“ I know how the other children in those families without breaks must be feeling. Our family couldn't spend any time together. Now all of us have a break and we spend time together. Everyone is less stressed out. We had to do things only when Natasha went to bed. I couldn't go out at weekends or spend time with mum and dad. I don't feel jealous any more. It makes a real difference when your family gets what they need.

Now we have been able to get the balance right. When Natasha is with us we have the energy to do all the things she enjoys and have fun together as a family. There will be many challenges ahead of her but now I feel that I can go on and fight for Natasha forever.

It is my hope that no family will have to go through what we went through. Breaking point is the worst situation any family could face. No family should ever be left without breaks and pushed to the point where it cracks, or almost cracks under the pressure. You'll read in this report that this is still happening to families. But there's a solution. It doesn't have to be like this. If families are listened to and provided with good quality breaks to suit their needs they'll be able to carry on and to enjoy family life – just like we do now. ”

Mandy and Natasha

"It is my hope that no family will have to go through what we went through. Breaking point is the worst situation any family could face."

Introduction

Mencap's 2003 Breaking Point report identified the appalling situation faced by the majority of families caring for children and adults with severe and profound learning disabilities. Despite highlighting the issues with central and local government at every opportunity, Mencap continues to meet families pushed to breaking point. We have revisited the issues in this report, as we have come across many more stories of families who are still not getting the short break they need. We can confirm that, sadly, nothing has really changed.

From May to July 2006 we followed up our work with a survey of 353 families in six local authority areas in England¹ and throughout Northern Ireland to find out about the short breaks they get and need. This report tells the shocking stories of families still being denied the right to a family life due to a continuing lack of short breaks.

Families are still left to reach breaking point, experience ill health and lead diminished lives as short break services are not being provided to help them care for their sons and daughters.

What is breaking point?

"Sometimes I feel like walking out and not coming back. I feel like I am living in a cage and can't get out. I look at my life and I don't have one."

(21 year-old man's mother, Northern Ireland)

Breaking point is a physical and emotional crisis, where the persistent lack of short break services and the endless pressure of providing intensive care finally take their toll. It is a dreadful situation for families, which causes pain and despair and, often, irreparable damage.

Caring without a break for children and adults with severe or profound learning disabilities damages these families. Sleep deprivation, moving and handling, and constantly being the only person who can provide what's needed can be physically and emotionally draining.

"I felt as if I was losing control of my life, like I couldn't go on anymore. I really wanted to just be a 'normal' family." (10 year-old girl's mother, Wakefield)

Breaking Point
Survey 2006

7 out of 10 families have reached or come close to breaking point because of a lack of short break services

But breaking point isn't inevitable. It can be prevented. It is not caused by caring – it is caused by caring without the right help. With the right kind of short breaks, families will cope and will continue to support and care.

Guy and Gail's story

Gail reached breaking point caring for Guy without breaks; getting short breaks that suited their family has changed their life, making it so much easier for everyone. Their family's story illustrates the importance of giving families the kind of short breaks that suit their needs. If families are supported with the right breaks they can have a quality family life together.

“ I'd been waiting for respite for over a year and the arrangement with the proposed link family was breaking down. I already lived life on a knife-edge, but this was the final straw, the breaking point. In tears on the phone I told social services that I couldn't cope any more. I was exhausted and my marriage and family was falling apart. If I didn't get respite they would have to take Guy away. Within a week I had overnight respite for Guy.

For the last nine years we have got four or five nights' respite per month at a children's centre near to our home. This means we can have a weekend where Guy goes to the respite centre from school on a Friday and comes back on a Sunday, or on a Monday evening after school.

Guy has really benefited from the short breaks. It is like a second home. He knows the routine and the staff so well that it really is a substitute family. The breaks we get are regular and good quality. The respite centre does activities with Guy that are appropriate to his developmental level and that we don't have the time and energy to do with him when he is at home. The breaks mean Guy is used to being away from home, and that's good because I do want Guy to be able to move on eventually. Just as his sisters go to sleepovers with their friends, time at respite is Guy's chance to do that. He can socialise with his friends and gets one to one attention. The breaks are a lifeline, but they only work because they are regular and reliable and a good length of time. ”

Why do families need a break?

"I just feel so tired and always have to be alert - 24 hours - in case she has a seizure." (12 year-old girl's mother, Northern Ireland)

Breaking Point Survey 2006

7 out of 10 families provide more than 15 hours of care every day

That support is always provided by a member of the family. Nobody gets a day off. The family does what paid carers do, but without pay, holidays or any rights.

Breaking Point Survey 2006

5 out of 10 families always provide care during the night

Constant caring and disturbed nights make these families ill – both physically and mentally². It affects their ability to cope and to continue. Caring without a break is bad for every member of these families, and their relationships with one another.

Breaking Point Survey 2006

6 out of 10 family carers who are in poor physical health say it is because of the amount of care they provide

On top of the everyday tasks, there are always other things that every family needs to do. Imagine what it's like if there are other family members who also need some of your attention, or even just a bedtime story, but you have no time to spare.

"Our three older children lost half of their parents with the arrival of our disabled son. As he needs at least one of us 100% of the time, it meant they got far less attention, and when there were concerts, sports days or parents' evenings, only one of us could attend." (12 year-old boy's mother, Somerset)

Breaking Point Survey 2006

9 out of 10 family carers who are in poor mental health say it is because of the amount of care they provide

There is phenomenal pressure on the main relationships in the family, coupled with tiredness and the monotony of doing the same tasks time and again without a break. Families report many incidents when relationships have really suffered.

"We've less time together as one of us is always dealing with her needs. It sometimes feels like a job share, rather than a regular marriage." (10 year-old girl's mother, Oxfordshire)

Harry and Katherine's story

Without breaks, families like Harry and Katherine's find it impossible to imagine being able to cope forever. Short breaks should be provided as soon as the need arises and should be guaranteed to be able to support a family whenever it needs them.

“ We've never had a break given to us by social services. As far as I'm aware social services don't even know that we exist. Sometimes the lack of support makes me think that Harry's support needs mustn't be that bad. Harry is four and has William's syndrome and is tube fed. He lives with me and my daughter Charlie, who is five. I reached breaking point over a year ago and I still haven't had any breaks. I'm propped up by anti-depressants and had to give up work.

We were hoping that Harry could go to a local children's short breaks centre, but it's been threatened with closure and has an uncertain future. We know he currently can't use it until he's eight anyway as they changed the age that children are eligible to go there. If Harry went to somewhere like that, how fantastic would that be? As an adult it is unlikely that Harry will live independently, so this would assist his long-term transition, as well as giving the rest of us some support.

Any breaks I get are from my mum and dad. It's hard to ask for help and I try my best not to. I wait for them to offer because they're retired and they didn't ask for this. The best thing in the world would be that, at aged 34, I wouldn't have to be dependent on my mum and dad anymore.

What I'd love for Harry is somewhere to go for regular breaks with his friends so he'd have a social life and that it would be lifelong. If it's somewhere good for Harry, where I trust the staff, then that would give everyone a break. ”

"Short breaks mean everything to our family. They give us the ability to recharge our batteries and carry on."

(22 year-old man's mother, Northern Ireland)

Short breaks are vital. They enable these families to have a quality family life, and so ensure that everyone in the family is equally and fully supported. Families who get breaks describe them as essential in helping them to continue caring.

"Our short breaks mean that we have time to shrug off the caring role and think of other things. For her, there's time to play, make friends and have new experiences we are unable to provide."

(12 year-old girl's mother, Surrey)

There are many ways to give families like Harry and Katherine's short breaks from their caring role, ranging from someone coming in to the family home and helping out, to the child or adult spending time away from home, perhaps with another family or in a residential setting.

Short breaks not only support carers like Mandy and Gail but also provide an opportunity for disabled children and adults, like Natasha and Guy, to have a break from being cared for by the same person all the time. They can experience new opportunities such as leisure activities. The better the break for the disabled child or adult, the greater the benefit for the carer, who knows the person they care for is being well looked after and having a good time.

"I recharge my batteries and feel able to cope with the rest of the week. I am a lot more patient and tolerant with both children."

(14 year-old girl's mother, Lancashire)

All short breaks give families time away from the stress of providing constant care, but there are a number of features that can make the breaks particularly beneficial. Families refer to the importance of breaks that are flexible, that they have confidence in, and which are long and frequent enough to provide them with a real break.

Conor and Angela's story

Short breaks need to be regular, reliable, of good quality and long enough to allow the whole family a real break. When this happens, families like Conor and Angela's can enjoy family life. Everybody benefits and nobody loses out.

“ When Conor was young, we had a totally one-way relationship. I felt really low. Conor's autism meant we had no interaction, he didn't interact with me at all. By the time he was five I thought he hated me. Because of Conor's complex needs, I had spent several years on my knees cleaning up after him, tasks that were much more demanding than they had been with Conor's older brother Thomas. The social worker saw that I was getting to a point where I couldn't cope. There was no one thing – it was five years of having to do everything for him myself. You have a constant feeling of being a bit worn out and weary.

Conor is now 15 and has been getting weekend short breaks at a residential children's respite centre near our home since he was five years old. Every fortnight, he goes from school on a Friday and comes home on a Sunday evening. Conor gets a break from us – it gives him a little bit of independence and he has to direct his needs at someone other than me.

It's because I love my child that I want a break – either that or I'd have crumbled or been reduced to providing a worn-out robotic basic level of care. It would affect the joy with which I do it. Because I get that break from doing everything for Conor, the whole family can do so much better and it gives me time to be a proper mum to both Conor and his brother Thomas.

The weekend break is substantial enough to get benefit from the time free from worry and stress. Conor's breaks are flexible. We get a list of dates three months at a time ... if I want to cancel or change one, I can. We get the right kind of break for us – overnight, out of home, regular, reliable, long enough. ”

“Some people reach
crisis point - that
shouldn't be allowed
to happen.”



Duke and Emily

Not every family gets the same level of support as Natasha's, Guy's and Conor's, and many of the families' stories do not have happy endings.

Our breaks aren't regular or long enough to make a real difference

Matthew and Clare's story

If families don't get the kind of short breaks they need, breaking point will never be very far away. Short breaks for Matthew and Clare's family cause stress and pressure on the family as they are not long enough and they can't rely on them. They are not a real break.

“ I reached breaking point after we had been on a waiting list for overnight residential breaks for two and a half years and I heard that the centre Matthew was waiting to go to was under threat of closure. I felt in a black hole with no light at the end of the tunnel. I felt I couldn't go on any more. I was distraught that there was going to be nothing. I rang social services; I was beside myself with grief as I felt there was no hope. I couldn't speak with emotion, and was told to ring back when I could speak.

Now Matthew gets one overnight break a month. He either goes from school for an overnight midweek or, if it's a weekend, he goes to respite on Saturday lunchtime, and comes back around Sunday lunchtime. This means we never get a full day and we can't really fit anything in. A while ago we thought about taking a trip to London with our other two children, but there just wouldn't be time.

The respite isn't regular enough, so often Matthew goes nuts when it comes around. He has a fabulous time, but I feel awful the whole time he is there because he will have cried on the way. ”

There is very little information available on short breaks for these families. They are paid scant official attention, and are invisible in their communities. Figures released in 2005³ report that only 1 in 13 of all disabled children receives a regular support service (including short breaks and direct payments) from their local authority. Only 1 in 5 adults with a learning disability who receive services get a short break, according to figures from the Valuing People Support Team⁴.

The Government reports these figures as being indicators of progress, but Mencap believes they are a shocking indictment of the lack of priority given by central and local government to these families and their right to family life.

Breaking Point Survey 2006

6 out of 10 families don't get a short break that fully meets their needs

"I always feel sick at his annual review as I think our short breaks are going to be taken away from us. We see the review as an opportunity for our short breaks to be cut, rather than an opportunity to get what we actually want."
(14 year-old boy's mother, Oxfordshire)

Access to services is becoming an increasing problem. Families report cuts in services, difficulties in getting an assessment and the tightening of eligibility criteria for essential services, despite their needs staying the same or, in many cases, worsening.

Breaking Point Survey 2006

1 in 3 families has experienced a cut in their short break services in the last year

Following the publication of Breaking Point, the then social care minister, Stephen Ladyman, stated that families needed to have a carer's assessment in order to get short breaks and that if they did, they would get a service:

"If the assessment says you do need a short break, then it's up to the local authority to provide it and they shouldn't, or can't, make the excuse that they haven't got the money."⁵

Breaking Point Survey 2006

5 out of 10 families have not had a carer's assessment

The minister was clear that when a carer's assessment states that a family should get a break then they will get one. Our evidence shows that for the majority of families this is not the case.

Breaking Point Survey 2006

5 out of 10 families who had a carer's assessment still didn't receive any services

Pressures on budgets and lack of a real increase in funding for services for people with a learning disability mean that local authorities up and down the country are looking at how they can limit the number of families getting short break services. Councils use rationing, which they call "eligibility criteria", to decide which families might get short breaks.

"The capacity of services is always under threat and I'm constantly worried that we could lose the little we get." (14 year-old boy's mother, Oxfordshire)

The Local Government Association has found that 80% of local authorities are now tightening eligibility criteria and 70% provide support only to those with the very highest levels of need (critical and substantial). Despite Breaking Point 2003 identifying that those families need access to more and better services, it now appears that these vulnerable families are at risk of even more cuts to services as both central and local government fail to prioritise and provide for them. These families are now at even greater risk of reaching breaking point.

We can't have a crisis in our house, there'd be nowhere for Jodie to go

Jodie and Stephanie's story

When we first met Stephanie and Jodie, their lack of short breaks had torn their family apart. Since then, the level of breaks they get is making family life more of a reality. However, the lack of emergency short breaks and enough funding to give them any extra support is a constant threat to this better family life.

“ Because Jodie has complex health needs it is a battle just to be able to live day to day in her own community. I have had to fight to get things for Jodie just so that we can carry on with daily life. I don't know why health and social services have to wait until you're in crisis before they step in to help.

I now get some home-based support, basically an extra pair of hands to help me care for Jodie. It isn't really a break, because I still need to be here doing everything for Jodie, but it just means that I have a bit of support to do it. But Jodie also goes to a short break centre for a weekend every six to eight weeks. This works pretty well but it's still not enough and my real worry is what happens in an emergency.

I had a carer's assessment and was told that I needed extra help and would be given direct payments and support from a sitting service. However, because of the cuts in my area, these extra services that I need have been put on hold. I have been told that I have a need, but no one is going to provide anything for me.

The short break centre has one emergency bed, but it is supposed to cover the whole county. This means that only one family at a time can have an emergency. My emergency came in May this year. I needed to go into hospital, but the bed in the respite centre was already filled. It meant that my appointment was cancelled. I really don't need the extra worry and stress.

I have had to fight every step of the way to get a short break and I know that some families just aren't able to do that. I really don't know if there's any fight left in me any more. What's important is that every family gets what's right for them. For me, that's having consistent and flexible support in caring for Jodie. ”

"The package we currently receive works very well for my family. However, it is under threat as the council is proposing to close the unit my son attends. There aren't any suitable alternatives in the area."

(12 year-old boy's mother, Lancashire)

As well as tightening eligibility criteria and cutting short break services, councils are also looking for cheaper, alternative ways to provide support. These include increased use of direct payments, home-based support and link families⁷. At the same time, residential short break centres around the country are facing closure. For some families, residential respite is the only way they get a real break. Cheaper options are only acceptable where they result in good quality support that meets families' needs and choices. But they are not acceptable where they are simply designed to save money, at the cost of quality and choice.

Breaking Point Survey 2006

7 out of 10 families have never been offered a choice of short break service

"Families are not offered the choice, it's what suits funding rather than the best interests of the disabled child and their family."

(12 year-old girl's sister, Somerset)

We lost the good breaks we had, now Lorraine gets poor care

Lorraine and Brigid's story

Lorraine's family benefited from breaks that she enjoyed and that provided her with a good standard of care. Since the centre she went to closed she has not been offered a suitable alternative and at one point was provided with a break in a nursing home for older people. She is 34 years old. Families need short breaks that are appropriate and provide good care.

“ Lorraine used to go for respite four times a year for a week. It was a home from home. Lorraine got on well there. She was happy there and she still got to go to her day centre and was taken on trips, and was around other young people.

The last time Lorraine had satisfactory respite was October last year. The centre has stopped providing respite. Someone who worked there told me that the three-bedroom unit was still empty, and was still not being used for respite.

In March this year, Lorraine got her respite at a nursing home for elderly people. She never got out, except for going to her day centre, and they didn't provide her with good personal care. Lorraine does not like showers, and the staff said that she would not co-operate with them when they tried to get her into the shower.


We don't want Lorraine to go there again. We have been told about another place but we are concerned about the ratio of staff to residents. We are also concerned that Lorraine would not get out to her day centre as the respite is too far away. It is not reasonable that Lorraine should miss out on going to the day centre so that we can have respite. ”

What is Mencap campaigning for?

Mencap believes that no family should be pushed to breaking point by the lack of short breaks. More and better short breaks are essential if families are to continue to provide the care that children and adults with severe and profound learning disabilities need to live full lives with their families.

Despite a raft of policy initiatives that emphasise the importance of breaks for families, there is no acknowledgement that these are failings on the part of central and local government. There is no sense of urgency to deliver breaks for these families. The limited amount of data on breaks continues to show a lack of any real improvement, and essential monitoring information is not available. For the most part, these families are invisible.

Jodie and Stephanie



"I have had to fight every step of the way to get a short break and I know that some families just aren't able to do that."

Every family should be entitled to a minimum level of short breaks

"The right package would be if and when a need for a short break arose, you felt you could ring up your social worker and you could feel confident that it would be unlikely that their hands would be tied."

(30 year-old woman's mother and father, Northern Ireland)

The problem faced by many families at breaking point is that there is no entitlement to short breaks. As a result, short break services are an easy target for funding cuts. Mencap wants every family in need of a short break to get one.

Mencap wants an automatic entitlement to short breaks for families of people with a learning disability who live in the family home and get the care component of Disability Living Allowance (DLA). Every family on higher rate DLA should get a minimum standard guarantee of one break a week. Those on other rates of DLA should have a proportionate entitlement⁸. The minimum standard should be delivered in a way that meets families' needs. Families need breaks that are flexible, consistent and reliable. They need to be in control of how, where and when their support is provided.

Every family should have their needs assessed and receive a written support plan

"It would help to have a clear plan of the level of help available for years to come."

(14 year-old girl's mother, Oxfordshire)

There should be no delay in getting a carer's assessment, which must address the family's need for breaks. The family must be given a written plan outlining the support necessary to meet their needs. It should say what short breaks the family will get, and who will make sure the family gets these breaks and that they are suitable.

Every local authority should audit its current provision

"I can't understand why the 'bodies' responsible don't provide adequate services for these people when they know from birth or early years of their existence."

(35 year-old man's mother, Northern Ireland)

Local authorities should produce information on the short breaks they provide, who they provide them to and how often. This would enable them to estimate the shortfall between what they currently provide and the amount of breaks families would be entitled to under Mencap's minimum standard guarantee. This would then help local authorities make the case for increased funding to give families the short breaks they need.

There should be a public service agreement (PSA) on the provision of short break services

"If the people 'meting' out respite care had to care for a disabled child themselves they would think and act very differently."

(14 year-old girl's mother, Oxfordshire)

Mencap wants a public service agreement (PSA)⁹ on short break provision and a complete review of short breaks by the agencies responsible for inspecting children's and adults' social care services¹⁰. This would ensure that central government, local authorities and health trusts were fully aware of the scale of the problems facing these families. It would also provide the leverage for the improvement of short break provision.

Families need a carers' strategy that delivers quality services to meet their needs

"Because the breaks are regular it means we are not limping from one break to the next and it means we can plan ahead. There are also two emergency beds at the respite centre, so if there was a family crisis it is a comfort to know they are there" (15 year-old boy's mother, Oxfordshire)

Our Health, Our Care, Our Say, the white paper on health and social care, includes commitments to revise the 1999 national carers' strategy and provide emergency respite beds to support all carers.

The new carers' strategy must contain a firm commitment to an entitlement to short breaks, based on Mencap's minimum standard. This must include reliable short breaks as well as emergency care.

Central government must provide increased funding to local authorities for short breaks

"Things will not improve until the Government gives more."
(18 year-old man's mother, Somerset)

Government must increase funding to local authorities for short breaks. Despite recent increases, the Carers' Grant has not had a significant impact on provision for families. Mencap believes that a substantial increase in funding is needed urgently. In addition, the way authorities spend the money should be properly tracked and closely monitored, to make sure that it creates more and better short breaks.

Families need a range of options. A one size fits all approach to short break services, based on cost savings, will not meet these families' needs. There must be a sufficient range of the right types of breaks to support all families.

"I wish the Government would fund more respite places, as it is essential for families like mine to function as a family." (18 month-old boy's mother, Surrey)

Until and unless short breaks are provided as a right to families with the highest needs, then these families will continue to reach breaking point.

No family should ever reach breaking point due to a lack of funding. Giving families a short break must be a priority for government, both centrally and locally.

I don't think we'll ever get short breaks now

Duke and Emily's story

When we first met Duke and Emily they received no short breaks. Emily's marriage had broken down under the strain of being the only person who could meet Duke's care needs, as she didn't get any help.

It is disgraceful that this family still doesn't get any short breaks to help them to enjoy family life. The strain of caring is taking its toll on Emily's health and well-being as well as depriving Duke of opportunities that every young man should have – to make friends and prepare to live an independent life.

“ I'm sorry to say that not much has changed for Duke and I since we first told our story in 2003. We still do not receive any short breaks. He received a holiday break in June of this year for four days. I was trying to fit everything in and there was not enough time for all the appointments.

I have a feeling of permanent tiredness. I need short breaks to do this. It has affected my marriage, health, socialising, my thinking – you are constantly living not your life but the life of somebody else. I talk for Duke. I live for Duke, I do everything for Duke. I have to change my plans all the time to think of Duke. I'm living for Duke, and my life becomes nil, zero. I can't have a holiday. Duke is always there with me. It's knocked my life off the radar in a very big way.

Duke needs a package of short breaks to recognise his age and his needs. All I want is for Duke to have a break. I can't carry on much longer and I shouldn't have to. It's not a life for me and Duke. I should be allowed to have some sort of life for myself. I've given up on social services as they have let me down so many times. How long must I wait?

Some people reach crisis point – that shouldn't be allowed to happen. Social services should have a conviction of the right thing to do. But I honestly don't think things will change for us. ”

- Every family should be entitled to a minimum level of short breaks.
- Every family should have their needs assessed and receive a written support plan.
- Every local authority should audit its current provision.
- There should be a public service agreement (PSA) on the provision of short break services.
- Families need a carers' strategy that delivers quality services to meet their needs.
- Central government must provide increased funding to local authorities for short breaks.

1. Gateshead, Lancashire, Oxfordshire, Somerset, Surrey and Wakefield.

2. Carers Week survey 2006 <http://www.carersweek.org>
www.carersweek.org

3. Commission for Social Care Inspection (2005)
Social Services Performance Assessment Framework Indicators, CSCI/ONS

4. Valuing People Support Team (2005)
The Story So Far ... Valuing People – A New Strategy for Learning Disability for the 21st Century, VPST and Valuing People Support Team(2005) *Valuing People – What Do the Numbers Tell Us?*, VPST

5. Viewpoint September/October 2003.

6. LGA (2006) Social Services Finance 2005/06 –
A Survey of Local Authorities. Research briefing 1.06

7. Support from families who provide short breaks for disabled children and adults in their own homes, also 'called shared care'.

8. The minimum number of short breaks families should get are:
52 nights a year, or the equivalent in hours if families don't want overnight breaks, for people getting higher rate Disability Living Allowance
26 nights a year, or the equivalent in hours if families don't want overnight breaks, for people getting middle rate Disability Living Allowance
13 nights a year, or the equivalent in hours if families don't want overnight breaks, for people getting lower rate Disability Living Allowance.

9. Public service agreements (PSAs) set out each government department's aims, objectives and key outcome-based targets. They form an integral part of the spending plans set out in spending reviews.

10. OFSTED, CSCI/Healthcare Commission.

Mencap's charter for short breaks

No family should ever reach breaking point.

Short breaks for the families of people with a learning disability should be based on respect for their right to family life.

Mencap believes that:

- good short breaks are fundamental to the health and well-being of the whole family
- families should have a right to a break
- families with the highest needs should have a break at least once a week.

A good short break is one that is:

- regular, reliable, flexible and frequent enough
- responsive to family life and cultural background
- available in an emergency
- enjoyable for the person with a learning disability.

Families should have:

- independent information about the full range of support available to them
- a carer's assessment and a short break action plan – which is carried out
- the right to choose when, where, and how short breaks are provided.

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