



Breaking Point

A report on caring without a break for children and adults with severe or profound learning disabilities

MENCAP
Understanding learning disability

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The Breaking Point Survey

The Breaking Point Survey was carried out between March and April 2003. Seventy-six families took part. They came from all across England and Northern Ireland.

Northern Ireland

Throughout this report, the term 'local authority' is used. 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'.

This report uses the words '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

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- all the families who participated in the Breaking Point Survey
- the parent campaigning group FORCe.

Photography by Peter Hamilton

What is breaking point?

Imagine having to ring a total stranger and tell them, through your tears of exhaustion, that you just can't cope anymore, that you are desperate for help.

“Stupidly, I thought that when I needed help from Social Services, I could expect to get it. To tell a stranger that you can't cope, to ask for help, is so hard. I didn't expect to have to fight.” (Clare, parent-carer)

Think about what it must be like to look into the face of someone you love, knowing that you just can't go on caring for them anymore.

“I rang my social worker. ‘I'm frightened’, I told her. ‘It frightens me how I feel right now and what I might do. I can't cope’.” (Gail, parent-carer)

This is breaking point. This is the experience of the people you will meet in this report and of many of the thousands of other family carers who care for children and adults with severe or profound learning disabilities at home. They are driven to breaking point because they do not get the help they need.

Breaking Point Survey

8 out of 10 families have reached breaking point



Mandy's story

“I reached breaking point one Monday morning in January. It had been a very difficult weekend. I had not had an uninterrupted night's sleep in weeks and I was desperately tired. The terrible thing is that I broke down in front of my kids. I told them, 'I just can't take this any more. I have to go'. Can you imagine how scared they were?

I planned to leave there and then, once my two older children were off to school, and I had waved off my younger daughter Natasha on the school bus. But thinking that maybe I had one last hope, I got the Learning Disability Helpline number through directory enquiries. I told them that I just couldn't go on, that nobody would help me and I was leaving home.

Natasha is eight years-old and has profound and multiple learning disabilities. In some ways she is like any other girl her age. She loves to be around the family, being read stories and playing with her favourite toys. We all love her very much, but she also has needs that are above and beyond what any family can provide without the right kind of help.

Natasha needs help with everything. She uses a wheelchair and as she gets bigger, she is getting harder for me to lift. She has lots of health needs. She is prone to chest infections and has epilepsy. She needs regular physiotherapy because one side of her body is weaker than the other and she is tube fed. She needs care and attention all the time and on top of that, we seldom get a whole night's sleep.

What makes me so angry is that I had been telling people for years that I needed more help, but nobody was listening. Just after Christmas we went to Natasha's school review. Natasha had been ill for over three weeks and we were pinning our hopes on getting some help sorted out at the meeting. All the agencies were there, Social Services, Education and Health, but we came away with nothing.

Only my close friends and family knew what it was doing to me. They helped as much as they could, but you can't carry on under that kind of pressure forever. It seemed utterly impossible to convince anyone else that I needed help. They thought I was coping, because I tried to keep my home tidy and my children were clean and went to school.

The final straw came when I hurt my back lifting Natasha. I physically and mentally just could not go on any more. I had finally reached breaking point, that Monday morning in January. And finally somebody was listening. Why did I have to completely break down before I was taken seriously?”

Why do families need a break?

It is hard for many of us to understand the extent of the caring role that some families face. Perhaps you might be able to recall how tired you felt when your new baby woke you up three times a night and how having to feed and change him/her at 4am took its toll. But can you imagine how you might feel if in 5,10, 15 or even 25 years' time you still needed to do that?

Like many of the families in this report, perhaps you would just try to get along as best you could. But what if on top of all that caring, all those sleepless nights, you had some sort of family crisis too? Perhaps you or your partner are taken ill, a grandparent dies or one of your other children starts refusing to go to school because they are being bullied. What would you do then?

“I cried bitter tears that I could not even attend my father’s funeral without a battle for care for my children. I don’t think I have ever felt as alone as I did that day.” (Jan, parent-carer)

Like the family carers in this report, you might expect that someone would be there to help.

Carers of children and adults with severe or profound learning disabilities love the people they care for. They care for them willingly but they need help to do so.

“We love our son, we want him here at home with us. We just need a break every now and then.” (Gail, parent-carer)

It doesn’t sound like much to ask. After all, these are families who face a daily challenge that goes way beyond what the rest of us would expect to be part and parcel of family life.

“This morning, after five hours of broken sleep, I washed and dressed Richard. He had two seizures in the night, so his co-ordination was all over the place. I needed more time than usual to feed him. Then I took him for his physiotherapy assessment. The whole of my life is centred around Richard. I have had no social life, no life of my own.” (Jacky, parent-carer)

Families carrying out these massive caring roles need to take a break to re-charge their batteries and take some time out for themselves. Research has shown that carers experience increased stress, ill health and depression compared to other members of the population.

“My own health has deteriorated. I have suffered with depression for over two and a half years. I don’t feel I can ever get off tablets. I have anxiety attacks that feel like I am having a real heart attack. I am only 26!” (Tina, parent-carer)

Giving families a short break is a crucial way of helping them to go on caring.

Pam's story

“The day I was diagnosed with cancer was breaking point for me. Not because I realised I was going to die, but because I was told that my three children could be split up and put into care. I was choked with fear for them. I came back from the hospital that day, sat down on my own and seriously thought about suicide for me and my children. It kept going round in my mind, how I would do it and when. Eventually I thought no, it's not right. What's happened to us isn't right and I'm going to fight. At that time I had been battling for seven years to get a break. I didn't think things could get any worse.

I adopted Katy, Tom and Adam when they were small. I was married at the time, but have been on my own for the past eight and a half years. All three of the children are severely disabled. I never expected loads of help but I was told that I would get regular breaks. I love them all enormously and would not have them any other way, but each of them needs one-to-one help which is totally exhausting. Adam is doubly incontinent and has no concept of danger. Katy is incontinent as well sometimes, and she has severe heart problems. All three of them need help with washing and dressing every day, and need to be watched all the time. The regular breaks have never arrived. Social Services have told me, 'the trouble is Pam, your family would just cost us too much'.

The school holidays are when I really need some help. Going shopping is so hard as I have to take all three of them with me. If I just had someone with us that would make a world of difference. There are 13 weeks of school holidays every year and every week of these is a struggle for us. Just someone to take them swimming in the holidays would be fantastic as I don't drive. Surely such a small thing isn't too much to ask?

I was told when I was first diagnosed with cancer that when I became unwell Social Services would be there to look after the children. But just recently, because the treatment I am having has weakened my immune system, I got a chest infection and was out of action for three weeks. I have never needed some help as badly as I did then, but the short breaks service refused to have the children during that time. This has left me more desperately worried than ever about what will happen to the children when I become too ill to look after them. Social Services have been unable to help me plan for this time and I have utterly lost faith in them. I am now in the process of moving house to find an area that does want to help me work things out for the children's future.

It is now nine years since I first asked for a break. All I want is a weekend every two months so that I can visit my fourth son who is at boarding school. I am dying and have not been able to talk to him about it. He gets forgotten about in the midst of all this. I wish someone would realise that leaving people to cope until they crack makes the whole family fall apart. Watching that happen to my family is unbearable. No family should have to go through this.”



What are short breaks?

There are lots of ways to give families short breaks from their caring role, from someone coming in to the family home and helping out, to the child or adult spending time away from home, perhaps with a foster family or in a residential setting.

Short breaks not only support carers, but also provide good opportunities for disabled children and adults 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.

“When we were away we felt like a different family. It was the only time Jack’s sister, who is 11, received any attention from us. Jack benefited too, he was great when we got back.” (Andrea, parent-carer)

For the most part, short breaks are about helping families of disabled children and adults to do some of the things the rest of us take for granted.

“I’m 85; I would love to have a lie in.” (May, parent-carer)

“It’s a real treat to have a shower.” (Christine, parent-carer)

Sometimes short breaks are the only thing that will stop a family reaching breaking point.

Why are families not getting the help they need?

Local authorities do not see families of disabled children and adults as a priority. They take the view that families are coping and do the very minimum to support them. Despite the fact that there is now a legal requirement to assess and review the needs of carers, this had not been the case for most families taking part in the Breaking Point Survey.

Breaking Point Survey

6 out of 10 families have never had a Carer's Assessment

5 out of 10 have not had their support package reviewed within the last year

Many carers said that they were very angry about this. They feel that they are taken for granted when their role should be valued. They point out that they are saving the Government a great deal of money.

“Carers work for nothing! It is about time that this was recognised. We care for our sons and daughters because we care!” (Eddie, parent-carer)

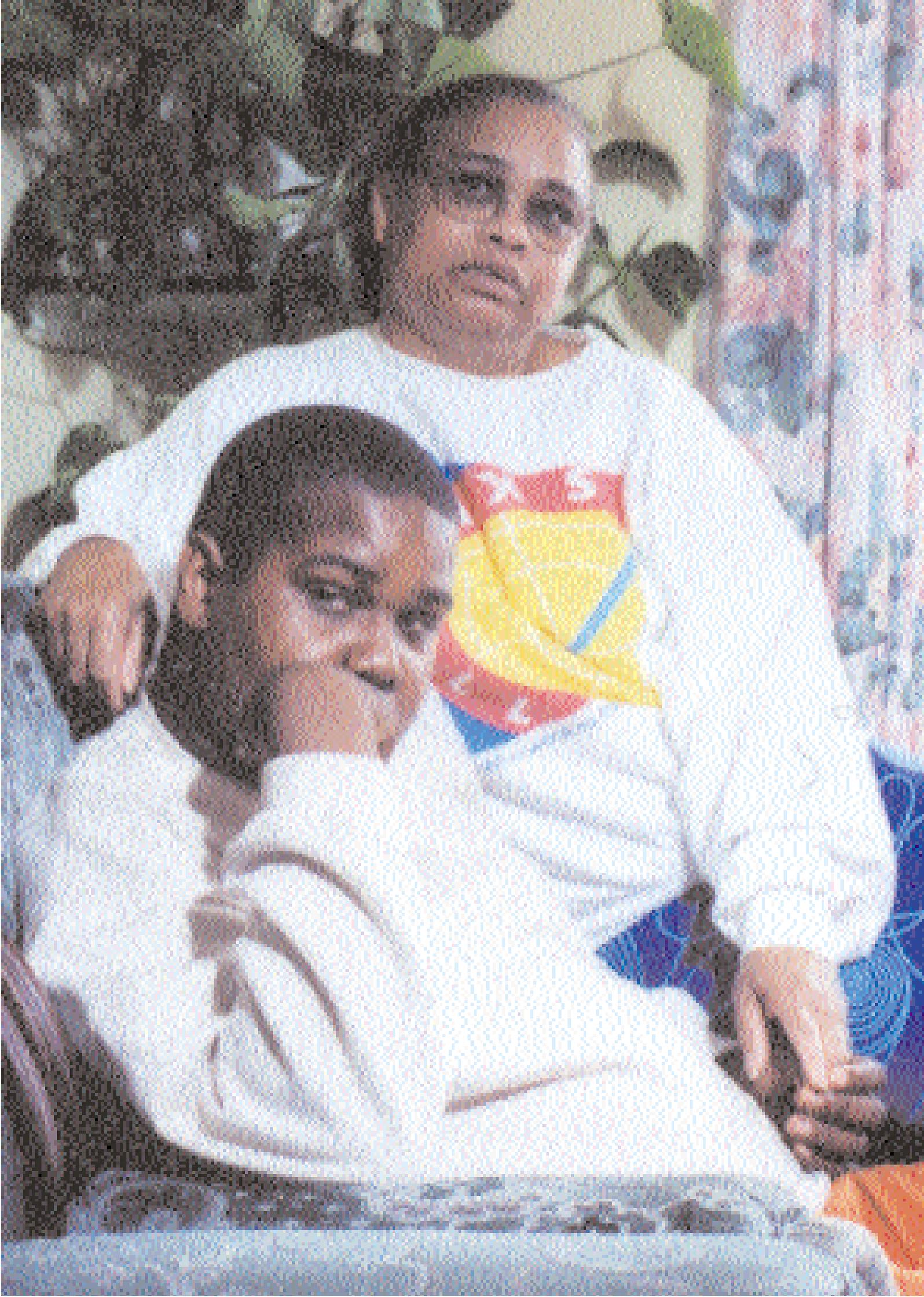
There are 210,000 children and adults with severe or profound learning disabilities living in England. Of these, 9 out of 10 children and 6 out of 10 adults live at home with their families.

Published information on the amount of short breaks that families receive is limited. According to the Government, only 1 in 5 people with a learning disability known to Social Services are getting a short break.¹ That leaves 4 out of 5 families with nothing.

“When you are an ‘up’ person, it doesn’t mean you don’t get down and don’t need support. When you are at breaking point, sometimes you are too far down to ask for help.” (Christine, parent-carer)

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1. Dept of Health (2003), *Making Change Happen: The Government's Annual Report on Learning Disability 2003*, HMSO



Emily's story

“One Sunday morning my husband turned to me and said, ‘you know caring for Duke is going to be a lifelong commitment, and I just can’t do it.’ He said it was him or Duke, our disabled grandson. The day I had to make that choice was the hardest day of my life.

I took Duke out with me and we rode around all day on the bus. I didn’t know what I was going to do. I thought about what my neighbour had said. She told me to put all Duke’s things in a bin liner and leave him on the Town Hall steps. As we rode around I tried to gather the courage to do it. But I love Duke and he needs me. Why should I have to humiliate either of us like that?

I have cared for my grandson Duke since he was a baby. He is 15 years-old now and six foot tall. He has severe learning disabilities and is autistic. He needs constant one-to-one attention. It’s impossible for me to be away from Duke for even a few minutes, because if he isn’t watched he will break everything in the room. He is kind and affectionate by nature, but he needs so much care and attention that I am totally exhausted all the time. Sometimes I sit and cry because I am not a part of the human race. I’m living without a reason. All I’ve got is Duke.

I have asked Social Services to help me, year after year. They tell me they can’t do anything. They tried to find Duke a worker so he could go to a play scheme, but they came and looked at him and said they couldn’t manage him. They say that Duke needs two workers, which they can’t give him. I fought to get him into a mainstream school, but every day they phone me and tell me to come and take him home because they can’t manage him.

That Sunday, Duke and I ended up sitting on a park bench together while I thought about what to do. I looked at the faces of all the people walking by. I thought, ‘some of these people must have a life that is worse than mine.’ In the end I took Duke home with me and told my husband I had made my choice. I couldn’t give Duke up. He needed me more. My marriage was over. And all because nobody would give me a little bit of help with Duke.

That day was my breaking point. The person I used to be died that day. I prayed to God to take me from this life. Since then the sadness of my life has blotted the sunshine away. I’m 55 now and it seems that I will never get to live my own life.”

Why are families not getting the help they need? (cont.)

The Breaking Point Survey shows that most families were not receiving short breaks at all, or were getting such a minimal level of service that it made very little difference to them. Some families also told Mencap that they were actually getting fewer short breaks than in the previous year. Some of these said that this was because their services had been cut.

“The withdrawal of the short break service has been a big blow to my husband and myself.” (Angie, parent-carer)

Breaking Point Survey

6 out of 10 families are getting no short break service at all or one that is so minimal, it does not meet their needs

3 out of 10 families received fewer short breaks than in the previous year

It is known that 9 out of 10 of family-based children’s services have a waiting list and 1 in 3 of the children on them will wait for over a year to get a service.² Those most likely to be on waiting lists are children and adults with severe or profound disabilities who have additional needs, such as complex health needs or challenging behaviour.

“With regard to home-based care there is a lack of trained staff who are able to cope with people with profound and multiple learning disabilities, particularly in view of my daughter’s health needs.” (Stephanie, parent-carer)

These are the families who need short break services most and yet they are the ones who are experiencing the most difficulty getting them.

2. Prewett B (1999), *Short-term break, long term benefit: Family-based short-term care for disabled children and adults*, Social Services Monographs: research in practice. University of Sheffield, Joint Unit for Social Services Research.

Breaking Point Survey

2 out of 3 families who are on a waiting list for short break services have been waiting for at least six months

The published information that is available does not tell us how well short breaks meet the needs of families, such as the length of each short break and how frequently families get them. It also tells us nothing about the quality of the services provided.

“From November through to January there was no respite. It all got on top of me and I thought I was going to crack.” (Helen, parent-carer)

Real breaks are ones that are flexible, reliable and trustworthy.

“She was offered two hours a week that was supposed to start yesterday, but they didn’t turn up to collect her.” (Brian, parent-carer)

Breaking Point Survey

8 out of 10 families have never been offered a choice of service

3 out of 10 do not trust the service offered to them

5 out of 10 have found services unsuitable

Stephanie's story

“When we found out, at three weeks, that Jodie was going to be severely disabled, my husband wanted me to leave her at the hospital. Jodie did come home with me, but my husband never did. I found myself left to cope with Jodie and my four year-old son on my own. I had no idea how to care for a baby like Jodie, but I was not prepared to give up on her. She has physical and learning disabilities and complex health needs, including epilepsy, heart problems and an irritable bowel. Even now that she is grown up, she needs help with everything. We will celebrate her 21st birthday this year.

There have been times when I have feared for Jodie's life because the services that were available when I needed some help could never do the job. One time I needed to go into hospital for surgery myself and there was nowhere that could take Jodie. In the end I had to leave her with a foster family who had never even met a child with special needs before, let alone a child with the complex needs Jodie has. Then there was the residential unit Jodie once went to where the staff gave her someone else's medication. Would you send your daughter back somewhere like that?

So I struggled on caring for her on my own for as long as I could. One day, having not slept properly for several weeks, I collapsed at Jodie's school, out of the sheer mental and physical exhaustion of it all. At this time, Jodie was being tube fed and having to be turned every few hours to stop fluid building up on her lungs. If it had not been for one of the school staff, who was also a foster carer, offering to look after Jodie, I would have cracked then.

But the hardest part of caring without a break is the impact it has on the rest of the family. My family reached breaking point when Jodie was 14 years-old. I hurt my back lifting her, which meant that I needed help to get Jodie to school every day. I asked Social Services to provide some transport but they said they couldn't do this. So Jodie's brother John became a carer at the age of 18. He took Jodie to and from school each day on his way to college. In the end he lost his college place because of it. John was so angry. He blamed Jodie for losing his father, said he wished she was dead and that she had ruined his life. He moved out after that and I didn't hear anything from him for two years. We are still not on proper speaking terms and I hardly ever see my granddaughter. All because no one could sort out some school transport.

I made the right choice to care for Jodie. She is my daughter and I love her. She needed to be brought up in a family home, just as much as John, just as much as any child. I have finally got a package of support that works pretty well, but only after endless arguments and countless crises. It's not right that I have had to fight so hard for every bit of help I have ever had. I could have held my family together if I could have had some regular help getting Jodie fed and washed and changed. Why did I have to cope on my own and lose everyone else who needed me?”



What is Mencap campaigning for?

Mencap wants every family who needs a short break to get one. Mencap has been campaigning for short breaks for family carers over many years. There has been some progress, such as the introduction of the Carers' Strategy. Local authorities have also been given extra money by the Government to provide more services. These are welcome initiatives, but the fact remains that most families are not getting short breaks that meet their needs.

This is despite the fact that most short breaks are relatively inexpensive to provide. It can cost as little as £50 for a child to go to a foster carer for one night or £150 a night in a residential service. This is a modest amount of money when it is compared with the cost incurred when a family reaches the point of feeling that they can no longer continue with the caring role. A local authority would have to spend anything from £50,000 to £100,000 each year to support a child or adult with severe or profound learning disabilities in residential care.

“Duke relies on me, but I can't rely on Social Services to pay for the services that Duke needs or to help me take care of him. I have paid with my marriage and with my health. All I need is a bit of help with Duke. Is that so much to ask?” (Emily, parent-carer)

There is now a legal requirement to assess the needs of carers, but there is still no legal obligation to provide short breaks. While Mencap would certainly like to see the law changed, this would take a long time. Carers in this position are desperate and action can be taken without waiting for the law to be changed.

Mencap believes local authorities should:

- Provide a short break service to every family looking after someone with severe or profound learning disabilities in the family home. This should be a real break that family carers can rely on.
- Give families a written family support plan. The plan should say what short breaks the family will get. It should also say who will make sure the family gets these breaks, and that the breaks are suitable.
- Spend more money on short breaks and track how this is spent. The Carers' Grant should be closely monitored to make sure that it creates more short breaks.

To ensure that this happens, Government must:

- Find out how many children and adults with a learning disability have received a short break service. Government should keep a check of how often this group is getting a short break, and whether the break is for long enough and meets the needs of the whole family.

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Mencap
123 Golden Lane
London EC1Y 0RT
Telephone 020 7454 0454
Fax 020 7608 3254

www.mencap.org.uk/breakingpoint
Learning Disability Helpline 0808 808 1111