



## **The effectiveness of short breaks in families where there are children with disabilities: A Systematic Review of the Evidence**

Prepared for the Health and Social Care Board on behalf of the Social Work and Social Care Research Advisory Group

2017

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## Foreword

The Health and Social Care Board (HSCB) is responsible for arranging health and social care services across Northern Ireland. Some services are commissioned directly by the HSCB and some indirectly through Health and Social Care Trust procurement. In 2017 the Health and Social Care Board, responded to a concern raised by the regional Social Work and Social Care Research Advisory Group relating to the extent to which it is possible to demonstrate if short breaks are an effective intervention in the management of crisis situations in families where there are children with disabilities.

It was considered that a more systematic approach to the evaluation of short breaks is required to improve how future services are delivered. The aim of this review is to summarise the existing evidence base around the outcomes and impacts of short breaks on children with disabilities and their families.

This call for evidence was designed with the Social Work Research and Continuous Improvement Strategy (2015-2020) in mind. The purpose of the research strategy is to increase the quantity and quality of research and evidence, relevant to Northern Ireland, to inform policy, commissioning and practice.

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This review and a summary are available at:  
<http://www.hscboard.hscni.net/swresearch/> under Evidence Reviews

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You are encouraged to use the evidence from this review .When doing so please cite the original source of the review.

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## Executive Summary

### What is the aim of this review?

The Health and Social Care Board, on behalf of the Social Work and Social Care Research Advisory Group, has identified a concern relating to the extent to which we can demonstrate if short breaks are an effective intervention in the management of crisis situations in families where there are children with disabilities. A more systematic approach to the evaluation of short breaks is required to improve how future services are delivered.

The aim of this review is to summarise the existing evidence base around the outcomes and impacts of short breaks on children with disabilities and their families.

### What is respite?

According to the Department of Health, Social Services and Public Safety (DHSSPS)<sup>1</sup>, a short break service can broadly be described as “any service which allows a disabled child to have enjoyable planned experiences away from his/her primary carers and gives carers and break from their caring responsibilities.”

### What is the gap in our knowledge?

Robertson et al. (2011)<sup>2</sup> undertook an international literature review of the impacts of short break provision on disabled children and families. They found that although progress had been made since the previous systematic reviews, important gaps remain in our understanding of what families want and need, as well as what is the most effective way to provide support to them.

The aim of the current review is to summarise what is known about providing this type of short break and respite provision effectively to young people with disabilities and their families.

### What did we learn from this review?

There have been very few robust evaluations undertaken of respite and short breaks provision where the impact is compared to families who have not received the same support. More than half of the studies eligible for inclusion in this review used qualitative techniques. Although they provide useful insights into the lived experiences of families caring for children with disabilities, their findings cannot be easily generalised to relate to other families.

There is some promising evidence of the effectiveness of short breaks and respite provision for families with children with disabilities. It is certainly very highly valued by families as a useful support in helping them cope. Families using respite tend to be those who are experiencing the highest levels of parenting stress and distress.

Overall one may conclude that short respite breaks positively impact on the wellbeing of carers (although these effects do not tend to be maintained over time). There is some evidence that family relationships and stress levels improve. In the child, increased independence, social skills, social awareness, interests and confidence are noted in some studies. A smaller number of studies (albeit more methodologically rigorous) that attempted to objectively measure change identified no significant differences in social outings, friends, or child behaviour problems. Although some studies explore the views of both parents, less is known about the effects of respite care on fathers, siblings,

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the synergistic effect of other interventions, and long-term effects.

Respite in an out-of-home setting for a short period of time may reduce immediate levels of parenting stress, but for more long-term effects on family functioning and improvements in child outcomes, other elements of effective interventions specifically targeting these outcomes may also need to be included.

There is not currently sufficient robust evidence to fully assess the effectiveness of in-home respite provision, although there is some promising evidence. Respite in the home setting appears to be preferred by carers of younger children and it may reduce immediate levels of parenting stress, but more robust evidence is required.

One randomised control trial shows the additional benefit of including more components of family support alongside respite and short breaks provision and this results in the longest effect on parental outcomes assessed in any of the studies. There are several multicomponent initiatives which offer flexibility to parents and families in order to better meet individual needs. These tend to be evaluated as single group studies. Although these can useful insight into changes over time, more robust evaluations including the use of comparison groups are required to examine whether the added value of providing support in this way. Currently there is not sufficient robust evidence to fully assess the effectiveness of this type of multi-component support to families with different needs.

Based on the available evidence, it is premature to make robust claims regarding the psychosocial impact of camp as a therapeutic intervention. Camps are widely used in America and usually comprise of overnight stays of several nights and day activities, often outdoor or adventure type activities. Some camp programmes aimed at young people with disabilities may include an element of psychoeducation about their particular conditions. Theoretically informed camp programs, long-term follow-up, and incorporating camp-based messaging into routine hospital care, may enhance the utility of camp as a potential psychosocial intervention in paediatrics. There is some evidence that regularly planned overnight clubs, participation in schemes such as the Duke of Edinburgh and befriending schemes may be useful in terms of improving outcomes for young people, but the available evidence is methodologically weak.

Several studies on the cost-effectiveness and cost-benefits of short breaks provision have been undertaken but many of these are now 7 or 8 years old. In 2009, it was estimated that the UK State could make an estimated saving of £174 million if short breaks were effectively delivered to all those eligible to receive them.

### **What are the recommendations for support in N. Ireland?**

In terms of using this evidence review to inform practice in N. Ireland, an important next step is to understand what the local needs are of families here. This will involve listening to families (parents and other carers, young people and other family members such as siblings) about what they want and need, as well as understanding their strengths and assets. Staff working in services and professionals providing support to families will also yield important insights. Co-production that is sensitively and meaningfully undertaken will be helpful: the evidence highlights the importance of parental choice and flexibility, as well as active involvement of the young person and their carer in

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planning services. This needs to go beyond consultation and examples of good practice in this regard can be found locally as well as elsewhere in the UK. A specific example of coproduction in action that might be helpful to learn from can be seen in the Welsh experience of developing children's budgets (where children and families actively engage in prioritising which services and projects should be funded). They have developed a useful guide for planning and running workshops in this area that can be freely accessed at <https://pbnetwork.org.uk/wp-content/uploads/2015/04/Welsh-Govt-PB-toolkit.pdf> and this approach could be used for the community of families with children with disabilities (either locally or regionally). One also needs to better understand the current provision both locally and regionally in terms of strengths and areas that require development, and gaps in provision, so that any changes can be integrated in an effective and sustainable way.

It would be useful to systematically review the evidence relating to the most effective ways to reduce parenting stress in families with children with disabilities. This would highlight the most effective components to include in any wrap-around support offered (including respite care) to families in the future.

Once the local context has been examined in this way, we would suggest that any changes to services are piloted and evaluated before being scaled up regionally. Although more robust research is needed into all the types of respite care provision, we have identified two areas in which it would be beneficial to prioritise undertaking further robust evaluations:

- the evidence suggests that short breaks may be most effective if it is delivered in a way that takes account of what each family wants and needs from it, and if additional support focusing on alleviating parental stress is offered alongside (offering respite by itself may improve short-term pressure but not have longer term effects on parental wellbeing or child outcomes). Including elements of intervention alongside the respite or short breaks aimed specifically at reducing parental stress and improve parental coping may be particularly beneficial.
- providing the young person with opportunities to undertake new activities through befriending, summer schemes or youth activities positively benefits both the young person and the family. This may be particularly important in developing life skills and supporting progress towards independence.

Finally, it should be noted that this review did not include the families of children with acquired care brain injuries, palliative end-of-life care or very complex healthcare needs. Further investigation needs to be undertaken to examine what is the most effective type of support to provide to these families.

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## Main report

### What is the aim of this review?

The Health and Social Care Board on behalf of the Social Work and Social Care Research Advisory Group has identified a concern relating to the extent to which we can demonstrate if short breaks are an effective intervention in the management of crisis situations in families where there are children with disabilities. A more systematic approach to the evaluation of short breaks is required to improve how future services are delivered.

The aim of this review is to summarise the existing evidence base around the outcomes and impacts of short breaks on children with disabilities and their families.

Considerable evidence exists which describes the challenges and additional stresses which may be faced by families whose children have disabilities. Woodgate et al (2015)<sup>3</sup> highlighted that the experience of caring for a child with complex care needs is an evolving process, changing with the illness trajectory and as the child matures. They undertook ethnographic research with parents in Canada and identified the following themes around the parenting role:

- *Parenting is intense* – in addition to the day-to-day challenges all parents experience in raising children, parents of children with complex needs had additional pressure. Parenting was described as labour intensive and requiring a readiness to provide care at any time. Parents were left with minimal time to do any other activities (social life, vacation and couple time) that was not associated with caring for their child.
- *Needing to be seen as the 'good parent'* – this meant not only maintaining their child's health and safety, but also ensuring their child had a good life. This could be tricky when a child's challenging behaviour in public left parents feeling that others were judging them as not being good enough parents
- *Parents are more than a nurse* - Intense parenting involved parents taking on a variety of roles to meet the needs of their children: health care provider, case manager, student, teacher, detective, guard, and advocate.
- *There's just not enough support* - While parents acknowledged receiving a variety of services and supports, they nonetheless expressed that, for the most part, the services offered usually fell short of what was required to help them parent their child with complex care needs.
- *It takes a toll on the health of parents* - Parents experienced physical and mental health difficulties as a result of intense parenting and the multiple roles that they had to assume in meeting their child's needs. The sleepless nights and the overall lack of sleep that are often reported by parents of an infant were among the prevailing concerns and complaints for parents in this study, extending well past the infant stage for many families.

Caples & Sweeney (2010)<sup>4</sup> examined the quality of life of parents of children with an intellectual disability who were using respite care in Ireland. Several caregivers had given up their careers because of caregiving responsibilities. Health of the family was seen as the most important domain relating to quality of life. Much of the caregiving and household responsibility fell to the mother, with fathers and siblings also playing a smaller role. Many of the families reporting having little support and this impacted on overall quality of life, with many parents experiencing reduced social lives as a result of their caregiving responsibilities. With respect to leisure and recreation, many parents pursued separate forms of leisure and recreation so that one parent would be available to mind the child.

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## What is respite?

Most children with disabilities in Northern Ireland live at home and are supported by their own families. These families can experience higher levels of stress than families who are not living with the effects of disability. This is mediated by many different factors including the effect of the disability on the child's quality of life, the difference that is required to develop the family's narrative and approach around what is 'normal' for them, and each individual's own resources for parenting and coping. Their capacity to mobilise support within their family as well as access support from others is also important, and this may vary at different times.

Support is sometimes provided to carers of children with disabilities in the form of short breaks (also known as respite). There is a lack of consensus regarding how short breaks and respite should be defined and variations include:<sup>5</sup>

- the use of an organized service that is designed to provide temporary relief from the caretaking responsibilities associated with parenting a child with a developmental disability. This can also include an implicit intention to prevent institutionalization and to maintain the ability of families to provide a home for their children
- care given by paid carers when the primary carer is absent, including after-school and holiday care
- respite care can also be integrated as a component of a formal social support.

According to the Department of Health, Social Services and Public Safety (DHSSPS)<sup>6</sup>, a short break service can broadly be described as "any service which allows a disabled child to have enjoyable planned experiences away from his/her primary carers and gives carers and break from their caring responsibilities."

Models of respite and short breaks vary across four dimensions: purpose, location, provider and duration:<sup>7,8</sup>

- *Purpose*: services can be described as having a primary or secondary respite purpose. A primary service is when the specific intent is to provide the family with a break from caregiving. Secondary services include those where the purpose is to meet the needs of the individual with a disability, and respite occurs as a by-product, for example when a child attends a summer day camp programme.
- *Location*: Respite care and short breaks can be provided in various settings including in-home (the family or caregivers may remain there or not be present), or out-of-home in the community, hospital or in a residential facility.
- *Provider*: The providers of respite care can be formal, such as nurses, or informal (family or friends). Some respite providers involve paid or professional caregivers who often have special training. This model of respite can be more formally constructed and may be less flexible. Cooperative models of respite include friends, parent-cooperatives, and family-to-family support groups.
- *Duration*: Respite care can also be short-term (from a few hours to a day or two), intermittent, long-term (for a week or more), ongoing, or provided as an emergency intervention.

Black (2013)<sup>9</sup> highlighted that short break provision in Northern Ireland can be diverse and includes, for example:

- Day or overnight periods of care in the home of an approved carer
- Overnight periods of care in a residential children's home



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- Sitting and care services provided in the child's home to allow the family to do other things
  - Overnight care in the child's home (in particular for children with complex physical healthcare needs to enable parents to have a night's rest)
  - Befriending services aimed at undertaking specific activities with the child
  - Community activities, including after-school, evening and weekend group activities, day trips and holidays.

The need for respite or short breaks will vary between families and also within the same family at different times. Caring responsibilities in a family change as the child gets older, and this can be further complicated in families with children with disabilities as their needs change, not only developmentally but also as their condition varies over time.

A recurring theme from the literature on parent preferences for respite services is choice. Several qualitative studies suggest there needs to be a match between the type of respite care service and unique needs of the family.<sup>10</sup> The timing of services, as well as frequency of services influences whether parents feel that the support offered to them provides them with a 'true break.' Families often place their child's need for a positive, enriched and supportive environment ahead of their own needs for respite.<sup>11</sup>

Carers tend to prefer respite to be provided in-home as they are seen to be the least disruptive to child and family, and families are able to monitor the quality of care provided.<sup>12</sup> When this is not possible, they prefer out-of-home care to be in conditions which are as 'homely' as possible. Carers in Australia<sup>13</sup> described optimal respite for children with complex health needs to be similar to a family home with suitable facilities, equipment and activities for children. Flexible respite services and enthusiastic competent staff were considered very important by the family carers.

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### What is the gap in our knowledge?

Although children and young people with disabilities can be labelled a group, their needs, strengths and experiences are diverse, as are their family experiences.

Nef Consulting (2009)<sup>14</sup> identified that in order to be effective, short breaks and respite care should address the following needs:

- Disabled children need to get the support that is right for them, that will help them develop and that is flexible to their changing needs at different stages in their life. This involves:
- Gaining new experiences that are fun and positive
- Activities that they want to do
- Ordinary activities that mix with their peers, both able and disabled
- Activities that are locally accessible
- Reliable, stable activities that they can look forward to
- Parents need support, knowledge and information to help them cope with the pressures of caring for a disabled child. These services need to reflect the changing circumstances of the family at different stages of the child's life
- Society needs to accept that caring for a disabled child is everybody's responsibility by making mainstream services more inclusive and accessible.

They suggested that customized short breaks services should comprise elements of the following:

- Overnight breaks
- Family-based/ individual day care/ sessional provision
- Group-based services – specialist provision
- Group-based services – non-specialist provision.

They proposed that this may lead to the following initial outcomes for the young people with disabilities:

- Improved health through physical activities
- Improved well-being through social contact and by enjoying activities they have chosen to do
- Improved ability to form and maintain relationships
- Increased interaction with peers through participation in mainstream leisure activities
- Learning and developing a range of skills and abilities through a variety of activities
- Strengthened family relationships through an increased sense of well-being (from short breaks and having breaks from family)
- These initial outcomes may in turn then lead to longer-term outcomes including:"
- Leading more ordinary lives
- Journey towards independence in adulthood
- Improved emotional and physical health (health and wellbeing).

The evidence base has been growing over the last couple of decades, Robertson et al. (2011)<sup>15</sup> undertook an international literature review of the impacts of short break provision on disabled children and families and found although progress had been made since the previous systematic reviews. Important gaps remain in our understanding of what families want and need, as well as what is the most effective way to provide support to them.

The aim of the current review is to summarise what is known about providing this type of short break and respite provision effectively to young people with disabilities and their families.

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## How did we do this review?

### *Search strategy*

A search using google Advanced Scholar on 25<sup>th</sup> April 2017 with the following search terms: '(child \* or adolescent \* or teenage \*) and (respite or short break) and (disabilit \* or disabled) and (trial or evaluation or effective\*)' returned 3040 results. These were screened for relevance.

A search was done for articles citing: Robertson et al. 2011<sup>16</sup> - The impacts of short break provision on disabled children and families: an international literature review. This returned 40 articles which were screened for relevance.

The following databases were searched on 26<sup>th</sup> April 2017 using the following search terms: (child\* or adolescen\* or teen\* or young) AND (respite or 'short break') AND (Disab\*) AND (trial or evaluat\* or effective\* or experiment\* or qualitative):

- Cochrane Central Register of Controlled Trials (CENTRAL)
- MEDLINE
- EMBASE
- CINAHL
- PsycINFO
- Cochrane Database of Systematic Reviews (CDSR)
- Clinical Research Network Portfolio Database ClinicalTrials.gov
- Networked Digital Library of Theses and Dissertations

This returned 3385 results which reduced to 2750 when duplicates were removed. Screening of the titles and abstracts of these identified 367 articles as potentially relevant.

In summary, the screening of titles/ abstracts identified 475 potentially relevant articles. Full text was obtained for as many of these as possible in the time available and further checking was undertaken to see if they matched the eligibility requirements. Data was extracted from eligible studies. A sample data extraction form is shown in Appendix 1.

### *Selection of studies*

Articles were assessed as relevant if they contained direct reference to respite or short breaks and children with disabilities and some data on effectiveness.

### **Criteria for inclusion:**

#### *Types of studies:*

All relevant evaluations will be sub-categorised by:

- randomised controlled trials with or without blinding
- quasi-experimental trials
- one group longitudinal (pre-post measures)
- qualitative information

#### *Types of participants*

Young people aged up to 21 years with disabilities (either physical or severe emotional/ behavioural problems) who have participated in short breaks/ respite. Studies were excluded if the focus was on children with life-limiting conditions or palliative care.

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Inclusion criteria relating to methodological quality were that details had to be provided on characteristics of sample, how data was collected and analysed, and the impact on at least one parental or child outcome had to be described. Both qualitative and quantitative studies were included. Reference lists and citations were hand-searched for other relevant papers. The information presented in patient guidebooks and handbooks was not included unless primary data was presented with methodological information or the source of the primary data was referenced. There was no exclusion by language and if non-English abstracts were returned, these were translated using Google Translate.

The author reviewed the titles and abstracts of references retrieved from the searches and selected all potentially relevant studies. Copies of these articles were obtained. The author was not blinded to the names of the trial authors, institutions or journal of publication. The author then extracted data from included trials and assessed trial quality.

#### *Data extraction and management*

For each included study, the review author extracted and recorded the following data using a data collection form:

- study design and methods
- sample characteristics
- intervention characteristics (including theoretical underpinning of services, delivery, duration, outcomes and within-intervention variability)
- outcomes
- time points
- outcome measures.

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### What did we learn from this review?

Studies have been summarised according to their primary function and mode of delivery. Within each section, studies are further organised by methodological quality (randomised control trial, quasi-experimental studies, single group studies).

The strongest evidence comes from randomised control trials. Due to the use of randomisation in these studies, we can be more confident that it was the use of absence of respite which explains the improvements shown by participants.

The next level of evidence comes from the quasi-experimental studies. The use of a control group in these studies provides useful insights about the added value of the respite support, but here may be important pre-existing variations between the two groups which may underlie the changes as well as the use of respite, so more caution needs to be used with interpreting findings.

Single group studies provide the weakest level of evidence and caution should be used with these studies in terms of assuming any changes observed are due to the use of respite or short breaks, and not to any other underlying or associated factors. Many of these studies used qualitative approaches and self-report, and had small samples (usually fewer than 10 families). The aim of qualitative research is to provide rich insight into the lived experience of a group of individuals, and not to generalise the learning from those experiences to others.

Full data extraction tables are provided in Appendix 2, and key findings for each type of respite are synthesised below.

Methodological quality varied widely with very few randomised control trials or use of comparison groups when assessing effectiveness. Many studies relied on qualitative techniques to explore the lived experience of the families. Around a third of the studies were undertaken in the UK. Care should be taken when trying to generalise the learning from other countries to the local situation here as the context may vary in important ways which will influence the effectiveness of the approach being used. These may include different cultural factors, as well as variances in professional competencies and approaches, service settings and infrastructural support.

#### *Primary respite (where main focus is to provide parents with a break from caring)*

#### **National/ Community/ Cohort Surveys showing associations of factors with respite use (the direction of the associations or other influencing factors cannot be inferred from these results)**

A total of six studies were identified for inclusion in this section (described in more detail in Appendix 2, Table 2.1, page 26). These studies undertook surveys of groups of children and used statistical modelling to examine the associations between different variables. These studies found associations between respite use and higher levels of stress, although the effect on specific factors varied by type of disability. Four studies were undertaken in America and two in the UK. The main findings from these studies included:

- a positive association between receiving respite care services and academic achievement across time for children with disabilities
- the amount of respite care received by families with Autistic Spectrum Disorder (ASD) influenced the rate of improvement. More respite care was associated with improved marital quality, increased uplifts and reduced stress

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- families with children with Down syndrome showed no association between respite care for either wives or husbands. However, respite care was associated with stress which indirectly influenced marital quality
  - families with children with autistic spectrum disorder (ASD) showed high levels of stress and low levels of informal support. Families were most likely to feel they needed respite if they had a social worker, if their child was in a special educational setting, over 11 years of age and had a diagnosis of ASD (possibly with severe learning disabilities). Families of children with severe disability who were under significant amount of distress and parental stress were more likely to need to use respite care. Exhaustion was the most common reason stated by carers for using respite
  - single mothers of children with ASD showed no relationship between the amount of respite care and depression or stress. A relationship was found between the amount of respite care and daily uplifts – as respite care increased, daily uplifts increase. These daily uplifts may mediate the effect between respite care and depression.

Summary: Although most of these studies used reasonably large samples which were representative of the group of children as a whole (e.g. children with special needs or diagnosed with specific conditions such as ASD), the direction of the associations or the presence of other influencing factors cannot be inferred from these results.

### Out of home respite care

A total of 13 studies were identified for inclusion in this section (described in more detail in Appendix 2, Table 2.2, page 29). Of these one was a randomised control trials (RCT), 5 were quasi-experimental and 7 were single group studies. Six studies were from the UK, three from America, and a study from each of the following countries – Canada, France and Republic of Ireland. A final study does not note the country in which data was collected, but the authors were located in Israel and America.

The strongest evidence comes from the RCT which shows that families with children with developmental disabilities who received 3 months of out-of-home respite showed significant reductions in stress from pre- to post-test, whereas parents receiving no respite showed no such change. The use of randomisation in this study, allows us to be more confident that it was the use or absence of respite which explains the improvements shown by the mothers and fathers.

The next level of evidence comes from the quasi-experimental studies. The use of a control group in these studies provides useful insights about the added value of the respite support, but there may be important pre-existing variations between the two groups which may underlie the changes as well as the use of respite. Most of these studies used longitudinal approaches.

Key findings from these studies include:

- receiving 10 months of intensive respite in a centre based unit that included social and play activities for the children aged 3 to 8 had no effect on the child's mental health status. Specific evidence-based child mental health interventions may need to be paired with respite care to improve child mental health outcomes.
- neither respite care in a centre for developmental disability (4 to 11 days inpatient admission)

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nor short term hospitalisation (30 to 90 days) resulted in significant effects on child abuse potential or family relations, although trends were found in the expected direction. Respite care by itself may be insufficient to directly target child abuse potential and additional interventions targeting variables related to abuse (such as quality of family relations and parenting stress) may be required

- brief 3-7 day respite care admission in a centre for developmental disabilities was as effective at reducing parenting stress at time of discharge as a longer 30 day inpatient treatment. Six months later parenting stress had returned to admission levels for both groups.
- families of young people with a learning disability taking part in a project using person-centred planning showed significantly higher measures of family functioning and greater levels of self-rated support compared to families receiving usual support. There were no significant effects on parental health or stress
- maternal self-esteem, family cohesion and adaptation mediate the reduced stress and improved coping associated with the use of respite care. Respite care was of most benefit to mothers with high self-esteem who had younger and more severely disabled children. Families with younger children preferred home-based respite care.

Single group studies provide the weakest level of evidence and caution should be used with these studies in terms of assuming any changes observed are due to the use of respite or short breaks, and not to any other underlying or associated factors. Many of these studies used qualitative approaches and self-report, and had small samples (usually fewer than 10 families). The aim of qualitative research is to provide rich insight into the lived experience of a group of individuals, and not to generalize the learning from those experiences to others. Key findings from these studies included:

- parents describe respite as an essential service
- parents tended to feel stronger following respite and more confident about caring for their child
- parents saw the benefits as including changes of medication or equipment, accessing expert advice, reassessment of the clinical condition
- when the children with disabilities were away from home, it gave the family opportunities to involve siblings in normal community life and for parents to catch up on tasks not related to the care of the child with disabilities and do other things
- improvements were seen in the disabled child's behaviour and happiness
- parents reported improvements in relationships and family functioning following respite
- studies did not tend to follow-up the duration of the perceived benefits, so it is not clear how long these persisted for
- although most studies showed perceived improvements in the child's wellbeing following respite, one study found that more than half of the 35 highly dependent children showed medium or strong negative reactions following respite.

Summary: Using out of home respite care was seen as a valuable resource by parents of children with disabilities. When more robust studies are undertaken which use more objective measures of changes in parental stress and family functioning, these present a more mixed picture of the impact on families. The findings suggest that respite in an out-of-home setting for a short period of time may reduce immediate levels of parenting stress, but for more long-term effects on family

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functioning and improvements in child outcomes, other elements of effective interventions specifically targeting these outcomes may also need to be included. Some interventions like this are described later in the report (p.17) in the section describing Wrap-around respite or short breaks including more than one component.

### In-home respite care

A total of 9 studies were identified for inclusion in this section (described in more detail in Appendix 2, Table 2.3, page 39). Of these, none were randomised control trials, 7 were quasi-experimental and 2 were single group studies. Four of these were from the UK, one from America and the country of the remaining four is not known.

Key findings from the quasi-experimental studies included:

- Families with emotional and behavioural disturbances showed significantly better outcomes than those in the waiting list control group including reduced parental stress, increased optimism and reduced need for residential placements
- Although useful, respite plus other individualised services and supports would be more beneficial to meet the substantial caregiving challenges faced by families with children with emotional and behavioural difficulties (EBD)
- Positive outcomes tend to relate to the amount of respite services received – the more time families used respite care, the lower their scores on measures of perceived family conflict, and the more time they spent on recreation/ leisure activities
- Improvements following in-home respite care change over time – they tend to be most apparent in the first 6 to 12 months and then decline from 12 to 18 months
- Providing in-home support reduces levels of parenting stress which is an important mediator of other outcomes.

Single group studies tended to use small samples (fewer than 10 families) and qualitative methods.

They found:

- Parents valued being involved in influencing the type of support provided to their children, for example helping to train the carer so they interacted with the child in the same way as the parent
- Parents valued having access to well-trained staff who understood the challenges associated with caring for the child and who could be flexible in how they provided support to the family.

Summary: There is not currently sufficient robust evidence to fully assess the effectiveness of in-home respite provision. Respite in the home setting appears to be preferred by carers of younger children and it may reduce immediate levels of parenting stress, but for more long-term effects on family functioning and improvements in child outcomes, other elements of effective interventions specifically targeting these outcomes may also need to be included.



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### Wrap-around respite or short breaks which included multiple components

A total of 15 studies were identified for inclusion in this section (described in more detail in Appendix 2, Table 2.4, page 44). Of these one was a randomised control trial, one was quasi-experimental and 13 were single group studies. Seven studies were undertaken in the UK, five in America and one in each of the following countries – Canada, Korea and the Republic of Ireland.

The randomised control trial assessed the effectiveness of providing different levels of respite support. Parents (both mothers and fathers) in both groups showed significant improvements in depression and anxiety levels. The more intensive support groups showed additional benefits from also providing parent skills training and parent support groups. The parents in these groups showed greater improvements, particularly in terms of reduced distress. Treatment gains for mothers were maintained for over a year following respite.

The quasi-experimental study had a small sample (seven in each of three intervention groups) and showed the following key findings:

- providing respite care had positive effects on family quality of life compared to not receiving respite
- combining respite care with other forms of family support led to greater improvements
- surprisingly the family support programme did not improve levels of parenting stress.

The 13 single group studies evaluated a variety of approaches including specially trained carers for children with specific diagnoses, specialized residential short breaks, Direct payments, clubs and recreational activities, activity holidays, multiagency teams, and intensive family support. There was also a wide variety of disabilities: some studies focused only on children with only one disability such as ASD, whereas others included a wide variety of physical and learning disabilities. Key findings included:

- factors identified as important in helping make short breaks effective for children with ASD included the physical environment, consistency across environments, use of ASD appropriate approaches, staff attributes (including their understanding of ASD), individualisation, successfully accessing the community and grouping of children
- beneficial outcomes can be identified for the child, parent and other family members
- service providers need to explore with parents what kind of break they feel would be most beneficial to meet the needs of their child and family
- families use short breaks for different reasons and to get different benefits. These can include getting a break from caring so they can continue to cope; get a chance to catch up on everyday activities such as sleeping, cleaning and running errands; allow them to undertake other caring duties such as meeting the needs of their other children; reducing social isolation when they were able to do things with their child and other similar families; helping parents think about not being able to provide care; and helping them to get normality back into their lives
- children show benefits from getting to experience activities and situations they would not normally. These can include increases in self-confidence, acquiring new skills, and improved behaviour as well as social, physical and emotional wellbeing
- children tended to value the immediate outcomes such as enjoying activities and participation, whereas parents tended to acknowledge these but focus more on the longer- term developmental outcomes for children

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- quality respite care may reduce the need for out-of-home placements or foster placements
  - siblings can benefit from the short breaks by having opportunities to do things they cannot usually do with their families and to receive more of the parents' attention. Sometimes the siblings may have negative feelings about the short breaks such as worry, guilt or jealousy
  - being excluded from short breaks, for example, if a child's behaviour was too challenging can have a negative impact on families
  - families benefit from coordinated and effective packages of support – specialist services should not be stand-alone and strong partnership are required
  - merely providing a break is insufficient to help reduce the stresses that families experience
  - Parents benefit most when their support needs are identified and trusted relationships forged.

Summary: One randomised control trial shows the additional benefit of including more components of family support alongside respite and short breaks provision and this results in the longest effect on parental outcomes assessed in any of the studies. Many of the studies which did not include parental support recommend that this would be beneficial and more robust evaluations are needed to examine whether this is the case. Currently there is not currently sufficient robust evidence to fully assess the effectiveness of this type of multi-component support to families with different needs.

### *Secondary respite care*

In these studies, the main focus is to provide the young person with activities or experiences, and respite for the carer is a by-product. A total of 27 studies were identified for inclusion in this section (described in more detail in Appendix 2, Table 2.5, page 66). Of these, one was a randomised control trial, 4 were quasi-experimental and 22 were single group studies. Eleven of these studies were undertaken in America, five in the UK, three in the Republic of Ireland, two in Belgium, two in Canada, two in Hungary and one in Thailand. The country of the remaining study was not specified.

Many of these studies relate to the use of summer camps in America for specific disabilities where the scheme involves some psychoeducational elements relating to the care of their specific condition (e.g. asthma or diabetes) and also opportunities to undertake physical activities and interact socially with their peers. Physical activities were often outdoors and included canoeing, horse-riding. Schemes also included unstructured activities such as pool tables, games consoles and outside play, along with staff-led session aimed at developing social and life skills. Other include summer schemes and supported participation in ongoing youth schemes such as the Duke of Edinburgh and befriending schemes.

The Randomised control trial showed an increase in asthma knowledge and problem-solving abilities 3 months post-camp, but could not identify benefits of the problem-solving intervention offered as part of the camp experience. They suggested that interventions may be more effective if targeted to patients with identified problems with disease management.

The quasi-experimental studies showed the following key findings:

- young people attending camp showed improvements in health-related quality of life and coping skills

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- improvements in self-confidence varied across studies. Some showed significant improvements whereas others did not.

Single group studies usually had smaller samples (less than 10 participants) and rely on qualitative techniques. Key findings include:

- children and young people enjoyed the experiences and particularly valued the social interaction and opportunity to try new activities
- changes in disease specific knowledge persisted after the end of camp
- benefits were observed in young people's well-being, social interaction and self- management and progress towards independence. These benefits often persisted following the end of the intervention
- parents reported learning 'how to let go' and supporting their young person to try to the activities which sometimes took them out of their comfort zones
- benefits could also be felt in the family in terms of providing carers with a break, improved family time and better family relationships
- involving families and young people in deciding what activities to do and giving parents feedback on how well their young people are doing is beneficial.

Summary: Based on the available evidence, it is premature to make robust claims regarding the psychosocial impact of camp as a therapeutic intervention. Theoretically informed camp programs, long-term follow-up, and incorporating camp-based messaging into routine hospital care, may enhance the utility of camp as a potential psychosocial intervention in paediatrics. There is some evidence that regularly planned overnight clubs, participation in schemes such as the Duke of Edinburgh and befriending schemes may be useful in terms of improving outcomes for young people, but the available evidence is methodologically weak.

### *Cost studies*

A total of 14 studies were identified for inclusion in this section (described in more detail in Appendix 2, Table 2.6, page 81). These were identified from the search and from extracting information from reviews if specific costing information was presented. Several studies on the cost-effectiveness and cost-benefits of short breaks provision have been undertaken but many of these are now 7 or 8 years old. In 2009, Nef Consulting (2009)<sup>17</sup> concluded that the State could make an estimated saving of £174 million if short breaks were effectively delivered to all those eligible to receive them.

### *Systematic reviews*

Five systematic reviews were identified as relevant (described in more detail in Appendix 2, Table 2.7, page 93). Robertson et al. (2011)<sup>18</sup> reviewed 60 evaluation articles and reports. They concluded that short respite breaks positively impact on the wellbeing of carers (although these effects did not tend to be maintained over time) but also benefitted the children receiving the breaks as well as the family as a whole. Family relationships and stress levels improve. In the child, increased independence, social skills, social awareness, interests and confidence were noted in some studies. A smaller number of studies (albeit more methodologically rigorous) that attempted to objectively measure change identified no significant differences in social outings, friends, or child behaviour problems. They identified key gaps in the literature, namely little is known about the effects of

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respite care on fathers, siblings, the synergistic effect of other interventions, and long-term effects.

Whitmore (2016)<sup>12</sup> undertook an integrative review of respite care and stress. They identified a final sample of 11 primary research reports. While most studies found that respite care was associated with lower stress, several found that respite care was associated with higher stress. One study found no association. Overall, the results of this integrative review provide some evidence that respite care use may be associated with a decrease in stress among caregivers of children with ASD. However, due to the lack of consistency and quality across the studies, these findings must be interpreted with caution.

Strunk et al. (2010)<sup>13</sup> undertook a systematic review aimed at integrating the findings from reports of both quantitative and qualitative studies of families, with children suffering from disabilities, receiving respite services. Fifteen relevant research reports were retrieved during the search period. All 15 reports were published in journals and appeared between 1995 and 2006. A synthesis of findings from the research indicate that respite care can be an appropriate and effective intervention to decrease stress and should be used as an appropriate coping strategy for parents of children with disabilities. Studies also indicate that despite the severity of the disability, parental income level, or demographic location, respite is a needed support service for families of children with special needs. The use of respite increased parent/child relationships and decreased the risk of child abuse. Studies report that there is definitely a need for respite services among families of children with a disability.

Further research is needed concerning implied outcomes and cost of supplying respite care to those families in need. There is virtually no information available to date as to influence of respite care upon the families of disabled children and abuse potential and little information exists on the interrelationships between respite care, child abuse potential, family relations, and parenting stress over time; therefore, future research would do well to assess multiple types of abuse using multiple informant sources as a means of demonstrating the possible impact of respite services.

There is little research on effective models of respite care for individuals with developmental disability and severe behaviour problems. Another area that needs to be more fully explored is the benefit of respite care on outcomes for individuals with a developmental disability and their families. Little is known about the planned versus the emergency use of respite care; therefore, further research exploring the availability, use, and benefits of respite care is needed so that service providers and funding agencies will be in a better position to plan and manage this vital service. More research that includes fathers and other members of the family in addition to mothers is clearly warranted. There has also been limited follow-up on the longer-term benefits of respite care on measures such as stress; therefore, more studies of long-term outcomes are needed.

Moola et al. (2014)<sup>14</sup> undertook a Systematic review to assess the psychosocial impact of camp for children with chronic illnesses. 21 studies were included in the review. Although overall methodological quality was weak, camp participation appeared to offer short-term psychosocial benefits on some parameters in children with a variety of chronic illnesses. There was some consistency in improved social outcomes, such as social interaction and acceptance. Based on the available evidence, they concluded it is premature to make robust claims regarding the psychosocial impact of camp as a therapeutic intervention. Theoretically informed camp programs, long-term

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follow-up, and incorporating camp-based messaging into routine hospital care, may enhance the utility of camp as a potential psychosocial intervention in paediatrics.

Novak et al. (2013)<sup>19</sup> undertook a Systematic review of interventions for children with cerebral palsy which includes references to effectiveness of respite as an intervention with this client group. The review concludes respite is a yellow intervention which means the evidence supporting its use was either lower-level or inconclusive. There was not robust evidence of effectiveness when strict systematic review criteria about design quality, adequate sample size and independent replication were used to judge the evidence.

### Summary

There have been very few robust evaluations undertaken of respite and short breaks provision where the impact is compared to families who have not received the same support. More than half of the studies eligible for inclusion in this review used qualitative techniques. Although they provide useful insights into the lived experiences of families caring for children with disabilities, their findings cannot be easily generalised to relate to other families.

There is some promising evidence of the effectiveness of short breaks and respite provision for families with children with disabilities. It is certainly very highly valued by families as a useful support in helping them cope. Families using respite tend to be those who are experiencing the highest levels of parenting stress and distress. Overall one may conclude that short respite breaks positively impact on the wellbeing of carers (although these effects do not tend to be maintained over time). There is some evidence that family relationships and stress levels improve. In the child, increased independence, social skills, social awareness, interests and confidence are noted in some studies. A smaller number of studies (albeit more methodologically rigorous) that attempted to objectively measure change identified no significant differences in social outings, friends, or child behaviour problems. Although some studies explore the views of both parents, less is known about the effects of respite care on fathers, siblings, the synergistic effect of other interventions, and long-term effects.

Respite in an out-of-home setting for a short period of time may reduce immediate levels of parenting stress, but for more long-term effects on family functioning and improvements in child outcomes, other elements of effective interventions specifically targeting these outcomes may also need to be included.

There is not currently sufficient robust evidence to fully assess the effectiveness of in-home respite provision, although there is some promising evidence. Respite in the home setting appears to be preferred by carers of younger children and it may reduce immediate levels of parenting stress, but more robust evidence is required.

One randomised control trial shows the additional benefit of including more components of family support alongside respite and short breaks provision and this results in the longest effect on parental outcomes assessed in any of the studies. There are several multicomponent initiatives which offer flexibility to parents and families in order to better meet individual needs. These tend to be evaluated as single group studies which provides useful insight into changes over time, but more robust evaluations including the use of comparison groups are required to examine whether the

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added value of providing support in this way. Currently there is not currently sufficient robust evidence to fully assess the effectiveness of this type of multi-component support to families with different needs.

Based on the available evidence, it is premature to make robust claims regarding the psychosocial impact of camp as a therapeutic intervention. Theoretically informed camp programs, long-term follow-up, and incorporating camp-based messaging into routine hospital care, may enhance the utility of camp as a potential psychosocial intervention in paediatrics. There is some evidence that regularly planned overnight clubs, participation in schemes such as the Duke of Edinburgh and befriending schemes may be useful in terms of improving outcomes for young people, but the available evidence is methodologically weak.

Several studies on the cost-effectiveness and cost-benefits of short breaks provision have been undertaken but many of these are now 7 or 8 years old. In 2009, it was estimated that the UK State could make an estimated saving of £174 million if short breaks were effectively delivered to all those eligible to receive them.

#### **What are the recommendations for support in N. Ireland?**

In terms of using this evidence review to inform practice in N. Ireland, an important next step is to understand what the local needs are of families here. This will involve listening to families (parents and other carers, young people and other family members such as siblings) about what they want and need, as well as understanding their strengths and assets. Staff working in services and professionals providing support to families will also yield important insights. Co-production that is sensitively and meaningfully undertaken will be helpful: the evidence highlights the importance of parental choice and flexibility, as well as active involvement of the young person and their carer in planning services. This needs to go beyond consultation and examples of good practice in this regard can be found both locally as well as elsewhere in the UK. A specific example of coproduction in action that might be helpful to learn from can be seen in the Welsh experience of developing children's budgets (where children and families actively engage in prioritising which services and projects should be funded). They have developed a useful guide for planning and running workshops in this area that can be freely accessed at <https://pbnetwork.org.uk/wp-content/uploads/2015/04/Welsh-Govt-PB-toolkit.pdf> and this approach could be used for the community of families with children with disabilities (either locally or regionally). One also needs to better understand the current provision both locally and regionally in terms of strengths and areas that require development, and gaps in provision, so that any changes can be integrated in an effective and sustainable way.

It would be useful to systematically review the evidence relating to the most effective ways to reduce parenting stress in families with children with disabilities. This would highlight the most effective components to include in any wrap-around support offered (including respite care) to families in the future.

Once the local context has been examined in this way, we would suggest that any changes to services are piloted and evaluated before being scaled up regionally. Although more robust research is needed into all the types of respite care provision, we have identified two areas in which it would be beneficial to prioritise undertaking further robust evaluations:

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- the evidence suggests that short breaks may be most effective if it is delivered in a way that takes account of what each family wants and needs from it, and if additional support focusing on alleviating parental stress is offered alongside (offering respite by itself may improve short-term pressure but not have longer term effects on parental wellbeing or child outcomes). Including elements of intervention alongside the respite or short breaks aimed specifically at reducing parental stress and improve parental coping may be particularly beneficial.
  - providing the young person with opportunities to undertake new activities through befriending, summer schemes or youth activities positively benefits both the young person and the family. This may be particularly important in developing life skills and supporting progress towards independence.

Finally, it should be noted that this review did not include the families of children with acquired care brain injuries, palliative end-of-life care or very complex healthcare needs. Further investigation needs to be undertaken to examine what is the most effective type of support to provide to these families.

## Appendices

### Appendix 1: Sample Data Extraction form

<b>Source 1.</b>	
Authors of article	
Title	
Citation and contact details	
<b>Eligibility</b>	
Confirm eligibility for review	
Reason for exclusion	
<b>Methods</b>	
Study design	
Total study duration	
If RCT: Sequence generation*	
Allocation sequence concealment*	
Blinding*	
Other concerns about bias*	
<b>Participants</b>	
Total number	
Diagnostic criteria	
Age at time of intervention	
Sex	
<b>Type of support/ intervention</b>	
Type of support	
Professional/ staff characteristics	
Delivery timing/ frequency	
Location of treatment (institutional, community, etc).	
Modality of treatment (individual versus group, or combination).	
<b>Main effects</b>	
<u>1. Parental outcomes:</u> 1.1 Parental coping 1.2 Parental stress 1.3 Parental self-efficacy 1.4 Psychological well-being	
<u>2. Child outcomes:</u> 2.1 health 2.2 psychological wellbeing 2.3 coping 2.4 Self-esteem 2.5 Social functioning 2.6 Problematic behaviour 2.7 Inclusion	



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<u>3. Programme/ service engagement:</u> 3.1 Completion of treatment programme 3.2 Drop-outs 3.3 Treatment refusers	
<u>4 Economic outcomes:</u> 4.1 Direct costs 4.2 Indirect costs	
<u>5 Broader effects on siblings/ other family members:</u> 5.1 Coping 5.2 Stress 5.3 Psychological wellbeing	
<b><i>Identification of key components for effectiveness</i></b>	
<b><i>Conclusions or observations of authors</i></b>	
<b><i>Other info</i></b>	
Country	
[Co-morbidity].	
[Socio-demographics].	
[Ethnicity]	
[Date of study]	

## Appendix 2: Further details on included studies

<i>Primary respite (where main focus is to provide parents with a break from caring)</i>				
<i>Table 2.1: National/ Community/ Cohort Surveys showing associations of factors with respite use (the direction of the associations or other influencing factors cannot be inferred from these results)</i>				
<b>Author</b>	<b>Characteristics of participants</b>	<b>Support evaluated</b>	<b>Methodology</b>	<b>Main findings</b>
Barnard-Brak & Thomson (2009) <sup>20</sup>	Nationally representative sample of children aged 6-12 years in America	Respite care	Structural equation modelling used to examine the association of receiving respite care with academic achievement for children with disabilities across time	Positive association between receiving respite care services and academic achievement across time for children with disabilities.
Harper et al. (2013) <sup>21</sup>	Families with children aged 1-33 years with ASD in America	Respite care	Survey data regarding respite care, marital quality, and daily hassles and uplifts were obtained from 101 mother-father dyads who were together raising at least one child with ASD (total n of children = 118). Both parents completed the questionnaire. The study included 118 children (42 females, 76 males) from 101 families. Parents who reported receiving respite care were compared to those who did not receive respite care.	Number of hours of respite care was positively related to improved marital quality for both husbands and wives. A one-hour increase in weekly respite care was associated with a one-half standard deviation increase in marital quality. More respite care was associated with increased uplifts and reduced stress; increased uplifts were associated with improved marital quality; and more stress was associated with reduced marital quality. The number of children in the family was associated with greater stress, and reduced relational quality and daily uplifts.
Hoare et al. (1998) <sup>22</sup>	Children with severe disability in Lothian	Respite use divided into current vs historical use, and also by type of respite	Cross-sectional study using an epidemiologically derived register of children with special needs. It used psychometric measures of psychosocial adjustment of children with severe disability and association with respite care. 143 children and their families identified from a regional case register for children with special needs. Study of the psychological and social characteristics of 143 children with severe disability. Compared distress among carers that use and do not use respite care.	Irrespective of the way in which respite was defined, the respite users' mental GHQ scores were significantly greater than no-respite users on several scales suggesting higher levels of distress and parental stress. Carers using respite care had significantly greater 'total' distress (p<0.001). The greater the amounts of respite usage the more distress among carers. Distress among carers consistently associated with increased disability in the child. Exhaustion was commonest reason stated by carers for the user of respite. Non-users more optimistic about their coping ability. Authors concluded even though respite care in a valuable resource for many carers, its use is indicative of underlying distress in the carer.
Preece &	Children with an	Compared	Postal survey of 256 families with a child with ASD in UK:	Results confirmed high degrees of stress and low levels of

Jordan 2006	autistic spectrum disorder (ASD) in UK	amount of respite use and informal support	155 families replied and the sample was identified as generally representative.	informal support for all families, but no significant difference in the informal support available to non-users as compared to users of short-break services. Both groups received little informal support, rarely extending beyond the immediate family. There was a significant difference in dependence and more difficult behaviours between children of respite users and non-users. Many non-users had children with high dependence. Parents who felt they needed short breaks were more likely to receive this support if they had a social worker, if their child was in a special educational setting, over 11 years of age and had a diagnosis of ASD (possibly with SLD).
Norton (2015) <sup>23</sup>	Parents of children with Down syndrome in America	Respite care defined as planned care for the child with Down syndrome to provide relief to the permanent caregiver.	Cohort study examining association between reported marital quality and respite care received. 112 married couples using psychometric tests including the Revised Dyadic Adjustment Scale, Experience in Close Relationships Questionnaire, Daily Hassles and Uplifts Scale, and a respite questionnaire. Fifty-seven percent of families reported receiving respite care (on average 5-6 hours a week). Amongst those receiving respite care, 68.3% (n = 43) of the care was provided by grandparents, 34.9% (n = 22) reported care provided by a babysitter, 22.2% (n = 14) reported care provided by extended family, 14.3% (n = 9) reported care provided by some other resource such as siblings or tutors, and 12.7% (n = 8) reported care provided by an agency. Twenty-two percent (n = 14) reported receiving respite care from multiple providers.	Results were mixed. Respite care did not predict marital quality for either wives or husbands. However, respite hours were related to wife stress, which was in turn related to wife marital quality. Respite hours was also related to husband stress, which was related to husband marital quality. In addition, wife uplifts were directly related to wife marital quality and to husband marital quality. Husband uplifts were related to husband marital quality. While not directly predicting marital quality, respite care was indirectly related to increases in marital quality through stress.
Dyches et al. 2016 <sup>24</sup>	122 Single mothers of children with ASD in America	Respite included care provided by a combination of providers, grandparents, community agencies, extended family,	Cross-sectional questionnaire examining associations between factors including respite care, daily/ hassles/ uplifts, depression and caregiver burden. Respondents who had used respite were compared to those who had not used respite.	There was no relationship between the amount of respite care and depression or stress. The amount of respite care was associated with daily uplifts and as respite care increase, daily uplifts increase. Stress did not mediate the relationship between respite care and depression, whereas daily uplifts were found to play a role. Authors concluded that the amount of respite care was related to daily uplifts and uplifts is a mediating variable between respite care and depression. Because it is a cross-sectional study rather than a longitudinal study, it is not possible to make conclusions about the

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		babysitters and unspecified others		directions of effects. They could not conclude whether uplifts affect depressive symptoms or depressive symptoms affect uplifts.
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Primary respite (where main focus is to provide parents with a break from caring)				
Table 2.2: Respite care facility				
Author	Characteristics of participants	Support evaluated	Methodology	Main findings
<i>Randomised Control Trials (RCTs)</i>				
Doto (2001) <sup>25</sup>	Children with developmental disabilities in America	3 months out of home respite compared to no respite	Randomised control trial - 2 group comparison of carers of children with developmental disabilities. Participants were 74 parents (n=53 mothers and 21 fathers) of children with Developmental disabilities, including 50 parents who were provided with three months of out-of-home respite, and 24 controls who did not have access to respite. The impact of out-of-home respite, parental coping styles, and child adaptive functioning, on parental stress and psychological symptomatology, was investigated.	Participants receiving respite showed significant overall reductions in stress from pre- to post-test while controls showed no such decrease. Participants receiving flexible respite did not demonstrate more positive outcomes than parents who scheduled their respite in advance. As hypothesized, emotion-oriented coping was positively related to parental stress and symptomatology. Task-oriented coping was significantly negatively related to one parenting stress measure in controls only. Social diversion coping was negatively related to this parenting stress measure at post-test, while distraction was found to be unrelated to the dependent measures as expected. Parents of children with lower adaptive functioning showed higher levels of overall parenting stress, parent and family problems and parental pessimism, but lower anxiety; while parents of children with more maladaptive behaviours showed higher overall scores on a measure of parenting stress. As predicted, placement likelihood was negatively associated with child adaptive functioning, and positively associated with parent and child age, maladaptive behaviour, and parental stress. Finally, among respite users, parents who were farther along the continuum toward placing their child prior to using respite, showed a greater decrease in overall parenting distress and severity of psychological symptomatology, than individuals low in placement tendency.

*Quasi-experimental studies (control group which has not been randomized)*

<p>Hutcheon et al. (2011)<sup>26</sup></p>	<p>Children 3 to 8 years of age with special needs in Canada</p>	<p>The intervention consisted of a centre-based respite program. Children attended for 6 hours per week for ten months. Children in the program were designated to a regular small group with a child to staff ratio of 3:1. Semi-structured social and play activities were provided for the children. The program social worker and respite staff were available to meet with caregivers, though caregivers were not required to attend and transportation</p>	<p>Mixed method quasi-experimental study of new centre-based respite in Canada compared to respite as usual over 10 months. Psychometric measures such as the SDQ were completed at baseline, mid-point and endpoint by the primary caregiver and respite staff. 31 families provided full data at baseline and end-point.</p> <p>Families with children with similar characteristics who were seeking urgent respite services through a different local respite provider were invited to participate in the study as a comparison group. The respite care provided in the latter case was short term and not pre-scheduled. Eleven families with 11 children in the comparison group had complete information at baseline and follow-up, again using the one child per family restriction. The follow-up point for the comparison group, approximately four months post baseline, corresponds to the midpoint for the intervention group.</p>	<p>Children’s primary caregivers perceived high levels of mental health difficulties in their children at baseline; significantly more than respite providers. No significant changes were found between SDQ baseline and endpoint values for either primary caregivers or respite workers. The amount of change between baseline and midpoint was no different for the intervention and comparison group. Although the respite service under investigation in this study had a number of the components Preece (2002) described as being important for improving child outcomes (i.e., consistency in respite providers’ approach to care, staff-to-child ratios, training, and skill), no evidence of improvement was detected in child mental health status by the end of the intervention by either the primary caregiver or respite staff. This occurred despite the relatively intensive service as reflected in the frequency and duration of the program. No evidence of a positive impact on child mental health status by the new respite program as measured by the SDQ was detected. Authors suggest that specific evidence-based child mental health interventions may need to be paired with respite care to improve child mental health outcomes.</p>
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		was available to ensure the caregiver had a break during the respite period.		
Aniol et al, 2004 <sup>27</sup>	Children with developmental disabilities, average age 13 years for respite compared to 9 years for short-term hospitalisation) in America	Respite care in a centre for developmental disability compared to short-term hospitalization. Respite care services consisted of a 4 to 11 day inpatient admission to the centre. During that time, children were provided 24-hr nursing care and supervision by recreational therapy staff.. Children who were admitted for the short-term inpatient treatment typically stayed for a 30- to 90-day time period	Longitudinal quasi-experimental examination of the impact of respite care services on child abuse potential and family relations in parents of children with a developmental disability. Parents (N = 14) whose children were admitted for respite care to a center for developmental disability. A sample of parents (N = 18) whose children were admitted for short-term hospitalization (STH) was used as a contrast group. Parents completed measures of child abuse potential, family relations, and parenting stress at time of admission, discharge, and at a 2-month follow-up.	Neither respite care nor STH resulted in significant effects on child abuse potential or family relations, although trends were found in the expected direction. Strong inter- relationships were found between child abuse potential, family relations, and parenting stress at each of the 3 time points. These preliminary results suggest that respite care may be insufficient to directly impact child abuse potential; however, interventions that target variables related to abuse (e.g., quality of family relations, parenting stress) might be beneficial.

		and received comprehensive evaluation and treatment (e.g., medical evaluations, physical therapy, occupational therapy).		
<i>Truesdale-Kennedy et al (2006)</i> <sup>28</sup>	<i>Young people with a learning disability</i>	<i>Families project in Northern Ireland</i>	An evaluation of a newly developed Families Project in one Health and Social Service Trust area in Northern Ireland aimed to identify the impact on parents and ways in which it could become more effective. The use of person-centred planning tools by the project was of particular interest. A mix of qualitative and quantitative approaches was used. Families participating in the project (n = 19) were contrasted with two other groups of parents recruited from the same Health and Social Services Trust (n = 25) and from an area served by a different Health and Social Services Trust (n = 25). Parents were interviewed at home on two occasions, 12 months apart.	Participating parents spoke highly of the project and reported benefits to their child, to themselves and to the other children in the family. In comparison with the other two parent groups, they had significantly higher scores on a measure of family functioning and reported greater levels of support. However, there were no improvements on measures of parental health and stress. The use of volunteer helpers allied with accessing community resources had opened up new forms of activities for the young people while offering respite breaks to families. Person-centred planning was welcomed by most, but not all, families, and greater efforts may have to be made by the Project if the personal needs of certain parents are to be met.
Mullins et al (2002) <sup>29</sup>	Young people with developmental disabilities in America	3-7 day respite care admission in a centre for developmental disabilities	Two-group study comparing children admitted for respite care against parents of children who were admitted for short-term (30 day) inpatient treatment. Parental measures included Brief symptom inventory and parenting stress index at time of admission, discharge and 6 month follow-up. Therapists completed measures of functional ability at admission and discharge.	Psychological distress was significantly lower at discharge and 6-month follow-up for both groups. Parenting stress was significantly lower at discharge, but at 6-month follow-up had returned to admission levels. Notably, both groups demonstrated improved functional ability from admission to discharge despite the respite care group receiving little formal therapy over a much shorter stay in the center. Respite care appears to result in reductions in psychological distress in parents of children with developmental disabilities; such reductions are comparable to that of a longer term stay. It is important to note that these improvements in functioning are maintained over time.
Rimmerma	Developmentally	Comparison of	78 mothers with minor and adult developmentally	The reduced stress and improved coping associated with the



n et al. 1989 <sup>30</sup> (cited in Chan and Sigafos 2001)	disabled children – country not clear from abstract but authors are located in Israel and America	home-based and centre-based respite care service	disabled children completed a series of questionnaires about stress, coping, self-esteem and perceptions of family functioning and support	use of respite care were mediated by the mother's self-esteem, family cohesion and adaptation, and to a lesser degree by the child's age and functioning level. Respite care was of most benefit to mothers with high self-esteem who had younger and more severely disabled children. Families with younger children preferred home-based respite care, whereas families with older adult children preferred centre-based services.
<i>Single group studies</i>				
Thomas & Price 2012 <sup>31</sup>	Families of children with complex health needs aged 3 to 14 years in Wales	Nursing respite care delivered through community children's nursing teams. They deliver respite care in the home and also provide an in-reach service when the child needed acute care in hospital.	Qualitative single group study with semi-structured in-depth interviews. Participants were 7 mothers whose families had accessed the service and previously received other forms of respite care.	Important emotional and physical relief among the entire family, including siblings with many caregivers describing respite as an essential service. Families valued the nursing respite care and saw it benefitting the child and family. They liked the flexibility and consistent support. Mothers felt the level of respite received was a good balance in terms of being supportive but not too intrusive. They emphasized the importance of clear lines of communication and the need for a stable, flexible workforce. The authors suggested that the community children's nurse is in a prime position to fill the role of keyworker for a family, but noted it is time consuming, potentially stressful and therefore needs to be resourced appropriately.
Javarel et al. (2012) <sup>32</sup>	Families of children with multiple disabilities in France	Short-term hospital respite stay in paediatric department of physical medicine and rehabilitation at University St-Etienne hospital when bed availability allows	Telephone survey after the respite stay asking parents to reflect retrospectively about levels of satisfaction and perceived impact. The child's primary care physician and senior health service physician were also interviewed	Most stays gave satisfaction, allowing changes of medication or equipment, access to expert advice, reassessment of the clinical condition, and an improvement in the children's relationship with their families when they returned home. Parents were reassured by the medical community and hospital. The authors concluded this survey provides arguments in favour of developing respite stays for children with multiple disabilities. Experience raises the question of the role of the hospital in this type of care proposition. It also highlighted the fact that general practitioners are unaware of this type of hospital care.

Brown et al. 2011	Children aged 6-19 years in Scotland with cognitive disabilities and extreme behavioural challenges. Disabilities included ASD, Down syndrome, OCD, ADHD and fetal alcohol and other syndromes. Most were in full-time residential care and received active, full-time day programmes.	Examines parental perceptions of full-day support in a specialized day and residential setting in Scotland (Camphill School Aberdeen: CSA)	Qualitative study with 19 families (23 children), including mothers and fathers, using 1:1 interviews and focus groups.	<p>Families faced major challenges when the children spent most or all of their time at home. This contrasted starkly with the changes in perceived family life once the children were in residential care and day support. Improvements in behaviour of the children were noted and children began to return home for periods of time. Parent noted increased stability of family life, involvement of siblings in more normal community life and increased opportunities for spouses to function more effectively in one or more life domains. Family members perceived a major improvement in overall quality of life. Following return home, over half of the parents noted overall and positive changes in their child, and viewed their child as contented, comfortable and happy. No negative changes were reported. Although no decline in behaviours was reported, under some categories one or two parents indicated no change. Half of the parents commented on their child's increased independence. For some, this appeared to be related to the environment of the CSA campus, where quietness, open space combined with safety gave their child freedom to explore. Around half of the parents observed better communication by, and with, their child. This seems to have had positive consequences for improved behaviour and a perceived improvement in their quality of life, through an ability to convey their wants and needs.</p> <p>Family life improved. Parents said they were able to enjoy time with their child and concerns appeared to be reduced while, generally, there were improved family relationships. Families slept better and were less stressed. Some families considered CSA had saved them from breakdown, and had enabled them to find a meaningful way of functioning while still remaining involved in their child's life. The development of greater stability in the family was also noted. There was a sense that family life was less restricted while the child was at CSA, allowing the family to function more effectively. Although there were still challenges for some families, such as some restriction</p>
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				of family outings when the child was at home, these families still considered that their lives had totally changed and in a positive way.
Wilkie & Barr (2008) <sup>33</sup>	Children with an intellectual disability aged 12-16 who had been using the care facility for a year or more in the Republic of Ireland	Respite care facility	Semi-structured interviews in a one group cross-sectional study of 5 parents (3 individual mothers, one father and one interview where both mother and father were interviewed together).	Parents saw respite care as beneficial. They felt a sense of renewal and confidence in caring for their child. Being adequately and appropriate introduced to the respite facility by the Health Services Executive staff increased their confidence in the service. The main impact for the parent and other family members was seen to be renewed energy and an increase in available time to undertake other activities not directly related to the care of the child with an intellectual disability. Parents often sought respite because their child had a behavioural outburst which had left them feeling powerless. Resolution of the child's distressing symptoms was therefore a priority when seeking intervention. They sometimes felt guilt and embarrassment about sending their child to the facility. This eased after a short period of time and the child began to enjoy the facility. They identified social benefits for the children, having the opportunities to interact with others, improve their social skills and increased opportunities to participate in leisure-based activities in the community.
Radcliffe & Turk (2008) <sup>34</sup>	Children with learning disabilities aged 2-18 in London. 88% were considered highly dependent for most or all aspects of living. Some had physical handicaps, epilepsy, visual impairment or hearing	Respite unit was two purpose-built adjacent bungalows, each containing two double and two single rooms and each staffed by three adults, providing places for up to 12 children between 0 to	Single group qualitative study relating to 35 children. Reports of behavioural reactions and views on distress were gathered from parents, teachers and respite staff. Children were also asked for their views.	Over half the children (54%) were reported to show medium or strong negative reactions lasting for 1 or more days by a parent or teacher. Reported reactions varied widely between home and school and no concordance was found between parents, teachers and respite staff groups regarding distress. Some children's views differed from those of their parent or teacher. The findings highlight the extent of differences in perspectives and suggest the need for greater awareness of the possible distress to children attending respite.

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	impairment.	19 years of age. Every 4 to 8 weeks, children were eligible to stay there for a three night weekend or a week-long stay. During term-time they attended school during the day. A shift system meant the children were not consistently looked after by the same members of staff. Children were organised into cohorts in the same groupings for around 70% of visits. Children and parents were discouraged from speaking by telephone during the visit as staff reported this led to feelings of distress.		
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<p>McConkey (2000)<sup>35</sup> (only abstract could be sourced)</p>	<p>NOT CLEAR FROM ABSTRACT WHAT TYPE OF RESPITE CARE THIS IS</p>		<p>Two single group studies Two studies were conducted. In the first study, a comparison was made between parental ratings (n = 64), obtained through individual interviews, of three different short-break services which they had experienced. This analysis covered the perceived benefits to the child, the benefits brought to the parents and their satisfaction with the service on a range of indicators. The characteristics which significantly discriminated the three services were identified. In the second study, parental ratings of one short-break service were compared over a period of one year (n = 36). This enabled changes in parental ratings of the service to be monitored, and for these changes to be related to child and family characteristics and to their usage of the service. These results should facilitate development of quality standards for short-break services. Specific ways in which these services can be responsive to the aspirations and needs of parents and their children were identified.</p>	
<p>Schroder et al. (2014)<sup>36</sup></p>	<p>Children with complex disabilities aged between 6 and 14 years old in England.</p>	<p>Cholmondeley Children's Centre, provides emergency and planned short term respite care and education for children aged 3-12 years old, whose families are experiencing</p>	<p>Single-group qualitative study. Qualitative, semi-structured interviews were undertaken with four groups of people essential to the day-to-day functioning of Cholmondeley. These included children who had attended Cholmondeley in the period between 2009 and 2013 (n=27), the carers of these children (n=25 carers from 22 families), Cholmondeley's referrers and brokering partners (n=12 people representing 9 different agencies) and staff members of Cholmondeley (n=7).</p>	<p>Positive outcomes included improved social interactions, and children experienced a change of environment and opportunity to experience new activities. Carers were provided with a much needed break, and had the opportunity to receive help with the children. Their parenting role was affirmed and they felt more confident about their parenting abilities. Children had positive experiences they could talk about and this was something the carers could talk to them about. The children were also seen to have developed new skills, become more confident, their mood and behaviour improved. They were exposed to positive role models and became more self-aware as able as helping of others. After the children returned home, families reported feeling closer and the home environment was calmer and more relaxed.</p>



		significant stress or difficulties. It is guided by a family preservation and early intervention philosophy.		
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Primary respite (where main focus is to provide parents with a break from caring)				
Table 2.3: In-home				
Author	Characteristics of participants	Support evaluated	Methodology	Main findings
<i>Randomised Control Trials (RCTs)</i>				
<i>Quasi-experimental studies (comparison group which has not been randomized)</i>				
Bruns & Burchard, 2010 <sup>37</sup>	Children experiencing emotional and behavioural disturbance	Respite care in America	Controlled, longitudinal study - 33 families caring for a child with EBD compared to 28 families in a wait-list comparison group	<p>Families who received respite care had significantly better outcomes over than those on the wait-list comparison group including fewer incidents of out-of-home placement, greater optimism about caring for the child at home, reductions in some areas of caregiving stress, and lower incidence of negative behaviors expressed in the community. However, significant between-group differences were not found for several other variables, and regression analyses suggested that more intensive allocation of service hours was necessary to have a more pervasive impact. The results support the hypothesis that moderate amounts of respite services benefit families with children experiencing EBD but suggest that respite plus other individualized services and supports will be necessary to meet the substantial caregiving challenges faced by most of these families.</p> <p>Respite care significantly reduces parent's stress levels (measured by personal strain subscale) (<math>p &lt; 0.1</math>). Respite care also increased parents' optimism and reduced anticipated need for services in the future. Respite care reduces the need for families to use home residential care placements. 15% of families used out of home placement before receiving respite</p>

				and only 6% during. In contrast the comparison group increased from 29% to 32%.
Halpern, (1985) <sup>38</sup> <i>(cited in Chan and Sigafos 2001)</i>	Children with disabilities	Home-based Respite care	Compared 30 families who used respite and 31 families who did not use respite	There were several benefits associated with use of respite care, including an overall improvement in family functioning and better parental attitudes towards the child with disabilities. The strength of the associations was related to the amount of respite services received. The more time the families made use of respite care, the lower were their scores on measures of perceived family conflict and the more time they spent on recreation/ leisure activities.
Rimmerman 1989 <sup>39</sup> Also Rimmerman et al (1989)	Children with developmental disabilities	Home-based respite care	32 families who had been using home-based respite care and 25 control families who did not use respite care. The control families were mother who needed respite but had no access to such a service in their community.	Families who used respite care self-reported better levels of stress and improved coping (maternal self-report) over a period of 18 months. Improvements were most apparent in the first 6 to 12 months and then ratings started to decline from 12 to 18 months. Reduction in stress among mothers that used respite care. In comparison, for those not receiving respite, study showed increased stress and reduced coping.  The effect on mothers' coping resources of five measures of utilization of respite care services (desire to use respite care services, actual use, accessibility, scheduling and helpfulness) were examined. Using the analysis of variance between utilization measures and coping resources with the following intervening variables as covariates - mothers' self-esteem, family cohesion and adaptation, and clients' and mothers' characteristics - it was found that respite care acts as a differential service that can enhance coping resources (i.e., stress reduction skills) and is of most benefit to high self-esteem mothers of young developmentally disabled children. A home-based model was found to be the most beneficial to mothers in terms of enhanced coping resources.
Stalker & Robinson, 1994 <sup>40</sup>	Families of children with disabilities in the	Families who made use of various models	Interviews conducted with 160 parents as to whether the service was helpful in reducing stress	The percentage of families reporting reduced stress was similar for those receiving family-based (44%) and local authority services (49%) but much lower for families receiving respite



	UK	of respite care (e.g. family-based, local authority, larger health authority)		services from the health authority (22%).
Bose (1991) <sup>41</sup>	Children with mental handicaps	Canterbury and Thanet Link Family Scheme is a community based family support programme. A family with a child with a mental handicap is linked to a family who will 'share the care' of that child. The Link Family can take care of the child for just a few hours, or for weekends, or even longer.	<p>Quasi-experimental study which used a waiting list control group. The study compares families who use a Link Family to families who are waiting to be linked to one. This is a quasi-experimental design: the Control-Series (ie. the waiting list group act as a comparative control of those with a Link Family). All the families in the study were registered with the Canterbury and Thanet Link Family Scheme in 1986. The study was carried out with 48 families who had a Link Family and these families will be referred to as the user group; another 18 families who were on the waiting list to be linked will be referred to as the non-user group.</p> <p>Interviews were undertaken in addition to psychometric questionnaires on maternal mental health, social support, child behaviour and general morale, and stress level.</p> <p>The research examines seven specific aspects of the effects of the service innovation on the families that use the scheme. 'These are: stress, social support, marital relationships, health, morale, effects on the siblings and the child with the mental handicap.</p>	<p>The Link Family had a significant effect in lowering the main carer's level of stress. From the interviews with the mothers who used a Link Family it was clear that they appreciated the help with the burden of caring for a handicapped child. The mothers who were waiting for a Link Family were much more anxious. Stress was significantly correlated with all the other outcome measures and in a regression equation, the six remaining outcome measures explained 47% of the variance in predicting maternal mental health. The users reported significantly higher levels of morale than the non-users.</p> <p>The user families were reporting significantly more perceived social support than the families without the service. <i>There was no significant differences in marital harmony between users and non-users of the service.</i></p> <p>Although the user children were more likely to have friends, this relationship did not reach statistical significance.</p> <p>None of the siblings showed behaviour problems to a 'maladjusted' extent. However, analysis of the range of data for this study shows strong support for the expectation that non-user siblings were more likely to have behaviour problems than the user siblings.</p>
Staker (1988) <sup>42</sup>	Children with severe learning difficulties in Scotland	Family-based respite care for children (the Lothian scheme)	UK quantitative and qualitative research using semi-structured interviews (30 parents and 30 respite carers) and postal questionnaires (22 social care professionals). The study examines the extent to which the service succeeds: (i) in reducing the incidence of stress amongst parents and strengthening their coping strategies; (ii) in	

			providing a beneficial experience for the child; and (iii) in offering parents a degree of choice in respite care facilities by providing a viable alternative to institutional provision. The research was designed both to elicit information about the characteristics, perceptions and experiences of families using the service and to examine the characteristics, motivations, rewards and dissatisfactions of 'respite carers'	
Joyce et al 1983 <sup>43</sup>	Families of disabled children	Respite care used over a four month period	Families of disabled children (n=32)	<i>Positive impact on family relations</i> , social activities, emotional and physical strains, and plans for institutional care. Families caring for younger children viewed the services as more helpful than parents caring for older children or adults.
<i>Single group studies</i>				
Runciman & McIntosh (2003) <sup>44</sup>	Children with complex disability in Scotland	The PATCH project was an intersectoral initiative between health, social and education services which provided support at home from two experienced children's nurses for parents of children with complex disability.	Single group qualitative study - Qualitative interviews with 8 families and 8 agencies.	Examples were given in the interviews of how much parents valued the carers being trained to undertake physical care activities in the way that the parents undertook them. The PATCH nurses worked in partnership with the parent to train the carers in the care of the child. Other examples were given as to when a child had to be hospitalized at the PATCH nurse met the family at the hospital to give them support. The authors concluded that the skilled approach to training adopted was successful in creating a network of carers, both lay and professional, which resulted in improved respite and rest for parents. Effective partnership working resulted in improved communication, the development of an innovative child record, effective help in crises and improved service co-ordination. Together, the training and partnership elements of the PATCH service addressed practical, emotional and social difficulties experienced by families. The freedom to work flexibly and to approach agencies directly and the ability to cut across established organizational structures were significant factors in improving support for families.
Wikler et al, 1986 <sup>45</sup>	Children with developmental	2 home-based respite care	5 children at risk of being re-institutionalised due to their severe behaviour problems were recruited. These children	There was no increase in problem behaviours or deterioration for any of the 5 children. There was some reduction in

	<p>disabilities and severe behaviour problems</p>	<p>projects aimed at providing trained respite carers (college students) which also gave the parents the opportunity to observe the respite worker's attitudes, skills and knowledge as their interacted with the child over a 4 month period.</p>	<p>had just been discharged from hospital and the project aimed to assist with transition to home care.</p> <p>Direct observational data on child problem behaviours as well as results from parent completed questionnaires on their attitudes towards the child and satisfaction with the service.</p>	<p>observed problem behaviours. Parents were all satisfied with the program and felt relieved at having access to well-trained staff to assist with the care and management of their child. There were no readmissions sought to hospital or other out-of-home placement during the 4 month period.</p>
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Table 2.4: Primary respite (where main focus is to provide parents with a break from caring)

Table 2.4: Wrap-around care or multiple component support (which includes respite)

Author	Characteristics of participants	Support evaluated	Methodology	Main findings
<i>Randomised Control Trials (RCTs)</i>				
Singer et al. 1989 <sup>46</sup>	School-aged children with developmental disabilities in America	Two types of community-based respite support services differing in level of support	<p>RCT - 49 parents from 32 families participated over a year. Families were randomly assigned to one of 2 groups:</p> <ul style="list-style-type: none"> <li>- Less intensive support group received a modest level of respite support (respite care and case management)</li> <li>- More intensive support included stress management, respite care, parenting skills training and parent support groups.</li> </ul> <p>Both groups received in-home respite care and case management services for 16 weeks, while the Intensive support group received additional training in scoping skills, extended social support in integrated community settings and access to community volunteers who provided out-of-home respite.</p> <p>Data was collected on the child's adaptive behaviour and parental ratings of their own levels of stress, depression and anxiety as well as satisfaction with the service.</p>	<p>Mothers in both groups showed significant improvement in measures of depression and anxiety, with mothers in the Intensive support group indicating less distress than the Less Intensive Support group. Fathers in the Intensive support group also experienced significantly more positive results on measures of stress, depression and anxiety.</p> <p>Mothers showed significant improvement on measures of depression and anxiety, with more intensive support group members achieving a clinically significant improvement. A power analysis revealed large treatment effects for fathers as well as mothers. Analyses of 1-yr follow-up data revealed that treatment gains were maintained for mothers.</p>
<i>Quasi-experimental studies (control group which has not been randomized)</i>				
Sung & Park (2012) <sup>47</sup>	Children with intellectual or physical disabilities in Korea attending a special school	<p>3 groups operated for 6 months:</p> <ol style="list-style-type: none"> <li>1. Experimental group A provided with respite care services (4 hour session twice a</li> </ol>	<p>Pre-post quasi-experimental quantitative. Groups were matched as far as possible on children's age, gender, disability level and the age and education level of primary caregivers.</p> <p>Measures were taken before and one week after the intervention ended. Three groups were compared with 7 families in each</p>	<p>There was a significant difference in the change of family quality of life between the Experimental Group B and the control group. However, there was no significant different among the three groups in parenting stress. Respite care services combined with a multifaceted family support program including recreation programs, counseling, and social support coordination had a positive effect on family quality of life whereas respite care services only did not make any statistically significant difference.</p>

		<p>week)  2. <i>Experimental group B provided with a multifaceted family support programme including recreational programmes, counselling (once a month for around an hour) and social support coordination in addition to respite care (4 hour session twice a week). Family support activities were done in the community such as movie theatres, culture centres, parks and department stores. Counselling session and social support coordination were provided either in homes</i></p>		<p>Parenting stress was not affected by the family support program implemented in this study. Results of this study were not consistent with existing literature. The children with disabilities in this study had quite severe disabilities and, caring the children was a very tough job for both primary caregivers and respite care providers. Many respite care providers expressed concern regarding their capacity to care for the children in spite of 8 sessions of training and monthly meetings. Therefore, it is possible that the parenting stress of the primary caregivers of children with severe disabilities is not a measure that can be easily changed in such a short amount of time unless long-term and comprehensive system of care is established.</p>
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		<p>or school.</p> <p>3. Waitlist Control group which received no support</p> <p>Respite care providers were also required to attend monthly meetings to discuss concerns and problems occurred during their service time. Also, various training sessions including music and art lessons were offered to the providers to improve their capacity for caring children.</p>		
<i>Single group studies</i>				
Preece, 2009 <sup>48</sup>	Families with children with ASD in England	ASD-specific 'contract carers' were contracted to provide 182 days of care per year, including 26 weekends, in their home,	Qualitative single group study. The research comprised three phases: a postal survey of 256 families, a survey of 27 social workers, and semi-structured interviews carried out with mothers, fathers, siblings and children with ASD from 14 families.	Benefits and shortcomings of short breaks were identified and quality indicators were suggested in a number of key areas: organisational, environmental, staff-, child- and family-related and psychological. Factors associated with short breaks use included family attitudes and values, information, service shortfall, family adaptation, child's age, diagnosis and school placement and allocation to a social worker. Social workers were identified as having inconsistent and at times incorrect understandings of ASD; the factors associated with access to

		<p>looking after one child, or sometimes two children, at a time. Contract carers support up to eight families each and this service has been targeted particularly towards families with younger children, or those who find it hard to cope with groups. ASD-specific residential short breaks are also provided at a six-bed residential home to 40 families with children aged between five and 18 years. It is open 360 nights per year. Stays are pre-booked, with children staying a maximum of</p>		<p>services were mediated by the views of the social worker involved.</p> <p>The young people with ASD themselves had only a limited understanding of the functions of short breaks (or indeed why they attended services). Families saw them as providing family members with opportunities to relax, providing social opportunities for both the family and child with ASD and developing the child's skills.</p> <p>The families interviewed in the studies identified seven factors as being important in contributing to making short breaks effective. These were:</p> <ul style="list-style-type: none"> <li>. the physical environment</li> <li>. consistency across environments</li> <li>. use of ASD-appropriate approaches</li> <li>. staff attributes, including their understanding of ASD</li> <li>. individualisation</li> <li>. successfully accessing the community</li> <li>. grouping of children</li> </ul> <p>Whereas breakdowns are generally high in family- based short breaks placements for children with ASD placement stability in this service has been good. The running costs of this home are in line with those of the county's other residential short breaks services (for children with multiple disabilities and for those with severe learning disabilities). The authors concluded the Nottingham model works effectively.</p>
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		four nights at a time. Each family's package of support is individualised, dependent on factors such as their assessed level of need, the child's age, needs and wishes, and availability. Currently, packages of care vary from 12 to 96 nights per year, with an average of 30–40 nights.		
Collins et al, 2014 <sup>49</sup>	25 parents whose children accessed short breaks in England	Parents had a range of experiences regarding short break provision including overnight residential, Saturday morning clubs, care worker support and Direct Payments to pay for	Qualitative study using interviews and a narrative tool. Data collection undertaken in 2009-2010	<p>Short breaks were crucial in helping parents with disabled children continue to provide care and they were used in other ways that addressed the wider consequences of caring. These other uses included reducing social isolation and caring for non-disabled siblings and were facilitated by novel forms of short break provision. Some parents reported that their needs for short breaks had not been met and this appeared to arise from contested interpretations of what 'breaks from caring' means. Our findings suggest social work assessments should not just identify that parents need a break from caring, but should also include an understanding of how parents make sense of their need for a break.</p> <p>There were 5 themes in the findings:</p> <ul style="list-style-type: none"> <li>- Obtaining a break from caring was an important</li> </ul>



		provision		<p>function of short break provision and was seen as crucial in helping families cope. Some parents needed a break from the physical activities associated with carrying for their child. Sometimes it allowed them to restore their energy levels. Sometimes it allowed parents to engage in activities that, whilst not directly related to the care they provided for their disabled child, attended to other needs that the parents had.</p> <ul style="list-style-type: none"> <li>- Providing wider care – sometimes they used short breaks to increase the amount of caring they did, for example, to attend to the needs of their other children. Short breaks also extended the social contexts in which they were supported in providing care.</li> <li>- Reducing social isolation – some parents described how short breaks that did not involve being physically away from their child helped them reduce feelings of social isolation. For example, when they went on day trips with other families. This provided them with support to be with their children in public contexts which they might usually feel quite reluctant to enter on their own (e.g. going bowling or to the pantomime). They also valued not having to explain or worry about their child’s behaviour because the rest of the group understood. This gives them a break from being so vigilant.</li> <li>- Preparing for not being able to provide care – parents found short breaks useful in thinking about caring for their child</li> <li>- The impact of exclusion from short breaks</li> </ul>
Nash et al (2009) <sup>50</sup>	Young people aged mostly 5-18 years with wide range of disabilities (including Autistic Spectrum Disorder, cerebral palsy, Down’s	Various respite and short break options were included such as visits to Fairway and to Keech Cottage Hospice, they attended a	Single group qualitative study. A total of 57 parents or carers of children with disabilities, 44 children and young people with physical or learning disabilities and approximately 20 professionals were consulted. Methods included questionnaires, face-to-face and telephone interviews, focus groups, and observation where communication difficulties precluded spoken responses.	The research recognised the important benefits that respite care and short breaks can offer children and young people with disabilities, and their parents and carers in terms of much needed respite. For the children and young people, the benefits of respite care and short breaks were very real; the researchers saw many of the children enjoying themselves, developing a sense of independence and achieving. Even children with very severe disabilities seemed to benefit from short breaks.

	<p>Syndrome, Asperger's disease, West's disease, Leigh's disease, Prader Willi syndrome, fluid on the brain, developmental disorder and severe learning difficulties). Frequently the disability was accompanied by other, sometimes associated, problems, such as blindness, hearing difficulties, reflux disorders, etc.</p>	<p>wide range of youth clubs, groups and sports clubs. These were: the Access Disability group at the Centre for Youth and Community Development, Access 2 Sport (Dance), Friends of Bright Eyes (FOBE), Loads of Autistic Fun (LOAF), the LBC Fun Club (Saturday and Wednesday), PHAB/Neet Teens, Pursuing Perfection, Tots and Toys, and an opportunity parents' group for very young children.</p>		<p>For parents and full-time carers the benefits of short breaks and respite care were invaluable. Parents reported using the breaks to bring an, albeit temporary, normality to their lives. It enabled them to do comparatively simple things - things which most people take for granted - like having a cup of tea in peace, having a bath or getting a full night's sleep. Many made the point that caring for a child or young person with disabilities was hard work and a twenty-four hour a day job. A short break was vital to them. The opportunity to give some attention to siblings was frequently mentioned by parents. Moreover siblings often do not have the same opportunities to take part in activities as their peers because of their brother or sister. One parent we talked to told us how her son was very angry about the amount of attention his sister received. The parents used the breaks that respite gave them to give him their attention.</p> <p>Whilst some good practice was noted, a number of issues and serious shortcomings were identified that require further development, notably a lack of information and awareness, inequalities in provision, inadequate provision, and future increased demand for services. In view of the many individual recommendations, seven key areas were identified for prioritisation:</p> <ul style="list-style-type: none"> <li>•Budget constraints and increasing capacity for unmet needs</li> <li>•Improving information and awareness among parents</li> <li>•Developing increased capacity for overnight residential care</li> <li>•School holiday provision and the extended use of schools</li> <li>•Greater transparency and equality for parents</li> <li>•Support for voluntary organisations</li> <li>•Addressing the cultural requirements specific to Luton with regard to BME groups</li> </ul>
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<p>Welch (2014).<sup>51</sup> Also Welch et al. (2010a) Welch et al (2012), Welch et al (2010b) Langer et al (2010)<sup>52</sup></p>	<p>Young people with disabilities in England aged 5 to 19 years.</p>	<p>Part of the evaluation of the AHDC Short Breaks Transformation Programme in England</p>	<p>Qualitative thematic analysis of open- question responses from 352 parents and 73 disabled children. The analysis uses data gathered in 2010 and 2011 during a mixed-methods study into the impacts of short breaks for families with a disabled child. It examines their accounts of the impact of short break services on disabled children. The study was conducted in 23 local authority areas in England selected to pilot the AHDC short breaks programme. The samples were selected from anonymised lists using stratified random sampling; where necessary, the sample was boosted to ensure sufficient coverage of different ages, genders and AHDC target groups. One sample was invited to take part in a longitudinal study; the other was invited to take part in a cross-sectional study. Data for the longitudinal study were collected at two time points 10 months apart; data for the cross-sectional survey were collected concurrently with the first application of the longitudinal survey. In total, views were gathered from parents in 352 different families and 73 disabled children/young people all of whom had a parent taking part in the study. Data arising from written responses to open questions was also analysed about use of services and the effects they have written by 239 parent-carers and 84 siblings.</p>	<p>Participants' perspectives differed; children tended to describe immediate outcomes such as enjoying activities and participation; parents acknowledged these, but focused on longer term developmental outcomes for children Seven themes were identified and these are described below from the child's and parent's perspective</p> <table border="1" data-bbox="1444 459 2130 1406"> <thead> <tr> <th data-bbox="1453 466 1675 523">Theme</th> <th data-bbox="1682 466 1904 523">Children's perspective</th> <th data-bbox="1910 466 2119 523">Parent's perspective</th> </tr> </thead> <tbody> <tr> <td data-bbox="1453 528 1675 820">Likes and dislikes – activities</td> <td data-bbox="1682 528 1904 820">Focused on the details of activity; different children express diverse preferences and explain how these are linked to their enjoyment of short breaks</td> <td data-bbox="1910 528 2119 820">Aware of many preferences and how these impact on the likelihood that the child will comply with and benefit from short breaks</td> </tr> <tr> <td data-bbox="1453 825 1675 1018">Novelty</td> <td data-bbox="1682 825 1904 1018">Short breaks can provide excitement, fun and sometimes relief from boredom</td> <td data-bbox="1910 825 2119 1018">Short breaks provide new experiences which can contribute to child's development</td> </tr> <tr> <td data-bbox="1453 1023 1675 1347">Ordinariness</td> <td data-bbox="1682 1023 1904 1347">Short breaks can feel secure, safe and predictable; they can include ordinary activities that other children do.</td> <td data-bbox="1910 1023 2119 1347">Consistency helps child settle and use short breaks, especially important for some groups of children. Breaks can help child to feel like other children.</td> </tr> <tr> <td data-bbox="1453 1351 1675 1406">Independence and freedom</td> <td data-bbox="1682 1351 1904 1406">Short breaks can provide</td> <td data-bbox="1910 1351 2119 1406">Breaks provide access to a range</td> </tr> </tbody> </table>	Theme	Children's perspective	Parent's perspective	Likes and dislikes – activities	Focused on the details of activity; different children express diverse preferences and explain how these are linked to their enjoyment of short breaks	Aware of many preferences and how these impact on the likelihood that the child will comply with and benefit from short breaks	Novelty	Short breaks can provide excitement, fun and sometimes relief from boredom	Short breaks provide new experiences which can contribute to child's development	Ordinariness	Short breaks can feel secure, safe and predictable; they can include ordinary activities that other children do.	Consistency helps child settle and use short breaks, especially important for some groups of children. Breaks can help child to feel like other children.	Independence and freedom	Short breaks can provide	Breaks provide access to a range
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					opportunities for freedoms and choices, some children enjoy being away from home. Many children feel 'grown up' and feel good about themselves	of activities which would not otherwise be possible. They can promote development of independence skills for the future	
					Relationships	Friendships are an important aspect of short breaks, children often emphasise friendships and aspects of relationships with care workers as well as other children	Short breaks can reduce isolation and enable child to have contact with suitable peer groups and role models. Short breaks promote the development of social skills
					Self-esteem and confidence	Taking part was enjoyable and made some children feel good about themselves	Short breaks can promote self-esteem and confidence, seen as instrumental in child's engagement with wider activities and general happiness
					Learning new skills	Not mentioned	New skills are an important benefit of short breaks, these included wider skills such

						as social, behavioural, communication and life skills as well as specific skills such as sports, crafts and play skills
					Physical development	Not mentioned Some parents highlight contributions short breaks can make to strength, stability, posture and motor skills
<p>The major findings of the study were as follows:</p> <ul style="list-style-type: none"> <li>• A wide range of short breaks provision were used</li> <li>• Parents use and value short breaks for different reasons. Breaks most highly valued by parents often provided a break both from the work and from the responsibilities associated with caring.</li> <li>• Breaks help parents to catch up with 'everyday' activities, such as sleeping, cleaning, or running errands; they allow parents to attend to their physical and psychological well-being, maintain and develop social networks and exercise their rights in the civil sphere.</li> </ul> <p>Short breaks have positive impacts on the lives of disabled children; benefits include developing and maintaining social relationships and being able to enjoy fun activities.</p> <p>Siblings appreciate short breaks as opportunities to do things they could not usually do with their families and to receive more of their parents' attention. The effects of short breaks on siblings were described as being mostly positive. Short breaks have the potential to ameliorate some of the negative impacts</p>						

				of being a sibling in a family with a disabled child whilst also promoting the positive impacts of having a disabled brother or sister. Reported benefits included more attention from parents and breaks from providing care. However, some siblings also reported some adverse effects of short breaks, specifically negative feelings such as worry, guilt or jealousy.
Reid et al (2013) <sup>53</sup>	Children with learning disabilities at risk of a move to residential care in Ealing, England. All young people accepted into the ITSBS are at risk of requiring a residential placement in the near future.	The Ealing ITSBS is a collaboration between the Child and Adolescent Mental Health Service (CAMHS) and Social Care. The team is managed by the Head of Social Care for Children with Disabilities, and all clinical work is led by the clinical psychologists. All cases seen have an allocated social worker and additional resources are requested from the wider multiagency	Single group study piloted over 3.5 years – case examples and early outcomes drawing on measures used routinely by the service to monitor clinical practice (when work began with a family and at point of discharge). Measure was the Developmental behaviour checklist which assesses emotional and behavioural difficulties in children with learning disabilities. Full data was available for 11 out of 16 young people.	<p>There were positive outcomes for young people with intellectual disabilities and challenging behaviour who were seen through the service with residential placements prevented in the vast majority of cases.</p> <p>The total raw score for participants on the DBC was found to improve between pre (median 89, range 99) and post-intervention (median 78, range 76). This difference was found to be statistically significant (<math>z = 2.045</math>, <math>p = 0.041</math>). In summary, this suggests that the total number of behavioural difficulties young people presented with had reduced following intervention.</p> <p>It should be noted that the contribution which short breaks makes to this improvement (as separate from the other elements of the service) cannot be disaggregated. Furthermore, all parent participants also expressed that the scheme was a very positive experience for both themselves and their child, further stating that they would recommend the scheme to others in similar situations. With that, all parent participants also expressed greater satisfaction with their child's behaviour and their relationship with their child upon completion of the scheme. These responses were further supported by a reported decrease in Parental Stress, <math>t(9) = -4.34</math>, <math>p = .005</math>, including factors such as; stresses associated with restrictions on life, conflict with child's other parent and social support. As well as a significant reduction in parental-child dysfunctional interaction, <math>t(9) = -4.58</math>; <math>p = .004</math>, including factors such as; believing their child is not meeting their</p>

		<p>service (ESCAN) as needed, such as Speech and Language Therapy and Psychiatry. This is usually apparent from the level of challenging behaviour across different settings, and through establishing with the family and professional network (e.g. school, social care, paediatrician) that a residential placement is likely (or is already being sought). Referrals are usually received from social care, paediatricians, the joint funding panel (where</p>		<p>expectations and stress problems related to the child's behaviour.</p> <p>In summary, the key themes that emerged from the adolescent's experience of the short break scheme were the benefits and overall satisfaction. This was further supported by the parent's reports of reductions in their child's emotional, conduct and hyperactivity problems and reductions in their own levels of parental stress. From the parental reports, the peer problems and prosocial sub-scales of the Strengths and Difficulties Questionnaire were not significantly reduced, <math>t(9) = -1.59, p = .162</math> and <math>t(9) = 1.58, p = .166</math>, respectively. Moreover, these areas did not emerge as themes from the adolescent interviews, therefore, this could be an area for future development in short break schemes.</p>
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		requests for residential placements would be presented) or CAMHS. Length of input by the ITSBS so far has ranged from four to 36 months. A step down approach is used whereby families are transferred back to less intensive services (e.g. CAMHS-LD, adult services) once the ITSBS is no longer required.		
McConkey (2011) <sup>54</sup> McConkey & Gent (2012) <sup>55</sup> McConkey et al. (2011) <sup>56</sup>	Learning disabled young people with severely challenging behaviours in Cardiff, Glasgow and Edinburgh	3 Action for Children services providing specialist short breaks and intensive support to families. The services are embedded within multi-agency	Information was obtained on 123 young people and families who use the services or had done so in the previous two years to examine their characteristics.  A further strand of information gathering entailed 48 individual interviews with the main stake-holders who were personally involved with a selected sample of 17 children – the primary carer; the key-worker in the service and a representative from one of the partnering agencies, such as a social worker. The aim was to gather rich qualitative data to illuminate their experiences of short breaks and intensive support services. From these accounts an analysis could be made of the dominant	The children had developed a range of skills which reduced their challenging behaviours. They had increased opportunities for participating in community activities although their social inclusion remained limited compared to their non-disabled peers. Parents benefited when their support needs are identified and trusted relationships forged. The authors concluded that merely providing a break is insufficient to help reduce the stresses families experience.  Key workers rated the changes in children and families over the preceding six months and reported that a sizeable proportion had shown some improvements in communication and personal care. Interviews with stakeholders involved with a



		<p>partnerships.          The services provided can be grouped into three broad categories.</p> <p><b>o Short Breaks:</b>          The children and young people stay overnight in a homely residential unit with a small number of other children (up to five) for an agreed number of nights per annum (usually from two to seven nights at a time). These stays not only provide the families with a break but also give the young people an opportunity to experience being away from home and perhaps learning to do</p>	<p>themes that typify their perceptions of these services and the impact they have on the lives of families.          Ratings were made by key-workers of changes in the children and families.</p>	<p>sample of children revealed a very positive evaluation of the services. The children benefitted from participating in a range of activities, but their social inclusion remains limited.</p> <p>Over the past six months, sizeable proportions of the children were reported to have shown some improvements in their communication and personal care. Likewise around half the children had improved in terms of their stereotyped behaviours and aggression to other persons. Children who had received Short Breaks tended to have improved behaviours and especially if they received a greater number of nights per annum. A much higher number of parents were rated as having improved in terms of the well-being indicators when the behaviours of the child had improved. But for small proportions of children the risk of moving out of the family home had increased rather than decreased. These estimates may underestimate the amount of change that had occurred in children and families since they commenced the services. Ratings taken over a longer time period would better reflect this.</p> <p>The over-riding opinion of these services by all stake-holders was very positive and respondents identified five sub-themes that justified this appraisal: The way services managed the complexity of the children, family and services; Coping with ambivalence among parents in their use of the services; The focus the services had on building and sustaining relationships; and the various benefits they brought to the children and families.</p> <p>Seven main lessons were identified to inform service delivery and commissioning.</p> <ul style="list-style-type: none"> <li>- the services are specialist, targeted provision for selected children with complex needs and their families. This emphasis needs to be promoted with commissioners.</li> <li>- Strong partnerships with commissioners and other service providers are key to providing co-ordinated and effective packages of support to families. Specialist services of</li> </ul>
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		<p>more for themselves, as well as taking part in a range of activities of their choice within the house and in the community.</p> <p>o <b>Intensive Support/Outreach:</b> This entails staff working with the children and young people in community settings both as a means of giving the family a break but also in helping the young person to manage better their behaviours and enabling them to access community facilities. Parental guidance and training in managing behaviours is</p>		<p>this type cannot function as 'stand-alone' services.</p> <ul style="list-style-type: none"> <li>- Parents benefit when their support needs are identified and trusted relationships forged. Merely providing a break is insufficient to help reduce the stresses they experience.</li> <li>- The amount of service provided to families is regularly reviewed to ensure responsiveness, effectiveness and cost efficiency.</li> <li>- The short breaks and intensive support provided by Action for Children improve children's and family's wellbeing. Children develop a range of skills and which help reduce their challenging behaviours. Parents also gain personally from improvements in their children. The expertise and experience of staff means they are well suited to advise and train others, such as parents or staff in other services.</li> <li>- The young people have increased opportunities for participating in community activities - a major achievement given the range of behaviours which are challenging to others. However, their social inclusion remains limited compared to their non- disabled peers.</li> <li>- No clear pathways exist for the transition to adult services. Major improvements are needed in the way adult services provide for these young people and their families.</li> </ul>
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		<p>also provided.</p> <p><b>oCombination of Intensive Support and Short Breaks.</b></p> <p>Some children and families may access both services, either at the same time, or else they will start with one – usually Intensive Support - and then move on to the other.</p>		
McDermid et al. (2011) <sup>57</sup>		<p>Eight different Action for Children short break services participated in the study: three residential short breaks (Sites A, B and C) which contributed primarily to the interim phase, two family based short break services, two community based short</p>	<p>Mixed methods single group study. Progress measured for each against outcome indicators every 6 months. This material was supplemented by survey and interview data gathered from staff, commissioners and delivery partners and the families of children who access the service.</p>	<p>Of the 12 families who identified in the surveys that specific pieces of work on areas such as sleep or personal care had been carried out with their child at the short break, the majority (11) considered that work to have had a positive impact on their child.</p> <p>Overall, the services had a positive impact on disabled children and their families:</p> <ul style="list-style-type: none"> <li>• they enabled disabled children and young people to access activities which may be readily available to non- disabled children</li> <li>• All of the staff members who completed a survey agreed that the short break had a positive impact on the children’s confidence, along with 91% (n=10) of partners who also</li> </ul>

		<p>break services and one service providing activity holidays (Sites D – H).</p>		<p>reported that that they considered the children to be less anxious as a result of the short break</p> <ul style="list-style-type: none"> <li>• Most staff surveyed indicated that children’s emotional wellbeing (94%), and behaviour had improved (75%) and that levels of anxiety had been reduced (75%) as a result of the short break service. The data suggest that Action for Children services are effective at seeking and acting on the views and wishes of children and enabling them to make informed choices</li> <li>• parents were primarily concerned with whether their child was having fun and enjoying the short break The findings suggest that Action for Children short break services participating in the study were meeting this target</li> <li>• Knowing that their child is having fun and making progress through developing new skills, can in turn help the families to cope</li> <li>• families felt that the short break had a profound and substantive impact on their own wellbeing and their family as a whole. 96% of families (n=23) reported in the surveys that the short break service had a positive impact on family life</li> <li>• The majority of families interviewed felt that the short break had contributed to enhancing the quality of their family life. Many families put this down to the short break affording them the opportunity to spend more quality time with their spouse or their other children and engaging in activities not possible before receiving short breaks</li> <li>• Some parents interviewed revealed that their capacity to care for their child had increased as they were able to cope</li> </ul>
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				<p>better when their child returned from their short break because they had had a rest and a break from providing continual care. Views and experiences of the short break services</p> <ul style="list-style-type: none"> <li>• Many parents were happy with the short breaks they were currently receiving, although some said that they would prefer more breaks from their current provider or access to a different short break as well as continuing with the short break they were currently receiving.</li> </ul>
Botuck & Winsberg (1991) <sup>58</sup>	School-aged and adult children with multiple (physical and intellectual) disabilities in America	Pre-planned 10 day Overnight respite (i.e. not emergency use) of respite care	Single group study using Repeated measures of 14 mothers of school age and adult children (aged 6-33 years) with multiple disabilities. Looked at changes in mothers' mood, well-being and activity.	Mothers had greater well-being and were less depressed during respite than they were before and after. Mothers also spent more time resting, sleeping, grooming and participating in leisure activities during respite. Concomitant changes in activity patterns were also found. After respite, increased feelings of well-being continued, and there was a strong tendency for mothers to be less depressed.
Marc & McDonald (1988) <sup>59</sup>	Children with developmental disabilities in Alberta	Residential respite care	Survey of families who used respite care compared to those who do not	Families who tend to use respite care are larger, make greater use of professional support services and have children who are more disabled and have more serious behaviour problems. Most participating families report many positive benefits from respite care – 81% reported they now got along better as a family, 83% reported being able to do more things for themselves, and 83% reported stress reduction.
Cowen & Reed, 2002 <sup>60</sup>	Children with developmental disabilities	Respite care programme from 4 rural community agencies in America. Respite care to provide parents	Single group description study using pre-post measures of stress following respite. The founded child maltreatment and foster care placement rates were also compared for the period of the study. 148 families participated (mostly mothers with 265 developmentally disabled children). 87 families completed pre and post-test questionnaires.	Comparison of matched pretest and post-test parenting stress scores did indicate significant decreases in total Stress scores, parent domain scores and child domain scores after the provision of respite care. A subpopulation of 17% of the respite parents accounted for all 81 incidents of founded maltreatment or foster care placement among the target children and their siblings. Only Life stress (which was not significantly decreased by the intervention) was associated

		<p>with a break from the stresses of child care and provide children with a safe environment in which to explore and interact. Parents could receive parenting information, support, positive role modelling and information regarding other community resources and agencies. Depending on the needs of the child, the child oriented interventions may have included: a) developmental stimulation, b) socialisation activities, c) help with negative</p>		<p>with the occurrence of child maltreatment during enrollment. Parenting stress, however, significantly decreased following respite care interventions resulting in a decreased risk for the development of dysfunctional parental behaviour.</p> <p>Respite care caused a significant decrease in overall stress score of parents (<math>p=0.0016</math>). Before the respite care 73% of parents were over dangerous stress levels, after 62% were over stress levels (NPC calculation from their stated standard deviation and mean). Assuming a normal distribution. The study also notes that high quality respite care programmes may have an effect on foster care placements. Foster care placement rate for the state was 6.3 per 1,000, compared to 4.8 for the county.</p> <p>Authors concluded that respite care can be an appropriate and effective intervention to decrease stress in the parent-child relationship.</p>
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		personality traits, e) activities to improve self-esteem and self-confidence, and f) help coping with the stress in their lives.		
Forde et al. 2004 <sup>61</sup>	Families with a dependent child with a disability in Cork. Criteria for selection included families who stated a need for support, families with more than one child with a disability, single parent families, families who provided a high level of physical care or supervision, extent of support and other stresses in the family.	In-Home practical support service delivered by Enable Ireland. The practical support required was deemed to be whatever support or intervention requested by the parent of the child/dependent adult which afforded the service user the opportunity to engage in social/recreational opportunities and that gave the parent free	Longitudinal one-group study with baseline and end-of-support measures (at the end of a year of support). 16 families participated (children aged 1-18+). Semi-structured interviews and standardised stress measure were used before and after the introduction of Link Family Support (LFS). Data could not be disaggregated separately for the 18+ offspring compared to the younger children.	<p>Although levels of stress continued to be high and scores on the Parenting Stress Index (PSI) did not show a statistically significant reduction after the programme, reported stress levels had improved. Parents reported LFS to be very helpful in reducing perceived stress and improving family's quality of life through providing free time and access to leisure and recreation facilities. This study provided limited but clear evidence of the need for regular, flexible, in-home support for families with children and dependent adults with a disability. LFS provided a personal, regular and effective means of meeting this need as the findings of this study demonstrated.</p> <p>The service was seen to meet a demand for regular, flexible, in-home support for families with children with a disability. The authors concluded that it improved the quality of lives of families, by alleviating the stress levels of parents, offering free time each week to parents, provided more time with other family members, and facilitated social and recreational opportunities for people with special needs.</p>

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		<p>time. The aim is twofold – to give parents a break from caring constantly for their children and also service users be given social opportunities and exposure to people other than family, and places and activities. Community based activities were undertaken including socializing (shopping, walks, cinema, library, meeting new people_) and trying new experiences. Experienced care workers (graduates with experience in child care), with a diversity of experience, were placed</p>		
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		with clients in their own homes or in the community for one 3 hour session per week to undertake these activities.		
Meltzer et al (2010) <sup>62</sup>	Ventilator-assisted children aged 3-14 years in America	Home care nursing support	Cross-sectional descriptive study examining the relationship between home care nursing support, sleep and daytime functioning in familial caregivers of ventilator-assisted children. Thirty-six primary caregivers (27 mothers, seven fathers, one foster mother, and one grandmother) of ventilator-assisted children completed measures of home nursing support, sleep, depression, fatigue, and daytime sleepiness.	Daytime nursing coverage was not related to caregiver sleep or daytime functioning, but caregivers with less night-time nursing coverage had significantly shorter sleep onset latency than caregivers with some night nursing (16–48 hours/week). Caregivers with regular night nursing (>48 hours/week) had a total sleep time of almost one hour more than caregivers without regular night nursing ( $\leq 48$ hours/week). Caregivers with clinically significant symptoms of depression and sleepiness received significantly fewer hours of night nursing/week than caregivers without significant symptoms of depression or sleepiness. Home nursing support, in particular night nursing, is important for the health and well-being of familial caregivers of ventilator-assisted children. Significant reductions in parental stress on a depressive scale with the allocation of increase night-time care hours. These benefits were negated, however, in the absence of familiar attendants, knowledge of the child's needs.
Sherman (1995) <sup>63</sup> – cited in Copps 2007	Children with chronic illness in America	Home-based respite	Single group study of 26 families caring for a child with a chronic illness. Measures stress and coping before and after receiving respite.	Reduced stress and improved quality of life among mothers. Statistically significant reduction in physical illness and somatic complaints by caregivers ( $p < 0.05$ ). Results also suggest an association between respite care and a decrease in the number of hospital admissions required by child ( $p < 0.07$ ).

Table 2.5: Secondary respite (where main focus is to provide the young person with activities or experiences and respite is a by-product)

*In-home, Overnight clubs, summer schemes or befriending*

Author	Characteristics of participants	Support evaluated	Methodology	Main findings
<i>Randomised Control Trials (RCTs)</i>				
Pulgaron et al (2010) <sup>64</sup>	Young people (mostly African-American) aged 7 to 14 in USA with persistent asthma	1 week camp which included 4 x 45 minute problem-solving sessions during camp	Randomised control trial including psychometric measures on asthma knowledge, coping and quality of life. Fifty campers were randomly assigned to receive camp plus a nightly problem-solving intervention activity or camp as usual. Changes in self-reported asthma knowledge and problem-solving skills and self- and parent-reported child self- and social competence health-related quality of life were assessed thrice: before camp, on the last day of camp, and 3-months post-camp.	There were no significant differences between the problem-solving intervention group and the camp as usual group in change across psychosocial variables from before camp to last day of camp or before camp to 3-months post-camp. Increases in asthma knowledge and problem-solving were found 3-months post-camp when groups were combined. Authors concluded that although support was found for improvements in disease knowledge and problem-solving skills after camp participation, there were no identified benefits to the problem-solving intervention. Children with asthma who participated in camp were functioning at a high level in terms of knowledge, problem-solving, and social and self-competence, suggesting that interventions may be more effective if targeted to patients with identified problems with disease management.
<i>Quasi-experimental studies (control group which has not been randomized)</i>				
Bekesi et al, 2011 <sup>65</sup>	Young people aged 10-18 in Hungary with oncology (cancer or leukaemia), diabetes mellitus and juvenile idiopathic arthritis	8 day camp including horseback riding, boating, arts and crafts and team games	Pre and post test comparing 115 camp attenders and non-attenders	The Self-perception subscale showed significant positive change from pre camp to post camp with small effect size. Autonomy scores showed time related decline as well as significant time and age group interaction: children under 14 years of age showed a significant moderate effect size decrease on the Autonomy subscale. 32 children (27.8%) showed clinically significant improvement (RCI > 1.96) at least on one subscale. All positive changes were independent of the type of disease, age, gender, and previous camp experience. Authors concluded that the therapeutic recreation camping program had a positive impact on

				HRQoL of children and adolescents living with cancer, diabetes mellitus and JIA. The experience enhanced their self-perception in all age groups and reduced the autonomy of children under 14 years of age.
McGill (1996) <sup>66</sup>	Children (aged 6-18 years) with learning disabilities	Pilot summer respite care play scheme set up and run by The Children's Society Medway Project. It ran during the summer school holiday period with between 2 and 5 places available on each of 4 days for 6 weeks. Children attended from 9am to 5pm with transport available if requested. The scheme was based in a large, ordinary house which also provided a long-term home for 4 children and young people with learning disabilities. A 1-1 staffing ratio was provided. As far as possible when allocated particular children to particular days, account was taken of the age of the children, their mobility and their likes/dislikes. A variety of in-house and outdoor (garden) activities were available. A number of planned outings were also made to swimming, the zoo, parks, dockyard and so on. Most children attended the scheme for 1-3 days	Quasi-experimental. Two group qualitative – semi-structured interviews completed with 18 families who had used the scheme and 5 who had not.	<p>The characteristics of 18 families who used the scheme are described and their needs for additional respite care explored. Mothers found the scheme very useful and wanted substantially more such provision both during the summer and at other times. 17 of the 18 mothers felt the scheme was a success. All 17 felt they (and sometimes their other children) had had a break and 14 reported being able to do things they would not have done otherwise, e.g. taking their other children out, having a rest, shopping and housework.</p> <p>All 18 children and young people were said to have enjoyed going. Fourteen of the young people were said to have done things they would not have done at home including mixing with other children, going out, swimming and painting. In terms of expressed needs, families want more of all kinds of respite, especially during holiday times. In particular, they highlighted the need to develop 3 types of service:</p> <ul style="list-style-type: none"> <li>- <i>Holiday schemes</i></li> <li>- <i>Day time and evening activities such as youth and after-school clubs</i></li> <li>- <i>Residential respite care either in existing or new facilities or with other families.</i></li> </ul>
Nicholas et al (2009) <sup>67</sup>	Young people in Canada aged 7-15 with asthma	2 week camp including canoeing, swimming and hiking. Asthmatic campers also participated in an asthma psychoeducational program which focused on asthma pathophysiology, disease and stress management and coping strategies	Comparison of group of asthmatic young people against non-asthmatic campers. Campers and parents engaged in separate informal group discussion. Children completed various questionnaires around locus of control, self-	All campers reported significant increases in coping skills after attending camp. Non-significant improvements in perceived social support were reported pre to post-test. There were no statistically significant differences among pre and post-camp scores among self-esteem, locus of control and quality of life. Findings suggest that residential camps and group work within camps are highly valued by children and their parents. Children

			esteem, social support and quality of life	predominantly valued recreational and educational aspects of camp programming whereas parents emphasized appreciation for the safety that a condition-specific camp can offer a child with illness. Within the camp program, group work and peer support were integrally provided along with clinical monitoring and health teaching.
Cheung et al 2006 <sup>68</sup>	Young people in USA aged 13-17 with Type 1 diabetes	1 week camp	Cross-sectional comparison of adolescents who had attended at least one diabetes camp and those who had never attended diabetes camp.	No significant differences between campers and non-campers although results provided evidence of the value of social support.
<i>Single group studies</i>				
Santiprathob et al (2008) <sup>69</sup>	Young people aged 10-46 (with 8 being older than 18) with Type 1 diabetes in Thailand	5 day camp. Children participated in a diabetes self-management education camp focusing on self-monitoring of blood glucose levels	Single group Repeated measures including blood glucose levels, patients' diabetes knowledge and psychosocial measures. 60 participants. 6 month follow-up	Glycaemic control improved upto 3 months post-camp but did not remain at the 6 month assessment. Diabetes knowledge and nutrition improved after the 5 day camp, and this knowledge persisted at the 6 month follow-up.
Spruin et al (2016) <sup>70</sup>	Disabled adolescents aged 11-18	Short break scheme over the summer holiday. The scheme was carried out three days a week (Monday, Wednesday and Friday) for a month over the summer holidays and was opened to young people with disabilities and special needs aged 11 to 18. The scheme incorporated a combination of unstructured youth activities (e.g., pool tables, computers, game consoles and outside play), along with various staff-led sessions (e.g., cooking classes, computing sessions, group games) to help in developing a number of social and life skills. Each	Mixed methods cross-sectional single group study with data collection from 11 disabled adolescents and their 9 corresponding parents (2 parent participants had 2 separate adolescents attending the scheme). Interviews were undertaken as well as psychometric tests such as the Strengths and Difficulties questionnaire	Benefits were identified around well-being and social interaction. When adolescent participants were asked if there were any benefits or learning outcomes to attending the scheme, all participants made reference to the benefits in their overall well-being, with the majority (N = 9, 81%) noting the impact on their emotional development. This pattern included a greater sense of belonging and enjoyment by the adolescents, along with a decrease in emotional symptoms such as anger, anxiety, fear and unstable emotions. For example, when adolescent participants were asked about whether they felt a sense of belonging at the scheme, all participants noted this feeling as a positive reinforcement to their short break enjoyment.  This was also partially supported by the quantitative responses from parent participants. A one-sample t-test was used to examine parental reports of their child's emotional problems

		<p>session cost £10, with parents who had more than one child attending receiving a discount depending on circumstances.</p>		<p>upon completion of the scheme. Results indicated a marginally significant reduction in adolescent's emotional problems sub-scale of the Strengths and Difficulties Questionnaire, <math>t(9) = -2.42</math>, <math>p = .052</math>, including factors such as unhappiness, worry, nervousness and fear. These benefits were further echoed by all parent participants when they were given the opportunity to elaborate on examples, whereby they noted that the life skills of their child vastly improved over the course of the summer. These skills included; greater communication, appropriate interaction, effective listening and building new relationships.</p> <p><b>Social interaction.</b> when adolescent participants were asked what they liked best about the short break scheme, all participants made reference to some form of social interaction, with the majority (<math>N = 9</math>, 81%) responding that the various group activities, such as the days out, organised games, local trips and use of technology, were their favourite aspects of the scheme. Most of the child participants (<math>N = 8</math>, 72%) also stated that the new friendships they made with staff and other adolescents was their favourite aspects of the scheme.</p> <p>Further support for the benefits of young people's social interaction came from quantitative responses from parent participants. A one-sample t-test was used to examine the conduct problems (i.e., aggressiveness, temper issues and anger regulation) and hyperactivity problems (i.e., restlessness, distraction and fidgetiness) sub-scales from the Strengths and Difficulties Questionnaire. The results indicated a significant reduction in their negative conduct, <math>t(9) = -2.70</math>, <math>p = .036</math>, and hyperactivity <math>t(9) = -2.83</math>, <math>p = .030</math>. When prompted to elaborate on their responses, all parents further noted that one of the main skills their child developed during the scheme was social skills, in particular, building and maintaining new friendships.</p> <p><b>Positive experience.</b> all young people found the scheme to be a positive experience, particularly the great satisfaction of new</p>
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				experiences, with all participants reporting at least one of the following: learning new things, new activities or new friendships as pivotal in their positive experiences.
Black et al. 2010 <sup>71</sup>	Child or teenager with severe learning (intellectual) disabilities.	Person-centred service 'Positive Futures' which promoted the social inclusion of young people in volunteer-run community activities, based around a person-centred plan developed with the child's family. Service operated in three areas in NI - Bangor, County Down; Lisburn, County Antrim; and "Lakeland", south east County Fermanagh. With the introduction of the Service, a number of opportunities to participate were made available to children e.g. holiday schemes, after schools clubs, and weekly activities. These activities are facilitated by paid staff and volunteers. The Services support children in a wide range of ways including sporting activities such as swimming, horse riding and football. In conjunction with local schools, a variety of recreational after-schools projects are available including computer skills, cookery and arts and crafts. Partnerships provide opportunities for the children to be included in local youth clubs. Children in Bangor and Lisburn have also participated in a number of courses and theatre productions in association with the KIC Drama Project. Buddy groups	3 year formative evaluation using interviews and focus groups. Data collected in 3 year formative evaluation from parents (N = 48), young people (N = 19), volunteers (N = 7), community workers (N = 4) and referring social services staff (N = 14).  Carers completed a number of initial questionnaires and were re-interviewed 12 months later to enable comparisons to be made. In total, over 800 questionnaires were completed.	Qualitative formative evaluation found the project helped parents to clarify their individual support needs and engaged their child in ordinary community activities.  On average, the children's levels of social activity increased from virtually zero to 2.5 activities per week, and in many cases exceed that of their siblings.  <ul style="list-style-type: none"> <li>In general, carers health was poor. Nearly half reported that they felt "run down and constantly under strain". Many felt exhausted and exhibited low self-esteem. Over one third had felt unable to cope because "everything was getting on top of them". Three carers admitted having regular suicidal thoughts. Stressors such as the challenging behaviours of the child, the limited support available and marital disharmony impacted on the carers' mindset and physical well-being. A number of carers are on medication for depression and anxiety. 9% were due to have surgery and this left them anxious as to who would assume the caring role for their child when they were in hospital. Many carers whose scores indicated extremely poor health at the first stage had improved health scores when they were re-interviewed.</li> <li>Opportunities for socialising were rare for carers. However, during the two timeframes, the number of 'weekly' and 'monthly' social opportunities for carers increased, suggesting that the Service may have freed-up more time for them to socialise. Few carers took time for themselves; 23% undertook regular exercise and 10% were studying a course to give them an outside focus. Many carers admitted that they were the last person they considered in the family as their efforts were mainly focused on other family members. One quarter also spoke poignantly of being excluded from family get-togethers or social events with friends. Carers believed that as a family, they were not accepted</li> </ul>

		<p>enable the children to choose their own programme of activities, such as going to an ice hockey match or out for a meal. Team-building and social and life skills are also developed through the Duke of Edinburgh Scheme and other courses such as First Aid.</p>		<p>by society, often reporting experiences of discrimination.</p> <ul style="list-style-type: none"> <li>. For parents, the opportunity to spend time together as a couple was limited by the difficulties associated with organising childcare from trusted sources. Older siblings and grandparents frequently stepped in. However, not all families could depend on older siblings and in many cases, grandparents were infirm or deceased. Carers were grateful for the flexibility the Service offered in facilitating breaks so that they could spend quality time with other offspring and their partners, or enabling them to attend social events.</li> <li>. Results indicate reasonable levels of family functioning, however disparities did exist. Carers had higher levels of stress than the general population. All found the parenting role challenging and 90% reported that they were giving up more of their life to meet their child's needs than they had ever expected to. Nevertheless, half of the 'parenting satisfaction' scores improved between the two timeframes demonstrating that these carers had become more positive about their parenting role. There was also a significant improvement in the child's behaviour indicated by their adaptive and aberrant behavioural scores. This may be attributable to the intervention of the Service which focused much energy on developing the children's social and practical skills. The improved behaviours of the children may help to explain the increase in parenting satisfaction levels in the follow-up analysis.</li> <li>• Carers commented about their experiences of using the Service, its delivery and the impact it had on their child. The consensus was extremely positive in all Service locations and carers cited multiple benefits for the child and family. Families spoke highly of the Service, its uniqueness and how grateful they were for the support it offered. The main benefits reported were the increased opportunities for their child to experience and learn new skills and the extended social networks for both child and carer. In addition, families expressed delight at the personal milestones their child had achieved; the Service had indeed transformed many lives. It opened up a whole new world for the</li> </ul>
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				<p>children and carers no longer felt like they were alone.</p> <ul style="list-style-type: none"> <li>• Carers also commented on the professionalism and genuine care shown by staff and volunteers and the reassurance they felt knowing their child was safe and with people they trusted. Others reported that initiatives such as the 'Sibs group' provided a supportive environment for siblings to experience opportunities and helped them to realise that they were not coping alone. Likewise the 'Women Carers Project' enabled mothers to meet together and embark on an emotional and empowering journey of personal development.</li> <li>• Additional key themes emphasised by carers included the person-centred ethos of the Service. This way of working also, for the first time, helped many parents to look to the future. Carers expressed high hopes for the Services to continue. Many referred to it as a 'lifeline', a 'blessing' or a 'godsend'. The consensus was that carers 'wouldn't be able to cope without it'. Irrespective of their own financial situation, carers were willing to contribute either financially or practically to the Service to ensure it continued. The final section of the report outlines the views of a number of key stakeholders obtained through semi-structured interviews and focus groups. Staff, community workers and volunteers reported that the Service 'filled a huge gap' in the lives of these children and helped to educate and raise awareness in the wider community. Their views echoed those of carers; that the Families Service is essential. Children with a learning disability reported that they enjoyed the Service; the activities, the fun, and the new friends they made. Very few stakeholders had anything negative to say about the Service. In fact, the vast majority commented on how rewarding their involvement had been. The commitment of volunteers and staff was evident, and many had gone to great personal lengths to make sure that the children received the best possible service. Other partners also reflected upon the positive working relationships. However, there was evidence that there should be more joined-up working between the Families Service and the statutory sector. In spite of funding limitations, stakeholders advocated that the Service</li> </ul>
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				brought tremendous value.
Farid, M. 2017 <sup>72</sup>	Young people aged 16-24 with neuromuscular disease in New South Wales	Although not described as respite, this examines impact of participating in a Duke of Edinburgh scheme. Duke of Edinburgh's Award, offered through a community support organisation, the Muscular Dystrophy Association New South Wales.	Single group, qualitative - Semi-structured interviews, conducted with each young person-parental caregiver dyad. There were 8 young person- caregiver dyad.	<p>Parents described learning to 'let go' and having quality time for themselves and other family members.</p> <p>Participants, called Dukies, and their parents described their initial motivations for enrolling in the Award, including the opportunity for the Dukies to engage in the community and participate in new activities and learn new skills. They also reported a number of outcomes for the Dukie including: a new outlook and purpose in life, increased self-belief, independence, and social confidence.</p> <p>A number of essential ingredients enhanced participation for the Dukies including: choice, challenge and access to resources and supports for parents.</p>
Lindsey (2014) <sup>73</sup>	<i>Children with special health care needs</i>	<i>8 week Therapeutic summer day camp programme in America</i>	<p>Mixed methodology combining quantitative data collection through pre-and post surveys and qualitative data collection through interviews that work to answer questions relating to the effects of a therapeutic summer day camp on parents' perspective and management of their child's condition.</p> <p>Twenty-two parents completed The Family Management Measure that was administered prior to and at the conclusion of an 8-week therapeutic summer day camp program. Qualitative interviews with 11 parents helped to better understand specific interventions and experiences of</p>	<p>Although the quantitative analysis did not yield statistically significant changes in the family's ability to manage their child's condition as a result of attendance at the camp, the qualitative interviews demonstrated robust evidence that the camp provided meaningful experiences for the campers and parents while alleviating stress within the family.</p> <p>Themes that emerged from the interviews include: (1) Family-Child themes of loss of normalcy, relationships affected, increased stress, family adaptations, and love for the child; (2) Camp-Child themes of meets individual needs, creates happiness, and behavior changes; and (3) Camp-Parent themes of improved perception of the child, decreased stress, parent involvement with staff, and need for specific environment at camp.</p>

			the therapeutic camp that benefitted their child and family.	
O'Halloran & Doody, 2013 <sup>74</sup>	Young people aged 9 to 19 years with Asperger Syndrome in Ireland	<p>Enable Ireland sleepover club initiative - a local sleepover club that is regulated mainly by the children themselves. Run by a community-based learning disability nursing service in County Clare, Ireland. These clubs involve groups of children with As spending one day and night together in a safe environment, under the supervision of trained staff. These are to:</p> <ul style="list-style-type: none"> <li>-expose the children to scenarios that they could come across in their everyday lives.</li> <li>-understand the difficulties that can arise when they go to, for example, cinemas, restaurants, shops or each others' homes.</li> <li>-Teach them how to introduce themselves to people and what to say when they meet friends.</li> <li>-Teach them basic etiquette and how to be cordial to others.</li> <li>-offer them opportunities to practise appropriate responses to people and situations</li> </ul> <p>After each sleepover, parents were given concise reports on their children's activities and achievements. These reports are written by staff with the help of the children concerned in a language that is appropriate to each child's</p>	<p>Larger evaluation of Enable Ireland services included an interim evaluation of this sleepover club initiative. Single group study with 30 young people using qualitative methods to explore the experiences and perspectives of young people, their families and staff.</p>	<p>The results of the sleepover club project exceeded expectations. The children have gone far beyond their comfort zones to be part of their groups. They have become more confident in accessing mainstream activities, trying new experiences and developing lasting friendships, while having fun and learning in a safe environment. Their families confirm that the children are applying what they have learned to other settings and, as a result, are better able to express themselves and achieve a fulfilled quality of life.</p> <p>The children have a sense of complete ownership of the clubs, which means they are responsible for ensuring they succeed, and for working hard at engagement and compromise.</p> <p>At times, the children have attempted to resist change by refusing to take part in activities, or have found working together and compromising difficult. In these situations, the objectives and rules of the group became helpful, and the children's attempts to manage their difficult feelings allowed everyone involved to form lasting, honest and trusting relationships.</p> <p>In addition, many of the children became anxious about working in groups, and needed regular reassurance and encouragement. staff have learned to recognise the stress and anxiety that is often masked by avoidance strategies or negative attitudes, and how ingenious some children can be at avoiding the things they fear.</p>

		<p>level of understanding and with which each child is familiar. The reports are then signed by the children, if they are aged 16 years or over, and by their parents and the staff.</p> <p>Groups of children attended the sleepover club once each month, from a Friday evening until late the following Saturday afternoon, all year round and for one week during the summer holidays. each club is run by two members of staff. Young people are divided into four groups depending on their ages and interests. The staff members designated to each group are to remain with them, if possible, throughout the members' transitions into adulthood.</p> <p>On arrival, members greet each other, unpack and share news, before helping to prepare and eat dinner. one member then decides what activities they should pursue during their stay, with members taking turns to decide at consecutive meetings. supporting the children to take turns and learn to compromise in this way is an essential part of their social-skills training.</p> <p>The children are encouraged to take part in activities that involve</p>		
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		<p>collaboration and physical effort, such as bowling, swimming, surfing and a game called Quazer that involves toy laser guns. The children also play board games and take part in group discussions, which encourage them to communicate, and to open themselves to change and new ideas. As members of their local community, they use the local public amenities whenever possible. staff assess the effectiveness of activities and encourage the children to have fun at all times. Humour can be a source of intuitive understanding and, by ensuring the children enjoy themselves, staff can help them to manage their anxieties.</p> <p>Staff consult and involve families as much as possible. Person and family centered approach means ensuring the clients and their families could take the lead in activities.</p>		
Hallett & Armstrong, 2013 <sup>75</sup>	Young people (11-18 years) with Autistic Spectrum Conditions and attending a Special School in the North West of England	Overnight residential experiences for young people with autism to help prepare them for later independence. 12 of the 16 young people went on to have a series of overnight stays.	Phenomenographic approach including four sets of interviews with young people and adults (one-to-one and group interviews, and picture diaries). There were interviews with 18 parents, nine educational staff members and 7 members of care staff three weeks after the pilot project.	Important progress toward educational and personal targets was seen to have been made, notably in the areas of behaviour, social skills and independence. Parents with several children said they had time, for the first time in years, to attend fully to the needs of their other children. Improved outcomes described by the young people included improved socialization, life skills, self esteem and community inclusion. The young people participating in the pilot described friendship opportunities beyond the classroom. They felt able to manage a variety of life skills for the first time and had a greater sense of freedom. The young people also described a great sense of pride and achievement, and increase self-competency. All of the young people also included reference to

				community inclusion in their picture diaries.
Bongiovanni et al 2010 <sup>76</sup>	Young people in USA with Celiac disease aged 7-17 years	1 week camp which provided gluten free meals for campers	Single group 77 young people assessed with pre-and post test measures	All campers showed improvements in well-being, self-perception and emotional outlook from pre to post camp experience.
Cushner-Weinstein et al 2007 <sup>77</sup>	Young people in USA aged 7 to 17 with epilepsy	1 week camp with rope course, swimming, arts and crafts. Campers participated in support group sessions three times a week	Single group using repeated measures (pre-post for 3 years)	Significant improvements in social interaction and communication in the first year. Social interaction significantly increased every year.
Devine & Dawson (2010) <sup>78</sup>	Young people aged 8-18 in USA with craniofacial differences	5 day camp with activities such as fishing, swimming, climbing, archery, arts, music, nature, and team building activities	Single group repeated measures pre- and post after 6 week follow-up with 31 young people	Significantly higher levels of self-esteem and social acceptance at the end of camp which remained above baseline at the 6 week follow-up
Goodwin & Staples (2005) <sup>79</sup>	Young people in Canada aged 14-19 with physical, sensory or behavioural disabilities (cerebral palsy, autism, multiple disabilities, sensory impairments)	1 week camp situated at a University. Activities include tennis, horseback riding, dancing, fencing, rock climbing, Jiu Jitsu	Single-group qualitative study using Semi-structured interviews, written documents, photographs taken by participants and field notes	Participant's experiences were grouped into 3 main themes: 1) not alone 2) independence and 3) chance to discover
Gillard et al (2011) <sup>80</sup>	Young people in USA with HIV and Aids	6 day camp included swimming, canoeing, dances, arts and crafts, challenge courses and team building activities. Campers aged 12-16 years attended an educational workshop called 'Teen talk' and received information about HIV treatment, and management, disclosure issues and how to set goals	Interpretive case study design using single-group of 51 young people. Data included semi-structured interviews and focus groups, participant observation and reviewed artefacts	Three main themes emerged: 1) forming caring connections, 2) feeling reprieve and experiences recreation 3) increased knowledge, attitudes and skills
Hunter et al (2006) <sup>81</sup>	Young people in USA with Type 1 diabetes	1 week camp (no other information provided)	Repeated measures single group study using psychometric tests on self-management skills, diabetes	All campers showed improvements in self-management skills throughout their camp experience. Significant differences observed for perceived athletic ability, global self-worth and

			family responsibility, self-perception and coping	friend relationships
<i>Keirnan et al (2004)</i> <sup>82</sup>	Young people aged 7-16 in Ireland with life threatening diseases: cancer, haematological, renal and immunodeficiency related illnesses	10 day camp (no other information reported)	Repeated measures single group study of 240 participants using psychometric tests of physical symptoms, self-perception, perceived illness, sibling perception, and social support. Data collected at start and end of camp, and 6 month follow-up.	Young siblings and patients decreased their physical symptoms from pre to post. No significant changes showed over time around physiological arousal and self-reported quality of life. Rating scores in self-worth decreased from pre- to post. However these results did improve at the 6 month follow-up.
<i>Keirnan et al (2005)</i> <sup>83</sup>	Young people in Ireland aged 7-16 with life threatening diseases: cancer, haematological, renal and immunodeficiency related illnesses	10 day camp. Activities included arts and crafts, camping, horse-riding and ropes courses	Qualitative single group study using open-ended questions at three time points (Moola et al do not specify these)	Children were looking forward to the new activities, social experiences and meeting other children with a similar illness. Campers learned new social (e.g. communication and cooperation), psychological (e.g. confidence) and practical skills at time 2 and 3. The majority of campers did not want to change anything about camps.
<i>Moons et al (2006a)</i> <sup>84</sup>	Young people in Belgium aged 10-14 with congenital heart disease	3 day camp including athletics (high and long jumps), tennis, baseball, and hockey all supervised by qualified sports teachers	Single group pre and post measures using Child Health questionnaire. 16 participants.	Significant improvements amongst physical functioning, role functioning, behavioural mental health and general behaviour shown from pre to post camp
<i>Moons et al (2006b)</i> <sup>85</sup>	Young people in Belgium aged 10-15 with congenital heart disease	3 day camp including soccer, tennis, judo, handball, hockey and, badminton. Non-sport activities included group and individual quizzes, colouring contests and party games	Single group pre and post measures including Child health questionnaire and Baecke questionnaire. Data collected at 3 time points but Moole et al does not specify when these were.	All variables within Child health questionnaire increased from pre to post – improvements in physical functioning, role functioning, physical, emotional and behavioural continued to persist at Time 3. No changes shown on Baecke questionnaire.
<i>Shepanski et al (2005)</i> <sup>86</sup>	Young people aged 9-16 in USA with inflammatory bowel disease	1 week camp including tubing, swimming, dancing, basketball, adventure, arts and crafts and cooking	Repeated measures single-group study of 61 participants using Impact-II questionnaire and State Trait anxiety questionnaire	Quality of IMPACT-II questionnaire scores increased from pre- to post-camp. No reported differences in anxiety at the two time points.

<i>Simons et al (2007)</i> <sup>87</sup>	Young people aged 8-18 with cardiac defects in USA	5 day camp including swimming, horseback riding, arts and crafts, archery, fishing and mountain biking	Single group Repeated measures study with 29 participants using psychometric measures of expectations, anxiety, separation experience, maternal separation anxiety, and parental camp expectations.	Clinical anxiety decreased from pre to post. Previous separation experiences, negative expectations reported by both child and parent, and parental anxiety scores were associated with high levels of anxiety. Overall reductions in anxiety were observed post-camp and maintained in the follow-up
<i>Torok et al (2006)</i> <sup>88</sup>	Young people with a mean age of 15 with oncology or diabetes in Hungary	8 day camp – no further details given	Single group Repeated measures with 97 participants assessing self-esteem, perceived self-efficacy and state-trait anxiety	Campers' self-esteem scores increased from Time 1 to 2. However, decreases were reported at Time 3. Trait anxiety scores stable from Time 1 to Time 2, then significantly increased at Time 3
<i>Murphy &amp; Verden (2013)</i> <sup>89</sup>	Children with autism	University undergraduate students in America were trained in the characteristics of autism and behavior-based principles, pairing the students with a family in need of respite support, and finally providing free respite care to families	Single group study. This article discusses the planning, implementation, and initial outcomes for a university-based respite care program designed to meet the need for autism respite services in a suburban community	No further details available from abstract and not possible to secure the full text in the timescale for this review.
Macdonald & Greggans (2010) <sup>90</sup>	Young people with cystic fibrosis aged 8 to 18 years in Scotland	'Cool friends' – a community befriending programme	Single group qualitative study with 17 participants - Ten of these were either befriended (aged 8-18 years) or their parents. Half of these families were interviewed twice; once at the beginning of the befriending relationship and another at one year later. Seven other personnel, closely involved with the young people, were interviewed; two play therapists and two education liaison personnel. A focus group was also held with three befrienders.	Befriending was seen as a good thing by all parties involved. It offered a distraction from illness, respite for carers and helped young people to raise issues of personal importance. Young people saw befriending as fun and a distraction away from everyday things. Physical activities that befrienders and young people chose to do were different from those that parents would undertake, such as rock-climbing and Go-Karting. Befrienders saw their role as providing a sense of fun, providing a safe place physically and emotionally, offering mentorship and widening young people's horizons, as well as creating space for parents.  Befriending was challenging for the befrienders given the diagnosis of this group of befriended. Negative experiences could result if pairs are poorly matched or if befrienders are not committed to the process. Exit strategies were not addressed. <b>CONCLUSION:</b> Sustainable befriending relationships are

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				dependent on commitment from both parties and transparency about the expected practices and processes from the beginning to the end of the relationship. RELEVANCE TO PRACTICE: The evidence that is available in support of befriending is mixed. To date this is the first study in relation to people with cystic fibrosis and will add to the body of knowledge of befriending in young people with a life-threatening chronic illness.
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Table 2.6: COST STUDIES

Author	Characteristics of participants	Support evaluated	Methodology	Main findings
Holmes (2010) <sup>91</sup>	Disabled children	Focuses on short break provision	<p>The aim of this study was to calculate the costs incurred by Children’s Services Departments of providing short breaks to disabled children and their families. The study aimed to calculate the costs of individual services, provided by both local authority and voluntary service providers. In addition, and in order to calculate the full range of costs associated with the provision of short breaks, the study aimed to identify and calculate the costs of the routes by which families are able to access short break provision, and any ongoing social care activity undertaken to support the child and family once in receipt of short break services.</p> <p>Two types of access routes were identified and costed for comparison: the ‘traditional’ assessment and referral route, which includes an initial or core assessment, resource allocation panels, and assessments carried out as part of the Common Assessment Framework; and a ‘local core offer model’ whereby a local authority offers the provision of a standardised package of short break services to a specific population of disabled children and young people, who meet an identified set of eligibility criteria.</p>	<p><i>Access to short break services</i></p> <p>Each of the participating authorities had developed, or were in the process of developing, a ‘tiered’ referral process, whereby the assessment undertaken with families was determined by both the presenting needs and the intensity of service likely to be required. Short break services could be accessed via a local core offer route for families with lower levels of need, and the traditional referral and assessment route for those with higher need.</p> <p>In each of the participating authorities, the local core offer was available to children with severe physical or learning difficulties, but low levels of social care need. Two of the participating authorities required no further assessment to be undertaken with families meeting the criteria for the local core offer. In both cases, the majority of activity to refer children and their families into local core offer provision, will be undertaken by lead professionals from other agencies. Therefore, costs to social care per child are estimated to be nominal. In Authority A, some families requesting local core offer services were discussed at the resource panel. It was noted by participants, that in the vast majority of cases, the needs of the families’ requesting services from the local core offer are minimal and can therefore be discussed quickly by panel members. The costs to social care of these discussions have been calculated at £12.03 per child. The traditional referral and assessment route was undertaken in the participating authorities where it was felt that a family may have a greater level of need, which could not be met the services provided in the local core offer. In such cases a more in depth assessment was undertaken, most commonly an initial assessment. One authority was also using the Common Assessment Framework where appropriate. Participating authorities reported that a core assessment was only undertaken</p>

				<p>with those families whose need is greatest, or where a more intensive service, such as an overnight short break, is requested.</p> <p>Two of the three participating authorities used panels in deciding how resources may be most usefully deployed to support families. In both cases, the panels consisted of senior managers from a number of agencies.</p> <p>Table 1 below summarises the costs of each referral process to social care in each of the participating authorities.</p> <p>7</p> <p>Table 1: Costs of referral processes in Authorities A, B and C</p> <table border="1"> <thead> <tr> <th rowspan="2">Level of need identified</th> <th colspan="2">Authority A</th> </tr> <tr> <th>Referral and assessment route identified</th> <th>Cost (£)</th> </tr> </thead> <tbody> <tr> <td>Local core offer: Low Need</td> <td>Panel discussion:</td> <td>12.03</td> </tr> <tr> <td rowspan="3">Medium need</td> <td>Initial Assessment</td> <td>307.36</td> </tr> <tr> <td>Panel discussion</td> <td>52.11</td> </tr> <tr> <td>Total Cost</td> <td>359.47</td> </tr> <tr> <td rowspan="4">High need</td> <td>Initial Assessment</td> <td>307.36</td> </tr> <tr> <td>Core Assessment</td> <td>710.12</td> </tr> <tr> <td>Panel discussion</td> <td>52.11</td> </tr> <tr> <td>Total Cost</td> <td>1069.59</td> </tr> </tbody> </table> <p><b>Ongoing Support</b></p> <p>In addition to the assessment of disabled children and their families and the delivery of services, children’s social care departments provide ongoing support to families receiving short break provision. This ongoing activity included regular support visits to the family and reviews.</p>	Level of need identified	Authority A		Referral and assessment route identified	Cost (£)	Local core offer: Low Need	Panel discussion:	12.03	Medium need	Initial Assessment	307.36	Panel discussion	52.11	Total Cost	359.47	High need	Initial Assessment	307.36	Core Assessment	710.12	Panel discussion	52.11	Total Cost	1069.59
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				<p><i>Support visits</i>  The cost of regular visits for the three short break authorities has been calculated as £99.32 in Authority A, £99.05 in Authority B, and £54.17 in Authority C, per visit. These costs include the time spent directly with the family and travel time to visits within the authority. All three short break authorities estimated that on average a visit takes 1 hour. However, travel time varied substantially between the authorities, ranging between 40 minutes and three hours across the authorities.</p> <p><i>Reviews</i>  Activities undertaken to complete reviews included: preparation prior to the meeting, including updating and collating relevant paper work and contacting other professionals; travel to and attendance at the meeting; and any administrative tasks after the meeting, including completing minutes and updating child care plan. The costs of reviews ranged from £186.90 to £260.63.</p> <p>The research found a wide range of short break services provided across the participating authorities. For example, in total, 35 different groups were listed, each working with a different group of children, at different locations, with different funding and delivery arrangements.</p> <p>It was possible to identify some generic service types under which the services identified could be categorised. However, a wide variety of services were found within each service type. For example, each of the groups identified as an afterschool club ran for a different number of hours, with different staffing, and were provided to a different number of children and for children with a variety of needs or ages. As such, costs of each service type also varied within and across participating authorities.</p> <p><b>The cost of the services varied according to:</b>  o the provider;</p>
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				<p>o the type and number of staff required;</p> <p>o the length of the activity;</p> <p>o the number of children attending;</p> <p>o the needs of the child or children accessing the service.</p> <p>Table two summarises the costs of each service type. The table shows the range of costs calculated for each service type.</p> <p>Table two: costs of services by service type</p> <table border="1"> <thead> <tr> <th>Service type</th> <th>* Costs</th> </tr> </thead> <tbody> <tr> <td>Residential overnight</td> <td>£69.97 – £373.00 per child per night (24 hour period)</td> </tr> <tr> <td>Family based overnight</td> <td>£140.36 - £226.26 per child per night (24 hour period)</td> </tr> <tr> <td>Day care</td> <td>£99.21 – £204.83 per child per session (8 hours)</td> </tr> <tr> <td>Domiciliary home care</td> <td>£16.74 – £25.60 per family per hour</td> </tr> <tr> <td>Home support</td> <td>£17.54 – £25.60 per family per hour</td> </tr> <tr> <td>Home sitting</td> <td>£10.98 – £26.07 per family per hour</td> </tr> <tr> <td>General groups</td> <td>£296.68 - £430.61 per session</td> </tr> <tr> <td>Afterschool clubs</td> <td>£239.77 - £331.17 per session</td> </tr> <tr> <td>Weekend clubs</td> <td>£296.68 - 324.17 per session</td> </tr> <tr> <td>Activity holidays</td> <td>   £113.38 (for a 2 day break) - £3,701.15 (7 day break)</td> </tr> </tbody> </table> <p><b>Data from voluntary service providers</b></p> <p>Like the participating authorities, the nature of the finance data supplied by the voluntary service providers (VSPs) varied. The costs of overnight services calculated from the data obtained from the local authorities were comparatively similar to those calculated from data supplied by the VSPs. Calculated costs of local authority provided residential services ranged from £223 - £419 per child per night for local authorities, compared to £229 - £500 per child per night for service providers. Family based overnights ranged from £140 – £226 per child per night for local authorities compared with £97 - £265 for the VSPs. A greater diversity in the unit costs were calculated across the other</p>	Service type	* Costs	Residential overnight	£69.97 – £373.00 per child per night (24 hour period)	Family based overnight	£140.36 - £226.26 per child per night (24 hour period)	Day care	£99.21 – £204.83 per child per session (8 hours)	Domiciliary home care	£16.74 – £25.60 per family per hour	Home support	£17.54 – £25.60 per family per hour	Home sitting	£10.98 – £26.07 per family per hour	General groups	£296.68 - £430.61 per session	Afterschool clubs	£239.77 - £331.17 per session	Weekend clubs	£296.68 - 324.17 per session	Activity holidays	 £113.38 (for a 2 day break) - £3,701.15 (7 day break)
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				<p>services types. On the whole, the unit costs of services calculated from VSPs were greater.</p> <p><b>Summary of key findings</b>          Costing short break provision for disabled children and their families can be complex. This study has found a wide variety of service types, alongside a diversity in delivery and funding arrangements. Moreover, the social care activity undertaken with children receiving short breaks varies between local authorities, according to different referral and assessment models and procedures, and different levels of social care need identified in the families. It was evident from the study that the costs of individual services or social care processes are best analysed in relation with one another, whereby different components are built up to calculate a more comprehensive cost to social care of the provision of short break services.</p> <p><i>Social care activity and need: direct payments</i>          The study found that in the vast majority of cases the levels of social care activity was determined by the needs of family. The referral routes used in each of the authorities reflected the level of need of each family. The frequency of visits undertaken with families was in part determined by the level of need identified. For instance, children receiving support as part of the local core offer were subject to lower levels of ongoing support, determined on a case by case basis in each of the authorities. Children with higher levels of need accessed services through initial or core assessments and received a higher level of ongoing support. However, in each of the participating authorities, where a request for direct payments is made by a family, an initial assessment is required, regardless of the needs of the child and their family. As a result of the initial assessment, a family receiving direct payments is subject to regular visits and reviews. Social workers in each of the authorities noted that this level of intervention was not always appropriate for the needs of some families, which may in many cases, be comparable to those receiving services as part</p>
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				<p>of the local core offer.</p> <p><i>Additional costs to services</i> Some of the services require additional activity before a child could access them. For instance, in addition to the costs of an overnight short break placement, costs are attributable to the time spent by social workers to introduce the child to the placement. The time that social workers spent introducing a child to a new overnight short break placement varied according to the needs of the child. Social workers reported that it took on average 7 1/4 hours at an average cost of £288.04. This includes visits to the new foster carers or unit prior to placement, a pre-placement meeting, and completing necessary paperwork.</p> <p><i>Commissioning and setting up services</i> The research has found that further consideration may need to be given to the costs of contracting and commissioning services. Service managers from the participating local authorities and service providers reported that setting up and maintaining contracts take up a substantial proportion of their time. Service providers reported that the tendering and negotiating for contracts was a time consuming process. Further work to identify the time spent on these activities would enable accurate and more comprehensive calculations of the full cost of commissioning services.</p> <p>It was also noted by participants that a considerable amount of time was spent on the development and implementation of various services and referral routes. Two of the participating authorities reported that they actively sought out families who would be eligible for local core offer services. This involved contacting special schools, GPs, specialist nurses and other professionals working with disabled children. These activities will also incur a cost.</p> <p><b>Conclusion</b> This study outlines that some of the services identified and</p>
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				<p>costed in this research are some of the most costly provided by Children’s Service’s Departments for children not looked after. Many disabled children require high levels of social care support and costly assessments. However, research suggests that short break services produce positive outcomes for some of the most vulnerable families. Some research has suggested that the provision of short break services can prevent children from being placed in more costly permanent placements (Beresford, 1994; Chan and Sigafos, 2001).</p> <p>This costing methodology enables local authorities to consider the costs of services in relation to the additional work required to access and support children in short breaks. Furthermore, decisions regarding resource allocation can be taken in light of the needs of children and desired outcomes. For instance, the methodology enables service providers to compare the costs of two different afterschool clubs. One of these clubs may be more expensive than the other, but may offer three hours of provision, rather than two hours. The higher cost after school club may also be delivered by more staff, resulting in a higher adult to child ratio. Therefore, this more “expensive” route may be more appropriate for children with more complex health needs, who may require more careful supervision. The additional workers may provide better value for money. Thus, the costs of the service can be balanced with the outcomes achieved. Consequently, we therefore advise that these findings are linked with the research currently being undertaken by CeDR at Lancaster University and the National Development Team for Inclusion (Hatton and colleagues, forthcoming).</p>
Nef Consulting (2009) <sup>92</sup>	Disabled children with complex needs	Explores the social and economic value created by the short breaks component of the Aiming High	To ascertain the social and economic value created by effective local delivery of short breaks, telephone interviews were conducted with ADHC lead staff from 5 Pathfinder authorities. This enabled the creation of a "theory of change" which is summarised in the form of an impact map. The social and economic outcomes for a range of beneficiaries (stakeholders) are described and	<p>Through independent analysis of data, Nef Consulting calculated that the State could make an estimated annual saving of <b>£174 million</b> if short breaks were effectively delivered to all those eligible to receive them.</p> <p>This saving has been based on the following data:</p> <ul style="list-style-type: none"> <li>- decreased cost of long-term residential care from reductions in the number of disabled children placed outside of the family</li> </ul>

		for Disabled Children (AHDC) programme for disabled children with complex needs in England.	two illustrative case studies are presented.	<p>home: <b>£135 million</b></p> <ul style="list-style-type: none"> <li>- decreased cost to health services from reduction in parents', families' and carers' stress: <b>£18 million</b></li> <li>- decreased cost to schools of educating siblings with behavioural and emotional difficulties: <b>£21 million</b></li> </ul> <p>These calculations have been based on the indirect impact on the family environment in terms of a reduction in stress for the parents, more time for other siblings and a reduction in family breakdown. It should be noted that the lack of a co-ordinated approach to the delivery of services, the social isolation of disabled children and their families, along with stress and potential family breakdown, can be calculated using additional indicators. Therefore, the figure given in this research should be interpreted as a minimum figure.</p>
Copps & Heady (2007) <sup>93</sup>	Disabled children	Focuses on short breaks and key workers	Focusing on two services (short breaks and key workers), this report aims to quantify the financial costs and benefits of supporting disabled children and their families to inform the 2007 Comprehensive Spending Review. It draws on a variety of published and unpublished sources, a search of academic journals, and interviews with experts in the field. It reviews what is known about disabled children living in the UK, describing an average family of a disabled child to provide a benchmark for subsequent calculations, provides unit costs for short breaks and key workers, describing the outcomes of each service, links the outcomes of short break and key worker services with the financial benefits they imply, including determining the 'total preventable costs' associated with living with a disabled child relative to an average family, compares the financial costs and benefits of short break and key worker services, including varying the assumptions used and presenting an estimate of the overall benefit of the services, and discusses the implications of the findings.	Overall, the report suggests that, taken over the whole population of disabled children, the cost of providing short breaks and key worker services is more than the financial benefit.
Carlin & Cramer <sup>94</sup> (cited in			Most comprehensive survey available of 'shared care' short break services. Survey includes responses from 120 schemes (94 public, 26 voluntary sector)	£44 UK average allowance/ wage payment for short break carers per overnight/ 24 hour period. Carers on average linked on to 1.3 children.



<p>Copps &amp; Heady, 2007 who gave a confidence rating of ***)</p>				<p>Carers receive an average of 14 hours training.  51% of disabled children placed are aged between 5 and 11. 34% are aged between 12 and 16.  Additional information – contract carers on average are linked to 5 children.  72% of carers required between 11 and 20 hours training.  55% of children placed are aged between 5 and 11. 34% are aged between 12 and 16.  63% care for between 16 and 20 nights per month. 26% between 10 and 15 nights.  Sitters paid average £6.94 per hour.  Each sitter is on average linked to 1.4 children.  64% required sitters to earn between 11 and 20 hours preparatory training.</p>
<p>Tapsfield &amp; Collier (2005)<sup>95</sup> (cited in Copps &amp; Heady, 2007 who gave a confidence rating of ***)</p>			<p>An analysis of the costs of providing foster care using national data and data provided by seven foster care providers (four public and three independent). Includes allowances paid to foster carers, fees, training and management.  Costs for financial year 2004/ 2005</p>	<p>It costs £13,416 per year to support one foster carer (costs including recruitment, management, ongoing support, equipment and training). Figure is based on one social worker supporting 10 foster care households.  Overheads are divided as follows (costs given per carer):  Supporting social workers - £3,249  Manager - £860  Support groups for foster carers - £240  Support for foster carers' sons and daughters - £40*  Out of hours crisis support - £182  Support events for foster families - £150  Support workers - £1,322*  Educational support for foster child - £1,645*  Equipment in foster home - £2,296  Independent legal support - £40  Panel (to approve foster carers) - £200  Training costs (for staff) – 240  Recruitment - £1,725  TOTAL - £13,416  This unit cost is likely to be lower for short break carers as a social worker can support more than 10 carers (* indicates those costs excluded for short break carers).</p>

				It costs around £40 for a 3.5 hour training session for foster carers. This equates to an hourly cost of £11.43.
Robinson (2003) <sup>96</sup> (cited in Copps & Heady, 2007 who gave a confidence rating of *)			A survey of short breaks available in the South West for children with learning disabilities from 13 councils. Questionnaire-based followed up with telephone interviews. Costs for financial year 2001/ 02	Unit cost of shared care scheme short breaks is £61.17 per day. Additional information: Unit cost £176.10 per day for residential (averaged between 21 in-house residential, voluntary sector and private sector scheme). Unit cost £12.30 per hour for sitting service (9 schemes)
Heslop et al (2003) <sup>97</sup> (cited in Copps & Heady, 2007 who gave a confidence rating of *)			Survey-based assessment of short break services. Intends to determine whether paying 'enhanced' carers on contract is more effective than just providing a basic 'standard' allowance. Data based on detailed questionnaires from ten schemes. Information on salaries, length of care, administration and equipment collected from schemes. Capital and overheads estimated on the basis of published costs for similar services (PSSRU 2001). Costs for financial year 2000/01.	Unit cost £37-284 for short breaks, provided by a 'standard' carer. Unit cost £97-592 for short breaks, provided by an 'enhanced' carer. Unit cost £14.31 for social services/Barnardo's sitting service for three hours. The health of parents of children that have received breaks deteriorates in the six months after first receiving short break services. 46% report emotional/psychological deterioration and 37% report physical deterioration (n=59), compared to 67% and 0% in waiting list group (n=21). Short breaks have no significant effect on the health of siblings. This pattern could be explained by the selection of families for short break services.
Curtis & Netten (2005) <sup>98</sup> (cited in Copps & Heady, 2007 who gave a confidence rating of ***)			Unit cost information compiled annually by the University of Kent. Data drawn from a variety of sources. Costs for financial year 2004/05.	Unit cost £33 per session (morning, afternoon or evening) for local authority day care for adults with learning disabilities. Inflated to 2005/2006 prices this is £34. Unit cost £77 per session (£18 per hour) for voluntary sector, activity-based respite care for people with learning disabilities Inflated to 2005/2006 prices this is £78. Unit cost of community homes for children £2,194 per day. Inflated to 2005/2006 prices this is £2,236. Unit cost of foster care is £477 per week. Inflated to 2005/2006 prices this is £486. Unit cost of a visit to a GP with a full prescription £53.40. Inflated to 2005/2006 prices this is £54.41.
Children's			Severely disabled children. Costs prepared as part of	Unit cost £454 per day. Includes on-site doctors and full-time

Trust <sup>99</sup> (cited in Cops & Heady, 2007 who gave a confidence rating of ***)			management accounting and updated annually. Costs for financial year 2006/07.	nursing care.
Bradford Metropolit an Borough Council. <sup>100</sup> (cited in Cops & Heady, 2007 who gave a confidence rating of **)			Interview to determine unit cost of services Costs for financial year 2005/2006.	Unit cost of £90-95 per break, based on the total budget for the scheme divided by the number of sessions provided.
Metcalfe (unpublish ed) <sup>101</sup> (cited in Cops & Heady, 2007 who gave a confidence rating of **)			Analysis of costing of services for Doncaster Metropolitan Borough Council. Costs for severely disabled children. Costs for financial year 2006/07.	Unit cost of £166.37 to £370.78 per 24 hour period for residential care short breaks.
Barnardo's <sup>102</sup> (cited in Cops &			Unit cost data provided by policy department. Based on information from Barnardo's Welsh short break service.	Unit cost £3,000 per year. Based on each child provided with a week-end short break once a month. Costs include project manager, carer allowances, training and reviews, and equipment

Heady, 2007 who gave a confidence rating of **)				costs. Does not include administration and management or office overheads. Day care for three hours a week (or 150 hours per year) costs £2,700.
NCH internal cost data, provided by Clare Gent, Service Development Manager, NCH <sup>103</sup> (cited in Copps & Heady, 2007 who gave a confidence rating of **)			Based on 33 residential short break services in the UK, provided for around 1,000 severely disabled children Costs for financial year 2005/2006.	Unit cost £400 per night for residential services. Annual cost per child, based on three nights per month plus a holiday break is £16,000 per year. Shared care services with trained professional foster carer is £140 per night.
Kavanagh (1990) <sup>104</sup>			The variety of care received by intellectually disabled children and adults in hospital, and in residential care, and the comparative costs were examined.	The cost of caring for the intellectually disabled was lower in communal homes. However the quality of life in terms of the development of social skills is better away from large hospitals. The costs of providing services to home-based clients include GP visits, out- and in- patient treatment, respite care, day and adult training centre visits and a social worker's time. The mean weekly cost for adults living in households was 255 (range 140 - 840) whereas in communal establishments the range was 296 to 834.

Table 2.7: SYSTEMATIC REVIEWS

Author	Characteristics of participants	Support evaluated	Methodology	Main findings
Robertson et al. (2011)			Reviewed 60 evaluation articles and reports	Short respite breaks positively impact on the wellbeing of carers (although these effects did not tend to be maintained over time) but also benefitted the children receiving the breaks as well as the family as a whole. Family relationships and stress levels improve. In the child, increased independence, social skills, social awareness, interests and confidence were noted in some studies (Robertson, et al., 2011). A smaller number of studies (albeit more methodologically rigorous) that attempted to objectively measure change identified no significant differences in social outings, friends, or child behaviour problems (Robertson, et al., 2011). They identified key gaps in the literature, namely little is known about the effects of respite care on fathers, siblings, the synergistic effect of other interventions, and long term effects
Whitmore (2016) <sup>105</sup>	Respite care among caregivers of children with Autism Spectrum disorder		An integrative review of respite care and stress. A final sample of 11 primary research reports were located using several databases. Articles were included that were: related to the focus of the review, written in English, and published within the last 10 years.	<p>While most studies found that respite care was associated with lower stress, several found that respite care was associated with higher stress. One study found no association. A model is presented that contributes to a new understanding of this relationship. Overall, the results of this integrative review provide some evidence that respite care use may be associated with a decrease in stress among caregivers of children with ASD. However, due to the lack of consistency and quality across the studies, these findings must be interpreted with caution.</p> <p>Many questions remain unanswered in the current literature and warrant future investigation. What factors make respite care adequate at reducing stress? How does frequency, duration, and timing of respite care impact this relationship? Do parents with more access to respite experience greater reductions in stress and does frequency, duration, or “dose” of</p>

				<p>respite care matter? Does respite care provide only a temporary reduction in stress or can effects be sustained over time? Does the quality of respite care impact the association with stress? If so, what is quality respite care? Is satisfaction an important variable that could potentially moderate the relationship between respite care and stress? With so many different types of respite care, how do we consistently measure it? Are there different types of respite care that are better for different families? Can we identify common characteristics to help screen for and refer families to respite care programs that match their needs? Why do some parents use respite care and others not? What additional factors impact access and utilization? How can we help reduce barriers to access? How can we expand opportunities for both informal and formal respite care, especially in rural areas and communities that lack adequate resources or cultural awareness? How is the relationship between respite care and stress the same or different among other non-traditional caregivers or in other cultures? These questions provide important implications for research, practice and policy.</p>
Strunk et al. (2010)	Respite care for families of special needs children		<p>A systematic review aimed at integrating the findings from reports of both quantitative and qualitative studies of families, with children suffering from disabilities, receiving respite services. All quantitative or qualitative study involving families living in the United States, Australia, and the United Kingdom, of any race, ethnicity, nationality or class receiving respite services were eligible for inclusion. Fifteen relevant research reports were retrieved during the search period. All fifteen reports were published in journals and appeared between 1995 and 2006.</p>	<p>A synthesis of findings from the research indicate that respite care can be an appropriate and effective intervention to decrease stress and should be used as an appropriate coping strategy for parents of children with disabilities.</p> <p>The comprehensive care needs of children and their families' inability to meet or cope with these needs are major factors contributing to high stress among the parent caregiver. Studies indicate that respite care can be an appropriate and effective intervention to decrease stress in the family caregiver. They also indicate that despite the severity of the disability, parental income level, or demographic location, respite is a needed support service for families of children with special needs. Studies also indicate that the use of respite increased parent/child relationships and decreased the risk of child abuse. Studies report that there is definitely a need for respite</p>

				<p>services among families of children with a disability.</p> <p>Service providers and funding agencies need to be in a better position to plan and manage respite as a service to families with children who have disabilities. Public health nurses, in particular, are in a position to enhance nursing's collaborative relationships with respite care programs and to improve nurses' effectiveness as case managers for families of children with developmental disabilities. Nursing education could employ the development and provision of continuing education courses aimed at increasing the awareness of the problems associated with parenting a child with developmental disabilities. Nurses and other healthcare providers are in a position to help parents identify specific stressors and to help develop coping strategies to deal with them in an effective manner. Most importantly, nurses can be used as contact points within the hospital to coordinate communication with other service providers who are involved in the child's treatment.</p> <p>Further research is needed concerning implied outcomes and cost of supplying respite care to those families in need. There is virtually no information available to date as to influence of respite care upon the families of disabled children and abuse potential and little information exists on the interrelationships between respite care, child abuse potential, family relations, and parenting stress over time; therefore, future research would do well to assess multiple types of abuse using multiple informant sources as a means of demonstrating the possible impact of respite services.</p> <p>There appears to be little research on effective models of respite care for individuals with developmental disability and severe behavior problems. Another area that needs to be more fully explored is the benefit of respite care on outcomes for individuals with a developmental disability and their families.</p>
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				Little is known about the planned versus the emergency use of respite care; therefore, further research exploring the availability, use, and benefits of respite care is needed so that service providers and funding agencies will be in a better position to plan and manage this vital service. More research that includes fathers and other members of the family in addition to mothers is clearly warranted. There has also been limited follow-up on the longer-term benefits of respite care on measures such as stress; therefore, more studies of long-term outcomes are needed.
Moola et al. (2014) <sup>106</sup>	Therapeutic summer camps for children with chronic illnesses (including cancer, epilepsy, celiac disease, diabetes, physical disabilities, HIV and Aids)		Systematic review to assess the psychosocial impact of camp for children with chronic illnesses. 21 studies were included in the review (these have been listed separately in the data extraction tables in this review, apart from studies which only included participants with cancer).	<p>Although overall methodological quality was weak, camp participation appeared to offer short-term psychosocial benefits on some parameters in children with a variety of chronic illnesses. There was some consistency in improved social outcomes, such as social interaction and acceptance.</p> <p>Based on the available evidence, it is premature to make robust claims regarding the psychosocial impact of camp as a therapeutic intervention. Theoretically informed camp programs, long-term follow-up, and incorporating camp-based messaging into routine hospital care, may enhance the utility of camp as a potential psychosocial intervention in paediatrics</p>
Novak et al. (2013)	Children with cerebral palsy	Respite care normally provided outside the home	Systematic review of interventions for children with cerebral palsy which includes references to effectiveness of respite as an intervention with this client group	The review concludes respite is a yellow intervention which means the evidence supporting its use was either lower-level of inconclusive. There was not robust evidence of effectiveness when strict systematic review criteria about design quality, adequate sample size and independent replication were used to judge the evidence.



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