

disabled

Every Child Matters

**Short breaks tracking
Interim Report
April 2009**

contact a family
for families with disabled children

**Council for
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Key findings

- While some evidence of good practice is emerging, there is still a long way to go before a consistent, sustainable service is available that works for all disabled children, including severely disabled children. This is in line with the ambitions and priorities of the Aiming High for Disabled Children programme.
- Parent groups in short breaks pathfinder areas involved in this report have reported improvements for those who know about short breaks services and are deemed eligible. They have also reported good opportunities to influence best practice provision.
- Parents in non-pathfinder areas involved in this report have expressed concerns about lack of flexibility, continuity of care, information and choice.

Levels, Quality, Choice and Control

- Services which work for families are those that are flexible, create individual solutions, are responsive to the needs of the child and have good quality short breaks workers who receive continued high quality training.
- Non-pathfinder areas reported a lack of real choice over the services their children receive, a lack of information and clarity about direct payments and lack of support for parents from local authorities in managing direct payments.

Information and transparency

- Information about local short breaks was identified as a key issue for improvement by both pathfinder and non-pathfinder authorities involved in this project.
- Both pathfinder and non-pathfinder authorities also identified that local application of eligibility criteria leads to confusion in many areas with some reporting no consistent system.

Assessment

- Parent groups in both pathfinder and non-pathfinder authorities involved in this project reported that assessment processes and length of time from being assessed to receiving breaks still varies widely.

Participation and feedback

- Good practice models of parent participation are emerging in the majority of areas involved and successful participation in short breaks service planning can be attributed to good relationships between the local authority and established parent groups. However variability still occurs and there is a need for more consistent standards.

Introduction and background

Short breaks – a new priority

Aiming High for Disabled Children: Better Support for Families (AHDC)¹ is the report from the disabled children's review, 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. The report was an excellent result for the campaigning work of EDCM partner organisations and wider disabled children's sector.

AHDC was published in May 2007 and committed significant additional resources – **£340 million** revenue funding, from 2008 to 2011, to transform 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 areas 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 Parliamentary Hearings process² who stated that their top priority was regular, reliable and appropriate short breaks.

In December 2008 the Children's Plan³ committed an additional **£90 million** capital funding for short break services from 2008 to 2011, bringing the funding allocation for short breaks to **£370 million**.

Furthermore, in February 2009 the Child Health Strategy '*Healthy lives, brighter futures*'⁴, clarified that an additional **£340 million** has been given to Primary Care Trusts for disabled children from 2008 to 2011, to be spent on short breaks, community equipment, wheelchairs and children's palliative care.

This brings the total government funding allocation for disabled children from 2008 to 2011 to **£770 million**. A significant portion of the funding from Department of Health is expected to go towards short breaks provision to ensure disabled children with complex health needs and their families can enjoy the same opportunities for short breaks, and to support PCT's to be equal delivery partners of the transformation programme.

See <http://www.edcm.org.uk/health> for more details.

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 Department for Children, Schools and Families (DCSF) from April 2008.

¹ HM Treasury and the Department for Education and Skills (2007) '*Aiming High for Disabled Children: Better Support for Families*.'

² Every Disabled Child Matters (2006) '*Parliamentary Hearings on services for disabled children*.'

³ Department for Children, Schools and Families (2007) '*The Children's Plan: Building Better Futures*.'

⁴ Department of Health (2009) '*Healthy lives, brighter futures – The strategy for children and young people's health*.'

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, Telford and Wrekin. Local authority funding allocations from 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'⁵.

Short breaks guidance

The government issued Short Breaks Implementation Guidance⁶ for local authorities and Primary Care Trusts to support them to transform short break services across England which states that all local areas must meet achieve a Full Service Offer in relation to short breaks by 2011. 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.

The Core Offer⁷

The Full Service Offer is strongly related to the Core Offer which is a national set of expectations for disabled children's services over five areas; information and transparency; assessment; and participation and feedback. We have based our evidence in this report under the Core Offer headings.

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.

⁵ Together for Disabled Children (2009) 'Readiness Criteria Standards: Guidance for local area assessment and tracker completion.'

⁶ Department for Children, Schools and Families and Department of Health (2008) 'Aiming High for Disabled Children: Short breaks implementation guidance.'

⁷ Department for Children, Schools and Families (2008) 'The National Core Offer.'

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' short breaks programme on the lives of disabled children and their families in England. EDCM will draw on evidence from parents co-ordinated through a local parent forum, other available data such as local surveys and any other available evidence being gathered.

EDCM will engage with around 27 parents from existing parent groups in 2 pathfinder and 2 non-pathfinder regions⁸. Families will document changes in their experiences of short breaks services in their local authority at quarterly intervals, gathering evidence in relation to levels, quality, process, choice and control.

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

- information and transparency
- assessment
- participation and feedback

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 experience 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.

This three year tracking project will be used as a campaigning tool, providing evidence to influence current delivery of the short breaks transformation programme; to urge government to go further to ensure that the transformation programme is properly evaluated; to justify a sustained commitment and to ensure there is further investment in short breaks services in the next government Spending Review.

⁸ Appendix 1

State of short breaks services in 2008

Our baseline discussions in summer 2008 revealed that the majority of parents involved in this research were on the whole pessimistic about services and support for disabled children and their families improving due to the AHDC programme. Some parents stated they were optimistic about the additional funding for short breaks, but pessimistic about how local authority bureaucracy would impact on the difference the funding could make. There was recognition from all participant areas that the AHDC programme had raised disabled children's issues up the political agenda.

"I'm disillusioned with the system as it has let me down. When I've struggled for everything and stamped my feet for 12 years... I've finally got some of the things I need, but I want to achieve it for everyone – not just me."

Parent of child with Down Syndrome, ASD and complex needs; Pathfinder authority

"They [local authorities] are people of real good will, but they're not sure how to go about this. It's a bit like they're in an exam and leaning over to look at their neighbour's work. If they copied the best that would be great. Our fear is that they copy the worst because they think it'll be cheaper."

Parent of child with complex autism, Non-pathfinder authority

Since then, parents from pathfinder areas involved in this project have reported emerging models of good practice and feeling optimistic about the changes that the funding will make. Parents in these areas have also reported improvements for those who know about the service, are deemed eligible and have also reported opportunities to influence best practice provision.

However, there is still a long way to go before a consistent, sustainable service is established that works for all disabled children, particularly those with the most complex needs. While some parents in non-pathfinder areas have reported feeling more optimistic about change, many still feel pessimistic citing lack of flexibility in services and not feeling listened to.

Short breaks tracking 2008-09

Levels

Towards the end of the first year of the AHDC programme, pathfinder areas involved in this project reported improvements in the levels of short breaks being offered to families and movement from a crisis to more preventative model, with the majority of families being happy with what they were receiving.

In non-pathfinder areas the 'on and off' nature of services means that parents feel even when they are getting services there is a risk that they will be withdrawn, creating a lack of confidence in the system.

Many parents reported a lack of flexibility and services not being responsive to families changing situations, for example a loss of short breaks hours when their child can't attend the service due to being sick or in hospital and these hours not being refunded. Parents also reported inconsistent emergency provision, little holiday provision or being offered services that do not meet their needs. There is major concern that children with the most complex needs are not receiving appropriate services and further concern over transition to adult short breaks services.

"They run a merry-go-round system where you get breaks for 6 months then you have to come off them again. You could not be-grudge getting off the merry-go-round because you knew there were families in at least as bad a way waiting to get on."

Parent of a child with complex autism, Non-pathfinder authority

"My daughter is 14 and I'm worried for the future. I'm unclear about services for 18 plus... adult and children services need to work together."

Parent of a child with complex autism, Non-pathfinder authority

"It's taken me quite a few months to get from what we were given to get to what we actually need. It took me a year before anybody got in touch with me about being entitled to anything. I was told I couldn't use direct payments."

Parent of child with complex physical and learning needs, Non-pathfinder authority

Quality

Whilst quality can differ, the majority of parents involved in this project in both pathfinder and non-pathfinder authorities reported good quality provision. However they were conscious that this is not everyone's experience. Where good quality provision exists this can be attributed to responsiveness to the needs of the child and the family and where services offer the opportunity for disabled children to mix with other children. Factors that make success more likely include creating individual solutions to meet the child's needs and good quality short breaks workers who match the needs of the child and receive continued high quality training. Consistency and good planning are crucial factors in ensuring short breaks make a real impact and families suggested regular short breaks reviews to ensure services continue to meet the needs of the child and family. However

parents reflected that planning is not always possible in crisis situations therefore it is crucial to have flexibility in provision.

"I'm satisfied - they called me one day to let me know that 'cos of staffing problems there was a male nurse on, and my husband went to pick her up."

Parent of a child with complex autism, Non-pathfinder authority

"They take him straight from school which is great for me because if they try to take him from the doorstep he just won't go – he wants to stay with me."

Parent of a child with high functioning autism, Non-pathfinder authority

Issues arise when parents feel that staff cannot offer appropriate support and where there is little co-ordination between providers and a lack of continuity of care. These are particular issues for children with communication difficulties and those with complex needs. Where services are offered in the family home there are concerns around lack of consistency of staff with parents reporting having to train staff themselves. This means the actual 'short break' is ultimately compromised.

"The worst thing is when they say we can't cope with him. There are 5 of them [staff] there in a centre built for this, and instead they bring him back to me by myself at home."

Parent of a child with Down Syndrome, ASD and complex needs; Pathfinder authority

"He has loved all these people coming in but it has been such hard work for us. It might get better if we can keep the same people and they get to know where everything is and what to do with my son. I have done a little book that gives all the information and it's good because there are two trainee social workers who come and hopefully they will see what it's like at the coal face so to speak."

Parent of a child with Down Syndrome, ASD and complex needs; Pathfinder authority

In participant non-pathfinder areas, parents reported that there are services that are delivering well but these are often over-subscribed. This can mean that families still have to fight to get access to good quality breaks. It is therefore crucial to ensure that local authorities use the good practice developed by the best providers to create consistent provision across authorities.

"They have one exemplary service, but they threatened to close it. They should be proud of it and expanding it, they could lead the way."

Parent of a child with Asperger Syndrome and PDA, Non-pathfinder authority

Choice and control

Families taking part in this survey have told us that they like to control the kind of short breaks they have to fit in with their individual circumstances. While choice and control over services has improved in participant pathfinder areas with parents reporting they receive different kinds of support even when presenting with similar sets of circumstances, many of our non-pathfinder participants report that there is simply not enough choice. Many parents

still feel that they have to fight for appropriate services and identified that a lack of choice is often due to a lack of information about what is currently on offer.

In all participant groups, parents challenged the old idea of 'respite' and described what a break from caring would really look like for them. They emphasised that different things are right for different families and that parents know what works for their children, and that it's not always the most expensive option.

Parents urged that their ideas be fed back to those planning services as what is on offer does not always meet families needs and some services do not focus on child development. Parents also reported lack of information and clarity about direct payments and concern that these are used as a last resort when services cannot meet the child's needs, as opposed to something that is routinely offered. There is further concern that direct payments can be too prescriptive and some authorities do not offer enough support about how to use direct payments where families may not want to manage a personal budget.

"There is the voucher system, and for some people that worked extremely well, but the difficulties we had were lack of continuity of care, and for children with communication difficulties or who are particularly vulnerable, having strangers coming in isn't helpful. They never seemed able to match the carer to the needs of the family – if you had a child that wanted to go swimming you'd get a carer that couldn't swim. You had people that wanted to come when they wanted to come and not when you needed them."

Parent of a child with Rett Syndrome, Non-pathfinder authority

"Flexibility is the key... planned breaks are important, but there must be some flexibility. If your child is in hospital the week you are supposed to get respite then you lose all the respite, but actually if you've just spent all your time in hospital for a week, then that's when you absolutely really desperately need [support] but can't get any."

Parent of child with complex physical and learning needs, Non-pathfinder authority

"I can't use my direct payments because I can't find a carer with the right skills to employ. You lose your direct payments if you can't find the right person within 3 months. Can't the local authority keep a database of people with the right skills, like they do for childcare?"

Parent of child with Duchenne Muscular Dystrophy, Non-pathfinder authority

Key recommendations:

Children's Trust Partnerships (including Directors of Children's Services and Chief Executives of PCT's) must demonstrate their commitment to families by taking a leadership role in meeting the Full Service Offer on short breaks by 2011, including ensuring this meets the needs of all disabled children, particularly those with the most complex needs.

Local authorities should develop local commissioning guidance using best practice short breaks models to inform service development.

Local authorities should increase flexibility and choice in service provision by building on best practice models of the AHDC individual budget pilots as part of a menu of services and support, and parents are involved to ensure that services meet the needs of families.

Information and Transparency

Availability and clarity of information

Since 1 April 2008, under the Childcare Act 2006, local authorities have had 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.

Information about short breaks and the AHDC programme more widely was identified by participant groups as a key issue for improvement.

While some parents in pathfinder areas involved in this project reported improvement in availability of information and increased communication through family newsletters and local authority updates, many parents in both pathfinder and non-pathfinder authorities told us that information is still inconsistent, with families failing to access sufficient and appropriate information and continuing to rely on word of mouth about services.

“It’s so hard to get any information. If you’ve got a computer and know where to look, and what the right terminology is, then you can at least try, but lots of parents don’t have the time or energy for that”

Parent of two children one with autism and challenging behaviour, one with Downs syndrome and autism, Non-pathfinder authority

“I’ve not had any information about any new groups, I have not received any flyers from social services or from school. I only know about them because other parents have asked me whether I was going or not”

Parent of twins, one with high functioning autism, one with complex autism and Cerebral Palsy, Non-pathfinder authority

There was widespread concern from all participant areas about how families who are not well engaged in services can access information and a clear message that information about short breaks should be better available from a range of sources including specialist and universal settings, mainstream schools and hospitals. While children’s centres hold information, challenges can arise in rural areas where centres have large catchment areas.

Parents reported that information about short breaks available from local authority family information services was variable and some participant areas felt that it did not accurately reflect local provision. Parents felt that family information services and other universal services should have better knowledge and understanding about disabled children’s services generally and should know where to signpost families to for information and support.

Furthermore there was concern over relying on disabled children’s registers to identify parents to target information to. These concerns are based on variability of registers between local authorities (some areas require threshold criteria to be met before inclusion on the register) and the voluntary nature of registers. Of an estimated population of 5000 disabled children in one pathfinder area, only around 2000 children were entered on the

disabled children's register. There is concern that families who are not on the register would not be identified as needing a service and therefore will continue to fall through the gaps in services provision.

"You meet people whose children are 16 and they haven't heard of anything and you think 'how can we get the information to them?' In [neighbouring authority] we've introduced an information pack that goes to doctors, children's centres etc"

Parent of child with Rett Syndrome, Non-pathfinder authority

"They could do with someone in the child development centre that you can ask that will actually know all the useful information. [The information person in the centre] didn't even know about DLA"

Parent of child with high functioning autism, Non-pathfinder authority

Participant groups identified several solutions they think would help improve the availability and clarity of information about short breaks. These included interactive elements on local authority websites, disability advice workers in family information services and other centres and Portage⁹ services to hold information on short breaks. Both pathfinder and non-pathfinder regions raised the idea of a single point of contact for families to provide and coordinate information, which would improve access and reduce inconsistencies, for example key workers. One pathfinder region reported use of the parent forum funding awarded through AHDC to set up satellite groups to engage with harder to reach parents, encourage participation and disseminate information.

Transparency in eligibility criteria

Local authority application of eligibility criteria is still leading to confusion and with some participant areas reporting no consistent system and many parents still being unclear how to get short breaks, who to approach and what they are entitled to. There is concern that AHDC funding is not being applied in a way that is flexible and responsive to the needs of individual children and families, and that those with most complex needs will continue to miss out on breaks.

"We need some way of knowing what support is available, and how you get it, and if you don't get it why."

Parent from a Non-pathfinder authority

A recent High Court ruling¹⁰ has stated that the use of 'eligibility criteria' by local authorities to limit access to disabled children's services can be unlawful. The judge in this case states that the law governing this issue is complex, and recognises the need for guidance for local authorities, which would ensure the role of eligibility criteria is better understood.

⁹ Portage is a home-visiting educational service for pre-school children with additional support needs and their families www.portage.org.uk

¹⁰ JL and LL v Islington London Borough Council [2009] EQHC 458 (Admin)

Key recommendations:

Local agencies should ensure that good quality information on short breaks services for disabled children are available from a wide range of sources including specialist and universal settings such as children's centres, hospitals and family information services.

Following the judgment in the case of JL and LL v Islington London Borough Council [2009] EQHC 458 (Admin), EDCM is backing the Council for Disabled Children's call on all local authorities to review their eligibility criteria and the Department for Children, Schools and Families to provide a central steer from government to issue guidance on the law governing eligibility criteria.

Assessment

Lack of consistency in assessment is a key issue identified by participant groups.

Within participant pathfinder areas there are variable experiences of assessment processes and length of time from being assessed to receiving breaks. Families have reported improvement with reduced waiting times in some cases and assessments being more straightforward and stress-free. Children with health needs and continuing care packages in both pathfinder and non-pathfinder areas reported a more positive experience of help being offered, but even within pathfinders practice development is far from consistent.

There is a strong feeling within participant non-pathfinder regions that assessments can be inconsistent and what is offered to families depends on where you live and available funding rather than the needs of the child or family. Furthermore there is a fear that services are under threat if you are coping.

“The assessment is airy fairy – it depends on who is doing the assessment as to what you get – there’s no clear eligibility criteria.”

Parent from a non-pathfinder authority

“You can’t say your child is coping, because then you’ll lose the support. But it’s only because they’ve got support that they’re doing well – you have to keep showing that they’re not coping, even when the support is working.”

Parent of a child with high functioning autism, Non-pathfinder authority

“I felt as if it was a trial. Two social workers were present. I was asked personal, irrelevant questions about my finances. I have received a written report, but still no services, just a recommendation to access youth groups.”

Parent of a child with Cerebral Palsy, Non-pathfinder authority

Participant non-pathfinder areas reported waiting times of between 3 and 18 months from assessment to receiving services. Some families reported having to reach crisis point before receiving services after assessment or having to chase to see if a referral for short breaks services had been made. Often care packages were delayed where direct payments were agreed but suitable staff could not be found.

All participant groups identified improvements that could be made to the assessment process. The process must be more robust in order to give parents confidence that the service is equitable; there must be a joined-up multi-agency approach to prevent families from having to re-tell their story to different professionals; local authorities must provide timescales from assessment to service provision so that families know what to expect and when and this must be consistent, transparent and widely available.

“Shouldn’t there be some kind of timescales for the assessment? With your education assessment it’s all set out really clearly that the stages need to be done in a certain number of weeks, and it helps keep people on track, but with this assessment there’s none of that.”

Shouldn't it be the same so we can expect the assessment and then the service in reasonable timescales?"

Parent from a non-pathfinder authority

"Parents see other families getting more care than them and think it's unfair, but they don't know what is going on at home, it isn't just the child's needs, it's also about the impact on the whole family."

Parent of child with hydrocephalus, Non-pathfinder authority

Key recommendation:

Local authorities must provide information to families as part of the Core Offer, which explains the purpose, timescales and likely outcomes of assessments.

Participation and feedback

Participation in design and delivery

Parents involved in this project reported that for them successful participation in short breaks service delivery relied on a good relationship between the local authority and parents, with local authority leadership championing issues for disabled children and groups who have established links and are involved in processes from the outset.

Based on the information from parent groups in this project, where parent participation in the short breaks programme is working well, there is recognition of parent's expertise. Participant groups in both short breaks pathfinder and non-pathfinder regions reported good practice models such as parental involvement in short breaks steering groups, strategy and communication groups; parental involvement in short-listing and interview processes for short breaks programme staff and parental involvement in delivery of training to other parents. Good practice also included the local authority understanding the barriers to participation and supporting parents to be involved by reimbursing travel and childcare expenses. Parent groups in both pathfinder and non-pathfinder areas also reported an agreement with their local authority to feed back their findings from this short breaks tracking process to inform service development was key to successful parent participation.

Additionally, parent groups in short breaks pathfinder authorities have used innovative ways to link the parent participation funding available from AHDC to the delivery of the short breaks transformation programme. Examples of this include using the principles of Early Support models to engage parents and push parent partnerships forward and parents being involved in advisory panels looking at providers bidding to expand inclusive universal services.

Challenges to participation seem to be linked to wider communication difficulties between the local authority and parents, with lack of clarity or feedback to parents on consultation processes. Parents explained that negative experiences can create problematic relationships between local authorities and parent groups. One non-pathfinder region reported a lack of opportunity to participate in local authority meetings if you are in full-time employment, as meetings tend to be scheduled during working hours with little flexibility offered. Difficulties also arose when consultation meetings had little direction or clear action plans and the use of jargon left parents feeling disengaged. This variability in experience demonstrates the need for consistent communication standards between local authorities and parents groups involved in the short breaks programme.

"We spent a lot of time getting parents views on short breaks last year. We're still waiting to hear what the results will be."

Parent of a child with Downs syndrome, Non-pathfinder authority

"I never heard back. I wrote to the chair and asked... what had happened to the consultation, were these meetings for parents... or professionals, and would they let me have the notes from the last meeting and the date of the next one, and I haven't heard anything back."

Parent from a non-pathfinder authority

There is concern across all participant areas that only parents who are already well engaged with services have the opportunity to participate in short breaks design and delivery, and parents sent a clear message to target those parents who have not previously been involved and families who are not receiving services. Dedicated participation workers and using parent participation funding to pull together all strands of the AHDC programme, building on innovative examples from pathfinder areas such as pilot satellite groups is crucial to ensure effective roll out of the short breaks transformation programme in 2009 to 2011.

Feedback mechanisms

Wider feedback mechanisms are also a crucial part of the consultation process with families. While many short breaks services provide service evaluation forms and individual parents reported good experiences of a complaints procedure, there was a general lack of consistency across services and the need for more uniform feedback and complaints systems. Many parents 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 can be particularly problematic in more close knit communities where staff and parents often live in close proximity.

Key recommendations:

When involving parents in the design and delivery of short breaks, local authorities must ensure there is a consistent mechanism for feeding back how views are used and decisions taken.

Local authorities should develop a strategy for engaging hard to reach groups of parents in short breaks consultation, for example those who have not previously participated, those in rural communities and those not in receipt of services.

Summary of key recommendations

Priority recommendations:

1. Children's Trust Partnerships (including Directors of Children's Services and Chief Executives of PCT's) must demonstrate their commitment to families by taking a leadership role in meeting the Full Service Offer on short breaks by 2011, including ensuring this meets the needs of all disabled children, particularly those with the most complex needs.
2. Following the judgment in the case of JL and LL v Islington London Borough Council [2009] EQHC 458 (Admin), EDCM is backing the Council for Disabled Children's call on all local authorities to review their eligibility criteria and the Department for Children, Schools and Families to provide a central steer from government to issue guidance on the law governing eligibility criteria.
3. Local agencies should ensure that good quality information on short breaks services for disabled children are available from a wide range of sources including specialist and universal setting such as children's centres, hospitals and family information services.

Further key recommendations:

Local authorities should develop local commissioning guidance using best practice short breaks models to inform service development.

Local authorities should increase flexibility and choice in service provision by building on best practice models of the AHDC individual budget pilots as part of a menu of services and support, and parents are involved to ensure that services meet the needs of families.

Local authorities must provide information to families as part of the Core Offer, which explains the purpose, timescales and likely outcomes of assessments.

When involving parents in the design and delivery of short breaks, local authorities must ensure there is a consistent mechanism for feeding back how views were used and decisions taken.

Local authorities should develop a strategy for engaging hard to reach groups of parents in short breaks consultation, for example those who have not previously participated, those in rural communities and those not in receipt of services.

Appendix 1 – Demographics

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

A total of 27 parents took part in the first year tracking project.

An additional 10 parents are expected to contribute to the EDCM short breaks tracking project in years two and three.

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

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

Contact EDCM

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Download copies of the EDCM short breaks tracking interim report at:
www.edcm.org.uk/shortbreaks