

Raised Expectations:

Parental experiences of short breaks

Every Disabled Child Matters (EDCM) is the national campaign to get rights and justice for every disabled child.

EDCM is a consortium campaign with four lead members: Contact a Family, the Council for Disabled Children, Mencap and the Special Education Consortium. Between them, the campaign partners work with and represent 770,000 disabled children and young people in the UK. EDCM has over 34,000 supporters

The Every Disabled Child Matters Campaign wants central and local government to:

- Give disabled children and their families new rights to the services and support they need to lead ordinary lives.
- Invest resources to make sure these rights can become a reality.
- Give disabled children and their families a new level of priority, and work with them to improve the services they receive.

For more information and to sign up to support the campaign please visit

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Aims of the Project

From 2008 to 2011 the Every Disabled Child Matters campaign (EDCM) has undertaken a 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 have documented changes in their experiences of short breaks services in their local area at quarterly intervals, gathering evidence in relation to levels, quality, choice and control.

They have also reported on the elements of the AHDC Core Offer:

- information and transparency
- assessment
- participation and feedback

The Core Offer was introduced in 2008 as part of the AHDC programme. It was 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

Parents in each of the four local authorities (LAs) involved in this research have reported that over the past three years they have been able to access more short breaks. Where disabled children and their families have been able to access these short breaks, they have reported that generally they have been of a very good quality. Parents have also reported that there is much more creativity in organising activities meaning that disabled children are getting the opportunity to do more activities than they have been able to do before. Parents feel that their children are growing up as more confident, included and independent young people.

Parental experiences of short breaks in the pathfinder areas and non-pathfinder areas we have looked at have aligned over the course of AHDC. One of the most positively reported outcomes of the work done in local areas over the past three years has been the establishment of Parent Carer Forums and their key role in commissioning services and acting as an intermediary in the local area.

However parents reported confusion about the application of local eligibility criteria, and experiences of feedback vary vastly. Parents also reported concerns throughout the three years about children with complex health needs being excluded from short breaks in some areas. In many cases this was due to a lack of joined up working between the LAs and the Primary Care Trust (PCT). Parents felt that 'health and safety' fears remain within LAs about children with complex health needs accessing short breaks services.

Issues outside the remit of the research that arose included concerns about the impact of a lack of adequate short breaks resulting in relationship strain and breakdown, and, issues around poor transport provision to and from short break provision. Additionally parents expressed their concern about the future of short breaks now that funding for them will no longer be ringfenced, they also spoke about the importance of knowing your rights to ensure

you are getting the services you are legally entitled to and to hold your LA to account. There were also worries about short break provision when a young person is approaching 18, and so moving from child to adult services, and for the initial months following that.

Levels, Quality, Choice and Control

- Families over the three year research programme have reported that they are generally happy with the levels of short breaks that they are accessing and that levels have increased since the beginning of AHDC. However there were concerns expressed that some groups of children, such as children with complex health needs continue to be excluded from local short breaks. Families had mixed experiences of short break provision during 'emergencies' reporting good experiences where the emergency could be predicted (such as the birth of a new child) but mixed experiences where an emergency could not be anticipated. Parents were worried about the future of short breaks in a tightened economy and without ring-fencing.
- Parents commented on the high quality of many of the short breaks that they and their children are accessing. Reporting that this had a positive impact on their child's development as it enabled them to have many opportunities that previously would not have been available. However issues with staff training continued to be raised and where there were negative experiences with short breaks this was invariably due to a lack of sufficiently trained staff.

- Choice and control are amongst the most important factors in parental satisfaction of short breaks. Direct payments are seen by many as a way of ensuring they get the short breaks that they want. However in many areas direct payments are still in their infancy and families can struggle to employ well trained staff and lose their short breaks as a result.

Information and Transparency

- There was a lack of consistent information on short breaks throughout the areas involved in the research. Parents reported that Parent Carer Forums have been disseminating information where LAs have not been doing this sufficiently. This is concerning as information dissemination is not part of Parent Carer Forums main role and so having to take part in information dissemination takes them away from their core purpose.
- Parents remain confused about the application of local eligibility criteria and reported that they felt that local short break allocation is inconsistent.

Assessment

- Parents, over the past three years have reported more consistent experiences of assessments; however they highlighted that they felt assessments continued to focus on what their child couldn't do rather than what they could do.
- Parents also commented that they felt that during assessments they frequently had to provide very personal information and they were concerned that this was not always relevant to the needs of their child and was distressing to discuss with a stranger.

Participation and Feedback

- Parents were happy with improved parent participation in service design and delivery. In many areas parents reported that parent participation has become entrenched. Feedback from LAs on actions taken following consultation with parents remains very important for parents to be able to see the value of their involvement.
- Parents were positive about ways that they could feedback to the LA about short break services. However, there was little knowledge about formal complaints procedures if something went very wrong.

Introduction and background

The Aiming High for Disabled Children Programme

“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.”¹

Aiming High for Disabled Children: Better Support for Families (AHDC)² is the report and accompanying service transformation programme 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 significant additional resources - £340 million revenue funding, from 2008 to 2011, to transform LA services for disabled children. This funding was 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 LAs 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,

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.’

reliable and appropriate short breaks.

In December 2008 the Children’s Plan⁴ committed an additional £90 million LA 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.

This brought the total government funding allocation for disabled children from 2008 to 2011 to £770 million. However it should be noted that whilst the funding for LAs was ring-fenced for disabled children, the funding announced for Primary Care Trusts was not.

Local Authority Funding

Following a bidding process, 21 English LAs 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 were: 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.

All other LAs 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’.

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.’

Short breaks – a Coalition Government Priority

In December 2010, the Government announced that there would be £800million available from April 2011 over the next four years to fund short breaks in England. This represents an increase in funding by the Coalition Government to LAs for short breaks of approximately £20million per year. This money is available as part of the Early Intervention Grant (EIG) – money that has been allocated to LAs to fund early intervention and preventative services to children, young people and families. However, unlike AHDC the money available for short breaks under the EIG is not ringfenced.

In order to ensure that short breaks remain a focus, the Coalition Government laid regulations under the Children and Young Person's Act regarding short breaks, which came into force in April 2011. Entitled *Breaks for Carers of Disabled Children Regulations 2011*, these regulations mean that LAs are required to:

- offer breaks as a preventive early intervention
- offer a range of services for parents
- publish a statement of those services on their website. This statement must include details of any eligibility criteria the LA applies to short breaks services.

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.

Short break services in 2010/11

Over the past three years the EDCM short break tracking research has looked at how optimistic or pessimistic parents of disabled children feel about short break provision in their local area. Optimism about the future has varied widely depending on personal circumstances as well as the general short break provision in the area. Last year EDCM reported that parents felt optimistic if they could see that there was a range of high quality short breaks for them to access in the local area. Parental optimism was also higher where there was good parent participation and when parents could see that there were outcomes from their involvement in local consultations. Parents also felt that AHDC had pushed disabled children and short breaks up both the national and local political agendas.

The same trends have continued into the final year of the project. Parental optimism was again dependent on individual experiences and local involvement of parents in commissioning short break services. The involvement of parents in commissioning in some areas during 2010/11 has led some local areas to seek opinions from parents when deciding how to prioritise services, as LA budgets were reduced. This allowed parents to highlight which services they thought were crucial – such as transport to short breaks – and ways in which local services could be delivered in a more cost effective way. Again, when involving parents in this way it was crucial that parents continued to be informed about how decisions were made. Parents felt that through being involved they saved money in the long term for the LA as vital services were not lost and families felt that they could continue to cope.

As the AHDC programme has come to an end, and there have been cuts in local budgets, some parents feel very pessimistic about what the future holds for them. Prior to the confirmation of funding through the EIG, families were concerned that short break provision would return to the pre-AHDC levels. Whilst families have been reassured to some

extent by the announced EIG funding, concern remains on its non-ringfenced nature.

“Optimistic – I am more involved in (Parent Carer Forum) and seeing what is going on. All along I’ve been the one saying I’m optimistic but with all the cuts... I am feeling very apprehensive. The whole of AHDC was brilliant. It put parents and our children with disabilities at the forefront and we don’t know what is going to happen in the future – are we going to be back to square one?”

“It is essential that my son is able to access the things he had done over the past two years otherwise how on earth is he going to learn to socialise and learn to live independently.”

“I’m pessimistic because they haven’t announced their plans and I don’t know what’s coming next.”

Pervasive themes

During discussions with parents there were 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. Transition

Parents involved in the research programme whilst their child turned 18, or in the lead up to their child turning 18 spoke of the difficulties in planning short breaks for the period directly after the child turned 18. Parents also spoke about a common problem during the six months leading up to their child turning 18 being told that they couldn't be assessed for short breaks by either child or adult services. This meant that when a child turned 18 there was a 'cliff-edge' of support and parents had to wait for, and frequently chase, assessments meaning there were frequently long periods of time between short breaks. This raises questions about the portability of assessments between children and adult services. Improving portability should be considered as part of the reform of adult school care and the Special Educational Needs (SEN) and Disability Green Paper agenda.

"We should have no problems because we are straight forward – transition is happening to people all the time so I don't understand what the problem is."

2. Impact of short breaks on relationships

Parents highlighted the important role that short breaks have in enabling parents to maintain relationships or for lone parents to establish new relationships.

"I am a young single parent, I want evening breaks so I could go on a date or something"

3. Knowing your rights

Parents also spoke about the importance of knowing their rights and what they are legally entitled to in terms of assessment and accessing short breaks. Parents often reported that they instinctively felt that something, such as being denied a needs assessment, must be illegal but without legal knowledge they lacked confidence to hold their LA to account and seek redress when things go wrong.

"It's all about knowing your rights and knowing what you are entitled to – you need to know how much fuss you can make when you are told the wrong thing. When you've asked and been told 'no' then do you take that at face value?"

Levels

Increase in levels of provision

Over the three years of the tracking research project parents in both pathfinder and non-pathfinder authorities have reported year on year improvements in the levels of short breaks they have been able to access. In particular there has been an increase in access to short breaks for families who have not accessed short breaks in the past and children with less complex health needs. Families report that they believe the increase in uptake is due to the better availability of short breaks that they can access without an assessment such as inclusive football clubs and swimming sessions. Parents in a non-pathfinder area have reported that the most notable change over the past three years was that families could now access short breaks for long periods of time without the fear that they would lose them because there wasn't enough provision to go around in the local area. This change was due to increased funding which meant that families were able to access longer or more frequent breaks as there were more hours available for short breaks and increased funding meant that services could run all year around, whereas previously they may have only been able to run in holidays or at term time.

“What I didn't like before (AHDC) was not knowing if he was going to get time at the (short break centre) again but for the last two years I've just sat back and he's got it.”

Impact of cuts

One of the important trends that parents reported over the first two years of the short break tracking research was that short break provision was moving from a crisis to a preventative model. However, in the last year there have been signs that LAs are returning to the crisis model. For example, there have been reports in both pathfinder and non-pathfinder authorities of parents having their short breaks substantially dropped without reassessment. In one case this was due to a funding dispute between the PCT and LA which resulted in the halving of a families' overnight breaks. This left a parent with such limited short breaks that they felt that it posed a risk to the child's health as they were unable to care for them effectively without short breaks.

“If he's having fits in the night sometimes I'm so tired I'll sleep through them. There's other times I wake up and he's sleeping in vomit and I haven't woken up, so for me the concern is if I'm not getting the breaks then I'm not able to care for him during the night properly.”

Children with complex or changing health needs

Parents over the three years of research have reported difficulties in accessing short breaks for children with complex or changing health needs because of a lack of joined up working between health and social services. This means when a child becomes ill, the family loses all their short breaks.

“I didn’t realise that the funding for the hospice came from health; to me it’s just a service that we want. I don’t know how to differentiate between whether it is health or social care paying for the services that I want so I don’t know who to go to, to get the services I need.”

Additionally, concerns have been raised throughout the three year research project that there are some groups of children that struggle to access short breaks. Some of the most common groups mentioned include: children with epilepsy or complex health needs who parents felt were viewed as a ‘health and safety’ risk by the LA; black and minority ethnic groups; and families where the disabled child attends mainstream school.

“My child can’t access services like other children do because she is epileptic so if she goes anywhere I have to go. We tried to change short breaks at the end of last summer from short break workers to residential breaks. I was told I would get the same level of assessed need as I had been getting – but that was a lie. I hadn’t been able to access direct payments for a year because I couldn’t find anyone, so I froze them. Then it comes to September and I was told I couldn’t have my overnights at the residential centre and I’d have to find a PA. So I found one but now my direct payments have been frozen by the local authority as they are doing a review into the use of PAs for any children with epilepsy. I was told it would all be resolved within a few weeks and here we are six months on and it still hasn’t be sorted – I’m still not getting direct payment and I’m still not getting my extra overnights so my short breaks have been halved since last year.”

Reports of cuts to valued services were particularly prominent in the lead up to the LA budget setting period in the winter of 2010.

Due to the non-ringfenced nature of the EIG parents remain concerned about the future of valued short breaks in a tightened economy and queried how the Government could ensure that the money was spent on short breaks. There was a mix of attitudes from *“this is the best it’s ever going to get”* to *“there’s no going back we have to retain services at the level they have reached under Aiming High”*.

Family emergencies

Throughout the short break tracking project parents have been anxious about what support there is in their LA during times of family emergency. In the second year of the research parents in both pathfinder and non-pathfinder areas reported that good practice was starting to be developed. Parents have this year reported mixed experiences. There have been some examples of good provision, particularly where the emergency could be predicted, such as the birth of a new child. However, there were also examples of parents not being able to access additional help during times of crisis and, on some occasions, parents felt that this risked both the child’s and the parent’s safety.

“My son has an operation due shortly where he will have both legs in plaster. I did ask for extra help but was told with all the cuts that wasn’t possible. When his legs are in plaster he will be so frustrated that he won’t sleep at all and that means we won’t get any sleep either. So we will eventually have to ask for help anyway”

Quality

Increased number of quality breaks

Parents in both pathfinder and non-pathfinder areas commented on the increased number of high quality short breaks that they are now able to access and the positive impact this has had on their children. Parents identified high quality short breaks as breaks that were run by well trained staff; that were a positive experience for, and met the needs of, all the family; and when parents knew their child was doing a positive activity. As in previous years the most positive comments related to the development of group-based non-specialist provision which has resulted in a wide range of creative short breaks. Families also spoke highly of the short breaks they have been able to access as a family, such as cycling schemes, and where investment has been placed in infrastructure that will be able to continue to run beyond the end of AHDC.

“The last eighteen months has been absolutely immense. My son has now done surfing, he wouldn’t climb before but now he’s got to the top of the wall, he’s been on the zip wire, kayaking, drama, pantomime. It’s made him come out his shell; he’s just grown and grown from it all. I had this little boy who was always around the house watching videos and he’s changed so much”

“Any family with a disabled child qualifies and that’s been one of the really nice things. We’ve had three generations pedalling around the track together, and it’s something that siblings can get involved in.”

Lack of adequately trained staff

Staff training has been raised as an issue throughout the three year research programme. There were some reports of poorly trained short break staff, resulting in disabled children and young people having distressing experiences as their needs were not adequately met. This has been particularly problematic for children with the most complex care needs. Problems have included staff not being aware of how to calm down or communicate

with children with speech, language and communication difficulties and not knowing how to discipline disabled children in mainstream settings.

“My son got excluded because he swore and a family complained about him. The only way the (short break staff) thought of dealing with it was excluding him, but that was sorted by the training. I said to them ‘what would you do if it was a child without a disability?’ and they said they’d tell him off and I said ‘that’s what you’ve got to do for him as well then.’”

“I took my daughter (to her short break) after sitting in traffic to get there. She has to have something in her hands whether it’s a toy or whatever. I went back for her an hour later and she was niggled and stressed and I thought ‘She’s not happy, what’s wrong?’ and I looked and she didn’t have her toy. A member of staff had taken her to the toilet and had left the toy in there. And the member of staff said to me – I wondered why she was a bit agitated. So I thought no – for two hours with me driving half an hour there and back, so time just for me to sit and eat my tea, it wasn’t worth it. She was agitated then all night and I don’t want to see her like that. I was angry. They called up to see what happened and they said we’d like to think you’d bring (daughter) back here but I just thought I’ll go to another (short break provider). I’d made a point from the outset of listing all her needs. That was the other thing no one even noticed. That made me think then is she just lying there on the floor doing nothing.”

“So they’ve decided to create a new policy – all PAs working with children with epilepsy have to do two lots of training before they can even be employed. The parents have to pay for the training on top of the £130 we pay at the moment for personal liability insurance. Now parents with a child with epilepsy have to pay £89 on top of this for training. After that we have to save our direct payments money to pay for the training – which I actually think is discriminatory.”

Good practice has seen LAs work with Parent Care Forums to deliver training to short break staff. However, issues with a high staff turnover can result in a lack of adequately trained staff to meet the specific needs of the disabled children they are caring for. Parents indicated that they felt that the high staff turnover was due to low wages and the lack of certainty about the future of short break funding.

Choice and Control

Inappropriate breaks

Choice and control are key to parental satisfaction of short breaks. Parents welcomed an increased range of short breaks which enabled them to choose from a wide range of options to select the ones that best reflect their child's needs.

However, families with children with complex needs continue to highlight problems in accessing short breaks that cater to their children's specific needs. Examples include children being forced to move onto new 'age appropriate' short breaks regardless of whether these breaks are appropriate to their development; where families are only offered day time short breaks but feel they require overnight care; and offers of inappropriate breaks during times of emergency.

"The difficulty is that I'm asking for specific help and I'm offered something else. The confusing thing is when (the help you want) is being offered to other people"

"When I hurt my back they said that I could only have someone come during the day time or during the evening, but my back is going to hurt all day long. I was out of action for two weeks – in the end I chose to have someone come in the morning to get him ready for school then I could rest all day, but at 4pm the driver wheeled him to the door and I had to then get him out of his wheelchair and change him. I was worried that if he had any fits I wasn't going to be able to get up and go over to him."

Direct payments

Parents view accessing direct payments as a way to increase flexibility and control over their short breaks. Where there are lots of appropriate short break options available for families to purchase then parental satisfaction is high. However, in many areas direct payments are still developing, meaning that issues reported in the first two years of this research, such as a lack of choice and poorly trained staff, continue.

In some areas parents have to spend a lot of time and money training direct payment funded carers so that they are able to provide the families with a short break. This requirement to provide training eats into short breaks and is an issue exasperated by high staff turnover. Parents reported that over the last year there has been better local support enabling parents to manage direct payments, for example training courses on paying National Insurance contributions, which is something families had previously reported difficulties with.

"It gives you flexibility which is good because I don't have that. I've never had in thirteen and a half hours a weekend off from (daughter). I just want a Saturday occasionally that's why I want direct payments so I can get that flexibility."

"One of the carers seems to have a lot of time off sick and 3 times this month I have had a call to say no-one is able to come. They only let us know they wouldn't be coming a few hours before she was due and meant my husband had to come out of work for a while on one occasion as I couldn't leave the hairdressers in the middle of having my hair dyed and on the other occasions I was working and had to leave work."

EDCM Response

EDCM welcomes the positive feedback from parents on the quality and levels of short breaks available as a result of ring fenced funding for short breaks. We are pleased that parents have reported that the financial investment in short breaks services over the past three years had been used to invest in short break infrastructure. Parents have provided us with evidence that there has been a step change in attitudes towards short break provision in the four areas involved in the research. This is resulting in more universal services being made available to disabled children, better trained staff and local infrastructure development so that families with disabled children will continue to be able to access short breaks.

The *Aiming High for Disabled Children: Short break Implementation Guidance 2008* identified that there were five groups of children who were struggling to access appropriate short breaks at the start of this service transformation programme – children and young people with Autistic Spectrum Disorder (ASD); children with complex health needs; children and young people with moving and handling needs; children and young people with challenging behaviour associated with their disability and disabled young people aged 14 +. Evidence provided by parents during this research has demonstrated that in the four areas involved short break provision has increased exponentially for some of these groups – such as children with ASD and over 14s.

However, we are concerned about the lack of improvements in short break provision for disabled children with complex health needs, where it appears that there have been limited improvements. In particular, children with epilepsy and other health conditions that result in fits appear to be excluded from many services as LAs view them as a 'health and safety risk'.

This issue is exacerbated by local area conflict between the LA and PCT regarding who is responsible for providing and funding short breaks for these children. The Government is currently introducing widespread changes to the health system through the Health and Social Care Bill. As there will no longer be a requirement on local areas to convene a Children's Trust Board, it is crucial that the Government clearly sets out where accountability will lie for ensuring that short breaks are delivered to meet both clinical and family support needs. We are particularly concerned that the Government has yet to make it clear where responsibility will lie for the co-ordination of health and social care services for disabled children within proposed Health and Wellbeing Boards and Clinical Commissioning Groups. If this is not clearly defined as the new system is developed, local areas will struggle to tackle the longstanding issues revealed in this report.

Finally, although direct payments are a positive mechanism of choice and control for many families, it is clear that they should never be the only way to access services. Families who are already struggling to manage their caring responsibilities may not want to take the additional responsibility of direct payments. It is therefore vital that direct payments are available as one option within a menu of wider services, regardless of the child's impairment. It is also important that there are safeguards in place to protect families who choose to use direct payments and then are unable to access any suitable services. The SEN and disability green paper, *Support and Aspiration: a new approach to special educational needs and disability*, proposes a new right to personal budgets from 2014. Whilst we welcome this move and the important access to personalised short breaks it will allow many families to access, personal budgets do not suit all families in all locations. It is therefore important that families can still access other types of support where they do not wish to access a personal budget.

EDCM Recommendations

Levels

- The Department of Education, through its short break delivery partner, should monitor and publish local resource allocation under the Early Intervention Grant in order to ensure the Government's intentions are being met.
- The Department for Education and the Department for Health should establish clear accountability for integrated planning and delivery of short breaks provision within the new health and social care frameworks, particularly in relation to Health and Wellbeing Boards, Clinical Commissioning Groups and HealthWatch.

Quality

- The Department for Education's delivery partner on short breaks should prioritise approaches to work force development to increase parental confidence in short break professionals. High quality training should be delivered to all professionals delivering health and social services to disabled children and their families.
- Parent Carer Forums should be central to the development and delivery of the *Support and Aspiration* pathfinder programme, at both a national and local level.
- Local authorities should continue to work with their local Parent Carer Forums on an ongoing basis on the design and delivery of short break services.
- Local authorities should continue to improve children and young person's participation in short break design and choice.

Personalisation

- Local short break provision must include high quality directly delivered services available without personal budgets.
- The Department for Health through Health and Social Care Bill needs to ensure that disabled children and children with SEN will be a priority for Health & Wellbeing Boards and there will need to be an equal responsibility between health and other agencies for outcomes for disabled children and children with SEN.
- The Government in the development of the personal budgets should prioritise: information and support, independent brokering systems and clear routes of redress.

Information and Transparency

Availability and Clarity of information

Under Section 2, Schedule 2 of the Children Act 1989 LAs have a duty to provide information, advice and assistance to parents of disabled children and children with SEN 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.

Last year parents in non-pathfinder areas reported that access to information on short breaks was much improved, however there had been mixed experiences in pathfinder areas. In the final year of this research there has been concern from all areas involved that there is a lack of information that families can easily access in one place within the LA – for example through a web page or a leaflet about all services available locally.

“Parent’s fed back (to the LA) that they wanted information sent to them as it was all word of mouth previously. Now you get a quarterly booklet either through school or through the post”

“The last thing that people coming to terms with their child being disabled want to do is come to a meeting so I think it’s important that information is easy to access – parents are saying we don’t know where we can go to get information. It would be good if you could find out information about services from the internet.”

Accessible, available information

In both pathfinder and non-pathfinder areas, parents have told us that they want usable and clearly accessible information on the internet about local short breaks including information on: what breaks are available; who is eligible; where and when they take place and who to contact to find out if you can attend. Parents stated that they want this information to be provided in a range of languages and to be well sign-posted for families new to disability or without a social worker. Parents also stated that they continue to value information on paper leaflets, for ease of reference and for parents who were not able to access the internet easily. Concerns over inaccurate distribution lists were raised, with parents anxious that people currently receiving short breaks would get the information, leaving new parents in need of a break unable to access information about them. Parents reported to us that Parent Carer Forums are playing an increasingly important role in the dissemination of local information about short breaks. They bridge a gap, reporting information from all different sources across the local area, rather than just LA funded breaks or PCT funded breaks. This is concerning because information dissemination it is not part of Parent Carer Forums main role and so having to take part in information dissemination takes them away from their core purpose.

“They tell you to go to the library or internet cafes to find out information but how long will it be before you get asked to leave because your children are making noise or not sitting still, and they’re not open in the evenings”

Information across boundaries

Concerns were also raised about information about short breaks getting to families who live on the boundary of two LAs, or who access education in a different LA to where they live.

“Our problem is that the school is on the county boarder so we get a lot of information about short breaks we can’t access.”

Parents in one pathfinder area raised unease about the level of knowledge parents are expected to have about local services and whether it was the social worker or the families’ responsibility to chase up support.

“They asked me after my child was in hospital did I call (short break centre) to let them know he was in hospital and I said ‘no’. They said if we don’t know about it then there’s nothing we can do about it, but the point is that beforehand when I hurt myself and I called and asked for help they said there was nothing they could do. How could I know there was help in this circumstance? I wasn’t to know they could help people in hospitals – you don’t know what help is available.”

Transparency in eligibility criteria

In the first and second year’s short break tracking report, it was reported that LA application of eligibility criteria was leading to confusion and that there was a lack of consistency. Many parents were unclear about how to get short breaks, who to approach and what they are entitled to. Despite LAs preparing for the duty to provide short breaks and the upcoming deadline to create and publish short break statements, parents continue to view local eligibility criteria as un-transparent and unclear. Families do not understand why the levels of short breaks that they receive are different to those of a family in apparently similar circumstances. This was an issue for parents in both pathfinder and non-pathfinder authorities.

“There are other people that seem to get it without a fight. There’s no consistency. They say it’s all about personal circumstances but I don’t know that it is. Some people just seem to get the services but I have to fight for everything.”

“We don’t know what the options are as parents – you hear other people have overnight care and you don’t know how they managed to get that.”

EDCM Response

EDCM is concerned that many parents are still unhappy with the information available about local short break services. This is disappointing as many parents have commented on the high quality short breaks they have experienced but without good quality information families will not be able to find out about and access these services. As highlighted by the comments from parents this is going to particularly impact on the hard to reach families who may not currently be accessing short breaks.

In the second year interim report EDCM recommended that the Secretary of State with responsibility for children 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. EDCM also recommended that LAs that operate eligibility criteria for short breaks should publish them on their websites to ensure they are available for local challenge. Following last year's report EDCM wrote *Calling for Clarity: Eligibility Criteria for Short Breaks* which examines 60 LAs short breaks eligibility criteria. It found that 28 per cent of LAs were operating potentially illegal eligibility criteria. Since the publication of *Calling for Clarity* the Government has brought out the Breaks for Carers of Disabled Children Regulations 2011 and accompanying guidance, *Short Breaks for Carers of Disabled Children: Advice for Local Authorities*. This guidance provides information on LAs duties under the Children Act 1989. The Breaks for Carers regulations required LAs to publish a short breaks statement on their website by October 1st 2011. This short breaks statement must include local eligibility criteria for short breaks. EDCM is concerned that it is currently unclear how LA compliance with the regulations will be monitored.

The Government's Green Paper on SEN and Disability, *Support and Aspiration: A new approach to special educational needs and disability*, proposes the creation of Local

Offer for services available to families with disabled children. EDCM believes that there is a crucial link between the development of a Local Offer and the way in which a local area gathers information on local needs and commissions services. The development of the short breaks service statements based on local need could be used as an early exemplification of this approach. EDCM believes that this approach has significant potential to improve clarity about what provision is available and to whom; this will have further benefits in terms of positive partnership with parents. A Local Offer, clearly articulated, should also be amenable to review as the evidence of the impact of different approaches develops, as children's needs and parents' wishes change. To make the local offer an effective tool there needs to be a clear duty to deliver the local offer. This needs to bite on all agencies through clear accountability in terms of statutory and financial responsibility to deliver.

EDCM Recommendations

- The Department for Education's new short breaks delivery partner should ensure that compliance is adhered to under the duty to provide breaks from caring by:
 - Ensuring that all LAs produce short break statements that meet the 'spirit of the law' to increase access to regular, reliable and appropriate short breaks.
 - Ensuring that local service planning and eligibility criteria are transparent.
 - Ensuring that short breaks statements and eligibility criteria are published in a way that makes them easily accessible to local parents, both by placing them in a one-stop-shop local website and by providing alternative routes of access to those who do not use the internet.
- As the Department for Education develops the Local Offer proposed in the SEND Green Paper there should be a clear duty to deliver. This needs to bite on all agencies through clear accountability in terms of statutory and financial responsibility to deliver.
- In order to support a holistic Local Offer, Parent Partnership Services should receive training on the delivery of advice on health and social care.

Assessment

In the first and second years of research, parents identified issues with a lack of consistency in assessing parents for short breaks. Fewer parents have reported this in the third year, although problems with lack of transparency about eligibility criteria can lead to parents feeling that there is inconsistency in short break awards. This particularly led to discontent when families in the same local area with apparently similar circumstances are awarded very different short breaks. Parents also raised concerns about the very personal nature of information about their home lives that they had to share and questioned how relevant this was to gaining short breaks.

“They are asking a lot of questions about your home life. Then they leave and you get a phone call a couple of weeks later telling you what you are going to get – you don’t know what the process is between the two. They know all about my family life and I just feel like they are trying to keep files on me and then at the end offer me services that don’t match my needs.”

In the last year parents have reported fewer examples of illegal bans on assessments for certain impairment groups, although some examples do continue. This improvement has been achieved in many cases by parents who are more aware of their rights, demanding assessments for their children under Section 17 of the Children’s Act 1989.

“I am interested that I recently found out that ADHD is included under the definition of disability and that it’s unlawful to not assess. I’m not exactly sure who I go to or where I go to to get assessed because in the past I’ve been dismissed with “no you don’t meet the full criteria”. I’d like to see what we can access because I’ve got three disabled children and some times it’s hard and we would all like a break. It’s difficult though because I’ve not got a social worker I don’t know where to go”

Parents also raised concerns that they still have to focus on what their child cannot do and the worst things that happen in the household to access short breaks. This is extremely demoralising to the family and can be very difficult for families to discuss. This is particularly an issue where families are being re-assessed relatively frequently.

“For the social worker to get the best and most services for your child she has had to portray you as the ‘family from hell’.”

Parents in one pathfinder area said that in order to try and reduce reassessments, the local area has attempted to re-use information collected in previous assessments – rather than to appropriately reassess to adapt the package of support based on families’ changing needs.

Parents also continue to discuss positive experiences of short breaks that parents can ‘self refer’ themselves to and accessible universal services. The development of services that families could access without a referral from a social worker means that families who have traditionally been less able to access short breaks have been able to be included. This included children who do not yet have a diagnosis, children who have less complex needs but benefit from more accessible facilities, and, families who do not have a social worker or whose child attends mainstream school.

EDCM response and recommendations

EDCM Response

EDCM is concerned by parental reports that families are being denied simple rights for their disabled children – such as being denied a need assessment. Whilst it is positive that parents are becoming more informed and demanding that they get their rights, this should not be the only available way to achieve support. This would simply mean that only the most informed and confident parents are able to ensure their rights are upheld. We also do not want to return to a culture of ‘fighting for your services’. It is imperative that LAs act within the law at all times. We hope that the *Short Breaks for Carers of Disabled Children: Advice for Local Authorities* will help increase legal compliance but we think it is imperative that there is some level of monitoring of LA short break provision and eligibility criteria to avoid a culture of legal cases to provide families with the level of short breaks that they are entitled to.

We welcome the ambition set out in the Green Paper *Support and Aspiration: A new approach to special educational needs and disability*, to streamline assessments for families with disabled children. This Green Paper proposes to introduce a new single assessment process and ‘Education, Health and Care Plan’ by 2014, which will align assessment and support across education, health and social care. This represents an ideal opportunity to address some of the concerns of parents set out in this report.

However, in order to be successful, the single assessment process will need to encompass the full range of existing assessment processes within children’s social care, including the Framework of Assessment of Children in Need and the Common Assessment Framework. It must draw on learning from recent good practice programmes such as Early Support.

In order to address parental concerns about sharing information, repeated unnecessary

assessments or lack of responsive assessment when needs change, there should be an identified individual or agency with responsibility for co-ordination of the single assessment process who provides a single point of contact for parents. The key worker, as part of the Team Around the Child, provides a good model for this role; it has been tried and tested and is valued by parents.

EDCM Recommendations

- The Department for Education’s short break delivery partner should monitor compliance of The Breaks for Carers of Disabled Children Regulations 2011 with a view to publish a national picture of short breaks.
- The Government should demonstrate how the single assessment process will encompass the full range of existing assessment processes within children’s social care, including the Framework of Assessment of Children in Need and the Common Assessment Framework. As well as how it will draw on learning from recent good practice programmes such as Early Support.
- *Support and Aspiration* pathfinders should pilot approaches to providing a single point of contact for co-ordinating the single assessment process with families, such as key workers.

Participation and Feedback

Participation in design and delivery

Strategic participation

In both the first and second year of this research parents reported positive experiences of participation in the design and delivery of short breaks. Over this time parents have felt that their strategic participation has resulted in short breaks services which have better reflected the needs of local disabled children and their families. Parent groups in both pathfinder and non-pathfinder areas reported that their involvement in the design of services and resources has been managed well.

“Parents, carers, grandparents are getting a say now, absolutely”

“I say ‘we’ about the commissioning board... I’m only a parent but because we are so involved it feels like I can say we.”

Parent-to-parent support to participate

Parent Carer Forums are playing an increasingly important role in linking parents up with the LA for the purposes of designing services. Many Parent Carer Forums now have permanent representatives on LA short breaks commissioning boards. Parent Carer Forums also use their role as an independent body to conduct consultations with local parents. They feel that this is particularly useful in raising issues that they feel that the LA is not looking at but are of local importance, such as the inclusion of Black and Minority Ethnic (BME) families, or families whose child attends mainstream school, in short breaks services

“The parent forum can run its own consultations in addition to the local authority, picking up on some of the areas that the local authority isn’t able to look at and holding the local authority to account on certain areas – such as short break provision to BME families.”

“What about parents in the playground, would they think they are involved? Not many... being part of the parent forum makes a big difference.”

LAs covered by this research are undertaking good practice approaches to participation by making efforts to engage a wider range of parents through parent-to-parent participation and questionnaires, and holding consultation events that enable disabled children to be involved in shaping services along with their parents.

“Consultation workshops – I took [daughter] to the one in the Spring and they have a theme, so this one was pirates... they’re looking at what the children enjoy doing, speaking to parents about what the children like and if the child is non-verbal its about helping them to communicate so they can. These consultations are very important for planning future services in the summer.”

Clear outcomes

The cornerstone of successful participation is parents seeing the outcomes of their involvement. Knowing how the information they provided was used and what went into the decision making process to make final decision on services design and delivery.

“There was a lot of consultation prior to the introduction of AHDC. There was an opportunity to say your piece but whether they took any notice I’ve no idea.”

“The sorts of things you’ve got – tea time breaks, youth clubs – the money has gone into running extra groups. There is less shoe horning children into the services that the Local Authority wanted and the services are more suitable to what parents want. We are being listened to.”

Feedback

Inconsistent approaches

Over the first two years of the short break tracking research parents reported good experiences of complaints procedures and evaluation forms. However, they reported that complaints and feedback procedures were inconsistent across services.

In the final year of this research project, parents in both pathfinder and non-pathfinder areas remain pleased with the feedback mechanisms they have for each session. One of the most common ways that parents' feedback is filling out feedback forms at the end of short breaks sessions. Parents commented that they were pleased with how the disabled children and young people using the services were able to feedback through accessible feedback forms as well. Whilst feedback forms are valued parents also stated that they thought the LA should seek feedback from parents who did not participate in that short breaks services to find out why and if it was because they didn't want to or because the service was designed in a way that excluded them and their children from accessing it.

"It would be good for the local authority to do monitoring about what's changed in the local area because for me nothing has changed so it's difficult to see what improvements there have been on a local authority level."

Lack of clarity on complaints procedure

There were mixed experiences in both pathfinder and non-pathfinder authorities on making a complaint about a service. Parents were unclear about what the process would be if they had a complaint to make. Responses included: speaking to the short break provider when they had a good relationship so knew their concerns would be taken seriously and acted on; asking their Parent Carer Forum to make the complaint for them; and going straight to the head of the short breaks services in the LA. Lack of certainty over the process meant that where parents had made complaints they frequently felt that their complaints hadn't been acted on or responded to appropriately.

"If we had a complaint to make it would be done informally, unless it was massive and then I'd have to ask what the process is."

"We wrote to representatives from youth services and AHDC and said (what had happened) was unacceptable. They did a thorough investigation, we went to a meeting and they told us what went wrong, why what they would do to remedy it and within what timescales. The other good thing was that they looked at other facilities and asked whether it could happen else where."

EDCM response and recommendations

EDCM Response

EDCM welcomes that parents continue to be satisfied by the levels of their strategic participation in the design and delivery of services. The past three years has seen a large increase in the valued role of parent participation in local areas. There is evidence that LAs are valuing the input of parents much more, due to the benefits of creating local services that met local needs. Additionally, Parent Carer Forums have gained a much strengthened role as parents are more enthusiastic about being involved in shaping local services as they can see the outcomes of their work. The Government has made clear statements on how much they value the input of parent participation in service design and delivery. However a lack of feedback to parents about how their views are used remains an issue in some areas.

Over the past three years, parents have stressed that feedback is an area that requires improvement. EDCM welcomes the many creative ways that local areas have sought feedback such as through play events to get feedback from the disabled children using services.

However it is of considerable concern that parents remain unsure about how to complain when things go wrong, or when services are being developed that do not meet their needs. LAs should demonstrate a clear feedback and complaints process as part of their short breaks statement. In *Support and Aspiration: A new approach to Special Educational Needs and Disability*, the Government has made it clear that it aims to provide greater control for parents in terms of personal budgets. However, there was much less clarity about how the Government intends to strengthen parents' capacity to raise concerns or seek redress when they do not receive the support they need. In order to address this, the new system of health and social care must include clear statutory and strategic accountability frameworks.

Without this, it will remain unclear where ultimate responsibility for short breaks services for disabled children lies within a local area.

EDCM Recommendations

- Local authorities need to be consistent on their feedback mechanism on how views are used and decisions taken following local consultation.
- Local authorities need to have clear feedback and complaints route so that all concerns and complaints are received and acted on.
- The Government needs to develop clear accountability frameworks to determine ultimate responsibility for short breaks services within local areas as part of the new systems being developed under the Health & Social Care Bill

Summary of EDCM Response

Over the past three years short break services in the local areas involved in this research have been transformed. The increase in regular, reliable and appropriate short breaks over the past three years has changed the lives of many disabled children, young people and their families. Additionally there is clear evidence that the positive impact of short breaks has been recognised by both Government and local areas and that continuing to provide short breaks to disabled children and their families is high up on local and national agendas. Disabled children and their families feel empowered from the short break provision of the last three years and believe there is no going back to the limited service provision prior to 2007.

To enable disabled children and their families to continue to access high quality short breaks the Government must continue to place short breaks high on their agenda. The Government must also continue to provide direction and guidance to local areas – both LAs and health agencies – to ensure that the local priority which has been given to short break in local areas, such as those included in this research, continues. It is only through short breaks being a local priority that families will be able to continue to access regular, reliable and appropriate short breaks.

Despite the progress that has been made over the past three years it is clear that there is still progress to be made. It is vital that no child's needs are seen as 'too complex' and misses out on a short break as a result. Accessible information about local short break provision is also crucial to ensure that all families who are able to access a short break in their local area are doing so.

Since EDCM's 2010 report's '*No going back: Parent's expectations of short breaks*' and '*Calling for Clarity: Eligibility Criteria for Short Breaks*' the Government has already taken steps to ensure that high quality short breaks continue such as: short break funding within the Early Intervention Grant; the

commencement of the new duty to provide breaks for carers of disabled children and the publication of guidance to local authorities on producing legally compliant eligibility criteria. However the Government must continue to provide local areas with the tools to deliver legally compliant short breaks services and to demonstrate the priority it places on short break provision.

This report makes a series of recommendations on how we think that local areas and the Government can continue to build on the positive work that has been achieved on short breaks. Many of these recommendations fit around wider Government reform such as the allocation of a new short break delivery partner; the *Support and Aspiration* pathfinder programme, and the Health and Social Care Bill. We also make recommendations to LAs on how they can build on the wealth of knowledge and experience that they have built up over the past three years.

Summary of EDCM Recommendations

Top priority recommendations

- The Government's short break delivery partner should monitor compliance of The Breaks for Carers of Disabled Children Regulations 2011 with a view to provide transparent information on the national picture of short breaks.
- Parent Carer Forums should be central to the development and delivery of the *Support and Aspiration* pathfinder programme, at both a national and local level.
- *Support and Aspiration* pathfinders should pilot approaches to providing a single point of contact for co-ordinating the single assessment process with families, such as key workers.
- The Government needs to develop clear accountability frameworks to determine ultimate responsibility for short breaks services within local areas as part of the new systems being developed under the Health & Social Care Bill.

Summary of further recommendations to Government:

- The Government should demonstrate how the single assessment process will encompass the full range of existing assessment processes within children's social care, including the Framework of Assessment of Children in Need and the Common Assessment Framework. As well as how it will draw on learning from recent good practice programmes such as Early Support
- The Department for Education should make sure that its new short breaks delivery partner ensures that compliance is adhered to under the duty to provide breaks from caring by:
 - Ensuring that all LAs produce short break statements that meet the 'spirit of the law' to increase access to regular, reliable and appropriate short breaks.
 - Ensuring that local service planning and eligibility criteria are transparent.
 - Ensuring that short breaks statements and eligibility criteria are published in a way that makes them easily accessible to local parents, both by placing them in a one-stop-shop local website and by providing alternative routes of access to those who do not use the internet.
- As the Department for Education develops the Local Offer proposed in *Support and Aspiration* there should be a clear duty to deliver. This needs to bite on all agencies through clear accountability in terms of statutory and financial responsibility to deliver.

- The Department of Education through its short break delivery partner should monitor and publish local resource allocation under the Early Intervention Grant in order to ensure the Government's intentions are being met.
- The Department for Education's delivery partner on short breaks should monitor and report on disabled children, young people and their family's experiences of the quality of short breaks they are accessing
- The Department for Education and the Department for Health should establish clear accountability for integrated planning and delivery of short breaks provision within the new health and social care frameworks, particularly in relation to Health and Wellbeing Boards, Clinical Commissioning Groups and HealthWatch.
- The Department for Education's delivery partner on short breaks should prioritise approaches to work force development to increase parental confidence in short break professionals. High quality training should be delivered to all professionals delivering health and social services to disabled children and their families.
- The Department for Health through the Health and Social Care Bill needs to ensure that disabled children and children with SEN will be a priority for Health & Wellbeing Boards and there will need to be an equal responsibility between health and other agencies for outcomes for disabled children and children with SEN.
- The Government in the development of the personal budgets should prioritise: information and support; independent brokering system and clear routes of redress.

Recommendations to local authorities:

- Local authorities should produce short breaks statements that comply with The Breaks for Carers of Disabled Children Regulations 2011, and publish them on their websites in an easy to access location.
- Local short break provision must include high quality directly delivered services available without personal budgets.
- Local authorities should continue to improve children and young person's participation in short break design and choice.
- Local authorities should continue to work with their local Parent Carer Forums on an ongoing basis on the design and delivery of short break services.
- Local authorities need to be consistent in their feedback on how views are used and decisions taken following local consultation.
- Local authorities need to have clear feedback and complaints route so that all concerns and complaints are received and acted on.
- In order to support a holistic Local Offer, Parent Partnership Services should receive training on the delivery of advice on health and social care.

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