

Short breaks
support is
failing
family carers:

reviewing progress **10 years** on from
Mencap's first **Breaking Point** report

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Foreword

In 2003, Mencap released a report on the insufficient amount of support people who care for family members with severe or profound learning disabilities receive. We found that 8 out of 10 family carers had reached or gone beyond their emotional, psychological and physical limits due to a distinct lack of short breaks. We called this ‘breaking point’. The report called for every family who needs a short break to get one. It also highlighted the need for more money to be spent on short breaks services, and for this spending to be tracked to ensure it improved provision.

In 2006, we launched a follow-up report, which found that 7 out of 10 families were still being pushed to breaking point. Again, this second report called for every family to be entitled to a minimum level of short breaks and for central government to increase funding available for local authorities to provide these services.

Now, 10 years on, we are revisiting the support available for family carers to see whether recent policy initiatives and investment have delivered the much-needed change.

A total of 264 family carers responded to our survey on short breaks provision and experiences of caring. We also sent Freedom of Information requests to all 152 local authorities in England that provide social care services.

This report looks at short breaks provision in a climate of cuts to central and local government budgets. It examines the extent to which these cuts have impacted on the lives of people with a learning disability and their family carers.

It also looks at the state of affairs for family carers of children and young people across the full spectrum of learning disability; from people with mild and moderate learning disabilities, to people with severe and profound disabilities.

The quotes throughout the report are the words of family carers who responded to our survey.

If you or your family are affected by the issues raised in this report, you can get information on your rights and how to secure them at www.mencap.org.uk/breakingpoint. You can also call Mencap Direct on **0808 808 1111**.

Executive summary

What is breaking point?

'Breaking point' is a term we use to explain the moment of crisis for a carer, often emotional, psychological and physical, where they feel they can't go on. This is frequently caused by the lack of short breaks services, the constant supervision and daily worries finally becoming too much. It is an unthinkable situation, which causes turmoil for all family members.

"I actually walked out of the family home and left for 10 days before I felt able to return."

What are short breaks?

The term 'short breaks' (also known as respite) is used to describe the time off that family carers and people with a learning disability receive. These breaks come in different forms. Some families access short breaks centres, others are part of schemes involving placements with families or receive direct payments to purchase their own support.

"This [short breaks] is the one thing that can help life be bearable and keep you going."

Caring is voluntary and saves the state money

It can be easy to forget that families are not obliged to care for a family member with a learning disability, as local authorities are legally required to provide social care services for those eligible. Family carers care for someone with a learning disability out of love and concern for their wellbeing, and short breaks are one vital way of making sure this care can continue.

This caring role also takes the pressure away from public funds. In 2011, Carers UK estimated that unpaid carers save the state £119 billion a year by eliminating the cost of paying for staff to provide full-time care in a residential setting.

Families are still at breaking point

Our new research shows **8 out of 10** family carers have reached, or are close to reaching, breaking point due to a lack of short breaks.

In our 2003 report, **8 out of 10** families said they were at breaking point and, in our 2006 update report, this fell slightly to **7 out of 10** families. Our new research shows that despite recent government investment of over £1.2 billion in services for people caring for children and adults, there has been no improvement in the wellbeing of family carers, a decade after the issue was first highlighted.

"[I feel] suicidal, tired, ill, exasperated."

People do not get the short breaks they need

8 out of 10 people feel they do not get enough short breaks.

The vast majority of families are not being offered the short breaks they so desperately need. Therefore both family carers and the people they care for are not getting adequate support. It is interesting that the same number of family carers who are at breaking point do not feel that they get enough short breaks.

“When you care for someone 24 hours per day and you know it’s going to be forever, sometimes a short break is your only hope.”

Most people with a learning disability are not receiving short breaks

8 out of 10 adults with a learning disability known to local authority social services did not receive any short breaks this year. Of this group, some will not be eligible for short breaks services as they will live independently or in residential care settings. However, a significant proportion of people with a learning disability live with their families, so it is very likely that many eligible individuals and families are missing out on this support.

This is not even the full picture, because only a small proportion of people with a learning disability are known to social services. Therefore many more people will be losing out because they have never had any contact with their local authority.

“We can’t keep running on empty and need a break.”

Services are not meeting family needs

Of those family carers who are accessing short breaks, most do not feel their services are adequate. A total of **7 out of 10** carers say they do not receive services that fully meet their family’s needs.

This is a higher proportion than the **6 out of 10** who said this was the case in 2006.

“The staff at the respite centre are not always fully trained to meet my son’s needs, so often he plays up because he is not being understood and then plays up because he is frustrated.”

Families are not having their needs assessed

Access to good quality and regular assessment is pivotal to individuals and family carers getting the support they need. However, many local authorities are failing to meet their duty to both assess needs and regularly review care arrangements.

6 out of 10 carers have never had a carer’s assessment to identify their needs. Worse still, **2 out of 10** people we surveyed in 2013 said they have been refused an assessment altogether. This figure is at the same level as it was in 2003, again suggesting that the problem has remained unresolved for a decade, even with the increase in investment over the last 10 years.

Half of families have not had their support package reviewed in the last year. Of these families, a third has never had their package reviewed.

“My daughter has never had or been offered a short break, nor has [she] ever been assessed by a social worker. I have never been assessed as a carer.”

Families do not know how to access short breaks

3 out of 10 family carers have never had a short break, and **half** do not know how to access short breaks.

There appears to be a fundamental failing on the part of local authorities to provide families with information on what support is on offer. This means there are likely to be many families out there who are not receiving the services they are entitled to.

“I have never heard about short breaks. I do not know of any help available and have never been given any information.”

Local authority spending is in decline

Spending figures provided by local authorities reveal that spending on children’s short break services peaked in 2010/11, probably due to government investment, but has since fallen away. **63%** of local authorities reduced their expenditure on short breaks for children in 2011/12 and **43%** projected cuts in 2012/13.

Spending on adult services has also fallen consistently over the past 3 years: **54%** of local authorities reduced their spending on short breaks for adults in 2012/13 when compared to 2009/10.

Worryingly, cuts to short breaks appear to be increasing year on year for both children and adults. **62%** of adult service cuts happened in the last two years and **53%** of children’s service cuts happened in the last year.

“[I feel] absolutely devastated... I have sobbed over the way [the council] has informed us of their decision to close this wonderful care home.”

Fewer people are accessing short breaks services

Unsurprisingly, cuts seem to have had an impact on the number of people with a learning disability accessing short breaks services. 6 out of 10 local authorities report a reduction in the percentage of children with a learning disability in their area accessing short breaks, and 6 out of 10 councils provided short breaks to fewer adults with a learning disability in 2012/13 than in 2009/10.

“I feel or have felt, certainly this year, totally let down by social care. Their lack of support is quite unbelievable and if I wasn’t the sort of person that could sort things out for myself, my family would have fallen apart a long time ago.”

Families are feeling the cuts

The experiences of family carers mirror the local authority figures.

4 out of 10 family carers have experienced cuts to their short breaks and the same number feel their short breaks services have got worse in the past 3 years.

This is an increase compared to our 2003 and 2006 surveys, which found that 3 out of 10 family carers had experienced a cut in their short breaks.

“We have been fighting the cuts for over a year ... It takes its toll on you.”

The impact on family carers is extremely damaging

The lack of access to short breaks support has a serious impact on family carers.

9 out of 10 family carers report high levels of stress.

8 out of 10 family carers claim that a lack of short breaks has had a negative impact on their family life.

Half of family carers say that their caring situation has led to them giving up work altogether or seriously considering doing so.

“I love my children and that keeps me alive but I’m worn down... When I can’t cope I self-harm as I have to carry on but it’s too much to handle at times.”

What Mencap wants to see

Feedback from families shows that the extra investment in short breaks is not helping those who are in desperate need of support, despite the enormous financial benefits of enabling family carers to keep on caring.

Mencap urges substantial and meaningful action from the government, local authorities and service providers to ensure that:

- no family carer is left to reach breaking point
- every family that needs a short break gets one
- money intended for short breaks is spent on providing them
- there is a more family-centred approach to planning and delivering short breaks provision
- services are person-centred and able to meet the differing care needs of the people who use them
- information about local need for short breaks is collected in a more consistent way, and used to inform what services are offered and to whom.

A full list of our recommendations can be found at the end of the report.

“Why are the most vulnerable always targeted when cut backs have to be made by local councils? We as carers do a fantastic job and save the council lots of money. Please let us have the respite service that we know works for our family.”

What is breaking point?

'Breaking point' is a term we use to explain the moment of crisis for a carer, often emotional, psychological and physical, where they feel they can no longer go on. This is frequently caused by the lack of short breaks services, the constant supervision and daily worries finally becoming too much. It is an unimaginable situation to find yourself in, causing turmoil for all members of the family.

Providing daily care for someone with a learning disability, making sure their every need is met while juggling everyday family responsibilities, can take its toll on anyone.

Breaking point is not the result of caring for someone with a learning disability, it is the result of constant care without a break.

"I felt as if I was in a black hole."

"Trapped by my circumstances ... fragile, abandoned by society."

"Frustrated, angry, exhausted and fearful for the future."

"Isolated, useless and worthless."

"Desperate, couldn't stop crying, useless, like a failure, overwhelmed."

These are the words of some of the people who responded to our survey. This is the experience of the majority of family carers we surveyed.

It is not easy for any carer to admit that they are at breaking point. It can be reached in front of total strangers, or, even worse, in front of their own children, on the school run, at the supermarket or at home.

This doesn't need to be the case. A short break of just a few hours a month can make all the difference.

8 out of 10 family carers say they have reached breaking point due to a lack of short breaks.



Gail's story

My story was featured in the second *Breaking Point* report in 2006.

I hope my story shows the importance of giving families the kind of short breaks they need.

The lack of sleep was the worst thing. From the age of 2 years old my son didn't sleep for more than 2 or 3 hours a night. I was exhausted, depressed and bad tempered, which was impacting on the way I parented my other kids, and my relationship with their dad. I'm told that sleep deprivation is used as a form of torture and I felt like I was being tortured every day.

My breaking point came when my son was 5 years old. My social worker rang me to say that the family who was going to look after him for 1 night a month was considering pulling out of the arrangement. The thought of having just 24 hours relief from looking after Guy had been the light at the end of a very dark tunnel and just the hope of this very short break had kept me going for over a year. The threat of not having this tipped me completely over the edge.

I can remember vividly the conversation we had... I told her that if I didn't get help now then I'd either be a single parent, in which case they'd need to come and take him away, or they should just come and take him now. I remember crying uncontrollably down the phone. "I feel like a failure," I sobbed. "You're not a failure Gail," she said, "no one could cope with what you're coping with without help."

Fortunately for me, and thanks to the understanding of my lovely social worker, within a week the crisis was averted. The family was placated and a first overnight stay arranged. After a year the family decided to end their arrangement and we were allocated a place for my son at a specialist respite centre. The breaks increased from 1 to eventually 5 nights every month until he was 16. These breaks were our lifeline.

They were not a treat but an essential way of supporting us. Overnight stays were the only way we could have a real rest and they benefited the whole family – for us these stays only worked because they were regular, flexible and of good quality. They enabled us to spend

precious time with our other children and get some guaranteed sleep a few nights a month.

Guy is an adult now and has a good life, but I still find it hard to think about those times and this period in my life remains the most difficult to revisit. I still struggle with the fact that I was at such a place in my life and such a state, emotionally, mentally and physically, that I thought the only option was to give up my much-loved little boy into the care of others. It was the most painful and difficult place I've personally ever been.

What are short breaks?

The term ‘short breaks’ is used to describe the time off that family carers and people with a learning disability receive.

These breaks come in different forms. Some families access short breaks centres, others are part of schemes involving placements with families. Some receive direct payments to buy their own support.

Breaks are an essential part of the support needed by the whole family. They provide much-needed time off for the carer to rest and focus on other activities and family members, and a chance for those they care for to spend time with others and take part in different activities.

While this report is framed in the context of a family carer’s need for short breaks, it is equally the case that this need is attached to the people they care for.

Of course, the predominant concern is to meet the needs of the person with a learning disability. But it is not clear whose needs are the trigger for short breaks provision – these of the carer or the cared-for. For example, while a decision should be led by a need to promote the wellbeing of the person being cared for, this might be achieved by providing support to the carer, to make sure they are able to continue with their caring responsibilities.

This lack of clarity over establishing when a short break is needed can lead to difficulty in identifying and providing for that need. Short breaks must be better defined in terms of the main recipient of the service to address this issue.

“Short breaks are vital, for both carers and [those being] cared for, to recharge batteries and to uphold a sort of normal bit of life!”

Recommendation

Legislation on community care and carers' services should be integrated in a single statute to clarify what – or who – triggers entitlement to short breaks. Associated guidance should be issued to make sure local authorities have a clear system of determining short breaks need.

The draft Care and Support Bill presents an excellent opportunity to do this, as it proposes to give “carers a right to support for the first time to put them on the same footing as the people for whom they care”. This should create a system in which a carer's need for short breaks services is consistently viewed as a valid trigger for provision to be made.

Until recently, short breaks were known as respite care and many local authorities and families still use this term. However, this term has been viewed by many as having negative connotations. It gave the sense that caring is an unpleasant obligation, while portraying children and adults with a learning disability as a burden on the family. Therefore we use the term ‘short breaks’ throughout this report.

We are aware that many people do not think ‘short breaks’ adequately describes just how important these services are, and conjures up an image of a free holiday or something of a luxury, which they certainly are not.

When we use the term short breaks, we are referring to the services that give family carers the emotional, physical and psychological break needed to enable them to care for their son or daughter, brother or sister, without which there would be little enjoyment of family life and many would simply be unable to cope.

Short breaks can be as little as a few hours each month, in the day or overnight. Yet often, many families do not receive the level of short breaks they so desperately need, while others have no access to these lifelines at all.

This culminates in breaking point.

“This is the one thing that can help life be bearable and keep you going.”

“When you care for someone 24 hours per day and you know it's going to be forever, sometimes a short break is your only hope.”

Pressures on carers

It can be hard for someone who hasn't experienced it to understand just how big a responsibility caring for a disabled family member can be.

More than **7 out of 10** family carers who responded to our survey provide more than 15 hours of care each day. That is 15 hours of unpaid care every single day, and this level of care is often needed throughout a person's life – it doesn't stop when they reach adulthood. While someone who looks after their family member with a learning disability does so willingly and out of love, such a responsibility can put immense strain on them.

Almost **9 out of 10** carers who took part in our survey felt stressed as a result of not getting enough short breaks. It is deeply concerning that the common experience of people we surveyed is that a lack of support has had a negative impact on their mental health.

"I have had thoughts about ending it all and on a few occasions (when I'm angry and at the end of my tether) even hurting my daughter."

9 out of 10 people also said not getting enough short breaks has affected their social life, with many telling us they feel "lonely" and "isolated". Many carers told us they suffer from a lack of sleep because of night-time caring, which adds to their stress and anxiety.

"(I) suffer from sleep deprivation, anxiety, depression... How can I carry on?"

Almost **8 out of 10** people said they have found family life harder due to a lack of short breaks, and many say their marriage or other children are affected.

"We have no life outside home, no friends, never go out – it's stifling our marriage... My other children suffer and now they see how we suffer too."

The pressures on carers extend beyond the emotional and physical. More than **half** have struggled financially as a result of not having enough short breaks. Family carers have to pay for the additional short breaks they need, over and above those provided by their council. Many carers told us they supplement the limited or non-existent short breaks they receive from

their local authority out of their own pockets to enable them to cope, which can leave families in precarious financial situations.

"[I] was worried about money and how we could cope – [it] put pressure on family relationships and my own mental health."

This is made worse by inadequate support for carers making it difficult for them to remain in paid employment. Over **half** of carers said they have had to give up work or considered doing so because of a lack of short breaks. A report from 2011 found that carers are less likely to be employed or in training or education than non-carers. 68% of male informal carers and 56% of female informal carers are in employment, compared to 82% of men and 66% of women with no caring responsibilities.¹

¹ *Informal Care in the UK: Constraints on Choice* (Report for the British Academy), Fiona Carmichael, University of Birmingham, 2011
<http://www.birmingham.ac.uk/schools/business/research/research-centres/crew/working-papers.aspx>

Being unable to work not only puts financial strain on the family, but also impacts on carers' quality of life. The government's 2010 strategy for carers acknowledges that "many carers currently feel forced to give up work because they feel they have no other options available to them". It aims to "empower carers to fulfil their work potential, to protect their own and their family's current and future financial position and to enjoy the health benefits and self-esteem that paid employment or self-employment can bring". However, this strategy doesn't appear to be fully in place.

"I have retired from the job I loved because I could no longer cope with the struggle."

Many carers expressed their frustration with having to fight for every bit of support they have received – 2 carers even said they have been made to feel like the "enemy" for needing help.

Several carers identified the transition process from children's to adults' services as especially difficult, with some saying their short breaks

stopped or were severely delayed when their child went through the process.

"The transition from children's to adults' services does not work... It feels like there is a precipice and you jump into the unknown."

"The transfer from children's services to adults' services was very poor with little forward planning, no involvement of outside agencies and very few discussions as to what was best for [my daughter's] future."

It can be easy to forget that families are not obliged to care for a family member with a learning disability, as local authorities are legally required to provide social care services for those eligible. Family carers care for someone with a learning disability out of love and concern for their wellbeing, and short breaks are one vital way of making sure this care can continue. This caring role takes the pressure away from public funds. In 2011, Carers UK estimated that unpaid carers save the state £119 billion a year by eliminating the cost of paying for staff to

provide full-time care in a residential setting. And yet, these caring arrangements are too often taken for granted.

"The lack of support and struggling financially makes life for us as a family very hard. If my son was to live in a care home it would cost about £2,000 a week, if not more, but as a carer I am paid £58 a week. This is morally wrong. Carers are saving the country enormous amounts of money and are being abused and emotionally blackmailed by the government because they know that we would not put our own ... children into care."

It is also important to note that it is not just the primary carer who experiences these stresses. Siblings also experience the impact of their family's caring responsibilities. This is not just in terms of providing direct care for their brother or sister, but also in terms of experiencing reduced attention and time with their parent(s), who may be almost solely occupied by caring for their sibling with a learning disability. In many cases they are children, and it may be hard to rationalise why their sibling commands more of their parents' time. This can lead to feelings of resentment, which impacts on their own development. Many parents raised this as a concern but felt it was out of their control. Nonetheless, this adds to their stress and anxiety.

"There is always something to fight for as nothing ever gets organised for us without a struggle."

“It is distressing also to see how much my other children suffer through the effects of their brother’s condition and through getting little attention to their needs.”

It is therefore clear that short breaks benefit the whole family, and should be seen in that context. Assessments should reflect this; a principle acknowledged by the government’s strategy for carers, which states a whole family approach to assessments is “much more likely to result in individual care packages that can be sustained effectively”.

“My daughter has to cope with a lot and she is only 8. I really feel for her sometimes, as it is really difficult to give her enough attention while [my son] is around. If he could access an activity one night a week – it would benefit both children.”

It is important to note that, for 2 out of 10 family carers, their situation has not reached breaking point and the same number believes they receive enough short breaks. Despite the unimaginable pressures on many family carers, some do receive the support they need. The fact that many of these individuals do

not report poor mental or physical health is testament to the benefits that adequate access to short breaks can have on families.

However, this is not the experience of the majority of families. The huge emotional, psychological, physical and financial pressures on family carers of people with a learning disability and their other family members were apparent in virtually all of the accounts from the 264 families who completed our survey. Carers told us loud and clear that they simply need a break, some time to themselves to recharge their batteries, give more time to others in the family, and have a rest from their caring responsibilities.

“We can’t keep running on empty and need a break.”

Recommendation

Every family looking after someone with a learning disability should be provided with the breaks they need. This means local authorities must identify and meet the needs of each family.

Recommendation

Local authorities must make sure the entire family’s needs are considered when short breaks provision is decided. It should be delivered by undertaking whole family assessments as a matter of standard practice.



Jeanette at home with her son Phillip. Jeanette has been refused a temporary increase in short breaks.



Jeanette's story

I am a full-time carer to my 27-year-old son who has Down's syndrome and a severe learning disability. Although I currently receive 28 nights' residential short breaks per year, I am worried that without a bit of extra help things could reach crisis point.

At the moment my son has 'vocal tics' which can be exhausting for both of us. On top of this I have severe anxiety and depression and sometimes I have to just walk out of the room. I have had a couple of weekends where I have spent the whole time trying to avoid him so I wouldn't lose it completely.

I asked for 2 nights' temporary increase in respite per year in order to see us through this difficult patch, but I was refused. In my carer's assessment I told the council things have felt 'critical' a few times but I've been told I cannot have any more and must only use it on an emergency basis. The manager said we get a lot of support already, especially in relation to people who are newly entering the service.

I think it's dreadful when success is measured by what you're already getting, without exploration of the issues involved. I feel so guilty because I feel I am not properly meeting my son's needs at the moment. I've had some awful times when I have felt completely devoid of energy. I have thought "this is it. I've got nothing left".

I've thought about lodging a complaint to get some temporary increase, but really I don't have the energy and I'm not sure I'd achieve anything constructive. I will use the emergency respite if I have to because I need to look after my health in order to look after my son. It would make so much more sense to have a little extra regular support until I get my strength back. I guess I'm lucky to have something but at the same time I feel totally let down.

Access to short breaks

In the context of the additional pressures of caring for someone with a learning disability, it is vital that carers are able to access those services that should be there to help them. Yet, **8 out of 10** respondents to our survey said they do not get enough short breaks and **half** have not received a short break in the last 6 months.

This clearly indicates that access to short breaks is not sufficient in order to meet the needs of family carers, who do not feel properly supported.

Lack of knowledge

Half of the carers who responded to our survey said they do not know how to access short breaks and **7 out of 10** respondents who cared for a child were unaware of their local authority's short breaks statement, in which the council is required to provide information on local short breaks provision for children.

“I have never heard about short breaks. I do not know of any help available and have never been given any information.”

“It is almost impossible to find out what services there are available.”

Recommendation

Local authorities should be required to publish local adult short breaks statements, similar to their current duty to outline their children's short breaks provision.

Both adults' and children's short breaks statements should be better publicised, through multiple platforms and in multiple formats to ensure they are widely available and accessible to everyone.

The draft Care and Support Bill outlines duties for councils to provide advice on local care and support for adults, which should help ensure that family carers are better informed about local short breaks provision.

Lack of suitable breaks

Given the diverse and individual needs of the families involved, it is particularly important that these services are flexible in their delivery and are staffed by well-trained professionals.

7 out of 10 family carers we surveyed believed that the short breaks services they receive are good quality. However, there seems to be an issue with the ability of those services to meet their particular needs, with only **3 out of 10** carers saying their services fully meet their family's needs. It is the responsibility of local authorities to commission services that meet the specific needs of families.

In line with this, there was significant concern about the suitability of services on offer.

“We were offered the most suitable services for our son, yet they proved totally inadequate. Staff did not wash or clean his teeth because they could not operate an electric toothbrush with one button you press for on/off. They were unable to safely hoist him from bed to wheelchair, disconnecting his safety straps before sending him home in transport.”

Recommendation

Local authorities should be under a requirement to ensure that short breaks provision in their area is responsive to local need by collecting relevant data to use to plan future provision. This includes services for people with more complex needs – for example, people with profound and multiple learning disabilities (PMLD) who are likely to have complex health and communication needs – and people with behaviour that challenges.

Local authorities should act on these findings by ensuring that service providers employ staff with – or train staff to have – the relevant skills to meet the needs of all people using the service; current and predicted.

From our survey, **6 out of 10** respondents believe short breaks services are inflexible. **4 out of 10** say they use or have used a short breaks service that could not meet the needs of the person they care for and, in these cases, half give a lack of adequate staff training as the reason for this.

Recommendation

Short breaks service providers should regularly review the skills of their staff to ensure they are able to provide good quality care to all people using their service, including those with more complex needs and behaviour that challenges.

In a 2009 Challenging Behaviour Foundation report into short breaks, over a quarter of the respondents to its survey said their family member had been excluded from a short break service.²

If services are not suitable or are unable to meet needs, it can have serious implications for many people with a learning disability. If one of the functions of a short break is to reduce the stress felt by a carer, an unsuitable service could easily undermine this. **3 out of 10** respondents believe services to be untrustworthy.

“I refuse to send my daughter to short breaks after making many complaints about uncaring, dishonest, non-trustworthy staff, and serious low standards of care.”

“The staff at the respite centre are not always fully trained to meet my son’s needs, so often he plays up because he is not being understood and then plays up because he is frustrated.”

² <http://www.challengingbehaviour.org.uk/learning-disability-files/Short-breaks-report.pdf>

Lack of assessment

Assessments are key to identifying the needs of both the person with a learning disability and their carer. These need to be done at regular intervals to chart changes in need and respond effectively to them. However, **6 out of 10** family carers we surveyed have never had an assessment of their needs and **2 out of 10** have been refused a carer's assessment.

Half of families have not had their support package reviewed in the last year and out of these, **3 out of 10** have never had it reviewed.

The law states that a carer's assessment must be offered to someone providing or intending to provide a substantial amount of care on a regular basis – but the word 'substantial' is not defined. However, there is guidance on how local authorities should interpret this word, including having a flexible approach to what constitutes substantial and focusing on the impact felt by the carer. Even when a carer's responsibilities are not deemed to be 'substantial', good practice will often dictate that an assessment be carried out anyway.

9 out of 10 people who responded to our survey provided more than 10 hours of care every day. Given that this amounts to many more hours than a full-time job, it would seem reasonable for almost all survey respondents to at least qualify for an assessment. Yet this has not happened in practice.

Without conducting proper assessments of individuals and carers in their local area, councils will not be aware of what the need for short breaks actually is, let alone be in a position to plan for it. For carers, the refusal of an assessment could lead to them missing out on vital services they are entitled to.

If someone's needs are unmet over a long period of time and are allowed to escalate, this is very likely to require more intensive intervention further down the line when a carer reaches breaking point and the family enters crisis.

“My daughter has never had or been offered a short break, nor has [she] ever been assessed by a social worker. I have never been assessed as a carer.”

Recommendation

Local authorities should be subject to strengthened duties and time frames to identify and assess all children and adults who may require short breaks in their area. There should also be a strengthened statutory framework for re-assessment intervals.

The single assessment process proposed in the draft special educational needs (SEN) clauses (to be included in the Children and Families Bill) could be a way in which a child or young person is subject to regular assessments of all their needs, including their care needs. This could be used to highlight any need for short breaks and to assess these needs in the context of their wider health and educational requirements.

Recommendation

The government should strengthen a local authority's obligation to conduct a carer's assessment of any carer who requests one, and any carer of a person who receives social care services.

This could be done through the upcoming Care and Support Bill, which makes provision to put carer's assessments on a statutory footing, and for local authorities to undertake assessments of any carer who appears to need care and support. In doing so, the local authority must assess whether the carer is able and willing to continue to care for the individual and have regard for their intention to work, study or volunteer. The government should produce strongly worded guidance which will ensure that the threshold for an assessment is as low as possible and that where carers request an assessment, the local authority should identify this as the appearance of need.

Recommendation

As best practice, local authorities should ensure that a carer's assessment is undertaken for all family carers of people with a learning disability.

Lack of early intervention

Carers will be unable to go on caring unless short breaks are made available to them.

Legislation defines a 'critical risk' to a carer as including "an inability to look after one's own domestic needs and other daily routines; a risk to employment or other responsibilities; a risk to significant social support systems or relationships".³ Guidance for local authorities indicates that if a critical risk is identified, the council is obliged to "make an appropriate response to address this risk". The pressures described by many of the carers who responded to our survey seem to constitute critical risks, but the appropriate response to address these risks does not appear to be happening.

Family carers told us that they are being left to reach crisis point when the chance to avert this 'critical risk' has been missed. In fact, half of our respondents said that, as a result of not getting enough breaks, they felt stressed, found it hard to have a social life, had to give up work or considered doing so, and found family life harder. This shows that local authorities are not intervening early enough and families are often left to reach breaking point before they receive the services they need.

"Family circumstances [are] not always taken into consideration. Eligibility and a higher level of service is often offered with the onset of a crisis. Those who shout loudest or are at breaking point get support."

"I have often felt that I can't take any more. I've told both social and health services about this and have received emergency respite. However, I have not received regular planned respite as I feel I need."

Not only is this failing families who need support to avoid reaching breaking point, it also costs local authorities more in the long-term. More intensive – and expensive – services are required if a family reaches crisis, and a lack of timely support could result in the individual being cared for going into full-time residential care, paid for by the local authority. As well as causing huge distress for people with a learning disability and their family, this will cost the local authority far more than taking steps to ensure disabled people can be well supported at home with their family.

Recommendation

Local authorities should adopt a preventative approach to short breaks provision and must listen to families and deliver the breaks they say they need.

³ Carers and Disabled Children Act 2000

Lack of choice

7 out of 10 respondents say they have not been given a choice in the type of short breaks they receive. This leaves carers facing the dilemma of choosing between breaks that are unsuitable or no breaks at all.

“It has been a challenge to get even an idea of the choices we might have.”

Short breaks can often involve lengthy waiting times. Of those respondents on a short breaks waiting list, **6 out of 10** have been on it for more than 6 months. Carers can often feel that they are unable to refuse or complain about a service that is offered to them as there is little alternative available and a complaint could result in a delay in receiving a short break allocation.

“The respite we get is great, but there is no flexibility about dates and duration. I am scared to complain in case they cut it or find out I’m complaining.”

Choice can also be limited by location, particularly for those individuals living in rural or isolated communities. For some parents it is not worthwhile to travel to the nearest short breaks service, as the travel time and cost create barriers for both the carer and the person with a learning disability.

Short breaks are all too often inaccessible for those who most need them.

“It was just too far away as we live in a rural county... when money is limited and you have an anxious child, an hour in the car isn’t workable.”

This is in opposition to a person-centred approach to service provision and, indeed, the government’s own carers’ strategy, which states that: “personalisation means that all services and support available to carers should be tailored to their specific needs... universally available services should be flexible in their approaches in order to respond to the variety of ways in which those with caring responsibilities can best be supported”.

Recommendation

Local authorities should be under a duty to consult with carers and people with a learning disability on the type of short breaks they want, and provide evidence of how their views have been taken into account when making decisions about the services on offer.

An improved system could take the form of the Short Breaks Fund model being trialled in Scotland, which encourages a more personalised approach to short breaks design and reshaping, which is led by family carers and disabled people.⁴

⁴ <http://www.sharedcarescotland.org.uk/short-breaks-fund.html>

Lack of progress

When looking back at our previous reports, it is clear there has been no real progress in the last 10 years. In fact, things have got worse in many ways.

Since our second report in 2006, there has been an increase in families with no carers' assessment, from **5 out of 10** to **6 out of 10**.

There has also been an increase in short breaks services that carers say do not fully meet individual needs, from **6 out of 10** in 2006 to **7 out of 10** now.

The lack of progress reported by family carers is despite greater awareness of the need for short breaks services, and investment from successive governments intended to expand the support available. The 1999 government strategy for carers identified 5 key outcomes for carers: being informed, having a break, accessing emotional support, maintaining their own health and having a voice. It is hard to find evidence that we are any closer to achieving these outcomes now than we were 10 years ago.

4 out of 10
family carers who
responded to our
survey said that
their services have
got worse, and only
1 in 10 say they
have improved.

New approaches are therefore needed to ensure that families do not experience another 10 years without the support they need.



Ann's story*

Shared Lives schemes recruit, assess and support family carers and are usually managed by local authorities or voluntary sector providers. There is evidence that, despite high demand for short breaks services from family carers, schemes such as these are not properly used and that those that are used are only eligible to people with the highest levels of need. This means that alternatives are not being adequately explored by local authorities when allocating short breaks provision.

“I work for a Shared Lives scheme but it doesn't feel like it gets used by families – it tends to be other Shared Lives carers using it for their break.

The Shared Lives scheme is managed by the local authority and is intended to provide family-based support for people with a learning disability. This support can be in the form of longer-term care or it can just be a night or 2 to

give a family a break. I know from other carers that there is high demand for short breaks services but I worry that schemes such as this are not properly used.

I was hoping for 6 or 7 nights a month – that's what I signed up for – but I'm getting much less. I am wondering where all those parents are going. It seems odd that the local authority is not using such cheap care when residential homes cost so much more.

At the moment, local authorities are only looking at people with substantial and critical needs for short breaks – they're not doing anything preventative.”

*name has been changed

Government strategy and investment

Since 2006, there has been significant debate among decision makers about the lack of short breaks for family carers. Parliamentary hearings in 2006 identified that “the lack of short breaks was the biggest single cause of unhappiness with service provision”, showing the clear need for an increase in these services.

In 2007, as part of the Comprehensive Spending Review, the government announced the Aiming High for Disabled Children programme, which committed £430 million to local authority services for disabled children from 2008–11. Of this, £280 million was allocated to local authorities in England, to significantly increase the range and number of short breaks they provide to disabled children and their families.

Since May 2010, short breaks services for children have been allocated £800 million (spread across 4 years: 2011/12–2014/15) as part of the Early Intervention Grant. This is an increase of £22 million per year – the highest

ever level of investment in short breaks for children in England. However, this money is not ring-fenced. This was accompanied by £40 million of capital investment in 2011/12 to help improve the way short breaks are provided.

Adult short breaks services have also received significant investment. In 2010, the government announced that £400 million would be given to primary care trusts (PCTs) over the next 4 years for the provision of breaks for carers. This was part of the refresh of the national strategy for carers and to fulfil the pledge in the government’s manifesto on improving access to respite care.

This strategy outlined the government’s intentions over a 4-year period to ensure the best possible outcomes for family carers and those they support. They said they would provide “personalised support both for carers and those they support, enabling them to have a family and community life” and “support [for] carers to remain mentally and physically well”.⁵

The strategy as a whole is relatively encouraging. It includes statements such as “Caring can be very rewarding and fulfilling, but it can also be emotionally and physically

draining without recognition and practical and emotional support”. Other statements include “supporting carers to remain physically and mentally well is therefore a key part of the prevention and public health agenda... this is particularly important for older carers and carers of children with complex, long-term disabilities”.

However, more than half way through the 4-year strategy, there is little evidence that this thinking has improved the support available to carers, particularly in light of the fact that **9 out of 10** family carers say they feel stressed due to a lack of short breaks. Also, this strategy does not focus enough on people who care for those with a learning disability. Indeed, the term ‘learning disability’ is only mentioned explicitly twice. This is in spite of the fact that a survey conducted by the Association of Directors of Adult Social Services (ADASS) in spring 2012 found that the largest demographic pressure on councils’ adult social care services is increased numbers of people with a learning disability. Therefore, there will be more and more families in need of support, and many of these will have high levels of need.

⁵ <http://www.dh.gov.uk/health/2011/07/carers-strategy/>

The £400 million additional investment was allocated to PCTs because the NHS has partial responsibility for providing short breaks services for carers. However, local authorities usually have the lead responsibility, which begs the question of why additional government funding wasn't, at least in part, directed towards local authorities.

For carers of people with a learning disability this is potentially even more of an oversight, because the criteria for receiving short breaks services from the NHS do not seem particularly relevant to people with a learning disability. The focus is more on those who require specialist medical supervision or who could benefit from rehabilitation. Although this could apply to some people, for example those with profound and multiple learning disabilities, those with less severe learning disabilities are unlikely to qualify.

It is therefore likely that carers of adults with a learning disability are not benefiting from this extra investment because they may not meet the criteria for health services. This suggests that carers of people with a learning disability are not at the forefront of the government's strategy.

Recommendation

The government should revisit its carers' strategy to ensure it works for carers of children and adults with a learning disability, particularly with regard to the focus on health rather than social care services.

Cuts

Increased government investment has happened in the climate of major austerity measures, which have seen local authority allocations in particular significantly reduced. Funding for adult short breaks is drawn from the block allocation received by local authorities as part of the Local Government Settlement. In 2010, it was announced that the local authority grant would be cut by 25.6% or £6.68 billion by 2015.

Similarly, the Early Intervention Grant is currently subject to a proposal to remove a top slice of £150 million in each of the next two financial years, to be retained by the Department for Education. There could also be a reduction of 27% in non-ring-fenced funding which will move to the Dedicated Schools Grant budget to be used to expand provision for disadvantaged 2-year-olds.

The NHS is also being called on to make £20 billion of efficiency savings by 2015.

Families' experiences

More than **4 out of 10** of the families we surveyed have experienced cuts to their short breaks services in the past three years. This is a considerable increase from our 2006 findings, when 1 in 3 of the family carers who took part in the survey had experienced cuts.

Of those who have experienced cuts, the most common type of cut described was getting fewer short breaks. This was followed by: paying more for short breaks; having a short breaks service closed; travelling further to access services; and losing eligibility for services altogether.

Similarly, **4 out of 10** respondents feel their short breaks services have got worse in the past 3 years. These cuts add further stress to the lives of already overworked carers, and push them closer to breaking point.

“We have been fighting the cuts for over a year... we are exhausted with it. No breaks, studying, caring, fighting the council, managing the home. It takes its toll on you.”

Carers told us how it felt to lose services they valued and relied on to keep caring for their loved one.

“... absolutely devastated... I have sobbed over the way [the council] has informed us of their decision to close this wonderful care home.”

As well as describing the type of cuts they had experienced, and what this meant for their families, carers identified 2 particularly problematic issues: transition and personalisation. The former has been briefly discussed previously in the report but is also relevant in the context of cuts, as many parents said their children had their short breaks services cut in the transition from children's to adults' services. This can be especially challenging as both parent and child gets older and caring becomes more difficult.

“At present breaking point is close, breaks are cut as she is an adult. But we need more breaks and continuity as she is moved to adult services. She gets physically bigger, more demanding and we get old and unable to cope emotionally and physically.”

Recommendation

Local authorities must integrate children’s and adults’ services to ensure families do not see a reduction in short breaks simply because an individual is going through transition. Adult short breaks services should follow on from children’s as smoothly as possible in terms of frequency, duration and being located nearby. Short breaks services should be arranged to accommodate the needs of the family rather than the local authority’s system of service delivery.

The transition elements of the draft Care and Support Bill could provide the lever to ensure that a child’s short breaks needs when they reach adulthood are arranged and planned for in advance. This would ensure continuity over the transition period as the services a child receives would be factored in to the planning for their provision under adult services.

Mencap fully supports the move towards more person-centred services with greater choice and control for people with a learning disability and their families. However, many family carers we surveyed feel the transfer from traditional commissioned services to a personal budget has not improved their short breaks services, and has in fact resulted in a cut in the support they receive.

“My son has recently been assessed for a personal budget. The social worker has controlled how the money will be used and spent. The personal budget is much less than the services that we had before. In other words a personal budget has been an excuse and used to make a cut to services. There is no provision on the new support plan for respite or short break services. We thought ‘personalisation’ was about choice and control. It definitely is not!”

Several carers also told us they receive direct payments but are not sure how much of this, if any, is meant to be spent on short breaks.

“Another issue for us is the direct payments the girls receive – vastly different amounts for very similar needs. I think this should be looked at again, as it does not pay for sufficient care e.g. we have had no respite care for over a year now as we cannot afford it after paying for day services from a support worker.”

Recommendation

When transferring an individual from commissioned services to a personal budget, the local authority must ensure the budget is enough to buy services that meet the assessed needs, including short breaks services. An adequate range of suitable services must also be available to choose from, and support must be given to enable families to buy suitable services.



Sarah's story*

I care for my son who has a severe learning disability, autism and behaviour that challenges.

It took my son having 2 mental health breakdowns before we got the time out we needed as a family. The first breakdown happened when he was 18. The stress of transition – moving from child to adult services – was just too much. Everything was different and he couldn't cope.

Our local authority uses a resource allocation system to decide on the amount of respite people can have. They offered us a place at a local authority preferred provider, but it was not suitable and did not meet my son's needs. I have learnt the hard way that parents and care plans are often ignored in order to get the best value and it is only when a crisis happens, or when someone ends up in hospital, that action is taken. The local authority accepted my choice of short break provider but it meant I could only have 17 nights a year, as opposed to 42, because it was more expensive.

The following year I didn't really sleep. My son was keeping me up at night and I was working

during the day. I was ready to snap and then my son had another major crisis following a placement breakdown. This is what finally persuaded the local authority to pay out the money to get us the 42 nights we needed.

We are thrilled with the support we are now getting but still feel anxious about the future and fearful of cuts. We couldn't cope without the breaks.

I do want my son to be able to move out eventually but I don't want it to be because of a crisis and needless penny pinching.

*name has been changed

Local authority figures

The information we obtained from local authorities reinforces the findings from our survey; that short breaks provision has reduced in the last few years. The following information is divided into ‘adults’ and ‘children’ as services for the two groups are provided by different departments within local authorities.

Adults

Over **half** (55%) of the local authorities that responded in full to our Freedom of Information (FOI) requests have cut short breaks expenditure for adults with a learning disability this year (2012/13) compared to 2009/10. Many of these cuts were significant; some councils have cut this funding by as much as 80% and the average spending cut was 17%.

This reduction in spending correlates with a reduction in the number of adults with a learning disability who receive short breaks services from local authorities. More than **half** (55%) of councils that gave full data provided short breaks to fewer adults with a learning disability this year than in 2009/10. Again, this reduction is considerable. Some councils now provide short breaks to 84% fewer people. The average reduction is 20%, or 50 individuals and families.

84% of adults with a learning disability who were known to local authority social services did not receive any short breaks whatsoever this year.

Shockingly, the information provided to us by councils revealed that **84%** of adults with a learning disability who were known to local authority social services did not receive any short breaks at all in 2012/13. Although many people live independently or in residential care settings and would not be eligible for short breaks, we know that well over a third of people with a learning disability live with family and friends⁶. So a significant proportion of those not getting any short breaks will live with family carers.

It is possible that this huge gap in provision is partly due to an assumption by local authorities that some families will receive short breaks services from the NHS. However, as previously discussed, many people with a learning disability are unlikely to meet the criteria of health services, and so could be falling through the gap between the NHS and local authorities.

Recommendation

To ensure adults with a learning disability and their families do not miss out on additional investment from the government and ultimately on the support they need, government funding must also be given to local authorities for the provision of short breaks via social care services.

There are other indications of reduced provision. More than a **quarter** (27%) of councils have closed short breaks services or reduced capacity within services since 2009/10.

⁶The housing needs of adults with learning disabilities in England and Wales, Cordis Bright, 2011

While local authorities are forced to make very difficult decisions about how to allocate their depleted resources, the significant cuts that have been made to short breaks for adults with a learning disability suggest that councils do not fully appreciate how vital these services are to families. These cuts also indicate short-term thinking on the part of councils, as we know that if carers are not given the necessary support to keep on caring, this is likely to lead to a crisis, and their family member going into residential care. This can cause huge upheaval within the family and will cost the local authority considerably more than supporting the individual to remain in the family home.

Recommendation

Local authorities must protect short breaks services for people with a learning disability from further cuts. Additional funding from the government for short breaks for carers should be used as intended.

Children

In light of the unprecedented levels of investment in children's short breaks services, more than 84% of local authorities that responded in full to our FOI requests showed a rise in expenditure in this area from 2009/10

to 2010/11. However, this extra funding seems to have been almost immediately curtailed. **63%** of responding local authorities reduced their expenditure on short breaks in 2011/12 and **43%** projected reductions in spending in 2012/13.

While there was initial additional funding available following the 2010 investment from the government, this has not continued in subsequent years. Given that we know an average of approximately £22 million of extra money has been going into the system each year, there is strong evidence that it is being diverted away from its intended purpose, possibly to fill other funding gaps in local authority budgets, which are facing sustained pressure.

Recommendation

To make sure short breaks money is spent on its intended purpose, the government should ring-fence these funds so they are distinct from other funding streams within local authority allocations.

When compared to the experiences of family carers, it is clear that the increase in expenditure on short breaks services in 2010/11 has not led to an increase in the quality of

service received by families. Only **1 in 10** respondents to our survey said that their short breaks services have improved in the past 3 years. Despite this extra investment, there is no evident improvement in short breaks provision for families, suggesting that while money may have been spent, it is not being spent in the correct way.

Recommendation

The government should ensure that an investigation takes place – for example by the National Audit Office – into the way local authorities and health services have been spending the different funding streams intended for short breaks, and make the findings public. This would establish whether investment in short breaks is being spent effectively and in a way that is driving up standards and family experiences. It would also help to identify failings and inefficiencies so subsequent funding achieves the desired improvements in short breaks provision.

Better monitoring of short breaks expenditure is required in the future. This should involve a national approach to data collection to ensure consistent and comprehensive expenditure information across all areas, so communities can compare how their council is performing.

Despite the additional funding, **29%** of responding local authorities have cut short breaks services for children with a learning disability over the past 3 years. And in 2010/11, when investment was at its highest, **15%** of councils still took the decision to cut services.

Recommendation

Local authorities should be under a duty to report on short breaks progress measures so they can be held responsible by local people for delivering against them. These measures should include factors such as number and variety of short breaks services, suitability of alternative provision offered if services are to close, and public satisfaction with short breaks in their area. Central government would also be able to look at this data to see if money is being well spent.

Budget reductions have had a major impact on the number of children with a learning disability who are able to receive short breaks. While alternative provision has been, or is in the process of being, made for those affected by cuts in the large majority of cases, our data suggests that **60%** of local authorities provided short breaks to a smaller proportion of children with a learning disability from 2010/11 to 2011/12.

The government had taken action to address concerns raised about short breaks for disabled children. Extra resources provided through the Aiming High for Disabled Children, along with new Breaks for Carers of Disabled Children Guidance in 2011, showed the problems with delivery were being taken seriously. It is all the more concerning that the experiences of family carers have not improved in line with this extra investment.

A report by Every Disabled Child Matters (EDCM) on parental experiences of short breaks, published in November 2011, indicated that parental experiences were beginning to improve on the back of Aiming High for Disabled Children funding and the first injection of money from the coalition's short breaks commitment ⁷

However, 14 months later – and following 2 financial years of cuts to local authority budgets – the mood is far less optimistic. 2010/11 marked a high point in short breaks expenditure and coincided with a perception among parent carers that short breaks had begun to improve. Following this, with the steady reduction in spending on short breaks across many councils, carers have experienced a decline in support. It is therefore clear that, for family carers to get the support they need, spending on short breaks must, at the very least, return to the levels seen in 2010/11.

Alternative provision

Many councils that have closed services said the families using them were transferred to other existing services. However, we know that it is rarely so straightforward for the families affected. A change of service can create great upheaval for families. Someone with a learning disability may struggle with a change in circumstance and families may lose established support networks as a result. Changes involve making a number of new arrangements which can be time consuming and stressful. Some councils did not even give the assurance of transfer to an existing service, but merely said the council was “yet to find an alternative” or people using the services “are in the process of considering alternative provision”.

It is unlawful for a local authority to close a service without putting an alternative in place, as this means the needs of the people who use the service are not being met. Our research found that several councils had closed services without arranging alternative provision. Of those councils that had put an alternative service in place, several told us that only some of the people who had used the original service were accessing the alternative, meaning the council was not fulfilling its responsibility to provide short breaks services to all families who need them.

⁷ http://www.edcm.org.uk/media/200/raised_expectations.pdf

This issue was also raised by survey respondents who referenced the length of time they had to wait to secure a new service once the old provision had been stopped.

“We were led to believe it would be for a few weeks. It has now been 8 months. An alternative has now been found but costs more, and for less time.”

This makes reference to the fact that, following a closure, alternative services that are provided are often not equivalent to those they are replacing. While a service change that means a family has to travel a bit further, pay a bit more or go less often may not seem significant, this can have a very real impact on family wellbeing.

Family carers raised other concerns about the lack of suitable alternative provision once services are closed. We are aware of many situations in which people with a learning disability have been unsuitably placed in local authority services, often without regard for individual needs, with greater distances to travel and certainly not in accordance with the wishes of the family or the individual concerned. Our survey found that **2 out of 10** respondents say they now have to travel further to access short breaks as a result of closures.

“The only alternative to be offered [was] an overnight respite service away from home, which is not suitable as he is far too young and it excludes him from family life, which is the opposite of what we want.”

In the absence of any suitable alternative, cuts can result in families having to choose between unsuitable services and no services at all.

Recommendation

Local authorities should ensure that, when changes to services are made, people using the service are offered alternative provision immediately, which is suitable and equivalent to the provision it is replacing. Alternative provision should be based on what the people who use the service need and want.

Lack of consultation

As many difficult spending decisions are being made by local authorities at the moment, it is more important now than ever that the people who are affected are involved in the decision making process. However, 8 out of 10 family carers we surveyed were either not asked what they thought about changes proposed to their short breaks services or feel their views were not listened to. Several carers told us they heard about cuts to their services through other parents rather than from their council.

If local authorities are not consulting with families on cuts to short breaks, not only will these cuts come as a huge shock to all those who rely on these services, but councils will not fully appreciate the impact their decisions are having. Changes to these services affect a specific group of people – those who use the service – so it is difficult to see why local authorities would not ensure they inform and consult with those people.

“18 months ago we were suddenly faced with cuts to our services - with no warning.”

Recommendation

Local authorities should hold a public consultation about any significant changes to short breaks services before final decisions are made, and ensure that all families affected by the change(s) have been properly consulted. The views of people who use the service, and their families, must be listened to and used to inform the decisions of local authorities, so short breaks provision is inkeeping with need. Local authorities must inform people with a learning disability and their families of any changes to their short breaks as soon as the decision has been made.

The wider context of cuts

Short breaks are not the only services for people with a learning disability that are being cut by councils. Research conducted by Mencap last year found that **32%** of councils had closed day services for adults with a learning disability since 2009/10. This led to **a quarter** of people with a learning disability who we surveyed spending less than 1 hour outside of their home every day.⁸ We also know that at least 23 local authorities have tightened their eligibility criteria for all adult social care services in the last 2 years alone, and many more are considering doing so next year. Most councils now only provide social care services to adults with substantial and critical needs, which means up and down the country people with a learning disability who have moderate needs are losing all their social care services. In a recent report,⁹ Mencap, Scope and a number of other disability organisations outlined the fiscal and moral case as to why

the government should introduce a minimum level of social care eligibility across England that should be no higher than the moderate needs threshold. Without this safeguard, the number of individuals and families reaching breaking point will continue to increase.

To make the situation for individuals and families even more difficult, in 2011/12 nearly half of local authorities increased social care service charges for people with a learning disability, and a further third expected to increase charges in 2012/13.¹⁰

Children’s social care has suffered similar cuts in the same time period. Research by the NSPCC found that, in 2011, local authorities reduced spending on children’s social care by £1.86 billion, an average of 24% and as high as 40% in some areas. As a result, expenditure in 2011 was estimated at £478 per head, a level not seen since 2005.¹¹

⁸ *Stuck at home: the impact of day service cuts on people with a learning disability*, Mencap, 2012

⁹ *Beyond the Crisis: Making social care funding work for disabled adults in England*, Scope, National Autistic Society, Sense, Leonard Cheshire Disability and Mencap, 2013

¹⁰ *Social Care in Crisis – the Need for Reform*, The Learning Disability Coalition Annual Survey, 2012

¹¹ http://www.nspcc.org.uk/Inform/research/findings/smart_cuts_pdf_wdf85752.pdf

Alongside the increasing squeeze on social care, the government's overhaul of the benefits system is leading to many disabled people seeing a reduction in their benefits packages. The UK welfare system has seen one of the biggest shake-ups since its introduction. The 2010 budget and spending review projected savings of **£18 billion** to the benefits bill by 2014/15. The Chancellor's recent autumn statement has added to this amount, with benefits claimed by many disabled people no longer rising in line with inflation.

The latest estimates suggest disabled people will experience **£9 billion** cuts to their benefits over the lifetime of this parliament.

Family carers of adults with a learning disability will also be affected by the benefit cap, which will restrict benefit income to £500 per week for a family. The government's impact assessment shows that there are around 5,000 people in receipt of carers' allowance who will have their benefits restricted as a result.

People with a learning disability and their families describe feeling "squeezed from all sides" and the cumulative impact of these changes will lead more families to breaking point, making the job of family carers even harder.

It seems neither local nor central government may appreciate the cumulative impact of all these cuts, and how they make the lives of families caring for disabled people more difficult and stressful. If cuts to short breaks services coincide with the closure of a day service, increased charges for transport or a reduction in benefits, the cumulative impact of all these cuts on the person with a learning disability and their family carers is huge.

Recommendation

Local authorities should assess the cumulative impact of all the cuts that affect families when deciding which services to cut and which to protect. Only through viewing all the services used by families as one package of support, can the local authority avoid families reaching crisis.

"Why are the most vulnerable always targeted when cutbacks have to be made by local councils? We as carers do a fantastic job and save the council lots of money. Please let us have the respite service that we know works for our family."



Nicola with her daughter Chloe who requires 24-hour care. Nicola is fighting the closure of their short breaks service.



Nicola's story

Both my children require 24-hour care, are non-verbal and are completely dependent on me for every aspect of daily living. My daughter has Angelman syndrome – a neurogenetic disorder characterised by severe delayed development, sleep disorder, epilepsy and scoliosis. My son has cerebral palsy and epilepsy.

Both my children currently receive 34 nights' short breaks per year, my son at a local authority children's unit and my daughter at a local authority adults' unit.

We have been told that our daughter will no longer receive her current allocation of short breaks every year, now that she is in adult services. In addition, there are plans to close both of the local authority short breaks units that my children use.

They are identical purpose-built units and fully meet the needs of my children. The staff are trained to the highest standard and have years

of experience dealing with the complex needs of children and adults in our city.

If these closures go ahead I will be forced to use private sector care facilities but we haven't been able to find anything that meets the needs of our children.

The stress, lack of social life and pressure on the wider family has made me feel like a failure and close to breaking point. The stress of the proposed closure is adding to this.

Without short breaks I am consumed by disability, lose friends, lose my identity, become isolated and unable to provide the care my children need.

Future outlook

It is not just the existing cuts that are taking their toll on people with a learning disability and their families, it is the fear of more to come. Many family carers who took part in our survey expressed their fears about future cuts. It was quite clear that many felt their support arrangements were precarious, and they feared what effects further cuts would have on their families. This uncertainty and anxiety adds to the stress felt by carers, and may well push more families towards breaking point.

“I am happy with my respite; it is flexible and of a good quality. If this respite is reduced or withdrawn I would no longer be able to manage to care for my son – it is a lifeline for all of us.”

The current financial outlook suggests that these fears of further cuts are well-founded. Although the Comprehensive Spending Review in 2010 only outlined cuts to local government funding up to 2014/15, the Chancellor’s Budget in March 2012 forecast 2 more years of cuts after this. Therefore, as it stands, local authority cuts will continue up to 2016/17. As most local authorities will have already maximised efficiency savings, each further year of spending reductions means deeper cuts to services and diminishing support for people with a learning disability and their families.

The data we have obtained from local authorities seems to indicate that cuts are growing in severity. Many more closures to short breaks services for adults have happened this year and last year (62% of the total) than

in 2009/10 and 2010/11 (38% of the total). Several local authorities warned of more closures in 2013/14. Cuts to children’s short breaks services also show a similar trend. The number of closures is steadily rising with 40% happening in 2010/11 and 50% in 2011/12. As mentioned earlier, this is expected to get worse, with 43% of councils projecting reductions in spending in 2012/13.

As austerity measures continue, local authorities are faced with making increasingly difficult decisions about what they do and do not provide, plus more and more services will face cuts or closure. Short breaks will continue to decline, unless their vital importance is recognised. Even with the substantial investment short breaks services have received, without a ring-fence around this funding, it

“Without short breaks I wouldn’t be able to carry on caring for my sister. The short breaks service she accesses is great, like a home from home. If it closed down, I don’t know what would happen.”

may be used to fill gaps in other budgets. As mentioned earlier, there is evidence that local authorities are diverting funds for short breaks to other areas. As cuts to budgets continue, this transfer of resources away from short breaks services may intensify.

This will clearly impact on family carers and people with a learning disability. Our figures show that many councils are closing services and many are providing short breaks to fewer people. This is extremely concerning, but not altogether surprising given the reduction in local authority expenditure.

Data from a number of local authorities show that all short breaks contracts are scheduled to expire in the same year, subject to review. In light of a steady reduction in expenditure on short breaks and ongoing and increasing pressures on local authority budgets, there is a very real danger that multiple contract reviews could result in cuts to several services at the same time.

This has implications not only for families who could again feel the force of service cuts, but also for the alternative provision that is offered. Widespread change could mean new services that are unable to prepare in time to adequately meet all local needs, thus giving families the familiar choice of unsuitable

provision or no provision at all. Family carers could be faced with an ever-dwindling range of short breaks services, making it nearly impossible to meet diverse needs.

Recommendation

There should be a central government direction which ensures that any mass contract review of local authority short breaks services cannot result in a reduction in available short breaks places.

Of local authorities who responded to our FOI request, **55%** are estimating an increase in the number of children with a learning disability needing short breaks services in the future. Additionally, the number of adults with a learning disability is increasing, as shown by a report by ADASS last year. In December 2012, the government released data from the census that revealed that the number of people providing unpaid care for disabled, sick or elderly relatives in England and Wales had increased by 11% – from 5.2 million to 5.8 million – between 2001 and 2011. This means that, while local authorities are spending less, closing services and providing short breaks to fewer people, there are more and more families who actually need these services.

Worryingly, almost half (48%) of local authorities that provided this information cited a decrease in the number of adults with a learning disability known to social services from 2009/10 to 2012/13. A similar trend can be seen in the number of children known to social services. Yet a 2010 Learning Disabilities Observatory report on ‘People with Learning Disabilities in England’ estimated that there are 1,198,000 people with a learning disability in England,¹² 154,551 higher than was predicted in a similar report they conducted in 2004.¹³

While the number of people with a learning disability is increasing, the number of those known to local authorities is decreasing. The responses received from local authorities with regard to children’s services suggest that this could be a result of current data collection methods. **22%** of councils were unable to say how many children in their area had a learning disability, with many citing data collection forms as the reason.

“Guidance for statutory returns requires us to record only if children have a disability without detail of individual need and therefore we do not accurately record the information [on learning disability] required.”

¹² http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9244_IHAL2011-02PWLD2010.pdf

¹³ http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7008_Estimating_Current_Need_Emerson_and_Hatton_2004.pdf

Of those that do record the number of children and young people with a learning disability, many provided estimated figures and an even greater number were unable to show the number of this group who access short breaks. The latter issue was attributed to the Aiming High for Disabled Children data collection categories, which a number of councils still employ but which do not classify by the type of disability. However, it seems questionable whether the effort of collecting data by disability is ultimately worthwhile if it is not replicated across all of a council's service provision to enable accurate tracking.

This is underscored by the fact that over **half** (52%) of those local authorities that provided full information on the population of children with a learning disability were unable to provide information on the numbers of individual children accessing short breaks. Instead, if a child accessed 2 different short breaks services, councils commented that they were highly likely to be counted twice. This means that the majority of local authorities do not have accurate statistics on how many individual children are attending their short breaks services, let alone what their needs are.

Therefore, local authorities do not seem able to accurately identify whether those who require short breaks are receiving them.

It is particularly alarming to consider this fact in relation to figures that suggest a surge in the number of children accessing short breaks since 2008. These show an estimated 184% increase in all disabled children and a 200% increase in children with the highest levels of need.¹⁴ With such a huge and evident demand for children's short breaks, it is likely that many more children and their family carers are not being identified as needing a break, something which is reinforced by figures suggesting that only an estimated 21% of disabled children receive short breaks.¹⁵

The problem of under-identification is also apparent in adult social care. In 2010, the Learning Disabilities Observatory estimated that only 21% of adults with a learning disability are known to social services,¹⁶ down on the 23% predicted in 2004.¹⁷

This could indicate why many family carers feel they do not get enough short breaks or, as in half of the cases, do not even know that

they can access short breaks. While some families may receive a number of short breaks in their local area, others may go without. Local authorities appear to be ill-equipped to identify this and rectify it.

¹⁴ http://www.edcm.org.uk/media/31295/commitment_and_transparency.pdf

¹⁵ *The Social and Economic Value of Short Breaks*, Nef Consulting, commissioned by Action for Children and Every Disabled Child Matters, 2010

¹⁶ http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9244_IHAL2011-02PWLD2010.pdf

¹⁷ http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7008_Estimating_Current_Need_Emerson_and_Hatton_2004.pdf

Recommendation

Local authorities should have robust data collection methods in place to be able to chart the number of children with a learning disability in their area, and show how many are accessing short breaks services on an individual basis. This is so that those who require a short break and do not receive one can be better identified. These methods should be contained under a new national framework with consistent impairment categories to ensure consistency in data collection and allow for both cross-council and national comparisons to be made.

For adult services, this could help a local authority to fulfil its obligations under the draft Care and Support Bill to ensure it is adequately aware of current and likely future demand for services.

An increase in the number of people requiring short breaks services, accompanied by a reduction in expenditure and an increasing number of closures, could result in fewer and fewer people receiving enough short breaks. We are very concerned that local authorities are losing their already-loose grip on this situation, and more and more families will miss out on the services they so desperately need – and will be pushed to breaking point.

*“At worst I have **imagined** changing my name, getting on a plane and not telling anyone where I have gone.”*



Lee's story

I am a carer for my 24-year-old son and also for my wife. I am worried about the future of my son's short breaks provision in light of the cuts to local authority services.

My son has Angelman syndrome, which makes him lively, outgoing and seeking constant reassurance. He has little sense of danger and needs constant supervision when we are out and about. It is an honour to care for my son but it can be tiring. He has so much energy and needs almost constant attention when he is awake. He can do some things for himself but he can't really go out on his own – he needs us there to keep an eye on him.

My son has 3 days a week at a day centre and for the last 13 years, up until March 2012, we received overnight short breaks under the Shared Lives scheme – once a week plus 5 nights in September. The people who looked after my son felt like an extended family to us. This 1 night a week allowed us to just do simple things – shopping together, visiting people or just sitting down and watching a film on TV without being interrupted. We really look

forward to our Wednesday lie-in as this gives us the chance to recharge our batteries and just spend a few hours together as a couple.

This suddenly stopped. After a visit from social services it was explained that there were some issues raised about adults and children at the same address and it would take a few weeks to resolve. After 10 to 12 weeks there was still no response other than “we are looking into it”.

After things reached crisis point, a place was found that cost us £9 a week (under the old set-up short breaks were free.) This has added a financial pressure because we don't have a lot of money and, at present, my son has no direct payment to cover short breaks. Even when he does get a direct payment – with all the cuts - we are scared that we won't get the hours we need any more.

We were given a block booking for respite with no promise that it would continue. On the day it was due to run out we were finally told that it had been extended. It feels like we can't relax and are just living month to month. It's just one worry after another. As carers we have so much to worry about.

Conclusion

In the last few years there has been considerable government investment in short breaks, as well as initiatives such as Aiming High for Disabled Children and a refresh of the government's strategy for carers. This is all intended to improve the situation that our original *Breaking Point* report highlighted in 2003. However, 10 years on, and despite recent investment of over £1 billion, no real progress has been made.

- Just as many families are at breaking point.
- Just as many do not trust their short breaks services.
- Just as many have not been given any choice in the type of short breaks services they use.
- Many more have experienced cuts to their short breaks services, making a bad situation even worse.

In 2003, the *Breaking Point* report found that **8 out of 10** family carers had reached breaking point. The figure improved slightly to **7 out of 10** carers in 2006, but this report has found that in 2013 the numbers reaching crisis point have returned to the levels seen in 2003, with the same number of people also stating they do not receive enough short breaks. Families continue to be left at the point where they feel they can no longer go on.

This situation is completely unacceptable, and unsustainable. Most family carers report high levels of stress (**9 out of 10**), a negative impact on family life (**8 out of 10**), and a major impact on their working life, leading to giving up work or seriously considering it (**5 out of 10**). These intense and wide-ranging implications can make it impossible to care for someone with high levels of need.

In these circumstances, it is easy to forget that caring for someone is voluntary. Family carers do it out of love for the person they care for and in the interests of that person's wellbeing and happiness. In the absence of enough short breaks for carers, people with a learning disability are more likely to become the permanent caring responsibility of their local authority, which is usually associated with significant additional costs.

“I feel or have felt, certainly this year, totally let down by social care. Their lack of support is quite unbelievable and if I wasn't the sort of person that could sort things out for myself, my family would have fallen apart a long time ago.”

Short breaks can be as little as 1 or 2 overnight placements a month – a small intervention with a huge impact. Supporting family carers to keep on caring is not only the right thing to do, it is also fiscally responsible.

Despite this, our findings show that widespread cuts are being made across the country. These cuts show no sign of slowing, with expenditure in both children’s and adults’ services reducing, and with a steady rise in the number of short breaks services being closed.

Without urgent and meaningful action by central and local government, more and more family carers will reach breaking point, with tragic consequences for them, the people they care for and their whole family.

Investment must be more targeted, provision must be more person-centred and appropriate short breaks must be made more readily available to those who need them.

Family carers are doing an incredible job caring for their loved ones. But they are being failed by those whose responsibility it is to ensure their wellbeing. This must change, and soon.



Clare's story

I reached breaking point after we had been on a waiting list for overnight residential breaks for 2 and a half years and I heard that the centre Matthew was waiting to go to was under threat of closure. 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.

Eventually we got the overnight breaks we so needed, beginning with 2 nights a month.

Matthew is now in his third year at Mencap's Lufton College and he's really thriving. I believe that short breaks helped his transition because he had become used to being away from home. Now Matthew is away during term time and with us for the holidays. Looking back I don't know how we did it!

You have to remember that there is an effect on the whole family when you don't have breaks. I still wonder how my other son managed to do his GCSEs through the sound of his brother's singing, lovely as it is!

Things are so much better for us as a family now, but I always worry that Matthew's support could be driven by "what's in the pot". I also worry that things haven't changed as much as they should have and saddened to still see friends struggling to get the breaks they need.

Our recommendations in full

The following recommendations are made in the context of current or upcoming mechanisms for implementation. Primary among these is the draft *Care and Support Bill* and the *Children and Families Bill*.

The recommendations in this report are grouped according to the target audience and within the following categories:

- Better identifying and meeting needs
- Improving short breaks provision
- Stopping further cuts
- More effective spending
- Increasing accountability

Local authorities

Better identifying and meeting needs

Recommendation 1

Every family looking after someone with a learning disability should be provided with the breaks they need. This means local authorities must identify and meet the needs of each family.

Recommendation 2

Local authorities must make sure the entire family's needs are considered when short breaks provision is decided. It should be delivered by undertaking whole family assessments as a matter of standard practice.

Recommendation 3

Local authorities should be under a requirement to ensure that short breaks provision in their area is responsive to local need by collecting relevant data to use to plan future provision. This includes services for people with more complex needs – for example, people with profound and multiple

learning disabilities (PMLD) who are likely to have complex health and communication needs – and people with behaviour that challenges.

Local authorities should act on these findings by ensuring that service providers employ staff with – or train staff to have – the relevant skills to meet the needs of all people using the service; current and predicted.

Recommendation 4

As best practice, local authorities should ensure that a carer's assessment is undertaken for all family carers of people with a learning disability.

Recommendation 5

Local authorities should adopt a preventative approach to short breaks provision and must listen to families, and deliver the breaks they say they need.

Improving short breaks provision

Recommendation 6

Local authorities must integrate children's and adults' services to ensure families do not see a reduction in short breaks simply because an individual is going through transition. Adult short breaks services should follow on from children's as smoothly as possible in terms of frequency, duration and location. Short breaks services should be arranged to accommodate the needs of the family rather than the local authority's system of service delivery.

The transition elements of the draft Care and Support Bill could provide the lever to ensure that a child's short breaks needs when they reach adulthood are arranged and planned for in advance. This would ensure continuity over the transition period as the services a child receives would be factored in to the planning for their provision under adult services.

Recommendation 7

When transferring an individual from commissioned services to a personal budget, the local authority must ensure the budget is enough to buy services that meet the

assessed needs, including short breaks services. An adequate range of suitable services must also be available to choose from, and support must be given to enable families to buy suitable services.

Recommendation 8

Local authorities should ensure that, when changes to services are made, people using the service are offered alternative provision immediately, which is suitable and equivalent to the provision it is replacing. Alternative provision should be based on what the people who use the service need and want.

Stopping further cuts

Recommendation 9

Local authorities must protect short breaks services for people with a learning disability from further cuts. Additional funding from the government for short breaks for carers should be used as intended.

Recommendation 10

Local authorities should assess the cumulative impact of all the cuts that affect families when deciding which services to cut and which to protect. Only through viewing all the services used by families as one package of support, can the local authority avoid families reaching crisis.

Increasing accountability

Recommendation 11

Local authorities should be required to publish local adult short breaks statements, similar to their current duty to outline their children's short breaks provision.

Both adults' and children's short breaks statements should be better publicised, through multiple platforms and in multiple formats to ensure they are widely available and accessible to everyone.

The draft Care and Support Bill outlines duties for councils to provide advice on local care and support for adults, which should help ensure that family carers are better informed about local short breaks provision.

Recommendation 12

Local authorities should hold a public consultation about any significant changes to short breaks services before final decisions are made, and ensure that all families affected by the change(s) have been properly consulted. The views of people who use the service, and their families, must be listened to and used to inform the decisions of local authorities, so short breaks provision is in keeping with need. Local authorities

must inform people with a learning disability and their families of any changes to their short breaks as soon as the decision has been taken to change the service.

Government

Better identifying and meeting needs

Recommendation 13

Legislation on community care and carers' services should be integrated in a single statute to clarify what – or who – triggers entitlement to short breaks. Associated guidance should be issued to make sure local authorities have a clear system of determining short breaks need.

The draft Care and Support Bill presents an excellent opportunity to do this, as it proposes to give “carers a right to support for the first time to put them on the same footing as the people for whom they care”. This should create a system in which a carer's need for short breaks services is consistently viewed as a valid trigger for provision to be made.

Recommendation 14

The government should revisit its carers' strategy to ensure it works for carers of children and adults with a learning disability, particularly with regard to the focus on health rather than social care services.

Recommendation 15

Local authorities should be subject to strengthened duties and time frames to identify and assess all children and adults who may require short breaks in their area. There should also be a strengthened statutory framework for re-assessment intervals.

The single assessment process proposed in the draft special educational needs (SEN) clauses (to be included in the Children and Families Bill) could be a way in which a child or young person is subject to regular assessments of all their needs, including their care needs. This could be used to highlight any need for short breaks and to assess these needs in the context of their wider health and educational requirements.

Recommendation 16

The government should strengthen a local authority's obligation to conduct a carer's assessment of any carer who requests one, and any carer of a person who receives social care services.

This could be done through the upcoming Care and Support Bill, which makes provision to put carer's assessments on a statutory footing and for local authorities to undertake assessments of any carer who appears to need care and support. In doing so, the local authority must assess whether the carer is able and willing to continue to care for the individual and have regard for their intention to work, study or volunteer. The government should produce strongly worded guidance which will ensure that the threshold for an assessment is as low as possible and that where carers request an assessment, the local authority should identify this as the appearance of need.

More effective spending

Recommendation 17

The government should ensure that an investigation takes place – for example by the National Audit Office – into the way local authorities and health services have been spending the different funding streams intended for short breaks, and make the findings public. This would establish whether investment in short breaks is being spent effectively and in a way which is driving up standards and family experiences. It would also help to identify failings and inefficiencies so subsequent funding achieves the desired improvements in short breaks provision.

Better monitoring of short breaks expenditure is required in the future. This should involve a national approach to data collection to ensure consistent and comprehensive expenditure information across all areas, so communities can compare how their council is performing.

Recommendation 18

To ensure adults with a learning disability and their families do not miss out on additional investment from the government and ultimately on the support they need,

government funding must also be given to local authorities for the provision of short breaks via social care services.

Recommendation 19

To ensure short breaks money is spent on its intended purpose, the government should ring-fence these funds so they are distinct from other funding streams within local authority allocations.

Increasing accountability

Recommendation 20

Local authorities should be under a duty to consult with carers and people with a learning disability on the type of short breaks they want, and provide evidence of how their views have been taken into account when making decisions about the services on offer.

An improved system could take the form of the Short Breaks Fund model being trialled in Scotland, which encourages a more personalised approach to short breaks design and reshaping, which is led by family carers and disabled people.

Local authorities and government

Better identifying and meeting needs

Recommendation 21

Local authorities should have robust data collection methods in place to be able to chart the number of children with a learning disability in their area, and show how many are accessing short breaks services on an individual basis. This is so that those who require a short break and do not receive one can be better identified. These methods should be contained under a new national framework with consistent impairment categories to ensure consistency in data collection and allow for both cross-council and national comparisons to be made.

For adult services, this could help a local authority to fulfil its obligations under the draft Care and Support Bill to ensure it is adequately aware of current and likely future demand for services.

Improving short breaks provision

Recommendation 22

There should be a central government direction which ensures that any mass contract review of local authority short breaks services cannot result in a reduction in available short breaks places.

Increasing accountability

Recommendation 23

Local authorities should be under a duty to report on short breaks progress measures so they can be held responsible by local people for delivering against them. These measures should include factors such as number and variety of short breaks services, suitability of alternative provision offered if services are to close, and public satisfaction with short breaks in their area. Central government would also be able to look at this data to see if money is being well spent.

Service providers

Improving short breaks provision

Recommendation 24

Short breaks service providers should regularly review the skills of their staff to ensure they are able to provide good quality care to all people using their service, including those with more complex needs and behaviour that challenges.

Methodology and acknowledgments

The survey

The survey was carried out between October and December 2012. A total of 264 families took part.

Local authority data

The Freedom of Information requests were made during August and September 2012. These were 2 requests to 152 local authorities within England, one for children and one for adults, asking for information on short breaks provision, expenditure and cuts.

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