

# The Impacts of Short Break Provision on Disabled Children and Families:

## An International Literature Review

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

Centre for Disability Research (CeDR)  
Lancaster University



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## Introduction

For over 30 years, short breaks have been part of the landscape of support provision for families with a disabled child. Historically, the term 'respite care' has been used in much of the research literature concerning short breaks for families with a disabled child. However, 'short breaks' has become the preferred term, partly due to the negative connotations of family carers requiring 'respite' from their children, and partly because short breaks now encompass a much wider range of supports than out-of-home placement in specialist residential facilities (Cramer and Carlin, 2008). As such, the term 'short breaks' will be used throughout this review, with the exception of direct quotes from research studies where the term 'respite' is used by study participants or study authors.

Short breaks are designed for disabled children to spend time in the company of other people than their primary family carers, both to give family carers a break and to allow children the opportunity to have new experiences with a wider range of people outside the immediate family. Short break services can be extremely diverse, and vary in:

- 1) Their location, which could include the child's own home, the home of a contracted short break carer, specialist residential settings, or any number of community settings.
- 2) Their duration, which could include anything from a few hours, to an overnight stay, to overnight stays of several days or even longer if needed.
- 3) Their timing, which could include weekdays, weekends, evenings and overnight.
- 4) Who provides them, which could include local authorities, health agencies, and a range of voluntary and independent sector agencies.

Although the volume and diversity of short breaks being offered to families with a disabled child in the UK are increasing (Carlin & Cramer, 2008), these increases may be insufficient to meet the needs of rising numbers of disabled children and increased expectations amongst disabled children and their families (Cramer & Carlin, 2007). There appears to be substantial inequity amongst families in who gets access to short break services that are acceptable to families, with children identified by the DCSF in 5 'target groups' (children with autism spectrum disorder; children with complex health needs; children with moving and handling needs; children displaying challenging behaviour; and young people in transition aged 14+) more likely to report problems in awareness, access, use and acceptability of short break services (Chamba et al., 1999; Tarleton & Macauley, 2002). The Department for Children, Schools and Families in England have responded to these concerns by substantially increasing investment in short breaks for families with a disabled child as a central component of the Aiming High for Disabled Children programme.

There are widespread assumptions about the potentially beneficial impact of short breaks on family carers and disabled children, including reduced carer stress and an increased capacity for family carers to continue caring, and increased child enjoyment of a wider range of social opportunities. This review aims to systematically evaluate the existing international research evidence concerning the impact of short breaks, to determine where there is robust evidence for the impact of short breaks on families with a disabled child and where more evidence is needed.

## Method

Searches of electronic literature databases were conducted in July 2009 to identify peer reviewed articles and grey literature published from 1980 onwards in the English language that included information on the impact of short break provision on disabled children and families.

The databases searched were:

- ASSIA
- Cinahl
- Web of Science
- PsycINFO

In each database, terms for disabilities and associated synonyms were combined with terms and associated synonyms for short break provision. Full details of the search strategies and terms employed can be found in Appendix One. All articles identified by searches were assessed for their relevance to the review objectives firstly by reading abstracts. If abstracts were unavailable, or did not provide enough detail to assess the relevance of the article, the full text of the article was obtained and relevance assessed from this. Data were extracted from the full text of articles identified as being relevant to the review. Articles based on data regarding short breaks for adults only were excluded from the review but those based on data in relation to adults and children were considered for inclusion in the review.

In addition, a request for information on research relevant to the review was sent by email in July and August 2009 to the membership of the International Association for the Scientific Study of Intellectual Disabilities (IASSID), the Intellectual Disability Research UK mailing list, and the Leeds Disability Research List. This enabled the identification of research literature not identified in the electronic searches, for example relevant articles which were “in press” or unpublished local reports. Finally, the reference lists of all publications included in the review were handsearched to see if additional publications could be identified.

# Results

## Overview of Studies and Study Designs

A total of 56 articles or reports were identified for inclusion in the review of the impact of short breaks for disabled children and their families. These are summarised in Appendix Two (in chronological order, starting with the oldest studies identified). Geographically, 17 articles were from the United States, 29 were from the United Kingdom (including England, Wales, Scotland and Northern Ireland), 3 were from Ireland, 5 were from Canada, and 1 was from Australia. One publication was a systematic review of international research. It seems likely that locality-based reports such as those identified in the UK (e.g. McConkey and Truesdale, 2000) may exist in other countries but it has not been possible to identify these in this review.

Of the 56 articles or reports, the vast majority of studies were cross-sectional with data collected from users of various short break services (in this context the term 'users' refers both to family carers and disabled children), using either structured questionnaires, semi-structured interviews, or other qualitative or mixed methodologies, to look at their perceptions and experiences of short breaks.

Nine cross-sectional surveys looked at the views of users of short breaks, some of which included users of more than one type of short break (Ptacek et al., 1982, Joyce et al., 1983, Rimmerman et al., 1989, Gerard, 1990, Stalker and Robinson, 1994, Neufeld et al., 2001, Robinson et al., 2001, Radcliffe and Turk, 2007, Shared Care Network, 2008). Six cross-sectional studies used mixed methods to look at the views of users of short breaks (Davies et al., 2005, Swift et al., 1991, McConkey and Truesdale, 2000, Thompson et al., 2009, Davies et al., 2004, Oswin, 1984). Ten cross-sectional studies looked at access to and/or views regarding short breaks for both users and non-users of short breaks (Abelson, 1999, Chamba et al., 1999, Damiani et al., 2004, McGill et al., 2006, McGill, 1996, Marc and MacDonald, 1988, Hatton et al., 2004, McConkey, 2008, Tarleton and Macaulay, 2002, McGill, 2009). Three cross-sectional surveys specifically compared users and non-users of short breaks on one or more measures of, for example, carer stress (Halpern, 1985, Bose, 1989, Bose, 1991).

In total, there were 14 qualitative studies looking at the views of users of short breaks (Smith et al., 1988, Stalker, 1988, Baxter et al., 1991, Hubert, 1991, Minkes et al., 1994, Platts et al., 1995, Kelly et al., 2000, Hartrey and Wells, 2003, MacDonald and Callery, 2004, McConkey et al., 2004, Eaton, 2008, Wilkie and Barr, 2008, Doig et al., 2009, Prewett, 1999), plus one report reporting comments in relation to innovative examples of short breaks which are flexible and family-centred approaches rather than traditional residential care solely for the disabled child (Social Care Institute of Excellence, 2008), one article presenting anecdotal impressions on the benefits of one short breaks scheme (Openden et al., 2006), and one article (Challenging Behaviour Foundation and Tizard Centre, 2009) providing additional comments from family carers in relation to the cross-sectional survey results reported in McGill (2009).

Far fewer studies used quasi-experimental pre-post designs or longitudinal designs, with the total being just 8 studies. Of these, 6 studies either employed no comparison group or compared users of different forms of short breaks (Botuck and Winsberg, 1991, Sherman, 1995, Cowen and Reed, 2002, Mullins et al., 2002, Aniol et al., 2004, Forde et al., 2004). Only one study used a control group which received no formal short break service (Bruns and Burchard, 2000). Only one study might be

considered as a randomized controlled trial (RCT) but this study compared two forms of intervention involving short breaks and had no control group receiving no short breaks (Singer et al., 1989).

Finally, this review also includes one study based on secondary analysis of a large scale survey (Barnard-Brak and Thomson, 2009); one chart review (Mausner, 1995); and one systematic review on carer well-being (McNally et al., 1999).

## **The Impact of Short Breaks on Carer Well-Being**

### **Introduction**

The most common focus of research has been the impact of short breaks on carer stress or other measures of carer well-being. This focus is reflected in the fact that the only existing systematic review in relation to the impact of short breaks was on the effect of short breaks on informal carers' well-being (McNally et al., 1999). This review identified a total of 29 studies assessing the effects of short breaks on informal carers, but the majority of these studies were concerned with carers of older people, most notably people with dementia. Only 6 of the studies are relevant to the effects of short breaks on carers of children with disabilities, mainly intellectual disabilities. Even taking all 29 studies as a whole, the review concludes that: "... there was little evidence that respite intervention has either a consistent or enduring beneficial effect on carers' well-being. This may be due in part to the fact that the majority of the work conducted has been methodologically poor" (p1).

In their systematic review, McNally, Ben-Shlomo & Newman (1999) outline methodological problems which include: lack of control over variables that may have influenced the findings (e.g. amount of short breaks received); the absence of a control group; insufficient sample sizes; and the use of outcome measures that are too insensitive to detect beneficial effects. They argue that: "Studies need to employ well controlled experimental or quasi-experimental designs, have sufficient statistical power to detect clinically important differences, make clearer assessments of the nature and duration of respite receipt, employ more sensitive multi-dimensional outcome measures, and have sufficiently long follow-up assessments to determine the duration of any benefits. Without these improvements, the potential beneficial effect of respite for carers remains controversial" (p13). In this section, we look at the research which currently exists to see if the evidence base is more compelling a decade on for families with a disabled child.

### **Carer Perceptions on the Impact of Short Breaks on their Well-Being**

In this section we describe studies which have looked at the potential benefits short breaks have on the well-being of carers as perceived by the carers themselves. These reported benefits have been extracted from studies that use either quantitative or qualitative approaches to identifying the benefits perceived by carers. Studies which look at carer perceptions on the impact of short breaks on their well-being are described chronologically below. Please note that studies which use objective measures of carer well-being are reviewed in a separate section.

- In a study of 24 mothers using in-home short breaks, 100% of mothers reported that they felt relief at having a trained person available to care for their son or daughter and 67% felt less physically strained (Joyce et al., 1983).
- In an early study based on predominantly hospital or hostel based short breaks, 54 of 92 parents mentioned the freedom short breaks gave, mainly for



rest and a general feeling of relief (Oswin, 1984). As one parent noted: "I'm more able to relax and sleep at nights. I am able to cope better when she comes home again because I have had that rest" (p100).

- In a study comparing 31 users and 31 non-users of home-based short breaks, 42% of mothers and fathers indicated that short breaks meant relief from stress (Halpern, 1985), with one mother commenting that for her short breaks took the place of therapy.
- In a survey of 124 users of residential short breaks, 83% of families reported that short breaks reduced the stress of caring for their child with ID (Marc and MacDonald, 1988).
- In a study of 17 female carers, carers reported being more relaxed and less pressured and enjoyed greater freedom (Smith et al., 1988).
- In a qualitative study of 30 parents using family based short breaks in Scotland, the most frequent benefit noted was a regular opportunity to relax (Stalker, 1988). As one carer noted: "I can actually come downstairs and sit in the chair and not do anything, which is a lovely thought" (p5). One family felt more relaxed just knowing that short breaks were available if needed and others reported feeling less under stress.
- In an Australian study, in depth interviews with 7 parents of children using shared family care revealed that parents reported a reduction in family stress and feeling more relaxed (Baxter et al., 1991).
- In Wales, a study on family based short breaks found that reported benefits for 150 carers included relief from the pressures of caring, getting a rest, and being able to get a social life (Swift et al., 1991).
- A study in England looked at the impact of 3 types of short breaks on 160 parents and found that the principal effect was the opportunity to relax and reduced stress (43% to 48% across types of short breaks) (Stalker and Robinson, 1994).
- In a cross-sectional survey of 574 families of disabled children in the US, 82% believed that short breaks would reduce burnout and fatigue (Abelson, 1999).
- In Northern Ireland, one of the benefits reported by 36 parents using one short break service was being able to have a break or rest (McConkey and Truesdale, 2000).
- In Ireland, case studies of two mothers of children with intellectual disabilities who used short breaks indicated that short breaks provided the opportunity for psychological calm, but also led to a sense of guilt (Hartrey and Wells, 2003). Short breaks also allowed parents to take part in social activities.
- An evaluation of the short break component of a Canadian children's hospice used postal questionnaires (65 parents) and interviews (18 families) to look at the impact of short breaks (Davies et al., 2004). Parents reported benefits for themselves in terms of a break from routine, sleep, comfort, freedom, time for themselves, a sense of privacy and 'normalcy'. It also gave them time to spend with their other children. Freedom and comfort came from knowing their child was happy and well cared for, allowing them to relax. Some parents found that knowing that other families lived similar lives helped them feel that their life was 'not as weird' as they had believed. It also helped them to prepare for their child's death, via materials available at the hospice and discussions with staff. However, this was a difficult process for parents: "It is very hard to go to (hospice) in many ways, because in many ways reality hits you" (p 281).
- In Ireland, link family support for 16 families (Forde et al., 2004) alleviated stress levels of parents, offering free time each week to parents.
- In a study of 136 carers of severely disabled children from UK South Asian families, it was found that very few families used short breaks, with many

being unaware of its existence, but that those who did valued it highly (Hatton et al., 2004). For example, one father noted: “ ... Umber goes every Monday and stays one night. It gives my wife a little bit of a break (the respite service provides halal food and a female carer) ... it releases the pressure on her (wife). It is better for her especially and we think it's better for the family as well” (p103).

- In a qualitative study of 19 families in England, it was noted that parents used the time for alleviating exhaustion (MacDonald and Callery, 2004).
- In a study of 108 family carers in Northern Ireland, one of the main themes to emerge was that residential short breaks enabled carers to have rest, relaxation and uninterrupted sleep (McConkey et al., 2004).
- In a Welsh study of 11 families with complex healthcare needs receiving either in-home or hospice based short breaks, the most commonly heard statement from all families was: “I don't know how we coped before” (p3200) with families in both groups reporting that they were 'close to cracking up' before they had accepted short breaks (Eaton, 2008). Short breaks enabled them to cope better with caring for their child and gave them the opportunity to do other activities (such as sleeping or reading a book).
- In Northern Ireland, 29 parents of children with complex physical healthcare needs reported that the benefits of short breaks for themselves were a complete day off, relaxation, and a night's sleep (McConkey, 2008)
- A qualitative study in Ireland of 6 parents using one short break facility found that benefits for parents included a 'sense of renewal' (Wilkie and Barr, 2008).
- In Canada in depth interviews with 10 carers of children, mainly with fetal alcohol syndrome, found that most carers were very grateful for the short breaks they had received (Doig et al., 2009). One quote is given to illustrate the impact for carers: “And so in that sense, you know, the respite for us is really important because we need to do something once in a while [for] ourselves. For the longest time we never had any breaks and, you know . . . once I did start getting these weekends I thought “Wow! I really missed a lot! You know? (Laughs). You can't even go for coffee! And it makes it pretty special if you never get to do it and then all of a sudden you can. So, it has meant the world to me” (p240).

## Measuring the Impact of Short Breaks on Carer Well-Being

As noted above, a large proportion of the work looking at the impact of short breaks on carer well-being is based on qualitative studies or surveys of users of short breaks to find out their perceptions regarding the impact of short breaks. Studies which attempt to objectively measure the impact of short breaks on carer well-being are less numerous. In this section we review studies which attempt to measure the impact of short breaks on carer well-being, either through cross-sectional comparisons of well-being related scores of users and non-users of short breaks, or through quasi-experimental pre-post designs looking at changes in well-being related scores following use of short break services. These studies are reviewed chronologically below.

- A study in England compared the Malaise Inventory scores of 48 users and 18 non-users of a family link scheme and found significantly lower stress levels in the user group (Bose, 1989). However, these differences could have been due to a number of potentially confounding factors, for example non-

user groups were more likely to be from low-income backgrounds, and being on a waiting list for short breaks may increase stress levels.

- In a further analysis of data from Bose (1989) above using the Malaise Inventory, Cantril's Ladder (as a measure of morale) and the Perceived Social Support from Friends and Family Questionnaire, there was significantly less stress, greater perceived social support, and higher general morale in the user group (Bose, 1991).
- A study in the US looked at the impact of one instance of a 10-day out-of-home short break for 14 mothers by collecting measures before, during and after the short break was used (Botuck and Winsberg, 1991). Measures used were: the Bradburn Affect Scale (to assess changes in perceptions of happiness and well-being); the Norwich Depressed Mood Scale; and the Activity Pattern Indicators (to document mothers' daily activities). Mothers were statistically significantly happier during the short break than they were either before or after. They also spent significantly more time during the short break taking part in rest and relaxation and personal care; less time on house and childcare; more time in active leisure; and more time on active social contact. Three to 4 days after their child returned from the short break mothers displayed continued increases in positive affect and had a tendency to be less depressed. A study in the US used the Coping Resources of Stress (QRC-F) to look at the relationship between 5 measures of short break use and stress (Rimmerman et al., 1989) amongst 78 mothers of people with intellectual disabilities. They found no relationship between reduced stress and each of the measures of short break use, although home-based services were associated with lower levels of stress than drop-off centres. However, there were limitations of the study including a lack of a control or comparison group who did not use short breaks and the use of cross-sectional measures.
- A study in the US used the Beck Depression Inventory (BDI) and the State-Trait Anxiety Inventory-Trait Scale (STAI) to look at the impact of a randomised high or low intensity short break intervention on 49 parents in 32 families (Singer et al., 1989). Those who received the intensive support maintained reductions in depression and anxiety at a 1-year follow-up. The low intensity intervention, consisting of case management and short breaks, did not impact on anxiety and depression. However, the authors did not explore how much simple contact with other parents and professionals influenced the treatment outcomes.
- In the US, a quasi-experimental 6 month pre-post evaluation design based on interviews with carers was used to look at the impact of home-based short breaks on psychosocial stress (measured using The Impact on Family Scale) and underlying psychological state (measured using the Brief Symptom Inventory) (Sherman, 1995). Higher rates of short break use were associated with lower expressed somatisation and a decrease in mothers' expressed somatic symptoms. Respondents reported relief from stress and time to spend doing other activities. However, the authors note that the results must be considered preliminary due to the small sample size and high attrition rate.
- Another US study used a quasi-experimental 6-month pre-post design with 3 groups of family carers (Bruns and Burchard, 2000). The short breaks group (SG) received 50 or more hours of short breaks during the 6-month study period (n=33); the control group (CG) received no short breaks and remained on a waiting list (n=28); and the "extra group" received between 1 and 49 hours of short breaks (n=12). Measures included caregiving stress using the Impact on Family Scale (IOFS) and parents' general stress using an abbreviated version of the Hassles and Uplifts Scale. Significant between-group differences at time 2 controlling for baseline scores were found for the

Personal Strain subscale of the IOFS. Additional short break hours were associated with increased optimism about caring for the child at home, elevated family functioning, and reduction in perceived stresses.

- In a study of out of home short breaks in the US, a pre-post design was used with 87 family carers to look at the impact of short breaks on scores on the Parenting Stress Index (Cowen and Reed, 2002). There was a significant reduction in total parenting stress scores and all subscales with the exception of 'life stress'. However, in this study short breaks were provided in conjunction with other interventions for both the parent and child.
- A longitudinal study in the US looked at the impact of either residential short breaks of 3 to 7 days duration (no therapeutic input; 39 parents) or inpatient admission of approx 30 days with comprehensive evaluation and treatment (41 parents) (Mullins et al., 2002). Information was collected at admission, discharge and 6 months post discharge using the Brief Symptom Inventory (BSI) as a measure of psychological distress; and the Parenting Stress Index (PSI). Parenting stress decreased at time 2 for both groups of parents but returned to admission levels at time 3. Psychological distress was lower for both groups of parents at time 2 and remained lower at time 3. Overall, short breaks were beneficial to parents but there was no no-treatment or waiting list control group as practical and ethical constraints precluded this.
- A longitudinal study in the US on short breaks (14 family carers) or short term hospitalization (18 family carers) included the Parenting Stress Inventory (PSI) at admission, discharge and 2 months post-discharge (Aniol et al., 2004). Whilst MANOVA results for the parenting stress inventory are not presented, it is noted that decreases in parenting stress occurred for both groups between admission and discharge but these were not maintained at follow-up.
- The PSI-SF (short form) was used in a study of link family support in Ireland with 16 family carers, with data collected before and one year after support began (Forde et al., 2004). Despite qualitative comments in the study suggesting that the link family scheme alleviated stress in parents, there was no significant change on the PSI-SF and the authors suggest that the measure may be insensitive to changes in all aspects of life stress.

### Summary: Evidence for the Impact of Short Breaks on Carer Well-Being

McNally, Ben-Shlomo & Newman (1999) note in their systematic review that in terms of methodology, 17 of the 29 studies had no control or comparison group so any improvements in well-being may have been due to some natural trend rather than short breaks per se. Often, practical and ethical considerations make randomization impossible. Studies use different 'doses' of short breaks, some just one e.g. a two week in-patient episode of a short break and others a 'course' of short breaks. Often those using short breaks receive varying amounts to the extent that someone in a treatment group may not be receiving many short breaks at all. 16 studies in the McNally et al. (1999) systematic review used samples of less than 45 and they suggest that to detect a moderate effect on a continuous outcome variable (with 80% power and alpha set at 0.05) 64 participants would be needed in each group.

A decade on, the evidence base for the impact of short breaks on carer well-being has increased but many of the shortcomings noted by McNally et al (1999) in relation to studies of all carers do still apply to the evidence base concerning the impact on the well-being of carers of disabled children. Methodological problems include small sample sizes, lack of control groups, single and short post-short breaks follow-ups, and interviewers not being blind to the study conditions. Whilst numerous

qualitative studies give weight to the evidence base in their consistent reporting of benefits for carers, the evidence from quantitative studies is weak. Only one quasi-experimental study has been identified which uses a “no short breaks” comparison group, so as noted above any improvements reported in well-being may have been due to some co-occurring confounding factors rather than short breaks per se. Whilst a few studies attempt cross-sectional comparisons of users and non-users on measures of well-being, as noted by Bose (1989) these differences could have been due to a number of other factors, for example non-user groups were more likely to be from low-income backgrounds, and being on a waiting list for short breaks may increase stress levels. The existence of differences in well-being between users and non-users of short breaks in these study designs cannot be taken as evidence of a causal link between short breaks and improved well-being.

## **The Impact of Short Breaks on Family Functioning**

The impact of short breaks on family functioning has been less of an exclusive focus of research studies than carer well-being, but family functioning has been examined in a number of studies. Whilst we are not presenting a specific definition of “family functioning” as we do not wish to exclude any potentially relevant data, the studies reviewed in this section look at the impact of short breaks beyond the well-being of carers to include relationships within the family, family activities and family quality of life. Studies regarding the impact of short breaks on siblings of disabled children are reviewed in a separate section below.

- An early study in the US looked at parents’ perceptions of the impact of short breaks on family quality of life by conducting a cross-sectional survey of 24 mothers of children or adults with intellectual disabilities or cerebral palsy who had used an in-home short break program (Joyce et al., 1983). Mothers strongly agreed or agreed that: they were relating better to their disabled son or daughter since using short breaks (53%); the family got along better since using short breaks (53%); short breaks relieved family stress (68%); short breaks allowed non-disabled family members to spend time together (52%); and short breaks allowed them to do things not possible before short breaks (76%).
- Thirty-seven family carers using residential short breaks for children with intellectual disabilities and behaviour problems in the US reported that the service allowed them to relate better to their child (89%); make social plans in advance (78%); and get along better as a family (81%) (Marc and MacDonald, 1988).
- In a US survey of 574 families with children with a range of disabilities, 76% agreed that short breaks would improve family functioning (Abelson, 1999).
- In a quasi-experimental study of family centred short breaks in the US with 73 families, additional short break hours were associated with improved family functioning (Bruns and Burchard, 2000). However, indicators showed evidence of continued high family stress.
- A study looking at the impact of short breaks in a children’s hospice noted that siblings were able to have overnight stays at the hospice, giving them time together to talk about the illness away from parents (Davies et al., 2004). Parents believed that this benefited relationships between the child and siblings.
- In Ireland, link family support was reported to lead to overall improved quality of lives for 16 families (Forde et al., 2004).

- Finally, in a Canadian survey of 468 family carers of children with cerebral palsy, of the 46% who used formal short break services over 90% agreed that these services were beneficial to their family and their child (Damiani et al., 2004).

### Being an Ordinary Family

One reported benefit of short breaks is that it allows time to be spent being a “normal” family by leading a lifestyle or doing activities considered to be “normal” by family members that would be viewed as impossible with the presence of the disabled child (Swift et al., 1991, MacDonald and Callery, 2004, Halpern, 1985, McConkey and Truesdale, 2000). In a study of one short break service in Northern Ireland, reported benefits for carers included being able to spend time with their other children or spouse to take part in family activities (McConkey and Truesdale, 2000). As reported in work from Northern Ireland regarding short breaks for children with physical healthcare needs, short breaks enabled families to go to places that a wheelchair cannot (McConkey, 2008). In a survey of 32 families of children with autism, 100% said that short breaks helped them and the rest of their family to live ‘a more ordinary life’ (Shared Care Network, 2008). A review by SCIE gives innovative examples of good practice which, in contrast to traditional residential provision solely for the disabled child, are flexible and family-centred, providing services at a time and place that suits the whole family (Social Care Institute of Excellence, 2008). As noted by one carer in this review: “The short break service allows us to have ‘me’ time and helps us to feel normal and allows family activities with our other children” (p8).

### Relationships with Partners

There is some suggestion that short breaks may play a role in improving relationships between parents but the evidence is limited. In a Scottish study of family based short breaks, four couples reported improved relationships as a result of short breaks (Stalker, 1988). Similarly, in a study of 164 users of 3 types of short break in England, reported benefits of short breaks included time to spend with partners, improved marriages and the family being closer (Stalker and Robinson, 1994). However, in England a study looking at a link family scheme which compared user and non-user carers on questionnaire based measures found no significant difference in marital relationships (Bose, 1991).

### Measuring the Impact of Short Breaks on Family Functioning

Whilst the reports of family carers seem to indicate that short breaks can have a positive impact on family functioning, studies which actually attempt to measure the outcomes of short breaks in terms of quantitative family functioning measures have reported inconsistent findings. In the US, a longitudinal study of short breaks (14 carers) and short term hospitalization (18 carers) found no significant changes on the Family Relations Inventory (FRI) (Aniol et al., 2004). As noted above, whilst Bruns and Burchard (2000) found that additional short break hours were associated with improved family functioning, indicators showed evidence of continued high family stress. Finally, in a comparison of 31 users and 31 non-users of short breaks in the US, scores of user parents on Moos’ Family Environment Scale (FES) did not indicate higher levels of family functioning than non-user parents on any FES subscale (Halpern, 1985). However, non-users were not excluded if they used services offering other relief outside the home such as camps or recreational programs.

## The Impact of Short Breaks on Disabled Children

Overall, the function of short breaks in the research literature has been seen largely as one of providing breaks for family carers and less attention has been focused on the impact of short breaks for disabled children themselves. Indeed, a qualitative study in England looking at 36 families of children with severe learning difficulties found that most parents admitted that short breaks were primarily a service for them rather than their children (Platts et al., 1995). Nonetheless, this study suggests that what children and their families wanted from short break services were similar: services which were fun and provided a range of experiences; a choice of services to suit the child's needs; confidence that the service will care for the child well; services that were reliable and flexible; local services where good relationships can be built; good information; and support. In this section we consider research that has looked at the impact of short breaks on disabled children themselves and whether these aspirations appear to be met.

### Reported Benefits of Short Breaks for Disabled Children

Generally, studies looking at the views of family carers regarding short breaks indicate that parents consider short breaks to be of benefit to the child. These studies are reported here in chronological order beginning with the oldest studies identified in the review.

- In an early US questionnaire survey of 57 parents of children with severe disabilities, 75% of parents felt that their child benefitted from short breaks (Ptacek et al., 1982).
- Early work in England including a small number of children using family-based short breaks suggested that for some children this was the first opportunity they had had to mix with non-disabled children (Oswin, 1984).
- Specific benefits were noted in a Scottish qualitative study of family-based short breaks involving 30 parents (mostly of children under 10 years of age with severe learning difficulties). Two thirds of the children were said to have gained in social skills, maturity and capacity for independence (Stalker, 1988). Some benefitted from learning to separate from their parents. Two thirds of parents were confident that their children enjoyed their visits to the carer but 11 out of 30 children experienced more marked homesickness which in some cases was persistent and severe.
- A cross-sectional postal survey in England obtained information from 253 family carers of children with severe learning difficulties who had used one of three short break services on whether short breaks improved the child's quality of life, was detrimental to their quality of life, or had an indeterminate effect (Gerard, 1990). Quality of life was deemed to have improved for 81%, 90% and 63% in each service and been affected detrimentally for 3%, 3% and 11% in each service. The authors suggest that short breaks produce overwhelmingly positive effects on the quality of life of children according to reports by carers.
- A qualitative study in Australia on Shared Family Care involving 7 parents found that all believed that it had been a positive experience for themselves and their child (Baxter et al., 1991). The quotes presented in the paper refer to the child getting new experiences and the child being happier due to attention from foster carers who have more time to spend with them.
- A Welsh study looking at family-based short breaks obtained information from a total of 150 family carers of children aged under 20 years with intellectual disabilities (Swift et al., 1991). Reported benefits for the children included: exposure to new stimuli and interests; increased social awareness and the

development of social skills; development of friendships with hosts' children; growing independence from the family; and increased confidence. Although a small number of carers reported difficulties experienced by their child, for example one or two reported worsening behaviour, the vast majority reported no difficulties at all. It was noted that host families appear to strive to broaden the experiences of the child and make active use of the time they spend with them rather than using it as a "holding operation".

- In the US, home-based short breaks were noted by 26 families to benefit the child by giving them the chance to socialise outside the family (Sherman, 1995).
- In England, telephone interviews were conducted with 18 mothers who had used a summer holiday day scheme for children with intellectual disabilities (McGill, 1996). All 18 children were said to have enjoyed going; 14 of them were said to have done things they would not have done at home (e.g. mixing with other children, going out, swimming, painting). However, one mother whose son had tantrums when she collected him was not sure if the break was worth the resulting disruption.
- A study in the UK looked at the impact of short breaks for children with autistic spectrum disorder (Tarleton and Macaulay, 2002). Data were collected via discussions with 6 adults with autistic spectrum disorder; 6 focus groups with parents of children with autistic spectrum disorder; questionnaires from 135 parents who used short breaks, and 136 who did not use short breaks; and questionnaires from 371 service providers. The reported benefits of short breaks for children included: enabling children to experience new activities; opportunities for the child to mix with others; giving the child a break from parents; and preparing them for adult life. Different services were seen as having differing benefits e.g. link families were seen as good for socialising, playschemes were seen as good for new activities, and in-home short breaks were seen as good for the child feeling safe.
- A Canadian study looked at the impact of short breaks in a children's hospice using postal questionnaires (65 parents) and interviews (18 families) (Davies et al., 2004). The majority of parents (63%) reported that their child benefitted 'a lot' or 'extensively' from short breaks in the form of specialist overnight care. It was seen as a place where the child could relax and enjoy themselves, with opportunities unavailable at home such as relaxing in the Jacuzzi or taking part in trips. It also gave the child the chance to talk to staff about death and dying: "Quite often you want to talk to someone who is not your parent or, you know, someone who is on the outside" (parent, p279). It also allowed the child to meet children like themselves and feel less different: "She has met a lot of friends her age. (She) knows that she's not the only one that uses an electric wheelchair, so it's easier for her to recognize herself as not completely different from others" (parent, p 279). It also allowed children some independence from their parents.
- A study in Northern Ireland conducted a thematic analysis of responses by 108 parents to open ended questions about the benefits of short breaks for their child with multiple disabilities (McConkey et al., 2004). The main benefit to the child perceived by parents was the opportunity to interact socially with others in a different environment (n=49). Mention was made of the child enjoying the break (n=21), getting used to being away from home (n=11) and becoming more independent (n=10), and being able to go on outings and join in different activities that they could not do at home (n=10).
- In Ireland, Link Family Support was reported by 16 family carers to facilitate social and recreational opportunities for children and adults with special needs (Forde et al., 2004).



- Anecdotal observations have been reported of the benefits of a US scheme whereby University students acted as short break providers for children with autism (Openden et al., 2006). Children were noted to benefit from opportunities for social communication. Parents were able to teach short break workers techniques that they were implementing in their parent education programs.
- Further work in Northern Ireland involving 29 parents of children with physical healthcare needs found that some parents reported benefits for teenagers who used short breaks in meeting other young people and increasing their confidence (McConkey, 2008). However, some parents were reluctant to use residential facilities due to the child having picked up infections on previous stays, unsuitable accommodation (such as hospital type wards) and concern over high staff turnover.
- A UK survey on shared care obtained responses from 32 families of children with autism (Shared Care Network, 2008). Over half said short breaks meant their child had opportunities to make friends; 92% said they had helped their child develop social skills; four fifths said they had helped their child take part in social activities; two thirds said they had helped their child learn independence skills; and three quarters said they had made their child happier.
- A qualitative study in Ireland used interpretative phenomenological analysis (IPA) to look at the views of 6 parents of children with ID who used one short break facility (Wilkie and Barr, 2008). Reported benefits for the child included: the opportunity to meet children outside the family and school; increased social skills; and increased opportunities to participate in leisure activities in the community.

### Disabled Children's Views on Short Breaks

The foregoing section outlines studies where family carers have reported benefits of short breaks for their disabled child. This section considers studies which have sought the views of disabled children themselves regarding short breaks.

- A study in England involved 63 children aged 10 to 19 years who attended residential short break services in 4 areas (Minkes et al., 1994). Using short breaks gave the children access to more toys, games and videos than they had at home as well as opportunities for sport, team games and social activities. There was little evidence that they had any contact with non-disabled children. Over the four areas, nearly all of the children enjoyed using short breaks, had friends amongst the staff and other children, and were offered a wide range of activities. For a minority of children, however, short breaks were second best to being at home and in a couple of instances children were clearly unhappy about the arrangements. In one area in particular, several children reported not enjoying their stays and other sources of data from the overall evaluation revealed that a lower standard of care was offered to those children than elsewhere.
- As part of a study into shared care schemes (family-based short breaks) in England Wales and Northern Ireland, 38 individuals (17 of whom were children aged from 8) provided their views on their experiences of short breaks via specially formed user groups of adults or children (Prewett, 1999). Short breaks ranged from one tea visit per week to two weekends a month. Users felt that their short breaks were organised mainly because they enjoyed them. All enjoyed the social interaction provided by their short breaks. Short breaks were seen as beneficial to their quality of lives in that it provides new relationships and social activities, including relationships with support carers,

their children, and their friends and neighbours. Three quarters had no dislikes regarding their short breaks at all. However, the small numbers of dislikes mentioned (for example, not liking the presence of another service user) indicate the importance of monitoring links for actual or potential problems.

- An exploratory pilot study in Northern Ireland sought the views of 3 children with intellectual disabilities regarding short break services (Kelly et al., 2000). All the children offered positive images and descriptions of their experience of short breaks, with two children saying how happy they felt there. For example: "I would like to stay there all the time only I would miss Mummy at night sometimes" (p124-125). However, the authors emphasise the exploratory nature of the study and the lack of generalisability of findings.
- A study in Canada looked at the views of children who received short breaks at a pediatric hospice program where the majority of children had neurological or metabolic conditions (Davies et al., 2005). Postal questionnaires were completed by 26 ill children and 4 ill children were interviewed. Children enjoyed the activities and physical environment of the hospice which was regarded as home-like: "I liked it ... it's very much more like a home than the hospital" (p256). Most enjoyed getting away from their home and family: "I get to meet new people who take the time to play with me and talk to me. Getting away from home, family and school" (p256).
- A mixed methods study in England included interviews with 20 children with autistic spectrum disorder or attention deficit hyperactivity disorder who were using some form of short break (Thompson et al., 2009). The children interviewed expressed both positive and negative experiences of short breaks. One 9 year-old boy asked about overnight trips said: "I don't like (name of service) because I miss my Mummy" (page 63). However, another 10 year-old boy at the same service enjoyed friendships and activities there.
- As part of an evaluation of one specific service providing 3 types of short break for children with intellectual disabilities, a study in Northern Ireland interviewed 5 young people who used the service (McConkey and Truesdale, 2000). Overall, the children enjoyed being there and all described positive experiences including developing friendships. Some felt they were not given enough notice of visits: "Mummy gets the bag out" (p56) and "I found out last night about today" (p56). Some did not know why they went there or held negative thoughts such as: "... because my Mum doesn't like me being at home all the time" (p58). However, negative comments were mostly about missing their families rather than the services provided eg "I cried once because I miss Mummy" (p56). It is suggested that the children should be consulted more about their stays and given explanations about why and when they go to the service. In addition, interviews were conducted with parents. For the overnight service, reported benefits for the children included: socialisation (n=12); new environment or experiences (n=7) and having a break (n=7). Of 22 families who had used the domiciliary service, reported benefits for children were: new activities (n=6); building relationship with same carer (n=6) and socialising with others (n=5).

In summary, little work has explored the views of disabled children regarding short breaks. The research that has been done suggests that whilst on the whole disabled children report enjoying their short breaks, this is not always the case with a minority of children being unhappy with the arrangement. This is reflected in some of the comments of parents as noted below in the section on the negative impacts of short breaks.

## “My Mum’s not ratty when I get back”

The findings regarding the impact of short breaks on family carers’ well-being outlined earlier in this review may mean that short breaks are likely to have an impact on the disabled child by virtue of receiving care from a less stressed carer. For example, one 8 year-old child in the study by Platt, Hughes, Lenehan et al (1995) noted that: “I quite like going to John and Jackie’s as they have ace computer games and my Mum’s not ratty when I get back” (p9). Similarly, in an exploratory qualitative study with 17 carers, some disabled children using a home care service were reported to benefit from their parent getting a rest (Smith et al., 1988). As one parent noted: “It gets him out of the house ... I get a break ... he doesn’t get yelled at as much by me” (p129). Similarly, in a study of the impact of short breaks in a children’s hospice one parent notes that: “ ... I just had time to socialize with friends and be on my own so that I was a little more sane. I found that when I was really stressed, I was obviously not very pleasant to be around” (Davies et al., 2004).

It has also been suggested that reductions in parental distress may directly or indirectly lead to a reduced propensity to engage in various forms of maltreatment (Aniol et al., 2004). A study in the US looked at the impact of short breaks upon caregivers’ potential for abusing their disabled child with cerebral palsy or ID (Aniol et al., 2004). This study employed a longitudinal quasi-experimental 2-month pre-post design with data collected at 3 times points. Two types of service were compared: short breaks consisting of 4 to 11 day inpatient admission to a center for developmental disabilities (n=14 carers); and short term hospitalization (STH) consisting of a 30 to 90 day stay along with comprehensive evaluation and treatment (n=18 carers). Carers completed the Child Abuse Potential Inventory (CAPI) at time of admission, time of discharge, and 2 months following discharge. Neither short breaks nor STH resulted in significant decreases in child abuse potential although mean child abuse scores were lower at discharge and at 2-month follow up, particularly for the short breaks group. They suggest that small sample sizes may have precluded the detection of significant changes in CAPI scores.

## Measuring the Outcomes of Short Breaks for Disabled Children

Despite the weight of evidence from the reports of carers and children themselves regarding the benefits of short breaks for disabled children, research which has attempted to measure improved outcomes for the children has thus far been poor at detecting improvements. It may be that either the outcomes which are being measured are not amenable to change by simply using short breaks alone (e.g. number of friends) or that the measures used have not been sensitive enough to detect change. Studies employing objective measures of outcomes are reviewed in this section.

- An English study of 48 family link scheme users and 18 families on the waiting list found that there was no significant difference between users and non-users in the number of friends or social outings for the disabled child (Bose, 1991). However, interviews suggested that the majority of children enjoyed going to the link family’s house.
- One study in the US attempted to measure the impact of short breaks on a number of outcomes including child behaviour using the Quarterly Adjustment Indicator Checklist (QAIC) in a quasi-experimental 6-month pre-post design with 73 families (Bruns and Burchard, 2000). The authors found that many outcomes remained unchanged, with indicators showing evidence of continued high family stress and child behavioural difficulties. The authors

conclude that whilst short breaks may benefit families, short breaks plus other individualised services and supports will be necessary to meet the caregiving challenges faced by these families.

- A longitudinal study in the US on the impact of two types of service for children with developmental disabilities (residential short breaks (n=39) versus short term inpatient admission (n=41; approximately 30 days with comprehensive evaluation and treatment)) used the Functional Ability Scale (FAS) to assess child functioning at admission and discharge (Mullins et al., 2002). Child functioning was found to improve at discharge for both types of service, even though the short break service was brief (3-7 days) and did not include therapeutic interventions. However, practical and ethical issues precluded the use of a no-treatment or waiting list control group.
- Finally, one study in the US used secondary analysis of a longitudinal survey of over 13,000 students aged 6 to 12 years receiving special education to look at the relationship between academic achievement (measured using the Woodcock Johnson III Revised Research Edition (WJ-III-R)) and receipt of short breaks (Barnard-Brak and Thomson, 2009). Structural equation modelling suggested that any increase in receipt of short breaks across time was positively associated with an increase in academic achievement. However, the authors acknowledge that there is no information on the severity of disabilities, the quality or amount of short breaks received, or on a multitude of mediating and moderating variables which may influence the relationship between receipt of short breaks and academic achievement across time.

In summary, there is very little research that employs objective outcome measures to look at the impact of short breaks on outcomes for disabled children. The research that does exist has, on the whole, not been successful in demonstrating improved outcomes for the child, although methodological issues such as small sample sizes, measures insensitive to change and limited time-spans for evaluation would result in any changes being difficult to detect.

## **The Impact of Short Breaks on the Siblings of Disabled Children**

Whilst there is a small body of research on the impact of short breaks for disabled children, there appears to be little research which focuses specifically on the impact of short breaks on the siblings of disabled children. Only one study has been identified which explicitly provides information on the impact on siblings (Davies et al., 2005). This study looks at siblings' perspectives of a pediatric hospice program, with 41 siblings completing a postal questionnaire and 10 siblings being interviewed. The hospice program enabled siblings to receive schooling and stay overnight at the hospice. Siblings (aged 3 to 19) also rated the activities at the hospice highly and 70% mentioned the novelty of getting special attention themselves. They also enjoyed spending time with hospice staff and spending more time with their parents. "They (hospice) let me have some time with my mum and dad ... we go shopping, we get to go to the movies and stuff like that" (p257). It also gave siblings the opportunity to talk to other siblings in the same position as themselves, diminishing feelings of being different from their peers. However, as for parents, visits also reminded siblings of what lay ahead for their brother or sister leading nearly all to have experienced sad times at the hospice. Information gathered from parents in the same study (Davies et al., 2004) indicates that some parents felt siblings benefited from staying at the hospice by getting special attention and that sharing the hospice experience made them feel less left out and less resentful.

Additional information on the impact of short breaks on siblings can be gleaned from the responses made by parents in other studies regarding the impact of short breaks generally. Being able to spend more time with their other children is a benefit of short breaks noted by carers in numerous studies (Stalker 1988; Stalker & Robinson, 1994; Swift, Grant & McGrath, 1991; Sherman 1995; McConkey & Truesdale, 2000; Tarleton & Macauley, 2002; MacDonald & Callery 2004; SCIE 2008; Wilkie & Barr 2008). Other studies which report on the impact of short breaks for siblings are described below.

- In a qualitative study of a US home care service with 17 families, Smith, Caro & McKaig (1988) found that some parents reported that home care enabled them to take their non-disabled children out.
- Bose (1991) looked at the behaviour problems of siblings, comparing those who were using a link family scheme (48 families) to those who were on the waiting list (18 families), but found no statistically significant difference.
- Sherman (1995), in a US study with 26 families, found that higher rates of home-based short breaks were associated with lower sibling strain as measured by the Impact on Family Scale although it is not clear exactly what this measure of sibling strain contained.
- It may also be that siblings themselves benefit from a break. McGill (1996) found that 18 UK mothers using a summer holiday day scheme reported that they, and sometimes their other children, had had a break, and that they could take their other children out which may not have been possible otherwise.
- Eaton (2008), in a Welsh study of 11 families, noted that for in-home short breaks privacy may be an issue, for example when siblings want to walk to the bathroom with little clothing on at night.
- McConkey (2008), in a Northern Ireland study of 29 parents, noted that for parents of children with physical healthcare needs, short breaks enabled them to spend more time with their other children and to go to places that would be inaccessible with a wheelchair.
- A UK survey of 32 members of families with a child with autism found that shared care enabled siblings to benefit from one-to-one time with parents and from the chance to do activities that would not be possible with a child with autism (Shared Care Network, 2008). It was noted that: "Both parents and siblings get a break from the stress and demands of caring for a child with autism. At the same time children with autism get a chance to have fun, take part in activities and gain social and independence skills away from the family environment" (p7).

As well as affording carers more time to spend with their other siblings, short breaks may also enable carers and siblings to engage in activities that would be otherwise impossible.

### **The Impact of Short Breaks on Seeking Permanent Out-of-Home Placement**

One oft cited outcome of short breaks is that they enable families to continue caring for their disabled child at home in the long-term, the assertion being that without this break from the demands of caring, carers may be unable to cope and seek a permanent out-of-home placement for their child. In their systematic review, McNally, Ben-Shlomo & Newman (1999) note that studies on the impact that short breaks may have on the decision to place the service user in permanent out-of-home

care suggest that, whilst a relationship may exist, the direction of this relationship is unclear. It is suggested that short breaks may not provide adequate relief from the demands of caring, or alternatively it may be very effective and remind carers of how much caring has altered their life thus encouraging the decision to seek an out-of-home placement (McNally et al., 1999). Studies which provide information on this issue relevant to families with a disabled child are described below.

- Of 24 mothers receiving in-home short breaks in the US, 30% indicated that they would be unable to care for their son or daughter at home without the short break service (Joyce et al., 1983).
- A study in England pointed to the potential role of short breaks in preventing permanent out-of-home placement (Oswin, 1984). As one parent noted: "I can cope if I get short-term care; this way I don't have to send Stevie away for long-term care do I?". However, the author suggests that if badly provided, short breaks may disturb the child and increase the likelihood of long-term care.
- Of 17 carers interviewed in the US regarding in-home short breaks, 2 said that without the in-home care they would have been unable to continue (Smith et al., 1988). As one carer stated: "... if I didn't have the services I would have cracked up by now. I have someone to help me care for the kids, someone to share the responsibility with" (p130).
- In light of findings regarding a reduction in hospitalizations following a short break program (see the next section), Mausner (1995) hypothesises that the program (costing US \$4,000 to \$5,000 per annum) may reduce the need for institutional placement of the child (costing US \$100,000 per annum) and thus may be cost effective. However, this chart review was based on a very small sample size and lacked a control group.
- Stalker (1998) reports that in one case an unfamiliar taste of 'normal life' led to disconcerting feelings about parenting a child with severe learning difficulties.
- In a series of case studies of 20 families of teenagers or young adults with severe or profound intellectual disabilities and serious behavioural problems in England, it was noted that it was short term care that made it possible to keep their teenage or adult child living at home (Hubert, 1991). As one carer noted, at one point they were considering their son going into permanent care as: "...they said the short term care might disappear – and it's the short term care which makes it tolerable" (p68).
- Bruns and Burchard (2000) found that for 73 US carers additional short break hours were associated with better outcomes including increased optimism about caring for the child at home.
- Tarleton and Macauley (2002) in a UK study with families with a child with autism reported one benefit of short breaks to be time out for parents from constant care allowing them to continue to care in the long run.
- In a qualitative study involving 26 carers of children requiring complex care in England, the majority stated that they would not have been able to maintain the family unit without it (MacDonald and Callery, 2004).
- In a qualitative study of 11 families with complex healthcare needs in Wales, the most commonly heard statement from all families was: "I don't know how we coped before", with families in both groups reporting that they were 'close to cracking up' before they had accepted short breaks (Eaton, 2008).
- A qualitative study of 6 parents in Ireland noted that one of the benefits of short breaks was confidence in their ability to continue caring for their child (Wilkie and Barr, 2008). All felt that short breaks were necessary in order for them to continue caring for their child at home.

- In a UK based survey of both users and non-users of short breaks, 5 families suggested that effective short breaks might prevent or delay long-term care (McGill, 2009).

## **Preventing Hospital Admissions**

There is also a suggestion that short breaks may play a role in preventing hospital admissions. In an examination of flexible, family-centred examples of good practice in the provision of short breaks, a report by the Social Care Institute for Excellence (SCIE) notes that short breaks seem to help prevent many hospital admissions, thus saving money for the NHS (Social Care Institute of Excellence, 2008), although detailed evidence for these statements was not presented. This possibility was examined by a study in the US in which a chart review was conducted for 6 children with complex needs who had received short breaks more than once, comparing the 6 months of the program to the same 6 months in the previous year in terms of hospitalizations and contact with a physician (Mausner, 1995). The number of hospitalizations decreased by 75%; physicians' visits decreased by 64%; and antibiotics use decreased by 71%. The authors suggest that the program helped parents feel more able to care for their child with less assistance from the physician. The authors note that it is not uncommon for hospitalizations to be organised for 'social' reasons, for example if the physician feels that the family is stressed to breaking point and this may underlie the decrease in hospitalizations. They hypothesise that the program (costing US \$4,000 to \$5,000 per annum) may reduce the need for institutional placement of the child (costing US \$100,000 per annum) and thus may be cost effective. However, they acknowledge that the chart review was based on a very small sample size and lacked a control group.

Similarly, a study in the US looking at the benefits of home-based short breaks for 73 families with chronic illnesses found that higher rates of short break use were associated with a trend towards a decrease in the number of hospitalizations ( $r=-.40$ ;  $p<.07$ ) (Sherman, 1995). The authors note that for each day of short break, the need for 1 hospitalization day or outpatient visit can be eliminated suggesting 'tremendous cost effectiveness'. However, the results must be considered preliminary due to the small sample size and high attrition rate.

## **Hospice Based Short Breaks for Children with Life Limiting Conditions**

A small number of the studies were concerned specifically with users of hospice based short breaks or included these as part of their sample (Eaton, 2008, Robinson et al., 2001, Davies et al., 2004, Davies et al., 2005). To a large extent, the impact of hospice based short breaks reported in these studies was in line with other types of short break and these studies are included in the foregoing sections. However, some aspects of the impact of hospice based short breaks are unique to this situation. Firstly, hospice based short breaks have been noted to include provision specifically for siblings, for example sibling activity days (Eaton, 2008), and siblings staying at the hospice themselves (Davies et al., 2004). As noted above, the involvement of siblings may improve relations between the child and siblings, reducing any resentment over special treatment received by the child (Davies et al., 2004). Secondly, it has been noted that hospice based short breaks may help parents and siblings prepare for the death of the child, although this also means that hospice based short breaks can be a source of sadness for parents and siblings (Davies et al., 2005, Davies et al., 2004).



## The Negative Impacts of Short Breaks

Whilst many studies suggest that short breaks provide a number of positive benefits for the child, at times it seems that a balance has to be struck between the needs of carers to get a break and the needs of the child. Positive experiences of short breaks are not always the case. For example, one parent in the study by Platts et al (1995) noted that: "She hates respite. She has to be lifted onto the bus. She swears, kicks and fights. She leaves me in tears. It's so undignified" (p19).

The use of short breaks has the potential to cause anxiety for parents. A series of 20 case studies in England looking at the use of residential short term care units for teenagers and young adults with severe or profound ID and behavioural problems paints a gloomy picture of the care received (Hubert, 1991). They note that the days of freedom offered by short breaks: "... are often more anxiety provoking than normal days with their children at home. They know that their sons or daughters will probably spend most of the time doing nothing except sit in their wheelchairs or, if they are mobile, will either be left to wander about aimlessly and, if they are difficult to manage, will probably be given extra medication" (p76). However, much of this work concerns adult short term care and it is not clear to what extent this applies to children's services. Such descriptions of short breaks are also in stark contrast to those reported by Swift et al (1991) in relation to family-based care where it was noted that host families appear to strive to broaden the experiences of the child and make active use of the time they spend with them rather than using it as a "holding operation".

One study has suggested that short breaks can have a negative impact on siblings (Oswin, 1984). Of 107 families who were asked about the impact of short breaks on siblings, 47 reported that siblings had anxieties or negative feelings about short breaks. Twenty one families mentioned that they missed their brother or sister: "Jenny messes up Mary's things and sometimes stops her playing or having her friends in, but she still misses her when she goes in the short-term care place. She keeps asking 'when is she coming home again'" (p67).

A small number of studies have considered whether short breaks may have a negative impact on the disabled child and these are considered below.

- An early study in England based on 150 families using predominantly hospital or hostel based short breaks found that over half of 123 parents said their children were probably homesick at short breaks and that the experience seemed to have an adverse effect on them (Oswin, 1984). Oswin concludes that: "Short-term care services are, at present, so badly organised that the children are likely to be harmed by the experience" (p181). However, descriptions of family-based short breaks in this study are more positive.
- A cross-sectional survey in England involved 160 parents of children with severe learning difficulties using family based short breaks, local authority homes, or health authority provision (Stalker and Robinson, 1994). 97% of children in family based schemes and 87% in residential homes were said to have benefitted from short breaks, for example with improved skills, greater maturity, and confidence. However, 37.5% of those using health authority short breaks were said not to have benefitted in any way. A small number of families reported no benefits associated with short breaks or a negative impact with deterioration in the child's behaviour following short breaks.
- In England, 35 parents, 32 class teachers and 34 short break staff described the behavioural reactions and homesickness of 'highly dependent' children

using residential short breaks in one unit (Radcliffe and Turk, 2007). Reactions were classed as positive, neutral, minor negative, medium negative and strong negative reactions. Overall, 37% of children were reported to show strong negative reactions; 54% report to show strong or medium reactions. There was no concordance between distress reactions reported by parents, teachers and short break staff. Two of six children interviewed did not like going for short breaks. The authors suggest that short break staff may only feed back positive aspects of the child's behaviour to give them a stress free break. However, the study did not use objective behavioural measures.

- In an English study involving 77 families looking at the accessibility of short breaks for children with disabilities and complex health care needs, it is noted that there is a widespread shortage of places that can cater for disabled children with complex health needs (Robinson et al., 2001). It is noted that children may be staying away from home in a range of settings just so their parents get enough breaks to cope. They note that: "This raises additional concerns about both child safety and possible psychological damage to children through lack of consistent care and carers" (p74). However, there is no data to back this up suggestion to date.

There is little evidence that short breaks can have an overall negative impact for carers and disabled children but it is evident that for a minority, the negative impact of short breaks may outweigh the potential benefits. However, these negative impacts may be minimised by tailoring short break services to the needs of families and disabled children and addressing some of the problems that have been reported in using short breaks. These problems are outlined in the following section.

## **Reported Problems with Using Short Break Services**

### **Criticisms of Short Breaks Provision**

The most common criticism of short breaks is simply that carers do not receive enough of them. Studies have reported a number of other criticisms of short breaks and these are described below.

- An early study in England which made contact with 150 families using predominantly hospital or hostel based short breaks presents accounts of children receiving a very low quality of care during short breaks (Oswin, 1984). However, Oswin notes that dislikes were related to the type of facility being used, with hospitals being most disliked and family-based short breaks being most satisfactory.
- A US study of a home care service found that reported problems included frequent turnover of staff and some unsatisfactory experiences with staff (Smith et al., 1988). For example, one carer reported that: "One day I left her there with Sandra and she fell asleep. Sandra ate some of the paint that was falling off the wall and got sick ... she (the home attendant) can't supervise the child if she is sleeping" (p131).
- In a Scottish study of family-based short breaks, some parents were reluctant to ask carers for a break, often related to their perception of carers as altruistic volunteers, with worry about imposing on them or around the non-reciprocal nature of the arrangement (Stalker, 1988).
- A study of 3 types of short break in England found that the main sources of disappointment included a lack of available care when needed and inflexible booking arrangements (Stalker and Robinson, 1994). Also, 7% of those in

the family based scheme did not like to ask carers to look after their child due to feelings of guilt or a fear of imposing.

- A study of 36 families in England found that choice, reliability and flexibility in local short break services was in short supply (Platts et al., 1995). There was continued reliance on hospital, hospice and residential provision and very few families were receiving the kind of services they valued.
- In a US quasi-experimental pre-post evaluation of home-based short breaks, the only complaints from parents were that they needed more hours of short breaks and would like the service available on an emergency basis (Sherman, 1995).
- In an English study of a summer holiday day scheme, the only common criticism of the scheme was that there was not enough of it (McGill, 1996). If the scheme were available in the future families would want to use it an average of 6 times more frequently.
- A study in Canada noted that the availability of qualified staff was the most cited concern regarding short breaks (33%) (Neufeld et al., 2001). As the authors note: "For primary caregivers of children with chronic conditions, lack of trust in others to care for this child, inability to afford appropriate respite providers, and concerns about the quality of respite care create a situation where they cannot leave their children with a respite care provider without worrying" (p241).
- In a UK study of carers of disabled children from South Asian families, only 43% of those who had used short breaks reported that the service had made arrangements to meet the child's cultural and religious needs (Hatton et al., 2004). Other reported problems with short breaks included: delays in accessing short breaks; lack of flexibility in accessing short breaks at short notice; and lack of parental confidence in short break services to look after their child.
- A study in Wales found that both hospice and in-home short breaks were regarded as inflexible with planning four weeks in advance not accommodating the reality of their needs for short breaks in times of crisis (Eaton, 2008).
- For family carers of children with physical healthcare needs in Northern Ireland, some were reluctant to use residential facilities due to the child having picked up infections on previous stays or unsuitable accommodation such as hospital type wards, and concern over high staff turnover (McConkey, 2008).
- In Ireland, carers reported that whilst they valued a short break service they were not satisfied with the frequency of provision, with a main issue being lack of short breaks during the summer holidays (Wilkie and Barr, 2008). It is suggested that short breaks need to be more flexible, local and fit in with family routines.
- In a UK survey of over 300 families by the Challenging Behaviour Foundation, nearly half of those who had used short breaks found at least some short breaks unsuitable, with 90% reporting that the main reason for this was staff not having training in and understanding of challenging behaviour (McGill, 2009).
- In an English study of 44 carers of children with autistic spectrum disorder or attention deficit hyperactivity disorder, 68% agreed that they had problems accessing short breaks (Thompson et al., 2009). Reported barriers included the quality of the care and lack of expertise/staff attitudes. Focus groups with carers illustrated concerns with the quality of care offered, for example: "... a friend's son escaped once; my son lowered the electric bed onto his legs – a minor injury" (page 34). The same carer also found adherence to guidelines

a problem: “ ... they only have prescription things, won't use nappy rash cream from supermarket and it takes four attempts to get Dr to write the prescription – it causes no end of stress ... it is worth me sending him? It detracts from the value of respite” (page 34). A significant barrier to short break provision was related to a lack of trust and training of staff.

### Inequity in Access to Short Breaks

A further problem noted with regard to short breaks is the lack of equitable access to short breaks for particular groups. For example, in a UK based cross-sectional postal survey completed by 66 family carers of children with ID and challenging behaviour, a total of 68% of respondents had received short breaks but of these 36% reported their son or daughter's exclusion from short breaks, mainly due to challenging behaviour (McGill et al., 2006). Similarly, in a survey of over 300 users and non-users of short breaks in the UK, 78 families reported that their family member had been excluded from a short break service, mainly due to an inability to manage their challenging behaviour (McGill, 2009). Further, 91 reported that their family member had been turned down by a short break service, mainly due to challenging behaviour or lack of funding or lack of provision. Hence, some families are excluded from experiencing the benefits associated with short breaks, as one family carer notes: “We hoped respite would give us a chance to rest, spend time with our other son and have some sort of life – but we never got that far before he was excluded” (p3) (Challenging Behaviour Foundation and Tizard Centre, 2009).

It has also been reported that children with autism are amongst those disabled children who wait longest for short break services, with a survey finding that a third of disabled children on waiting lists have autism (Shared Care Network, 2008). For carers from ethnic minority groups, as noted above, many may not use short break services simply because they do not know that they exist (Hatton et al., 2004). Similarly, a UK based survey of 587 carers of a severely disabled child under 15 years of age from minority ethnic families found over two thirds of parents did not get a break from caring as often as they needed it and that no more than 1 in 4 parents was using short-term care services (Chamba et al., 1999). The most common reason for not using them was lack of awareness that such services existed. Black families and families in poorer socio-economic circumstances also appear to have less access to family based services (Stalker and Robinson, 1994).

### Summary of the Problems of Short Breaks

In summary, whilst the majority of parents value the short breaks that they receive, a number of criticisms have been reported, often relating to the need to receive more short breaks, and to receive short breaks which are flexible and available when it is needed. Other commonly reported concerns relate to short break services being competent to work with children with complex needs and a potential lack of safety and staff continuity in short break services. As McConkey (2008) notes: “... more respite services per se will not necessarily meet the needs of families. Rather the emphasis needs to be on creating a range of provision that is focussed on child and family outcomes” (p17).

## **The Limitations of Short Breaks**

Short breaks cannot be seen as a “cure all” and it is evident from research that the benefits of short breaks may be limited to specific areas of carer, child and sibling well-being, with other areas remaining unaffected by short breaks. For example, one issue raised is whether short breaks afford carers the time to maintain socially supportive relationships which can be drawn on once the short break ends. In their systematic review, McNally, Ben-Shlomo & Newman (1999) note that this is not what happens, with short break time being used for other activities.

Many of the studies in this review note that the time afforded by short breaks is used for relatively mundane activities, such as sleeping. For example, in a study of 26 carers of children requiring complex care (MacDonald and Callery, 2004), short breaks were used for activities generally taken for granted: “We’d come home and perhaps just sleep. I’d just go to bed and sleep” (page 282). “Last night we went out shopping, that’s boring isn’t it, we went to Tesco’s all shopping together but there’s a little cafe next to it so we spent an hour ... just having cakes and coffee. And I think it is good for (sibling) to get some time on her own with us” (p283). Similarly, Eaton (2008) noted that short breaks enabled carers to do activities such as sleeping or reading a book. Finally, as noted by one parent (Challenging Behaviour Foundation and Tizard Centre, 2009): “When I say we are having a break people ask me if I am doing anything nice, but we have so few breaks I just use them to survive – to catch up on some sleep or do the ironing” (p3). The establishment of informal support networks is complex and unlikely to be an outcome of short breaks used for much more basic activities.

Similarly, short breaks may not have an impact on other areas of the lives of disabled children and their families. Even tiredness may not be alleviated sufficiently by short breaks. For example, a study of 24 mothers receiving in-home short breaks in the US found that only 27% felt less tired from caring since using short break services (Joyce et al., 1983). As noted by Bruns and Bruchard (2000) many outcomes in their study remained uninfluenced by short breaks and indicators showed evidence of continued high family stress and child behavioural difficulties. They suggest that whilst short breaks may benefit families, short breaks plus other individualised services and supports will be necessary to more comprehensively meet the caregiving challenges faced by these families.

This suggestion receives some support from the only randomised controlled trial identified in this review. In this US study, comparison was made between a low intensity intervention consisting of case management and 3 hours in-home short breaks a week (21 family carers), and a high intensity intervention consisting of case management, 3 hours a week in-home short breaks, 16 x 2 hour coping skills evening classes, and 3 hrs per week from a volunteer to involve the child in community activities (28 family carers; (Singer et al., 1989). Those who received the intensive support maintained reductions in depression and anxiety at a 1-year follow-up but this was not the case for the low intensity group. The authors conclude that for some parents, alleviation of anxiety and depression requires more than short breaks and case management. Similarly, in a study of 160 parents of children with severe learning difficulties in England, short breaks were found to be most effective

when it was part of a wider package of support services to families (Stalker and Robinson, 1994).

### **What Type of Short Break is Best?**

In relation to the type of short break provided, McNally, Ben-Shlomo & Newman (1999) note in their systematic review that: "No firm conclusions may be drawn regarding the relative effectiveness of various types of respite care" (p10). However, they note that there is a suggestion that out-of-home short breaks may be more effective as it may offer a more complete break, giving the carer more options on what to do with their time, a break from e.g. lifting in and out of bed, and the chance to get improved sleep in a way that in-home short breaks may not allow. More recently, McConkey (2008) noted that: "To date there has been no overall assessment of the benefits children and families may derive from different forms of respite provision, and no studies have attempted to link these with the costs" (p17). Nonetheless, some suggestions for the relative merits of different types of short breaks have been given by studies in this review and these are described below.

- An early study in England based on contact with 150 families using predominantly hospital or hostel based short breaks found that the quality of care and satisfaction of parents was highest for the small number using family-based short breaks (Oswin, 1984).
- In a study looking at home-based or drop-off centre based short breaks in the US for 78 mothers of children or adults with ID, it was noted that home-based services were associated with lower levels of stress than drop-off centres ( $F=4.23$ ,  $p<.05$ ) (Rimmerman et al., 1989). It was also noted that families of adults tended to choose drop off services rather than in-home short breaks.
- A qualitative study in Australia looking at shared family care found that a common perception of staff was that shared family care was better suited to younger rather than older children and it was noted to be difficult to find caregivers for adolescents (Baxter et al., 1991).
- A comprehensive study in England looked at parents' views on three types of short break: family based (n=64), local authority residential home (n=64) and health authority provision (n=32) including hospital beds, hostels and special short break units (Stalker and Robinson, 1994). The extent and nature of benefits to families did not differ by type of service used. However, 29% of those using health authority placements wanted a more appropriate environment for their child, and significantly more children using health authority short breaks than other types of short break were said to have not benefitted from short breaks in any way (37.5%). Parents using family based schemes expressed most satisfaction overall and parents valued the informal, personal nature of the arrangements.
- A study in the UK looked at the impact of short breaks for children with autistic spectrum disorder (Tarleton and Macaulay, 2002). Data were collected via: discussions with 6 adults with autistic spectrum disorder; 6 focus groups with parents of children with autistic spectrum disorder; questionnaires from 135 parents who used short breaks, and 136 who did not use short breaks; and questionnaires from 371 service providers. The reported benefits of short breaks for children included: enabling child to experience new activities; opportunities for child to mix with others; giving the child a break from parents; and preparing them for adult life. Different services were seen as having differing benefits e.g. link families were seen as good for socialising, playschemes were seen as good for new activities, and in-home short breaks were seen as good for the child feeling safe.

- In a phenomenological case-study with two mothers of children with learning disabilities who use short break services in Ireland (Hartrey and Wells, 2003), one theme that emerged was the emotional conflict associated with short breaks providing the opportunity for psychological calm but also leading to a sense of guilt. The authors suggest that to address the distress of short break separation, regular short breaks within the home may reduce the guilt of having to send their child away. Establishing a long-term relationship with a particular short break carer may make the carer feel more comfortable with having someone care for their child in their home.
- In an English study of 26 carers of children requiring complex care, it was found that parents used the time for alleviating exhaustion, attending to their other children and relationship with their partner, and spending time being a 'normal' family (MacDonald and Callery, 2004). In-home short breaks would not allow this feeling of 'normalcy' and having others in the home may increase feelings of being different. Nurses agreed that there could be benefits from removing children from their homes to provide short breaks as it provides children with a change of environment, people and activities as well as giving the family a 'real' break. However, social workers considered removing the child from the home to be the least desirable form of short break and promoted in-home short breaks so that children did not suffer in the knowledge that their parents required a break from them. Parents did not consider short in-home breaks sufficient to meet their needs.
- In a study of 108 parents in Northern Ireland, three services were rated and it was found that parents valued small, homely services in pleasant surroundings with a child oriented approach, high care standards, and a low risk of abuse (McConkey et al., 2004). The authors note that these are not easily achieved within cash-limited budgets.
- For 11 families in Wales, both hospice and in-home short breaks were regarded as inflexible with planning four weeks in advance not accommodating the reality of their needs for short breaks in times of crisis (Eaton, 2008).
- In an Irish study of 6 parents of children aged 12 to 16 years with intellectual disabilities, the views of parents indicated that direct support in the home would be of great value to them and that short breaks need to be more flexible, local and fit in with family routines (Wilkie and Barr, 2008).
- In a survey of over 300 users and non-users of short breaks, 30% of those receiving short breaks were receiving short breaks funded via direct payments (McGill, 2009). Families receiving direct payments got more frequent and varied short breaks, with direct payments sometimes being used as an alternative following the person's exclusion from other short break services.

In summary, the existing research does not identify a “best” type of short break provision, although generally hospital ward type provision is seen as less appropriate than other forms of short breaks. However, it should be noted that published research evidence inevitably lags behind rapidly developing innovations in service provision. The research evidence in this review therefore largely concerns different forms of overnight short breaks in specialist provision or family-based short breaks, rather than some of the more innovatory forms of short breaks being developed in various localities in England. It is evident that different types of short break provision potentially have distinct profiles of advantages and limitations, and that these advantages and limitations will vary according to a wide range of family and contextual factors such as characteristics and preferences of the child, the lifestyle and preferences of family carers, the presence of siblings, the goodness of fit between short break support and other forms of service provision for the family, and pragmatic factors such as transport. Highly valued short breaks are ones which best suit the needs of individual disabled children and their families, requiring a “family centred” approach to the provision of short breaks.



## Summary & Discussion

In this section we briefly summarise the main points to come out of the literature review in terms of the impact of short breaks on disabled children and their families. We also draw attention to those issues in relation to the impact of short breaks for which there is currently little, if any, research evidence. Overall, the quality of evidence included in this review is low in terms of widely accepted hierarchies of evidence (GRADE Working Group, 2004), with only one randomised controlled trial and a predominance of qualitative studies. Nonetheless, the consistency with which some findings have been reported lends weight to evidence for the effectiveness of short breaks in impacting upon particular aspects of the well-being of disabled children and their families.

### Carer Well-Being

In relation to carer well-being, the consistency of findings is strong in suggesting that short breaks reduce stress in carers, giving them time to rest and relax. However, attempts to quantify these benefits by measuring stress related outcomes for carers have been less consistent in demonstrating an impact of short breaks on carer well-being. This is partly due to methodological problems such as the use of insensitive measures, a lack of control groups, and the limited time spans for evaluations. In the absence of a control group, it is not possible to ascertain whether changes in carer-well being are a direct result of short breaks per se, or whether other variables such as the passage of time or maturation of the child lead to changes in carer well-being (Chan and Sigafos, 2001). Further, the long term benefits of short breaks have yet to be explored, with follow-ups in quasi-experimental studies being as little as 3 to 4 days following receipt of short breaks (Botuck and Winsberg, 1991) and 6 month follow-ups being relatively common (Sherman, 1995, Bruns and Burchard, 2000, Mullins et al., 2002). There is no evidence on whether the initial impact of short breaks on carer well-being translates into a long-term reduction in outcomes such as carer stress, or whether in fact these return to baseline levels once the “honeymoon period” of short breaks fades.

The evidence also suggests that short breaks enable carers to carry out what are relatively mundane activities, such as sleeping and social contact. The importance of such fundamental aspects of human functioning cannot be overemphasised, but as has been noted in this review, short breaks are frequently limited to such fundamentals and cannot be seen as a panacea in the absence of other forms of support. Short breaks in isolation are unlikely to impact on many other areas of carer well-being such as their informal support networks, or address, for example, the difficulties inherent in caring for a child with severe behaviour problems.

One area of research that has received little attention is how best short breaks can be combined with other interventions, such as teaching carers coping skills, relaxation techniques or behaviour management techniques. The one study which has addressed this topic suggests that maintaining improvements in carer well-being over a one year period required more than a simple package of short breaks and case management (Singer et al., 1989), with a high intensity intervention including classes on coping skills and a volunteer to work with the child resulting in maintained improvements in depression and anxiety after one year.

There is also a dearth of evidence in relation to a number of areas of carer well-being. For example, there appears to be no evidence in relation to whether short breaks enable some carers to gain or maintain some form of employment. Finally, the carer samples in the studies reviewed consist almost exclusively of female carers (generally mothers) with scant attention being paid to the impact of short breaks on fathers. Whilst this no doubt reflects the reality of mothers as the main carers for disabled children, research into family impact must also consider the well-being of fathers (Blacher & Hatton, 2007).

### **Disabled Children**

Studies consistently suggest that short breaks may benefit disabled children by providing new experiences, activities that they would otherwise not take part in, and interaction with people from outside the family. For older children, there is some evidence that short breaks can be beneficial in helping the child to separate from their parents as a step towards greater independence. There is some evidence that disabled children benefit by making new friends. However, there is little evidence to suggest that disabled children have increased contact with non-disabled children, or take part in more community based activities. There is also little evidence that these experiences and activities actually lead to any improvement in functioning for the disabled child. In addition, there is some evidence that, for a minority of disabled children, short breaks are a negative experience associated with distress and unhappiness. It also seems likely that disabled children benefit from being cared for by less stressed carers but, beyond a handful of qualitative comments, little evidence exists on this topic.

There is also a suggestion that short breaks may benefit the disabled child by reducing the number of times they are hospitalized but the evidence for this is very limited. A more consistent finding is that short breaks are perceived by carers to enable them to continue caring for their disabled child at home, although for some carers it has also been suggested that short breaks may increase the likelihood of carers seeking an out-of-home placement by giving them a taste of 'normal life'. However, studies employing permanent out-of-home placement as an outcome measure are lacking.

### **Siblings**

Evidence on the benefits of short breaks for siblings is limited but a consistent finding is that carers report being able to spend more time with their other children. It is also evident that short breaks can enable siblings to take part in activities that may otherwise be impossible. There appears to be no evidence on the impact of short breaks as perceived by siblings themselves. There is also limited evidence on whether it may impact on outcomes for siblings such as academic achievement, behaviour, or their social lives. Finally, it seems likely that some siblings themselves may take on some aspects of a caring role but research has not addressed this nor the extent to which short breaks may give siblings themselves a break from caring, or indeed reduce stress and increase well-being in siblings.

## **Family Functioning**

Little research has considered the issue of the impact of short breaks on family functioning per se. However, one consistent finding is that short breaks enable carers to spend more time with each other and with their other children. Further, a number of studies have reported that short breaks allow families to live 'a more ordinary life'. There is also a small amount of evidence that short breaks can lead to carers relating better to their disabled child and the family getting along better. There is some suggestion that short breaks may improve marital relationships but the evidence on this is extremely limited with inconsistent results. However, it should be noted that the small amount of research which has attempted to measure the impact of short breaks on family functioning has largely failed to find significant effects.

## **Areas for Further Research**

The foregoing summary has indicated a number of general areas where additional research into the impact of short breaks is warranted. Firstly, research needs to consider the impact of short breaks on fathers. Secondly, there is a need to consider in more depth how short breaks can impact on the siblings of disabled children. Thirdly, research could consider how best short breaks can be combined with other interventions to maximise the impact for disabled children and their families. Fourth, research needs to look at the longer term impact of short breaks on outcomes for disabled children and their families.

In addition, there are a number of areas that the current research on the impact of short breaks tells us little about. Firstly, little is known about how the characteristics of the disabled child, such as age, gender, and the nature of their disability, may lead to differences or inequities in the impact of short breaks. For example, we do not know what it is about some disabled children that leads to short breaks being an unhappy experience for them, whilst for other disabled children the same type of short break may be extremely enjoyable. It seems likely that different types of short breaks will have distinct profiles of impact and little is known about what type of short break is best for children with particular characteristics. Further, little is known about how the impact of short breaks changes as the child matures and whether the most appropriate type of short break changes as the child matures.

Similarly, little is known about how the characteristics of families, such as ethnicity, socio-economic position, carer age and so on, may lead to differences or inequities in the impact of short breaks. It is not known whether particular family characteristics are associated with particular types of short breaks being more or less successful in having an impact. Overall, there is little evidence on what type of short break is best for disabled children and their families. What is needed is evidence on what type of short break is best for children and families with particular characteristics at particular times during the course of the child's maturation towards adulthood.

Finally, there are inevitable limitations of reviews of published research evidence in areas of social policy where there is rapid innovation. This literature review inevitably lags behind the cutting edge of innovations in short breaks policy and provision that are currently taking place in England and elsewhere, largely focusing on historically

prevalent models of short break provision such as specialist overnight short breaks and to a lesser extent family-based short breaks. Obviously these historically prevalent models of service provision will remain as important short break options for families with a disabled child, but they are becoming part of a much wider array of short break options available to families. More research is clearly needed on the impact of more innovatory forms of short break support, including short break support provided via direct payments and personal budgets.

In conclusion, short breaks appear to have the potential to positively impact on not only the well-being of carers, but also the children receiving short breaks and their families as a whole. However, short breaks are not a panacea. In many cases, short breaks are simply allowing carers to engage in the basics required for human functioning such as sleep and social contact. To suggest that short breaks will somehow enable carers to build an informal support network or solve all the problems inherent in caring for their child is not warranted by the evidence. Research needs to consider optimal patterns of short break provision according to child and family characteristics across the life course and consider how the impact of short breaks can be maximised by combining them with other interventions to improve child, carer and overall family functioning and well-being.

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## Appendix One: Search Strategy

Searches were conducted using word searches as outlined below for each database. Where over 300 articles were identified using combinations of synonyms for short breaks and disability the word "child\*" was added to searches.

ASSIA

Respite or "shared care" or "short break\*" in anywhere

AND

Disab\* in anywhere

PsycInfo & CINAHL

Respite or "shared care" or "short break\*" in anywhere

AND

Disab\* in anywhere

AND

Child\* in anywhere

Web of Science

Respite or "shared care" or "short break\*" in topic

AND

Disab\* in topic

AND

Child in topic

Additional searches were also subsequently conducted to ascertain whether there was any information specifically on children's hospices and palliative care services in relation to short breaks. Additional searches were as follows:

PsychInfo and Cinahl

Palliative care & disab\* & child\* (all terms anywhere)

Hospice\* in ti & child in ti\*

Web of Science

Hospice in topic And Child\* in topic And Respite in topic

Palliative care in topic and Child\* in topic and Respite in topi



## Appendix Two: Summary of Studies on the Impact of Short Breaks on Disabled Children and Families

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
Ptacek, Sommers, Graves et al	1982	US	Short breaks provided by foster families in the foster family home for a minimum of two & maximum of 15 consecutive days	57 parents of children with severe handicaps who had used short breaks. Primary diagnoses of ID (22%), cerebral palsy (17%), epilepsy (15%) & hyperkinesia (10%).	Cross-sectional postal questionnaire survey	Ratings to questions on satisfaction with rating scales from 0% to 100% (negative to positive).	Parents had positive opinions about the delivery of short breaks for the child, with ratings of 85% for satisfaction with overall care provided, 90% for meeting the needs of their child, & 75% for the child benefitting from short breaks.	
Joyce, Singer & Isralowitz	1983	US	In-home short break service (mean use 88.5 hours, range 4-437 hours)	24 mothers of disabled children or adults (aged 1 to 29 years, mean 12.9 years; 46% with ID, 25% cerebral palsy & 13% both ID & CP) who had participated in an in-home short break program	Cross-sectional postal survey following participation in short break program	Parents' perception on the impact of short breaks on their family's quality of life	Strongly agreed or agreed that: relating better to disabled son or daughter since using short breaks (53%); family gets along better since using short breaks (53%); short breaks relieve family stress (68%); allowed non-disabled family members to spend time together (52%); allowed them to do things not possible before short breaks (76%); they felt less physically strained (67%); they felt	Overall, responses indicated that the service had a positive impact on the lives of families. This early study gave some empirical support for the benefits attributed to short breaks but authors note the small sample size.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							relief at having trained person available to care for son or daughter (100%). 30% indicated that they would be unable to care for their son or daughter at home without the short break service. Only 27% felt less tired from caring since receiving short break services.	
Oswin	1984	England	Mixture of short break services, predominantly hospital or hostel based and small number of family-based short breaks	Contact with 150 families of children with intellectual disabilities using mainly hospital or hostel based short break services; 9 families using family-based short breaks	Mixed methods: interviews & visits to services (81 families); postal questionnaire (42 families); unstructured casual meetings (25 to 30 families).	Comments of interviewees; responses to questionnaire; author observations of children during short breaks	54 out of 92 parents mentioned freedom given by short breaks e.g. to rest; 11 said it gave chance to be with siblings. Only 7 mentioned the child liking short breaks with more than half of 123 parents saying child probably homesick. Greater satisfaction associated with family-based short breaks. Descriptions of children during short breaks illustrate poor quality of care except in family-based settings.	Work presents a negative picture of short breaks with exception of family-based short breaks. However, work based predominantly on hospital and hostel based short breaks. Oswin concludes that: "Short-term care services are, at present, so badly organised that the children are likely to be harmed by the experience" (p181).

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
Halpern	1985	US	One of two home-based short break services	31 parents using short breaks in last year compared to 31 non-users of short breaks (all 2-parent families with child with ID aged under 25)	Cross-sectional. Comparison of two groups on questionnaire based scores of family functioning	Moos's Family Environment Scale (FES) & reported satisfaction with short breaks	81% of mothers & 84% of fathers were highly satisfied with short break services. When asking both mothers & fathers, 42% indicated that short breaks meant relief from stress, normalacy in family life, & freedom. One mother indicated that for her short breaks took the place of therapy. Scores of user parents on the FES did not indicate higher levels of family functioning than non-user parents on any of the FES subscales.	Non-users were not excluded if they used services offering relief outside the home such as camps or recreational programs.
Marc & MacDonald	1988	US	Residential short breaks	124 families eligible for short break services (child with ID aged under 18 with a behaviour problem). 37 had made use of short breaks during a two year period & 87 had not	Cross-sectional telephone survey of carers of children with ID	Questionnaire responses on benefits of short breaks	Most families said that they benefitted from the service, specifically it allowed them: to relate better to their child (89%); make social plans in advance (78%); get along better as a family (81%); do more things for themselves (83%); & reduce the stress	Those who used short breaks tended to have children with more severe ID & more serious behaviour problems compared to those who did not use short breaks.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							of caring for their child with ID (83%).	
Smith, Caro & McKaig	1988	US	Home care service in four or five hour segments from five to seven days a week (between 24-35 hours of service per week) - home care attendant to assist with varied tasks as required	17 carers (female) of children from infancy to 15 years of age with a range of developmental disabilities (including ID, ASD, CP) who were receiving home care services	Exploratory study based on interviews	Qualitative comments made by parents	Home care primarily provided short breaks from caregiving. Most parents rested, ran errands, or went to appointments. Short breaks were enhanced when parents could leave the home attendant alone with the child so they could go out. It enabled some parents to take their nondisabled children out. Some disabled children benefitted from the parent getting a rest. Parents reported being more relaxed, less pressured & enjoyed greater freedom. Two parents said that without the help of the home attendant they would have been unable to continue.	Problems reported included frequent turnover among workers. Some also had unsatisfactory experiences with home attendants.
Stalker	1988	Scotland	Family-based short breaks consisting of	30 parents (14 couples, 1 father & 15	Qualitative analysis of semi-structured	Comments made by respondents	Most frequent benefit noted was a regular opportunity	Some parents were reluctant to ask carers for a break, often

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
			matching families of children with ID to 'semi-voluntary' short break carers who received £10.80 per day spent with them, up to a maximum of 6 weeks a year	mothers) who applied to join the scheme of whom 15 were followed up after using the scheme for 6 to 8 months. Thirty short break carers also interviewed. Mostly aged under 10 years with SLD.	interviews		to relax. One family felt more relaxed just knowing that short breaks were available if needed & others reported feeling less under stress. Four couples reported improved relationships & being better able to care for the child on their return. Other benefits were: pursuing new interests; spending more time with their other children; or just staying at home doing nothing. Two thirds of the children were said to have gained in social skills, maturity & capacity for independence. Some benefitted from learning to separate from their parents. Two thirds were confident that their children enjoyed their visits to the carer but 11 out of 30 children experienced more marked	related to their perception of carers as altruistic volunteers, with worry about imposing on them, or around the non-reciprocal nature of the arrangement (this was not evident in a study of the Avon Family Support Scheme (Robinson 1987) which may be related to carers acting as part or full time workers rather than volunteers). Others feared seeming to 'reject' their child or appearing unable to cope without external support. One or two parents seemed bereft without their child as if losing a sense of purpose in their absence. In one case an unfamiliar taste of 'normal life' led to disconcerting feelings about parenting a child with SLD.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							homesickness which in some cases was persistent & severe	
Bose	1989	England	Family Link Scheme	48 users linked to a family for 6 months or more and 18 families on the waiting list	Cross-sectional comparison of user & non-user stress scores	Malaise Inventory	Significantly lower stress levels were present in the user group (4.6) than in the non-user group (7.3, level of sig not given). Income was found to be significantly associated with being a user or a non-user of the service ( $p < 0.03$ ), with significantly more people in non-user groups being from low income backgrounds than in the user group.	Higher stress levels in the non-user group could be due to this group not having the benefit of a link family, or as a consequence of low income backgrounds. Simply being on a waiting list could increase stress levels in the non-user group.
Rimmerman, Kramer, Levy et al	1989	US	Home-based or drop-off centre based	78 mothers of children or adults with ID, mean age 24.8 (no breakdown of numbers adult/child) who used short breaks	Cross-sectional questionnaire based study	Coping Resources of Stress (QRC-F); the self-esteem component of the Interpersonal Support Evaluation List (ISEL); & the Face-III scale which assesses how people perceive their own family	No relationship found between reduced stress & each of 5 measures of short break utilization. Using mother & child characteristics as covariates they suggest that short breaks were of most benefit to mothers with high self-esteem who have a young, low-	Authors do not mention limitations of study including lack of control/comparison group who do not use short breaks & use of cross-sectional measures.



Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
						systems & characteristics of an ideal family system. Data were analysed using ANOVA with covariates.	functioning child. Home-based services were associated with lower levels of stress than drop-off centres (F=4.23, p<.05). Families of adults tended to choose drop off services rather than in-home short breaks.	
Singer, Irvin, Irvine et al	1989	US	Case management & 3 hours a week in-home short breaks (low intensity - LI) compared to case management, 3 hours a week in-home short breaks, 16 x 2 hr coping skills evening classes, & 3 hrs per week from volunteer to involve child in community activities (high intensity - HI)	49 participants from 32 families with children aged 3 to 14 years with moderate & severe handicapping conditions (unspecified); 28 HI; 21 LI.	Randomised allocation of families to HI/LI group & 16 week pre- posttest (1 year follow-up for HI group only)	Beck Depression Inventory (BDI) & the State-Trait Anxiety Inventory-Trait Scale (STAI) to measure anxiety.	For mothers MANCOVA with pretest BDI & STAI & child behaviour scores as covariates yielded a significant effect for group. For mothers, intensive support group scores were lower at posttest for both measures (BDI F=10.9, p<.001; STAI-T F=6.00, p<.01). The effect was not significant for fathers probably due to the small sample size.	The authors conclude that for some parents alleviation of anxiety & depression requires more than short breaks & case management. Those who received the intensive support maintained reductions in depression & anxiety at a 1-year follow-up. They do not know how much simple contact with other parents & professionals influenced the treatment outcomes.
Gerard	1990	England	Use of one of 3 residential short break services (10 bed, 16 bed	253 carers of children with severe learning difficulties	Cross-sectional postal survey	Whether child upset or happy when told of imminent short	QoL was deemed to have improved for 81%, 90% & 63% in each service, &	The authors suggest that short breaks produce overwhelmingly good

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
			& 16 bed) for under 20 year olds in the past 12 months	(SLD) who had used the short break services in the past 12 months		break stay; whether child felt to benefit from short breaks. Responses used to categorise children as quality of life (QoL) improved, short breaks detrimental to QoL, & indeterminate effect of short breaks (exact procedure for this not stated)	been effected detrimentally for 3%, 3% & 11% in each service	effects on the QoL of children according to reports by carers.
Baxter, Cummins, da Costa et al	1991	Australia	Shared Family Care (SFC): care is provided by foster caregivers who receive an allowance to cover expenses but are otherwise unpaid.	In-depth interviews carried out with staff in 6 foster agencies providing services, 12 foster caregivers, & 7 parents of children under the age of 18 with ID or developmental delay using the service	In-depth interviews with foster agency staff, foster caregivers, & parent SFC service users	Comments made by respondents	All parents were satisfied with SFC & all believed that it had been a positive experience for themselves & their child. The quotes presented refer to: child getting new experiences; child happier due to attention from foster carers who have more time to spend with them; reduction in family stress; & parents feeling more relaxed. A common perception of staff was that	The foster caregivers & parent users were all selected by agency staff as those least likely to be stressed by the interview so the sample is biased towards the least stressed parents.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							SFC was better suited to younger rather than older children & it was noted to be difficult to find caregivers for adolescents.	
Bose	1991	England	Family Link Scheme	48 link scheme user families & 18 families on the waiting list; all children with ID	Cross-sectional; comparison of user & non-users carers scores on questionnaire based measures	Malaise Inventory was to assess maternal mental health; the Perceived Social Support from Friends & Family Questionnaire; the Children's Behaviour Questionnaire to look at siblings; & Cantril's Ladder as a measure of general morale.	There was a significant difference in mean stress scores ( $p < .05$ ), mean support scores ( $p < .01$ ), & general morale ( $p < .01$ ) with less stress, greater perceived social support, & higher general morale in the user group. There was no significant difference for: marital relationship; health measured by number of trips to the GP; number of friends or social outings for the child; or behaviour problems of siblings.	For both users & non-users the most common reason for visiting the GP was stress. Interviews suggested that the majority of children enjoyed going to the Link Family's house.
Botuck & Winsberg	1991	US	One instance of a preplanned 10 day overnight short breaks (out of the home)	14 mothers of school-aged or adult children who were nonambulatory with profound or	Collection of standardised measures from mothers preshort break, during short break, & 3 to	The Bradburn Affect Scale (to assess changes in perceptions of happiness & well-being); the	Mothers were happier during the short break than they were either before or after. Repeated measures	3 to 4 days after their child returned from the short break mothers displayed continued increases in positive affect & had a

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
				severe ID & cerebral palsy (ages 6 to 33 years; numbers of school aged children not given)	4 days postshort break	Norwich Depressed Mood Scale; & the Activity Pattern Indicators (to document mothers' daily activities)	ANOVA indicated significant changes on the Bradburn Affect Scale (F=11.31; p<.001) & the Norwich Depressed Mood Scale (F=4.97; p<.01). They also spent more time during the short break taking part in rest & relaxation (F=10.07; p<.001) & personal care (F=8.47; p<.01); less time on house & childcare (F=13.85; p<.001); more time in active leisure (F=16.39; p<.001); & more time on active social contact (F=3.41; p<.05). Postshort break scores on the Bradburn Affect Scale were significantly higher than preshort break scores (F=8.63; p<.01). Scores on the Norwich Depressed Mood Scale were lower post short break but this was not statistically	tendency to be less depressed. Limitations of the study include the small sample size, lack of a control group, the single postshort break follow-up, & the fact that interviewers were not blind to the study conditions

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
Hubert	1991	England	Residential short term care units	20 families of teenagers or young adults with severe or profound ID & serious behavioural problems	Qualitative study based on case studies	Issues raised in case studies	<p>significant.</p> <p>It is short term care that makes it possible to keep their teenage or adult children living at home but parents quite often feel guilty about sending their child away, even for a night or two, feeling that they are shirking their duty as a parent or admitting to the world that they cannot cope. For one adult, it was noted that in the past he went to a residential school &amp; in the school holidays his Mum: "... climbed the walls &amp; went on to valium" (p67). At one point they were considering him going into permanent care as: "...they said the short term care might disappear – &amp; its the short term care which makes it tolerable" (p68). They note that the days of freedom</p>	Much of this concerns use of adult short term care units although some children were under 18 years of age

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							offered by short breaks “are often more anxiety provoking than normal days with their children at home. They know that their sons or daughters will probably spend most of the time doing nothing except sit in their wheelchairs or, if they are mobile, will either be left to wander about aimlessly and, if they are difficult to manage, will probably be given extra medication” p76.	
Swift, Grant & McGrath	1991	Wales	Family-based short breaks in Dyfed	Postal questionnaires (98 carers); written replies (26 carers); interviews 26 carers. All of children aged under 20 years with ID	Cross-sectional mixed methods	Satisfaction ratings & qualitative comments of carers	91% found family-based short breaks useful. Reported benefits to families included: a more normal lifestyle; relief from pressures of caring; time to do other activities; time to spend with other children; getting a rest; & ability to get a social life. Reported benefits	Host families appear to strive to broaden the experiences of the child & make active use of the time they spend with them rather than using it as a “holding operation”. Host families were paid (in 1991) £4.50 per six hour session. Particular difficulties existed in arranging host families for difficult-to-manage

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							for the children included: exposure to new stimuli & interests; increased social awareness & the development of social skills; development of friendships with hosts' children; growing independence from the family; & increased confidence. Although a small number of carers reported difficulties experienced by their child, for example one or two reported worsening behaviour, the vast majority reported no difficulties at all.	children who have some of the greatest needs for short breaks.
Minkes, Robinson & Weston	1994	England	Residential short break services in 4 areas	63 children aged 10 to 19 years who attended short breaks	Consultation conducted by teachers who knew the children well in form of an "interview"	Responses of children to questions about their short break stays	Being in short breaks gave the children access to more toys, games & videos than they had at home as well as opportunities for sport, team games & social activities. There was little evidence that they had any contact with non-disabled	

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							<p>children. Over the four areas, nearly all of the children enjoyed using short breaks, had friends amongst the staff &amp; other children, &amp; were offered a wide range of activities. For a minority of children, however, short breaks were second best to being at home &amp; in a couple of instances children were clearly unhappy about the arrangements. In one area in particular, several children reported not enjoying their stays &amp; other sources of data from the overall evaluation revealed that a lower standard of care as offered to those children than elsewhere.</p>	
Stalker & Robinson	1994	England	Family based short breaks (n=64), local authority residential homes (n=64),	160 parents of children with SLD (average age 12 years 7 months) using family based	Cross-sectional study using semi-structured interviews with parents	Parent views on short break service used	The extent & nature of benefits to families did not differ by type of service used. Principal effect was	Parent using family based schemes expressed most satisfaction overall & parents valued the the informal, personal



Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
			or health authority provision (n=32) including hospital beds, hostels & special short break units	short breaks (n=64), local authority residential homes (n=64), or health authority provision (n=32)			the opportunity to relax & reduced stress (43 to 48%). Other benefits were: time to spend with other children; time to spend with partners; improved marriages; family closer; engaging in activities otherwise impossible to do. A small number of families reported no benefits or a negative impact with deterioration in child's behaviour following short breaks. The main sources of disappointment were: lack of available care when needed; inflexible booking arrangements; & for 29% of those using health authority facilities parents wanted a more appropriate environment. 97% of children in family based schemes & 87% in residential homes were said to have benefitted	nature of the arrangements. Black families & low SES families appeared to have less access to family based services. The majority of respondents (50% to 61%) wanted additional support, most beneficial being a sitting service (n=25), domiciliary care (n=19) & day care (n=9). Short breaks are most effective when it is part of a wider package of support services to families.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							from short breaks, for example with improved skills, greater maturity, & confidence. However, 37.5% of those using health authority short breaks were said not to have benefitted in any way (chi square 21.4; p<.001). 7% of those in the family based scheme did not like to ask carers to look after their child due to feeling of guilt or a fear of imposing.	
Mausner	1995	US	Families helping families: 6 month program where a social worker linked families to an appropriately selected & trained 'sharing' family	8 families of children with complex medical needs; chart review for 6 children	A chart review was conducted for 6 children who had received short breaks more than once, comparing the 6 months of the program to the same 6 months in the previous year.	Hospitalizations, contact with physician.	Then number of hospitalizations decreased by 75%; physicians visits decreased by 64%; anti-biotics use decreased by 71%. The authors suggest that the program helped parents feel more able to care for their child with less assistance from the physician.	The authors note that it is not uncommon for hospitalizations to be organised for 'social' reasons, for example if the physician feels that the family is stressed to breaking point & this may underlie the decrease in hospitalizations. They hypothesise that the program (costing US \$4,000 to \$5,000 per annum) may reduce the need for institutional placement of the child (costing

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
								US \$100,000 per annum) & thus may be cost effective. However, the chart review was based on a small sample size & lacked a control group.
Platt, Hughes, Lenehan et al	1995	England	Any	36 families of 38 children aged 2-16 years, 37 with severe learning disabilities, all with additional health needs; 13 children at interviews	Interviews with families; case studies & quotes	Comments by families & children	Most parents admitted that short breaks were primarily a service for them rather than their children but they wanted services which were fun for their child & provided a range of experiences. For some this was not the case: "She hates respite. She has to be lifted onto the bus. She swears, kicks & fights. She leaves me in tears. It's so undignified" (p19). They note that what children & their families want from short break services are: services which are fun & provide a range of experiences; choice of services to suit the child's needs; confidence that the	choice, reliability & flexibility in local short break services are in short supply. There is continued reliance on hospital, hospice & residential provision & very few families are receiving the kind of services they value.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							service will care for the child well; services that are reliable & flexible; local services where good relationships can be built; good information; & support. Some of the quotes illustrate the benefits of short breaks. eg ss one 8 year old noted: "I quite like going to John & Jackie's as they have ace computer games & my Mum's not ratty when I get back" (p9).	
Sherman	1995	US	Home-based short breaks consisting of placing a nurse in the home to offer relief for a scheduled period of time on a regular basis, ranging from 24 hours per week to 8 hours a month.	73 families of children aged from infancy to 19 years (mean 3 years) with a variety of chronic illnesses such as disorders of the central nervous system (17%) or illnesses of congenital or perinatal etiology (50%). However, it was only possible to	A quasi-experimental 6 month pre- post evaluation design based on interviews with carers	The Impact on Family Scale to measure psychosocial stress; & the Brief Symptom Inventory for underlying psychological state. Information was also collected on number of short breaks per month.	Higher rates of short break use were associated with lower sibling strain ( $r=-.61$ ; $p<.02$ ); lower expressed somatisation ( $r=-.38$ ; $p<.05$ ); decrease in mother's expressed somatic symptoms ( $r=-.60$ ; $p<.05$ ); & a trend towards a decrease in number of hospitalizations ( $r=-.40$ ; $p<.07$ ). Respondents reported relief from	The authors note that for each day of short breaks, the need for 1 hospitalization day or outpatient visit can be eliminated suggesting 'tremendous cost effectiveness'. The results must be considered preliminary due to the small sample size & high attrition rate.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
				collect follow-up information from 26 (36%) of the sample.			stress, time to spend doing other activities, & benefits to the child from the chance to socialise outside the family. The only complaints from parents were that they needed more hours of short breaks & would like the service available on an emergency basis.	
McGill	1996	England	Summer holiday day scheme for children with learning disabilities: 1 to 1 staffing & a variety of in-house & garden activities were available, as well as planned outings to e.g. swimming, the zoo & parks	18 mothers who had used the scheme & 5 who had enquired but not used it. Children aged 6 to 18 years, mean 13 years	Cross-sectional retrospective semi-structured telephone interviews with mothers following scheme	Mothers' opinions on the scheme & its' impact	Reaction to the scheme was almost universally positive. All 18 children were said to have enjoyed going; 14 of them were said to have done things they would not have done at home (e.g. mixing with other children, going out, swimming, painting). All 18 mothers were happy with the standard of care. 17 mothers reported that the scheme was a success from their own & their families point of view: 17 felt that they (and sometimes their	The only common criticism of the scheme was that there was not enough of it. If the scheme were available in the future families would want to use it an average of 6 times more frequently

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							other children) had had a break; 14 were able to do things they could not have done otherwise (e.g. taking their other children out, having a rest). One mother whose son had tantrums when she collected him was not sure if the break was worth the resulting disruption. For the 5 families who had not used the scheme, all wanted to do so in the future.	
Abelson	1999	Iowa, US	n/a	574 families of children with a range of disabilities	Cross-sectional postal survey completed by families of children with developmental disabilities	Perceived belief of benefits of access to affordable short breaks	76% agreed that short breaks would improve family functioning, & 82% believed that short breaks would reduce burnout & fatigue. A greater degree of child disability was associated with stronger positive feelings about the benefits of short breaks	Authors note a void in short breaks for children with developmental disabilities in Iowa
Chamba, Ahmad, Hirst et al	1999	UK	Any including short-term care centre, in-home	587 carers of a severely disabled child	Cross-sectional postal survey completed by	Parental report	Over two thirds of parents did not get a break from caring	

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			care, & link families	under 15 years of age from minority ethnic families	parents (Black African/Caribbean, Indian, Pakistani & Bangladeshi)		as often as they needed it. No more than 1 in 4 parents was using short-term care services. The most common reason for not using them was lack of awareness that such services existed although some had chosen not to use them. Most who used short-term services were satisfied or very satisfied with the quality of the service, but 2 out of 5 were dissatisfied with the amount of short-term care available.	
McNally, Ben-Shlomo & Newman	1999	Any	Any	Any	Systematic review of the effects of short breaks on informal carers' well-being	Systematic review	29 studies identified but most related to carers of elderly people; 6 relevant to carers of children with disabilities. " ... there was little evidence that respite intervention has either a consistent or enduring beneficial effect on carers' well-being. This may be due in part	Whilst most studies involved carers of elderly people some of the issues raised may be pertinent to discussions on the impact of short breaks for children with disabilities. The methodological problems of existing work are outlined.

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							to the fact that the majority of the work conducted has been methodologically poor" (p1).	
Prewett	1999	England, Wales & Northern Ireland	Shared care (family-based short breaks)	38 children or adults who used family based-short breaks. 17 were children aged from 8. Needs included physical impairment, learning disabilities, & challenging behaviour	User group interviews subjected to grounded content analysis.	Emerging themes from content analysis of interviews.	All enjoyed the social interaction provided by their short breaks. Short breaks were seen as beneficial to their quality of lives in that it provides new relationships and social activities, including relationships with support carers, their children, and their friends and neighbours. Three quarters had no dislikes regarding their short breaks.	A small numbers of dislikes were mentioned (for example, not liking the presence of another service user) indicating the importance of monitoring links for actual or potential problems.
Bruns & Burchard	2000	US	Preplanned, flexible, family centered short breaks consisting of in-home (27% of SG), out-of-home (79% of SG) or overnight short breaks (33% of SG). 30% received more than one type of short	73 carers of child/adolescent with EBD of whom 33% had additional needs including physical disability (18%), developmental disability (9%), chronic illness (3%) & ID (3%).	Quasi-experimental 6-month pre-post design with 3 groups. The short break group (SG) received 50 or more hours of short breaks during the 6-month study period (n=33); the control group (CG) received no short	Number of days of out-of-home placement (OHP) in the study period; number of crisis interventions (CIs) required during the study period; carer ratings of their likelihood of needing OHP or CI over the next	The SG group experienced a decrease in mean OHP days from 2.2 to 1.1; for the CG group there was an increase from 12.5 to 22.5. ANCOVA controlling for baseline days OHP indicated that this was significant (F=3.98; p<.05). SG group ratings of	The authors note that many outcomes remained uninfluenced & indicators showed evidence of continued high family stress & child behavioural difficulties. Whilst short breaks may benefit families, short breaks plus other individualised services & supports will be necessary to meet the



Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
			break.		breaks & remained on a waiting list (n=28); & the "extra group" received between 1 & 49 hours of short breaks (n=12)	6 months at follow-up; family functioning using the General Functioning Subscale of the McMaster Family Assessment Device (FAD); caregiving stress using the Impact on Family Scale (IOFS); parents' general stress using a abbreviated version of the Hassles & Uplifts Scale; & child behaviour using the Quarterly Adjustment Indicator Checklist (QAIC). At follow-up respondents also completed a history of services used in the last 6 months & a services satisfaction	likelihood of needing OHP days (controlling for days in OHP during the study in ANCOVA) were marginally significantly lower than CG ratings (0.77 vs 1.32; $F=3.11$ ; $p<.1$ ). There were no differences for CIs or optimism about future use of CI. Between-group differences at time 2 controlling for baseline scores were found for the Personal Strain subscale of the IOFS ( $F=3.67$ ; $p<.1$ ); & the Community Externalizing subscale of the QAIC ( $F=4.78$ ; $p<.05$ ). SG group scores on the Community Externalising subscale decreased from 0.6 to 0.2 whereas CG scores increased from 0.6 to 0.8 ( $F=4.85$ ; $p<.05$ ). Finally, hierarchical multiple	caregiving challenges faced by these families.

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						survey.	regressions were employed using those in the SG & EG (n=45) to look at associations between service allocation & outcomes. Additional short break hours were associated with better outcomes with increased optimism about caring for the child at home, elevated family functioning, & reduction in perceived stresses.	
Kelly, McColgan & Scally	2000	Northern Ireland	Short break services (unspecified)	3 children with learning disabilities aged 4, 10 & 16 years.	Exploratory pilot study seeking views of children with learning disabilities	Responses of children	All the children offered positive images & descriptions of their experience of short breaks, with two children saying how happy they felt there. For example: "I would like to stay there all the time only I would miss Mummy at night sometimes" (p124-125).	The authors note that the findings are exploratory & in no way representative of services in general to all families.
McConkey & Truesdale	2000	Northern Ireland	Beechfield Services: incorporates 3 types of short	Interviews were conducted with parents 6 months after	Semi-structured interviews with carers of children with learning	Reported benefits of short breaks for carers &	For the overnight service, the two main benefits to carers were having	Overall, the children enjoyed being there & all described positive experiences including

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			break provision for children with learning disabilities: an overnight residential service based in a purpose built bungalow; a domiciliary scheme which provides support in the home; & a mix of overnight breaks & domiciliary visits	the service began (33 interviews) & then again 14 months or so later (36 carers, 21 included at both times). Interviews also conducted with 5 young people who regularly stayed there	disabilities using short break services	children; child views on short break service	a break (n=16) & being able to spend time with other children or spouse to take part in family activities (n=13). Benefits for the children included: socialisation (n=12); new environment or experiences (n=7) & having a break (n=7). Of 22 families who had used the domiciliary service, benefits were: chance to do normal activities (55%); time to spend with other children/spouse (41%); chance for a rest/break (27%). Benefits for the child included: new activities (n=6); building relationship with same carer (n=6) & socialising with others (n=5).	developing friendships. Some felt they were not given enough notice of visits: "Mummy gets the bag out" (p56) & "I found out last night about today" (p56). Some did not know why they went there or held negative thoughts such as: "... because my Mum doesn't like me being at home all the time" (p58). However, negative comments were mostly about missing their families rather than the services provided eg "I cried once because I miss Mummy" (p56). It is suggested that the children should be consulted more about their stays & given explanations about why & when they go to the service.
Neufeld, Query & Drummond	2001	Canada	Short breaks including in-home short break care, in-home babysitting, host family short breaks, group	55 female carers (76% mothers) of children age 2-19 yrs with chronic conditions and/or disability	Cross-sectional postal survey of carers who had received short breaks in past 12 months	Parental ratings of perception of having a break	Overall, 77% of respondents identified limited breaks (perceived as sometimes/seldom or never an adequate break).	As the authors note: "For primary caregivers of children with chronic conditions, lack of trust in others to care for this child, inability to afford appropriate

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			home use, institutional short breaks & day or overnight "camps".				The availability of qualified staff was the most cited concern regarding short breaks (33%).	respite providers, & concerns about the quality of respite care create a situation where they can not leave their children with a respite care provider without worrying" (p241). However, there was a low response rate (21%) to the questionnaire & the findings may not generalize beyond the all female sample within the Canadian care system.
Robinson, Jackson & Townsley	2001	England	Accessibility of short breaks for children with disabilities & complex health care needs	77 families: 39 children using hospice based short breaks (aged 2.5-20 years); 40 children who were tube fed (aged 1 to 19 years)	Semi-structured interviews with parents	Comments of parents	The research focuses on accessing short breaks & it is noted that there is widespread shortage of places that can cater for disabled children with complex health needs. It is noted that children may be staying away from home in a range of settings just so their parents get enough breaks to cope. They note that: "This raises additional concerns	

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							about both child safety & possible psychological damage to children through lack of consistent care & carers" (p74) although there is no data to back this up.	
Cowen & Reed	2002	US	Short breaks (out of home) & opportunity to receive parenting information, support, positive role modelling & information regarding other community resources & agencies. Child oriented interventions may have included developmental stimulation, socialization activities, help with negative personality traits, activities to improve self-esteem & confidence, & help with coping with stress.	87 carers (mainly mothers) of children with developmental disabilities from larger study of 148 families who self-referred for short break service	Pre-post design with unspecified time frame	Parenting Stress Index	There was a significant reduction in the total parenting stress scores (t=3.27; p<.01) & all subscales with the exception of "life stress".	No information is given on the amount of short breaks received or the timespan covered by the study. Short breaks were used in conjunction with other interventions.

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Mullins, Aniol, Boyd et al	2002	US	Residential Short breaks of 3 to 7 days duration (no therapeutic input) or inpatient admission of approx 30 days with comprehensive evaluation & treatment	80 parents of children (82% mothers) with developmental disabilities: 39 short breaks; 41 inpatient admission	Longitudinal study with 3 data collection points: admission; discharge; 6-months post-discharge	Functional Ability Scale (FAS) to assess child functioning; the Brief Symptom Inventory (BSI/GSI) as a measure of psychological distress; & the Parenting Stress Index (PSI).	2 (type of service) x 3 ANOVAs showed no effect of type of service but effect of time for psychological distress & parenting stress. Parenting stress decreased at time 2 but returned to admission levels at time 3. Psychological distress was lower at time 2 & this was remained lower than time 1 at time 3. Child functioning was found to improve at time 2 for both types of service (not measured at time 3)	Overall, short breaks were beneficial to parents & child functioning also improved even in the brief short break group despite lack of therapeutic interventions. Ideally they would have used a no-treatment or wait list control group but practical & ethical constraints precluded this.
Tarleton & Macauley	2002	UK	Any	Discussions with 6 adults with ASD; 6 focus groups with parents of children with ASD; questionnaires from 135 parents who use short breaks, 136 who do not use short breaks; & 371 service	Discussions, focus groups & cross-sectional postal survey	Comments & ratings of respondents	Benefits of short breaks included: enabling child to experience new activities; opportunities for child to mix with others; time out for parents from constant care allowing them to continue to care in the long run, to spend time with their other children,	Children with ASD make up a third of all children on the waiting list for short break services. Nearly half of families said that short break services were their only form of support.

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				providers			& do other activities; giving child a break from parents & preparing them for adult life. Different services seen as having differing benefits e.g. link family good for socialising, playschemes good for new activities, in-home short breaks good for child feeling safe.	
Hartrey & Wells	2003	Ireland	Out-of-home short breaks	2 mothers of children with learning disabilities who use short breaks	Phenomenological case-study approach based on Heideggerian principles of interpretation to explore the subjective meaning of short breaks to mothers of children with learning disabilities who use short break services	Both women kept a diary of events over 24 hours & recorded a taped narrative reflection of life with their child. They also provided a written reflection of their use of short break services. Information was analysed for thematic content	One theme that emerged was the emotional conflict associated with short breaks providing the opportunity for psychological calm but also leading to a sense of guilt. Another was that the social limitations placed on parents were relieved by short breaks, allowing parents to take part in social activities.	The authors suggest that to address the distress of short break separation, regular short breaks within the home may reduce the guilt of having to send their child away. Establishing a long-term relationship with a particular short break carer may make the carer feel more comfortable with having someone care for their child in their home.
Aniol, Mullins, Page et al	2004	US	Short break consisting of 4 to 11 day inpatient admission to a	14 carers using a short break & 18 carers using STH; children with cerebral	Longitudinal study with 3 data collection points: admission; discharge; 2-	Child Abuse Potential Inventory (CAPI); Family Relations	Repeated measures MANOVAs revealed no significant changes in CAPI or FRI scores for either	Authors suggest that small sample sizes may have precluded the detection of significant changes in

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			center for developmental disabilities; & short term hospitalization (STH) consisting of a 30 to 90 day stay along with comprehensive evaluation & treatment	palsy or ID in sample	months post-discharge	Inventory (FRI); Parenting Stress Inventory - short Form (PSI-SF)	the short break or STH groups although authors note that mean child abuse scores were lower at discharge & at 2-month follow up, particularly for the short break group. PSI MANOVA results are not presented although it is noted that decreases in parenting stress occurred between admission & discharge but these were not maintained at follow-up.	CAPI & FRI.
Damiani, Rosenbaum, Swinton et al	2004	Canada	Formal short break services (in home, out of home, in non-relative home, in relative home, & other)	468 caregivers (89% mothers) of children with cerebral palsy (mean age 10 years)	Cross-sectional interview survey	One question on reported benefit of short break service use	46% used formal short break services. Nearly all of the caregivers (>90%) who used short break services agreed that these services were beneficial to their family & their child	No further information is given on benefits of short breaks to families & children
Davies, Steele, Collins et al (see also Davies et al 2005)	2004	Canada	Children's hospice offering 10 days respite every 6 months with comprehensive family centred care	18 families interviewed; 65 parents completed postal questionnaire on short breaks	Cross-sectional survey and face to face interviews	Comments of interviewees & responses of survey respondents	63% of parents reported child benefitted 'a lot' or 'extensively' from short breaks. 88% noted short breaks benefitted whole family, particularly	A third of parents noted difficulty in booking respite because of the erratic nature of their child's condition or their work schedules, with a quarter missing



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							<p>siblings. Child could: relax, enjoy themselves, do new activities, meet children like themselves, talk to staff about dying, and gain independence. Siblings could also stay at hospice so got time away from parents &amp; attention from volunteers so feel less left out/resentful. Parents get a break, sleep, time to themselves, time for other children, freedom, &amp; meet others in similar position. Also helps them prepare for child's death.</p>	<p>booked days because the child was too ill to travel to the hospice. Priority was given to dying children and some parents found it hard in that they would have to miss anticipated short breaks if such need arose. Concerns included: child may get spoiled by attention which could not be sustained at home; child not getting enough sleep due to busy days; &amp; possibility of picking up infections. Reality of issues of death &amp; dying at at hospice difficult for parents.</p>
Forde, Lane, McCloskey et al	2004	Ireland	<p>Link Family Support consisting of 3 hrs per week over 1 year. Care workers placed with client in own home or take client out to take part in community-based activities</p>	<p>16 carers (94% mothers) of children (81%) &amp; adults (19%) with cerebral palsy, spina bifida, developmental delay, ID</p>	<p>1 year pre-post design with quantitative &amp; qualitative analysis</p>	<p>Parenting Stress Index - short Form (PSI-SF); qualitative comments</p>	<p>LFS improved the quality of lives of families, by alleviating stress levels of parents, offering free time each week to parents, providing more time with other family members &amp; facilitating social &amp; recreational opportunities for</p>	<p>Many qualitative comments are presented to describe the impact of the LFS. The authors suggest the the PSI-SF may be insensitive to changes in all aspects of life stress.</p>

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							people with special needs. However, there was no statistically significant change on the PSI-SF.	
Hatton, Akram, Shah et al	2004	England	Short break services	136 carers of severely disabled children from South Asian families	Mixed methods: interviews phase 1 (n=26); structured interviews phase 2 (n=136); interviews phase 3 (n=20)	Carer reports on awareness & use of short break services	in phase two, only 35% were aware of short-term short breaks & only 5% had used this in the past 3 months. Only 33% were aware of long-term short breaks & only 1% had used this in the past 3 months. Only 32% of parents reported getting enough breaks from caring for their child & breaks were mostly provided by unpaid family members (34% of parents) or school holiday playschemes (17%) rather than short break services. Only 43% of those who had used short breaks reported that the service had made arrangements to meet the child's cultural & religious needs. However,	Families from South Asian families had low levels of awareness & use of short break services

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							<p>where short breaks were received it could be a highly value support for parents &amp; some noted that cultural &amp; religious needs were met. For example: "... Umber goes every Monday &amp; stays one night. It gives my wife a little bit of a break (the respite service provides halal food &amp; a female carer) ... it releases the pressure on her (wife). It is better for her especially &amp; we think it's better for the family as well" (p103). Reported problems with short breaks included: delays in accessing short breaks; lack of flexibility in accessing care at short notice; &amp; lack of parental confidence in short break services to look after their child.</p>	
MacDonald & Callery	2004	England	Meanings of short breaks to parents, nurses	19 mothers & 9 fathers of children aged 8-	A qualitative study consisting of in-depth	Themes identified from qualitative	Parents described three categories of short break: short	Short breaks were used for activities generally taken for

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			& social workers	16 years who required complex care, & 13 nurses & 4 social workers who were involved in short breaks	conversational interviews about the meaning of short breaks	analysis of interviews regarding categories of short break	breaks provided by family or friends; short breaks of 3-4 hour duration provided by an outside agency; & overnight short breaks outside the home. All parents said they needed overnight short breaks & the majority stated that they would not have been able to maintain the family unit without it. Parents used the time for alleviating exhaustion, attending to their other children & relationship with their partner, & spending time being a 'normal' family. In-home short breaks would not allow this feeling of 'normalcy' & having others in the home may increase feelings of being different. It was also used for doing activities generally taken for granted such as shopping. Nurses	granted: "We'd come home & perhaps just sleep. I'd just go to bed & sleep" (page 282). "Last night we went out shopping, that's boring isn't it, we went to Tesco's all shopping together but there's a little cafe next to it so we spent an hour ... just having cakes & coffee. & I think it is good for (sibling) to get some time on her own with us" (p283).

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							<p>agreed that there could be benefits from removing children from their homes to provide short breaks as it provides children with a change of environment, people &amp; activities as well as giving the family a 'real' break. However, social workers considered removing the child from the home to be the least desirable form of short break &amp; promoted in-home short breaks so that children did not suffer in the knowledge that their parents required a break from them. Parents did not consider short in-home breaks sufficient to meet their needs.</p>	
McConkey, Truesdale & Conliffe	2004	Northern Ireland	Residential short break services	108 parents who had children under 19 years of age with multiple disabilities, notably SLD along with	Thematic analysis of responses to open questions (validated at consultation seminar)	Reported benefits of short breaks for carers & children	Carer benefits: 4 main themes were apparent – the break from the demands & routines of caring (n=40); a change to spend time with other	The study went on to rate three services using items generated from the first phase of the study. Parents valued small, homely services in pleasant surroundings with a

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
				physical & sensorial impairments and/or challenging behaviour. All had used at least one residential facility in the last 12 months for short breaks			family members (n=37); opportunities to do things they could not do otherwise (n=26); & having rest, relaxation & uninterrupted sleep (n=33). Benefits to the child: main benefit to child perceived by parents was the opportunity to interact socially with others in a different environment (n=49). Mention was made of the child enjoying the break (n=21), getting used to being away from home (n=11) & becoming more independent (n=10), & being able to go on outings & join in different activities that they could not do at home (n=10).	child oriented approach, high care standards, & a low risk of abuse. The authors note that these are not easily achieved within cash-limited budgets
Davies, Collins, Steele et al (see also Davies et al 2004)	2005	Canada	Children's hospice offering 10 days respite every 6 months with comprehensive family centred care	Postal questionnaires to 26 ill children who had stayed at hospice & 41 siblings; interviews with 4 ill children &	Cross-sectional survey and face to face interviews	Comments of interviewees & responses of survey respondents	Children enjoyed the activities and physical environment of the hospice which was regarded as home-like. Most enjoyed getting away from	As for parents (see Davies et al 2004), visits also reminded siblings of what lay ahead for their brother or sister leading nearly all to have experienced sad times

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				10 siblings (ill children aged 6 to 19; siblings aged 3 to 19).			their home and family. Siblings also rated the activities highly and 70% mentioned the novelty of getting special attention. They also enjoyed spending time with hospice staff and spending more time with their parents. It also gave siblings the opportunity to talk to other siblings in the same position as themselves, diminishing feelings of being different from their peers.	at the hospice.
Mcgill, Papachristoforu & Cooper	2006	UK	Short breaks (any)	66 parents (90% mothers) from Challenging Behaviour Foundation mailing list; children aged 3-19 yrs, mean 12.3 yrs	Cross-sectional postal survey completed by carers of children with ID & challenging behaviour	Parental ratings of helpfulness	A total of 68% of respondents had received short breaks & 72 short break packages were identified of which 49% were rated as being helpful. However, 36% of those in receipt of short breaks reported their son or daughter's exclusion from short breaks, mainly due to challenging behaviour.	

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Openden, Symon, Koegel et al	2006	US	List of University students willing to act as short break providers for children with autism	No information collected - scheme had been run over 10 years	Not a systematic study - impressions of authors	Impressions of authors on benefits of the scheme	The authors note that the scheme benefitted families by: making it easy to access short break providers; allowing them to devote more time to other aspects of their lives; leading to improved quality interactions with their autistic child; providing a source of flexible short breaks; & enabling them to teach short break workers techniques that they were implementing in their parent education programs. Children were noted to benefit from opportunities for social communication & short break providers were noted to benefit from both payment & hands on experience in a field related to their career interests.	The authors note that a next step is to assess the benefits of the scheme more systematically.
Radcliffe & Turk	2007	England	Residential short break unit	Questionnaires completed by	Cross-sectional survey with	Parent, class teachers & short	37% of children reported to show	It may be that short break staff only feed



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			(12 place) for ages 0-19 years. Children eligible for 3 night weekend or week-long stay every 4-8 weeks	35 parents, 32 class teachers & 34 short break staff regarding children aged 2-18 years, 88% 'highly dependent' for most aspect of living. Six children interviewed.	matched questionnaires from parents, class teachers & short break staff regarding child's reactions to short breaks	break staff descriptions of behavioural reactions to short breaks & homesickness - classed as positive, neutral, minor negative, medium negative & strong negative reactions	strong negative reactions; 54% report to show strong or medium reactions. No concordance between distress reactions reported by parents, teachers & short break staff. Two of six children interviewed did not like going to short breaks.	back positive aspects of the child's behaviour to parents to give them a stress free break. Study did not use objective behavioural measures.
Eaton	2008	Wales	6 families receiving hospice based short breaks (3 or 4 times a year for 3 or 4 days) & 5 families receiving short breaks at home (2 to 6 hours a week)	11 families of children aged 3-16 years with life-limiting & life-threatening conditions & complex healthcare needs, including epilepsy, cerebral palsy & complex special needs.	Semi-structured interviews with parents	Interviews analysed using the "constant comparison method" with interviews being transcribed & reduced to descriptive codes which were organised into categories.	The most commonly heard statement from all families was: "I don't know how we coped before" (p3200) with families in both groups reporting that they were 'close to cracking up' before they had accepted short breaks. Short breaks enabled them to cope better with caring for their child & gave them the opportunity to do other activities (such as sleeping or reading a book). Short breaks during the school holidays were particularly	Both hospice & in-home short breaks were regarded as inflexible with planning four weeks in advance not accommodating the reality of their needs for short breaks in times of crisis.

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							helpful. However, negative aspects of short breaks were noted. Some found it difficult to let go: "I miss her dreadfully when she's not home" (p3200). For in-home short breaks, privacy was an issue, for example in the night when siblings wanted to walk to the bathroom with little clothing on, & several parents did not sleep as well when nurses were in the house.	
McConkey	2008	Northern Ireland	Any for children & young people with complex physical healthcare needs	29 parents of children aged 0 to 19 years with complex physical healthcare needs, including children requiring technological supports such as tube feeding or oxygen (in two families the child had recently died).	Face-to-face or telephone interviews with parents	Comments of parents	Short breaks were limited, one or two days four times a year at best but often less. The benefits of having a break were: a complete day off; relaxation; time to do things with other children; being able to go places a wheelchair cannot; a night's sleep. They felt that there were also benefits for teenagers in short breaks in	Some parents chose not to use short-breaks as they saw the child as part of the family & wanted to take holidays & breaks together. Some were reluctant to use residential facilities due to the child having picked up infections on previous stays or unsuitable accommodation such as hospital type wards, & concern over high staff turnover.

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							meeting other young people & increasing their confidence.	
Social Care Institute for Excellence	2008	England	Innovative examples of good practice. These examples, in contrast to traditional residential provision solely for the disabled child, are flexible and family-centred. They provide services at a time and place that suits the whole family.	n/a	Collection of examples of good practice & telephone interviews with respondents	Comments of respondents	Schemes identified included an under fives group offering two-hour breaks to parents, Saturday play schemes, summer holiday play schemes, school holiday play schemes for children with complex needs, youth clubs on weekday evenings in term time, a summer holiday club for young people in transition to adulthood, & home-based care provided by a trained carer or trained nurse. Quotes are given to illustrate the positive characteristics of these short break schemes e.g. : “The short break service allows us to have ‘me’ time & helps us to feel normal & allows family activities with our	There is little evidence on the financial costs & benefits of these new types of short break. Experience of commissioners & service providers suggests that these services do offer better value for money. For example: “Home-based nursing probably works out cheaper because there are no capital costs” (p14). One provider reduced costs by training nursery nurses to provide home-base care, which was estimated to cost £38 per three hour session including on-costs (p14). It is also noted that breaks seem to help prevent many hospital admissions thus saving money for the NHS.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
Shared Care Network	2008	UK	Disabled children linked with carers who provide short term care on a regular basis	32 members of families of children with autism	Details of methodology not given but cross-sectional survey based on semi-structured interviews with members of families of children with autism	Responses of family members	Over half said short breaks meant their child had opportunities to make friends; 92% said they had helped their child develop social skills; four fifths said they helped their child take part in social activities; two thirds said it had helped their child learn independence skills; three quarters said they made their child happier; 100% said they helped their families cope; & 100% said they helped them & the rest of their family to live 'a more ordinary life'. Short breaks were noted to enable siblings to benefit from one-to-one time with parents & from the chance to do activities that would not be possible with a child with autism. Parents were able to spend time with each other & their	other children" (p8). Children with autism are amongst those disabled children who wait longest for short break services. A SCN survey found that a third of disabled children on waiting list have autism (reference not given).

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
Wilkie & Barr	2008	Ireland	One established short break facility offering care ranging from a few hours after school to one or two weeks over holiday periods.	6 parents of 5 children aged 12 to 16 years with ID who had used the service for over one year	Qualitative study using interpretative phenomenological analysis (IPA) involving interviews with parents (1 father)	Comments of parents regarding the benefits of short breaks & perceptions of service provision	Benefits included: a sense of renewal; confidence in their ability to continue caring for their child; time to undertake activities unrelated to caring; & time with other children. However, parents expressed guilt & embarrassment about sending their child to the facility with one recounting how she cried the first time her child attended the service. Benefits for the child included: opportunity to meet children outside the family & school; increased social skills; increased opportunities to participate in leisure activities in the community. Whilst parents valued the service they were not satisfied with the frequency of provision with a main issue being lack of short breaks during the summer	The views of parents indicate that direct support in the home would be of great value to them & that short breaks need to be more flexible, local & fit in with family routines. However, the study has a small number of participants & focuses only on one short break service.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							holidays. All felt that short breaks were necessary in order for them to continue caring for their child at home.	
Barnard-Brak & Thomson	2009	US	Reported receipt of Short breaks (any) in past 12 months	13,176 students receiving special education covering ages 6 to 12 years	Secondary analysis of longitudinal survey using three time points. Structural equation modelling used to examine relationship between receipt of short breaks & academic achievement	Woodcock Johnson III Revised Research Edition (WJ-III-R)	Any increase in receipt of reS Short break receipt across time was positively associated with an increase in academic achievement (p<.05; moderate association with a standardized path value of 0.34)	The authors acknowledge that there is no information on the severity of disabilities, the quality or amount of short breaks received, or on a multitude of mediating & moderating variables which may influence the relationship between receipt of short breaks & academic achievement across time
Challenging Behaviour Foundation & Tizard Centre	2009	UK	See McGill 2009	See McGill 2009	See McGill 2009	See McGill 2009	See McGill 2009	Report based on McGill 2009 accompanied by additional comments made by family carers around exclusion from short breaks.
Doig, McLennan & Urichuk	2009	Canada	Short breaks (any)	10 carers of children mainly with fetal alcohol syndrome	In dept interviews analysed using qualitative grounded theory	n/a	The authors note that regardless of the type or quantity of services being used, most were very grateful for the short breaks they had received. One	'And so in that sense, you know, the respite for us is really important because we need to do something once in a while [for] ourselves . . . For the longest time we never

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							quote is given to illustrate the impact for parents.	had any breaks and, you know . . . once I did start getting these weekends I thought "Wow! I really missed a lot!" You know? (Laughs). You can't even go for coffee! & it makes it pretty special if you never get to do it & then all of a sudden you can. So, it has meant the world to me . . .' page 240.
McGill 2009	2009	UK	Any	321 (some partial responses only) users & non-users of short break schemes for family member aged 3 to 48 (227 aged 19 or under). 60% autism or ASD; 94% ID.	Cross-sectional postal survey	Ratings and comments of respondents	78 reported that their family member had been excluded from a short break service, mainly due to an inability to manage their challenging behaviour. 91 reported that their family member had been turned down by a short break service, mainly due to challenging behaviour or lack of funding or provision. Nearly half of those who had used short breaks found at least some short breaks unsuitable, with 90% reporting that the main	30% of those using short breaks used short breaks funded by direct payments. Families receiving direct payments got more frequent and varied short breaks, with direct payments sometimes being used as an alternative following the person's exclusion from other short break services.

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							reason for this was staff not having training in or understanding of challenging behaviour. More than half of families said they needed more short breaks. 5 families suggested that effective short breaks might prevent or delay long-term care.	
Thompson, Whitmarsh, Southern et al	2009	England	Any including overnight breaks, weekend breaks, sitting schemes, holiday playschemes, & before/after school care	Total of 110 carers of & children with ASD or ADHD (20 children)	Mixed methods: telephone interviews with carers; face to face interviews & focus groups with carers & children	Comments of respondents	Of 44 carers interviewed by phone 36% had accessed short breaks . 68% agreed that they had problems accessing short breaks. Reported barriers included the quality of the care (14 respondents) & lack of expertise/staff attitudes (13 respondents). Focus groups with carers illustrated concerns with the quality of care offered, for example: “ ... a friend’s son	Overall, parents perceived short breaks as being synonymous with respite care



Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							<p>escaped once; my son lowered the electric bed onto his legs – a minor injury” (page 34). The same carer also found adherence to guidelines a problem: “ ... they only have prescription things, won’t use nappy rash cream from supermarket &amp; it takes four attempts to get Dr to write the prescription – it causes no end of stress ... it is worth me sending him? It detracts from the value of respite” (page 34). A significant barrier to short break provision was related to a lack of trust &amp; training of staff. The children interviewed expressed both positive &amp; negative experiences of short breaks. One 9 year old boy asked about overnight trips said: “I don’t like (name of</p>	

Author	Year	Country	Short Break Service	Sample Size & characteristics	Design & data sources	Outcome Measures	Results	other comments
							service) because I miss my Mummy” (page 63). However, another 10 year old boy at the same service enjoyed friendships & activities there.	

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