

disabled

Every Child Matters

No going back! Parents' expectations of short breaks

SHORT BREAKS TRACKING SECOND INTERIM REPORT
JUNE 2010



Thank You

Every Disabled Child Matters (EDCM) is very grateful for the support of all the parents that have shared their experiences with us to help us to produce this report. Their comments are quoted throughout this document. We would also like to express thanks to the parent forum coordinators who have assisted EDCM in collecting information for this report.

Every Disabled Child Matters is the campaign to get rights and justice for every disabled child. It has been set up by four leading organisations working with disabled children and their families - Contact a Family, the Council for Disabled Children, Mencap and the Special Educational Consortium.

Find out more and sign up to support the campaign at **www.edcm.org.uk**

This report and the first years report can be downloaded from our website **www.edcm.org.uk/shortbreaks**. For hard copies or for further information, contact the campaign team:

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AIMS OF THE PROJECT

From 2008 to 2011 the Every Disabled Child Matters campaign (EDCM) is undertaking an ongoing qualitative research project with the aim of tracking the impact of the 'Aiming High for Disabled Children' (AHDC) short breaks programme on the lives of disabled children and their families in England. EDCM is engaging with around 27 parents from existing parent groups in two pathfinder and two non-pathfinder regions. Families will document changes in their experiences of short breaks services in their local area at quarterly intervals, gathering evidence in relation to levels, quality, process, choice and control.

They will also report on the elements of the AHDC Core Offer:

- ⦿ information and transparency
- ⦿ assessment
- ⦿ participation and feedback

The Core Offer¹

The Full Service Offer is strongly related to the Core Offer which was introduced in 2008 as part of the Aiming High for Disabled Children programme. The Core Offer is a national set of expectations for disabled children's services over five areas; information and transparency; assessment; and participation and feedback. Consequently, we have based our evidence in this report under the Core Offer headings.

We have also asked parents to discuss the question:

Overall, are you feeling optimistic or pessimistic about services and support for disabled children and their families?

The purpose of this report is to provide a snapshot of the experiences of parents of disabled children in order to highlight examples of good practice and identify possible areas of concern. Our findings do not cover a representative sample, so cannot reflect the progress of the short breaks programme as a whole, but they provide us with real life examples of the way that impact can be made on the ground.

KEY FINDINGS

- ⦿ The second year of the research reveals that a balance remains between feelings of optimism based on experiences of good practice, and feelings of pessimism based on the slow pace of change and the fact that individual families are still not receiving services.
- ⦿ There has been progress in short break provision in non-pathfinder areas over the last year and the parental experience of short breaks is now very similar to that experienced in pathfinder areas. Both pathfinder and non-pathfinder areas are creatively looking at challenges that parents experience. Parents report a particularly high level of satisfaction around parent participation and information.
- ⦿ Issues outside the remit of the research that arose were: the impact on relationship breakdown where short breaks were not adequately provided; the issue of poor transport provision and; the experiences of short breaks for children with challenging behaviour and children with additional health needs.
- ⦿ Examples of good practice continue. However work still needs to be done before regular, reliable and appropriate short breaks come into line with the ambitions and priorities of AHDC, and are available to all disabled children, including severely disabled children.

Levels, Quality, Choice and Control

- ⦿ There have been increases in the levels and the range of short breaks that families are accessing. Both pathfinder and non-pathfinder areas are moving towards a preventative model of assessing short breaks rather than the crisis models of the past. This has led to parents having more confidence in the system and reduced the fear that their short breaks will be taken away. Concerns remain about consistent short break provision in holiday periods, emergency provision and that some services offered do not meet the real needs of families.
- ⦿ Parents have reported that the quality of short breaks remains high and have given positive feedback on the new services developed.
- ⦿ The pressure of having to repeatedly train home-based short break workers was highlighted as an area of dissatisfaction.
- ⦿ Flexible access to short breaks that meet families' individual needs and knowing about short break provision in emergency situations were raised as important issues affecting parental satisfaction. There were mixed experiences around choice and control throughout all parent groups.

Information and Transparency

- ⦿ Parents have experienced improvements in the last year around information provision with many good practice models being created.
- ⦿ Local application of eligibility criteria has remained a source of confusion and distress to parents in both pathfinder and non-pathfinder areas. However towards the end of the second year some local authorities have started to address this issue.

Assessment

- ⦿ In both pathfinder and non-pathfinder areas there had been a move from the crisis model to preventative model in assessment for short breaks. However there remain families who are unable to access appropriate short breaks. The assessment process continues to vary widely.

Participation and Feedback

- ⦿ Good practice models around parent participation continue to emerge in the majority of areas. Feedback in response to consultation is an area that has been identified for improvement. Feedback mechanisms continue to vary widely.



INTRODUCTION AND BACKGROUND

Short breaks – a new priority

“Short breaks provide opportunities for disabled children and young people to spend time away from their primary carers. These include day, evening, overnight or weekend activities and take place in the child’s own home, the home of an approved carer, a residential or community setting.

Provision of short breaks should be based on an assessment of the whole family, addressing both their personal and social needs. Short breaks occur on a regular and planned basis and should be part of an integrated programme of support which is regularly reviewed. No short break should exceed 28 days continuous care and total provision over a year should not exceed 120 days.”¹

Aiming High for Disabled Children: Better Support for Families (AHDC)² is the report that came out of a review of disabled children’s services, part of the Government’s Comprehensive Spending Review 2007. This was a joint review between HM Treasury and (the-then) Department for Education and Skills, aimed at improving services for disabled children in England.

AHDC was published in May 2007 and committed **£340 million** revenue funding, from 2008 to 2011, to transform Local Authority services for disabled children. This funding is allocated to four specific service areas: short breaks, childcare, transition and parent forums.

£280 million of the original revenue funding was allocated to transform short break provision, to enable Local Authorities to expand the types of short break service available and increase accessibility to disabled children, young people and their families. This was in response to evidence from families gathered during the 2006 Parliamentary Hearings process³ who stated that their top priority was regular, reliable and appropriate short breaks.

In December 2008 the Children’s Plan⁴ committed an additional **£90 million** local authority capital funding for short break services from 2008 to 2011, bringing the funding allocation for short breaks to **£370 million**.

In February 2009 the Department of Health’s Child Health Strategy ‘Healthy lives, brighter futures’⁵ announced that **£340 million** of Primary Care Trust baseline funding for 2008/09 – 2010/11 should be allocated to disabled children to be spent on short breaks, community equipment, wheelchairs and children’s palliative care.

However it should be noted that whilst the funding for Local Authorities is ring-fenced for disabled children, the funding announced for Primary Care Trusts is not.

¹ Together for Disabled Children (2008) ‘Definition of a short break’ ² HM Treasury and the Department for Education and Skills (2007) ‘Aiming High for Disabled Children: Better Support for Families.’ ³ Every Disabled Child Matters (2006) ‘Parliamentary Hearings on services for disabled children.’ ⁴ Department for Children, Schools and Families (2007) ‘The Children’s Plan: Building Better Futures.’ ⁵ Department of Health (2009) ‘Healthy lives, brighter futures – The strategy for children and young people’s health.’

Local authority short breaks funding

Following a bidding process, 21 English Local Authorities were selected as pathfinders to take forward best practice in short breaks provision. These authorities received significant funding from the then Department for Children, Schools and Families (DCSF) from April 2008.

The pathfinder areas are: Bolton, Bournemouth-Dorset-Poole (joint pathfinder), Bradford, Brighton and Hove, Derbyshire, Dudley, Enfield, Gateshead, Gloucestershire, Halton, Kent, Norfolk, North Tyneside, North Yorkshire, Nottinghamshire, Suffolk, Sunderland, Sutton and Telford and Wrekin. Local Authority funding allocations from the then DCSF for short breaks over the three year spending period 2008 to 2011 are detailed at <http://www.everychildmatters.gov.uk/resources-and-practice/IG00319/>

All other local authorities received an average of £50,000 in April 2008. To receive additional funding from April 2009, all non-pathfinder authorities were required to demonstrate they were ready to provide high quality breaks by March 2009 according to a set of 'Readiness Criteria'⁶.

Short breaks guidance

The Government issued Short Breaks Implementation Guidance⁷ in 2008 for local authorities and Primary Care Trusts to support them to transform short break services across England. This states that all local areas must meet a Full Service Offer in relation to short breaks before April 2011, and pathfinder areas before April 2010. The Full Service Offer is a set

of standards for short breaks designed to ensure that all children can access the breaks they need. These standards include quality, appropriateness, range and capacity as well as volume of provision.

Why short breaks and not respite?

The literal definition of 'respite' is 'the laying down of a burden' or a 'temporary cessation of something that is tiring or painful'. This language is not positive. The term 'respite' reinforces the view that disabled children are passive recipients who have things done to them, rather than active citizens with lives to live. EDCM believe that the wider transformation for services for disabled children must be cultural, not just financial.

The language of disability has rightly changed over the years, and the term 'short breaks' is part of that process. The crucial difference in short breaks is that both the parent and the child get a break that suits their individual needs. As we move towards transformation, the child's break is valid and valued by all.

⁶ Together for Disabled Children (2009) 'Readiness Criteria Standards: Guidance for local area assessment and tracker completion.' ⁷ Department for Children, Schools and Families and Department of Health (2008) 'Aiming High for Disabled Children: Short breaks implementation guidance.'

STATE OF SHORT BREAKS SERVICES IN 2009

The first 'Short Breaks Tracking Interim Report' was published in April 2009 and identified a 2008/09 baseline level of parent satisfaction with regards to short breaks. The baseline revealed that there was a rising level of optimism about the additional funding for short breaks that AHDC would provide, but that parents felt pessimistic about how local authority and Primary Care Trust bureaucracy would impact on the difference that funding could make. There was also a recognition from participant areas that AHDC had raised disabled children's issues up the political agenda.

During 2008/09 parents in pathfinder areas noted emerging good practice and felt optimistic about the future. However feelings of optimism were not felt across the board. In non-pathfinder areas many parents felt pessimistic due to a continuing lack of flexibility in services and because they felt that they were still not being listened to.

The second year of the research reveals that a balance remains between feelings of optimism based on experience of good practice, and feelings of pessimism based on the slow pace of change and the fact that individual families are still not receiving services. Parents in the non-pathfinder areas are feeling more optimistic as examples of good practice start to emerge and levels of short breaks are rising. Optimism has been particularly linked to good practice around parent participation. There also remains recognition that AHDC has pushed disabled children's issues up the local political agenda with staff being more engaged with the issues and more knowledgeable about the local services that parents can access.

However in pathfinder areas, feelings of optimism are dependent on individual circumstances

and towards the end of the second year a significant number of parents are starting to feel pessimistic again. There is frustration at the length of time for changes, discussed in consultation meetings, to happen and information to filter down from professionals to families. However, most parents are accessing more good quality short breaks.

Pervasive themes

During discussion with parents there are some issues that were raised repeatedly in both pathfinder and non-pathfinder groups. Whilst these issues do not fit under the Core Offer categories that are examined in this research they remain important when assessing the success of short break programmes.

1. Risk of Relationship Breakdown

The issue of relationships breaking down because families were unable to access short breaks was raised in both pathfinder and non-pathfinder areas. Where families were unable to access short breaks or appropriate short breaks, parents described the huge strain this had on their relationship as they were unable to spend any time as a couple away from their role as a carer.

"It has gotten to the point that my relationship has broken down and we are talking about splitting up".

2. Impact of Poor Transport

In both pathfinder and non-pathfinder areas concerns were raised around transport provision to and from short breaks that were outside the

home. For example in one area children with epilepsy or challenging behaviour now need a qualified escort with them on all short break transport. This can mean that the parent has had to act as an escort or transport the child themselves, meaning a significant amount of time in the short break is taken up by overseeing the transportation of their child.

“We appreciate the issues about transport and the costs of providing it but feel professionals do not understand why transport is so important for parents of disabled children. If it were not for their disability they would not be travelling right across the borough to attend a playscheme. Instead, they might be dropped off round the corner at a friend’s house.”

working between Primary Care Trusts and Local Authorities has compounded these issues.

“On the one hand the family are told Jess is too heavy for a single worker to lift and, on the other hand, they are not sending workers to help the family at crucial times of the day.”

“There is currently a freeze around transport for short breaks for children with epilepsy (if they require emergency medication) and challenging behaviour, as the escorts are not trained in how to deal with such events. 30 families have been affected and each case has been looked at and resolved as a pilot scheme. It is hoped that the results will be put into policy. Overall training for escorts is poor and should be addressed.”

3. Health and Safety Fears

Cultural and procedural barriers were reported in both pathfinder and non-pathfinder areas as preventing certain groups of children from accessing appropriate short breaks. These barriers are in particular preventing children with additional health needs and children with challenging behaviour from accessing short breaks that are appropriate to their and their families needs.

A ‘culture of fear’ was reported around the health and safety issues of caring for these groups of children. Parents have reported: long delays in accessing breaks such as overnight care; inappropriate breaks being offered; missing out on short breaks when their child is ill and an exclusion from short break transport services. Parents have reported that a lack of joined up

SHORT BREAKS TRACKING 2009-10

Levels

At the end of the first year pathfinder areas reported improvements in the levels of short breaks being offered and a movement from a crisis to a preventative model. One year on there is still a general feeling that short break provision has improved and better communication has meant that even where parents have not yet seen improvements they feel confident that they will. However in one area there have been closures or reduced hours of popular services without proper consultation or explanation. Parents are concerned that this is happening at a time when there is clearly extra money in the system.

In the first year report it was stated that in non-pathfinder areas there was a lack of confidence in the system and a fear that services may be withdrawn once parents were coping. Parents have since reported positive experiences with a wide range of new services being provided and the majority of parents are now accessing more short breaks. There has been a move away from a crisis model towards a preventative model of short break allocation and this has been reflected in a reduction of parents fearing that services may be withdrawn as soon as families are out of crisis mode. Good practice models in moving away from the crisis model have seen parents being able to refer themselves to receive direct payments or access services such as after school clubs or holiday schemes.

In both pathfinder and non-pathfinder areas there were concerns about the exclusion of specific groups of disabled children based on their impairment, and cases of families not accessing short breaks either because they are not offered or are offered inappropriate services. Parents

also reported concerns about emergency break provision, including not understanding what would be available in an emergency situation. However examples of good practice in this area are starting to be developed, particularly in pathfinder areas.

“My son is in a hospice and they’ve cut his hours so he doesn’t even get as many nights this year and that’s all I want, overnight respite but I’m being offered cheaper alternatives like after school things that I don’t want him to do necessarily because I can take him out. What I actually need is overnight breaks - I’m not getting that.”

“My hours increased to 10 hours in direct payments due to my broken arm but that finishes this month when I will be back to normal. This was really helpful at a time when I needed it.”

“My son has a potential operation looming and the Child Development Unit will be giving us extra help until he has gotten over it. The hospice might help as well. They will do hospital visits as well and because it is a 2 and half hour drive each way this will be so helpful. A very positive experience which gives me confidence.”

The summer holidays were seen by parents as a test for how short breaks are working and improving. This is a time when parents want to see their short break provision increase in a flexible way as their own need for a break increases whilst children are out of school. There were mixed experiences in both pathfinder and non-pathfinder authorities as the breaks that families were offered differed greatly depending

on capacity, funding and the sorts of activities that their child can access and enjoy. Parents also reported mixed messages and experiences of when they could access extra breaks and support to enable families to go away for a holiday. However, parents have reported that local authorities are building on the feedback that they received around school holidays for example diversifying the range of breaks offered.

“One parent had been assured she would be getting a minimum of three days short breaks during the holidays however when it came down to it there was only the capacity for two days.”

“Our short breaks have continued to be great over the summer holidays. We used the hospice twice and had great help from the Child Development Unit (CDU) and the CDU play scheme. We have been told that extra help will be available next month when my son has his operation.”

Therefore across the board there have been increases in levels of short breaks and families are accessing a much wider range of breaks. Improvements in funding have led to more areas leading a preventative model of organising short breaks rather than the crisis models of the past.

This has led to parents having more confidence in the system and reduced the fear that their short breaks will be taken away. Concerns remain however about consistent short break provision in holiday periods, emergency provision and where services are offered but do not meet the needs of individual families.

Quality

The first year tracking report stated that the quality of short breaks in both pathfinder and non-pathfinder areas was in general very good. The quality of the short breaks has remained high in the second year of AHDC particularly in group-based non-specialist provision where local authorities have been putting more money into producing a range of creative short breaks. Short breaks that are responsive to the needs of the child and family are seen as the most successful.

“[Him] being non-verbal, it’s hard to know if he’s happy so you look at facial expressions, it’s the one place we feel he is happy, he looks happy when he gets here and seems happy when he comes home. I think what they have in regards to the sensory room and the music room is good.”

However, as reported in the pervasive themes section of this report there are certain groups of children such as those with additional health needs and children with challenging behaviour that experience barriers to accessing short breaks or are offered inappropriate short breaks. The issues that these children face indicate a culture of fear around health and safety issues, as well as a lack of joined up working between health and social services to provide regular, reliable, flexible and appropriate short breaks for children with additional health needs.

“I have been trying to change my short breaks as my child is 12 now and I want her to have her short breaks in a more sociable environment. Therefore I wanted to change from a overnight carer to a hostel. However she had a severe seizure and now I have been told that she is a high risk and so has to go to a unit 20 miles away where she isn’t getting any social experience of being with others that are her age or that have the same disability as her.”

Parents continue to raise concerns about training short break staff that come into their home. Parents frequently report having to train their short break workers for periods of up to a month before they are happy to leave them alone with their child. This issue is exacerbated by the fact that short break workers tend to be transient therefore families will frequently have to train up new staff. This experience continues to compromise the intended outcome of having a good quality break from caring. Parents indicated their view that a high level of staff turnover was due to low wages.

“It’s great hearing you and I wish we had the same package instead of wondering whether they are going to leave which happens with agency workers.”

“I wish they would give us the money so we could give them a decent wage so we could keep them.”

“We have agency workers and they are always changing. It is very stressful leaving your child with people who don’t understand them. It’s the training element that takes time. So a lot of the time you are allocated is used up in training especially when they are changing all the time. The service seems to be around who [you] can get not what you need. When I was offered this help in the beginning I had no idea the enormity of the training issues. I know we get a lot of help compared to some but the actual benefit can be minimal due to the stress and training.”

There have been reports of parents getting involved in overcoming issues around training by developing formal training programmes or through the involvement of parents in speaking to groups of personal assistants about dealing with specific impairments.

“The staff at [a local disabled children childcare unit] have all had a one hour introduction to autism training which I gave them and are asking for more, for two morning sessions, because the staff really want it. I think it is fabulous that they are actively seeking training. I think they liked the fact that I have the knowledge and training and also am a parent.”

There have been fewer reports in the second year of services being over-subscribed, but children with more complex needs can still be waiting for long periods to access more specialist services.

“She’s been on the waiting list since she was a year old (she’s now 3 and a half).”

Parents with more than one disabled child raised concerns about a lack of joined up provision. Whilst best practice says local services should speak to each other to ensure short breaks for each child are co-ordinated to give parents a real break, in reality it can often come down to parents to play a co-ordinating role.

Choice and control

The first year report of this research revealed that control over the sorts of short breaks that families receive is important to their satisfaction. This has remained the case. Improvements in the choice and control of short breaks continues due to the increased number of services being developed. Families are now able to access more information and so are able to find out about the different short breaks that are on offer in their local area.

However some parents raised concerns over the lack of flexibility in the short breaks that they are offered. Families with a child with challenging behaviour report particular difficulties accessing suitable breaks within a short time frame. Some parents report that the short breaks they are offered do not suit the needs of the child and family either in terms of timing, activity or location. Parents continued to stress that different short breaks suit different families.

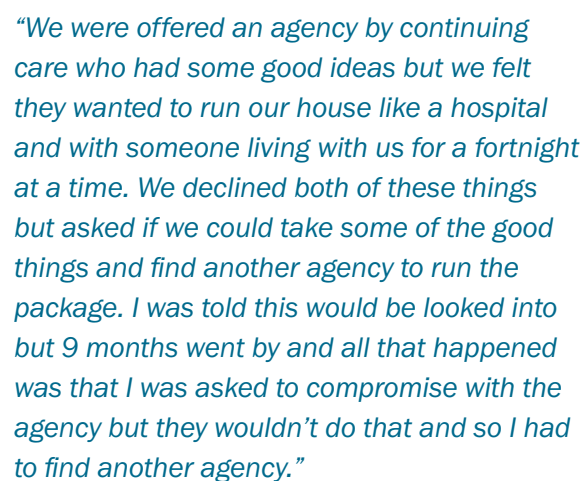
“I was saying can we please use some of these hours during the daytime because we were really shattered, but they won’t let us do it even though it would actually cost less because I was willing to lose some of the help at the weekend. Saturdays and Sundays are horrendously expensive. But they wouldn’t let us do that.”

Some parents have moved to using direct payments due to the increased level of flexibility that this allows them. Direct payments do work very well for some families, particularly when they find a good short break worker. However other families are unhappy with the service that they receive through direct payments but feel that they are offered no alternative. In rural areas lack of alternative provision can be a particular problem with families offered no alternative to direct payments, even if it does not meet their child’s needs. Issues around training short break staff can add to dissatisfaction levels in these circumstances. In rural areas if there are no staff that live within a reasonable distance then families may be unable to access short breaks at all.

“I don’t want my break to be me sat in a car reading a book”

Parents raised concerns around joined up working between health and social services for those with changing health needs. Local Authority short break providers can be scared of taking on a child with changing health needs. This means a family could lose their short break provision if, for example, their child had to start taking antibiotics. The then Department for Children Schools and

Families (DCSF) commissioned Short Breaks Pathfinder Evaluation: Interim Report – Phase One⁸ states that “where strong partnership working exists between the Local Authority and the PCT there is a greater understanding within health about the role of short breaks for children with complex health needs (not just palliative care which it is sometimes understood as), which in some cases has resulted in additional funding/posts being created.” However feedback from parents suggests that there is not currently a sufficient level of joined up working and that this has led to poor experiences for children with complex health needs. The ‘Short breaks Pathfinder Evaluation’ also noted that PCTs were often less engaged with short breaks and this is something that has been reflected by parent groups who have mainly viewed their dealings with short breaks as an issue for their Local Authority. The report claimed that ‘the failure to earmark or ring-fence the NHS funding for the Pathfinder initiative at best meant that it was not seen as a significant priority for the PCT and obtaining the resources proved difficult, and at worst it provided an excuse for the PCT’s disengagement from the Pathfinder programme.’ The findings of this research backs up the conclusions of the report by the National Development Team for Inclusion.



“We were offered an agency by continuing care who had some good ideas but we felt they wanted to run our house like a hospital and with someone living with us for a fortnight at a time. We declined both of these things but asked if we could take some of the good things and find another agency to run the package. I was told this would be looked into but 9 months went by and all that happened was that I was asked to compromise with the agency but they wouldn’t do that and so I had to find another agency.”

⁸ Short Breaks Pathfinder Evaluation: Interim Report – Phase One, by the National Development Team for Inclusion, point 27



EDCM RESPONSE:

EDCM welcomes evidence of a move from a crisis model to a preventative approach. This demonstrates that these areas are making the cultural shift towards creating a local offer for families with disabled children and are looking at the needs of families in order to find a constructive way forward. However, this report shows that there is a long way to go before this approach is common practice and is delivered for all families who need it. We feel that all local areas should address this as part of their local Children and Young People's Plan (CYPP) in preparation for the implementation of the duty to provide breaks from caring that will come into force in April 2011 under section 25 of the Children and Young Persons Act 2008.

We are concerned that parents have reported impairment specific exclusions, and that they are prevented from accessing short breaks either because they are not offered or are offered inappropriate services. We are also concerned that those with more complex needs can still be waiting for long periods of time to access more specialist services and that, whilst services are supposed to work together to ensure that breaks are delivered, parents feel they are required to play a co-ordinating role. These issues appear to be compounded by the fact that there is a lack of joined up working between PCTs and Local Authorities.

We welcome the clear statement in the consultation version of the guidance for Children's Trust Boards: 'the CYPP must contain an outline of key actions to achieve outcomes for three groups of children...so the needs assessment must include an analysis of available data on outcomes for these groups.'

Children's Trust Boards (including Directors of Children's Services and Chief Executives of PCT's) should use their CYPPs to strengthen their preventative approach by setting out a local offer for disabled children and their families. This local offer should include an outline of key actions to achieve outcomes for disabled children, a statement of the support that every disabled child and their family can access without formal assessment, and confirmation that all children who are 'in need' because they are disabled have the right to an assessment for further services.

Although direct payments can lead to increased choice and control for families, we are concerned by the statements indicating that parents feel they have no alternative but to accept direct payments. Direct payments should be offered as part of a menu of services which includes direct provision and support.



EDCM RECOMMENDATIONS:

Levels

- ⦿ The Government should make an early commitment to a national vision for disabled children and their families.
- ⦿ Every Children's Trust Board should create a strategic level sub-group for disabled children to oversee delivery of the actions set out in their Children and Young People's Plan to achieve outcomes for disabled children and to prepare for implementation of the duty to provide breaks under Section 25 of the Children and Young People Act 2008.
- ⦿ This strategic sub-group should work in partnership with parents, children and young people to develop a 'local offer' which is available without formal assessment for all disabled children.

Quality

- ⦿ The new Government should clarify how it will monitor local authorities delivery of the Full Service Offer and their readiness to implement the duty to provide breaks under Section 25 of the Children and Young Persons Act 2008.

Choice and Control

- ⦿ The Department of Health should provide greater clarity on what actions PCTs should take to ensure their full contribution to the provision of short breaks.
- ⦿ Both Local Authorities and Primary Care Trusts should ensure that families can access services in the way that they choose, and that direct payments or individual budgets are offered as part of a range of delivery options

INFORMATION AND TRANSPARENCY

Availability and clarity of information

Under Section 2, Schedule 2 of the Children Act 1989 Local Authorities have a duty to provide information, advice and assistance to parents of disabled children and children with special educational needs on the services, facilities and publications that are available to them. This duty has since been reinforced by the Childcare Act 2006. However in the first year tracking report access to information was identified as a key issue for improvement.

Over the past year non-pathfinder areas reported a vast improvement on information and felt that good quality information was being made widely available. Parents praised the range of avenues that local areas used to get information to them. In addition it was reported that staff that parents came into contact with seemed much more knowledgeable and gave more consistent information out to parents.

"I was given lots of information about the family who are doing introductory sessions for overnight stays for my son. This is much better than last time when it all fell to bits."

The pathfinder areas had mixed experiences with one area seeing good improvements and information being distributed through a more diverse stream of avenues rather than just through parents groups.

"The information recently from [a local parent group] was good because it all came together from one place and all tied in." This information included parent group newsletter, Short breaks update and flyer on provider fairs, short breaks booklet, SEN update, Positive handling information.

"[A local parent group] work closely with the short breaks team, Positive Handling Group and the SEN Strategy, this was why we were able to send everything out together, because we have representatives on all these groups."

However the other pathfinder area felt a huge amount of frustration that it had taken the local authority until January 2010 to distribute information about the short break transformation programme. Although once this information was produced it was of very high quality, parents felt the time delay was unacceptable, and prior to its distribution there was a lot of confusion about what services parents could access.

In both pathfinder and non-pathfinder areas parents raised concerns about how minority groups such as home educators, BME groups and those without access to the internet, are receiving information. A lack of communication about emergency care provision was reported, and there was confusion on how breaks would adjust to changing circumstances such as breaks during the summer holidays. There are continuing concerns around the accuracy of the database that local authorities keep of local families with a disabled child. However in all of these areas of concern pilot schemes and examples of good practice are beginning to take place in response to concerns raised by parents.

“I’ve not got a computer, I’m not online, it’s hard to look up these things”.

“There is no policy around emergency care provision. If a sole carer were taken ill at any time what would happen to the disabled child?”

An issue raised in both pathfinder and non-pathfinder areas was around accessing services if you live on the boundary of two Local Authorities or live in one authority but your child is educated in another one. These parents were unsure about where to access services, received confusing messages and felt that no one Local Authority would take responsibility for funding their child’s short breaks.

“I wanted my child to go to a hostel one night a week and was told that it was too expensive. The hostel is outside of county... Everyone is saying that everyone else is responsible.”

Transparency in eligibility criteria

In the first year’s short break tracking report, it was reported that local authority application of eligibility criteria was leading to confusion and parents reported no consistent system. Many parents were unclear about how to get short breaks, who to approach and what they are entitled to. Following the case of R (JL and LL) v Islington London Borough Council [2009]EWHC 458(Admin), the Council for Disabled Children has

been working with Local Authorities across the country to improve their eligibility criteria.

However parents in non-pathfinder areas report that they remain concerned and confused about their local eligibility criteria. Parents raised two sets of particular concerns: the first relates to access to assessment, the second in relation to access to support. In the first parents were being told that decisions were being made on their child’s impairment and that these impairments, even though the child was disabled, did not meet the ‘Aiming High Eligibility Criteria’. Children were then being unlawfully refused an assessment. In the second scenario families were able to access assessment but again were told that the ‘Aiming High Eligibility Criteria’ meant the child could not be offered support.

“A colleague’s child with pervasive developmental disorder (PDD) had an assessment and was deemed as having a need but because PDD doesn’t come under the local eligibility criteria they weren’t offered support.”

In addition, poor information about eligibility criteria has led to some parents feeling that they have received “veiled threats from the local authority”, telling them not to challenge the level of their award for Disability Living Allowance (DLA), because they would risk losing the DLA and therefore also their local services.

Parents also report that they are told not to compare their short break provision to what others are receiving as every child has different needs. But parents want to see the criteria that is used to allocate short breaks and why certain

families are prioritised. Local Authorities are in the process of publishing documents outlining their eligibility criteria, but parents say this is taking too long. Where Local Authorities have produced documents explaining eligibility criteria and what parents are entitled to, there is a higher level of parent satisfaction.

The findings of EDCM's research has been backed up by DCSF commissioned research which stated that "almost all Pathfinder sites stated that they are waiting for and expecting some further national guidance and/or clarity on [eligibility criteria] and so local innovation and initiative has perhaps been suppressed because of this expectation"⁹.



EDCM RESPONSE:

Comments from parents in pathfinder areas demonstrate that timely information is crucial in directing parents to services. Concerns reflect the fact that many local areas still need to do much more proactive work to ensure they are providing information to 'hard to reach' groups. Points of crisis or high demand such as holidays demonstrate weaknesses in the system, which need to be addressed to ensure that services are able to respond to families' changing needs.

Most worrying is the fact that parents remain concerned and confused about eligibility criteria. In March 2009, the JL and LL v Islington London Borough Council judgement directed the then Secretary of State for Children, Schools and Families to provide guidance on eligibility criteria for local authorities. We are extremely concerned by reports in this research that local areas are using eligibility criteria to exclude whole groups of children from receiving services, even before individual assessments of children and families are carried out.

Although we welcome the good practice advice that has been issued by the Council for Disabled Children, this report demonstrates that local authorities require more direct intervention from the Secretary of State for Education to ensure that they are complying fully with the law.



EDCM RECOMMENDATIONS:

- ⦿ **The Secretary of State for Education should issue guidance to local areas to clarify the interface between the Chronically Sick and Disabled Persons Act 1970 and the Children Act 1989 to ensure they are acting within legal guidelines and to provide statutory practice guidance to support the development of eligibility criteria.**
- ⦿ **The Department for Education should publish a guide for parents on eligibility criteria to support them to enter into a constructive dialogue with their local authority.**
- ⦿ **Local authorities and Primary Care Trusts that operate eligibility criteria for short breaks should publish them on their websites to ensure they are available for local challenge.**

⁹ Short Breaks Pathfinder Evaluation: Interim Report – Phase One, by the National Development Team for Inclusion, point 26

ASSESSMENT

In the first interim short break report, a lack of consistency in assessment was identified as a key issue and parent groups continue to identify this as a problem.

Many of the parents involved in the short break tracking programme are now accessing short breaks. Good practice models include running information sessions for parents to help them to understand the assessment process and act as advocates for their family during assessment meetings. These sessions have been made available to a wide range of parents as they are held in a variety of venues, days and locations.

Both pathfinder and non-pathfinder areas are moving away from the crisis model towards a preventative model. Good practice has included pilots where families can 'self-refer' to receive short breaks and direct payments; incentive schemes to get more families on the local disabled childrens register; and better communication with families. These have all assisted the move away from the crisis model and a reduction in the fear that services are under threat if you are coping.

However there are still some families that are unable to access short breaks. This is a particular issue for families with a child with challenging behaviour or where the local area has set an unlawful blanket exclusion based on a child's impairment within local eligibility criteria. Many of these families feel that they are at crisis point but not receiving any help. Parents also raised concerns about the amount of time between being assessed and receiving breaks, that there can be limited options for families in rural areas, and that it is the more engaged parents who get the most services.

"They don't even help when I am crying down the phone"

"There is no help even when you are warning that you are going to hit crisis point."

"If I ruled the world the minute you had a diagnosis there would be this package that comes into place with information, help and everything."

"I feel I have to had arrange everything for my son. I have been hanging on, feeling stressed and desperately wanting to hand over the responsibility to someone so that I am mum and not care manager."



EDCM RESPONSE:

We are concerned that families report they are still not receiving the short breaks they need, and are reaching crisis point due to issues with the assessment process. Blanket exclusions of whole groups of disabled children are unlawful. All disabled children are children 'in need' for the purposes of section 17 of the Children Act 1989. The duty on Local Authorities under section 17 of the 1989 Act is to provide a range and level of support services for children in need in their area where possible, to support them in the context of their families. Local Authorities are required to assess and prioritise the way they meet the needs of children in their area. Local Authorities are permitted to use eligibility criteria and to take into account available resources when deciding whether to provide services following assessment. However, they should have due regard to their duties under Section 49a of the Disability Discrimination Act 1995 in reaching this decision.

Guidance on delivering the Full Service Offer states that local authorities should 'use fair, understandable and transparent eligibility criteria that enable Short Breaks to be used as a preventative service and which do not restrict provision to those threatened by family breakdown or other points of crisis'¹⁰. It is clear from this report that families are reaching breaking point but are still not receiving short breaks. This further highlights the need for the Government to respond to our recommendations to provide guidance on developing eligibility criteria and to ensure that local areas are monitored on their delivery of the Full Service Offer.

We are also concerned that local areas are still failing to ensure that 'hard to reach' groups are accessing services. Short breaks implementation guidance states that funding should 'transform the quality, appropriateness, range and capacity of provision to meet the needs of those eligible children and young people who are commonly unable to access provision'¹¹. It is evident from this report that some local authorities are not successfully targeting 'hard to reach' groups, or offering a real choice in terms of provision. This reinforces the data gathered by the National Indicator 54 survey, which states that 72% of parents have received no care and family support services over the past 12 months¹².



EDCM RECOMMENDATIONS:

- ⦿ Local Authorities should move towards a local offer approach, and provide a minimum level of support to all children identified as 'in need' as they are disabled without formal assessment.
- ⦿ Local Authorities and Primary Care Trusts must provide information to families as part of the Core Offer, which explains the purpose, timescales and outcomes of assessments. This information should explain how different assessment processes link together and be available through a range of settings and agencies which families use.

¹⁰ Aiming High for Disabled Children: Short breaks implementation guidance, DCSF, 2008 ¹¹ Ibid ¹² Aiming High for Disabled Children November 2009 National AHDC results, DCSF and DH, 2009

PARTICIPATION AND FEEDBACK

Participation in design and delivery

In the first year's short break tracking report parents reported that good participation relied on a good relationship between the Local Authority and parents, as well as established links between parent groups and Local Authorities. There were a range of good practice models being displayed in both pathfinder and non-pathfinder areas.

Parent groups in both pathfinder and non-pathfinder areas have continued to report that they are well involved in the design of services and resources. Where parent participation is working well the Local Authorities are feeding back on how they have acted in response to feedback in consultation events. Good practice models have also seen the inclusion of a wider range of parents in consultations and moves towards involving more fathers. In addition, parental involvement in the short listing and interviewing process for short break programme staff and providers has continued. Parents have also been involved in running parent-to-parent consultations and questionnaires, and Local Authorities have continued to reimburse parents for travel and childcare to make sure a wide spectrum of parents can be involved in participating. This has led to a wider range of parents being involved in consultations across the board. Local Authorities are also starting to consult children when developing the services that they will be using. The majority of participatory work that parents have been involved in has been coordinated by the local authority therefore discussions focused on these experiences. No parents groups discussed any examples of participation run by the PCT.

"I've been involved in doing some parents consultancy for the borough and even now I've started to think 'oh god, this is great' a real air of positivity and things are going to change."

"I am still on many project and steering groups in the county and feel that issues brought up by parents are being listened to and I can see that these are being taken seriously."

Other examples of good practice include where sufficient funding and support has been given to parent groups to enable them to become more effective. For example parent participation groups: organised skill building courses for parents new to disability; created networking opportunities between parents and services; put on courses on how to have constructive conversations in assessment meetings; and organised courses on managing challenging behaviour.

The main challenge to successful participation remains feedback to parents about what is being done in response to parent consultation. This feedback needs to include information about the decision process the Local Authority has taken when it decides to make different choices to those recommended by parents.

"I am concerned that siblings can no longer attend playschemes, at a time when results of short break consultations are saying that parents want support for siblings."

"Parents were so great giving up their time and coming to [consultation] groups, filling in questionnaires and then [they heard] nothing."

Feedback mechanisms

The 2008/09 interim report stated that many short breaks services provide service evaluation forms and individual parents reported good experiences of complaints procedures. However there was a general lack of consistency across services and there was the need for more uniform feedback and complaints system. Into the second year of the research parents have reported good experiences of evaluation forms. Whilst these do not seem to be consistently provided at all services, where they are, parents have felt that their feedback has been acted on.

Parents would like to see evaluation forms more consistently applied. In addition parents in the first year of the research reported a lack of clarity on how to proceed if they were unhappy with their social worker or when turned down for short breaks. This uncertainty continues into the second year of the research.

“Our care package from the agency means that I have an agreement that when I don’t fill in anything on the feedback form they know I was unhappy with the care worker.” “Do [local childcare service] have a feedback form?” “No they don’t but that sounds like a really good suggestion.”

“My new [personal assistant] is doing alright and the manager of [local childcare service] has said that I must say if I don’t think it will work because we don’t have to have that lady and so I feel that the quality of service is very good and is thinking about us as a family.”



EDCM RESPONSE:

Increased parent participation has led to higher quality provision but also to higher expectations. Parents are becoming skilled at designing the services that support them, providing crucial peer support and providing training to professionals and to other parents. Parent forums are a vital driving force for change. Their impact on the quality of provision demonstrates that concrete, long term engagement of parents, at a local and national level, will be the key to the successful transformation of services. It is also clear from what parents have told us that participation structures must be appropriately supported and backed with financial resources.

Feedback has been flagged as an issue of concern by parents in their response to the Government's National Indicator 54 survey.¹³ It is clear that parents are still not receiving clear information on how to feedback on services or make an approach. In order to move towards an inclusive, best practice approach, Local Authorities and PCTs must be open to feedback and provide clear and transparent responses to complaints from families.



EDCM RECOMMENDATIONS:

- ⦿ The new Government should support concrete, long term, strategic engagement of parents and disabled young people.
- ⦿ When involving parents in the design and delivery of short breaks, Local Authorities and Primary Care Trusts must ensure there is a consistent mechanism for feeding back how views are used and decisions taken.
- ⦿ Local Authorities and Primary Care Trusts should ensure that all their activities in relation to short breaks are transparent and accountable. There should be clear feedback routes in place so that concerns and compliments from parents and young people can be received and acted on.

¹³ <http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/nationalindicator/nationalindicator/>

SUMMARY OF EDCM RESPONSE:

Feedback from parents in this report demonstrates that, when delivered appropriately, the short breaks improvement programme is changing lives. Not only has it facilitated the development of innovative practice and ensured many families are able to access regular, reliable and appropriate short breaks, it has also raised the expectations of disabled children and their families. As a result, a transformation process has been set into motion and will be expected to continue. Parents and disabled children will demand the support that they need to ensure that they can enjoy the same quality of life as any other family.

However, if disabled children and their families are not given the continuing, long term political priority they deserve, the services will be severely undermined and

will risk closure. Local Authorities have spent the money that has been given to them over the past few years establishing the foundations of better service provision for disabled children and their families. If funding is not renewed in the forthcoming Spending Review many of these services will not be able to continue. In addition to this, it is clear that much more work needs to be done to ensure that eligibility criteria are set according to legal requirements, and hard to reach groups are aware of and can access services.

It is crucial that central Government and Children's Trust Boards make a clear statement about what disabled children and their families can expect from year three of the current programme, and the policy framework and investment that will be made from April 2011 onwards.

EDCM'S RECOMMENDATIONS:

EDCM Top Priority Recommendations

- ⦿ **The Government should make an early commitment to a national vision for disabled children and their families**
- ⦿ **The Secretary of State for Education should issue guidance to local areas to clarify the interface between the Chronically Sick and Disabled Persons Act 1970 and the Children Act 1989 to ensure they are acting within legal guidelines and to provide statutory practice guidance to support the development of eligibility criteria.**
- ⦿ **Every Children's Trust Board should create a strategic level sub-group for disabled children to oversee delivery of the actions set out in their Children and Young People's Plan to achieve outcomes for disabled children and those with special educational needs and to prepare for implementation of the duty to provide breaks under Section 25 of the Children and Young Persons Act 2008 on April 1st 2011.**

Summary of further recommendations to Government:

- ⦿ The new **Government** should clarify how it will monitor local authorities delivery of the Full Service Offer and their readiness to implement the requirement of implementation of the duty to provide breaks under Section 25 of the Children and Young Persons Act 2008 on April 1st 2011.
- ⦿ The **Department of Health** should provide greater clarity on what actions PCTs should take to ensure their full contribution to the provision of short breaks.
- ⦿ The **Department for Education** should publish a guide for parents on eligibility criteria to support them to enter into a constructive dialogue with their Local Authority.
- ⦿ The new **Government** should support the concrete, long term, strategic engagement of parents and disabled young people.

EDCM'S RECOMMENDATIONS:

Summary of further recommendations to local areas:

- ⦿ **Children's Trust Board's** strategic sub-groups should work in partnership with parents, children and young people to develop a 'local offer' which is available without formal assessment for all disabled children.
- ⦿ Both **Local Authorities and Primary Care Trusts** should ensure that families can access services in the way that they choose, and that direct payments or individual budgets are offered as part of a range of delivery options
- ⦿ **Local Authorities and Primary Care Trusts** must provide information to families as part of the Core Offer, which explains the purpose, timescales and outcomes of assessments. This information should explain how different assessment processes link together and be available through a range of settings and agencies which families use.
- ⦿ **Local Authorities** should move towards a local offer approach, and provide a minimum level of support to all children identified as 'in need' because they are disabled without formal assessment.
- ⦿ When involving parents in the design and delivery of short breaks, **Local Authorities and Primary Care Trusts** must ensure there is a consistent mechanism for feeding back how views are used and decisions taken.
- ⦿ **Local Authorities and Primary Care Trusts** should ensure that all their activities in relation to short breaks are transparent and accountable. There should be clear feedback routes in place so that concerns and compliments from parents and young people can be received and acted on.
- ⦿ **Local Authorities and Primary Care Trusts** that operate eligibility criteria for short breaks should publish them on their websites to ensure they are available for local challenge'. to this section.

Appendix 1 – Demographics

This report was produced using evidence gathered from parent groups in two short breaks pathfinder and two non-pathfinder local authorities.

A total of 27 parents have taken part in the tracking project. Families taking part in this project also have contact with other parent groups and have fed in their discussions from other families outside of the short breaks tracking participants.

Children with the following impairments are represented in this process

- ⦿ Pierre Robin Sequence, infantile scoliosis
- ⦿ Global developmental delay
- ⦿ Epilepsy
- ⦿ Canavan disease
- ⦿ Complex health needs
- ⦿ Down syndrome
- ⦿ Children with Autistic Spectrum Disorder, including those with complex autism, challenging behaviour and high functioning autism
- ⦿ Cerebral palsy
- ⦿ Heart condition and rare syndrome
- ⦿ Duchenne muscular dystrophy
- ⦿ Hydrocephalus and significant chiari malformation
- ⦿ Sensory impairments including deafness and blindness
- ⦿ Rett Syndrome
- ⦿ Asperger Syndrome

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Download copies of the EDCM short breaks tracking reports for years one and two at:

<http://www.edcm.org.uk/shortbreaks>

