

# every disabled child matters

## Short Breaks in 2015:

An uncertain future



Every Disabled Child Matters (EDCM) is the national campaign to get rights and justice for every disabled child. It is run by four leading organisations working with disabled children and their families: Contact a Family, Council for Disabled Children, Mencap and the Special Educational Consortium.

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EDCM is a consortium campaign run by four national organisations working with disabled children and their families – Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium.

Every Disabled Child Matters is based at the Council for Disabled Children, which is hosted by National Children’s Bureau.

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## SECTION 1: INTRODUCTION

“We don’t want a break from our daughter. This is for her self-confidence and self-esteem. So, that’s why we wanted to do it and the difference it’s made is just phenomenal. She’s so much more confident...She loves it.” **Mandy, parent carer**

“He’s got a lot of additional needs. He’s non-verbal. So to just leave him with somebody you don’t know makes you very anxious. I can’t imagine how I would survive without them now. So I’ve gone from really anxious to being really confident.” **Cindy, parent carer**

Short breaks are among the most fundamental services for supporting families with disabled children. By providing breaks from caring and positive experiences for children and young people, they allow parent carers to focus on relationships with other children, or to have time to themselves or with their partner, leading to lower levels of psychological distress, higher levels of life satisfaction and better health. As a result, fewer parent carers reach ‘breaking point’ and fewer children require access to emergency provision or enter the looked after system.

Short breaks also have a direct positive impact on the disabled children and young people that benefit from them. They play an essential role in improving disabled children’s outcomes, by providing opportunities to develop skills required to live more independently, prepare for adulthood and achieve their potential. Most importantly, quality short breaks provide opportunities for disabled children and young people to have fun, opportunities which are much more readily available to their non-disabled peers, and these are highly valued by children, young people and parents alike.

The overwhelming positive impact of short breaks on outcomes for disabled children and their families, and the resulting cost saving for the state, estimated to be up to £174 million annually<sup>1</sup>, is well-established. The reasons to continue to invest in short breaks remain as strong today as ever.

Despite this, the future of short breaks is a source of increasing anxiety for many families with disabled children. Since 2010, they have felt the impact of austerity through reduced spending by local authorities on children’s services and welfare reforms introduced by the Coalition. With widespread acknowledgement that the 2015 Spending Review will result in further reductions to local authority funding, it is unsurprising that the sustainability of short breaks has become a pressing concern for parent carers. Ensuring that these essential services meet families’ needs, must be a priority for any government committed to achieving the best possible lives for disabled children.

## Recommendations

1. The Government should secure continued funding for short breaks through the Spending Review, in order to ensure local authorities can continue to meet their duties to provide short breaks set out in the Regulations for Breaks for Carers of Disabled Children 2011.

At a minimum, this requires continued investment of £800m over four years to sustain levels of provision. The announcement of further funding for short breaks will signal to local authorities that maintaining investment in this area should be a priority.

2. The Government should require all local authorities to publish data on the levels of short break provision in their area, including the number of disabled children, how many access short breaks, and the volume of different types of short breaks being accessed.

This information should be published annually by local authorities as part of a Short Breaks Sufficiency Report, to be included in the short breaks services statement, setting out how levels of available provision meet the duty to provide short breaks sufficient to meet the needs of carers in their area. This information should complement the Ofsted and CQC reports on the quality of short break provision.

3. The Government must clarify to local authorities, practitioners and parent carers the right of disabled children to a social care assessment, following the appeal of L & P v Warwickshire CC & Safeguarding Children Board in October 2015.

## Summary of findings

In December 2010, government committed £800m funding to short breaks over the next four years, to ensure that local authorities could meet their legal duties under The Regulations for Breaks for Carers of Disabled Children 2011. However, EDCM's research has found that:

- A majority (**58%**) of local authorities who responded to our freedom of information request cut spending on short breaks between 2011/12 and 2015/16. The average cut by these local authorities was **15%**.
- There was a huge variation in changes to levels of local authority spending on short breaks. The average cut for the bottom quartile of local authorities on the short break spending index was **26%** between 2011/12 and 2015/16. The average spending increase for the top quartile was also **26%**.
- Almost half of local authorities (**48%**) introduced spending cuts or increases of 10% or less since 2011/12. This shows many local authorities have worked hard to protect spending on short breaks in a challenging financial climate.

These spending cuts are having an impact on parent carers' experiences of short breaks:

- Only **9%** of respondents to EDCM's survey of parent carers agreed or strongly agreed that families with disabled children can access the short breaks they need.
- **56%** of respondents agreed or strongly agreed that it is becoming more difficult for families with disabled children to access short breaks.
- Many parent carers said they accessed fewer short breaks than in the past due to service closure (**24%**), cuts in available hours (**14%**), and changes to eligibility criteria (**11%**).
- In addition, **53%** of parent carers said they had never accessed any form of short breaks service, suggesting large numbers of eligible disabled children are not being reached by provision.

These findings call into question the ongoing sustainability of short breaks unless government secures continued funding specifically for this purpose. EDCM held focus groups with parent carers across England, which revealed that many families were struggling to access short breaks that meet their needs due to limited provision of universal and targeted services, a lack of personalisation and choice, and a failure to reach parent carers with available information. Some parent carers also faced barriers to accessing targeted or specialist services via children's social care, and many perceived social workers to be primarily concerned with safeguarding issues above helping families with needs for support. Inevitably, the impact of a lack of access to short breaks is worse outcomes for disabled children and parent carers feeling they were approaching crisis. Evidence from the Family Fund grant programme, shows that cuts to spending has resulted in rising unmet need for short breaks since 2011/12, and these issues will only increase in severity without additional funding.

A failure to sustain current levels of provision could challenge the ability of local authorities to meet their duties to provide short breaks, and may risk returning to a crisis-model

of delivery in some areas. It would also undermine the successful implementation of the Special Educational Needs and Disability (SEND) reforms, introduced by the Children and Families Act 2014. Short breaks are a fundamental element of the provision that underpins the Local Offer, which sets out the services a local authority expects to be available for the children with SEND it is responsible for. Historically, parent carer participation has been most well established in the development of short breaks and it assumes central importance in the SEND reforms, including in the section 19 principles of the Act. Local authorities are required to involve children and young people with SEND, and their parents, in preparing and reviewing the Local Offer. This participation is referred to as co-production, a process 'which ensures that children, young people and parents feel they have participated fully in the process and have a sense of co-ownership'<sup>3</sup>. For the Local Offer and the concept of co-production to be meaningful, local authorities must be able to respond to parent carer concerns around short breaks provision.

## The social and economic case for investing in short breaks

### What are short breaks<sup>2</sup>?

'Short Breaks' is a term which is used to describe a range of services which are designed to support parent carers to be better able to continue to care for their children, and to do so more effectively; and services which support disabled children to enjoy different experiences, develop new skills and help them to achieve their ambitions in life. Short Breaks services can include day-time or overnight care in the home or elsewhere, educational or leisure activities outside their homes, or services to assist parent carers in the evenings, at weekends and during the school holidays.

### Why do families with disabled children need short breaks?

- **76%** of parent carers experience stress or depression and **72%** suffer from lack of sleep<sup>4</sup>.
- **80%** of parent carers of children with learning disabilities say they have reached or are close to reaching 'breaking point'; a moment of emotional, psychological or mental crisis where they feel they can no longer cope with their caring responsibilities<sup>5</sup>.
- Disabled children make up **10%** of children in care compared to 5% in the general population<sup>6</sup>.

### What is the impact of short breaks?

- There is a direct relationship between the level and range of short breaks and 'lower levels of psychological distress, higher levels of life satisfaction and better health'<sup>7</sup>.
- Parent carers cite short breaks as the single most important factor in **helping their relationship** and avoiding marital breakdown<sup>8</sup>.
- Short breaks have a direct positive impact on the disabled children and young people that benefit from them, leading to **improved confidence and independence**<sup>9</sup>.
- Short breaks could save the State up to **£174 million annually**<sup>3</sup>, if all eligible children received them. This saving is based on:
  1. decreased cost of long-term residential care: £135 million
  2. decreased cost to health services from reduction in parents', families' and carers' stress: £18 million
  3. decreased cost to schools of educating siblings with behavioural and emotional difficulties: £21 million

*<sup>2</sup> Short breaks refers to services also commonly known as 'respite'. The literal definition of 'respite' is 'the laying down of a burden' or a 'temporary cessation of something that is tiring or painful'. These negative connotations mean that 'short breaks' is preferred by many who want to emphasise that both the parent and the child get a break that suits their individual needs.*

## SECTION 2: THE POLICY CONTEXT

### The transformation of short breaks

The transformation of short breaks over the previous decade has been one of the most significant policy successes achieved by government for families with disabled children. In October 2006, the Parliamentary Hearings into Services for Disabled Children identified a lack of access to short breaks as the single biggest cause of unhappiness with service provision among parent carers<sup>10</sup>. As a result, the Aiming High for Disabled Children (AHDC) programme invested £280 million to make provision for an additional 40,000 short breaks. This was backed by an additional £90 million local authority capital funding through the Children's Plan in 2009.

This unprecedented funding to increase the level and range of short breaks was a huge success; the final programme report states that by 2010-11 over 105,000 more disabled children were receiving short breaks, an increase of 184% from 2008<sup>11</sup>. Most significantly, the transformation programme allowed the replacement of a high-cost crisis-led model with a preventative-model, focused on short break provision that met the needs of children and families for support and community inclusion, and improved disabled children's outcomes. This transformation was backed by a new short break duty in the Children and Young Person's Act 2008, which embedded the move towards a preventative-model into law (see box below).

Under the Coalition, government commitment to short breaks continued. The Regulations for Breaks for Carers of Disabled Children 2011 expressed the new preventative-model of delivery, requiring local authorities to provide a range of short breaks sufficient to 'assist individuals who provide care for such children to continue to do so, or to do so more effectively'. This was backed by the announcement of an additional £800m in December 2010 by the Department for Education (DfE), made

available through the Early Intervention Grant (EIG) for four years, allocated in sums of £198m/ £202m/ £206m/ £210m between 2011/12 and 2014/15. This sum was based on the estimated cost of meeting the new short breaks duty, the DfE stating it was necessary to 'establish short breaks as a priority in local authorities and sustaining the availability of services for the most vulnerable in society.'<sup>12</sup>

### The Children and Families Act 2014

The transformation of short breaks had a profound influence on the Special Educational Needs and Disability (SEND) reforms introduced by the Children and Families Act 2014, which build upon best practice developed through short breaks in a number of significant respects. Under AHDC, the commissioning of new short break provision was closely intertwined with the development of parent carer forums, funded to deliver parent carer participation. The partnerships between local authorities and parent carer forums developed innovative models of delivery that were more person-centred and outcomes-focused. Some local authorities developed 'Local Offers' to help parent carers understand the increasing range of short breaks provided through universal, targeted and specialist provision, and how to access them.

The short break regulations were a step towards establishing the Local Offer approach across the country, by requiring local authorities to prepare a short break services statement, keep this statement under review, and have regard to the needs of local carers when preparing and revising the statement. The accompanying guidance makes clear that local authorities should engage parents in the design of services and ensure that those who use short breaks services have the chance to shape their development.<sup>13</sup>



The intention of the SEND reforms is expressed in the four general principles set out in Section 19, Part 3 of the Children and Families Act 2014. These translate into a system that is more outcomes-focused and person-centric, with the participation of children and young people with SEND, and their parents, at its heart. The SEND reforms expand the concept of the Local Offer to encompass all services for children with SEND a local authority expects to be available across health, education and social care. Local authorities must involve children and young people with SEND and their parents in its preparation and review. The nature of this consultation is intended to be significant and is described as ‘co-production’ in the SEND Code of Practice 2014, a process ‘which ensures that children, young people and parents feel they have participated fully in the process and have a sense of co-ownership’<sup>14</sup>. Families should benefit from more responsive services provided by a system they actively shape, where families are empowered to access the support they need, when they need it.

## **Funding for short breaks 2011/12 - 2014/15**

Despite the obvious priority given by government to short breaks, funding was increasingly under pressure from the wider financial environment. The Early Intervention Grant (EIG) brought together a range of ringfenced and non-ringfenced funding streams into a single non-ringfenced grant for children’s early intervention services. According to the Local Government Association (LGA), the total EIG represented a 32 per cent funding cut compared to all the previous grants that it replaced<sup>15</sup>. Funding for expanding early education for disadvantaged children was subsequently taken out of the EIG, amounting to £534 million in 2013/14 and £760 million in 2014/15. In addition, a ‘top-slice’ of £150m per year was retained by the DfE and later allocated back to local authorities as specific non-ringfenced grants, including the special educational needs reform grant of £70m in 2014/15.

The LGA reported that early intervention funding within the latest Settlement Funding Assessment for 2015/16 represented a further 8.9% cut, and warned that, ‘Local authorities will be less able to provide support for children and families affected by disabilities or existing/potential development delays.’<sup>16</sup>

## **EDCM research into short breaks in 2015**

Under AHDC, spending by local authorities on short breaks was ringfenced. However, the subsequent £800m investment for 2011/12-2014/15, intended to sustain levels of provision established under AHDC, was not ringfenced and a challenging financial climate has meant increasing pressure on local authority budgets. Throughout this period and up to the present, EDCM has received frequent reports of changes to short break provision from individual parent carers and Parent Carer Forums. Indeed, 48% of Parent Carer Forums said their local authority was introducing changes to short breaks provision in 2015/16.<sup>17</sup>

In response, we undertook research in 2015 to track changes to local authority spending on short breaks, and find out how this may have influenced parent carer experiences of provision and optimism about the future of these services. To find out local authorities spending on all short breaks between 2011/12-present, EDCM submitted a series of Freedom of Information requests in May 2015<sup>18</sup>. By 1st August 2015, we had received 126 responses.

To explore parent carer experiences of short breaks during this period, EDCM held focus groups with 29 parent carers in three local authority areas in summer 2015<sup>19</sup>. The local authorities were selected to achieve a spread across geographical and demographic factors. Approximately half of the parents were existing members of Parent Carer Forums and other participants were recruited through the forums’ networks. Although these focus groups cannot provide a truly representative sample of parent carers, they do provide a snapshot

into a range of parent carer experiences and views of short breaks provision across the country. EDCM also undertook a survey of parent carers to find out the prevalence of cuts to short breaks provision and parent carers' views about the future of short breaks, which was responded to by 1978 parent carers.

### **The duty to provide short breaks**

The 'Short Breaks duty' introduced by section 25 of the Children and Young Persons Act 2008, amended the Children Act 1989 (para 6) to include a new duty to 'to assist individuals who provide care for [disabled] children to continue to do so, or to do so more effectively, by giving them breaks from caring'.

The Breaks for Carers of Disabled Children Regulations 2011 requires local authorities to not only provide crisis care, but to provide short breaks that help them care more effectively for their disabled children. Short breaks should enable family carers to study or undertake leisure activities, meet the needs of other children or carry out household tasks (Regulation 3).

Regulations also require local authorities to provide a range of services 'sufficient to assist carers to continue to provide care or to do so more effectively'. This 'sufficiency duty' means local authorities must know the number of disabled children in their area and their level of need for short breaks, as well as the level of service available to meet that need, and exercise their judgement about whether provision is sufficient (Regulation 4).

Local authorities must also publish a 'Short Breaks services statement' setting out the range of services provided, any eligibility criteria and (importantly) 'how the range of services is designed to meet the needs of carers in [the] area'. The statement must now be published on the website for the 'local offer' introduced under section 30 of the Children and Families Act 2014 (Regulation 5).

The Short Breaks Duty does not create an individual right to short breaks for disabled children and their families. An individual right to short breaks is only established under the Chronically Sick and Disabled Persons Act 1970, when they are assessed as necessary to meet that child's needs.

## SECTION 3: SPENDING ON SHORT BREAKS

In May 2015, EDCM submitted a series of freedom of information requests to local authorities in order to track changes in levels of spending on short breaks between 2011/12 and 2015/16. We received responses from 126 local authorities by our deadline of 1st August 2015.

The results are set out in the graphs below:

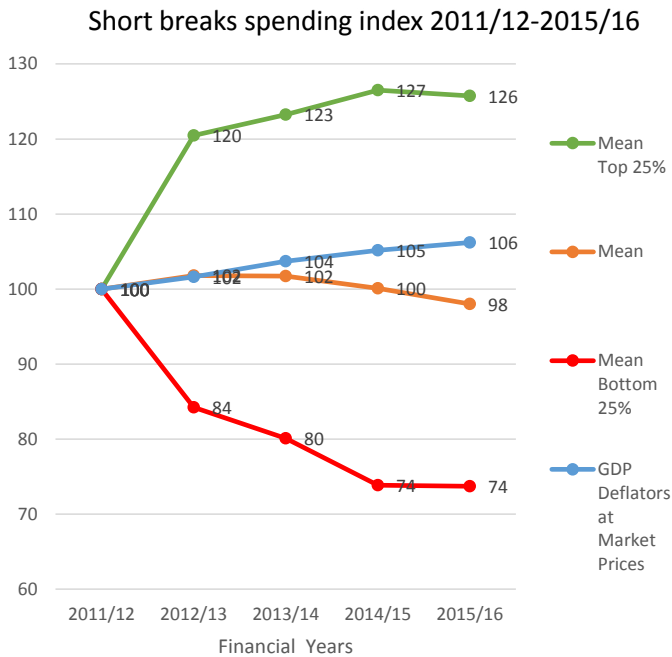


Figure 1

**Figure 1** shows spending by local authorities on short breaks provision between 2011/12 and 2015/16 (budgeted). We used 2011/12 as the base year and then compared spending with each subsequent year to create a spending index. The GDP Deflator at Market Prices measures inflation.

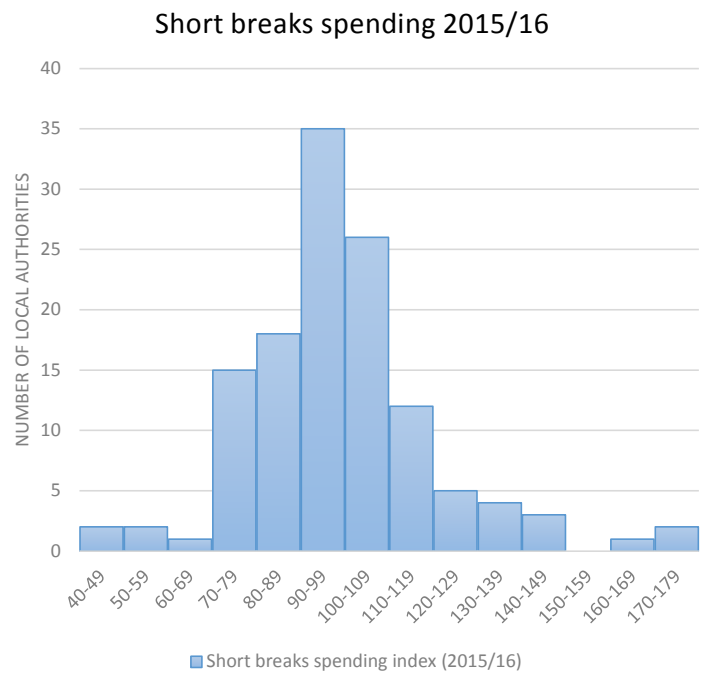


Figure 2

**Figure 2** shows the distribution of local authorities across the range of index points in 2015/16. An index point of 90 represents a 10% cut in spending between 2011/12 and 2015/16.

58%

of local authorities have cut spending on short breaks since 2011/12

30%

a third of local authorities have introduced cuts greater than 10% since 2011/12

48%

of local authorities have introduced spending cuts or increases less than 10% since 2011/12

## Findings:

- The average level of spending on short breaks in 2015/16 by local authorities who responded to our FOI, has fallen by **2%** since 2011/12.
- However, this average hides huge variations in changes to levels of spending. The average cut for the bottom quartile of local authorities on the short break spending index was **26%** between 2011/12 and 2015/16.
- A majority (**58%**) of local authorities cut spending on short breaks in absolute terms between 2011/12 and 2015/16. The average cut was **15%**<sup>20</sup>.
- When inflation is taken into account, the proportion of local authorities that cut spending on short breaks was even higher; **75%**<sup>21</sup> cut spending on short breaks between 2011/12 and 2015/16 in real terms (index less than 106 in 2015/16).
- A large proportion of local authorities have made very significant cuts to short breaks funding since 2011/12. A third (**30%**<sup>22</sup>) of local authorities introduced cuts greater than **10%**, before inflation is taken into account.
- The top quartile of local authorities increased spending on short breaks by **26%** between 2011/12 and 2015/16. This is partly explained by a low baseline in 2011/12 among local authorities that made extensive cuts to spending on short breaks at the end of AHDC.
- Almost half of local authorities (**48%**) introduced spending cuts or increases of **10%** or less since 2011/12. This shows many local authorities have worked hard to protect spending on short breaks in a challenging financial climate.

## Levels of spending on short breaks

These figures show a mixed picture of how well local authorities have managed to protect spending on short breaks in a challenging financial climate. Figure 1 and figure 2 above, show that many local authorities have worked hard to protect spending on short breaks. The average level of spending falls only 2% during this period, and the distribution of local authorities in figure 2 shows almost half (48%) have introduced comparatively small cuts or increases to spending of 10% or less since 2011/12. This demonstrates the importance of the

government announcing an allocation of funding explicitly for short breaks, which has helped local authorities prioritise spending in this area. However, it should also be noted that the impact of inflation means even many of these local authorities may be struggling to sustain levels of provision. A large minority of local authorities have introduced significant spending cuts to short breaks despite their legal duties to provide these services. It is very doubtful that the level of cuts in many areas could be implemented without significant impact on levels of provision and outcomes for disabled children and their families.

Given this context it might be difficult to explain large increases in the level of spending in other areas. However, Together for Disabled Children's final programme report in 2011, found that many local authorities were planning to introduce significant budget cuts for short breaks immediately following the end of AHDC. 35 of the 42 local authorities that responded before the publication of the report, introduced cuts to spending compared to the previous year, with 22 local authorities cutting spending by more than 40%<sup>23</sup>.

Therefore, large increases in the level of spending between 2011/12 and 2015/16 can probably be explained by cuts immediately following AHDC, followed by a recovery in spending levels in subsequent years. In addition, the impact of reduced funding from central government to local authorities has been uneven. We might assume that local authorities who have increased spending in short breaks are those that have fared comparatively better, and so have less pressure from other priorities.

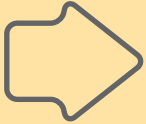
## Levels of provision

The link between spending levels and levels of provision is not direct. Local authorities may be able to cut spending whilst maintaining levels of provision through achieving cost efficiencies in existing services, or commissioning new services that meet the needs of families with disabled children at lower cost. EDCM attempted to gather evidence on changing levels of provision for different types of short breaks through freedom of information requests. However, it was impossible to gather comprehensive and comparable data for a number of reasons. Under AHDC, local authorities were required to collect data on the number of disabled children in their area, the number accessing short breaks and the amount of short breaks being accessed. Some

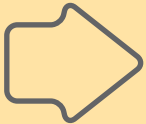
local authorities responded that they were no longer required to collect specific data on levels of short break provision and the information was not readily available. Local authorities that did provide information on levels of provision, collected different types of data that prevented comparison including the number of disabled children, the number of short breaks, and the number hours/overnights and frequently were not able to break down data by type of provision. This was often not consistent over the period we were examining, with many local authorities changing their data collection practices, ceasing to collect any data centrally or not being able to produce data across the period we requested. These limitations mean that it is impossible to say how the level of provision has changed accurately since the end of AHDC, in terms of both the number of children receiving breaks and the volume of different types of breaks being provided.

In many cases, it is likely that the lack of quality data that was readily available could raise issues about how local authorities were meeting their legal duties, in regard to judging the sufficiency of short breaks and demonstrating how this duty had been met. This is particularly significant in the context of changing short break provision. According to the Parent Carer Forum SEND Implementation Surveys, in 2015/16, 48% of respondents said that their local authority was introducing changes to short breaks in their area, and this rose to 67% when changes planned for 2016/17 were included<sup>24</sup>. Local authorities are required by the Public Sector Equality Duty to gain an understanding of how policy changes will impact groups with protected characteristics, including disabled children, and this should require local authorities to consider how changes to short breaks impact the sufficiency of that provision to meet families' needs.

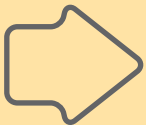
## KEY MESSAGES



**Many local authorities have worked hard to protect spending on short breaks. This demonstrates the importance of the Coalition Government announcing an allocation of funding in December 2010, specifically to ensure local authorities could meet their duties to provide short breaks.**



**A large minority of local authorities have introduced significant spending cuts to short breaks despite their legal duties to provide these services. It is very doubtful that the level of cuts in some areas could be implemented without significant impact on levels of provision and outcomes for disabled children and their families.**



**Without continued funding allocated by central government to local authorities to sustain short breaks over the next four years, spending on these services will be increasingly vulnerable to further cuts.**

## SECTION 4: PARENT CARER EXPERIENCES OF SHORT BREAKS

In summer 2015, parent carers told EDCM about their experiences of short breaks and their feelings about the future in a series of focus groups.

### Levels of provision

“Whenever I use the term universal I get shouted at and get told he’s not entitled to provision. It’s not universal because universal says it’s open to everybody... there’s a waiting list as long as your arm.” **Andrew, parent carer**

“There’s no thought about people transitioning whether that’s a parent or the child. There’s no forethought going into if it does cease in August what planning and forethought’s going in to help you through that.” **Julie, parent carer**

“As a general rule there are still parents feeling lucky to get what you get, lucky. It’s a right, it shouldn’t be like that.” **Helen, parent carer**

Insufficient levels of provision is a significant cause of parent carer dissatisfaction with short

breaks, although the extent of dissatisfaction varies considerably. Key factors that influenced whether parent carers identified levels of provision as being a serious issue, included the local authority they lived in and their child’s impairment. Many parents felt fortunate that they could access the short breaks that were available to them, but said that they were not sufficient to meet their needs. Other parents struggled to access short breaks at all. Some parents said that they had access to sufficient short breaks to meet their needs.

Many parent carers complained about waiting lists to access universal and targeted short breaks, due to limited availability. For these parents there was often a short window of opportunity to apply for short breaks, otherwise they would not be able to access anything. Most parent carers felt that the levels of provision were in decline and many had personally experienced either a reduction in the numbers of hours of provision they were offered, the closure of a service they accessed, or reduced levels of personal budgets. For some parent carers, cuts to the provision they relied on removed their only opportunity for short breaks. They felt there was limited planning in how the needs of their children and family would be met in the absence of provision that had been cut.

“She needs wherever she goes, to be accessible for her. Cognitively she’s very, very able...She doesn’t fit into most of the short breaks that were on offer. She needs to have one to one, she needs to be given an opportunity to socialise with her peers but there just isn’t anything out there aimed at children like her.” **Clare, parent carer**

In addition, some parent carers discussed gaps in the provision that was available for specific groups of children, including provision for children with complex health needs, challenging behaviour and mental health needs. These children were less likely to be able to access group-based provision or required more qualified staff to provide care and support. Unless they had access to specialist short breaks or specialist staff support to access short breaks, there was little provision available.

## Quality of provision

“My child always comes out of there, he’s confident, he’s had social interaction with people that understand him, he’s got no edge to him. He’s just happy. So is my daughter.” **Foy, parent carer**

“We had a Time Out, we had one session and my son had a meltdown and they went oh we can’t offer you that service at the moment because it’s obviously not suitable for you. It was pointless.” **Diane, parent carer**

Parent carer perceptions of quality varied widely. The majority of parent carers accessed at least some provision that they perceived as high quality and this made a huge positive impact to their family’s quality of life. Two key factors in terms of quality were the choice of provision available and the level of personalisation. Choice influenced perceptions of quality because families could select short breaks that met their needs. In the absence of choice, many parent carers felt dissatisfied with provision that was unsuitable. Choice

was lowest in rural areas, where there was less demand for provision, and for children with higher needs. In particular, children who struggled to access group provision were likely to have less choice. Some parent carers said that cuts to services had resulted in less choice and even the loss of the only suitable provision for their child.

“The workers there are on zero hour contracts so when they get an opportunity to go off to the next job there’s no commitment...the whole issue is around whether they’re skilled enough or not, experienced enough.”  
**Debbie, parent carer**

In regard to a lack of personalisation, many parent carers felt that this often resulted from insufficiently trained and poorly paid staff, often on zero hours contracts, and that this was influenced by efforts to keep cost low. Frequent complaints were that the turnover of staff was high, there was little incentive for staff to understand their children, they often lacked skill or knowledge to personalise their breaks, and as a consequence parent carers often had to struggle to shape provision that could meet their child’s needs. Where personalisation was poor, parent carers often felt that local authorities were wasting resources on ineffective provision.

Poor quality provision and a lack of choice act as barriers preventing some disabled children from accessing short breaks, both because parent carers are less likely to want to use available provision and because service providers may not have the ability to meet children’s needs. As a result, they lead to unmet needs for short breaks and worse outcomes for disabled children and their families.



“It’s worked for us because we’ve had a personal budget as a family...which has given us a lot more flexibility around what we can do as far as short breaks go.” **Kathy, parent carer**

“I have to say I have been on the Local Offer website and I would say I’m a reasonably intelligent person but I still struggle to find where I can look for the right service and also to know what I’m actually entitled to.” **Ruth, parent carer**

“In a situation where you’ve got a child that only accesses one thing because actually that’s the only one thing that meets their needs, where else is she going to then spend that personal budget? Because there isn’t any other providers out there that are meeting her needs now.” **Caroline, parent carer**

For many parent carers, a lack of information about what short breaks are available and what they are entitled to access, remains a significant barrier to accessing provision. Despite the requirement for local authorities to publish short breaks services statements, many parent carers still cited a lack of information as a key reason why they felt they struggled to access provision that met their needs. These issues were most strongly felt by parent carers who were less engaged with their parent carer forum and so knew less about the SEND system in their area. Most parent carers said that word of mouth was the most common way of finding out about services, and many complained that key professionals did not signpost them to provision.

Parent carers had mixed views about personal budgets. Some valued the extra control and flexibility they afforded them, whilst others felt it was an unwanted additional responsibility. Some parent carers complained that personal budgets were not provided at a level that allowed them to replace services they would otherwise access directly. In some areas, parent carers felt their personal budgets did not provide any advantages because there was not a sufficient choice of provision to access.

Clearly, the Local Offer is designed to overcome these challenges. However, awareness of the Local Offer was low except among parent carers engaged in their local parent carer forum. Among parent carers who had accessed their local offer, some were positive about its potential to help parent carers access provision, but the majority felt that significant progress was necessary before it might address these issues adequately. None of the parent carers we spoke to felt that the Local Offer currently met their need for information on short breaks effectively.

## Access and information

“It’s quite often word of mouth that people actually hear about what Aiming High is and if they don’t hear about it, then they can’t access it because they don’t know it’s there.” **Clare, parent carer**

“I found it quite an easy process because I suddenly decided that Emily hadn’t had a social worker ever and she was 14 and perhaps I ought to at least let them know that we existed. So, I did and a lovely lady came round and said she thought it would be a good idea for Emily to have some short breaks and she would apply at the next meeting for Emily to have some funding, which she did.” **Mandy, parent carer**

“I had to battle for five years. I had different assessments from different social workers. Up until I got the one I’ve got now, they all said, no, you don’t meet the criteria.” **Jane, parent carer**

Parent carer experiences of accessing targeted and specialist short breaks provision varied considerably. In some areas, many parent carers felt that they were discouraged or prevented from accessing targeted services. These parent carers were much more likely to complain that they struggled to access appropriate provision and that they needed repeated referrals, often from key professionals, to do so. Some thought that eligibility criteria and routes of referral were unclear or inconsistently applied. It took some parent carers years to access provision that met their needs and was appropriate for their child. Some parent carers felt that universal services were used as gateways, and that before being considered for appropriate targeted provision they were forced to first try to rely on universal services alone. These barriers could lead to high levels of dissatisfaction with short breaks provision and significant unmet need. It appears that in some areas, parent carers access to targeted services was being

limited due to insufficient levels of provision.

“I think people sometimes are being driven down the pathway of non-targeted short breaks when actually they should be looking at targeted services. There should be enough professionalism, enough know how to know to direct people to targeted rather than just to lump everybody together because it’s more cost effective. It isn’t - in the short term it causes more chaos and the family can go more into crisis.” **Kathy, parent carer**

The role of social work teams and the social care assessment process were key influences on parent carer experiences. Parent carers who had negative experiences faced common issues, including: difficulty getting social work assessments, social workers and assessments that were narrowly focused on safeguarding issues, assessment processes that were not completed, a lack of support in understanding assessments, a perceived lack of consistency in how resources were allocated. These issues contributed to a common perception among some parent carers that social care was only concerned with families who were ‘failing’ in some way, rather than in helping families of children with significant needs for support. Some parent carers felt they were being pushed towards crisis, and that the only way to access the support they needed was to say they could no longer cope.

However, these negative experiences were far from universal. Other parent carers across all local authorities, said they accessed targeted and specialist provision with a minimum of fuss and had the involvement of social workers without having to fight. In part, this reflected the fact that some children had

social care involvement due to the very high level of their needs, or because they had an early diagnosis which led directly to support. However, the variation in experiences between different areas also appeared to reflect differences in resources, culture and parent carer expectations. Some parent carers described a children's social care system that was resource poor and was struggling to maintain a focus on family support above crisis intervention. This reinforced a lack of understanding among some parent carers that social care could help them access suitable short break provision.

## The future of short breaks and SEND reform

"Two hours a week literally is all we get. With no family support for him, if he loses that he then loses those social connections and understanding of the world and then the confidence that he can go away for a couple of hours and manage without mum and dad."

**Caroline, parent carer**

"I have all this help I live in fear that it will disappear, I really do. I just wonder, okay, when is ours going? When are they going to tell me I'm not going to get it, what we need. That is how we live." **Anonymous, parent carer**

Almost all of the parent carers we spoke to expressed concern about the future sustainability of short breaks, regardless of whether they were currently satisfied with the

short breaks they accessed or not, or had already experienced cuts to provision they accessed. This concern stemmed both from personal knowledge about proposals to reduce provision in their area, and general anxiety about the impact of funding cuts to local authorities and changes to benefits for families with disabled children. Parent carers expressed particular concern about the negative impact the loss of support would have on their children's outcomes and their ability to cope.

"Parent participation will only have life in it and longevity in it, if the parents feel that it's been of value, of meaning, is going to make a difference...I've been part of parent participation for the last year and I'm thinking what's the outcome of that, where have we got? Jackie's services are being done away with and she doesn't know. Nothing there about transitioning the family...That's a targeted service and it's just going, that doesn't make sense to me." **Debbie, parent carer**

"I made this point a long time ago when someone was talking to me about the Local Offer. That anything that doesn't actually involve more professionals spending more time with my child is just shuffling the deck chairs on the Titanic, really. It doesn't make any difference whatsoever." **Ian, parent carer**

“I think there’s definitely going to be fewer services around and they will become much harder to access. I also think any idea of personalisation will just disappear, if there is any at all, it will be gone. You’ll just have to have what you’re given and if it doesn’t meet your needs then you’ve just got to sink or swim basically.” **Kathy, parent carer**

Some parent carers were involved with parent carer participation in regard to short breaks, often because of the Local Offer process introduced by the SEND reforms. These parents valued the relationships they had built with local authorities and the opportunity to shape provision in their area. Some had already been working closely with local authorities to ensure that the needs of families with disabled children were met despite cuts to spending on short breaks. However, parent carers doubted whether these relationships could be sustained if short breaks provision faced significant or further cuts, because it reduced the ability of the local authority to respond to their proposals.

The concept of ‘co-production’ relies on meaningful partnerships being developed between parent carers and local authorities. Many parent carers felt that budget cuts would be introduced irrespective of their views and participation would be limited to a box-ticking consultation exercise. The national development of parent carer participation was built under AHDC and the successful short breaks transformation programme. Whilst parent carer participation has developed beyond short breaks, its sustainability remains of central importance to families with disabled children and parent carer forums. The ability of parent carers to influence changes to

short breaks provision will undoubtedly have a wider impact on effective parent carer participation through the SEND reforms.

The future of short breaks, the implementation of the SEND reforms, and meaningful parent carer participation, are closely interlinked in other respects. The aspiration of the reforms to introduce a more outcomes-focused and person-centred system of support relies on the availability of sufficient provision, co-designed with parent carers, to meet the needs of families with disabled children. The majority of parent carers felt that cuts to short breaks would undermine families’ access to provision and reduce the focus on children’s outcomes. Parent carers were sceptical about the reforms’ potential to improve the SEND system, in an environment where the level of provision underpinning the Local Offer was facing the prospect of continued cuts.

## The national picture

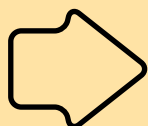
Although focus group data cannot be representative of the national picture as a whole, these findings are consistent with the results of a survey of 1978 parent carers undertaken by EDCM in summer 2015. This survey found widespread experience of cuts to short breaks, a lack of access to provision, and general anxiety about the future of short breaks provision.

[See overleaf]

## Findings:

- Many parent carers said they accessed fewer short breaks than in the past due to service closure (24%), cuts in available hours (14%), and changes to eligibility criteria (11%).
- In addition, 53% of parent carers said they had never accessed any form of short breaks service, suggesting large numbers of eligible disabled children are not being reached by provision. A lack of information was most frequently identified as a barrier to accessing short breaks.
- Only 9% of respondents to EDCM's survey of parent carers agreed or strongly agreed with the statement, 'Families with disabled children can access the short breaks they need.'
- 56% of respondents agreed or strongly agreed with the statement, 'It is becoming more difficult for families with disabled children to access short breaks'.
- 63% agreed or strongly agreed with the statement, 'I am worried that short break services will face funding cuts'<sup>25</sup>.

## KEY MESSAGES



**There is wide spread concern among parent carers about cuts to short breaks services, the negative impact on their children's outcomes and their own ability to cope with reductions in provision.**



**Quality of provision can act as a barrier to accessing short breaks for some families. Spending cuts risk undermining choice and personalisation of provision, leading to unmet needs and worse outcomes for disabled children.**



**Spending cuts have already led to reduced levels of provision in some areas. A failure to sustain current levels of funding could challenge the ability of local authorities to meet their duties to provide a range of short breaks that are sufficient to meet the needs of carers in their area.**



**The transformation of short breaks has been uneven across the country. A failure to sustain current levels of funding could risk returning short breaks to a crisis-model of delivery in some areas.**



**A failure to ensure the sustainability of short breaks provision risks the successful implementation of the SEND reforms, by undermining parent carer participation, challenging the focus on improving children's outcomes, and cutting the services underpinning the national offer.**

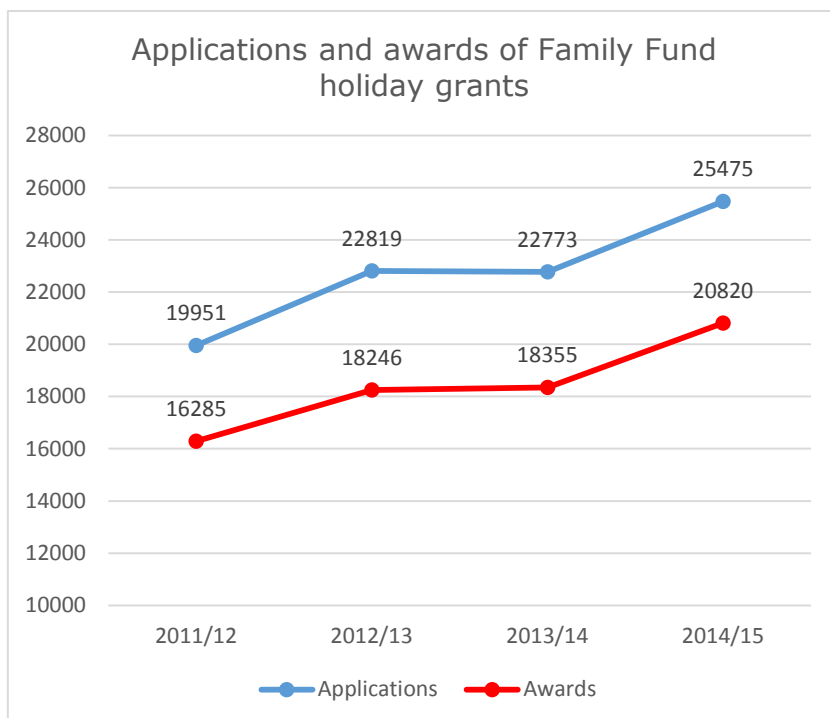
## SECTION 5: RISING UNMET NEED

“It’s not just the case that money will be transferred to social care. I think it’ll get transferred to the healthcare profession as a whole. There’ll be more carers on anti-depressants, there will be more people having breakdowns, alcohol problems, whatever. It’s just going to have a significant impact on families’ health, ultimately breaking down.” **Foy, parent carer**

“This funding hasn’t got to be cut, actually it’s got to be increased because more children are going to be diagnosed. More families are going to find out about this support and be accessing it through things like the Local Offer, and they’ll need to be pumping more money into it, not cutting it.” **John, parent carer**

The inevitable result of reduced short breaks provision is an increase in unmet need and worse outcomes for families with disabled children. Evidence of increasing unmet need is provided by data from the Family Fund grant programme<sup>26</sup>. These grants provide financial support to families with disabled children, including awards of holiday grants for short breaks. Figure 3 below shows that both applications and awards for holiday

grants have risen by 22% since 2011/12. Family Fund clients frequently use holiday grants to replace the loss of short breaks provided under the statutory framework. A survey of Family Fund clients who had been awarded a holiday grant, found that 32% had experienced a reduction in their access to short breaks provided by their local authority, whilst 41% had never accessed short breaks at all<sup>27</sup>.



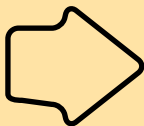
**Figure 3**

This graph shows applications for, and awards of holiday grants by the Family Fund. This demonstrates increasing unmet need for short breaks.

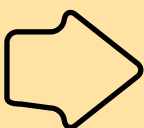
In addition, if the Local Offer is successful in engaging harder to reach parent carers and empowering them to access services, it will pose a challenge to the capacity of short breaks provision. The impact assessment for the short breaks regulations made clear that the proposed funding levels were intended to maintain levels of provision established under AHDC<sup>28</sup>. However, the impact assessment stated that AHDC reached approximately only one third of its estimated target population of eligible disabled children. It is not surprising that in EDCM's surveys of parent carers and Family Fund clients, so many families with disabled children have never accessed short breaks and do not know how to. Increasing parent carers knowledge of available provision through the Local Offer, and engaging harder to reach families, will result in unprecedented demand for short break provision. Funding must be available to ensure access to short breaks is not increasingly restricted.

Where access to universal and targeted provision is increasingly limited, it is important that local authorities meet disabled children's right to a full social care assessment as a 'child in need'<sup>29</sup>. If their needs are not being met through services provided under local authorities' general duties to provide short breaks, this is the only way disabled children can establish an individual right to services. However, disabled children's right to a full social care assessment has been put in doubt by the verdict of 'L & P v Warwickshire CC & Safeguarding Children Board', which found the local authority's proposal to restrict social care assessments to children whose needs were very complex, was not unlawful. In the context of increasing pressure on provision, this could leave many vulnerable children without support. Government must provide clarity to families and local authorities following the appeal in October 2015.

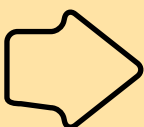
## KEY MESSAGES



**Reduced levels of short breaks provision are leading to rising unmet need for short breaks among families with disabled children.**



**If the Local Offer successfully engages harder to reach families, demand for short breaks will increase to unprecedented levels and place huge pressure on existing provision.**



**In the context of increasing pressure on short breaks provision, it is important that disabled children's right to a full social care assessment is met, to avoid vulnerable children being left without support.**

## CONCLUSION

The fundamental importance of short breaks to families with disabled children is beyond doubt. Short breaks are vital to improving the lives of disabled children and helping them reach their potential. They provide parent carers with essential support to help them cope with their caring responsibilities. It is no exaggeration to say that by increasing family resilience, short breaks help keep families with disabled children together. This has been recognised by successive governments, who have established a legal framework and committed funding to ensure families with disabled children have access to the short breaks they need.

However, the financial environment is challenging the sustainability of short break provision, and its future is uncertain. Whilst most local authorities have worked hard to protect spending on short breaks, a significant minority have already introduced substantial cuts. Those who remain committed to maintaining short break provision are facing the reality that it will become increasingly difficult to protect short break budgets from spending cuts. Without a commitment of further funding from central government following the Spending Review to maintain levels of provision that is sufficient to meet need, it will be almost impossible for local authorities to sustain the progress made in developing short breaks over the previous decade.

The pervasive anxiety among parent carers around the future of short breaks should serve as a warning for policy makers. Spending cuts have already had an adverse impact on short breaks provision, limiting access to universal and targeted breaks in some areas and challenging the focus on quality, choice and personalisation. This can only undermine the significant progress made under AHDC and the short breaks transformation programme. The consequences of losing access to short breaks for families with disabled children are stark, resulting in rising unmet need, parent carers

approaching crisis, and disabled children losing opportunities for social interaction and inclusion in their community. In this context, reports of parent carers facing challenges accessing social care assessments are extremely worrying, as vulnerable families will be left without support.

The importance of short breaks also goes beyond the impact on individual children and their families. The Parliamentary Hearings on Services for Disabled Children initiated a shift in the approach of government to supporting families with disabled children. The result has been a decade of policy making emphasising the empowerment of parent carers and their children to shape the support they rely on to maintain family life, and the development of services that are person-centred and outcomes-focused. This policy direction culminated in the introduction of the 'biggest reforms for 30 years' to the SEND system, by the Children and Families Act 2014<sup>30</sup>. The sustainability of short breaks are of paramount importance to the successful implementation of the SEND reforms.

Short breaks are essential services for improving disabled children's outcomes and a fundamental element of the provision that underpins the Local Offer. Historically, parent carer participation has been most well established in the development of short breaks and influencing their future will test the extent that co-production is meaningful. Government must take action to ensure the sustainability of short breaks and demonstrate its commitment to achieving the best possible lives for disabled children.



## Recommendations

1. The Government should secure continued funding for short breaks through the Spending Review, in order to ensure local authorities can continue to meet their duties to provide short breaks set out in the Regulations for Breaks for Carers of Disabled Children 2011.

At a minimum, this requires continued investment of £800m over four years to sustain levels of provision. The announcement of further funding for short breaks will signal to local authorities that maintaining investment in this area should be a priority.

2. The Government should require all local authorities to publish data on the levels of short break provision in their area, including the number of disabled children, how many access short breaks, and the volume of different types of short breaks being accessed.

This information should be published annually by local authorities as part of a Short Breaks Sufficiency Report, to be included in the short breaks services statement, setting out how levels of available provision meet the duty to provide short breaks sufficient to meet the needs of carers in their area. This information should complement the Ofsted and CQC reports on the quality of short break provision.

3. The Government must clarify to local authorities, practitioners and parent carers the right of disabled children to a social care assessment, following the appeal of L & P v Warwickshire CC & Safeguarding Children Board in October 2015.

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- [1] *The social and economic value of short breaks*, nef consulting (2009)
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- [3] *The social and economic value of short breaks*, nef consulting (2009)
- [4] *No time for us. Relationships between parents who have a Disabled Child: A survey of over 2,000 parents in the UK*, Contact a Family (2004)
- [5] *Breaking Point reports*, Mencap (2003, 2006, 2013)
- [6] *Aiming High for Disabled Children*, Department for Education and Skills and HM Treasury, (2007)
- [7] *The Impact of short breaks on families with a disabled child over time: The second report from the quantitative study*, Department for Education (2011)
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- [17] *Parent Carer Forums Survey 4: - Implementation of the SEND Reforms*, Contact a Family (2015)
- [18] We asked local authorities: 'How much overall funding was provided for the provision of short breaks for disabled children, in accordance with *The Breaks for Carers of Disabled Children Regulations 2011*, in the years 2011/12, 2012/13, 2013/14, 2014/15 and what funding is allocated for the same purpose in 2015/16?'

- [19] We held focus groups in Derbyshire, Oldham and Surrey
- [20] 73 out of 126 respondents
- [21] 95 out of 126 responding local authorities
- [22] 38 out of 126 responding local authorities
- [23] *Towards a more ordinary life....A report on the progress of parent carer participation and the development of short breaks: 2008 – 2011, Together for Disabled Children (2011)*
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- [25] EDCM survey of parent carers, June-July 2015.
- [26] Previously unpublished Family Fund grant data.
- [27] EDCM survey of Family Fund clients, July 2015.
- [28] *Impact Assessment of Breaks for Carers of Disabled Children (England) Regulations 2011, Department for Education (2010)*
- [29] Under section 17 of the Children's Act 1989
- [30] Sarah Teather, Minister for Children and Families, September 2012.

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child matters

