

# **A Report on Themes Emerging from Qualitative Research into the Impact of Short Break Provision on Families with Disabled Children**

Susanne Langer, Michelle Collins, Vicki Welch,  
Emma Wells, Chris Hatton, Janet Robertson and  
Eric Emerson

Centre for Disability Research (CeDR)  
Lancaster University

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Susanne Langer, Michelle Collins, Vicki Welch, Emma  
Wells, Chris Hatton, Janet Robertson and Eric Emerson

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Lancaster University

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## Executive Summary: Major Findings

The major findings of the study were as follows:

- A wide range of short breaks provision was evident in our research.
- Parents use and value short breaks for different reasons. Breaks most highly valued by parents often provided a break both from the work and from the responsibilities associated with caring.
- Breaks help parents to catch up with 'everyday' activities, such as sleeping, cleaning, or running errands; they allow parents to attend to their physical and psychological well-being, maintain and develop social networks and exercise their rights in the civil sphere.
- Short breaks have positive impacts on the lives of disabled children; benefits include developing and maintaining social relationships and being able to enjoy fun activities.
- Siblings appreciate short breaks as opportunities to do things they could not usually do with their families and to receive more of their parents' attention.
- The diversity of short breaks and the range of impacts they have can lead to difficulties in evaluating them. They should not be interpreted over simplistically, for example solely as an instrument to help parents into employment.
- It is important to assess the impact of short breaks in terms of how they benefit families long-term and in the context of their everyday lives.
- A changing population of disabled children may lead to changing demands posed by these children, for example on their physical environment. Despite substantial improvements, there still exists considerable scope to improve the accessibility and usability of mainstream facilities for disabled children.
- The nature and availability of transport had an effect on the impact of short breaks provision. Transport should be considered as an integral aspect of the provision of short breaks, rather than as a separate issue to be provided by families.
- A flexible approach to the administration of short breaks is appropriate if they are to be used most efficiently, that is, proactively and preventatively.
- Local Authorities need to think carefully about how to engage families with disabled children in consultations. Feedback is crucial to successful participation. Informal networks, such as those associated with support groups, schools, or children's or carers' centres helped parents find out about short breaks. However parents expected their main source of information to be their Local Authority; this suggests that there is still scope to review information strategies.
- Parents valued the qualifications and training held by short breaks carers, but felt that personality characteristics and attitudes were equally or more important. The most important factor for parents was that a relationship of trust existed between parent and carer and that the carer could establish a rapport with the child.
- Leaving the child with a carer could make parents feel vulnerable; furthermore effective short breaks could not happen without the agreement of the child.
- Parents drew on existing trusted networks when recruiting carers. Kin and friends do provide support for many families in diverse ways.

- Use of direct payments extends the pool from which carers can be drawn.
- Short breaks carers transgress the boundaries of the nuclear family, symbolically, as well as spatially and emotionally. This can obscure their employment relationship which has implications for both parents and carers.

## Introduction

The Aiming High for Disabled Children programme was launched in May 2007 with the intention of transforming services for disabled children. The programme was intended to be delivered jointly between the Department for Children, Schools and Families and the Department of Health. The development of provision of short breaks is only one of the areas covered by the programme, the others being childcare, parent participation and transition support. However, short breaks have received by far the most significant investment in comparison with these other areas. In addition to funding, the programme put in place a national set of expectations through the Aiming High for Disabled Children Core Offer (published in May 2008) and a way of measuring parental experiences through the National Indicator set 54. In April 2009 a set of Short Breaks Full Service Offer descriptors was produced.

Although Aiming High for Disabled Children is a national initiative, its delivery necessarily occurs at a local level. In order to facilitate the process of transforming local services for disabled children, twenty-one Local Authorities were identified as Pathfinders in April 2008. These authorities have been given significant amounts of funding to take forward their provision of short breaks and to act as exemplars of best practice. From April 2009 those non-Pathfinder authorities who met the criteria of readiness defined by the DCSF were eligible to apply for new funding to develop their short break provision.

According to the document 'Aiming High for Disabled Children: Best Practice to Common Practice' one of the drivers for the focus upon improving short break provision came from the Disabled Children Review. This review found that disabled children and their families saw the provision of regular and reliable short breaks as their biggest priority. The perception that short break provision has positive impacts on disabled children and their families is supported by research literature in this area.

A systematic review of the international literature assessing the impacts of short break provision on disabled children and their families carried out by the Centre for Disability Research at Lancaster University (Robertson et al., 2009) identified studies that found that parents perceive short breaks as leading to reductions in stress for their family (Marc & MacDonald, 1988) through a variety of means, including providing regular opportunities to relax (Stalker, 1988) and providing an opportunity for uninterrupted sleep (McConkey et al., 2004). Other studies looking at the impact of short breaks on disabled children found that parents felt short breaks provided improvements in the quality of their children's lives, for example in being exposed to new experiences or receiving increased attention (Gerard, 1990). Disabled children themselves spoke about short breaks as enabling them to form new friendships with workers and other children (Minkes et al. 1994). Parents also saw short breaks as an opportunity to spend more time with their non-disabled children (Shared Care Network, 2008).

The review also identified common criticisms of short break provision described in the research literature. For example, parents expressed concerns about the availability of qualified staff (Neufeld et al., 2001) or the inflexible nature of short break provision (Stalker & Robinson, 1994).

The sometimes inflexible nature of short break provision and the suitability of staff delivering the short breaks were also issues raised through the preliminary themes in the interim report of this study (Collins et al., 2009). This report reaffirmed the importance of short break provision to disabled children and their families. Short breaks were seen to be hugely diverse in terms of the activities and events they included, the locations in which they took place and the people and organisations involved in delivering them. This diversity of provision was important to ensuring that short breaks were beneficial to all disabled children and their families, given the range of different needs and expectations that they had. Crucially, provision of short breaks was found to have raised expectations around disabled children reaching their full potential whilst also supporting families in their attempts to lead ordinary lives.

The analysis discussed in this report builds upon and extends the findings from the preliminary report. Six main themes were identified from the data and are presented in separate sections. The first focuses upon the ways in which disabled children and their families use short breaks, identifying the range of short breaks we encountered during the research. The next theme looks at the physical location of short breaks and how access issues and the suitability of the location and venue can affect their beneficial impact. The ways in which information and communication affect access to and experience of short breaks is considered in the third theme. What families and disabled children want from the people who provide the short breaks forms the focus of the fourth theme. The relationship between family members and short breaks carers is considered in the fifth theme and the final theme examines issues around sustainability and support for disabled children and their families to lead normal lives.

## **Background**

This report is based on evidence from qualitative research into the impact of short break provision on disabled children and their families carried out by researchers at the Centre for Disability Research (CeDR) at Lancaster University.

The CeDR, in association with the National Development Team for Inclusion (NDTi) were commissioned by the Department for Children, Schools and Families (DCSF) to evaluate the Aiming High for Disabled Children Short Breaks Pathfinder Programme. The NDTi's role in the research programme is to evaluate the implementation of the Short Breaks programme by the twenty-one Local Authorities identified as Pathfinders. The role of CeDR is outlined below.

### **Overview of the research carried out by CeDR**

The purpose of the research conducted by CeDR is to assess the impact of short break provision on the lives and well-being of disabled children and their families. This part of the research project consists of four components. Firstly, a systematic review of the international literature on the impacts of short break provision on disabled children and their families was produced in September 2009 (Robertson et al., 2009).

The second component, which forms the basis of this report, consists of a qualitative research study. This research was designed to provide a sense of the experiences and perceptions of disabled children and their families concerning the impacts of short breaks on their wellbeing. Individual interviews, group discussions and narrative tools (e.g. 'story space') were used to gather evidence. This evidence was analysed using a qualitative approach. An interim report on the preliminary themes emerging from the early stages of this research was produced in November 2009 (Collins et al., 2009). This final report is based on research generated throughout the duration of the project.

The third and fourth components of the research project are survey-based quantitative studies designed to identify in what ways and to what extent the provision of short breaks impacts on family well-being. This research will consider a number of factors including family and individual characteristics and circumstances as well as how families use short break provision and their experience of short breaks. These quantitative studies comprise a cross-sectional carer experience and satisfaction survey and a longitudinal cohort study which will assess the impact of short break provision over two time-points, twelve months apart in order to begin to evaluate the impact of short break provision on disabled children and their families beyond their immediate short-term impacts. The quantitative studies will produce reports throughout 2010 with a final report in March 2011.

### **Qualitative component of the research project**

Through the use of client-centred techniques of data collection such as interviews and group discussions and the application of qualitative analytic methods, this component of the research project provides valuable perspectives on the experiences and views of families. Qualitative research allows the voice of the participant to be heard in a way that quantitative analyses of fixed-choice survey responses cannot. The data obtained in this study should not be considered to be statistically representative of the population of disabled children and their families. The value of this form of research lies in its ability to bring the views, perceptions and voices of disabled children and their families to a wider audience. This can

help to generate a deep understanding of the impacts of short breaks for families as well as providing explanations of how these come about.

In order to collect the data that forms the basis of this analysis the researchers engaged in a number of research activities including conducting interviews and group discussions, being present at workshops and meetings and attending short breaks activities. A tool ('story space') through which parents could convey their experiences and perceptions of the impacts of short breaks was developed and placed on the project's website ([http://www.lancs.ac.uk/shm/research/short\\_breaks/](http://www.lancs.ac.uk/shm/research/short_breaks/)) to provide access to parents from across the country. Together these approaches were important in gaining an understanding of the issues and debates about short break provision amongst the key stakeholders; disabled children and their families, short breaks providers, Local Authorities, parent/carer support workers etc.

The short amount of time in which the qualitative phase of this research needed to be completed had some consequences for the research process. In order to maximise the number of contacts and leads that could be followed up, data collection was not confined to the Pathfinder authorities. However this also provided an opportunity to gain an understanding of the impact of short break provision within its wider national context. The number of children (disabled children and siblings) who took part in the study was not as large as originally anticipated. This was a result of adopting a human rights approach to gaining informed consent from the children (discussed in the Research Sites and Methods section of the report). In many cases parents were keen for the researchers to speak with their children about short break provision, but when asked, the children themselves sometimes declined to take part.

This report builds upon and extends the preliminary themes discussed in the initial report and tells a compelling story about the experiences of families with disabled children and their perceptions of the impacts of short break provision on their wellbeing.

## Research Sites and Methods

As noted in the initial report we adopted a pragmatic, flexible and ethical approach to identifying potential research participants in the limited amount of time available to us. In an attempt to visit as many research sites as possible, we approached a number of Local Authority and voluntary organisations that had some connection with short break provision. Sometimes these approaches yielded contacts with people who could facilitate our introduction to potential research participants. Sometimes we were invited to attend events relevant to short break provision and parent participation. Attending these meetings provided us with a further opportunity to make contact with people who might be interested in contributing to our research. It also represented an opportunity for us to become familiar with debates around short break provision and parent participation. See Table 1 for a summary of the events we attended.

*Table 1: Summary of events and activities attended*

<b>Short Breaks Activities</b>	One half-term holiday play-scheme in the North West of England	One half-term holiday play-scheme in the East of England	One Saturday morning family session
<b>AHDC/Local Authorities/Parent Engagement Meetings</b>	Two NDTi regional workshops with representatives from the Pathfinder authorities	One regional Parent Partnership Participation event organised by 'Together for Disabled Children'	One Local Authority Parent/Carer Forum in North West England
<b>Meetings with Independent Organisations</b>	One meeting with providers of a specialist holiday and after school club service in North West England	One meeting with a local Parent/Carer Support Group	
<b>Consultations</b>	One Parent/Carer Workshop	One Young Disabled People's Forum	

### Events

The data gathered at these events were recorded in the form of field notes and used to supplement our understanding of the analysis and group discussions. Examples of the kind of event we attended include:

*Local Authority parent carer forum:* this provided a formal opportunity for parent carers to meet with each other and a parent participation worker to share experiences, concern and information. At the particular meeting we attended representatives from the local leisure centre had been invited to address parental concerns expressed in the previous meeting about short break provision.

*Regional parent partnership participation event organised by Together for Disabled Children:* this event was attended by a range of professionals and parents interested in increasing parent and professional partnerships. The morning consisted of formal presentations about parent participation including models of best practice. The afternoon saw a range of small, local groups speak about their experiences of increasing both parent participation and short break provision.

*An independent support group for parents with disabled children:* This was attended by a number of parents and a parent participation worker. The main focus of this meeting was feedback from meetings connected with Aiming High Short Breaks provision. One parent in particular was keen to explore the opportunities that might be available to them to either bid for money themselves around short break provision or to prompt local potential providers to do so.

### **Short breaks activities**

Table 1 also shows the short break activities that we attended. Attendance at these activities allowed us to conduct a number of interviews with parents and disabled children, as well as helping us to become familiar with the kind of provision that is available. Examples of the provision visited include:

*Saturday morning family session:* This is run by an organisation based in North West England that received funding from a number of sources including the Big Lottery and Children in Need. It provides a well-equipped space for disabled children, their siblings and their parents to spend some time together in a supportive and relaxed environment. A number of care-workers were available to support parents – although parents still had ultimate responsibility over their children.

*Holiday Club:* This was run by a charitable organisation founded by parents with disabled children. The week-long holiday club operated between 8.00am and 6.00pm. A range of activities were provided for the children who attended. Importantly from the point of view of parents one of the members of staff was a trained nurse.

### **Interviews**

As well as attending the events and short break activities described above we also conducted a number of interviews (both individual and group) with disabled children, siblings and parents. Table 2 has a summary of these research methods and participants.

Table 2: Summary of research methods and participants

<b>Individual Interviews</b>	17 parent/carers	3 disabled children or young people	3 siblings of disabled children or young people
<b>Group Interviews</b>	4 interviews with 8 parent/carers		
<b>Participant Observation</b>	1 half-term holiday play-scheme		
<b>Story Space</b>	9 parent/carer responses		

The interviews we conducted took place in different venues. Some interviews were conducted in the research participants' homes and some conducted during the short breaks. The interviews we conducted were semi-structured. We developed topic guides for use with parents, with disabled children and with siblings prior to the interviews taking place. These topic guides were subject to approval by the ethics committee of Lancaster University. Although we followed the topic guides whilst conducting interviews we also took our lead from what our research participants wanted to talk about. This meant that sometimes issues were raised that had not been considered whilst preparing the topic guides however these provided a rich source of additional material. We were also responsive to the needs of our interviewees in adapting our approach. For example interviews with children and young people tended to be a lot shorter than those we conducted with adults.

### **Story Space**

The development of the story space form was an attempt to extend to parents who would like to contribute to the study, but who were unable or disinclined to participate in interviews, an opportunity to do so. The story space form asks parents to provide in as many or as few words as they wish their experiences of and views about short break provision. Paper-based versions of this form were made available at the meetings and events we attended. A web-based version was also posted on the project's website which potentially made the form available to a wider audience. We gained some valuable insights into parents' experiences from this approach, although we obtained a relatively small number of responses.

### **Ethics**

The study gained approval from Lancaster University's Division of Health Research Research Ethics Committee. All researchers involved in collecting data for the project had been subjected to a recent, enhanced Criminal Record Bureau check. In addition, a number of ethical principles were adhered to during the conduct of the data collection, including:

*Informed Consent:* Parents who expressed an interest in taking part in the research were given an information sheet that explained its purpose and nature. The researchers also explained about the project verbally and answered any questions that the potential participants had. If the parents were happy to continue they were asked to complete a consent form.

A different procedure was followed for potential child participants. Initial written consent was obtained from parents or carers to approach the children they cared for to see if they were interested in taking part. Information sheets explaining the project had been designed for the children or young people and these were used as well as verbal explanations about the nature and purpose of the project. If the child or young person expressed an interest in taking part they were asked to complete a consent form. The consent form was completed in the presence of an adult who had some formal responsibility for the child – a signature was also obtained from this adult. Copies of consent forms and project information sheets are available on request.

*The Right to Withdraw:* All participants were informed of their right to withdraw from the research project at any stage. They were told of their right to not answer specific questions if they felt uncomfortable doing so, to not continue with the interview or to withdraw either the audio recording or transcribed materials. No participants who took part in our study took up this right of withdrawal.

## **Analytic Methods**

The methods used to collect, transform and store the data to create the final report did not change substantially from those described in the initial report. The interviews were recorded using digital voice recorders. The recordings were subsequently transcribed aided by use of 'Express Scribe' transcription software. Names and personal details were anonymised at the transcription stage and pseudonyms assigned. The data, consisting of transcriptions of interviews, narrative tool responses and field notes from the events, meetings and activities that we attended, were imported into NVivo8, a specialist software package which facilitates the coding of qualitative data.

The approach to coding the data in the current analysis did differ somewhat from that described in the initial report. Although a grounded approach (Strauss & Corbin, 1998) continued to be our main method, the analysis was informed by the themes that had been derived for the initial report. An iterative process of close reading and re-reading of the data using the existing preliminary themes led to the development of a new framework of themes described below. It is important to note here that data collected both before and after the production of the preliminary report were treated as a unified set of data.

For the final report we identified six themes, the majority of which developed from the original preliminary themes. For example, two of the preliminary themes remained broadly the same, although extended in the nature and scope of their coverage – these themes were 'Who are the short breaks carers?' and 'Relationships with carers'. In other cases, subsequent analysis of the data suggested that the preliminary themes 'Who are the short breaks for?' and 'What are the short breaks for?' were considered to cover broadly similar areas of concern and so they became merged into a single theme entitled 'The use of short breaks'. The preliminary theme 'Flexibility, routines and being 'ordinary'' developed in a new direction and became 'Sustained support to lead normal lives'. However two new themes also emerged from this final stage of analysis; 'Access to and suitability of short breaks locations' and 'Information and Communication'.

## **Theme One - Using Short Breaks**

This section examines the ways in which short breaks are used and builds upon the preliminary themes four and five ('What are short breaks for?' and 'Who are short breaks for?') from the initial report. In those preliminary themes it was suggested that the most beneficial short breaks were those that offered something to all family members. The ways in which short breaks were used differed according to individual family circumstances, expectations and need. It was also suggested that the positive impact of short breaks could be reduced by a range of factors including the timing and location of the activity, lack of suitable transport and the inflexible nature of provision.

This section focuses on how short breaks are integrated into the lives of families with disabled children and also pays attention to the symbolic meaning families of disabled children attach to short breaks. It complements Theme Six which is concerned with the kind of qualities that are needed for a short break to be considered successful. The section begins by summarizing the range of short break provision that we encountered and considers how disabled children, their siblings and parents use short breaks. It then goes on to explore the difficulties that parents encountered when their understanding of what short breaks are and what they should be used for differed from the Local Authority.

### **The range of short breaks**

The range of short breaks activities that we attended or that the families we spoke with accessed varied according to the type of providers, the length of stay, the venue and the kinds of activities engaged in. Table 3 summarises the range of short break provision discussed by the disabled children and their families that we spoke with. It should be noted that the majority of short break provision that we encountered was specialist rather than mainstream. It is likely that still further examples of provision will emerge from other elements of the research.

Table 3: Summary of short break provision

Organiser	Type of Short Break
Local Authority	Regular residential stays
	Regular stays with family carers
	Sessional activities including arts, crafts and days out to places like Alton Towers
Parents (e.g. through direct payments)	Care-workers take the disabled child or young person bowling, swimming, to the cinema, to clubs
Schools	Sessional activities during the holidays including days out
	Week-long holidays at a specialist centre for disabled children
Voluntary organisations	Family sessions
	Family trips to bowling or the pantomime
	After school clubs
	Holiday clubs
	Regular multi-sports events
Private sector organisations	Riding for disabled children activities
	Outdoor activities and sports
Kin	Varied, included support at home, trips out and stays away from home

### The use of short breaks

*The views of disabled children:* The disabled children we spoke with talked about the immediate social benefits they obtained from attending sessional short breaks activities. At after school and holiday clubs disabled children could engage in a range of fun activities including playing on console games, building dens outside, face-painting, getting dressed up in fancy dress and watching DVDs. One disabled child who had some communication difficulties described the different activities she engaged in at the holiday club and the after-school club:

*Interviewer: And what do you do when you're here [at the half-term holiday club]?*

*Holly: Face paints [...] watch DVDs [...]*

*Interviewer...So what do you like about coming to ...holiday club?*

*Holly: I like to have a foot spa [...] have snacks*

*Interviewer: ...What do you do at the after school club then?...*

*Holly: We chill out...*

These clubs also provide a space and appropriate facilities for the children that we spoke with to play with their disabled friends, in particular friends who they may not see that often because they have moved on to a different school. Joe who attended a half-term holiday club talked about his friend Glenn:

*Interviewer: And does Glenn go to your school?*

*Joe: No he doesn't go to my school he goes to a different one*

*Interviewer: So do you just see Glenn when he's here?*

*Joe: Yeah I just see him here, I see him when I go to after school club...but I don't really see him much*

Specialist holiday club provision appears to provide an important opportunity for disabled children to maintain friendships they might otherwise lose. Another child attending a half term holiday club commented on how his attendance was connected with his parents' pattern of working:

*Interviewer: Can you tell me a bit about your family?*

*Jack: My mum works for the government and my dad's the same job they work in [NW town] and they come back sixish, so I'm here until 8 to 6*

Short breaks are being used in this case to reduce any potential sources of stress around organizing the family's childcare and work commitments. However this kind of provision for disabled children is relatively rare (especially in the Local Authority in which it is located). It is interesting to note that this service is provided by an organization founded by parents of disabled children. These parents became involved in providing short breaks after becoming aware of the lack of provision in their local area for families who wanted to maintain employment.

*The views of siblings of disabled children:* For siblings, short breaks where their disabled brother or sister went away for a short period of time provided an important opportunity for their family to do things (like going on holiday) that they might not normally be able to do in the presence of their disabled brother or sister. For example, Abi speaking about her brother who has cerebral palsy, Down's syndrome and epilepsy said:

*Abi: He doesn't go on holiday that often cos we can't really like get him on the planes and things easily so...*

*Interviewer: So does that affect the amount that you're able to go on holiday?*

*Abi: Yeah definitely cos we have to wait until he can get a holiday – cos he sometimes goes on holiday for like a week or so with the church group – so when he does that we go*

As well as being able to go on holiday, siblings also appreciated the time they spent in their house without their disabled brother or sister. Isabelle described how she had more freedom to do what she wanted to do when her brother was accessing a residential short break:

*"It's quieter, definitely quieter. And also you don't...we always have to be ...that's another thing that annoys me a bit cos like the piano or something if you want to play the piano you can't play it past eight because he's [disabled brother] in bed obviously...so you can play the piano til ten." (Isabelle)*

The benefit that siblings gain from short breaks are connected with being able to do things they would not normally do (McConkey, 2008), or being able to relax more and enjoy greater freedoms in their home. From the very small number of siblings that we spoke with we did not find evidence that short breaks were used as an opportunity to relieve them from caring responsibilities – however this remains an under-researched area as noted in the literature review (Robertson et al., 2009). The parents that we spoke with had mixed feelings about the potential consequences of children undertaking caring responsibilities for their siblings. On the one hand there was the perception that caring for a disabled sibling may have a positive effect on the non-disabled child, as seen in the response from Laura:

*“It’s surprising though how many people who have siblings with special needs end up going into the caring professions, I know of quite a few that are definitely interested in that sort of thing, rather than switched off for life [...] it must be character building to grow up with it you know you must and seeing different things and [...] it must help your personality a bit in terms of your understanding.” (Laura)*

On the other hand another parent talked about how her daughter had attended a support group for siblings but had not gained much from it. There was a perception that many of the other siblings attending the support group were full of anger.

*The views of parents of disabled children:* The parents we spoke with articulated a range of benefits and uses of short breaks. For some parents the provision of short breaks simply means the difference between being able to cope with their disabled child and not being able to cope. Other parents see short breaks as enabling their disabled child to access the same activities as non-disabled children. The clearest demonstration of how the use of short breaks vary according to family circumstances came from one of the parents we spoke with who had recently split up from her husband. Joanne, who has a child with Dravet syndrome, explained how she and her then husband were hoping to use short breaks. Joanne’s request for short breaks was initially turned down:

*“But by this time me and Dave had split so it was quite sad really because we wanted it [direct payments to pay for short breaks] to take John [non-disabled sibling] places and have some time to ourselves” (Joanne)*

Having appealed against the initial refusal for direct payments, but having also split up from her husband, Joanne finds that she now uses short breaks in a different way:

*“Sometimes they’ll [the carers] come for a couple of hours in the evening so I can go off and do my shopping because Liam’s a bit hard work in the supermarket now. Sometimes on a Sunday which is really ideal they’ll come in the afternoon ...and I’ll get myself off for a run...and then I’ll come back so...I’ll have had my morning with Liam and I’ll have my break and then I can come back refreshed...cos it’s a long day if you’re...here all day with Liam.”(Joanne)*

Here the role of short breaks is to support Joanne as a lone parent in caring for her disabled child. But Joanne's initial intention for short breaks was that they would provide an opportunity for her to spend some time with her husband and non-disabled son. This raises another important point. Families obtain different benefits from short break provision according to their needs, circumstances and expectations. The provision of short breaks needs to be timely and flexible enough to respond to the changes that may occur within individual families.

The biggest benefit of short break provision for parents appeared to be a break from the responsibilities associated with caring for their child. This could be achieved most commonly through having a physical separation from their child. An alternative way of gaining some of the benefits of a short break was obtained from the support of other families. For example, two providers of short breaks arranged for disabled children and their families to attend a pantomime en masse. This was seen as an opportunity to access a mainstream entertainment that parents would not usually consider doing on their own. Parents felt that this was possible because of the support provided by the presence of carers and other families in the same situation.

Parents gave specific examples of what they were 'having a break from'. This depended on the particular needs of their disabled child. Barbara and Gary talked about short break provision as giving them a break from the noise made by their daughter:

*Barbara: ...it's nice just to have a break*

*Gary: It is, yeah*

*Barbara: She has this constant rattling. She has these beads [Gary laughs]...and when she's not around it's so nice. Just to have that...you don't have that constant background...cos that's her obsessive side of the autism*

As can be seen in this example short breaks can mean a break from something as apparently mundane as the rattling of beads, or as in the next case of enjoying the quiet and calm of the house in the absence of the disabled child:

*As much as we all love Catherine, the house has a completely different atmosphere when she is away – much calmer [Story Space 2]*

It can also provide a break from being constantly vigilant over a child's health needs. Sylvia whose son has complex health and handling needs described how short breaks in the form of carers providing overnight cover allows her some respite from attending to her son's monitor and gives her support in the event of her son having an epileptic seizure during the night.

As well as giving the opportunity for parents to have a break from the particular issues associated with their disabled child, short breaks also allowed parents to engage in other activities that were important to them. For some parents the opportunity to relax was identified as an important need, and a rare occurrence:

*"But occasionally she [non-disabled daughter] will stay at my mum's...for a night when Dave's in respite so I actually you know have a shower, have a glass of wine*

*put my feet up and think God this house is so quiet where are they?...and I actually sit down and think well you know that I will be around for another...maybe ten or twenty years.” (May)*

It was these rare moments of relaxation that gave parents the resilience to cope with their caring responsibilities. Parents were able to draw upon their memories of short breaks in moments of crisis and appeared to increase their capacity to cope with the challenges they may face in caring for their disabled child. This matter will be addressed in more detail in the final section.

The demands that looking after a disabled child made on parents' time meant that many of them used short break provision to catch up on 'everyday' things like sleeping, cleaning, going to the bank, going to the shops or going to the hairdressers. But some parents also talked about how they used short break provision to engage in activities that went beyond the everyday, that were unique to their needs or situation and from which they derived great benefit. One parent used short breaks to enable her to attend meetings of an alcohol support group. Another parent's use of short breaks allowed her to engage in campaign work for people with autism or to attend meetings:

*“...but if I need to do something, say I need to...campaign or I've got a meeting to go to, I tend to find I use up all my respite hours to do that, so I come back equally shattered, which is ridiculous...but I feel it's productive, it helps to move things on (Linda)*

This use of short breaks did not give Linda a break in terms of allowing her to relax and rebuild her energy levels, but it did provide a clear benefit in enabling her to feel engaged, useful and that she was achieving something. Thus the benefits that Linda derived from the short break may differ from, and extend, the benefits anticipated in short breaks policy.

As well as providing a break from caring responsibilities, parents also used short breaks to obtain relief from feeling different, or feeling the need to explain the behaviour of their child. One way in which this was achieved was in accessing specialist sessions that the whole family could attend. For example, one organization that works with people with autism in North West England runs a session on Saturday mornings which all members of the family are invited to attend. The session takes place in a complex of large and small rooms in a renovated old mill and has a variety of console games, a bouncy castle, a large, fixed climbing frame, pool table and a range of games and arts and crafts activities. Attending these sessions was viewed as a short break by the parents that we spoke with. More than one parent spoke about appreciating that they could just 'be themselves' at this session and not worry about what their child was doing. Debbie and Phil who have a son with Asperger's syndrome gave a response that is typical:

*“It's very very helpful ...talking to other parents and finding out about their children and the similarities with our children. You just get so much help from that, really brilliant.”(Debbie)*

*"It certainly made a difference to all of us really. Partly because he [their son, Daniel] could run around for himself...you don't have to apologise for him, you don't have to tell him to be quiet and not disturb other people and we can sit down in the knowledge that he's fairly safe and fights that do happen can be resolved and...it's just a massive relief...just sit and not worry about what he's breaking." (Phil)*

This highlights the importance of specialist provision to parents' sense of wellbeing. Furthermore the space that is provided for them and their disabled children to act as they normally would allowed them to not be 'on guard' about the reactions of others. Parents also see this kind of session as providing a benefit for siblings:

*"There's not much that...your mainstream child can do with your special needs child that's why ABC [voluntary organization providing short breaks] is very good they have a family session so siblings can go ...it's really good - cos then the whole family can go and hopefully the sibling not have to be embarrassed because ...'well you're sibling's at it too'." (Laura)*

This kind of short break provision gives siblings an opportunity to interact with their disabled brother or sister in a context away from their home and in an environment where their own behaviour and that of their disabled brother or sister will not appear unusual.

Another important contribution to the sense of wellbeing that parents gain from family sessions is that of being able to talk with other parents and become involved in the sharing of experiences and information. But although many parents appreciate being able to share experiences in this way, others saw short breaks as a way of averting what they considered the threat of social isolation and of becoming confined to a "parallel world of disability". For example short breaks that allowed parents to maintain employment were seen as a way of allowing them to temporarily enter a world in which their child's disability was not the central concern.

*"I do... three short days [at work] and it just keeps my mind active because you could very easily wallow in you know get swallowed up by the whole disability end and get yourself depressed and sit at home and think 'oh...this is it now'...but I found that I go down there [to work] and if Liam's had a seizure...or something's bad I can go down there and take my mind off it I mean it'll always be important to me but it won't be constantly there mulling it over." (Joanne)*

So whilst short breaks can provide parents with an opportunity to be involved with other families, and share their experiences of disability, they can also provide a distance from the concerns associated with caring for their disabled child.

### **Attending to the needs of siblings**

Family relationships and family functioning benefit from the uptake of short breaks. Parents who have more than one child are acutely aware of their responsibilities to their other children and feel that often the attention they need to pay to their disabled child has a negative effect on their non-disabled children. This can be seen in parents' perceptions about how all their attention can be absorbed by their disabled child:

*“Cos it’s two children I’ve got and ...I do spend all my time worrying about Dave [May’s son Dave who is at the severe end of the autistic spectrum] Katie’ll [May’s non-disabled daughter] be talking to me and I wouldn’t be paying any attention...cos I’d be...’where is Dave he’s gone a bit quiet’ and I’d make a mad dash to the sitting room...and I wouldn’t be listening to her she had no sort of attention.” (May)*

It can also be seen in descriptions of the way in which short breaks enable parents like May to spend high-quality time with their non-disabled child:

*“They actually had him for two nights Friday and Saturday and that was the first weekend, I took my daughter to [Northern city] to see a show...and all of a sudden the relief a great weight was off my shoulder and I actually...relaxed...Katie calls it ‘girlie time’.” (May)*

Using short breaks to pay attention to siblings has three main effects. Firstly it reduces parental stress or guilt about the way in which they are able to attend to their parental responsibilities for all of their children. Secondly it is a way of trying to ensure that siblings of disabled children feel that they are as important and as valued as the disabled child. Thirdly it helps parents to reduce a perceived risk of their non-disabled child growing to resent their disabled sibling for having all the attention, or preventing them from doing things they would normally be able to do. Most of the families with more than one child that we spoke with said that their children got on relatively well with each other – this may potentially be a result of the ways in which families use short breaks to take into account the needs of non-disabled siblings. A further assessment of this will be provided by the Family Experience and Cohort studies.

Finally, one important and often over-looked function of being assigned short breaks relates to the symbolic meaning that it conveys to parents about the ‘work’ they do as a carer. The act of assigning short breaks was seen as significant in that it represented an acknowledgement that the parent must need short breaks:

*“...and also it’s ...the psychological thing...’they think I need a break’ well I must be doing a good job you know I must...cos sometimes you feel other people don’t understand...you know...all the things you’ve to do and all the ...responsibilities that you have that all go with a disabled child.” (Joanne)*

This symbolic function of short breaks shows how crucial they are and why conflict might sometimes arise when parents feel they are being unduly denied a short break. Parents sometimes felt under-valued by Local Authorities whose definitions of what short breaks are and what they can be used for differed from their own understanding.

### **Potential sources of conflict in the use of short break provision**

Parents have clear ideas of what short breaks are for but often this conflicted with the procedures that Local Authorities and Primary Care Trusts have in place to fund and allocate the provision. For example, one parent told how the carer support that her son received to attend a local sports club for young people with disabilities was withdrawn on the basis that this support did not meet a health need. The parent was greatly concerned about the potential consequences of this lack of support and the break in routine on her child with autistic spectrum disorder.

Some families used their direct payments for purposes that were deemed inappropriate by some Local Authorities. One family described how their decision to use direct payments to meet their particular needs was undermined by the Local Authority who withdrew the payment:

*We previously were in receipt of direct payments for a proportion of our care. We used a small element of this to assist us in laundry, such is the amount produced by our family. The LA [Local Authority] decided this was an inappropriate use of such provision and withdrew it. This now means that we have to undertake this ourselves during respite time, meaning it is no respite from caring at all. [Story Space 8]*

This refusal on the part of the Local Authority to valorise decisions made by the family may reflect well-intended bureaucratic procedures which are put in place to guide decisions about the allocation of direct payments. The experience of this family shows that families arrange their use of direct payments with regard to their particular needs and priorities and that this may not always match what Local Authorities perceive to be the uses and benefits of short breaks. The implication then is that Local Authority procedures need to be flexible and give parents the opportunity to exert real choice when deciding how best to use the support they have been allocated.

The divergence between parent and Local Authority understandings of what short breaks are and what they should be used for may have potentially negative consequences for Local Authority evaluations of the impact of their short break provision. This problem may be confounded by the change in terminology from respite to short breaks. One parent talked about what short breaks as a term meant to her:

*"I always think that short breaks implies a weekend away...short breaks...isn't two hours down the local activity centre...no...short break I would define as a weekend, not two hours at 'Snakes and Ladders' (Ann)*

In many cases, parents do not realize that the support they are receiving is either classed as a short break, or is funded by the Local Authority. For example two parents that we met, when asked whether they received short breaks or whether they accessed short breaks from the Local Authority, answered no, but it soon became clear from their subsequent discussions that they did. This issue was also identified as important by the representatives from the Pathfinder authorities at the regional NDTi workshop that was attended by the researchers. At this workshop it was felt that parents would not realize they had received short breaks funded by the Local Authority, so that if and when the parents' views about short break provision were elicited then parents would respond negatively and this would have a damaging impact on the assessment of the Local Authority's performance. Another concern expressed at this workshop was that parents might be using short breaks and see them as enabling their child to access the range of activities that non-disabled children would. But if the need for emergency short break (or respite) provision arose, then parents would be told that they had used up their quota. It was suggested however, that one way to tackle this problem was to encourage greater parental involvement in deciding local policy for short break provision.

This theme has reviewed the ways in which disabled children and their families use short breaks. Disabled children focused upon the immediate social benefits of the provision they accessed. Siblings appreciated being able to do things they would not normally be able to do. Parents spoke about the different ways in which short break provision gave them a break from the responsibilities associated with caring for their disabled child, as well as being able to organize how they engaged with their non-disabled children.

Sometimes parents' perceptions about what a short break was and what it should be used for differed from that of the Local Authority. This is a potential source of conflict and distress that could affect any positive impact that short break provision may have for disabled children and their families.

## Theme Two - Access to and Suitability of Short Breaks Locations

### Physical environment

A key concern about short breaks that parents expressed to us was the need for them to be accessible. This category included physical aspects of the venue itself, such as the presence of ramps, hoists and changing facilities, and less obvious markers of a space's suitability for children with disabilities, such as the presence of locked doors. However, parents assessed an activity's accessibility not solely on the grounds of the venue itself, but also in terms of how easy or how difficult it was to get there. A further factor was the training and suitability of staff, and we will address this matter when asking 'Who are the short breaks carers?' Finally, access to short breaks was also affected by their location and geographical distribution in relation to the parents' home.

The physical aspects of a venue are the most obvious indicators that it is accessible for children with disabilities. The Disability Discrimination Act (1995) has made it illegal to discriminate against people with disabilities in a range of areas, including access to goods and services. Combined with the Act's extension in 2005, which requires public bodies to promote equality of opportunity, many sports and leisure facilities now have put ramps in place and have made other improvements to their facilities. Local Authorities are increasingly involving disabled children and young people in decisions about their lives and their communities and consult them in a number of ways. For instance, disabled children and young people may be engaged in a programme of rating local facilities on the grounds of how accessible and how welcoming they are.

Despite substantial advances in terms of making adaptations to the physical environment, our research suggests that there exists considerable scope to improve the accessibility of mainstream facilities for disabled children. Ramps and automatic doors are important, but as the mother of George, who is in his teens, pointed out, they were insufficient to enable him to take part in short breaks activities. George has complex health and handling needs and the absence of specialised changing facilities severely restricts where he can go to, as his sister Isabelle recognised:

*"...you can't go out for more than 2-3 hours, 'cos it would just be unfair, if he needed his nappies changing, he'd have to sit in it for the rest of the time, which isn't nice."  
(Isabelle)*

Without such provision in place in the locations that disabled children may use during their short breaks, the range of where they can go and what they can do will remain limited. In the case of George, the only venue that currently offers suitable changing facilities in his community was the local supermarket. Such facilities would also have been welcomed by other parents whose children have continence issues.

Shortcomings of the built environment – such as the presence or absence of changing facilities – also affected the activities that carers could do with children during a short break. Whether or not local public spaces were accessible mattered to families using short breaks, because one of the aspects they valued about short breaks was that they expanded the child's range of experiences and social relations in their immediate community:

*“That’s the thing that’s missing, the hard thing. Yeah. Just someone to come and take them out for 3 hours, to access something in the community once a week.”*  
(Barbara)

This ‘community’ includes the use of outdoor spaces such as parks and playgrounds, but it also covered a wide range of indoor facilities such as gyms, swimming pools, youth clubs, libraries, cinemas, or shopping centres, operated and owned by private, public and voluntary sector organisations. The accessibility of such public spaces plays an important role in the continued exclusion of disabled people (Kitchin, 1998) but it can equally provide opportunities to further integration. Yet as Sylvia, George’s mother argued, improving the accessibility of the local environment and extending the range of facilities disabled children can use also had a positive effect on their families. Sylvia was lobbying her local YMCA to install a changing table on their premises:

*“You know, because if you’ve got a disabled child and you’re going to football with your siblings you have to take the disabled child with you and that sibling needs a disabled changing area. So, it’s like a family thing. So they need that changing table.”*  
(Sylvia)

In other words, changing the physical environment to make it accessible for disabled children with their family can achieve similar effects to putting on short break activities, because it widened the family’s choice of activities they could do together.

Thus, our research suggests that a ‘bricks and mortar’ approach to inclusion is still relevant, especially if it does not stop at the door of buildings but treats accessibility as the outcome of an integrated system. Such an approach might for instance encompass safe drop off points and convenient parking, or easy to use, safe, affordable, and frequent public transport provision, when assessing how suitable a facility is for a short break activity.

The wheelchair has traditionally been the symbol of disability and the presence of ramps, hoists, disabled toilets, changing tables and other facilities may be essential for some children in the priority groups for AHDC, but the criteria that make a location suitable for a child with a different set of disabilities may be less obvious. While the question of whether there has been a genuine rise in incidence of Autistic Spectrum Disorders remains open, there has certainly been rise in the numbers of children diagnosed with the condition (Wing & Potter, 2002). These children are often mobile, and yet they need their environment to be adapted to their needs. Such adaptations may include suitable changing facilities, as well as the importance of locked doors to prevent the children from running away. A safe environment that minimises danger to these children might also include making sure that any furniture is sturdy and well secured and that bodies of water are well protected and that any potentially harmful objects and substances are securely stowed away. Disabled children using short breaks are a diverse group with different needs which can also bring them in conflict with each other.

An example of the different requirements disabled children have for a short break is illustrated by the mother of 11-year old Oscar who is severely autistic. His carers wanted to take him to the bowling alley, which would have made a wonderful break for a child like George, but was full of hidden dangers for Oscar as his mother Linda recounted:

*“...the bowling alley, I used to have to say ‘Don’t take him bowling, don’t take him!’ ‘But we take all the other kids’, and I said ‘Look, take them anywhere else, but don’t take Oscar bowling, because I know there’s a lake, there’s the carpet, there’s the door’.” (Linda)*

The bowling alley’s brightly coloured carpet, Linda thought, triggered sensory overload in her son, causing him to run to the other end of the room, only to stop right in a corner, where he was at risk of being pushed against a wall, by a door opening. The ornamental duck pond outside represented a further source of anxiety to Linda because Oscar would insist on throwing any object he could get hold of into the water, including cigarette butts and water fowl excrement, with no awareness of how appropriate it was.

Disabled children are a diverse community with very different needs and the provision of short breaks has to reflect and accommodate these needs if short breaks are to have a positive impact on the lives of all disabled children and their families. In a related matter, it is worth keeping in mind that the accessibility of public spaces for disabled people has improved, but that these successes can easily be compromised by other factors. To illustrate, a local swimming pool offering children with handling needs, children with autistic features, and non-disabled children an accessible, safe, and local leisure opportunities had been closed despite protests by the community. This deprived a wide range of children of a popular and healthy short break activity. This example also helps to highlight the importance of transport and of provision that is locally situated.

## **Transport**

While Local Authorities aim to increase the local provision of short breaks, such provision might, at present, be patchy and making full use of it may require children to travel considerable distances. Many of the parents of disabled children we interviewed were willing to provide such transport. For example Phil regularly drove his son, who has Asperger’s syndrome, to a specialised Saturday play scheme for children with autistic spectrum disorder more than 10 miles from their home:

*“...so it’s about a half hour drive over here. It’s worth it, if it were an hour’s drive it would be worth it, you know.” (Phil)*

In this case, the play scheme required the parents to stay, so was strictly speaking not a short break, but even where the child would do activities away from their parents, the parents’ time could easily be consumed by the drive. The availability of transport also affected the activities a short breaks carer and the child could take part in and where they could take them. For certain activities, not only would the carer need access to a car, but it may also require adaptations for the child. Furthermore the driver required additional insurance cover to transport the child. Laura, who had originally intended for her autistic son to go to a local sports centre, learned that her care worker would not be insured to drive the child but that the journey would take too long on public transport:

*“...so that was a shame ‘cos that would have been exercise as well so the care worker would have gone in supporting him not doing exercise himself but just being with him. So it’s pretty much the cinema...” (Laura)*

Laura was aware that free transportation may be available, but felt such a request would put an unjustifiable strain on already limited resources:

*“...a lot of special needs things you know you can tick if you need transport [...] but obviously there’s a huge financial impact on the clubs for that and I think I would feel a bit guilty ticking it when there’s two of us and we’ve got two cars.” (Laura)*

While Laura’s family had the means to take their child to various short break activities, other families may not and taxis, as another participant pointed out “cost a fortune.” Therefore, the availability of free transport enhanced the benefit parents derived from a short break. While willing and able to take her 13 year old daughter, who has Down’s syndrome and autistic features, to a local specialist play scheme, Barbara wished that transport was available:

*“[If they would take her and bring her back, it] would be great for us because we do so much running around, it would be nice to have someone. See at [a play scheme they used to attend previously but that had closed down] they’d take her, stay with her and then bring her home.” (Barbara)*

Transportation is already an integral part of the daily lives of those disabled children who attend special schools. These schools are often well suited to accommodate the children’s needs, they have trained staff, the children are familiar with the facilities, and they develop friendships with their fellow students. Hence, special schools are frequently a fortuitous location for breaks, such as after school clubs or holiday play schemes. Yet, transport may again be a sticking point. In one instance, the Local Authority refused to pay for transport from a child’s special school, which was in a different Local Authority, to home if he stayed-on for the after school club. The club would have been ideal for this child who had complex handling requirements and a need for familiar routines. It also (so the mother believed) would have increased her chances of finding work, as she would not have to be home by 4 o’clock. Yet even where transportation is in place, special schools typically tend to be further from the child’s home than mainstream schools. The daily journey to and from school can add to a child’s long day. It can mean that by the time they arrive home it is too late to join in with any local after school activities. In addition it may mean that their parents are reluctant to add to an already long day, by sending their child out again for a short break activity. The distance disabled children live away from their special school is also a factor that affects holiday play schemes. Such provision offers an opportunity for disabled children to meet their friends, yet again long journeys to and from school may be involved that will not be covered by regular school transport provision. Therefore, for short breaks to be optimally beneficial for the family of a disabled child they have to become an integral part of family routines. As for most other children, this usually includes school, as an important site of learning and socialising. Disabled children’s schools may be further away from home and their friendships may be more dispersed. School-based activities potentially allow them both to maintain links with their friends and to establish relationships with other children in their local community.

Transportation may at first seem peripheral to short breaks, but our research suggests that it can have a considerable effect on how much benefit the family will gain from them. Time spent in transit is not usually time for parents to relax, nor is it time that is commonly spent to the benefit of other family members, such as non-disabled siblings. The issue of transport in relation to short break gains particular prominence in the context of the time pressures already existing in the lives of families with disabled children. In the words of the father of a severely autistic teenager:

*The constant round of meetings, forms to sign, phone calls to make etc. etc. also creates a huge demand upon our time. It becomes almost impossible to create suitable opportunities for time as a couple, or as individuals. People who do not have our pressures do not fully appreciate that, for us, there is no such thing as 'spare time'. Our life is a constant round of demands, pressures and lack of sleep. It becomes very difficult to relax as it nearly always comes at the expense of another aspect of our life, regardless of how resourceful or well planned we are. (Story Space 8)*

In a context where time is precious, transportation that is treated as an integral part of short breaks can noticeably boost the positive impact of short breaks in the lives of families with disabled children.

To conclude this section, the provision of short breaks for disabled children raises many issues. Disabled children need spaces to spend their leisure time. These spaces have to be safe and suitable, they should not be expensive to use, they should be at a convenient distance to the child's home or school, and they should facilitate the development and maintenance of diverse, abundant and resilient friendships. Many of these requirements for disabled children are shared by non-disabled children. Yet, in the case of disabled children their need for such spaces is exacerbated by their particular requirements, the extra costs disabled children face, the specialist activities that disabled children enjoy, and the often substantially limited resources that families with disabled children possess in terms of money and time.

### **Access to 'the system'**

The preceding section was concerned with the physical adaptations required to give disabled children access to short breaks. However, a related facet of accessibility is also about how people gain access to 'the system'. From the Local Authorities' point of view access to 'the system' and by implication to services was inextricably linked up with the question of how best to ensure that limited resources were equitably distributed. This concern for equity was shared by the parents we interviewed for this study.

Disabled children and their families have vastly different needs; this means that equity is not created by a 'one size fits all' approach. In terms of short breaks, this means that the degree of short breaks support required, including the provision of respite, varied considerably. The parents who seemed most satisfied with their short break arrangements often supplemented overnight care arrangements with a few hours of additional support during the week.

*“...the package we’ve got at the moment is excellent. If we can get someone to do direct payments that would be absolutely perfect and I don’t think we really want any more than that. That’s probably more than we wanted, actually. They’ve been really good.” (Barbara)*

Although Barbara had encountered some difficulties finding a suitable short breaks carer for her daughter, she was generally happy with the support she received. In her case, her experience as a nurse and as a long-standing foster carer for her Local Authority meant that she was familiar with the kind of support available, the people to contact, and the procedures necessary to access it. For other parents who had complex short breaks arrangements in place, access to these services had often been established in a moment of crisis.

*“...and it wasn’t until I got quite ill and I was rushed into hospital and you know [...] the hospital wanted to know what help I got and I just laughed and I said: ‘Help? What do you mean, help? There is no help!’ And it was actually them that got in touch with social services and [...] I got a social worker. [My son] then started to go for tea two hours a week, right? He wasn’t old enough for respite; you have to be about nine.” (May)*

May’s experience and that of other parents who participated in this research highlights the positive difference committed professionals can make in the lives of families with disabled children. Their expertise, ingenuity and willingness to fight their clients’ corner were hugely appreciated by parents such as Melanie:

*“...my social worker and the one before it every time they went into panel for me they said: ‘Well Melanie is really in need of stuff like this!’ [...] so I’ve been very lucky, y’know both my social worker, well [my son’s] social workers – [...] will fight for what they think I have.” (Melanie)*

The support these dedicated social workers offered and the resources they could unlock made a difference to parents’ lives. Even so, some respondents suspected that support was not forthcoming until it was too late. Certainly as we have seen in the preceding section, at least one mother felt that had short breaks been made available to her sooner, she may not have split up from her husband. Others, such as Linda, questioned how fair such a focus on crisis intervention was for those like herself, who seemed to be coping:

*“A lot of marriage break down, mine stayed together. Because marriages break down, or relationships break down and there’s a disabled child, everybody runs to help the single mother [...]. It doesn’t mean that my son is any less needy, nor am I for the break that we require. If anything, I think I deserve it more, because, I’m trying to hold everything together and trying to keep a family together.” (Linda)*

Although parents would have liked to see short breaks being made available to them sooner, on more flexible terms, and more frequently, they were equally aware that their requests were being dealt with in a context of severely stretched resources that had to be distributed fairly. This meant that parents were very careful to justify what they were asking for and why it was needed, they emphasised that they had not received preferential treatment and stressed that they were not taking more than they needed. Even Linda, who had staged a demonstration in front of offices of her Local Authority’s social services department, insisted

that the circle of standard and equitable procedure and her and her family's needs had been squared:

*"I phoned radios and newspapers and just said 'I've never had a break and I need a break. I need help with my son and I want it! I demand it!' I was on a waiting list, I'd been on a waiting list for something like two years before then [...] and suddenly things moved on. I was assured that I wasn't given the respite that magically appeared out of nowhere...quite soon....for any other reason other than I was due....so, I hadn't queue jumped and I was very concerned that I wouldn't because I don't also like to think that anybody else who's even less vocal than I am would have to wait just because they're less vocal." (Linda)*

Whether Linda had forced her Local Authority's hand is irrelevant in the context of this report. Yet what matters is that she was buying into a rhetoric that was poised between individual rights and needs and limited collective resources. Linda did not emphasize the precedence of her own needs and her family's difference, but rather presented herself as a law-abiding, authority-respecting, community-spirited person. In so doing, she positioned herself as 'normal'. However, universal services for 'normal' families, that is, those without disabled children, are rarely rationed to this extent. Hence, Linda's claim to normality is constantly undermined by the necessity to justify hers and her family's needs. Short breaks are intended to enable families with disabled children to lead lives that are comparable to those of families with non-disabled children. However, as long as short breaks provision is patchy and access to them is rationed, such 'normality' will remain largely elusive. Furthermore, as we have argued elsewhere in this report, families with disabled children may need additional support to lead 'normal' lives and even those who seem to be functioning may be only just hanging on:

*Our greatest fear – and [this] is an outcome seen in other families- is that one of us will no longer be able to cope and it will be at the detriment of the whole family. We have seen couples and families split while the disabled child has to go into care because of the level of needs involved. (Story Space 8)*

Therefore, the access that families with disabled children have to short breaks has to be proactively and preventatively administered to reduce the stress that families with disabled children are under. Finally, the desire of families with disabled children for a degree of 'normality' might also suggest that a sensitive and low key approach is most appropriate to encourage those families with disabled children who are reluctant to engage with 'the system' to take advantage of short breaks.

## Theme Three -Information and Communication

Information and communication is a theme that has emerged strongly from our data throughout the research. The provision of information forms an important part of the core offer for disabled children and their families and the disabled children's services national indicator. Although parents reported a variety of experiences with regard to accessing information about short breaks, mostly this was problematic. This appears to be despite significant attempts made by some Local Authorities to engage in a consultation and information process with parents. This section is divided into two parts. In the first part, the focus will be upon issues around the ways in which disabled children and their families are seen as information providers and involved in formal consultations by Local Authorities in their planning for and commissioning of short break services. The second part of this section will focus upon the perceptions that parents have about their access to information that will meet their needs.

### Formal consultations

Regular, accessible and acted-upon consultation is important if Local Authorities are going to meet the needs of disabled children and their families. This applies equally to Primary Care Trusts and short break providers – although it must be noted that most of our evidence relates to Local Authorities. Such effective consultation depends upon Local Authorities being flexible in the ways in which they engage with disabled children and their families.

At the NDTi regional workshops for representatives from Pathfinder authorities much good practice around involving parents and disabled children and young people in planning and commissioning short break provision was noted. For example one Local Authority operated a scheme whereby young disabled people inspected and reported upon the facilities in venues such as leisure centres. In another Local Authority parents had been involved in assessing the tenders put forward by potential providers of short breaks services. In some cases this had led to the bids by large, national organisations being rejected because they did not meet the needs of the parents. However, the move to involve parents and young people was felt to have potential drawbacks. One such problem with consultation that was noted by some parents that we spoke with was around the lack of feedback or indeed action on the consultations that had taken place. For example, one parent spoke about her experience of being consulted by her Local Authority:

*Interviewer: So have you been involved in any form of consultation about short breaks from the council?*

*Barbara: I did send an email off to someone at the council a couple of years ago. I never got any reply and I emailed them again, and they said they'd be in touch, but they never got back*

Parents need some indication that their views and opinions with regard to short break provision are valued and acted upon. A failure to acknowledge parental input leads to cynicism about and disenchantment with any new drives to consult with parents. This experience was echoed by professionals who worked with parent carers and who attended the NDTi regional workshops. There was a concern about the potential for 'over consultation'

of parents especially where this appeared to be a paper exercise only and was not followed by any feedback or perceptible changes in provision.

During our fieldwork we attended a parent consultation event held by one Local Authority in North West England that was one of a number being held across the county. This appeared to be part of an attempt to engage parents with the Aiming High short breaks programme. At this event, the formal opportunities for parental involvement in decision-making at various levels within the Local Authority were outlined. However some parents at this particular meeting did not know about even the most basic grass-roots level of involvement (parent carer forums) which could lead on to higher levels of involvement within the council. The council had employed parent carer workers to engage with parent carers, published a regular newsletter and had information about Aiming High on their website. Even so it was clear that information was still not reaching all of its intended audience in a way which was useful to them. It is important that councils think carefully about their information and communication strategy with regard to short breaks provision. This is especially important because the target audience may be harder to reach because of the demands and restrictions that are placed upon them by their caring responsibilities. These include spending more time on caring for their disabled child, reduced financial resources, the physical and emotional demands and increased 'logistical complexities' (Reichman, Corman & Noonan, 2008).

Another potential drawback identified in the move to involve parents was that of the so-called 'super parent' who is involved in decision-making at high levels and is good at representing their own concerns. However because the population of disabled children and their families is extremely heterogeneous it is likely to be the case that these parents would not always be in a strong position to reflect the experiences and expectations of all parents. This was a concern held mostly by the professionals that were at the workshops and meetings that we attended, rather than an opinion that was expressed by the parents.

At a meeting for parent professional partnership working that we attended, speakers from one Local Authority shared their model of engagement which provided a realistic and perhaps more constructive understanding of the ways in which parents are involved in participating in decision-making. This particular model highlighted that not all parents are able to be involved in consultation and decision-making at the same level. The model describes how families differ in the resources, time and interest they have in participating in decision-making. This model could be usefully employed by Local Authorities to develop their understanding of the information needs of all parents when planning for parental involvement. Consultation should not only take place with those families who have the resources and interest, but should be tailored to take place in some form with all different groups of families.

As well as consulting with parents about provision, Local Authorities or others commissioning short break provision should ensure that they have the right systems in place to maintain up to date, reliable and useable information about the range of disabled children and their families who need to use short breaks. A representative from one Local Authority at the NDTi regional workshop highlighted the importance of this for promoting greater equity of access to short break provision. But if parents are going to be asked to provide such information there is an expectation that the responsibility will then lie with the Local Authority to ensure that all parents find out about their entitlements and the range of provision

available to them locally. This means that consultation and information gathering should not be treated as a one-off information extraction exercise, but should be a process of continuous engagement and feedback. Parents want consultations to result in positive outcomes and they also want to be informed about them.

### **Finding out about short breaks**

The parents that we spoke with had clear expectations about how they should find out about short break provision and these differed from their accounts of what they experienced. Two parents at a specialist holiday play-scheme spoke about their expectations around how they should get access to short breaks:

*Mairi: "I think it should be an automatic...rather than us have to get in contact with the social worker or the disability teams or whatever come and see us. If they have a list of people that have got children with disabilities it should be an automatic thing that they get in touch with you and that you have an allocated social worker that comes and keeps in contact regularly."*

*Isma: "Because it's always up to you to contact people and you don't always...you haven't got the time or you think it's too much of a headache to do it and you just don't do it."*

There was an understanding that the difficulties (e.g. lack of time) associated with caring for a disabled child mean that parents perceive that it is easier for Local Authorities, typically through social workers, to inform parents about short breaks than it is for parents to find out for themselves. The experience of having to seek out information was also shared by another parent:

*"I referred her [a mother with a disabled child] to go finding it because, again, nobody will ever offer it to her because they thought she was okay, and she didn't need it, and cos she'd not asked for it she wouldn't get it." (Linda)*

In this parent's view the need to seek out information or ask for help was understood as being necessary to signalling that support was needed. In this model the parent must identify and define their own needs and actively seek the service. This is in contrast to the point discussed in the first section which highlighted the important symbolic function of being 'awarded' short breaks. If simply not asking about short break provision is seen as an indicator that breaks are not required, it seems likely that many more parents will face the experience of May only obtaining access to much-needed support at a moment of crisis.

Some parents found out about short break provision for themselves using resources such as the internet, but acknowledged the difficulties in doing so:

*"I spent an awful lot of energy trying to find out [about short break provision] and I'm reasonably intelligent and I've got the time to do it so how do you expect...someone on the breadline...it doesn't come easily for people." (Linda)*

There were numerous difficulties that were perceived to be associated with finding out about short breaks. In some cases this was because the detailed information about short break provision was understood to be fragmented and held in lots of different places by a variety of people and organizations. Sometimes it was the sheer hard work and use of valuable time and resources that made it difficult for parents to get access to information about short break provision. It is also likely that if short break provision is designed to meet the needs of disabled children and their families and if the range of short breaks providers is to grow and diversify then the information that needs to be communicated will change frequently. Robust strategies for the dissemination of this information should be developed to ensure that families get the maximum benefit from short break provision.

The different information giving and seeking strategies discussed by the parents that we spoke with revealed how information about short break provision becomes available to parents and families with disabled children. The central way of finding out about short break provision discussed by a lot of the parents we spoke with was through support groups and children or carers' centres. Word of mouth was an important and trusted source of information about short break provision:

*"Anything I need to know, we just word of mouth through each other, really and from here [specialist holiday play scheme for children aged 0-19 with special needs or disabilities]..." (Isma)*

Sometimes the kinds of information needed by parents required a more formal process of signposting. This tended to be taken on by parents who had a greater involvement in the process of providing short breaks:

*"I mean Gemma [who runs a holiday play-scheme for disabled children] is quite good if you've got any problem and you can ring up Gemma and Briony and they can usually guide you... (Isma)*

Two women who were both parents of disabled children and providers of services talked about how they frequently signposted other parents onto other sources of information and advice.

Another parent who was not formally involved in the provision of short breaks, but did get in touch with a local voluntary organization providing support for parent carers and is a representative on a Local Authority parent-carers forum, expressed real concern about the lack of information that other parents had:

*"If I hadn't tapped into ... [a voluntary organization providing information and support to carers] I wouldn't know half of the stuff that I do...so as soon as anybody new comes through the door like Louise from the meeting the other week ...I mean she didn't know...and I felt flipping heck but that was me 18 months ago really...so it's not easy and there are organizations but to find them locally in your own area is sometimes quite difficult." (Melanie)*

Melanie had access to information about short breaks because of her position as a parent carer representative and also because she got in touch with a local voluntary organisation. This kind of involvement can increase the parent's access to information about what short break provision is available. It may also lead to a further benefit in providing a sense of having an important role to play in the transmission of information within the community of parents of disabled children. Another form of information that parents shared related to the level of service or provision that could and should be expected. For example, Joanne talked about how she found out about direct payments from another parent in a support group:

*"I think it was the Dravet's lady [from the IDEA league, a support group for families with children with Dravet Syndrome] Ellen ...said 'have you got DLA' yeah 'higher rate?' no 'well go for that'...and even the direct payments ...I got two hours and she said 'well I've got six hours and six extra in the school holidays...so I've kind of pushed for some more and I've managed to get...three a week and two extra in the school holidays which is fine for me cos Nancy like I say she is a bit more disabled."*  
(Joanne)

Parents share their experiences and are able to gauge what their entitlement 'should be' in comparison with other parents and families. This information increases parents' confidence in requesting greater access to short break provision. However, it should be noted that these parents are not trying to get as much short break provision as possible, but as much as they consider is fair for their needs and their circumstances.

Parents can also provide advice to other parents about how to engage with the direct payments process. One parent told us how her brother (who has a disabled son and had already used direct payments) gave her advice about what kinds of questions to ask when interviewing potential carers.

Although information obtained from other parents is perceived to be trustworthy and reliable, there are wider issues connected with the transmission of information about short break provision through informal parent networks. The reach of such information is limited. Also, parents may have only a partial understanding of the nature and extent of short break provision in their local area.

One important source of information for parents of children who attend special schools is the school itself. But as previously noted, often the geographical location of the school and the way in which transportation for the disabled child to and from school is arranged means that parents may lose the opportunity to mingle 'at the school gate' and share information and experiences. Even so, parents whose children attend special schools are likely to be in a better position than parents whose children attend mainstream schools in terms of information provision. Special schools are often treated as a convenient way of disseminating information or as providing an audience for consultation for the majority of disabled children and their families. But this means that the access that disabled children and their families have to information and their opportunities to be consulted are limited.

Although information about short break provision is required on an ongoing basis it may be especially important at the point of diagnosis. Some families found out about one Saturday morning family session for young people with autism and their families through leaflets that they had been given at the point of diagnosis, these had been sent out by a consultant. This seemed to be a good time at which to receive the information for these families and prompted them to find out more about the session and to begin attending them. The usefulness of information obtained at this stage will depend upon the individual family's circumstances.

This theme began by considering some of the issues around attempts to increase the involvement of disabled children and their families. Local Authorities need to involve disabled children and their families in decision-making processes about commissioning and provision at a range of different levels. The heterogeneous nature of disabled children and their families mean that it can be difficult to gain a comprehensive picture of their needs, but this very heterogeneity means that it is essential to do so.

The second section focused upon how families with disabled children find out about short breaks. Although parents had clear expectations that the information should be provided to them, this did not always match their experiences. Parents reported several information-seeking strategies including word of mouth from other parents, signposting and involvement in carers' centres and support groups. The types of information that parents shared was concerned not only with various types of short break provision, but also about how to access different levels of short break provision.

In planning for how to communicate information about short breaks to disabled children and their families, Local Authorities and providers of short breaks need to engage both with the ways in which parents currently find out about short breaks, and with the ways they want to find out about short breaks. Attention also needs to be paid to the constantly changing nature of information about short breaks, given the drive to grow and diversify the providers of short breaks; this means that up to date information will become more challenging to deliver.

## Theme Four - Who Provides Short Breaks?

This section will build upon the issues raised in the initial report regarding who the short breaks carers are. In the initial report it was suggested that parents were more likely to get a benefit from short breaks if they felt that their children's needs were also being met by the short break. Parents were more likely to feel that their children's needs were being met if they thought that the people working with their children were competent. Competence meant different things to different parents. On the one hand parents said that they valued qualifications and training, however they also felt that the personality characteristics and attitudes of the person doing the caring were also important. It was also noted that direct payments appeared to offer parents greater flexibility and choice in the people they employed.

### Workforce development

According to some Pathfinder authorities who attended one of the NDTi regional workshops, the workforce engaged in short break provision is somewhat under-developed. Whilst we do not have any formal evidence about this, it was generally the case that a career in care-work in particular was seen by parents to be intrinsically precarious. Parents were concerned about the short-term and low-paid nature of such work in that it affected their perceptions of the quality of care that was being provided for their disabled children. For example, a mother whose son is at the severe end of the autistic spectrum expressed her views about the link between pay and quality of care:

*"These people [carers] are our life-line, you do not pay them the minimum wage, you pay them [so] that the quality and type of work that they're doing is appreciated...and...I want to see those people being respected the same way I respect them for giving me freedom..." (Linda)*

The perceived consequences of a failure to value the workforce has an impact both on the quality of care being provided, and also on the rate of staff turn-over. Both of these issues have a direct effect on the impact of short break provision on disabled children and their families. Parents receive more benefit from short break provision if they have confidence in the people caring for their children. Signalling that a workforce is valued can include ensuring appropriate rates of pay for the work being undertaken and also by providing a system of training and qualifications which acknowledges the skills and development of individual workers. But it is clear that what parents want most from the people who work with their children goes beyond training and qualifications. The next section will consider what parents feel are important characteristics of the people working with their children. Then the impact of direct payments on parents' experiences of short break provision will be considered alongside the implications of expanding the workforce to support the process of direct payments. The final part of this section focuses upon parents as providers of short breaks as one way of extending the amount and range of provision.

## **What disabled children and their families want from their carers**

As part of an activity at a young person's consultation event, that involved children identifying the attributes their carers should have, the attributes that the children put forward were that the carers should be interested in them, be caring and know what they are doing. This view about what people who work with young people should be like was also shared by most of the parents that we spoke with. One worker explained that some of the children he cared for were concerned that carers should be 'funky', 'young' and cool', not people wearing drab uniforms.

The one requirement that was held in common across the parents we spoke with was that the carer should understand their child. Understanding was framed in terms of getting to know the specific needs of their child as well as knowing what to do if they were faced with strange or unusual behaviour. Often this understanding was treated as something that was not necessarily gained from generic training and previous experience but as something that was obtained through the carer's relationship with the child. One parent talked about the time it takes to build up this relationship:

*"It's gonna take ages to build up a relationship and for them to get to know her funny little quirks and what they're gonna let her get away with and what they're not gonna let her get away with..." (Barbara)*

It is this time and effort in developing an understanding in the carers that work with their children that makes the high turn-over of care staff so difficult for families to deal with. This was especially challenging where the child's behaviour was affected by a lack of continuity:

*"And I think the downside of somewhere like Sunshine Cottages is... I mean it's fantastic... but obviously you can't guarantee that you're going to get the same carers every time. Although they do have a link worker, they can't always guarantee that they're going to be there when they're staying there... They do try to place them in the same group of children every time and in the same house every time. But I think it's only when they get a different carer in that's quite hard for her [Barbara's daughter], so they do tend to play up then – as you would at 13. It's alright. It's quite normal." (Barbara)*

So from the point of view of Barbara, the high turn-over of care staff is a potential cause of disruption to her daughter's positive experience of short breaks. The impact of this on the child and family can be very detrimental; the child may show their unhappiness through a range of behaviours during the short break, later at home or even in their school setting. This in turn has an effect on the impact of short break provision on parents. A sibling we spoke with said she was not particularly concerned about carers leaving but she went on to make some perceptive comments about how these changes might affect her disabled brother:

*“Gemma’s [Isabelle’s brother’s carer] only just started and she has to leave in April cos she’s going to university so, it depends...cos you can’t tell them not to change because at the end of the day it’s their life as well isn’t it...it doesn’t really bother me about them changing...I think it’s probably hard for him [Isabelle’s disabled brother] because obviously he’ll have to deal with the change and then some of them he’ll never see again...cos to him they’ll be like friends and then suddenly they’re just gone.” (Isabelle)*

The concern about the negative impact of lack of continuity in carers is emphasized by those parents who talk about the positive benefits of working with the same carer over time and the problems associated with using temporary agency staff:

*“I know I’m lucky because I have a carer that I’ve used for quite some time and she’s brilliant, but she’s my only steady one. Others I kind of get in and train up. I wouldn’t ever use an agency because you have to explain constantly what your kids like, what they don’t like, what they need, what they don’t...it’s not ideal.” (Ann)*

The confidence that parents have in the people working with their children is fundamental to any potential positive benefit they will receive from short break provision. The requirement that the people working with their disabled child understand their specific needs represents a substantial barrier in terms of parents accessing mainstream short break provision for their child. For example one parent was concerned that the leader of The Beavers (a club that is part of the Scout Association and for young people between the ages of six and eight) would not ensure that the door was locked. This was considered to be a problem because her autistic son might bolt out of the door.

However, parents also talked about the skills and qualities that they specifically wanted the person working with their disabled child to have. This depended to a large extent upon what they wanted the short breaks to do for their child. In one case a parent with a son who has autistic features and DAMP (Deficit in Attention Motor Control and Perception) wanted a carer who could meet the specific developmental and social needs of her teenage son. This meant that the parent had few special requirements beyond the carer being male and being fun so that they could engage in age-appropriate and gender-specific activities:

*“...we specifically asked for a man because ...Will spends most of his time with him mum and he’s growing up so we thought that a man would be good...we were offered Lee...he’s fun for Will to be with ...so that...does work well.” (Laura)*

Another parent (Joanne), whose son had Dravet syndrome, had a specific requirement that her son had access to challenging developmental opportunities during short breaks. Joanne employed two carers through direct payments. One of the carers also worked at a special school, whilst the other carer did not. Joanne made a distinction between the kinds of short break the different carers were able to offer as a result of their training and experience:

*“The important thing is that Amanda [special needs teacher] knows the techniques with Liam to get the most out of special needs... Nancy [another carer] is more... cautious, a bit more... you know kind of babysitting. Whereas Amanda kind of comes in [with] her professional head on... so that’s good for me because I know that when I go off and do my run she’ll be here giving him input for an hour so he’ll be getting the best of both worlds.” (Joanne)*

The type of support provided by the special needs teacher was an important part of helping Joanne to get some benefit from short break provision.

In the initial report we pointed out the great cross-over of staff working with young people with disabilities. One disabled child accessing a specialist half-term holiday club noted that the manager of the holiday club also worked at their school. People who worked in special schools were seen by parents to have the perfect combination of training as well as having the child and disability-centred values that parents wanted in the people working with their disabled children. Staff at special schools were also seen by parents as a ready and often available source of short break workers that could be employed using direct payments. In the case of direct payments, these staff were seen as being advantageous on a purely pragmatic level, for example because they had been Criminal Record Bureau checked.

The experiences that parents reported of direct payments were positive in the main. Parents reported that they appreciated the flexibility and choice that direct payments afforded them with regard to employing staff that they thought were suitable to meet the needs of their disabled child.

*“...you can pick and choose who you want to actually care for your children...I like the idea that even if you didn’t want to go down and interview somebody you could use them to buy agency workers in so you have that flexibility...having said that it’s a bit more expensive are the agencies...”(Melanie)*

When parents reported problems around using direct payments this tended to be with regard to not having enough direct payment hours to be able to give a particular carer enough work which meant that the carer looked for or found work elsewhere. The amount of paperwork involved was seen by some parents to be a problem:

*“I like direct payments for its flexibility. But that’s about the only thing I do like about it. I think it’s a complicated system that parents struggle to do the payroll and keep up with the paper work. It also means that you still have carers...you have to find your own carers.” (Ann)*

It is likely that there will be individual difference in the ability to cope with direct payments, but this may be mitigated to some extent by the level of support around the direct payment process. For example, Melanie, another parent who used direct payments was impressed by the level of support she received from staff, not directly involved in providing short breaks:

*Melanie: ...the direct payments people...the helpline people have been fantastic...they help me set up all the interviews...*

*Interviewer: ...So it sounds like it's been a really smooth...positive process*

*Melanie: It was...and I am terrible at ...keeping the paperwork up to date as long as you keep on top of it every week and log the right number of hours ...it's a doddle because the money side of it gets worked out for you anyway.*

The move to increase direct payments will involve an expansion of the short breaks workforce, bringing in more workers with a fundamental role to play in the positive impact of short break provision. Furthermore the Short Breaks Implementation Guidance (DCSF, 2008) has already noted that there will have to be an increase in suitably qualified professionals able to recruit, train and support the workforce. As well as carers themselves it is also important to get into place well-trained and approachable staff that can act as an interface between parents and processes connected with short break provision such as direct payments.

### **Parents as providers**

A report by PricewaterhouseCoopers (2007) suggested that increasing the diversity of disabled children's services was one approach to opening up short break provision. Parents as providers of short breaks services occupy a valuable role as experts on what forms of short break provision would be most useful for both disabled children and their families. We met a father of a disabled child and short breaks provider and also spoke with two parents who together had become providers of specialist short break activities for disabled children and their siblings after becoming disenchanted about the lack of provision for their disabled children. We also attended one Local Authority parent consultation event where parents were actively encouraged to think about forming management committees to apply for Aiming High funding to provide short breaks and to enter into an arrangement with special schools whereby they could hire the facilities. However, if this is to happen then relevant support tailored to needs of these parents-providers has to be put into place. This might include formal sessions on running businesses etc. and also peer-support from parents who have had experience of becoming providers.

Two parents who became providers told us about their experiences of attending courses. Many of these courses were not thought to be useful, especially because disability tended to play only a marginal role and was confined to diversity training rather than any formal consideration of the issues specific to developing provision for young people with disabilities. Local Authorities need an awareness of the specific requirements of this novel group of short breaks providers who already have a deep understanding of the challenges faced by families with disabled children. While some of the Pathfinder Local Authorities were seen to be actively nurturing innovative local providers who were often new to the intricacies of Local Authority tendering, others reported difficulties in terms of fitting new or non-traditional providers into their existing commissioning processes. These parents also related an incident during which their decision to use play-workers rather than qualified teaching staff at their after school and holiday clubs was called into question by professionals who appeared to misunderstand what the parents wanted to achieve with their short break provision. Parents would be more likely to feel able to begin this process if they see it as a process that draws down lots of support. In addition, Local Authorities should consider whether there is

scope to change their own procedures in terms of commissioning and administration to make them more accessible to small groups and new providers.

This theme has explored the perceptions of parents regarding the people providing short breaks services. Parents in general required that the person working with their child understood their needs. Parents also had more specific ideas about what they wanted from the person providing short breaks and this depended upon their circumstances and expectations. Direct payments were found to have the potential to improve parents' experience of short break provision, but this depended upon the support that was available. Parents also potentially have a role to play as providers of short break services. This would not be appropriate to all parents and significant tailored support would need to be available.

## Theme Five - Relationships with Short Break Carers

This section considers the complex and sometimes contradictory relationships between short break carers and families with disabled children at the interface of the private sphere and the labour market.

### **Kin**

Caring for a child is deeply sensitive and personal work that requires a high degree of responsibility and trust. The primary site of child care often tends to be within the extended family. This also applied to the families with disabled children that we interviewed and observed over the course of this research. For instance, we met older siblings looking after their disabled brother or sister, and grandparents who would regularly embark on long journeys in order to play a role in the upbringing of their disabled and non-disabled grandchildren. In a related vein, families with disabled children experience similar developments and strains as do families with non-disabled children. This includes - as in the case of the grandparents mentioned above – that relatives are often widely dispersed, making it potentially difficult for family members to play a substantial role in the lives of their younger kin, let alone being regularly involved in their care. As the grandparents showed, it was not impossible to assist family members, nor did such familial support necessarily require physical presence. For example, the mother of an autistic son whose brother lived far away drew on his experience of raising an autistic child, he acted as her mentor and offered her information and advice.

Conversely, closeness of relatives did not always equate with a ready-made support network. Caring for a disabled child can be highly complex and demanding. Not all family members are able, willing or confident enough to accept this challenge. Thus even those families with disabled children that had kin nearby could find themselves coping largely on their own.

*“...sometimes it would be nice for [my son] to like stay at my mum and dad’s. Maybe just for one night to give me a night off, but it won’t happen because he doesn’t sleep all night and because they’re worried about not being able to understand what he wants.” (Kate)*

Relatives were concerned that they may not be able to communicate with the child, attend to his or her needs, and know what to do in a medical emergency or deal with the child if he became distressed.

Yet, even in families where other family members were willing to look after the child, questions could arise over whether they were in fact suitable. May’s daughter loved her gymnastics class, but May had to find someone to look after her autistic son, while she was training:

*"...gymnastics, I can't even take him there, because it's for an hour and he wouldn't sit for an hour. So my mum has him, but she's 77. She's got a heart condition and it always worries me, you know, 'what if?' and it's not fair on her." (May)*

Under such circumstances of limited familial support, direct payments and the short break care that they bought could be a life-line to parents, because they extended the pool from which carers could be drawn.

## **Trust**

What made a carer suitable for a short break in the eyes of a particular family involved a whole range of factors, including if they had any pets, or smoked, and, depending on the short break arrangement, whether their home was set up to accommodate a disabled child. However, the most vital factor was that a relationship of trust existed between the carer and family and that the carer was able to establish a rapport with the child. Such conditions were often already fulfilled if a carer could be recruited from within the family's extended kinship network. Direct payments have an important role to play because they allow families with disabled children to compensate their relatives for child care that may exceed that typically required by non-disabled children. Direct payments could both improve parents' position to bargain for such care, and make them more confident and willing to ask for it (Blyth, 2007).

Another important social network parents drew on when looking for short breaks carers were the child's teachers and support workers, especially if the child attended a special school.

*"...well it's kind of a case of my partner's mother's sister's friend, you know. So yeah it was word of mouth. But I am actually going to try and get somebody else on my books as well and I'm gonna go to special schools [because my friend] Lyn over in [a nearby city] she does the same and she gets her people from the special schools." (Joanne)*

Being able to recruit from a pool of people with whom relationships of trust already existed helped parents to take the sometimes quite difficult step to leave their child in the care of another person, even if this was only for a few hours.

*"I'd be worried if he went away with someone else. I would constantly worry. I would be worried, you know, what if he doesn't like it, would he cry, what would they do, how would they know what he wants? I wouldn't do it. I wouldn't send him away. I wouldn't!" (Isma)*

For Isma, leaving her autistic son in someone else's care was unthinkable, but even those parents who were looking forward to a short break from their children might initially struggle with the separation.

*"I went to see this place, Laburnum Grove, that [my social worker] recommended, and he started going there for odd evenings for tea, just for tea, and then the woman that runs it, the manager, she said: 'I think he's ready to stay but is mum ready for him to stay? For one night, you know?'" (May)*

Such difficulty to 'let go' is not surprising, where parents (in this case mothers) have for many years been the sole or primary carer of their disabled child. Landsman has pointed out that the expectation that the mother's identity becomes subsumed into the care of the child is conveyed by professionals involved in the child's treatment and care (Landsman, 2003). Hence, leaving the child in the care of another person may not only represent a change in habit, it may conflict with the mother's identity, and further may also come up against the real or imagined scepticism (or even disapproval) – of family, friends, and professionals. Given this context, it is not surprising that parents felt vulnerable:

*"...just say something happened and [my son's carer] let me down because, I said something out of turn to her...or she poked my son, or she spited my son, or she put..she smacked my son, or she got angry with him, or she walked out on him. She just decided it's not worth my time and walked home or walked off and left him [...] it's very hard because I have to trust her with my baby." (Linda)*

Against these worries parents sought to maximise the reassurances that the carer can be trusted and will be good for the child. Being recognised as a good employer is one way to ensure quality of care:

*"As long as I send the cheques off to make sure that the girls get paid, everything's fine [...] everybody gets their money for what they do because I need them. I need them reliable, and if we're reliable then everybody else [can be] relied upon, and everything works." (Linda)*

In addition Linda also successfully enlisted the support of her local social services, suggesting that professionals have an important role to play in empowering parents:

*"We have a wonderful lady [...] who runs the direct payments department up there. She is mustard, because in our last review [...] she actually said [to the carer]: 'It's not about you, it's about the family here being represented'." (Linda)*

However, the most common strategy families with disabled children used was to spread their services and employ more than one carer. They did this even though finding a suitable carer could represent a substantial challenge, because of the capabilities, reliability, availability and flexibility required. These requirements place many demands on a small and not particularly well-paid workforce. It is important to remember that the relationship between parents and short break carer was not simply an employment relationship, certainly not from the parents' point of view. Characteristics such as professional expertise and personal aptitude existed within a complex environment which mixed the economic sphere where everything had a price, with the private sphere where exchange was free and unquantifiable. This complexity and entanglement was evident from the way carers were selected.

A pre-existing familiarity with the carer and a recommendation from a trusted source, especially when combined with the carer's professional expertise could contribute to putting a parent's mind at ease when selecting a short break carer. Yet, with the exception of professional expertise, existing familiarity and personal recommendations all draw on informal social relationships. Therefore, they are at odds with the official rhetoric and ideal practice of the labour market which emphasise that the best candidate has to be objectively and transparently selected, irrespective of his or her subjective relationship with their future employer. This divergence of the selection criteria for short breaks carers from those of other

jobs is relevant here, because as we have already pointed out, when direct payments are used parents are technically the employer of the short breaks carer. Having said this, these carers look after vulnerable children, outside of school time, and in the family home. As a consequence their role temporarily becomes interchangeable with that of trusted family members and close friends. Hence, as carers they transgress the boundaries of the nuclear family symbolically, spatially and emotionally, and their employment relationship may become obscured. We have already seen the distress and worries that parents of disabled children can experience when using (or even imagining using) short breaks. This is exacerbated by the need to 'familiarise' and orientate carers, by linking them into a network of already existing social relationships that encompasses particular people as well as places, such as a special school. This process of familiarisation is an important precondition to establishing trust between parent and carer. Yet, this was not only a process of symbolic integration, but also of providing physical and spatial accommodation:

*"But at the moment, my carers tend to come from 10 to 4, so they go out for a mini activity in the morning and then they come back, have their lunch at my house, you know, depending if there's anything they can do in the afternoon, you know, they either go out in the afternoon, or they bum around the house. And then you kind of feel...the house gets pretty full or you feel that you need to go out now to give them a bit of a space." (Ann)*

The presence of the carers in the house also affected what activities Ann considered appropriate doing in her own house while the carers were there:

*"...sometimes with respite you'd like just to chill out in front of the telly rather than feel that you have to go out." (Ann)*

Ann's ambivalence about sharing her house with the carers was echoed by another mother who was also aware that the range of activities that the carer could do with the disabled child was sometimes limited:

*"...it's difficult sometimes to know what your child can do if they go out with a care worker, because you don't really want them at home, partly because that would mean you would have to go out and it's nice to have free time at home, and also because you wouldn't necessarily trust someone in your home. You don't want to give your home over." (Laura)*

Laura's observation stressed the importance of accessible spaces for short breaks activities, but it also highlights the implications for parents. She had originally intended for her son to be taken to a nearby sports centre and pool, but this had turned out to be impossible because of a lack of appropriate transport. Hence, the child's options were restricted to the cinema and the library. Such limitations on what the carer and the disabled child could do were not uncommon, especially in winter when parks and other outdoor spaces become less easy to use.

However, mothers were not the only ones who felt ambivalent about the presence of carers in their home; non-disabled siblings also experienced these feelings. Ann's eldest son, for instance, confessed that at first he minded the carers being there, but that since he had got to know them, he was ok with them. 17-year old Isabelle, whose brother George has Down's syndrome, cerebral palsy and epilepsy, acknowledged the possibility of conflict between family members and carers and was aware that having carers around could be difficult for some people, though she herself did not mind:

*"I don't know whether that might annoy my sister a bit but depends on... 'cos most of [the carers] are really nice, but some are a bit irritating. [N]one of them have ever been horrible but some of them are a bit bossy or summat and you're like: 'It's my house!' But I'm not really bothered to be honest." (Isabelle)*

Isabelle admitted that if everything got too much for her she could retreat to her room, but on the whole, she felt that the carers had become a normal part of family life.

### **Roles and boundaries**

Some parents worked at integrating the carers into the family's relational fabric. For instance one mother we spoke to was preparing her son for a family-based short break by introducing the carer as 'my friend Lynne', after another respite arrangement had not worked out for her son. In this case 'friendship' became a code for short break care arrangement but it can also work the other way round. Martin's son Simon was looked after by another family, who were also caring for other disabled children, for one day a month. Martin's family and the fostering family had struck up a friendship before Simon stayed with them for a short break through the special school their children attended. This blurring of the boundaries between short breaks carers and family and friends might also happen from the side of the carers:

*"[Carer] takes John out quite a few different places. They have a car, him and his partner and they've just had a little baby girl. She's really lovely isn't she? Baby Megan, [...] you had hold of her when she was only a week old didn't you?" (Melanie)*

Those arrangements where carer and disabled child were doing "normal teenage things" together, like friends, could be very successful and came close to the idea of short breaks as providing new experiences for the disabled child as well as respite for the rest of the family.

This theme has highlighted some of the strategies by which families aim to maximise assurance that their child is in safe hands and at the same time try to minimise disapproval and worries for doing so by replicating family-like structures between their family and the short break carers, provided these carers are not kin already. Direct payments play an important role in allowing parents to cast their net wider for suitable care, but they have also introduced new concerns about the quality of care. In this situation parents often draw on existing trusted networks (predominantly through friends and family and through the disabled child's school) to recruit short breaks carers. The boundaries between family members and non-family members are further blurred through the purpose and the location of the carers' work, i.e. supporting the disabled child in the local community, which includes the family home. Finally, some parents and carers will further encourage the development of a friendship-like relationship between disabled child and carer. This is sensible given the degree of familiarity and trust required to ensure that both the disabled child and his or her family gain optimal benefit from a short break. However, such familiarity has to be carefully

managed, because it can potentially weaken the parents' position as an employer, introduce the greater autonomy of a voluntary carer and again create a dependency on a limited supply of suitable carers. Having said this, there also appear to be serious issues from the perspective of short breaks carers. These include the often casual and unpredictable nature of their working arrangements, and potentially their de-professionalisation by casting them as 'friends' rather than as 'carers' with a potential effect on their pay and recognition as multi-skilled workers.

## Theme Six - Sustained Support to Lead Normal Lives

In this section we will focus on the characteristics and qualities that short breaks require in order to become an integral and valuable part of the fabric of everyday life of families with disabled children. In the main this means regular and reliable provision of short breaks that provides a positive experience for the disabled child. Such breaks need to sustain or improve the ability of the carer to care for the child, or enhance the quality of life of the carer (and ideally also of other family members). These characteristics have to be the guiding concerns when considering which short breaks should be offered. The key message that emerged from our interviews with parents was that the most valuable short breaks were not the 'wild and wacky' breaks, but rather those short breaks that were regular, reliable and nurtured the ability of all family members, including the disabled child, to lead normal lives.

### **Reliability, normality and lasting impact**

Building on this finding, we suggest that if short breaks are to enhance the extent to which families with disabled children have access to comparable activities, opportunities and experiences as other families, short breaks also have to incorporate mundane activities that are often taken for granted by families with non-disabled children and by those commissioning and providing short breaks. Rather counter-intuitively, we venture, being considered mundane and unremarkable may even be an indicator of the extent to which the short break has become invaluable to a family with a disabled child. By raising the profile of 'routine' short breaks provision, we certainly do not want to direct attention away from the essential provision of overnight respite. For many parents we spoke to, quality overnight respite was pivotal to their ongoing ability to provide care. Hence, the kinds of short breaks that are mainly under discussion in this section are predominantly activity-based leisure and social activities that aim to enhance the quality of life of all members of families with disabled children and which can be relatively special occurrences or events.

Such breaks can be invaluable in their positive effect on the lives of families with disabled children. This certainly was the case for some longer short breaks. On the one hand they help the disabled child to gain new positive experiences:

*My son went on an activity weekend at the beginning of 2009. This was the first time that he had been away with non family members. The photographic evidence verifies that he had a brilliant time and that he is more able to fend for himself than I thought he could. (Story Space 7)*

At the same time the family could enjoy time together without the disabled child. The positive impact such separation could have was anecdotally conveyed to us by one of the speakers at a parent-carer participation event that we attended. Her Local Authority had paid for carers to work with the two severely autistic children in a family during the school summer holidays. Apparently, this arrangement had been very successful and everyone in the family had had a great time, until the last week when no carers were at hand and the family were left to cope on their own.

Such longer short breaks could impact positively on all members of the family, including non-disabled siblings.

*"[George, my disabled brother] went to Lourdes with the Faith and Light Group at church and we could go away on the same week. That was good, 'cos he...when he goes away we go away." (Isabelle)*

While such holiday-like short breaks may appear non-essential to the superficial observer, they can make a crucial difference to the ability of the main carer to care for a disabled child, as Joanne describes:

*"...by the end of the year I was cracking up [...]. I went to the doctors. I went on anti-depressants but they didn't work for me [...] and I had this holiday. And that was it! I was able to cope again! I was back to strength." (Joanne)*

Joanne was a working mother who had recently split up with her husband and was now the sole carer of her disabled son. She had paid for the holiday herself, but had received financial support from a charity dedicated to the well-being of carers. An extended break was also made available to Caroline whose youngest son was 15 and has autism and severe learning disabilities. She was given four extra days of care by her Local Authority so that she could visit her husband who lives abroad. These cases show longer-term short breaks had an important and positive role in the lives of families with disabled children, yet they were special, and therefore by definition, rare events. AHDC has encouraged Local Authorities to be more innovative and creative in the provision and commissioning of short breaks. This has led to some unusual activities being made available for children with disabilities on a more regular basis.

For instance, we heard about short breaks involving autistic boys playing golf or going kayaking, and a boy with cerebral palsy being taken skiing. Two aspects are important here when considering the place of such short breaks in the lives of families with disabled children. Firstly, how sustainable is the activity and is there any lasting positive impact after it has finished? This question is pertinent, because short break activities were often one-off or short-term occurrences. Secondly, there is the issue of whether such a short break benefits not only the disabled child but also has a positive effect on the quality of life and sense of well-being of other family members, in particular of the parents/carers.

The pertinence of the first question can be illustrated by the experience of the mother of a 13-year old boy with developmental delay. Through his special school her son had been able to access riding for disabled children, an activity that he had very much enjoyed. However, this short break was very popular and was rationed to eight weeks per child. While the mother felt that her son had benefitted from the activity, she considered the multi-sports club that he attended twice a week to be much more valuable. Like the special riding course, it encouraged her son to be physically active, but unlike it, the multi-sports club was regular and open-ended. This does not mean that unusual, one-off, or time-limited activities do not have a role to play in short break provision, but it raises the fact that the most useful and beneficial short breaks for families with disabled children are not necessarily the most dazzling or spectacular ones. It also points at a need to assess the effect of short breaks in terms of how they benefit families with disabled children, long-term and in the context of their everyday lives. An example of the impact an unusual and time-limited short break can have

comes from what we learned at one of the NDTi workshops and concerned a wrestling course that a Pathfinder site had offered. This activity had paired up disabled children and vulnerable youngsters and had not only been very popular with the children, but also had a sustained positive impact on the children's behaviour and social interaction at school.

Whether a short break was only available for a limited time was not necessarily due to its popularity as in the example of the riding course for disabled children, nor was it due to an absence of the service, but it could also be because funding was no longer available to pay for it, or many other reasons:

*[My son] also used to love going out once a month with a group of other kids and young adults swimming which was run by the home base break team called swim & chips but due to costings it was cancelled. (Story Space 4)*

The implications of a short break activity ceasing to exist can be far reaching. Potentially, not only do the family's routines have to be reorganised, but there can also be knock-on effects for the different family members, such as siblings. In this case, the short break itself does not seem to have been discontinued, but rather the parent decided that a different activity would be more beneficial to her son.

*My son is 16 years old, has classic autism and accesses short breaks on a Sunday morning. [...] Previously the activity was walking with another person and two support workers. The Saturday afternoon time slot was more conducive to spending time with my daughter as we could go out for lunch or go shopping. (Story Space 3)*

The point here is that the family's activities are structured around the needs and abilities of the disabled child, sometimes at the expense of siblings and parents. Given the way in which small changes can affect all family members, coupled with a constantly evolving funding environment for providers, it is again opportune to highlight the extent to which short breaks contribute to the resilience of families with disabled children in the long run.

We already touched on the second issue when discussing how transportation can impact on short breaks. Transport matters gained in prominence if short breaks only lasted for a couple of hours, rather than extending over a longer period. Yet, transport is only one aspect that can compromise the positive effect short breaks can have. The family member most likely to be disadvantaged by this were the parents, because as providers, carers, facilitators, coordinators, and chauffeurs amongst other roles they found themselves at the centre of many often conflicting demands that jostled for prominence at the expense of their own needs, interests and personal development. Several factors could exacerbate these tensions such as if there was more than one child in the family, or the disabled child was growing up in a single parent family, or the parent-carer was in paid employment, to mention just a few. To illustrate, if a short break activity lasted for two hours, in addition to providing transport, parents might find their day broken up into short segments that allowed them limited time to recuperate from the pressures of family life with a disabled child or to pursue their own interests.

*"But half the time then you think: 'Oh God I've got to take him there and then I've only got an hour, and then I've gotta go and I've gotta go get, and get back. And I've got dinner to put on, and I've got this to do, and God it's too much I can't fit it in. You*

*know, so it needs to be good enough so that it's not causing the parent any more pressure than they're already under.” (Linda)*

Having said this, the parents we spoke to were well practiced at making use of any available snippets of time irrespective of their duration and of where and when they presented themselves. So an odd hour here or there was considered precious, irrespective of whether it enabled the parents to accomplish essential family maintenance work, such as getting the shopping done, or by doing things their other children enjoyed, or by allowing the parents to spend time together for instance by having a nice meal. Nonetheless, the better a short break fitted into the family's everyday life the more likely it was to be continued and have a positive influence.

These examples give a flavour of what families used their short breaks for. For instance Martin, who is the father of Simon who has physical and other disabilities, told us that his family might go to the cinema together when his son was on a family-based short break, but on the last occasion, he and his other children had simply taken their dog for a longer walk than they could usually do when Simon was with them. Nine year old Reuben, whose younger twin brothers are both autistic, said that sometimes when his brothers are with their short break carers, he gets to go out with his parents, but at other times they do things that they would normally do if the twins were with them. In other words, families with disabled children often use the time that the disabled child is away from the family to do 'ordinary' things, but this was only possible because the family received 'extra' help in the form of short breaks.

This paradox could lead to misunderstandings between families of disabled children and their Local Authority's social services, because the family may require help in situations that are usually not expected to call for the involvement of outside agencies. For instance, a married mother of two school-age children found that her local social services were unwilling to pay for what they considered child care:

*“...and I did approach social services if they would be able to assist if I needed an hour after school while I needed to collect Sarah. They said no very, very, very unlikely not worth asking, which given that most children of Will's age you just give them the key, if you're going to be half an hour late. And the problem's not going to go away, now to me that would be an element of respite or a short break.” (Laura)*

Laura had argued her case with social services on the grounds that the care her son required, even in this relatively short period until Laura arrived home, was more than ordinary child care and therefore could not be expected to be provided by family and friends. Already mentioned was the family that had used their direct payments for laundry, but had their provision withdrawn because their Local Authority considered such use inappropriate. This family were unusual in the way they identified the sort of support they needed to have respite. During the research we came across different ways in which short breaks for families could be organised. Usually, either the disabled child was 'taken out' of the family, or an extra pair of hands was 'added' to the family to take care of the disabled child. In this case, however, the family decided that respite should not be provided by having a break from interacting with the child, but rather having a break from the other chores that accumulate in a family with three children one of whom is disabled. This family did not feel

that overnight respite care would suit them, rather they saw caring for their children as a long-term commitment that they were only able to fulfil if they were able to manage their resources and draw on additional support wherever necessary.

Other parents felt that it was precisely this overnight respite that allowed them to continue as carers, parents and as individuals. May's severely autistic son Dave had regular overnight respite. Only since this support package had been put into place did May realise the pressure she had been under and now wondered how she had coped previously:

*"I couldn't manage now if they took it away. I don't know what I'd do. I think I'd just curl up into a ball and cry."* (May)

May's relief of getting overnight short breaks and her fear of what her life would be without it illustrate how crucial this form of short breaks provision was. The parents we spoke to considered it important that their schedule offered a degree of flexibility, either by rearranging matters with the care providers or by pooling direct payments if necessary. They also valued the fact that these regular short breaks gave them a noticeable break from caring and from the responsibility of caring, providing benefits during the short break and beyond:

*"...I use them in two ways. One is at the time that they're happening [...] I go to some concerts and music totally takes me out of my situation that I'm in [...] I'm totally enthralled in everything so my mind is resting from that stress and that's very important. And the other thing is when things are going bad and I'm having a really bad day, I can go back and look at that time that I've had away and I go: 'Oh I remember that time,' you know, and that will pick me up as well."* (Joanne)

Hence, for Joanne, short breaks had a long-lasting positive effect on her ability to care for her son. Indeed we would like to emphasise the extent to which short breaks generated sustained benefits for the well-being of families.

This theme has shown that short breaks come in many different forms, because they have to fit into the complex lives of different families with disabled children and because they provide disabled children with a range of experiences and ways to improve their abilities and skills. All these are important aspects that demonstrate the valuable role short breaks play in the lives of families with disabled children. However, our research indicates that reliable and regular provision of short breaks, in particular those kinds of breaks that truly offer the parent/carer a break from caring, have the greatest impact.

## Discussion

Our qualitative research has highlighted a number of issues with regards to short breaks and their potential to enhance the well-being of families with disabled children. The overall evidence from our study suggests that short breaks play an important role in enabling families to care for disabled children and to enhance the quality of life of all family members. It is one of the limitations of our qualitative approach that we cannot assess the full impact of short breaks on the well-being of families, nor were our field sites and our participants representative of the total range of short breaks and the diverse community of their users. These are questions that will be addressed in the family experience survey and the longitudinal cohort study. The strength of this qualitative research is that it has raised a number of pertinent issues which were not necessarily evident from the literature review (Robertson et al., 2009).

It was evident from the testimony of parents, siblings and disabled children that short breaks were important in their lives, but also that they meant different things for them and were valued for different reasons. This heterogeneity of views and experiences was further complicated by the enormous diversity of short break provision that was on offer. Yet, one finding that emerged from our interviews was the continued importance of quality overnight respite. This was often the lynchpin around which other short breaks could then be arranged. In the preceding sections we have primarily been concerned with those short breaks that could be classed as adding to the range of experiences and opportunities available to families with disabled children and enabling them to participate more fully in the wider social sphere. This was because those were the kinds of short breaks that potentially caused families concern. We have already highlighted the numerous issues, for instance accessibility, transport, information, time constraints, and the availability of suitable carers – that could make it difficult for a family with a disabled child to make full use of a short break. In contrast, we heard relatively little about overnight respite. Even so it was clear that those parents who received it valued it highly and felt that their child was well cared for and would gain from the experience. Most of the children we met who used overnight respite would go to residential homes run either by Local Authorities or by charities, rather than use NHS-managed respite. Only a few had a shared-care arrangement with another family. Parents held overnight respite in high esteem, this finding is in keeping with a recent study identifying the preference of carers and some professionals for respite care away from the family home (MacDonald, 2004). It should be noted that none of the parents we spoke to send their child on respite against the child's will. They were very careful to ensure that the child settled well into the respite facility and if necessary experimented with different forms of respite. Once a suitable arrangement had been found they could rest safely in the knowledge that the disabled child was well cared for and that he or she enjoyed the respite.

An issue that had become apparent in the literature review was the need to evaluate the longer-term impacts of short breaks. This is perhaps not surprising as the literature review is necessarily retrospective and will not yet have been able to take account of the impact of AHDC. AHDC has encouraged Local Authorities to be creative and innovative when commissioning short breaks. This has led to a considerable expansion in the range of short break activities available to disabled children and their families, in particular those breaks that aim to enhance the range of experiences available to disabled children. Our research has drawn attention to the fact that such short breaks have to be assessed in terms of their sustainability and long-term impact on all family members. This means that in many instances, 'normal' and 'reliably available' short breaks will have a greater impact on the well-being of families with disabled children than more spectacular and 'special' short breaks.

The growing availability and use of direct payments has had a noticeable impact on the provision of short breaks. Specifically, it has enabled parents to develop flexible short break arrangements and to employ their own carers. However, the tailoring of short break provision to the requirements of individual families creates inputs and outcomes that may be so subtle that they are difficult to identify and by implication to evaluate. Therefore, it is necessary that Local Authorities are aware that in order to live 'normal' lives families with disabled children may require help in areas that are not normally considered appropriate for intervention and support by outside agencies. Furthermore, it is worth keeping in mind that the sign of a successful and sustainable short break may be that it is so thoroughly embedded in the fabric of a family's daily life that it has become difficult to recognise as 'special' or even as a short break.

Another issue related to the growing use of direct payments concerns the workforce of short breaks carers. Our research has been focused on the effect short breaks have on the lives of families with disabled children, rather than on the people who provide them. Yet, the availability of a qualified, suitable and reliable workforce is directly related to the benefits families with disabled children receive. Parents have high expectations of their carers and can make considerable demands, for instance in terms of ability, flexibility, availability, motivation, reliability and trustworthiness. Hence parents highly appreciated those carers that managed to meet their expectations and held them in high regard because they were in many ways exceptional. Such carers brought a diverse range of skills and a high degree of commitment to a demanding role that was not particularly well paid. The shortage of male carers was especially acute. Plans to increase the uptake of direct payments and extend the availability of short breaks provision requires urgent improvements in the availability, qualification and skills of the caring workforce. In addition an increase in the proportion of men working in this overwhelmingly feminised sector would provide the carers that were suitable for some families.

Local Authorities are increasingly involving parents and children and young people with and without disabilities in their decision making processes. We have heard some very encouraging early evidence of how increased participation and consultation can shape the provision of services for disabled children and their families. At the same time, our research has shown that there remains considerable scope for improvement. In particular there is a need to carefully consider the use of existing channels of engagement in light of the specific requirements of families with disabled children and of disabled children and young people

themselves. Feedback in particular is a feature that needs to be built into the process in order to ensure that consultation is meaningful and effective. The targeted, reliable and thorough dissemination of information is a key constituent of successful participation and according to our participants in urgent need of attention. This is all the more important as families with disabled children are already under considerable time pressures. Rather than adding to the demands placed on individual families, we would like to encourage Local Authorities to pay greater attention to the role that grassroots organisations, such as support and action groups, play in the lives of families with disabled children. Such groups are often highly valued by the parents of disabled children and can enjoy considerable credibility. They also possess detailed knowledge of their members' needs and preferences, and can become a reliable and efficient conduit of the wishes, grievances and requirements of families with disabled children, a population that is often hard to reach.

Finally, our research has also shown that access to short breaks is an issue that has to be addressed. This includes improving access to short breaks by adapting the physical environment to the needs of children with disabilities; especially provision that takes place in mainstream facilities, much of which is in need of such changes. Access can also be understood in terms of having the means of transport available that allow a short breaks user to get to where the short break takes place. Transport is often treated as external to the short break, but our research demonstrates that it can have a substantial effect on the impact of a short break on the well-being of a family with a disabled child. Access also includes the question of how those eligible to receive short breaks enter into processes that will ultimately allow them to use short breaks. Lastly, access can also refer to access to information about short breaks and we have suggested in the preceding paragraphs that there exists a pronounced need to improve this aspect.

In conclusion, access to short breaks by families with disabled children is a matter of crucial concern. Whether access can be improved is not merely a question of customer satisfaction but will ensure that families with disabled children are active and effective participants in society. It is this additional ability to encourage social and civic engagement by families with disabled children, rather than just supporting parents caring for disabled children to take up paid employment, that short breaks may be most valuable for.

## Conclusion

This report has been concerned with the impact of short breaks on the lives of families with disabled children. It is based on qualitative research conducted with a range of participants in many different field sites, predominantly in North West England. We interviewed parents of disabled children, siblings of disabled children and disabled children themselves. We spoke with Local Authority representatives, short breaks providers, and action group facilitators. In addition, we observed participation events and workshops. Web-based and paper versions of our story space form provided opportunities for those parent/carers who we could not meet face-to-face to share their experiences of short breaks.

The research has confirmed the important role that short breaks can play in the lives of families of disabled children. It has drawn attention to the wide range of different types of short breaks available and the diverse and creative uses families have made of them. A number of major themes have emerged from the data. These include persistent challenges in relation to families' access to short breaks. This applies to practical matters of access to suitable short breaks locations, as well as to political and ethical issues such as the circumstances and conditions under which short breaks are made available to families with disabled children. The research has also highlighted some problems with the processes by which Local Authorities currently consult with families with disabled children as well as the communication strategies they employ to inform and advise parent-carers about short breaks. Furthermore we have shown that the existing workforce needs to expand to incorporate more carers with the right qualifications, experience and characteristics. Such carers will enjoy the parents' trust and be able to establish a rapport with the disabled child.

We have also seen some indications that the growth of the short breaks sector can offer opportunities for parents of disabled children to become providers themselves. The research shows that relationships that carers are able to develop with the children they care for and also with parents and other family members are crucial to whether short breaks are considered positive and worthwhile. The research has especially shown that those carers that come into the family's home occupy a very sensitive, as well as ambiguous, position that encompasses both the private and public sphere. Finally, we have highlighted the need to consider the effect of short breaks in the long term and assess their success from the point of view of families with disabled children. This includes the pivotal role of quality overnight respite and a raised awareness that the most subtle and reliable short breaks interventions can sometimes be the most successful.

The research has shown that short breaks make a positive impact in the lives of families with disabled children. However, it has also drawn attention to a number of important issues that need to be addressed in order for these families to derive maximum benefit from short breaks.

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