Research Report DFE-RR063

The impact of short breaks on families with a disabled child: report one of the quantitative phase

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Executive Summary

The study

This document reports on a cross-sectional sample of families with a disabled child using short breaks in England; it describes the characteristics of children and families using short breaks, the nature and quantity of the short breaks they are using, their experiences of and satisfaction with short breaks and which factors are associated with a range of outcomes for family carers, disabled children and their siblings. This report uses both quantitative data derived from standardised questions and qualitative data from family members' written responses to open-ended questions in the survey instruments.

This is the first report from the quantitative elements of a study of the impacts of short breaks for families with a child with disabilities across 23 local authority areas in England; 21 Aiming High for Disabled Children Short Break Pathfinder and 2 Change Champions. It incorporates findings from a cross-sectional survey of families with a disabled child using short breaks and the first wave of a longitudinal study of the ongoing impact of short breaks over time. Survey responses were received from 336 main carers, 15 additional carers, 27 children using short breaks and 27 siblings of children using short breaks.

The families

Families using short breaks in this sample were a highly diverse group of children and families. In terms of the characteristics of the disabled children:

- More boys than girls use short breaks and carers of boys were more likely to complete a questionnaire than carers of girls.
- Children and young people using breaks were aged from 0 years to 23 years; most children were aged between 5 and 18 years. 44.3% of children had an autistic spectrum disorder and 91.9% had a learning disability.
- Most children met the criteria for at least one AHDC target group[a]; more children were in target groups A and D than in groups B and C and 31.6% of children were in target group E.
- Most disabled children were described as having good or very good health; however main carers described 27.3% of children using short breaks as having fair, bad or very bad health.
- There was wide variation in children's outcomes on various measures of well-being, relationships and behaviour, although this sample as a whole were reported to have more difficulties and fewer strengths than other samples of disabled children.

In terms of the main carers responding to the surveys:

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[a] AHDC Target groups (A to E)- A = Children and young people with Autistic Spectrum Disorders who may have other impairments such as severe learning disabilities or challenging behaviour. B = Children and young people with complex health needs including palliative care needs. C = Children and young people aged 11+ with moving and handling needs that require adaptations and equipment. D = Children and young people where challenging behaviour is associated with other impairments. E = Young people aged 14+ who are severely disabled

- Most carers who responded were female and most were parents of the child using short breaks; 92.0% were biological parents, others were step parents, adoptive parents, foster parents, grandparents and others.
- Carers' ages ranged from 30 to 70 years.
- The majority of carers were married but a sizeable minority were separated, divorced or single and 21.5% considered themselves to be a 'lone parent'.
- Carers were from a number of different ethnic groups, although the largest group (89.6%) was White British.
- Large variations in terms of carer's physical and mental health, well-being, financial situation, relationships and educational level are noted, with 45.5% of carers reporting a long-standing illness or disability. Main carers overall reported much higher levels of psychological distress than other samples of family carers of disabled children.
- In terms of other people in the household and other household information: Households contained between two and 14 members. Other adults in the household included parents, step parents, adoptive and foster parents, adult siblings, grandparents and others.
- Most partners were working full-time or part-time, some were looking after the family, retired, looking for work or not working because of sickness or disability.
- Ages of other children in the household ranged from 0 to 17 years, there were more females than males. Most were biological siblings of the child using short breaks; others were step siblings, adoptive siblings, foster siblings and cousins. The general health of the eldest sibling in the household was described as good or very good in most cases, with 28.9% of eldest siblings reported as having a long-standing illness or disability.
- In 11.7% of households there were at least two disabled children.
- English language was used in all households, but in a sizable minority of households a second or third language was also used.
- The socio-economic position of families varied, nearly half of carers had worried about money quite often or almost all of the time over the last few weeks. Over 20% of carers reported that their family were not managing well financially or having some level of financial trouble and 36.6% stated that their financial situation had got worse over the last 12 months.
- There was a very high level of variability in the level of deprivation of the lower level super output areas (LSOA) where these families lived. These included LSOAs in the 1% most deprived on both the Index of Multiple Deprivation (07) and the Child Well-being Index (09).

Short break usage and funding

In terms of usage of short breaks:

- Most carers (88.7%) indicated that their family was currently using short breaks; many used more than one type of break. Breaks included those that could be classed as leisure activities, overnight breaks, centre-based breaks and breaks that took place at home or in community settings (not mutually exclusive categories).
- In total families received an average of 570 hours of short break support per year, although there was massive variation from 1 hour per year to 4290 hours per year; 53.8% of families used 400 hours or less of breaks per year, 28.6% used 200 hours or less per year and 16.8% used 100 hours or less per year.
- 20.5% of families had experienced being turned down for at least one short break, 9.3% of children had been excluded from at least one short break and 8.3% of carers stated that their child was currently on a waiting list for a break.

- Leisure and play short breaks were used by 62.5% of families (for an average 123 hours per year).
- Overnight short breaks were used by 54.2% of families (for an average 603 hours per year).
- Paid carer but non centre-based short breaks were used by 57.1% of families (for an average 361 hours per year).
- Centre-based short breaks were used by 41.1% of families (for an average 506 hours per year).
- Almost a quarter (24.7%) of family carers used unpaid carers for short breaks (for an average 226 hours per year).

Funding for breaks came from a range of sources; many families used breaks funded by several different sources. 67.3% of families had breaks which were funded by local authorities, 10.9% had breaks funded by health authorities, 19.8% of families had breaks they funded themselves, 16.0% of families had breaks funded by other sources including charities and other government sources. 29.4% of families received direct payments to fund short breaks.

Short breaks: Family experience and satisfaction with short breaks

Carers provided rich details concerning their good and bad experiences of using short breaks. Problems using short breaks fell into five areas, resources, processes, information, family factors and child factors.

Some carers were reluctant to use short breaks and were concerned about whether short break providers would cope with their child or provide a suitable service. The report details the ways in which carers considered short breaks to be suitable and unsuitable for their families, particularly in terms of issues of staffing, personnel, venues and facilities, systems and structures, care and activities as well as sufficiency of breaks and the fact that some short breaks were not seen as providing a true break for the carer.

In terms of satisfaction with short breaks:

- Main carer satisfaction is highest with aspects related to the people involved in providing breaks and lowest with aspects of the processes involved in getting and keeping short break provision.
- Generally, disabled children are very positive about their breaks. Children identify a number of aspects which they particularly liked, these were themed into aspects of activities, relationships and confidence or independence and these themes are also reflected in the aspects of breaks that they did not like.
- Sibling's opinions of short breaks are also generally positive. Siblings are concerned that their brothers and sisters have a safe and enjoyable break, they also report benefits for themselves including having a break or a rest, being able to do a wider range of things and receiving more attention from their parents. Siblings also disliked some aspects of short breaks including being worried about their brother or sister while they were away, missing their brother or sister, feeling guilty about enjoying themselves without their brother or sister and missing out on the fun their brother or sister was having.

Factors associated with family outcomes and policy implications

The diversity of the group of families needing short breaks and the changing needs of families over time provides significant challenges to agencies planning and delivering short break services. Consequently the availability of a wide range of different services appears to help families and they further benefit if services are as accommodating as possible. Systems for accessing short breaks work best when they are simple and responsive; capable of taking account of a wide range of factors and open to finding flexible solutions for families. The study has identified many different types of breaks which are being used in diverse ways by different groups of families.

Overall, overnight (both centre-based and family or paid carer supported) and centre-based short breaks provide families with more hours of short break support and are more likely to be used by children who are older, have more complex disabilities, health needs and physical needs, but lower levels of actively challenging behaviour involving other people. This pattern suggests that these types of short breaks may be more ‘traditional’, long-standing forms of local authority-funded short break services that pre-date Aiming High for Disabled Children and they are highly valued by family carers. However, they may not be optimally focused in terms of accepting younger children, children with more actively challenging behaviours, or children of family carers who require overnight or centre-based short breaks to improve their own health and well-being.

In contrast, more innovative forms of short breaks such as leisure-based short breaks and non centre-based short breaks offered overall fewer hours of short break support to families of children who had less complex disabilities, health and physical needs, but who tended to show more actively challenging behaviour involving other people. These forms of short break support were more likely to be used by main carers with a greater level of education and in circumstances where they were needed, such as when main carers were lone parents. Again there are issues around how these short break services are focused, for example in terms of their attractiveness for use by older children with more complex disabilities, health and physical needs and particularly in making sure that they are practically useful in terms of giving family carers slices of time that are actually useful to them.

Across almost all types of short breaks, families in less financially and materially deprived circumstances had greater access to short break services. Targeting short breaks more effectively is particularly important here, as family economic and material disadvantage was also associated with a wide range of poor health and well-being outcomes for main carers and with poorer general health for the disabled child. Ensuring that decisions about access to short breaks are determined by a more balanced approach that takes into account the needs of the whole family (and also the behavioural needs of the disabled child) rather than primarily the disability, health and physical needs of the child, could help in reducing current inequities in access to short break services.

In terms of family satisfaction with short breaks, having more hours of short break support overall and using overnight short breaks were robustly associated with a range of aspects of main carer satisfaction with short breaks. Of concern was that main carers from ethnic backgrounds other than White British were less satisfied with various aspects of the suitability of short break support and short break carers. It is crucial that local authorities and short break providers ensure that securing equity across ethnic groups moves beyond access to services (where there were no differences across ethnic groups) to consider the suitability of short break provision across ethnic groups.

Again, family socio-economic circumstances were consistently associated with a wide range of aspects of main carer satisfaction with short breaks. However, although families in more deprived circumstances tended to receive less short break support, they rated themselves as more satisfied with the short break support they did use and were more satisfied with both the amount and range of short break support available. It is unclear whether families in more deprived circumstances have lower expectations of short break support or are less assertive in making their views known for fear of losing the support they do have. It is certainly the case that families in less deprived circumstances were more likely to articulate shortcomings in short break supports and to suggest improvements. Agencies undertaking consultations will need to take particular care to include the opinions of the whole range of families using and needing short breaks including families in more materially and financially deprived circumstances, as these families may bring different views about current and desired future short break supports than more assertive families in more affluent circumstances.

Families have highlighted a number of groups of children they feel are less well served by short break services, the AHDC target groups identify some of these, a further group being young disabled children (under 8 years). Many respondents suggest that more access to overnight short breaks is needed. Families have also highlighted their concern that care for disabled children before and after school and during school holidays is insufficient. Families differ in their approach to such care, some seeing it primarily as ‘childcare’ and others being happy to use it as ‘short break’ care. Families who have responded to this study have clearly stated a belief that some disabled children do not have equal access to wider services including childcare and in some areas leisure services, some carers feel that short break services are unfairly being used to compensate for deficiencies in other services rather than to provide additional support.

In policy terms, it is crucial that a consideration of short break support is integrated into wider considerations of family support taking the whole family as a focus. More personalised approaches to family support that allow the family to take a holistic view of their needs and design their support accordingly, without falling foul of artificial bureaucratic compartmentalisations of family support (short breaks vs. childcare is a particularly vexed issue for many families), may be one way of addressing this issue. Such an approach may also be helpful in helping families to find their preferred balance of short breaks that are booked well in advance and provide predictability for the family versus an allocation for short break support that the family holds back to use flexibly at relatively short notice. However, there are likely to be significant challenges for local authorities in moving towards effectively targeted and equitable personalised support, as the findings concerning direct payments illustrate.

Short breaks funded via direct payments have been shown to have a number of advantages for families and are viewed positively by most carers who use them. However, along with some examples of good practice families have described difficulties in accessing and using direct payments. Furthermore families who currently use direct payments tend to be those with higher levels of education, White British carers, female carers and those who live in less deprived areas. This suggests that some local authorities need to consider how to extend the use of direct payments beyond assertive and relatively affluent families – these issues will become even more relevant as part of a broader personalisation agenda.

- First, information concerning direct payments needs to be made more readily accessible to all families.
- Second, direct payments must have the potential to be of sufficient size to enable families to invest in significant quantities of overnight and centre-based short breaks if that is what the family needs and wants.
- Third, the process of applying for, allocating, using and monitoring direct payments needs to be considerably simplified.
- Fourth, local authorities may need to offer additional support (either directly or via other agencies) to families in administering and managing their direct payment.
- Fifth, arbitrary rules concerning how direct payments allocations may be used may need to be reviewed and relaxed to ensure that families can use direct payments in ways that make sense for the family’s functioning.
- Finally, local authorities will need to maintain a strategic development role to ensure that local markets for short break provision are delivering short breaks that are valued by families.

An important finding for policy-makers is the near-invisibility of NHS-funded short break support for the families in this study. This may be because families were identified via local authorities rather than Primary Care Trusts, but comments from several families mentioned the difficulty of gaining support from the NHS for short breaks. Given current policy proposals around the replacement of many of the functions of PCTs with GP commissioning consortia, an important issue for policy-makers is to consider whether the NHS should retain a commissioning responsibility for short breaks for families with a disabled child and if so where that commissioning responsibility should best reside. With less ring-fencing of budgets and less top-down control over local authorities on the horizon, it will also be important for policymakers to consider how local authorities will be made accountable to their local communities of families with a disabled child on the effectiveness of their family support, to ensure that these families do not become invisible and fall through the net in terms of local authority-commissioned support.

Finally, there are clear imbalances in short break support that represent a considerable challenge for policymakers and local authorities. Overnight and centre-based short break services are more likely to be used by older children with more complex disabilities, health and physical needs and it seems that family carers using these services are very satisfied with them and are unlikely to ‘trade’ some of these forms of support for more innovative leisure and non centre-based short breaks. Yet this may mean that these forms of short break support are effectively ‘blocked’ to younger children, children with more behavioural needs and family carers with more needs around health and well-being, who are more likely to use leisure and non centre-based short breaks. Unless there is to be a considerable expansion in overnight and centre-based short breaks, local authorities will have to manage very carefully a transition to more balanced profiles of short break support. This process will be made more challenging by the likelihood that the family carers using overnight and centre-based short breaks may be less likely to embrace processes such as direct payments or personalisation that could be used as tools to effect such a rebalancing.

Policymakers and local authorities will also need to consider such a rebalancing beyond the provision of ‘child’ services, as many young disabled people move into adulthood whilst still living with their family carers. Such a transition point is often felt as catastrophic by families as an array of family supports, including short breaks, are drastically reduced as their child officially becomes an adult, although the needs of the disabled young person and their family carers may change little over this transition point.

1 Introduction

In May 2009 the Centre for Disability Research (CeDR), Lancaster University, in partnership with the National Development Team for Inclusion (NDTi), submitted a proposal in response to an invitation to tender for a research project entitled: 'Evaluation of the Aiming High for Disabled Children (AHDC) Short Break Pathfinder programme and research into the impacts of short break provision on families with disabled children'. Through commissioning this research the Department for Education (then Department for Children, Schools and Families) had two aims; the first was to commission research to provide information about the impact and outcomes of short break provision for disabled children and their parents, carers and siblings; the second was to commission a programme evaluation of the AHDC Short Break Pathfinder programme. The Department intended that the results of the research would be used to enable improved provision and commissioning of short breaks at a local level, to provide information to underpin local guidance, to inform the national policy direction of the AHDC programme and to inform future government spending decisions.

The submission was successful and research began in the summer of 2009. In order to be relevant to emerging policy and practice as well as to have a benefit on longer term debates and service delivery the research project was tasked with staged deadlines for different components of the research programme (see below for more details). Whilst each element of the research project has produced a significant body of research in its own right, it is important to recognise that each is also contributing to a larger coherent corpus of knowledge in the form of the overall research programme.

This report is the first report of the quantitative element of the impact study and comprises pooled findings from two studies investigating the impact of short break provision on disabled children and their families.

1.1 Policy context

The term 'short breaks' has largely replaced the term 'respite' which was seen by some as having negative connotations. The term 'respite' potentially suggests a simplistic view of the removal of a burden - caring for a disabled child. By contrast it is claimed that 'short breaks' does not carry these same negative connotations and takes better account of the needs of the disabled child as well as their family. The term 'Short breaks' is also preferred as it provides scope to describe a wider range of services for children and families than 'respite' which is often associated with centre-based care, typically including overnight stays.

In May 2007 the then Government launched Aiming High for Disabled Children (AHDC), a programme aimed to improve a wide range of services for disabled children and their families. Significant additional funding allocations were made both to local authorities in England and to Primary Care Trusts in England to enable their joint delivery of this programme. A key component of AHDC was the transformation of services providing short breaks to families with disabled children. Local authorities across England were allocated total revenue funding of £269M for financial years 2008/9, 2009/10 and 2010/11 for this strand of the programme plus an additional £90M for capital works associated with short breaks. Of this, over £69M revenue and £14M capital was allocated to 21 Pathfinder authorities for these three financial years; these Pathfinder authorities also each received £15000 to support initial planning and preparation in February 2008. Funding was profiled across the main three year period, Pathfinder authorities received an average of 13.4% of their total revenue funding allocation for 2008/9 and around 43.3% for each of the years 2009/10 and 2010/11.

Capital funding allocations for Pathfinder areas were on average 30% for 2008/9 with the remaining 70% allocated for 2009/10. This funding profile is contrasted by the allocations of funding for non-Pathfinder authorities who were allocated around 3.2% of their revenue allocation for 2008/9, 22.9% for 2009/10 with the remaining 73.9% for 2010/11. Capital allocations for non-Pathfinder areas provided an average of 30% of capital funding in 2009/10 with the remaining 70% during 2010/11. AHDC funding to local authorities was conditional on the authority undertaking and acting on consultations with disabled children, disabled young people and their families. It was also conditional on their working in partnership with local Primary Care Trusts (PCTs) and others including a diverse range of short break providers. During this three year period PCTs in England were also allocated an additional £340M to be used for short breaks, community equipment, wheelchairs and palliative care. National standards for the AHDC programme were published in the form of a Core Offer in May 2008 followed by Short Breaks Implementation Guidance later that year incorporating the ‘Short Breaks Full Service Offer’ (FSO) (DCSF and DOH, 2008b, DCSF and DOH, 2008a). Further details on meeting the FSO were published in April 2009 by Together for Disabled Children, the organisation tasked with providing support and guidance to authorities delivering AHDC (TDC, 2009a). The FSO described short break services that:

- Are based on an assessment of local needs which included consultation with children and families.
- Significantly increase the volume of breaks available beyond 2007/8 levels.
- Have fair and transparent eligibility criteria.
- Provide a wide range of reliable short breaks including help to access universal services, overnight breaks at home or elsewhere and significant day time breaks at home or elsewhere.
- Provide positive experiences for children, for example helping them to socialise, form friendships and spend time with supportive carers.
- Are culturally appropriate.
- Include planned regular breaks when needed by families, including at evenings, weekends and holidays.
- Have the capacity to respond to urgent needs.
- Use the service providers best able to provide the highest quality and most efficient service.
- Provide information to the public, including information about eligibility, service thresholds and routes into services.
- Provide breaks which are fit for purpose and age appropriate. In particular services should ensure that groups are not disadvantaged in accessing short breaks. Five such groups were identified. It should be noted that these groups are not mutually exclusive and a child may belong to one or more group.

  A. Children and young people with Autistic Spectrum Disorders who may have other impairments such as severe learning disabilities or challenging behaviour.
  B. Children and young people with complex health needs including palliative care needs.
  C. Children and young people aged 11+ with moving and handling needs that require adaptations and equipment.
  D. Children and young people where challenging behaviour is associated with other impairments.
  E. Young people aged 14+ who are severely disabled.

Pathfinder areas were expected to meet the full service offer by April 2010. In June 2009 a further document was published which reviewed early progress toward AHDC, clarified the various strands and gave examples of practice (DCSF and DOH, 2009).

In May 2010 the new coalition Government indicated, in general terms, their commitment to continuing to improve services for disabled children (EDCM, 2010). For example, this commitment included a reference to using a proportion of the money saved by discontinuing the Child Trust Fund for provision of an additional 8,000 week-long respite breaks, made in a Treasury press release and in speeches by the Chancellor of the Exchequer and the Chief Secretary to the Treasury (HMT, 2010b, HMT, 2010c, HMT, 2010a). It was confirmed by the Deputy Prime Minister that this additional spending would amount to a further £20M per year from 2011/12 (Cabinet Office, 2010). Similar references were made in the Conservative Party Contract for Equalities (May 2010) which further stressed a desire to simplify the assessment of need and to give greater control to parents in respect of care services for their child (Conservative Party, 2010). At the time of writing it is undoubtedly early days for the new government, it is likely that the ongoing and future policy directions will soon become clearer; readers are advised to consult the Department for Education website to gain a fuller understanding of the current position.

1.2 Research context

The existing research literature provides some evidence of a range of benefits of short breaks as well as a number of problems related to accessing and using them. However the strength of this evidence is variable and studies have not been able to conclusively demonstrate causal links between, for example short breaks and well-being (McNally et al., 1999, Robertson et al., 2009). In part this is due to several intrinsic difficulties which have constrained research in this area and which make certain types of research design inherently difficult. For example research into short breaks has been subject to ethical and practical constraints on randomisation and there is an intrinsic inability to 'blind' recipients and providers to research conditions. Furthermore to date there has often been a lack of suitable control groups, many studies have small sample sizes and there have been few examples of longitudinal studies. Despite this, a growing body of qualitative studies is producing some descriptive and explanatory evidence and some quantitative work has been conducted. Together these studies offer a number of findings which are particularly relevant to the current study, including qualified evidence of a range of benefits for family members and a number of service delivery challenges.

Benefits identified for parents and carers include reduced levels of stress (Marc and MacDonald, 1988, Bose, 1991) and opportunities for rest and relaxation (Stalker, 1988, McConkey et al., 2004). Several studies have identified the importance of opportunities for uninterrupted sleep (Eaton, 2008, McConkey et al., 2004, McConkey, 2008, MacDonald, 2004, Davies et al., 2005). These benefits have in turn been connected with parents' ongoing or increased capacity to continue to care for the disabled child (Eaton, 2008, MacDonald, 2004, Tarleton and Macaulay, 2002, Smith et al., 1988).

Benefits identified for children include enjoyment of high levels of attention (Gerard, 1990), opportunities for new experiences (Gerard, 1990, Davies et al., 2005, McConkey et al., 2000) and chances to form friendships and socialise with peers and workers (Minkes et al., 1994, Tarleton and Macaulay, 2002, McConkey et al., 2004).

Benefits identified for siblings include the opportunity to spend more time with and have more attention from their parents (McConkey et al., 2000, MacDonald, 2004, Shared Care Network, 2008) as well as reduced stress and improved functioning within the family as a whole (Marc and MacDonald, 1988, Abelson, 1999). In addition studies have identified that siblings benefit by being able to take part in a wider range of activities than possible in the presence of their disabled sibling (Shared Care Network, 2008).

Issues identified with short break provision include a lack of flexibility (Stalker and Robinson, 1994, Collins et al., 2009), insufficient availability of trained staff (Collins et al., 2009, Thompson et al., 2009, Neufield et al., 2001) and negative reactions from children such as homesickness and distress (Thompson et al., 2009, Radcliffe and Turk, 2007, McConkey et al., 2000). Family members have also experienced negative feelings such as guilt or missing the child (Wilkie and Barr, 2008, Stalker and Robinson, 1994, Hubert, 1991, Hartrey and Wells, 2003). A range of barriers to participation in short break services have been identified; these have included general barriers such as a lack of suitable information and poor communication (Langer et al., 2009, Platts et al., 1995) as well as barriers which impact differently on different groups including children with complex health needs (Robinson et al., 2001, Social Care Institute of Excellence, 2008), children with challenging behaviour (McGill et al., 2006, McGill and Honeyman, 2009, Challenging Behaviour Foundation & Tizard Centre, 2009) and families from minority ethnic backgrounds (Hatton et al., 1998, Hatton et al., 2004).

As mentioned previously this study has been undertaken in the context of a larger research programme involving several elements and being undertaken by Lancaster University and The National Development Team for Inclusion (NDTi). This particular aspect of the research uses survey methods, primarily to investigate the wide range of impacts that may be associated with families' use of different types of short breaks. This report is the first report to be published from this component of the research, with further reports due after a second wave of surveys early in 2011. This research should be understood in the context of the learning emerging from the other parts of the overall research project, these include –

- A comprehensive review of the international research literature related to the uses of short breaks and their impacts on families with a disabled child; this covered a total of 56 publications from the United Kingdom, the United States, Canada and Australia (Robertson et al., 2009). The review highlighted a number of gaps and weaknesses in the existing body of literature; however it did find some evidence to suggest a number of positive impacts for individual carers, disabled children and siblings as well as limited evidence for positive impacts on overall family functioning.
- A qualitative study of the impacts of short breaks on families; this reported findings from a number of interviews, focus groups, observations and other research opportunities conducted in late 2009 with families using short breaks, short break providers and others involved in short break provision (Collins et al., 2009, Langer et al., 2009). The findings covered aspects of short breaks including issues around suitability, accessibility, information and communication as well as the impacts for families and some ways in which these might be maximised. The findings also provided insights into the short break workforce and into relationships between families and their short break carers.
- An evaluation of the implementation of AHDC in 21 Pathfinder areas. This component of the evaluation was conducted by the National Development Team for Inclusion (NDTi). This research used a Realist Evaluation approach to explore aspects of short break delivery such as the processes and mechanisms used to deliver the programme in the Pathfinder areas, the context and environment in which these services were developed and the likely outcomes of provision. To date an interim report has been published which

identifies a number of emerging theories of change (Greig et al., 2010). The final report from this component is being prepared and it is hoped it will be published soon.

Whilst many components of the research have run simultaneously or overlapped to some extent it has been possible to use the findings of some components to inform other aspects of the research. For example areas of interest identified in the literature review and early outputs from the qualitative study informed the questions incorporated into the surveys and outputs from all areas of the research project were considered when analysing the findings from the surveys.

1.3 What this report contains and what research questions it addresses

This report describes the combined findings from two survey based studies, the first being the initial iteration of a longitudinal cohort study the second being a cross-sectional study. The design of these studies and the methods used are described in more detail below. Both studies seek to answer questions about how different families experience their use of short breaks and to identify outcomes that are associated with the use of breaks, for example outcomes for the well-being and welfare of carers and children. The longitudinal study seeks to examine in further detail how the ongoing use of short breaks may have an impact on the nature and extent of these outcomes by following up families after a further year of short break use and by comparing outcomes for families who have used breaks for some time against those newer to using breaks. The longitudinal study additionally aims to examine short break experiences from the perspectives of different family members.

In general terms the research aims to answer the following questions

- What are the characteristics of families and family members using short breaks?
- What short breaks are these families accessing and what are the patterns of use?
- What is the position of families using short breaks on a number of measures (of well-being, relationships, financial welfare and so on)?
- How does use of short breaks (now and over time) impact on families' position on these measures?
- How do families experience short breaks?
- How satisfied are family members with the breaks they use?
- Do different types of family have different experiences or different levels of satisfaction with short breaks?
- What are the outcomes and impacts of short breaks for different types of families and for different family members?

Method

1.4 Design

The research comprises two quantitative research studies investigating the impact of short breaks on families with a disabled child. The first of these is a detailed longitudinal study investigating the experiences of families who were variously new, recent or ongoing users of short break services. The second of these is a cross-sectional survey of satisfaction and experience of families using short break services.

1. Longitudinal study: This research design involves a survey of families with a disabled child; these families are asked to complete an extensive questionnaire assessing the impacts that short breaks have on a number of key outcome measures at two time points spaced approximately 12 months apart. Information regarding the various measures and questions used in the questionnaires is given below. Families were recruited to include those that were relatively new to using short breaks as well as those who had used some form of short breaks over a period of time. ‘Time one’ data collection occurred between January and May 2010 with ‘Time two’ data collection planned for approximately 12 months later. In addition to a questionnaire for the main family carer three further questionnaires were developed that allowed different household members to participate. These comprised questionnaires suitable for additional family carers, for the disabled child using short breaks and for siblings of the child using short breaks. All questionnaires were designed primarily for self-completion, but potential respondents were offered a range of support including administration via telephone interview, face to face interview or translation into different languages or formats more suited to their needs or preferences.

2. Cross-sectional Study: This research was designed to be administered to a cross-section of families using short breaks and to run alongside the longitudinal study. The aim of the study was to survey a larger sample of families, investigating family well-being, use of and satisfaction with short break services. Families involved in the longitudinal study were not approached to participate in this aspect of the research. The data collection for the cross-sectional study also occurred between January and May 2010. A single questionnaire was designed for completion by one main carer in each family. The cross-sectional study used a subset of measures from the longitudinal study, thereby allowing the possibility of combining data where appropriate. The questionnaire was designed primarily for self-completion but again potential respondents were offered appropriate support to participate according to their needs or preferences.

As discussed above the longitudinal and cross-sectional studies form part of a larger mixed methods research programme. The design therefore sought to be complementary to the other research activities in terms of the areas covered, the methods used and ultimately in terms of the research questions which could be answered. Particular strengths of this component of the research are –

- That it provided an opportunity to seek views from a large number of families; thus enabling researchers to gain an understanding of how findings might be generalisable to all families in England using short breaks as well as giving a strong voice to family members.
- That although most of the information was gathered from the main carer (usually a parent) other people in the family also had the opportunity to participate, this included other carers, the child or young person using breaks and other children in the family; thus providing the researchers with the opportunity to explore different perspectives, importantly including those of children which may otherwise be overlooked (longitudinal cohorts).
- That the questionnaires themselves incorporated questions of two types, short answer pre-categorised questions and open response questions; this offered the potential for different analytic strategies, a range of opportunities both to measure and explain the phenomena being investigated and an opportunity for families to describe aspects of their experience in their own words.
- Where appropriate the studies incorporated pre-existing tools known to be valid and reliable and in many cases where data for similar populations is known; thus allowing the researchers to understand how much confidence could be given to findings as well as providing opportunities to compare the experiences of these families to others.
- The use of a subset of items from the longitudinal study for the cross-sectional study provided flexibility in how data could be combined and analysed; providing particular benefits in the case of low response rates.
- The opportunity to build up a large body of data of different types which could be interrogated in different ways; allowing opportunities to further test findings from other parts of the research as well as potentially to investigate further emerging questions of interest in relation to provision, experience and impact of short breaks.

1.5 Ethical issues

Given the sensitivity of the research topic and the potential vulnerability of respondents (including children) particular care has been taken to ensure that the research meets the highest possible ethical standards and that everyone involved in the research has been protected and supported as far as possible. Ethical approval for each study was given by the Ethics Committee of the Division of Health Research, School of Health and Medicine, Lancaster University. One local authority required a further application to their Research Governance Committee; this was made and granted before proceeding in this area. One further local authority required an application to their Research Governance Committee; this was made but unfortunately a decision could not be made in the timescale required for these studies; consequently research did not proceed in that locality.

Informed consent was gained from participants via the following process. Potential participant families were sent introductory materials (detailed later in this report) these were aimed at adults and provided information about the research such as who had commissioned it, what would be involved and the types of questions to be covered as well as practical issues such as how data would be anonymised, used and handled. In addition the materials provided contact details to enable prospective respondents to seek further information (by phone, letter or email) and contact details in case of a complaint or concern. If they wished to be part of the study the main carer was invited to give their written consent and to provide the research team with their contact information. In addition to the main carer the longitudinal study allowed the possibility for other members of the family to take part.

Where it was indicated that a child might also want to take part written consent to contact the child was first gained from an adult. Further information sheets and consent forms in an appropriate format were sent to each individual to consider, details of these are given below (introductory materials). Parents and carers were asked to support children where necessary in reading or understanding information. Children's consent forms were countersigned by an adult. Respondents were made aware of their right to stop giving information at any time and reminded that they could omit particular areas of information if they chose to do so. Respondents were also made aware of how the research findings would be disseminated and given a link to the study website where they could gain access to published materials. Measures to protect personal information included storage of written materials in locked filing cabinets in locked offices and password-protecting electronic files within password-protected computer directories. One respondent further requested that their original completed questionnaire was confidentially destroyed as soon as it had been processed, this was done.

Several prospective respondents contacted the research team for clarification or to seek further information, most often this centred on eligibility and whether or not the services they used were indeed short breaks.

During the course of the research a small number of respondents contacted the research team requesting further information about short breaks themselves, these enquiries were often specific in their nature relating to local provision. Where this happened the research team most often provided the respondent with contact details for the most appropriate local officer or provided information or links to further information such as websites. In a few cases the researchers acted as intermediaries forwarding printed materials (local newsletters etc) from local authorities directly to the enquiring respondent; at no stage were names, identifiers or contact details of families passed to local authorities to protect the anonymity of respondents.

In all dealings with families the research team have been acutely aware of the need to avoid raising unrealistic expectations, of the AHDC programme, of short break provision and of the impact of the research. For example whilst we were keen to point out to respondents that these were important studies it was important that they were also aware of the levels of complexity involved and of the presence of competing perspectives. This may have been especially true for child respondents, some of whom may otherwise assume that because they had given their time and stated what they wanted from short breaks, that this would be forthcoming. Our respondents remained keen to be involved, understanding that the researchers, commissioners of the research and other users of research outputs would be particularly interested in the perspectives of children and families using these services and hopeful that this would indeed have a positive impact on service provision and on debates around the needs of families with disabled children.

1.6 Sampling and Procedures

Recruitment to the surveys was made with the assistance of 23 local authority areas in England. These areas were all engaged in delivery of the Aiming High for Disabled Children Short Breaks programme, 21 being designated Pathfinders and the remaining two Change Champions. In order to equalise workload in different authorities and ensure a good geographical spread of responses approximately equal numbers of families were selected to be invited by each authority.

Local Authorities were initially asked to provide the researchers with anonymised data containing basic information about each family using short breaks in their area. From this data potential respondents were selected to be invited to take part in the studies. Local authorities were asked for information about date of birth, gender and membership of the five original Aiming High for Disabled Children target groups (A-E) as well as the dates that the family had first used short breaks and the date they had most recently used a short break. Many local authorities were unable to supply all of this information for each family but were willing to give as much information as they could. For example this often included only information related to the revised A/B target groups (TDC, 2009a, TDC, 2009b) which consolidated four of the original target groups (A, B, C and D) into two. In addition many local authorities had particular difficulties supplying information about the dates over which families had used breaks. Local authorities were asked to supply information only relating to families whom they would be able to invite to take part in the studies, in practice this usually meant families for which they held contact details or whom could be contacted through a third party such as a short break provider. The process of generating this data involved considerable work for many local authorities and consequently took some time.

The lack of completeness of the databases mandated a somewhat pragmatic approach to sampling. The data from each local authority area were initially ordered by the date of the families' most recent short break and families where it was known that they had not used a short break since April 2009 were removed from the sample frame. A sample was then constructed to promote sufficient representation of families having children of different ages, genders and representing target groups A to E.

This was achieved by a combination of probabilistic and non-probabilistic methods using systematic sampling commencing from a random start point with the data being ordered by date of their first use of a short break (if known) or by date of birth. This method was used to initially select at least 50% of the required total number for each local authority before boosting the sample where necessary to ensure sufficient numbers within each target group (as far as allowed by the data). In addition the sample of families to be invited into the longitudinal study was also boosted to ensure representation of new and recent users of short breaks as well as families who had used breaks for some time; again this depended on the availability of this information. Where key items of data were not available the sample was constructed systematically from the data ordered by the most relevant available characteristic. In a few cases where detailed data was not available the whole of the sample was constructed systematically from a random start point and it was not possible to boost the sample in any way.

Most local authorities initially were asked to invite around 20 selected families to the longitudinal study and around 50 selected families to the cross-sectional study. When it became apparent that fewer families than hoped were opting in to the studies 20 local authorities were asked to send out a further batch of invitations in order to help increase the overall number of responses. Most of these authorities sent an additional 50 to 100 families selected from the original local authority databases in a similar way to that described above.

Table 1 Summary of important characteristics of families invited to take part in the studies, based on data provided by local authorities.

	Longitudinal study	Cross-sectional study
Total number of families invited to take part	1030	1939
Number where child known to be male	461	871
Number where child known to be female	380	731
Child's DOB known to be 1995 or earlier	319	637
Child's DOB known to be 1996-1998	193	421
Child's DOB known to be1999-2002	223	436
Child's DOB known to be 2003-2009	188	309
Identified by LA as target group A	402	812
Identified by LA as target group B	340	649
Identified by LA as target group C	101	167
Identified by LA as target group D	147	202
Identified by LA as target group E (during 2009)	319	637
Recent user of short breaks (since 01.07.09)	299	---

The majority of families accepting the invitation to be part of the study were able to do so by completing a postal questionnaire. These families were sent an individual pack containing a covering letter welcoming them to the study and explaining how to proceed, a freepost return envelope and the appropriate questionnaire(s) together with any further information sheets and consent forms required for other members of the household. Families who were unable or who did not wish to complete a postal questionnaire were contacted to discuss their individual requirements, in most cases a suitable time was arranged to administer the questionnaire via telephone interview, 29 interviews were conducted in this way. In one case a family was visited to administer the questionnaire via personal face to face interview. This type of support was sufficient to enable respondents to take part, with none wishing to use the further support offered such as translation of materials or interviews into different formats or languages. Up to two reminder letters were sent starting from the fourth week after the questionnaire had been sent to the family, these reminder letters gave respondents the opportunity to request further copies of questionnaires or return envelopes, indicate that they would soon be sending the form or to ask the researchers to contact them to discuss queries or concerns.

Respondents who received telephone interviews were contacted at a time convenient for them negotiated with a researcher. Telephone interviews mostly lasted from 25mins to 50mins, in one case the interview was broken into three telephone calls on separate days to fit with the respondent's requirements. No children were interviewed over the phone. The one face to face interview took place in the respond's home at a time convenient to them and lasted a little over one hour.

Table 2 Summary of response to studies

	Longitudinal Study	Cross-sectional Study
Opted into study	166	305
Dropped out due to unforeseen / difficult circumstances	5	8
Known to have been lost in post	0	2
Returned completed, included in analysis	113	223
Returned completed, after analysis commenced	4	6
Total returned completed to date July 2010	118	229
Outstanding as of July 2010	45	70
Response to date as % of those opting in to study	71.1%	75.1%
Response to date as % of those invited to study	11.5%	11.8%

There are a number of potential explanations for the low levels of response to the original invitation to take part, some related to the families, some to external factors and some to the research itself. For example many of the respondents discussed the fact that they were very busy and found it difficult to find time for any additional tasks not directly related to their caring responsibilities, this is likely to have been equally true for non-respondents. Other families may not have identified the services they use as ‘short breaks’, the researchers had several discussions about this with potential respondents who contacted us for further clarification. Similarly some families who were invited to take part may not identify their child as ‘disabled’ and therefore decided the research was not of any relevance to them. A small number of families who originally opted in to the research later dropped out due to various changes in circumstances including deaths in the family, family breakdown and children being taken into care. Some local authorities expressed concern that there may be a high level of ‘consultation fatigue’ as these families may have been approached on several recent occasions during local AHDC consultations, needs assessments and service evaluations. It is also possible that the records held by local authorities may occasionally be incomplete or out of date and that some intended families did not receive their invitation to take part. There is also a certain amount of inherent unreliability in the postal system, for example the researchers were in contact with a small number of respondents who confirmed that they had sent completed questionnaires which were apparently then ‘lost’ in the post, in most cases respondents were kind enough to complete a second copy, however there may be other families who did not draw this to the research team’s attention. Furthermore a small number of questionnaires were received after Royal Mail first wrongly delivered them to another local freepost address. Factors intrinsic to the research include the fact that the questionnaires themselves were relatively long and asked detailed questions about sensitive areas, some family members may have been put off by this and chosen not to complete the form, indeed one non-respondent contacted the researchers to state that they found the questionnaire inappropriately long and intrusive.

The research team is therefore especially grateful to those families who did become part of the studies; they have provided information that was both rich and extensive. Indeed the level of detail that many respondents have provided to ‘open’ questions has greatly increased the overall quantity of data available. This in turn has afforded the research team opportunities to analyse data using a range of different approaches and we have been keen to supplement our intended analytical strategies to make full use of the data available. In this way data in a range of formats has been used to address the research questions and provide detailed information.

1.7 Materials and measures

1.7.1 Introductory materials

A number of introductory materials were prepared in order to provide potential respondents with information about the studies and what was involved.

Potential respondents to both studies were sent copies of -

- A covering letter from their local authority which introduced the research and explained how and why the family had been contacted.
- An invitation letter / information sheet from the Centre for Disability Research, Lancaster University. This outlined the purpose and methodology of the research as well as giving contact details for further information.
- A short consent form for those families wishing to take part. This gathered the main carer's consent, preferences, access information and contact details.
- A consent to approach child form (longitudinal study, only completed if children were to be invited to the study).
- A freepost envelope.

There were a few small differences between the introductory materials used for the longitudinal and cross-sectional studies, for example to allow other members of the household to be identified in families invited to the longitudinal study. Where the main carer indicated that other household members may wish to take part further appropriate information sheets and consent forms were sent out with the questionnaires. Two versions of the children's information sheets and consent forms were made to cater for the needs of children of different ages. There were slight differences between these, for example whilst both contained a number of symbolic pictures to aid comprehension; these were fewer in the older child's version.

Slight refinements were made to the introductory materials as the research progressed to ensure that they were as informative and unambiguous as possible. For example it became obvious that potential respondents required a clear explanation of what a 'short break' could encompass. Examples of these materials from the longitudinal study can be found in Appendix A, as mentioned previously the materials used for the cross-sectional study were very similar.

1.7.2 The questionnaires - general

The questionnaires developed for these studies utilised key outcome measures capable of detecting a number of potential impacts of short break use. Where appropriate a variety of previously used and validated measures were used or adapted. In addition some items were specifically created for the purpose of the study. Several of the measures used were selected in view of the fact that they have previously been used in large-scale surveys such as the Millennium Cohort Study (2003/05) since this would enable a comparison between the families approached in this study and UK family carers more generally. The researchers are grateful to members of the policy steering group who provided suggestions and comments throughout the process of selecting and developing the measures as well as commenting on the final questionnaires.

Areas covered in the studies included:

a) The well-being of the disabled child using short breaks and their siblings (i.e. emotional and behavioural health, physical health, health-related behaviour, school involvement and educational performance, peer relationships and self-efficacy and esteem).
b) The well-being of carers (i.e. emotional health, employment, social participation and relationships).
c) Other factors that may influence the impact that short breaks have on families, such as household composition, lone parent status, hardship, ethnicity, age and gender of both carer and child, the nature of the child's impairment and area deprivation (the latter based on postcode information provided with respondent's contact details).
d) Families' use of and experiences of short breaks services.

Five different questionnaires were developed to be administered to different groups of respondents in the two studies. These are outlined below and examples may be found in Appendix B. In order to make the questionnaires clear and easy to use they were professionally printed on appropriate paper and bound into booklet format. Each questionnaire was given a colour theme to ease identification during discussions with respondents and make it more attractive.

Longitudinal study – Main Carer Questionnaire (LS MC)
This questionnaire was used for all main carers in the longitudinal study. It contained a full set of questions and measures including demographic questions, various measures of carer and child well-being and questions to elicit information about use of and opinions about short breaks. For many families in this part of the study this was the only form completed. The questionnaire was in large (A4) booklet format, running to 35 pages.

Longitudinal study – Additional Carer Questionnaire (LS AC)
This questionnaire was used when an additional carer in a family had opted in to the study. It contained a subset of questions and measures from the main carer questionnaire. In particular it focused on briefly eliciting measures of additional carers' thoughts and feelings as well as their opinions of the short breaks they used. The questionnaire was in large (A4) booklet format, running to 10 pages.

Longitudinal study – Child or Young Person using Short Breaks Questionnaire (LS CYP)
This questionnaire was used when a child or young person using short breaks wished to take part in the study. Two versions were produced, one for children known to have siblings which included questions relating to sibling relationships and one for children not known to have siblings which missed this section. Both versions also contained questions about relationships with friends, feelings about school and feelings and opinions of short breaks used. The questionnaire was in small (A5) booklet format running to seven or eight pages.

Longitudinal study – Sister or Brother of a Child or Young Person using Short Breaks Questionnaire (LS Sib)
This questionnaire was used when a sibling of a child or young person using short breaks wished to take part in the study. It covered areas such as sibling relationships, relationships with friends, feelings about school, feelings and thoughts about their sibling's short breaks and any benefits they themselves accrued. The questionnaire was in small (A5) booklet format running to eight pages.

Cross-sectional study – Main Carer Questionnaire (Family Experiences Questionnaire) (CS MC)

This questionnaire was used for all main carers in the cross-sectional study. No other questionnaires were used in this study. It contained a reduced set of questions and measures taken from the longitudinal main carer questionnaire. The questionnaire included shortened demographic questions, various measures of carer and child well-being and questions to elicit information about use of and opinions about short breaks. The questionnaire was in large (A4) booklet format, running to 22 pages.

1.7.3 The questionnaires - measures

1.7.3.1 Parents and Carers – well-being and relationships

A number of measures were used to assess emotional and mental well-being and relationships; these are summarized in Table 3 below before a more detailed explanation of each measure.

Table 3 Summary of measures of parent and carer well-being

	Incorporated into questionnaire(s)				
Measure	**LS MC**	**LS AC**	**LS CYP**	**LS Sib**	**CS MC**
Psychological distress, the K6 Scale (Kessler et al., 2002)					
Life satisfaction item from the Millennium Cohort Study (MCS, 2003/05)					
Items from Positive Gains Scale (Pit-ten Cate, 2003)					
Items from Transitional Daily Rewards and Worries Questionnaire (Glidden and Jobe, 2007)					
Items addressing general health and Illness from the Health Survey for England (HSE, 2006)					
Social Relationships item from the Millennium Cohort Study (MCS, 2003/05)					
Partner relationships items from the Millennium Cohort Study (MCS, 2003/05)					

Note; LS MC = Longitudinal Study Main Carer Questionnaire, LS AC = Longitudinal Study Additional Carer Questionnaire, LS CYP = Longitudinal Study Child or Young Person Questionnaire, LS Sib = Longitudinal Study Sibling Questionnaire, CS MC = Cross-sectional Study Main Carer Questionnaire.

The K6 scale has been developed as a short screening scale of psychological distress (Kessler et al., 2002). The measure asks respondents to report how often they have experienced various feelings over a 30 day period. It contains six items (e.g. nervous, restless, depressed) and responses are made on a 5-point Likert scale with 4 points being allocated for 'all of the time' through to 0 points being allocated for a response of 'never'. Scores from the six items are summed together to create an overall score of non-specific psychological distress. A score of 13 or more is often used as an indication that the person may have a serious mental illness (Kessler et al., 2003). This scale has been found to have consistent psychometric properties across major socio-demographic subgroups and it has the ability to strongly discriminate cases of DSM-IV disorders from non-cases (Kessler et al., 2002). This measure also has the advantage that it is relatively short. Given its brevity and psychometric strengths, it was incorporated into the two main carer questionnaires in its original format.

A single 'life satisfaction' question was taken from the Millennium Cohort Study (MCS, 2003/05) and used in its original format. It asked parents/carers to indicate how satisfied they were with the way their life had turned out so far on a 10 point scale, with 10 being scored for 'completely satisfied' through to 1 for 'completely dissatisfied'. Again this was used for both main carer questionnaires.

The Positive Gain Scale (Pit-ten Cate, 2003) was used in the adult questionnaires in the longitudinal study (main carer and additional carer) as a way of assessing perceived positive aspects of raising a disabled child. The measure contains two items relating to the perceived benefits for the family as a whole and 5 items relating to the perceived benefits that raising a disabled child has for the individual parent, such as increasing understanding of other people and growing as a person. Respondents are asked to indicate how much they agree or disagree with each of the statements using a 5-point Likert scale. Scores for each item are added together to create an overall PGS score. Preliminary evidence suggests that the PGS has good internal consistency and face and content validity for parents of children with hydrocephalus and spina bifida (Pit-ten Cate, 2003). More recent studies also show high internal consistency (McDonald et al., 2010). In the present study the scale was used in its original form, except that one of the two family items was removed, primarily in order to reduce the overall length of the questionnaire. Items from the Positive Gain Scale also have the potential to be analysed individually in relation to social relationships; for instance an indication of overall family relationships could be obtained from the family oriented item which asked whether having a disabled child had brought the family closer together.

The Transitional Daily Rewards and Worries Questionnaire (TDRWQ) was used for its sub-measure of sibling relationships (to be discussed below). In addition it was decided to utilise some of the other items regarding parents' rewards and worries about their child's future, as the rewards and worries faced by parents of disabled children may be different to parents and carers of children without disabilities. These items were incorporated into the adult questionnaires in the longitudinal study (main carer and additional carer). The TDRWQ inventory was developed to assess the daily rewards and worries faced by parents as their children make the transition from childhood to adulthood (Glidden and Jobe, 2007). In its original form it includes 28 items that are categorised into 4 factors: Positive Future Orientation (items a, b, c, d), Community Resources (items e (adapted) and f), Financial Independence (items g, h) and Family Relations (items i, j, k). It also includes 7 items looking at sibling relationships. Respondents are asked to indicate their agreement with statements using a 5-point Likert scale. The inventory is scored by allocating one point to a score of 'strongly disagree' through to five points for a score of 'strongly agree', with statements relating to worries being reverse-scored when computed. In its full original form, individual subscale scores can be calculated by adding up the responses to individual items within that subscale and an overall score can be calculated by summing up all items from all subscales. In its entirety this measure has been shown to have good internal and test-retest reliability and well as discriminant and convergent validity (Glidden and Jobe, 2007). It has also been used in research with children with developmental disabilities (Glidden and Natcher, 2009). Subscale scores and overall TDRWQ scores were calculated in the same way as the original scale. However given that individual items from the inventory were selected for the purposes of this research and that the age range of the children in this study exceeds that of the original, validity and reliability cannot be assumed to be identical to that of the un-adapted version.

Aspects of general health and illnesses were assessed by a small number of items taken directly from the Health Survey for England (HSE, 2006). In these items, respondents were asked to rate their general health on a 5-point Likert scale, from ‘very good’ through to ‘very bad’. They were also asked to state whether they had any long standing illness, disability or infirmity, what these were and whether these limited their normal daily activities. These items were used in the main carer questionnaires of both studies (longitudinal and cross-sectional).

Social Relationships were assessed using a question from the Millennium Cohort Study (MCS, 2003/05). This asked respondents to choose how often in the last week they had spent time with their friends from a series of five options. This item was used in both main carer and additional carer questionnaire in the longitudinal study. Relationships with partners were assessed using two questions taken directly from the Millennium Cohort Study (MCS, 2003/05). The first of these asks parents with a partner how often they disagreed with their partner over issues concerning their child; responses were elicited via a 7-point scale. The second of these asks respondents to rate how satisfied they were with their relationship on a 7-point scale. These items were used in both main carer and additional carer questionnaires in the longitudinal study.

1.7.3.2 Children – well-being and relationships

A number of measures were used to assess children’s and young people’s well-being and relationships; these are summarised below and followed by further detailed explanation.

Table 4 Summary of measures used to assess child well-being and relationships

	Incorporated into questionnaire(s)				
Measure	**LS MC**	**LS AC**	**LS CYP**	**LS Sib**	**CS MC**
Items formulated to ascertain basic information about disabled child (diagnoses, assessments etc)					
Items to detect presence and level of learning disability, taken from earlier survey (McGill and Honeyman, 2009)					
Items investigating impact of disability, adapted from proposed Census 2011. (Census, 2011)					
Item to assess amount of supervision required throughout the day and night (Chamba et al., 1999, Hatton et al., 1998)					
General health items from Health Survey for England (HSE, 2006)					
Items related to educational participation, SEN and aspects of schooling adapted from previous survey (Hatton et al., 1998, Chamba et al., 1999)					
Strengths and Difficulties Questionnaire (SDQ) (Goodman, 2001)					
Short items relating to feelings about school and teachers and about making new friends formulated for this study.					
Sibling relationships subscale from Transitional Daily Rewards and Worries Questionnaire (Glidden and Jobe, 2007)					
Adapted items from Sibling Relationships Questionnaire (Buhrmester and Furman, 1990)					
Items from the Positive and Negative Affect Scale (Watson and Clark, 1988)					

Note; LS MC = Longitudinal Study Main Carer Questionnaire, LS AC = Longitudinal Study Additional Carer Questionnaire, LS CYP = Longitudinal Study Child or Young Person Questionnaire, LS Sib = Longitudinal Study Sibling Questionnaire, CS MC = Cross-sectional Study Main Carer Questionnaire.

Respondents were asked to indicate whether or not they received Disability Living Allowance (DLA) for their child and whether their child had any diagnosed syndromes or conditions. If so, they were asked to name these. Further questions were formulated which asked parents to indicate any syndromes or conditions that they felt the child may have but which had not at that time been diagnosed and further whether their child was currently undergoing any assessments. These items were used in the main carer questionnaires of both studies (longitudinal and cross-sectional).

The presence and severity of any learning disability that the child had was measured by two questions taken directly from a previous survey looking at short break experiences of families with children with learning disabilities and challenging behaviour (McGill and Honeyman, 2009). Again, these items were used in the main carer questionnaires of both studies (longitudinal and cross-sectional).

In order to gain insight into the ways in which the disabled child was affected by their disability, the proposed Census 2011 disability categories were taken and formulated into a question (Census, 2011). Slight adaptations were made to these categories in order to allow for better identification of moving and handling needs and one single category for ‘mobility’ was split into two subcategories specifying whether the child used help from a carer to move around and whether they used equipment to move around. An additional category was added to identify children affected by depression. These items were used in the main carer questionnaires of both studies (longitudinal and cross-sectional).

The amount of supervision that the child required was assessed by three questions taken directly from surveys used by Chamba et al. (1999) and Hatton et al. (1998), whereby parents/ carers were asked to state on a 4-point Likert scale how much supervision the child needed over three different time periods of the day. Options ranged from ‘Almost constantly’ through to ‘Very little’. These items were used in the main carer questionnaires of both studies (longitudinal and cross-sectional).

Aspects of general health and illnesses were assessed by a small number of items taken directly from the Health Survey for England (HSE, 2006). In these items, parents were asked to rate the child’s general health on a 5-point Likert scale from ‘very good’ through to ‘very bad’. They were then asked to state any illness or infirmity experienced by the child that had not been recorded in other parts of the questionnaire, what these were and whether these infirmities limited the child’s normal daily activities. Again these items were used in the main carer questionnaires of both studies (longitudinal and cross-sectional).

Respondents were asked to identify whether their child was currently attending preschool, school, or further education and whether the child had a statement of educational needs. The child’s educational participation, enjoyment and performance along with various aspects of the school’s performance were assessed by asking respondents to indicate the truth of a series of eight statements. Each of these statements was scored on a 3-point Likert scale from ‘not at all true’ through to ‘very true’. These items were developed from previously conducted surveys (Chamba et al., 1999, Hatton et al., 1998). Some of the original items used in these surveys were removed as they were specific to families from minority ethnic backgrounds, or were not necessary in the context of the present research. One extra item was added, namely ‘my child has a good attendance record at school’. All other items taken from these surveys remained in their original formats and were used in the main carer questionnaires of both studies and in the additional carer questionnaire in the longitudinal study.

The Strengths and Difficulties Questionnaire (SDQ) developed by Goodman (2001) is a behavioural screening tool that has been well validated for use in children within the age range of 3 to 16 years old, is widely used and has been used successfully with disabled children (Emerson, 2005, Goodman, 1997, Goodman, 2001). It consists of 25 attributes, some of which are positive and some of which are negative. These are split into 5 subscales: emotional symptoms (items f-j), conduct problems (items k-o), hyperactivity (items a-e), peer relationships (items p-t) and prosocial behaviour (items u-y). The SDQ can be completed by children, parents/ carers and teachers. For this study the SDQ was used in both the main carer questionnaires of both studies (longitudinal and cross-sectional). Parents were asked to state how true each attribute was of the child in question on a 3-point Likert scale consisting of responses for 'very true', 'somewhat true' and 'not at all true'. In most cases items are scored 0 points for 'not at all true', 1 point for 'somewhat true' and 2 points for 'very true', with the exception of items d, e, l, q and r which are all positive attributes and are therefore scored in the opposite direction. Individual subscale scores can be calculated by adding together the scores for each attribute within that subscale (thus giving a subscale score between 0 and 10). An overall difficulties score was calculated by adding together the scores of all attributes from each subscale, with the exception of the prosocial behaviour scale (thus giving a total score between 0 and 40). The prosocial subscale score is not added to the overall difficulties score in the reverse direction as the presence of prosocial behaviour is conceptually different to the absence of psychological difficulties. Accordingly the prosocial subscale was calculated separately. The SDQ was used twice in the main carer questionnaire of the longitudinal study, once in relation to the child using short breaks and once in relation to the eldest sibling. It was used once in the cross-sectional study in relation to the child using short breaks. Thresholds for scoring SDQ subscales as indicating 'normal', 'borderline' or 'abnormal' functioning as available at http://www.sdqinfo.com/ScoreSheets/e1.pdf (see also (Emerson et al., 2010a)).

In addition, within the children's questionnaires (short break user and siblings) two questions were developed for the purpose of the study, whereby children were asked to indicate on a 4-point scale ('like all' to 'like none') how they felt about their time spent at school and their teachers. Options for 'don't know' and 'don't go to school' were also included. These were used with the disabled child and with siblings.

Relationships with peers and siblings were assessed in several ways. First, the peer relationship subscale of the SDQ mentioned above was used; as highlighted previously the SDQ includes a subscale that measures peer relationships. Secondly the TDRWQ sibling subscale also mentioned above was used. The sibling subscale was used in its entirety and analysed separately given its importance in specifically examining the relationships between the child using short breaks and his/her siblings from the parent or carer's perspective. This scale asked parents to determine how much they agreed or disagreed with a series of statements regarding the strength of sibling relationships, concerns about the disabled child coming to rely on his/her siblings, future potential resentment towards the disabled child and so on. As with the main body of the TDRWQ, all items were measured on 5-point Likert scales. This subscale was used in all three adult questionnaires (longitudinal study main carer, additional carer; cross-sectional study).

Thirdly the Sibling Relationship Questionnaire (SRQ) is a self-report measure consisting of 39 items that measures the perceived quality of sibling relationships (Buhrmester and Furman, 1990). In its original format it has been used successfully by children aged 8-18 and studies show that it has acceptable internal consistency, test-retest reliability, low correlations with social desirability and adequate construct validity (Buhrmester and Furman, 1990 , Brody et al., 1992, Moser and Jacob, 2002, East and Khoo, 2005). The SRQ consists of 15 scales that correspond to four factors: Relative status/ power, warmth/ closeness, conflict and rivalry. Children are required to respond to each item on a 5-point Likert scale from ‘hardly at all’ to ‘extremely much’. Decisions regarding the inclusion of items for the purpose of this study were based upon an adapted version of this measure (Yelland and Daley, 2009). In this version the relative status/power factor was removed to reduce length and a number of items were re-worded in order to make them more understandable to younger children. The internal consistency of this adapted measure was still considered acceptable on all factors and was similar to a previous study (Buhrmester and Furman, 1985).

From the adapted version of the SRQ five items were selected for use in the child and sibling questionnaires for the present study. Two of these adapted items (‘How much do you and your brother/ sister do nice things for each other?’, ‘How much do you and your brother/ sister care for each other?’), were split into two parts making four questions. In particular, it was thought that since the present context was likely to include child carers splitting these double questions would enable a more sensitive identification of each child’s individual position. The wording of one of the adapted SRQ questions looking at conflict was further changed from ‘How much do you and your brother/ sister get mad and get into arguments with each other?’ to ‘How much do you and your brother/ sister get cross and argue with each other?’ in order to be more culturally appropriate. A further item asked the child to state how often they went places and did things with their siblings. Finally two separate questions that asked the child to state who out of themselves and their siblings got more attention from their mother and father were combined into one single question. These adapted SRQ questions and response categories were used again in a suitably adapted form in order to assess peer rather than sibling relationships. In this way children were presented with a consistent format as far as possible. Most SRQ questions were scored on a 5-point Likert scale from ‘hardly at all’ to ‘extremely much’; the exception being the question regarding parental attention in which children simply had to indicate who usually got more attention from their parents, themselves, their sibling or about the same. These were incorporated into both questionnaires aimed at children and young people (for the user of short breaks and their siblings).

Children’s perceived self-efficacy and self-esteem were explored in a number of ways. This included use of the Emotional Symptoms subscale of the SDQ, discussed above. This consists of items that measure related constructs, such as worry, happiness, nervousness, fears etc. and so in the present study may potentially give some indication of esteem and efficacy of the child from the carers’ perspectives. As mentioned previously the SDQ was used in both main carer questionnaires (longitudinal and cross-sectional).

The Positive and Negative Affect Scale (PANAS) was also used (Watson and Clark, 1988). This scale is a psychometric inventory that is used to measure the largely independent constructs of positive and negative affect. It consists of two separate 10-item mood scales, one positive (e.g. ‘interested’, ‘excited’ and ‘proud’) and one negative (e.g. ‘upset’, ‘scared’ and ‘ashamed’) and asks respondents to indicate to what extent they have experienced each item on a 5-point Likert scale (‘very slightly or not at all’, through to ‘extremely’). Overall positive and negative affect scores are calculated by summing together the scores allocated to each individual item within each scale. The time frame measuring how much each feeling is experienced can be altered depending on the period of time of interest, for instance, for the purposes of this study, children were asked how much they had felt each feeling ‘in the past few weeks’.

This measure has been found to be highly internally consistent, with positive and negative affect scales being largely uncorrelated and appropriate stability over a two-month time period (Watson and Clark, 1988). There is preliminary evidence for its reliability and validity for use in children and young adults (Lonigan et al., 1999) and the scale has been used in studies looking at the well-being of parents of children with disabilities such as autism and Down syndrome (Griffith et al., 2009, Pottie and Ingram, 2008). In the context of the current research and in view of the need for simplicity and brevity just four key PANAS items were selected and used in the children’s questionnaires. These were selected from the positive affect scale. Furthermore some items in the whole scale were thought to be potentially too complex or abstract for young children (e.g. ‘enthusiastic’, ‘inspired’). As a consequence reliability and validity measures of the original schedule cannot be assumed to apply to the current adaptation.

It was also anticipated that some of the open questions may provide significant information about self-efficacy and esteem when discussing short breaks, such as questions that were posed in the adult questionnaires about how their child may have developed via using short breaks (to be discussed later).

One question incorporated into children’s questionnaires asked children whether or not short breaks had helped them to meet new friends. This was a simple ‘yes’ or ‘no’ response question.

1.7.3.3 Family Context

The main carer questionnaires for both studies contained items aimed at determining family context and composition since short breaks are likely to have different impacts for different families due to a wide range of differing circumstances and situations (see Table 5 below for a summary).

Table 5 Summary of measures used to determine family composition and context

	Incorporated into questionnaire(s)				
Measure	**LS MC**	**LS AC**	**LS CYP**	**LS Sib**	**CS MC**
Items investigating household composition items adapted from Millennium Cohort Study (MCS, 2003/05)					
Items for this study identifying lone parents and the presence of further disabled children					
Items identifying ethnic groups from the proposed Census 2011 (Census, 2011)					
Employment, training and qualifications using items from Millennium Cohort Study (MCS, 2003/05)					
Items assessing current financial situation and financial worries from Family and Children’s Study (FACS, 2005)					
Further selected family finance items from Family and Children’s Study (FACS, 2005) inc’ ability to afford consumer items and debt repayments					
Area-based measures of deprivation (ID, 2007, CWI, 2009)	Assessed from home postcode				

Note; LS MC = Longitudinal Study Main Carer Questionnaire, LS AC = Longitudinal Study Additional Carer Questionnaire, LS CYP = Longitudinal Study Child or Young Person Questionnaire, LS Sib = Longitudinal Study Sibling Questionnaire, CS MC = Cross-sectional Study Main Carer Questionnaire.

A number of factors, likely to be influential, were investigated; these included household composition, age, gender and ethnicity. These were assessed using a small number of carefully selected items taken from the Millennium Cohort Study in order to determine the number of adults and children living in the household, their ages, gender and relationships to the child using short breaks, as well as the respondent's marital status (MCS, 2003/05). Although the content of these questions was not altered, a household grid was created in which respondents could enter this information quickly and easily (longitudinal study only). Lone parent status was assessed by a single 'yes' or 'no' question formulated by the researchers, as was the presence of any other disabled children living in the household (with the addition of stating how many children in the household were disabled if the question was answered 'yes'). Ethnic group of the respondent was measured via the application of the proposed 2011 Census categories and also for the child using short breaks in the longitudinal study (Census, 2011).

Employment and training position was investigated using two questions were taken from the Millennium Cohort Study (MCS, 2003/05). Respondents were asked to indicate which situation best described their current activity from a series of six work and training options. They were then asked to state the name of their present or last occupation; where appropriate, similar questions were used to assess partners' situation. Again these were incorporated into the main carer questionnaire of both studies.

Questions from the Millennium Cohort Study were also used to indicate respondents' possession of a range of academic and vocational qualifications and to identify whether respondents had day to day problems with reading, writing or maths (MCS, 2003/05). In the longitudinal study similar questions were used where appropriate with reference to partners.

Socioeconomic disadvantage/ hardship was investigated in the longitudinal study using various financial hardship and expenditure items from the Family and Children's Study (FACS, 2005). The first asked about families' ability to afford various items such as food, clothes, appliances, family outings/ holidays and continued to questions that ask about financial worries and how the respondent assessed their current financial situation. Given concerns over questionnaire length it was decided that only a select number of FACS (2005) expenditure items would be used. The selection was made in consultation with the research steering group who rated individual items in terms of importance and relevance. Eighteen of the original household items were then removed leaving a total of thirteen. For each, respondents were asked to state whether they had the item, would like it but could not afford it, or did not want or need it. Further questions from FACS (2005) were used, for example respondents were asked to identify whether there was anything that they themselves or their children needed at the moment. They were then asked how often they had been worried about money in the last few weeks (on a 4-point Likert scale from 'Almost all the time' to 'Never') and how well they feel they are managing financially (via six predetermined responses from 'Manage very well' to 'In deep financial trouble'). Finally they were asked whether their financial situation had improved over the previous 12 months and how often they had been struggling with debt over the last 12 months (again on a four point Likert scale). Just the questions that ask about financial worries and how the respondent assesses their current financial situation were used in the cross-sectional study.

A further measure of socioeconomic disadvantage was ascertained using the families' home postcode to generate information on local deprivation using the Indices of Deprivation 2007 and the Child Well-being Index 2009 (ID, 2007, CWI, 2009). Both ID and CWI scores and ranks were obtained at Lower Super Output Area level together with information about key domains (e.g. CWI material domain and CWI health and disability domain). It should be remembered that this information relates to the area in which the family live rather than to each specific family. Lower super output areas generally have a population of around 1500 people.

1.7.3.4 Use and experience of short breaks

The use and experience of short breaks was investigated using a number of measures and from a number of perspectives. These are summarized below in Table 6 and further explained after the table.

Table 6 Summary of measures used to examine use and experience of short breaks

	Incorporated into questionnaire(s)				
Measure	**LS MC**	**LS AC**	**LS CYP**	**LS Sib**	**CS MC**
Items and adapted items exploring types of breaks used and their suitability from previous survey of short break use (McGill and Honeyman, 2009)					
Items for this study identifying funding for short breaks and whether direct payments were received for other purposes					
Items for this study investigating satisfaction with various aspects of short breaks					
Items for this study identifying breaks used, enjoyment, what children liked or disliked, befits they felt and whether they wanted more or less breaks (self or siblings)					

Note; LS MC = Longitudinal Study Main Carer Questionnaire, LS AC = Longitudinal Study Additional Carer Questionnaire, LS CYP = Longitudinal Study Child or Young Person Questionnaire, LS Sib = Longitudinal Study Sibling Questionnaire, CS MC = Cross-sectional Study Main Carer Questionnaire.

Since these two studies form part of a larger programme of research it was possible to use earlier stages of the research to inform the development of measures for the questionnaires. This principally involved information from the international literature review and the initial qualitative reports looking at the impact of short breaks on families with disabled children (Collins et al., 2009, Langer et al., 2009, Robertson et al., 2009). For example these were particularly helpful in formulating questions to identify the types of short breaks which might be used. Consultations with the policy steering group were also of particular help in order to finalise which questions should be included.

Some questions were taken directly or adapted from a previous survey studying families' experiences of short breaks (McGill and Honeyman, 2009). These included questions asking about short break funding, whether the family had been on a waiting list for a short break (and for how long), whether a child had been turned down or excluded from a short break (if applicable this was followed by an open question asking them to explain why) and whether or not the family's experience of short breaks had improved or not over the last 12 months, again followed where appropriate by an open question for further explanation. These items were used in unaltered form from the previous survey (McGill and Honeyman, 2009). Two further questions from this survey were also used, one which asked whether or not short breaks had been suitable for the child using them and if so, in what ways. This was altered slightly to become suitable for the family as a whole.

An additional complementary question was formulated in the same format asking if the breaks were unsuitable for the family and in what ways. The format of a further question used from McGill and Honeyman's study was used, this asked what types of short breaks families had used, however the categories were significantly altered to suit the context of the current study and in light of our previous research. Some of the original categories such as 'adult placement scheme' were removed, some categories such as 'residential overnight' were split into several separate categories in order to be more sensitive to the types of residential support (e.g. with a paid carer or family, in a centre, or via an unpaid friend/ family member). Further new categories were also added, such as three categories for a daytime break away from home with a paid carer, unpaid friend or family member, or in a centre. These items were used in both main carer questionnaires (longitudinal and cross-sectional studies).

Based on earlier project phases new questions were developed, such as asking if families received direct payments for any other services, as well as a series of statements asking families to indicate on a 3-point Likert scale how satisfied or dissatisfied they were with various elements of short breaks. These included satisfaction with areas such as standard of care, meeting the child's needs, amount and range of care, flexibility of breaks, etc. These were incorporated into the main carer questionnaires of both studies as well as into the additional carer questionnaire of the longitudinal study.

A number of measures were also formulated for the children's questionnaires in order to cover use of short breaks and contextualise other responses. The child using short breaks was asked a small number of open questions such as what types of short breaks they had experienced, what they liked and disliked about them and what they would like their next short break to be like. They were also asked a series of scaled questions, such as to indicate how much they enjoyed their short breaks (3-point Likert scale from 'enjoyed it a lot' to 'did not enjoy it at all'), whether they would like more or fewer short breaks (5-point Likert scale from 'lots more' to 'lots less') and if they had had any help filling in the form (3-point Likert scale from 'no help' to 'lots of help'). In addition two yes/ no questions were also asked in order to determine whether short breaks had helped the child to try new things and make new friends.

Several of the questions in the sibling questionnaires were similar to those posed to the child using short breaks. For example these questions asked what short breaks their brother or sister had experienced, what they liked and disliked about their brother or sister having short breaks, what they would like their brothers' or sisters' next break to be like. They also asked whether short breaks gave the sibling the chance to do new things and meet new friends and whether they would like their brother or sister to have more or fewer short breaks. Some additional questions were created specifically for siblings, such as two yes/ no questions that asked siblings whether their brothers' or sisters' short breaks allowed them to have more time to themselves and whether these breaks allowed the sibling to spend more time with their parents. An open question also asked siblings what benefits they got out of their brother or sister having short breaks.

1.7.3.5 Open questions

In all of the questionnaires significant use was made of open ended questions in order to allow respondents to expand upon their unique circumstances and to provide more detailed reflections and explanations. Some of these have already been referred to above, particularly where they formed part of specific measures or gave opportunities to expand on responses to categorised questions. Further open questions included a question which prompted adult respondents to describe how their child may have changed or developed as a result of short breaks, one which asked them to explain benefits that short breaks can potentially have for the different family members and at the end of the form an opportunity to provide any additional comments about short breaks or the questionnaire itself.

1.8 Analytic strategies

1.8.1 Quantitative analyses

The questionnaires in these studies contained a large number of questions designed to be answered by selecting from ‘closed’ pre-categorised responses. There were also some questions where respondents were given the opportunity to enter a more suitable category, for example an ethnic group or language spoken if the categories on the form did not adequately describe their situation. There were also a small number of questions that asked respondents to provide very short, written responses such as naming occupations, diagnoses etc. Responses in these formats were analysed using various numerical approaches, to facilitate this, data were entered into databases using SPSS Statistics 17. These types of questions elicited data on more than 500 variables from the longitudinal main carer questionnaire, 58 variables from the additional carer questionnaire, 35 variables from the child or young person using short breaks questionnaire and 35 variables from the sibling’s questionnaire. Data from these four questionnaires were entered into separate SPSS databases. Data from the cross-sectional study main carer questionnaire were entered into the same database as the longitudinal study main carer questionnaire in order to allow maximum flexibility when analysing the data. Each family was identified by a unique code which was used in each of the databases in order to facilitate merging of databases as and where this was required.

Descriptive statistics were produced to summarise key characteristics of the families taking part, family use of, satisfaction with and experience of short breaks.

Factors associated with short break usage, family experiences of and satisfaction with short breaks and outcomes for main carers and disabled children, were examined using the following quantitative analytic strategy. As many of the relevant variables were highly skewed, non-parametric quantitative analyses were used throughout. A very high number of statistical tests were conducted for these analyses and despite the risk of Type 1 error all associations with a statistical significance of $p<0.01$ are reported as significant and all associations with a statistical significance of $0.01<p<0.05$ are reported as trends (all tests are 2-tailed or 2-sided). This strategy, rather than using a more stringent significance level, was adopted to allow broader patterns in the dataset to become more clearly visible. Appendix C provides a set of tables summarising the results of these univariate analyses.

Once a set of univariate analyses was conducted, the examination of which factors were most closely associated with the measure of interest was conducted using a series of logistic regressions. The dependent variable of interest was, if required, classified into a two-category variable using either a median split or a split that was meaningful in terms of the variable scoring (for example, classifying general health into Very Good/Good vs. Fair/Bad/Very Bad).

All variables showing a univariate association with the dependent variables (at $p<0.05$) were entered as independent variables into a logistic regression using conditional forward entry, where independent variables are sequentially entered into the regression equation if they have a $p<0.05$ when controlling for their associations with other independent variables. Potential independent variables that would substantially reduce the size of the sample available for the regression (for example, variables only completed by the cohort study sample) were not used in the regression equation. Appendix D provides a set of tables summarising the results of the logistic regression analyses.

1.8.2 Qualitative analyses

The questionnaires also contained a number of opportunities for respondents to provide more 'open' responses. These were transcribed and imported as 'cases' into QSR Nvivo 8. Cases were assigned attributes to enable the identification of the age and gender of the respondent and the child and the unique family code as used in SPSS. Throughout and after the data gathering phase various qualitative analyses were conducted using a number of processes outlined below. These processes were not conducted sequentially; rather they were ongoing, complementary and overlapping.

- Each transcript was initially pre-coded to identify sections of text arising from specific questions using the 'auto-code' function of Nvivo 8.
- Iterative reading of each transcript allowed the identification of various concepts, ideas and explanations embedded in respondents' accounts. Thematic codes representing these concepts, ideas and explanations were generated and all transcripts (existing and new) were examined to identify examples of further relevant text.
- The transcripts were examined to explore concepts and questions arising from earlier research, areas of policy interest and from the quantitative elements of this study. Where appropriate further thematic codes were devised and all transcripts re-examined to identify examples of further relevant text.
- Occasional word frequency analyses were conducted and the results considered in order to inform the process of identifying concepts and ideas.
- A number of text searches were devised and used to facilitate identification of further examples of text related to emergent thematic codes. Using words and phrases used by respondents as well as likely synonyms and alternate phrasing.
- All text linked to each theme was re-examined taking particular account of the variation within the data in order to identify sub-themes, contradictory positions and further explanatory concepts.
- Where useful, groupings and relationships between concepts were considered and links formed in order to develop a conceptually coherent account.

Together these processes allowed the identification of 'in vivo' themes generated from the data as well as allowing a number of existing concepts and observations to be further explored using these data. This strategy provided thematic analyses which could be used in a number of different ways

- to provide detailed information to illuminate emerging findings from quantitative aspects of these surveys,
- to allow further exploration of ideas and concepts identified in earlier phases of this research programme,
- in their own right to provide new insights and explanations of the impacts of short breaks and the delivery of short breaks services.

Findings from the qualitative analyses are presented throughout the sections below where they provide further detail and evidence which may assist greater understanding or explanation of complex observations. The qualitative findings may also be helpful in describing the breadth of variation in the views and experiences of families. Selected quotes from children and adults are used to illustrate a number of areas under discussion; names and other identifiers have been changed or removed to protect respondent’s identity. Whilst it is extremely enlightening and helpful to read respondent’s own words, readers are advised that these quotes have been selected to be illustrative rather than representative. The quantitative and qualitative aspects of this study and indeed the research programme as a whole are designed to be complementary.

2 The Families

2.1 General information about households

Households (n=336) ranged in size from two family members to 14 family members. Most households (84.8%) contained between three and five members with most (82.7%) containing more than one adult and most (68.5%) containing more than one child. Adults in households included the disabled child’s parents (biological, step, adoptive and foster), adult siblings, grandparents, aunts, uncles and au pairs. Children in households included siblings (biological, step, adoptive and foster) and cousins. Table 7 below summarises the numbers of people in households.

Table 7 Household composition (numbers in households)

All family members			Adults			Children		
	Frequency	Percent		Frequency	Percent		Frequency	Percent
2	23	6.8	**1**	58	17.3	**1**	106	31.5
3	78	23.2	**2**	217	64.6	**2**	142	42.3
4	136	40.5	**3**	49	14.6	**3**	62	18.5
5	71	21.1	**4**	10	3.0	**4**	17	5.1
6	17	5.1	**5**	2	0.6	**5 or more**	9	2.7
7 or more	11	3.3	**Total**	336	100.0	**Total**	336	100.0
Total	336	100.0						

Some respondents indicated that their family included more than one disabled child (11.7%, n=39). In these families there were most often two disabled children (76.9%, n=30), however some families included up to five disabled children.

Data on the number of people in various ethnic groups are given later in this report, both for the respondent to the main carer questionnaire and for the child using short breaks. Respondents were also asked about the languages used in households. English language was used in all households, 7.4% (n=25) also used another language, one family used three languages. The languages spoken in respondents’ households are listed below in Table 8.

Table 8 Languages spoken at home

Igbo / Igbu / Ibo	Punjabi	English	British Sign Language (BSL)
Yoruba	Urdu	Welsh	Makaton
Shona	Gujarati	Italian	
Khmer	Tamil	French	
Thai	Pushto	Greek	
Other un-named	Arabic	Dutch	

2.2 Information about main carers

Most respondents (74.7%, n=251) to the main carer questionnaires identified themselves as having the main responsibility for caring for the child who uses short breaks; 19.6% (n=66) stated that this responsibility was shared between themselves and their partner; and 4.2% (n=14) indicated that their partner had the main responsibility for caring. Other descriptions of caring arrangements included shared between all adults in household, self and a grandparent, self and school, respondent's ex-partner and respite home.

All respondents to the main carer questionnaires recorded their gender; most were female (91.1% n=306) and 8.9% (n=30) were male. Most respondents (92.0% n=309) were biological parents of the child who used short breaks; others included both adoptive and foster parents as well as grandparents and uncles.

Table 9 Relationship to child using short breaks, respondents to main carer questionnaires

	Frequency	Percent
Biological parent	309	92.0
Adoptive parent or adoptive grandparent	9	2.7
Foster parent	8	2.4
Biological grandparent	7	2.1
Others including uncles and step parents	3	0.9
Total	336	100.0

331 respondents to the main carer questionnaire indicated their date of birth, ages ranged from 30 years to 70 years, mean age was 44.5 years, $\overline{\mathbf{x}}$ 6.8, median age was 44.0 years. Mean ages for selected groups are given in Table 10 below.

Table 10 Mean ages (yrs) of selected groups, respondents to main carer questionnaires

	All	Male carer	Female carer	Biological parents	Adoptive parents	Foster parents	Grand-parents
n	331	30	301	304	7	8	7
Mean age (yrs)	44.5	47.0	44.3	43.8	53.3	51.1	58.7

Respondents to the main carer questionnaires came from a variety of ethnic groups; 301 classified themselves as White British, 9 as African or Caribbean, 8 as Mixed or multiple ethnic groups, 6 as other European groups, 5 as Indian, Pakistani or Srilankan. Other descriptions included Jewish, Thai and Egyptian Arab.

Respondents to the longitudinal study main carer questionnaire were asked to indicate whether they belonged to a particular religion. 30.6% (n=34 of 112) did not belong to a religion, most respondents (65.1% n=73) belonged to a Christian religion, 4.5% (n=5) belonged to another religion including Islam and Buddhism.

331 respondents indicated their current marital status, most were married (70.7% n=164), 19.3% (n=64) were divorced or separated, 8.8% (n=29) were single and others were widowed or in civil partnerships (see Table 11).

Table 11 Marital status, respondents to main carer questionnaires

	Frequency	Percent
Legally separated	18	5.4
Married, 1st and only marriage	188	56.0
Remarried, 2nd or later marriage	46	13.7
Single, never married	29	8.6
Divorced	45	13.4
Others including widowed or civil partnerships	5	1.5
Total	331	98.5

76.5% (n=237) of respondents indicated that they lived with someone as a couple, whilst 21.5% (n=72) indicated that they consider themselves to be a lone parent. A small number of parents not living in couples do not consider themselves to be lone parents; this may be due to the fact that they get support from an absent parent or have shared custody. A small number of main carers who are not parents are also not living as part of a couple and may consider themselves to be ‘lone carers’ rather than ‘lone parents’.

Respondents to both main carer questionnaires were asked to indicate whether they held various qualifications. Table 12 below shows the level of the highest qualification held.

Table 12 Highest academic or vocational qualification held, respondents to main carer questionnaires

	Frequency	Percent
First Degree or higher	108	32.4
A level, NVQ3, Trade Apprenticeship or Diploma	101	30.3
GSCE A-C or NVQ2	88	26.4
GSCE D-G or NVQ1	7	2.1
None of these	29	8.7
Total	333	100.0

By combining the above with information about main carers’ partners’ qualifications it is possible to indicate the highest qualification for the carer and partner couple to give an indication of the household highest level of qualification (see Table 13 below).

Table 13 Highest academic or vocational qualification held in household (longitudinal study main carer or their partner)

	Frequency	Percent
First Degree or higher	48	42.5
A level, NVQ3, Trade Apprenticeship or Diploma	35	31.0
GSCE A-C or NVQ2	27	23.9
GSCE D-G or NVQ1	0	0
None of these	3	2.7
Total	113	100.0

Respondents to both main carer questionnaires were asked whether problems with reading, writing or maths make it difficult to manage day to day activities like paying bills or writing letters; 3.3% (n=11) indicated that they did have these problems. Respondents to the longitudinal study main carer questionnaire were also asked to indicate whether they had attended any courses to improve reading or number skills; 9.8% (n=11 of 112) had attended courses to improve number skills, whereas 0.6% (n=2 of 113) had attended courses to improve reading skills.

Respondents to both main carer questionnaires were asked to select a description of their current employment situation or to tick 'other' and provide a more appropriate description. Table 14 below summarises the results.

Table 14 Employment descriptions, respondents to main carer questionnaires

	Frequency	Percent
Looking after family full time	156	46.4
Working part-time	116	34.5
Working full-time	48	14.3
Looking for work	6	1.8
Retired	2	0.6
Not working due to disability or sickness	4	1.2
Carer (including foster carers)	4	1.2
Total	336	100.0

2.3 Information about disabled children using short breaks

All respondents gave a gender for the child who used short breaks; 63.1% were male and 36.9% were female. This contrasts both to the proportion of males and females identified by local authorities as short break users and to the proportions invited to take part in the studies and suggests that not only are short break users more likely to be boys, but that parents and carers of boys were more likely to respond to this study (see table 15 below).

Table 15 Gender of children using short breaks (identified, invited to studies and responding)

Identified by LA		Invited to take part		Family responded	
Male	68.1% (n=4579)	Male	54.5% (n=1332)	Male	63.1% (n=212)
Female	31.9% (n=2144)	Female	45.5% (n=1111)	Female	36.9% (n=124)

335 respondents to the main carer questionnaires provided information about the date of birth for the child or young person who uses short breaks. Whilst ages ranged from 0 years to 23 years most children and young people (94.4%, n=316) were aged between 5 years and 18 years. The mean age was 11.9 years. Table 16 below gives the percentages of children in different age groups.

Table 16 Age breakdown for children and young people using short breaks

	Frequency	Percent
Under 5 years	10	3.0
5 – 7 years	44	13.1
8 – 10 years	78	23.2
11 – 13 years	75	22.3
14 – 16 years	79	23.5
17 – 19 years	45	13.4
20 years and over	4	1.2
Total	335	99.7

Respondents to the longitudinal study main carer questionnaire were asked to describe the ethnic group of the child using short breaks; 90.2% (n=101 of 112) classified their child as White British, 3 as African, 2 as mixed or multiple ethnic groups, 2 as Pakistani. Other descriptions included Egyptian Arab, Greek Cypriot and Cambodian.

As mentioned previously there were five target groups identified within AHDC (groups A to E). The definition of each target group is given in the AHDC guidance (DCSF and DOH, 2008a); these definitions contain a certain amount of flexibility. For the purposes of these analyses the following indicators have been used.

Target group A – respondent to the main carer questionnaire either named an autistic spectrum disorder when writing in the child's diagnosis **and / or** ticked to indicate that the child had been diagnosed with autism, Asperger Syndrome or Autistic Spectrum Disorder.
Target group B – respondent indicated **two or more** of the following six items apply to the child (incontinence, problem of consciousness or palliative care needs, or mentions a respiratory problem, diabetes or gastronomy in the child's diagnosis).
Target group C – respondent to the main carer questionnaire indicates that the child is aged 11 years or older **and** uses equipment to move around inside or outside the home.
Target group D - respondent to the main carer questionnaire indicates that the child's behaviour is affected by their disability resulting in a condition such as hyperactivity, short attention span, getting frustrated or behaving in a socially unacceptable manner **and** the child either falls into one or more target groups A-C **and / or** has severe learning disability.
Target group E - respondent to the main carer questionnaire indicates that the young person is aged 14 years or older **and** the child falls into at least one other group (A-D).

A minority of children (16.4%, n=55) are not known to fall into any target groups. The AHDC target groups are not mutually exclusive, indeed most (66.6%, n=224) children and young people using short breaks identified in this study fell into two or more target groups.

Table 17 Number of target groups per child or young person using short breaks

Target groups per child	Frequency	Percent
0	55	16.4
1	57	17.0
2	124	36.9
3	76	22.6
4 or more	24	7.1
Total	336	100.0

The number of children in each target group is shown below in Table 18. The most frequently observed was target group D (challenging behaviour associated with another impairment); this description was applicable to 66.3% of children (n=220) using short breaks. The least often observed was target group C (aged 11 and over with moving and handling needs requiring equipment), this was applicable to 21.4% (n=72) of children using short breaks.

For administrative and monitoring purposes the original target groups A to D were superseded in later guidance by new priority groups named A and B (TDC, 2009b). The new priority group A comprised all children in the old target groups A and D. The new priority group B comprised all children in the old target groups B and C. Again these two groups are not mutually exclusive and some children fall into both priority group A and priority group B. Information is given in Table 19 about the numbers of children who could be identified as priority groups A or B using the definitions above.

Table 18 Number of children or young people in each target group

Target group	Frequency	Percent	n
A	160	47.9	334
B	74	22.0	336
C	72	21.4	336
D	220	66.3	332
E	105	31.6	332

Table 19 Number of children or young people in each of the revised priority groups

Revised priority group	Frequency	Percent	n
A	242	73.1	331
B	112	33.3	336

It had been assumed there was significant overlap and that target groups A and D have similar needs and similarly that groups B and C have similar needs. Whist there is indeed significant overlap in the current sample, there are also significant differences, for example 37.0% of children in target group D were not also in target group A and 52.8% of children in target group C were not also in group B. By consolidating four target groups into two priority groups for monitoring purposes it may be that some precision has been lost, with the potential to mask the continued exclusion of some groups of children.

Respondents to the main carer questionnaires reported that nearly all children (98.5%, n=330) received Disability Living Allowance (DLA), with the remaining five respondents indicating either that their children did not receive DLA or that they did not know.

Most respondents (92.4%, n=306) indicated that their child had a diagnosed syndrome or condition. Some respondents (n=3) whose child had been described as having conditions such as ‘a global developmental delay’ did not count this as a ‘diagnosis’ whilst others did consider this to be a diagnosis. Respondents were asked to write in their child’s diagnoses, the responses were very varied with many respondents offering a mixture of named conditions as well as symptomatic and functional descriptions. Where possible respondents’ descriptions were categorised under a number of headings; Table 20 below summarises the occurrence of the most frequent categories and gives percentages of all children using short breaks, it should be noted however that the fact that a respondent did not volunteer a particular description is not indicative that they would not have responded positively if asked directly whether the category applied. This effect is exemplified by the category of ‘learning disability’ which was offered as a description by 20.2% of respondents whereas when asked directly if their child had a learning disability 91.9% indicated that they did.

Table 20 Categories of children's diagnoses as described by respondents to main carer questionnaires

	Frequency	Percent
Autistic spectrum disorders (including ASD, Autism, Aspergers etc)	146	44.3
Learning Disability (including PMLD, severe LD, moderate LD, global LD)	68	20.2
Cerebral palsy	66	19.6
Epilepsy (including seizures etc)	63	18.8
Chromosomal or genetic condition or syndrome other than Down’s	51	15.2
Sensory problem (including blind, deaf)	35	10.4
Developmental delay (including global delay)	34	10.1
ADHD (including ADD, DAMP, hyperactive)	34	10.1
Down’s syndrome	23	6.8
Behavioural problem	22	6.5
Communication problem (including speech, language etc)	20	6.0
Dyspraxia	15	4.5
Mental ill health (including depression, anxiety, bipolar, OCD)	9	2.7
Respiratory (Asthma, chronic lung disease, ventilation, tracheomalacia)	8	2.4
Gastronomy (including gastroscopy or ‘tube fed’)	8	2.4
Diabetes	4	1.2
Other named syndrome or condition	56	16.7

Other named conditions included various neurological conditions, head (and brain) injuries, various heart problems, various limb problems, arthritis, cleft palate, scoliosis, spina bifida, leukaemia, user of various technologies (O_2, drug pumps etc), incontinence, Lennox – Gestaut syndrome, foetal alcohol syndrome, Raynaud’s syndrome, CREST syndrome, thyroid problems, toxoplasmosis, hypermobility and ataxia.

Respondents to the longitudinal study main carer questionnaire were also asked to provide information about conditions for which children were currently undergoing assessments and asked to name any conditions they felt the child had but which had not been diagnosed. 20.7% (n=23 of 111) of respondents reported that their child was currently undergoing an assessment for a syndrome or condition. Conditions being assessed for included ASD, ADHD, sensory conditions, chromosomal and genetic assessments, psychiatric assessments, learning assessments, Russell-Silver syndrome, Sotos syndrome and scoliosis. 28.9% (n=33 of 114) of respondents felt that their child had undiagnosed conditions, these included ASD, ADHD, Angelman syndrome, Tourette syndrome, Russell – Silver syndrome, dyspraxia, OCD and unknown genetic conditions.

Respondents to both main carer questionnaires were asked whether the child who used short breaks had a learning disability and if so at what level. 91.9% (n=308) of respondents indicated that their child did have a learning disability. The level of disability is given in Table 21 below.

Table 21 Level of learning disability of child using short break

	Frequency	Percent
Severe/ profound learning disability	180	58.4
Moderate/ mild learning disability	100	32.5
Learning disability (level not known)	28	9.1
Total	308	100.0

Respondents to both main carer questionnaires were asked to indicate whether their child's disability resulted in them being affected in a number of different areas of daily life. The numbers and percentages of children affected in each area are shown in Table 22.

Table 22 Areas in which disability affects child

	Frequency	Percent
Mobility (uses help from a carer)	170	50.6
Mobility (uses equipment)	124	36.9
Hand function	141	42.0
Personal care	283	84.2
Eating and drinking (difficulty eating or sickness or appetite)	165	49.1
Medication (difficulty taking or side effects)	131	39.0
Incontinence	172	51.2
Communication	289	86.0
Learning	311	92.6
Hearing	63	18.9
Vision	104	31.1
Behaviour	249	74.1
Consciousness	80	23.8
Autistic Spectrum Disorder (ASD)	155	46.5
Palliative care needs	19	5.7
Depression	23	6.9

Respondents wrote in a range of other areas in which their child was affected, these included stoma, breathing problems, severe pain, severe anxiety, self-esteem, mood swings, aggression, paranoia, aversion to change, risk perception, social skills, head banging, loud screams (happy or sad), synaesthesia (with strong aversion to some colours and numbers) and sleep disorder.

Respondents were also asked to indicate the level of supervision their child needed throughout the day, evening and night. The results are shown in Table 23 below.

Table 23 Levels of supervision required throughout the day and night for child using short breaks

	6am-5pm	5pm-10pm	10pm-6am
Almost constantly	67.9% (n=228)	52.1% (n=175)	20.0% (n=67)
Most of the time	25.0% (n=84)	33.6% (n=113)	14.6% (n=49)
Some of the time	6.5% (n=22)	12.8% (n=43)	44.5% (n=149)
Very little	0.6% (n=2)	1.5% (n=5)	20.9% (n=70)
Totals	100% (n=336)	100% (n=336)	100% (n=335)

Respondents to the longitudinal study main carer questionnaire were asked to indicate whether the child who used short breaks attended any educational settings; 4.4% (n=5) attended a nursery or preschool, 85.8% (n=97) attended a school and 9.7% (n=11) attended a further education setting. These respondents were also asked to indicate whether the child who used short breaks had a ‘statement of special educational needs’; 95.5% (n=106) of children had such a statement. Respondents were then asked to indicate whether they felt that a series of statements about various aspects of schooling were true. The findings are summarised in Table 24. Respondents to the additional carer questionnaire were asked the same questions about aspects of schooling; the results are broadly similar to those of respondents to the main carer questionnaire.

Table 24 Aspects of schooling for child using short breaks, respondents to main carer questionnaire

	Very True	Somewhat true	Not at all true
My child is progressing well	26.6% (n=29)	63.3% (n=69)	10.1% (n=11)
School keeps me informed about my child’s progress	66.7% (n=74)	31.5% (n=35)	1.8% (n=2)
My child enjoys school	67.3% (n=74)	28.2% (n=31)	4.5% (n=5)
School supports me as a parent	55.6% (n=60)	38.9% (n=42)	5.6% (n=6)
Staff at the school do not understand my child	5.5% (n=6)	27.5% (n=30)	67.0% (n=73)
School is unable to cope with my child	3.7% (n=4)	16.7% (n=18)	79.6% (n=86)
School does not meet my child’s needs	5.5% (n=6)	21.1% (n=23)	73.4% (n=80)
My child has a good attendance record at school	82.0% (n=91)	14.4% (n=16)	3.6%(n=4)

The feeling that children using short breaks have towards their schooling was investigated by the inclusion of two short questions in the child or young person using short breaks questionnaire. These questions asked the child first to indicate how much they like the time they spend at school then to indicate their liking for their teachers. These questions were also included in the sibling questionnaire detailed later in this report. Results for children using short breaks are shown below in Table 25.

Table 25 Feelings about school, respondents to longitudinal study children using short breaks questionnaires

	Like all / Like most	Like some	Like none	Don't know
How do you feel about the time you spend at school?	73.6% (n=19)	19.2% (n=5)	0%	7.7% (n=2)
How do you feel about your teachers?	57.7% (n=15)	11.5% (n=3)	11.5% (n=3)	19.2% (n=5)

2.3.1 Children completing the child or young person using short break questionnaire

27 children using short breaks in 25 families taking part in the longitudinal study opted to complete a questionnaire. This included 77.8% (n=21) males and 22.2% (n=6) females, 96% (n=24) of these children were White British, one was African and two were from unknown ethnic groups. 100% (n=25) of these children received DLA. 92.3% (n=24) of these children had diagnosed conditions, two did not. Their ages ranged from 6 to 18 years (mean 12.9, median 13.3, $\bar{x}$ 3.1). 88.0% (n=22) of these children were known to have a learning disability, three were known not to have a learning disability. Of children with a learning disability 18.2% (n=4) had a severe or profound learning disability and 63.6% (n=14) had a moderate or mild learning disability. 48% (n=12) were known to have an autistic spectrum disorder (target group A), 3.8% (n=1) was known to have complex medical needs (target group B), 23.1% (n=6) were known to be over 11 and have moving and handling needs requiring equipment (target group C), 53.8% (n=14) were known to have behaviour difficulties (target group D) and 30.8% (n=8) were known to be over 14 years and have a severe disability (target group E). The pattern of characteristics of these 27 children seems to be somewhat aligned to that of the 336 children described in the main carer questionnaires with two exceptions; children with a severe learning disability and children with complex health needs both appear to be under-represented in the subset of children who opted to complete a questionnaire.

2.4 Information about other adults in the household

Respondents to the longitudinal study main carer questionnaire were also asked to provide age, gender and relationship details for additional adults in the household. Ages of adults ranged from 18 to 75 years, with mean age being 42.8 years (n=111). 80.4% (n=112) of additional adults were male, contrasted to the main carers in these families where 91.2% (n=103) were female. Additional adults varied in their relationships to the child who used short breaks, these are summarised in Table 26 below.

Respondents to the longitudinal study main carer questionnaires were asked to indicate whether their partner (if they had one) held a number of qualifications. Two respondents were unable to respond, 90 respondents had a partner and were able to respond. Table 27 below shows the level of the highest qualification held by partners.

Table 26 Relationship of other adults in household to child or young person using short breaks

	Frequency	Percent
Biological parent	72	64.2
Step parent	9	8.0
Adoptive or foster parent	7	6.3
Sibling	13	11.6
Grandparent	5	4.5
Other (Aunt / Uncle / au pair)	6	5.3
Total	112	100

Table 27 Highest academic or vocational qualification held (partners of respondents to main carer questionnaires)

	Frequency	Percent
First Degree or higher	30	33.3
A level, NVQ3, Trade Apprenticeship or Diploma	25	27.8
GSCE A-C or NVQ2	23	25.6
None of these	12	13.3
Total	90	100.0

Respondents to the longitudinal study main carer questionnaires were asked whether problems with reading, writing or maths made it difficult for their partner to manage day to day activities like paying bills or writing letters; 2.2% (n=2 of 92) indicated that their partner did have these problems. Respondents to the longitudinal study main carer questionnaire were also asked to indicate whether their partners had attended any courses to improve reading or number skills; 5.6% (n=5 of 90) had attended courses to improve number skills, whereas 2.2% (n=2 of 90) had attended courses to improve reading skills.

Respondents to both main carer questionnaires were asked to select a description of their partner’s current employment situation or to tick ‘other’ and provide a more appropriate description. Table 28 below summarises the results.

Table 28 Employment descriptions (partners of respondents to main carer questionnaires)

	Frequency	Valid Percent
Working full-time	173	65.5
Working part-time	33	12.5
Looking after family full-time	31	11.7
Retired	9	3.4
Looking for work	5	1.9
Not working due to disability or sickness	3	1.1
Disabled	2	0.8
Carer (including foster carers)	2	0.8
Other not stated	2	0.8
Self employed	2	0.8
On government training scheme	1	0.4
Voluntary worker	1	0.4
Total	264	100.0

2.4.1 Adults completing the additional carer questionnaire

In 15 families taking part in the longitudinal study a further carer opted to complete a copy of the additional carer questionnaire. This included 12 males (80.0%) and 3 females aged between 36 and 55 years (mean age 44.8 years, $\bar{x}$ 5.8). All were in a parenting role in relation to the child with 86.7% (n=13) being biological parents. Three of these respondents had a degree level qualification or higher, five had A levels or NVQ level 3, three had GSE O' level or equivalent and two had none of those qualifications. 53.5% (n=8) of these respondents were working full time, a further five were working part time, one was looking after the family full time and one was not working due to being disabled. Thus these 15 respondents are not dissimilar to all 'other adults' in households.

2.5 Information about other children in the household

Respondents to the longitudinal study main carer questionnaires were asked to give information on the age, gender and relationships of other children living in the household. Ages of other children in these households ranged from 0 to 17 years, with the mean age being 10.1 years (n=105). 57.1% (n=60) of these children were female. Most (85.7%, n=90) of these children were biological siblings, others included adoptive, foster and step siblings and cousins.

2.5.1 Children completing the sibling questionnaire

27 children from 24 families opted to complete a sibling questionnaire. 81.5% (n=22) of these children were female, 18.5% (n=5) were male. Ages of these children ranged from 5 to 18 years (mean 12.0, $\bar{x}$ 3.6). All of these children were siblings of the child using short breaks and this included one foster sibling. Compared to all 'other children' in the household the children responding to the sibling questionnaire contain a slight excess of females.

2.6 Other support for families from service providers and family friends

Respondents to both main carer questionnaires were asked to indicate whether their child had used a diverse range of 32 services over the last three months. These ranged from establishments such as schools, hospitals and Sure Start Children's Centres through various therapists and practitioners to services such as Connexions, volunteer transport and home adaptation service (see Appendix B for full list). They were also asked to indicate whether they had used 6 adult focused services in the last three months, this included Job Centres, various parenting groups and sessions and the services of a volunteer supporter. 325 respondents completed this question; the results are summarised in Table 29 below. This is followed by Table 30 which lists the seven most frequently indicated child-focused services.

Table 29 Number of services used (other than short breaks)

	n	Min	Max	Mean	$\bar{x}$
Child focused services [of 32]	325	1	16	7.1	3.2
Adult focused services [of 6]	325	0	4	0.6	0.9

Table 30 Top 7 child-focused services (other than short breaks)

	Frequency	Percent
Special school	233	71.7
Speech therapist	181	55.9
Social worker	177	54.5
General Practitioner (GP) services	170	52.3
Hospital Outpatient departments	158	48.6
Public Transport	103	31.7
Mainstream school	73	22.5

The most frequently indicated adult focused service was 'parent group for families with a disabled child' which had been used by 25.8% (n=84) of respondents.

Respondents to the main carer and additional carer questionnaires of the longitudinal study were asked how often during the last week they had spent time with friends. The results for main carers are presented below. Slightly more than half (50.4%, n=57) had seen friends once or twice during the week, 37.2% (n=42) stated that they had spent no time with friends or had no friends.

Table 31 Frequency have seen friends, respondents to longitudinal study main carer questionnaires

	Frequency	Percent
Everyday	2	1.8
3-6 times	12	10.6
1-2 times	57	50.4
Not at all	42	37.2
Total	113	100.0

2.7 Family socio-economic position

Respondents to both main carer questionnaires were asked to provide general information about their financial position. Respondents to the longitudinal study main carer questionnaire were asked to provide further detail in relation to financial situation and expenditure.

Respondents were asked how often they have been worried about money during the last few weeks. 45.5% (n=151) of respondents had worried ‘quite often’ or ‘almost all of the time’, 16.9% (n=56) had never worried about money over the last few weeks (see Table 32).

Table 32 Family finance - How often worried about money over last few weeks, respondents to longitudinal study main carer questionnaires

	Frequency	Percent
Almost all the time	51	15.4
Quite often	100	30.1
Only sometimes	125	37.7
Never	56	16.9
Total	332	100.0

A second question asked respondents to select a phrase which best described how they and their family were managing financially these days (see Table 33). A significant minority (22.0%, n=73) were not managing well or had some level of financial difficulty.

Table 33 Family finance - How family is managing financially these days

	Frequency	Percent
Manage very well	48	14.5
Manage quite well	84	25.3
Get by alright	127	38.3
Don't manage very well	7	2.1
Have some financial difficulty	58	17.5
In deep financial trouble	8	2.4
Total	332	100.0

Respondents to the longitudinal study were asked about their financial situation over the last 12 months. 12.4% (n=14) of respondents indicated that their financial situation had got better, whilst 36.3% (n=41) reported that it had got worse, 51.3% (n=58) reported the situation had stayed more or less the same (see Table 34).

Table 34 Family finance - Changes over last 12 months

	Frequency	Percent
Got better	14	12.4
Got worse	41	36.3
Stayed more or less the same	58	51.3
Total	113	100.0

Respondents to the main carer questionnaire of the longitudinal study were also asked how often they had experienced trouble with debt repayments over the last 12 months. 18.8% (n=21) had experienced these problems quite often or all of the time (see Table 35).

Table 35 Family finance - Trouble with debt repayments over last 12 months

	Frequency	Percent
Almost all the time	3	2.7
Quite often	18	16.1
Only sometimes	34	30.4
Never	57	50.9
Total	112	100.0

These respondents were also asked about the affordability of different areas of family expenditure and whether children or adults had any needs which could not currently be met due to lack of money. The items most frequently identified as being needed but unaffordable included holidays (41.4%, n=46), trips and outings (40.5%, n=45), a monthly night out (32.1%, n=34) and quality / brand name clothes and shoes (25.5%, n=28).

There were similar findings about the affordability of items specifically needed by children in these households. 52 respondents (48.1%) indicated that their child or children really needed things which they could not find the money for; some of these children needed more than one item. The most frequently identified items were holidays (25%, n=27), bikes or sports equipment (19.4%, n=21) and beds / cots or high chairs (11.1%, n=12). Other items needed by children included: clothes, footwear, toys, alterations to bathroom, creating a wet-room, alterations to garden, larger bedroom, extension to home, sensory room, furniture, decorating, personal computer, musical instrument, music lessons, place on specialist course or at specialist college, new wheelchair, specialist buggy, trips out and a carer to take away on holiday.

There were again similar findings in relation to adults. 55 respondents (51.4%) indicated that they or their partner really needed things which they could not find the money for. The top two items identified were home improvements (38.3%, n=41) and holidays (29.9%, n=32). Other items that were identified included curtains, carpets, electrical equipment, furniture, car, bedding, clothes and footwear, repairs to roof, house alterations – wet room, trips out with child.

Ranks from the Indices of Deprivation (ID 07) for lower super output areas (LSOA) for family postcodes were investigated. On this index the LSOA with a rank of 1 is the most deprived and 32482 the least deprived. There is considerable variation in the ranks for the postcodes of these families, the lowest rank being 322 (1st percentile), the highest rank being 31938 (98th percentile) with a mean rank of 17134 (53rd percentile), the standard deviation of the ranks was 8572.

Ranks from the Child Well-being Index 2007 (CWI09) were obtained for family postcodes; in addition to the overall index the material domain and the ‘health and disability’ domain were examined. It should be noted that on this index the LSOA with a rank of 1 has the highest level of well-being and 32,482 the lowest well-being. Again there was a high level of variation in the ranks of the postcodes of these families. The results are summarised in Table 36 below.

Table 36 Child Well-being index 2007 ranks and (percentiles)

	n	Min	Max	Mean	$\overline{x}$
CWI 09 Overall index	333	47 (1st)	32089 (99th)	15201 (47th)	8515
CWI 09 ‘Material’ domain	333	10 (1st)	31335 (97th)	15197 (47th)	8781
CWI 09’Health and Disability’ domain	333	68(1st)	32454 (100th)	18391(57th)	8973

3 Family Health and Well-being

3.1 Health and well-being of main carers

Respondents to the main carer questionnaire of both the longitudinal and cross-sectional study were asked to indicate their general health on a five point scale from very good to very bad. The results are summarised below in Table 37; 63.5% (n=212) indicated that their health was good or very good, this can be compared to 76% of general population adults aged 16+ in the 2008 Health Survey for England (Information Centre, 2009). 5.7% of main carers in this survey reported their health as bad or very bad compared to 6% of general population adults aged 16+ in England (Information Centre, 2009).

Table 37 General health, respondents to main carer questionnaire

	Frequency	Percent
Very good	58	17.4
Good	154	46.1
Fair	103	30.8
Bad	14	4.2
Very bad	5	1.5
Total	334	100.0

These respondents were further asked to indicate whether they had any long-standing illnesses, disabilities or infirmities lasting or expected to last for 3 months or more. 45.5% (n=152) indicated that they had such a long-standing condition. This compares to 42% of general population adults aged 16+ in the Health Survey for England 2008 (Information Centre, 2009). Respondents were asked to name these long-standing illnesses, disabilities and infirmities, the responses were very diverse and at times detailed. Many respondents named more than one condition. Where possible these descriptions were classified under a number of headings the most frequently occurring categories are summarised below and percentages given as a percentage of all respondents reporting a long-standing condition (see Table 38).

Other conditions mentioned by a smaller number of respondents include cancer, leukaemia, insomnia, restless legs, Milroy’s disease, chronic fatigue syndrome, ME, urinary conditions, skin conditions and thoracic outlet syndrome. Respondents were also asked if their long-standing illness or disability limited their activities in any way; 65.8% (n=98) said that they did.

Table 38 Long-standing illness and disability, respondents to main carer questionnaire

	Frequency	Percent
Mental health problem (depression, anxiety, stress, bipolar)	40	26.1
Musculo-skeletal problems other than arthritis (inc' back, limb, pain)	36	23.5
Asthma	18	11.8
Hypertension (high blood pressure)	15	9.8
Arthritis (including osteo, rheumatic, psoriatic)	15	9.8
Gastrointestinal (IBS, Crohn's, bowel, reflux, acid, hiatus hernia)	14	9.2
Gynaecological (menstrual, endometriosis, fibroids, menopausal)	9	5.9
Circulatory other than hypertension (including heart, angina, valve)	8	5.2
Diabetes	8	5.2
Migraine	7	4.6
Sensory (blind, partially sighted, eye problems, deafness)	7	4.6
Thyroid (including overactive and underactive)	6	3.9
Neurological (including brain, hemiplegia, cadasil, meningioma)	6	3.9
Epilepsy (including fits or seizures)	5	3.3

The K6 scale of psychological distress was incorporated into both main carer questionnaires (Kessler et al., 2003, Kessler et al., 2002). Total scores for the K6 scale were calculated for respondents who had completed all six items. There was considerable variation in the scores, which ranged from 0 to 22 (the maximum score possible being 24), the mean score was 7.0 with a standard deviation of 4.9. 15.3% (n=50) of respondents reached a score of 13+ thereby meeting the criteria to indicate serious mental illness. A further 10.4% (n=34) of respondents had scores of 11 or 12 points.

A recent secondary analysis of data from the Millennium Cohort Study, of UK parents of young children (Emerson et al., 2010b) used a less stringent cut-off of 8+ on the K6 scale. Using this threshold, 41.6% of main carers in this sample reported K6 scores above the threshold for psychological distress/probable psychiatric disorder. This compares to the following data from the secondary analysis (Emerson et al., 2010b): 21% of mothers and 14% of fathers of children aged 5 with more severe early cognitive delay; 20% of mothers and 17% of fathers of children aged 5 with less severe early cognitive delay; and 11% of mothers and 8% of fathers of typically developing children aged 5.

Table 39 below compares individual items from the K6 scale by reporting the proportions of responses which were high scores, i.e. 'most of the time' or 'all of the time'.

Table 39 Percentage of respondents scoring K6 item at 'most of the time or 'all of the time', respondents to longitudinal study main carer questionnaires

During the past 30 days, how often did you feel...	Frequency	Percent
That everything was an effort	61	18.3
Restless or fidgety	50	14.2
Nervous	30	9.1
Worthless	27	8.2
Hopeless	25	7.6
So depressed that nothing could cheer you up	17	5.1

Respondents to the main carer questionnaires were also asked to provide an indication of how satisfied they were with how their life has turned out so far, they did so on a 10 point scale where ‘1’ represented completely dissatisfied and ‘10’ represented completely satisfied. The mean score was 5.9 with a standard deviation of 2.0. The results are shown in Table 40 below.

Table 40 Life satisfaction scores, respondents to main carer questionnaires

Score	Frequency	Percent
1 completely dissatisfied	5	1.5
2	14	4.3
3	28	8.5
4	36	11.0
5	51	15.5
6	49	14.9
7	63	19.2
8	55	16.8
9	23	7.0
10 completely satisfied	4	1.2
Total	328	100.0

Respondents to the longitudinal main carer questionnaire and the additional carer questionnaire were asked to indicate their level of agreement with six statements of positive gain (Pit-ten Cate, 2003). Scores were summed giving a potential range of 6 to 30, with a score of 6 representing strong agreement with all positive statements, scores of less than 13 representing some level of agreement with all positive statements and scores over 23 indicating some level of disagreement with all positive statements.

There was considerable variation in responses given by main carers, scores were observed across the whole range from 6 to 30, with a mean value of 11.8, median of 12.0 and standard deviation of 4.0 (n=110). 62.7% (n=69) of scores were less than 13 and 1.8% (n=2) were greater than 23. This would indicate that typically respondents are at least in partial agreement with these positive statements. Despite this general agreement there were some differences between the items in the scale with some attracting higher levels of agreement than others, this is examined in Table 41 below. Of particular note is the lower level of agreement with the statement about the family becoming closer, where although 39.6% (n=44) of respondents did agree, 31.5% (n=35) disagreed or strongly disagreed.

Table 41 Percent of respondents to longitudinal study main carer questionnaires responding to PGS items with 'Agree' or ‘Strongly agree'

	Frequency	Percent	n
Having this child has helped me to learn new things/ skills	102	91.1	112
Since having this child I have grown as a person	98	87.5	112
Since having this child I have a greater understanding of other people	93	83.0	112
Raising this child helps putting life into perspective	92	82.1	112
Since having this child I have become more determined to face up to challenges	80	72.1	111
Since having this child, my family has become closer to one another	44	39.6	111

The worries and rewards associated with caring for a disabled child were examined using the Transitional Daily Worries and Rewards Questionnaire (TDRWQ) (Glidden and Jobe, 2007). Respondents to the longitudinal study main carer questionnaire were asked to complete 11 items from the TDRWQ. A small item non-response of between 0.9% and 2.7% was noted, missing value analysis suggested that data were missing completely at random (MCAR) and accordingly imputed values were substituted for the missing values. Total scores were calculated along with a number of subscales, these are reported below in Table 42. The TDRWQ is positively orientated, that is higher scores indicate more positive outcomes. There is a wide variation in the scores on all scales, of particular note is the fact that the financial independence subscale mean score is relatively low compared to the total whereas the family relations subscale mean score is relatively high. This might suggest that worries about the child’s financial future might be a particular concern for these respondents whilst they are relatively confident that their child will continue to have good support from their family.

Table 42 TDRWQ scores [potential range], respondents to longitudinal study main carer questionnaires

	n	Min	Max	Mean	$\bar{x}$	Mean % of poss. Max
TDRWQ Total 11 item score [11-55]	113	13	45	28.9	6.7	52.5
TDRWQ Positive futures subscale [4-20]	113	4	18	9.1	3.6	45.5
TDRWQ Community resources subscale [2-10]	113	2	10	5.4	1.9	54.0
TDRWQ Financial independence subscale [2-10]	113	2	10	3.7	1.9	37.0
TDRWQ Family relations subscale [3-15]	113	5	15	10.6	2.4	70.7

Respondents to the main carer questionnaire of the longitudinal study who had partners were asked how frequently they disagreed with their partner over issues concerning their disabled child. Disagreements occurred once a week or more in 29.4% (n=27 of 92) of households. The results are presented in Table 43 below.

Table 43 Frequency of disagreement between partners concerning disabled child, described by respondents to longitudinal study main carer questionnaires

	Frequency	Percent
‘More than once a day’ or ‘Once a day’	2	2.2
‘Several times a week’	11	12.0
‘Once a week’	14	15.2
‘Less than once a week’	40	43.5
‘Never’	23	25.0
‘Cannot say’	2	2.2
Total	92	100.0

These respondents were also asked to rate their happiness with their relationship on a 7-point scale; 10.8% (n=10 of 93) rated their relationship satisfaction at 3 or below, 66.7% (n=62) rated it as 6 or higher, see Table 44 below. The mean score on this scale was 5.6 ($\bar{x}$ 1.5).

Table 44 Happiness with relationships, respondents to longitudinal study main carer questionnaires

‘1’ =’Very unhappy’ and ‘7’ = ‘Very happy’	Frequency	Percent
‘1’ or ‘2’	5	5.4
‘3’	5	5.4
‘4’	9	9.7
‘5’	12	12.9
‘6’	34	36.6
‘7’	28	30.1
Total	93	100.0

3.2 Health and well-being of disabled children

Respondents to the main carer questionnaires of both studies were asked to indicate the general health of the child who uses short breaks using a 5-point scale from ‘very good’ to ‘very bad’. Although most children were described as having ‘good’ general health or better there was some variation with a considerable minority describing their child’s health as ‘fair’ or worse. The findings are presented below in Table 45. In the current sample, 82.8% of children were reported to have very good or good general health, compared to 94% of general population children aged 0-15 in the Health Survey for England 2008 (Information Centre, 2009).

Table 45 General health of child using short breaks, described by respondents to main carer questionnaires

	Frequency	Percent
Very good	78	23.4
Good	165	49.4
Fair	74	22.2
Bad	15	4.5
Very bad	2	0.6
Total	334	100.0

Respondents to the longitudinal study main carer questionnaire were also asked to indicate whether their child had any long-standing illnesses or infirmities other than those they had already described when asked about their child’s disability; 27.3% (n=110) stated that they did. This compares to 17% of general population children aged 0-15 in the Health Survey for England 2008 who were reported to have a long-standing illness or infirmity (Information Centre, 2009). They were asked to describe these; conditions listed included asthma, eczema, allergies, food intolerances, chest infections, lung disease, heart murmur, epilepsy, haemophilia, scoliosis, Perthes disease, constipation, stoma, hypospadias, cleft palate, diabetes, kidney problems and issues caused by post-transplant treatment. Of those children with a further illness or infirmity 75.9% (n=20) were limited in their normal activity by this condition.

Respondents to both main carer questionnaires were asked to complete the Strengths and Difficulties Questionnaire (SDQ) for the child who uses short breaks (Goodman, 2001). Some respondents felt that some items within the scale were inappropriate to their child or difficult to answer for their child. For example some parents of children with severe communication problems felt that their child was unable to 'complain' and were unsure whether their child was often 'worried' or 'unhappy' and some parents of profoundly disabled children felt their child was effectively unable to 'steal' or 'share', or be '(dis)obedient' or 'helpful'. Therefore the following results below are likely to be biased somewhat towards children with less profound physical and communication difficulties. 242 respondents were able to complete all 25 items in the SDQ , 251 respondents were able to complete the 20 items required to calculate a total difficulties score and the five subscales were completed by between 281 respondents (emotional subscale) and 298 respondents (peer problems subscale). Minimum and maximum values along with means and standard deviations are presented in Table 46 below. There was considerable variation in children's scores with most subscales scoring across the whole potential range (0 to 10). For these children the subscale giving the highest mean value was 'hyperactivity'.

SDQ scores for this sample were compared with those from a smaller sample of children with intellectual disabilities, aged 11-15 drawn from a nationally representative sample of children aged 11-15 in the UK (Emerson, 2005). Children in this sample scored similarly on the SDQ total difficulties scale to children with intellectual disabilities in the UK sample (18.2 this sample vs. 16.6), conduct problems subscale (2.7 vs. 3.2), emotional problems subscale (3.6 vs. 3.4) and hyperactivity subscale (6.9 vs. 6.5). However children in this sample on average scored higher on the SDQ peer problems subscale (4.9 vs. 3.6) and much lower on the prosocial behaviour subscale (4.2 vs. 8.0), possibly reflecting the inclusion of younger age bands and more children with ASD in the current sample. All the mean SDQ scores for the current sample reported more difficulties or fewer strengths than children aged 11-15 without intellectual disabilities (Emerson, 2005).

Using standard thresholds for scoring SDQ scales and subscales into 'normal', 'borderline' and 'abnormal' functioning, SDQ scores for this sample were considerably higher than for a nationally representative sample of Australian children with intellectual disabilities aged 6-7 (Emerson et al., 2010a), which in turn were higher than scores for typically developing children in the Australian sample, with: 45% of this sample scoring in the 'abnormal' range for SDQ total difficulties (vs. 24% children with intellectual disabilities and 5% typically developing children in the Australian sample); 33% scoring 'abnormal' for SDQ conduct problems (vs. 24% and 8%), 25% scoring 'abnormal' for emotional problems (vs. 13% and 6%); 53% scoring 'abnormal' for hyperactivity (vs. 26% and 8%); 65% scoring 'abnormal' for peer problems (vs. 35% and 11%); and 62% scoring 'abnormal' for prosocial behaviour (vs. 14% and 3%).

Table 46 SDQ scores for children using short breaks described by respondents to main carer questionnaires [potential range of scale]

	n	Min	Max	Mean	$\bar{x}$
SDQ Total difficulties (without prosocial subscale) [0-40]	251	4	39	18.2	6.7
SDQ Hyperactivity subscale (difficulties) [0-10]	297	1	10	6.9	2.5
SDQ Emotional symptoms subscale (difficulties) [0-10]	281	0	10	3.6	2.7
SDQ Conduct problems subscale (difficulties) [0-10]	295	0	10	2.7	1.9
SDQ Peer relationships subscale (difficulties) [0-10]	298	0	10	4.9	2.2
SDQ Prosocial behaviour subscale (strengths) [0-10, 10]	289	0	10	4.2	3.1

The psychological well-being of children using short breaks was further investigated using four positive items from the PANAS (Watson and Clark, 1988) which were included in the child or young person using short breaks questionnaires. All 27 children completed this questionnaire, with 25 completing all of these items; scores were summed giving a potential range of 4 to 20, with 20 indicating extreme positive responses given to all four items. Scores for these children were observed ranging from 7 to 20 (mean 13.5, $\overline{x}$ 3.9), scores for individual items are summarised in Table 47 below.

Table 47 Summary of PANAS item scores, respondents to longitudinal study children using short breaks questionnaires

Over the past few weeks...	Very slightly or not at all	A little / Moderately	Quite a bit / Extremely
...how much have you felt proud (of yourself)?	7.4% (n=2)	44.4% (n=12)	48.1% (n=13)
...how much have you felt strong?	12.0% (n=3)	44.0% (n=11)	44.0% (n=11)
...how much have you felt excited?	7.4% (n=2)	40.7% (n=11)	51.8% (n=14)
... how much have you felt interested (in something)?	7.4% (n=2)	33.3% (n=9)	59.2% (n=16)

Relationships and contact with peers was further investigated via the inclusion of 6 adapted items from the sibling relationships questionnaire (SRQ) into questionnaires for children using short breaks (Buhrmester and Furman, 1985, Yelland and Daley, 2009). These items were changed to make the subject of each question ‘friends’ rather than ‘brother or sister’. Individual scores were summed to produce and overall score, this potentially ranged from 6 to 30, with 30 indicating a strong positive response to all 6 items. 27 children completed this questionnaire, with 25 completing all of these items; scores between 12 and 28 (mean 19.5, $\overline{x}$ 4.4) were observed. Responses for individual items are summarised in Table 48 below.

Table 48 Relationships with peers (adapted SRQ), respondents to longitudinal study children using short breaks questionnaires

	Hardly at all / Not much	Somewhat	Very much / Extremely much
How much do you and your friends go places and do things together?	77.8% (n=21)	18.5% (n=5)	3.7% (n=1)
How much do you care about your friends?	16.0% (n=4)	20.0% (n=5)	64.0% (n=16)
How much do your friends care about you?	24.0% (n=6)	16.0% (n=4)	60.0% (n=15)
How much do you do nice things for your friends?	28.0% (n=7)	44.0% (n=9)	28.0% (n=7)
How much do your friends do nice things for you?	40.0% (n=10)	28.0% (n=7)	32.0% (n=8)
How much do you and your friends get cross and argue with each other?	84.0% (n=17)	8.0% (n=2)	8.0% (n=2)

3.3 Health and well-being of other adults

As with respondents to the longitudinal main carer questionnaire respondents to the additional carer questionnaire were asked to indicate their level of agreement with six statements of positive gain (Pit-ten Cate, 2003). Scores were summed giving a potential range of 6 to 30, with a score of 6 representing strong agreement with all positive statements, scores of less than 13 representing some level of agreement with all positive statements and scores over 23 indicating some level of disagreement with all positive statements. 15 additional carer questionnaires were completed; there was less variation in PGS scores of additional carers than for the main carers. Scores were observed from 6 to 16, with a mean value of 10.6, median of 10.5 and standard deviation of 3.2 (n=14) ; these scores being somewhat lower than the main carer scores, possibly suggesting that main carers experience greater positive gains than additional carers.

Respondents to the additional carer questionnaire were asked to complete a number of items from the TDRWQ to investigate their daily rewards and worries in relation to the child who uses short breaks. As with the main carers a series of sub scales were calculated, the results are summarised in Table 49 below. The results follow a very similar pattern to those seen for the main carers, again suggesting that concerns about their child's future financial independence may be a particular concern for these families.

Table 49 TDRWQ scores [possible range], respondents to the longitudinal study additional carer questionnaire

	n	Min	Max	Mean	$\bar{x}$	Mean % of poss. max
TDRWQ Total 11 item score [11-55]	14	18	39	27.9	6.1	50.7
TDRWQ Positive futures subscale [4-20]	15	5	14	8.8	3.0	44.0
TDRWQ Community resources subscale [2-10]	15	4	8	5.5	1.5	55.0
TDRWQ Financial independence subscale [2-10]	15	2	6	3.1	1.3	31.0
TDRWQ Family relations subscale [3-15]	14	7	15	10.3	2.1	68.7

Respondents to the additional carer questionnaire were asked to indicate how frequently they and their partner disagree over issues concerning the child who uses short breaks. 73.3% (n=11) indicated that they disagreed over their disabled child once a week or less.

Respondents to the additional carer questionnaire were asked to indicate their satisfaction with their relationships on a 7 point scale; 20.0% (n=3) rated their relationship satisfaction at 3 or below, 60.0% (n=9) rated it as 6 or above. The mean score on this scale was 5.4 ($\bar{x}$ 1.8).

Respondents to the additional carer questionnaires were asked how often during the last week they had spent time with friends. 46.7% (n=7) had not seen friends during the last week or had no friends, this is compared to 37.2% (n=42) for respondents to the main carer questionnaire.

3.4 Health and well-being of other children

Respondents to both main carer questionnaires were asked to give information about the general health of the eldest sibling in the household of the child using short breaks. Most of these siblings (89.3%, n=234) were described as having ‘good’ or better health with 55.3% (n=145) having ‘very good’ health. Thus the general health of the eldest sibling seems to be somewhat better than that of the child using short breaks.

Table 50 General health, eldest sibling living in household, described by respondents to main carer questionnaires

	Frequency	Percent
Very good	145	55.3
Good	89	34.0
Fair	24	9.2
Bad	3	1.1
Very bad	1	.4
Total	262	100.0

Respondents to these questionnaires were also asked whether there was more than one child with disabilities living in the household; 11.7% (n=39) respondents indicated that there were. Respondents to the longitudinal study main carer questionnaire were asked to indicate whether the eldest sibling living in the household had any long-standing illnesses, disabilities or infirmity; 28.9% (n=22) indicate that they had. These conditions included asthma, eczema, allergies, heart problems, cerebral palsy, quadriplegia, incontinence, stoma, scoliosis, epilepsy, hearing loss, sight problems, learning disability, global delay, communication difficulties, ASD, dyspraxia, pica disorder and Raynaud’s syndrome. Of those siblings with such a condition 59.1% (n=13) of respondents stated that this limited their activities.

Respondents to the longitudinal study main carer questionnaire were asked to respond to a number of items about the eldest sibling’s schooling. Findings are shown below in Table 51. Comparing these findings to Table 24 which examined these aspects of schooling for the child who uses short breaks the most marked difference is that siblings are more often described as progressing well at school. In addition respondents appear to be less likely to feel well informed about their child’s progress and less well supported by the school of the eldest sibling than the school of the child who uses short breaks.

Table 51 Aspects of schooling, eldest sibling in household, described by respondents to longitudinal study main carer questionnaires

	Very True	Somewhat true	Not at all true
My child is progressing well	68.9% (n=47)	27.5% (n=19)	4.3% (n=3)
School keeps me informed about my child's progress	54.5% (n=36)	34.8% (n=23)	10.6% (n=7)
My child enjoys school	62.1% (n=41)	30.3% (n=20)	7.6% (n=5)
School supports me as a parent	40.9% (n=27)	45.5% (n=30)	13.6% (n=9)
Staff at the school do not understand my child	7.5% (n=5)	26.9% (n=18)	65.7% (n=44)
School is unable to cope with my child	3.0% (n=2)	3.0% (n=2)	94.0% (n=63)
School does not meet my child's needs	4.5% (n=3)	14.9% (n=10)	80.6% (n=54)
My child has a good attendance record at school	89.6% (n=60)	4.5% (n=3)	6.0% (n=4)

The feelings that siblings of children using short breaks have towards their schooling were also investigated using two questions in the questionnaire for siblings. 27 children responded to this questionnaire, the results are summarised in Table 52 below.

Table 52 Feelings towards schooling (siblings), respondents to longitudinal study sibling questionnaires

	Like all / Like most	Like some	Like none	Don't know/ not at school
How do you feel about the time you spend at school?	62.9% (n=17)	18.5% (n=5)	11.1% (n=3)	7.4% (n=2)
How do you feel about your teachers?	51.8% (n=15)	29.6% (n=3)	11.1% (n=3)	7.4% (n=2)

Respondents to the longitudinal study main carer questionnaire were also asked to complete the SDQ in relation to the eldest sibling in the household. 63 respondents were able to complete the 20 items required for calculation of a total difficulties score and it was possible to calculate subscales for between 67 siblings (hyperactivity) and 73 siblings (conduct). The results are shown in Table 53. Compared to the children using short breaks (Table 46) the mean scores for these siblings are lower for all difficulties scales and higher for the prosocial behaviour subscale.

Table 53 SDQ scores, eldest sibling in household [potential range], data from respondents to longitudinal study main carer questionnaires

	n	Min	Max	Mean	$\overline{x}$
SDQ Total difficulties (without prosocial subscale) [0-40]	63	0	27	8.8	6.8
SDQ Hyperactivity subscale (difficulties) [0-10]	67	0	10	3.2	2.6
SDQ Emotional symptoms subscale (difficulties) [0-10]	71	0	10	2.4	2.7
SDQ Conduct problems subscale (difficulties) [0-10]	73	0	7	1.6	1.8
SDQ Peer relationships subscale (difficulties) [0-10]	70	0	8	1.8	2.0
SDQ Prosocial behaviour subscale (strengths) [0-10, 10]	71	1	10	7.8	2.6

Sibling's psychological well-being was also investigated by inclusion of the same four PANAS items as for the child using short breaks in the sibling questionnaires. 24 children completed all four items, allowing a total score to be calculated. Scores were similar to those observed for children using short breaks and ranged from 7 to 19 (mean 13.8, $\overline{x}$ 3.3). Results for individual items are summarised in Table 54 below.

Table 54 Summary of PANAS scores, respondents to longitudinal study sibling questionnaires

Over the past few weeks...	Very slightly or not at all	A little / Moderately	Quite a bit / Extremely
...how much have you felt proud (of yourself)?	0.0%	48.1% (n=13)	51.9% (n=14)
...how much have you felt strong?	12.0% (n=3)	44.0% (n=11)	44.0% (n=11)
...how much have you felt excited?	7.7% (n=2)	23.1% (n=6)	69.2%% (n=18)
... how much have you felt interested (in something)?	7.4% (n=2)	28.5% (n=5)	74.1% (n=20)

Respondents to the sibling questionnaire were also specifically asked whether they help to look after their brother or sister; 88.9% (n=24) indicated that they did.

Siblings' relationships and contact with peers was further assessed using 6 adapted items from the sibling relationships questionnaire (SRQ) within the questionnaires for siblings of children using short breaks (Buhrmester and Furman, 1985, Yelland and Daley, 2009). These items were changed to make the subject of each question 'friends' rather than 'brother or sister'. Individual scores were summed to produce an overall score with a potential range between 6 and 30, where 30 would indicate a strong positive response to all 6 items. 27 children completed these questionnaires and all completed all 6 items. Scores were observed between 12 and 25 (mean19.8, $\bar{x}$ 2.9). The results of individual items are summarised in Table 55 below.

Table 55 Relationships with peers (adapted SRQ), respondents to longitudinal study sibling questionnaires

	Hardly at all / Not much	Somewhat	Very much / Extremely much
How much do you and your friends go places and do things together?	18.5% (n=5)	29.6% (n=8)	51.8% (n=14)
How much do you care about your friends?	0.0%	11.1% (n=3)	88.9% (n=24)
How much do your friends care about you?	0.0%	18.5% (n=5)	81.4% (n=22)
How much do you do nice things for your friends?	3.7% (n=1)	29.6% (n=8)	66.6% (n=18)
How much do your friends do nice things for you?	0.0%	33.3% (n=9)	66.6% (n=18)
How much do you and your friends get cross and argue with each other?	62.9% (n=17)	25.9% (n=7)	11.1% (n=3)

3.5 Relationships between siblings

Sibling relationships were examined using the sibling relationship items from the TDRWQ. These items were included in both main carer questionnaires and in the additional carer questionnaires. This subscale is positively oriented, with higher scores representing more positive outcomes. For the main carers a small item non-response of between 0.0% and 1.6% was noted, missing value analysis suggested that data were missing completely at random (MCAR) and accordingly imputed values were substituted for the missing values. The TDRWQ sibling relationship subscale was calculated and the results presented in Table 56.

Table 56 TDRWQ Sibling relationships subscale [potential range], respondents to main carer questionnaires

	n	Min	Max	Mean	$\bar{x}$
TDRWQ Sibling subscale [7-35]	255	7	34	22.9	5.2

The TDRWQ sibling relationship subscale scores derived from the additional carer questionnaires was similar to those from the main carer questionnaires.

Relationships between siblings were further examined through inclusion of an adapted set of items from the sibling relationships questionnaire (SRQ) into questionnaires for children using short breaks and questionnaires for their siblings (Buhrmester and Furman, 1985, Yelland and Daley, 2009). These items were tallied to produce a combined score for each child; these scores had a potential range from 6 to 30, with 30 indicating an extreme positive response to all items. Scores were observed between 14 and 28 (mean 21.6, $\bar{x}$ 4.5) for the child using short breaks and between 15 and 28 (mean 22.4, $\bar{x}$ 3.4) for the siblings of children using short breaks. The result of individual items are summarised below in Table 57 for the child using short breaks and Table 58 for siblings of children using short breaks.

Table 57 Sibling relationships SRQ items, respondents to longitudinal study children using short breaks questionnaires

	Hardly at all / Not much	Somewhat	Very much / Extremely much
How much do you do nice things for your brother / sister?	23.5% (n=4)	52.9% (n=9)	23.5% (n=4)
How much does your brother / sister do nice things for you?	23.6% (n=4)	17.6% (n=3)	58.8% (n=10)
How much do you care about your brother / sister?	0.0%	23.5% (n=4)	76.5% (n=13)
How much does your brother / sister care about you?	11.8% (n=2)	17.6% (n=3)	60.5% (n=12)
How much do you and your brother / sister get cross and argue with each other?	41.1% (n=7)	29.4% (n=5)	29.4% (n=5)
How much do you and your brother / sister go places and do things together?	23.5% (n=4)	17.6% (n=3)	58.8% (n=10)

Table 58 Sibling relationships SRQ items, respondents to longitudinal study sibling questionnaires

	Hardly at all / Not much	Somewhat	Very much / Extremely much
How much do you do nice things for your brother / sister?	11.1% (n=3)	7.4% (n=2)	81.5% (n=22)
How much does your brother / sister do nice things for you?	37.0% (n=10)	25.9% (n=7)	37.0% (n=10)
How much do you care about your brother / sister?	0.0%	3.7% (n=1)	96.3% (n=26)
How much does your brother / sister care about you?	11.1% (n=3)	11.1% (n=3)	77.7% (n=21)
How much do you and your brother / sister get cross and argue with each other?	53.9% (n=14)	26.9% (n=7)	19.2% (n=5)
How much do you and your brother / sister go places and do things together?	25.9% (n=7)	33.3% (n=9)	40.7% (n=11)

Children using short breaks and their siblings were also asked who usually get more attention from their parents (themselves or a sibling) the results are summarised below.

Table 59 Children's view of which child gets more attention from parents, respondents to both longitudinal study children's questionnaires

	Myself	About the same	My sibling
Child using short breaks	52.9% (n=9)	35.3% (n=6)	11.8% (n=2)
Sibling of child using short breaks	0.0%	30.8% (n=8)	69.2% (n=18)

4 Short Breaks

4.1 Patterns of short break usage

4.1.1 Short break type

Respondents to both main carer questionnaires were asked to indicate their current usage of short breaks. 88.7% (n=298) indicated that they currently received short breaks whilst 3.0% (n=10) had used short breaks in the past but did not currently use them. 7.4% (n=25) indicated that they had never received short breaks but would have liked to have done so and 0.9% (n=3) have never received short breaks but never wanted them. These results are interesting given that all families in the sample had been identified by their local authority as a recipient of short breaks. As mentioned previously the term ‘short breaks’ is not always clear or well understood, it is possible that these families have used a service which the local authority defines as a short break service but which the recipients do not identify as such. This may particularly be the case with short break services which are embedded in universal provision such as leisure or childcare since some families may regard these as part of the gamut of services available to all children and not as services which have been provided in order to facilitate a break from caring.

The amount of different short break types used, the total hours used and the types of short breaks used varied widely. Most respondents (50.0%, n=168) indicated that they used one or two different types of break a further 42.5% (n=143) used between three and five types of break, the maximum different types of break used was 9. The different types of breaks were grouped by different characteristics as shown in Table 60; these categories are not exclusive but represent areas of particular interest. The frequency that a respondent indicated at least one break type within each group is indicated below. The breaks used by the most families are leisure or play type breaks and the breaks used by the least families are from unpaid carers such as family members or friends.

Table 60 Family had used different categories of break types, data from respondents to main carer questionnaires

	Frequency	Percent
Leisure and play (including sports, arts, play, afterschool / holiday clubs)	210	62.5
Overnight break (paid or unpaid carers / home or away)	182	54.2
Non-centre-based paid carer (home or away / day or night)	192	57.1
Centre-based (e.g. respite centre / day or night)	138	41.1
Unpaid carer (family, friends etc / home or away)	83	24.7

Univariate analyses and logistic regressions were used to examine factors associated with the type of short breaks used by families (see Appendix C and Appendix D for details). As Table 61 below shows, with the exception of the use of overnight short breaks, usage of short breaks was not strongly associated with characteristics of the child, their main carer or household factors. Overall, children using overnight and centre-based short breaks were more likely to have severe/profound learning disabilities and more complex health and physical needs but less likely to have behavioural needs. Children using leisure and other non centred-based short breaks were more likely to have behavioural needs. Across almost all forms of short breaks, indicators of greater household socio-economic deprivation were associated with children being less likely to use short breaks.

Table 61 Factors associated with usage of different categories of break types, data from respondents to main carer questionnaires

Category of short break usage	Wald (p)
Disabled child uses leisure short breaks	
(n=247, % correct classification 64.4%-66.0%, Nagelkerke R^2=0.06)	
Child in TDC Priority Group A	11.50 (p=0.001)
Disabled child uses overnight short breaks	
(n=250, correct classification 52.8%-71.6%, Nagelkerke R^2=0.28)	
Girl	5.09 (p=0.024)
Child in Target Group C	7.64 (p=0.006)
Child in Target Group E	9.56 (p=0.002)
Child severe/profound level of learning disability	6.71 (p=0.082)
Less household hardship – general household items	3.71 (p=0.054)
Less deprived neighbourhood – CWI Material Domain	5.06 (p=0.025)
Disabled child uses paid carers (not centre-based) for short breaks	
(n=272, correct classification 59.2%-65.1%, Nagelkerke R^2=0.15)	
Child higher SDQ conduct problems	8.32 (p=0.004)
Main carer higher level of education	11.47 (p=0.001)
Less household hardship – general household items	9.83 (p=0.002)
Disabled child uses centre-based short breaks	
(n=216, correct classification 61.6%-73.6%, Nagelkerke R^2=0.18)	
Child in Target Group E	24.03 (p<0.001)
Child severe/profound learning disability	18.82 (p<0.001)
Child lower SDQ emotional symptoms	10.33 (p=0.001)
Disabled child uses unpaid carers for short breaks	
(n=332, correct classification 75.6%-75.6%, Nagelkerke R^2=0.03)	
Household fewer money worries	5.60 (p=0.018)
Total number of types of short breaks used	
(median split, n=282, % correct classification 57.8%-56.0%, Nagelkerke R^2=0.04)	
Main carer fewer money worries	7.23 (p=0.007)

Many respondents gave descriptions of their frequency and duration of use of each break type in a format that could be directly converted to a total number of hours per year, for example ‘two hours every fortnight’. A few respondents gave vague descriptions such as ‘occasionally’ or ‘rarely’ when referring to how frequently they used a particular break type, in these cases it was not possible to calculate the hours used. Others gave intermediate statements such as ‘an afternoon a week during school holidays’ which together with the context of the break type and other available information allowed an estimate of the hours used to be calculated. Where possible the number of hours used per year was calculated in total and within individual groupings of short break types to give an indication of the intensity of use of each type, this information is summarised in Table 62 below. Overnight break types provide the highest mean number of hours whilst leisure and play type breaks provide the least.

Table 62 Total yearly hours used in (all breaks and different categories of break type), data from respondents to main carer questionnaires

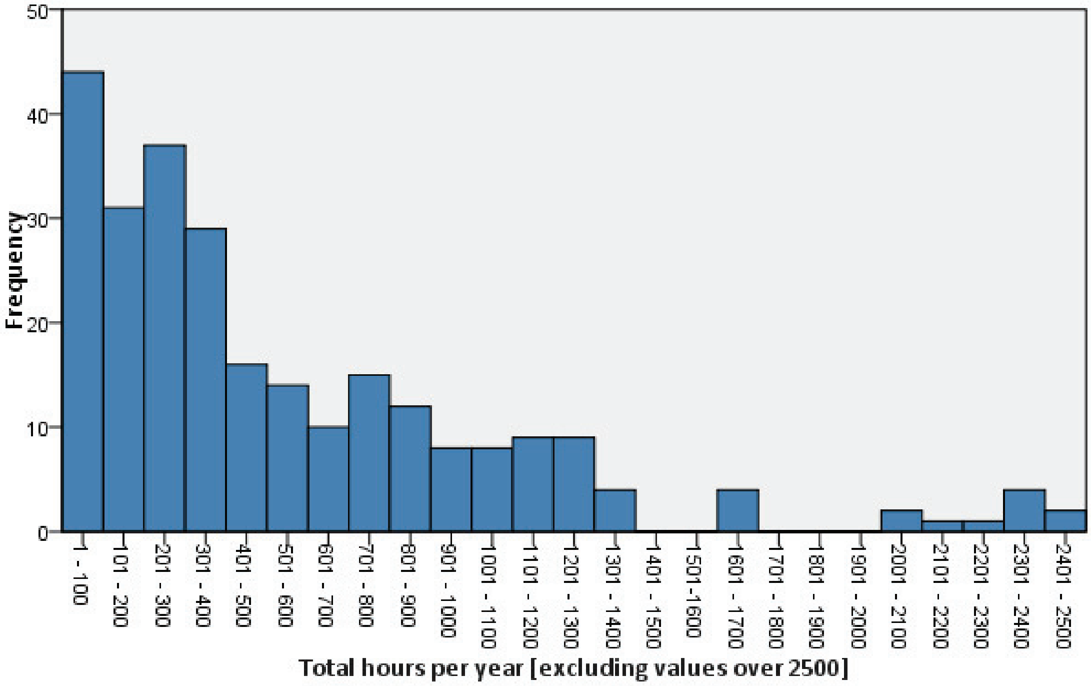
	n	Min	Max	Mean	$\bar{x}$
Total hours used – all short break types	262	1	4290	569.8	607.8
Overnight break (paid or unpaid carers / home or away)	140	10	3540	603.0	577.6
Centre-based (e.g. 'respite' centre / day or night)	113	8	2496	506.2	482.6
Non-centre-based paid carer (home or away / day or night)	160	2	3670	360.9	498.7
Unpaid carer (family, friends etc / home or away)	58	4	2000	226.0	363.5
Leisure and play (including sports, arts, play, afterschool / holiday clubs)	173	1	440	122.8	96.0

There was a large amount of variation in the number of hours of short breaks used per year with one respondent stating that they had used a single one hour break only, whilst others used up to 4290 hours a year. This high value exceeds the maximum for a short break as defined in guidance that total provision should not exceed 120 days a year (i.e. 2880 hours per year)(TDC, 2008). Only two families appeared to exceed this limit, in both cases the child using short breaks had complex disabilities and medical conditions and it may be that some of the hours indicated were for other primary purposes than short breaks per se, for example providing nursing care or family support. This again underlines the difficulty of defining 'short breaks'. Most families (53.8%, n=141 of 262) used 400 hours or less of breaks per year, 28.6% (n=75) used 200 hours or less per year and 16.8% (n=44) used 100 hours or less per year, i.e. less than two hours a week. The distribution of hours of short breaks used per year is presented in more detail in Table 63 and Figure 1 below.

Table 63 Total hours of short breaks used per year, data from respondents to main carer questionnaires

Hours / year	Frequency	Percent	Cumulative Percent
1 - 100	44	16.8	16.8
101 - 200	31	11.8	28.6
201 - 300	37	14.1	42.7
301 - 400	29	11.1	53.8
401 - 500	16	6.1	59.9
501 - 600	14	5.3	65.3
601 - 700	10	3.8	69.1
701 - 800	15	5.7	74.8
801 - 900	12	4.6	79.4
901 - 1000	8	3.1	82.4
1001 - 1100	8	3.1	85.5
1101 - 1200	9	3.4	88.9
1201 - 1300	9	3.4	92.4
1301 - 1400	4	1.5	93.9
1601 - 1700	4	1.5	95.4
2001 - 2100	2	.8	96.2
2101 - 2200	1	.4	96.6
2201 - 2300	1	.4	96.9
2301 - 2400	4	1.5	98.5
2401 - 2500	2	.8	99.2
3801 - 3900	1	.4	99.6
4201 - 4300	1	.4	100.0
Totals	262	100	

Figure 1 Total hours of short breaks used per year, data from respondents to main carer questionnaires



Univariate analyses and logistic regressions were used to examine factors associated with the amount of hours of short breaks used by families (see Appendix C and Appendix D for details). For specific categories of short break, these calculations were only conducted with families who received at least one hour of that type of short breaks.

As Table 64 below shows, child factors were exclusively associated with the quantity of paid carer short breaks (non centre-based), overnight short breaks and centre-based short breaks; children with severe/profound learning disability, more complex and a wider range of needs and lower prosocial behaviour were more likely to receive more hours of these forms of support. There were similar findings for overall hours of short break usage, which are heavily weighted towards overnight and centre-based short breaks. In contrast, more hours of leisure short break usage was exclusively associated with main carer characteristics, namely the main carer reporting themselves to be a lone parent and the main carer not reporting any longstanding illness or disability.

Table 64 Factors associated with more hours of usage of different categories of break types, data from respondents to main carer questionnaires

Hours of short break usage	Wald (p)
For children using leisure short breaks, how many hours leisure short breaks used (median split, n=159, % correct classification 50.3%-61.0%, Nagelkerke R^2=0.12)	
Main carer not long-standing health or disability	5.75 (p=0.016)
Lone parent household	8.37 (p=0.004)
For children using overnight short breaks, how many hours overnight short breaks used (median split, n=102, correct classification 50.0%-69.6%, Nagelkerke R^2=0.24)	
Child severe/profound level of learning disability	10.87 (p=0.004)
Child lower SDQ prosocial behaviour	4.14 (p=0.042)
For children using paid carers (not centre-based) for short breaks, how many hours overnight of paid carer short breaks used (median split, n=136, correct classification 58.8%-61.0%, Nagelkerke R^2=0.04)	
Child in TDC Priority Group B	3.87 (p=0.049)
For children using centre-based short breaks, how many hours centre-based short breaks used (median split, n=76, correct classification 52.6%-73.7%, Nagelkerke R^2=0.31)	
Child in more Target Groups A-E	4.11 (p=0.043)
Child severe/profound learning disability	8.37 (p=0.015)
For children using unpaid carers for short breaks, how many hours unpaid carers for short breaks used (median split, no variables univariately associated with this variable)	
Total hours of short breaks used (median split, n=202, % correct classification 53.0%-66.3%, Nagelkerke R^2=0.22)	
Child in Target Group E	24.65 (p<0.001)
Child lower SDQ prosocial behaviour	4.34 (p=0.037)
Child needs more supervision 6am-5pm	5.28 (p=0.022)

4.2 The process of getting, keeping and funding short breaks

Respondents to both main carer questionnaires were asked whether they were currently on a waiting list for short breaks and if so for how long they had been on the list. 8.3% (n=27) were currently on a waiting list with a further 9.5% (n=31) not knowing if they were on a waiting list. Of those on a list 40% (n=12) had been waiting less than 3 months, 20% (n=6) less than 6 months, 16.7% (n=5) less than a year and 23.3% (n=7) a year or more. Two respondents stated that they had been on a waiting list for two years or more.

Respondents to both main carer questionnaires were asked whether they had been turned down for a short break service and if so, to describe why this was. 20.5% (n=65) of respondents stated that they had been turned down, 71.9% (n=228) had not and a further 7.6% (n=24) did not know.

Respondents to both main carer questionnaires were asked if their child had been excluded from a short break service and if so, to describe the reasons given. 9.3% (n=29) respondents indicated that their child had been excluded from a short break, 84.5% (n=265) had not and 6.1% (n=19) did not know.

Respondents to both main carer questionnaires were asked to indicate from a range of funding options which were used to fund their short breaks. 9.3% (n=28) did not know how some or all of their breaks were funded. More than half of respondents (55.0%, n=165) received breaks funded from just one source, 25% (n=75) received breaks funded from two sources, 10.7% (n=32) received breaks funded from three or four sources.

Health sources funded breaks for 10.9% (n=33) of families; of these health sources were the only funder for 7 (21.9%) families. Local authority sources funded breaks for 67.3% (n=204) of families; of these the local authority was the only funder for 54.5% (n=110) families. The higher number of families in the sample having local authority funding is to be expected given that the sample was drawn from families known by the local authority to be receiving short breaks. In addition 29.4% (n=89) of families received direct payments for some or all of their short breaks; most of these families (75.2%, n=67) receiving direct payments for breaks also used at least one other source of funding. 19.8% (n=60) of families had a private arrangement to fund their short breaks; of these families most (71.6%, n=43) also received funding from at least one other source. 16.0% (n=49) of respondents also provided another description of funding arrangements. 26 of these referred to local or national government funding, these included ‘education’, ‘school’ or ‘Aiming High’ or to ‘government funding’ or ‘Arts and Sports Councils’. 25 of these respondents referred to local or national charitable sources including Family Fund, Lottery, Barnardos, Mencap, Cerebra, YMCA, Rotary Club and several hospices (see Table 65).

Table 65 Family using different categories of funding for short breaks, data from respondents to main carer questionnaires

	Frequency	Percent
Health service	33 (only funder 7)	10.9
Local authority	204 (only funder 110)	67.3
Direct payments	89 (only funder 7)	29.4
Private source of funding	60 (only funder 17)	19.8
Other (e.g. charity)	49	16.0

Univariate analyses and logistic regressions were used to examine factors associated with aspects of short break funding (see Appendix C and Appendix D for details).

As Table 66 below shows, few child characteristics were strongly associated with short break funding. Children with a wider range of needs were more likely to receive local authority funding and younger children were more likely to use short breaks funded via direct payments. Otherwise, main carer characteristics were most closely associated with short break funding. Older main carers living in less deprived areas were more likely to receive short breaks funded by local authorities. Female, better educated (and White British in the case of direct payments) main carers were more likely to access short breaks via direct payments and a wider range of funding sources for short breaks.

Table 66 Factors associated with aspects of short break funding, data from respondents to main carer questionnaires

Type of funding	Wald (p)
Disabled child uses short breaks funded by the local authority (n=290, % correct classification 64.5%-69.7%, Nagelkerke R^2=0.09)	
Child in more Target Groups A-E	6.56 (p=0.01)
Older main carer	7.19 (p=0.007)
Less deprived neighbourhood CWI Health & Disability Domain	4.97 (p=0.026)
Disabled child uses short breaks funded via direct payments (n=296, % correct classification 70.6%-69.9%, Nagelkerke R^2=0.14)	
Younger child	5.05 (p=0.025)
Female main carer	5.07 (p=0.024)
White British main carer	6.70 (p=0.01)
Main carer higher level of education	5.06 (p=0.024)
Disabled child uses short breaks funded from a wider range of sources (median split, n=294, % correct classification 67.3%-67.3%, Nagelkerke R^2=0.13)	
Female main carer	4.42 (p=0.035)
Main carer higher level of education	18.60 (p<0.001)

Respondents to the main carer questionnaires provided extensive information in the open questions about their experiences of the processes for getting and keeping short breaks. There were some examples where the processes had been effective or had recently improved.

> **“Our looked after children’s team has (disabilities) dramatically improved over a year or so. It’s far more ‘professional’. We’ve seen an independent social worker and a social worker from the local team for reviews and they are far more child / family centred. In the past our point of contact was a social work assistant, she was good but not in a place to help us.”**
>
> **“The service has improved over the last few years. The training/understanding of children’s needs are better. Before my husband died I got 3 nights a month – when he became ill 2 years ago they were increased to 5 a month but could ring in an emergency and ask for more help. The service for us has been excellent.”**
>
> **“The service has improved in that as a family we get more breaks than previous years, we also know the breaks we have for the entire year in advance giving is the ability to plan more as a family.”**

However a considerable number of comments in this area described problems, difficulties and experiences of being turned down for breaks or excluded from them. These experiences could be broadly divided into five areas, 1) resources, 2) processes, 3) information, 4) family factors and 5) child factors.

Resource problems tended to focus on insufficiency (or lack of availability) of suitably trained workers or insufficiency of funding. For example a simple lack of funding was the explanation given to many families when they were turned down for short breaks and many children who needed 'one to one' or 'two to one' care were told there was insufficient staffing to meet their needs or a lack of staff with appropriate experience or qualifications. Other resource constraints were also evident, several families reported losing short breaks because a carer had left their job and no suitable replacement could be identified, others reported applying for activities which were already over-subscribed and others described being unable to use breaks due to a lack of buildings and facilities which matched their child's needs.

> **"Requested additional funding for Harry to have overnight breaks, due to ongoing sleep / OCD related issues. Request declined due to cost."**
>
> **"The main problem has been access to them. I was receiving 20 nights per year from [respite home]. This was cut back to 10 nights per year due to funding. PCT would not provide the additional funding. Rather ironic considering they were given extra money by the government!"**
>
> **"Wanted boys to go to respite care home facility but at the time we didn't feel ready for overnight stays so they would not accept them at all – even for day time. It then took quite a long time to find suitable carers to come into the home."**

Process problems often included issues with assessments and reassessments, families reported long-winded processes which frequently stalled or took months to complete. Respondents used terms such as 'made to jump through hoops' to describe processes. One respondent described feeling judged, humiliated and disempowered by the assessment process and another described simply being ignored in their attempts to access short breaks. Process problems were also evident when services ceased and no alternative provision was put in place and when services changed and became unsuitable for the child. A number of similar difficulties related to direct payments, these are discussed in more detail later in this report.

> **"[what is needed is] A smoother process for receiving them, e.g. Not losing out on the services as noted above. Not having to continually chase social services... I had to jump through hoops to get it - 1st requested in July, finally got it in February! Once services received, services are good."**
>
> **"... We were assessed being eligible but 'low priority' by a very inflexible, mean eligibility grading system ... 18 months ago. We have heard very little since then – social worker never contacts us. When we chase up, she says they have not been able to identify the necessary support for personal care."**
>
> **"I have had to spend hours on the telephone, writing letters etc to try and retain the services we do receive (which are constantly under threat of being removed or reduced which is incredibly stressful and upsetting). Also, I waste far too much time trying to obtain new services/more time (with little success)."**

Information problems were described by many respondents. Information was not timely and arrived too late to enable families to book into activities or too late for them to make arrangements around other commitments such as working hours. Information was sometimes not clear, especially in relation to which services were suitable for which children and who was entitled to use them. Families were often unclear about what short provision they would be entitled to and when they did receive printed information they did not always have time to read it. Some families who contacted local authorities and service providers did not get a response whilst other families encountered workers who seemed to be poorly informed. Day to day communication between families and short break providers was sometimes problematic and this was especially acute for families of children who had communication difficulties.

> [What would improve services?] **"Information, I was unaware that we could be entitled to short breaks until your survey request came with an accompanying leaflet from [local] council. I am still awaiting a call back from them though."**
>
> **"Advertising of events is very patchy. If you have a child with special needs in a mainstream school you have little chance of hearing about it."**
>
> **"Short breaks need to be planned in advance. I would like a calendar of dates (six months in advance ideally) where I could see what I had and make my own arrangements... I would like to know what is available in our area too so that we could access other services – just a simple A4 list would be sufficient, not an expensive booklet"**
>
> **"Feedback after visit arrives sometimes over a week later. Although I am told it is OK to phone while Paul is staying, staff are often not very communicative. I would like more immediate feedback when I collect Paul. I have to spend half an hour booking him in, but there is very little feedback when he is collected and his own ability to communicate is limited."**

Family factors included instances when the family disputed the findings of assessments of their need or when their needs had been reassessed and services withdrawn. There were also families who felt their needs had been overlooked by social workers who assumed since they were relatively affluent they were not in need of support. Others were told their family was ineligible to be assessed or to receive short breaks for reasons which respondents felt were arbitrary; these included not already having been assigned a designated social worker and the fact that the child was adopted. Finally several families were turned down for breaks because they were told they had already used up their entitlement.

> **"We were reassessed by a student social worker and the sessions were stopped. I had to appeal against this decision. We had been assessed when the short breaks were in place, after they were stopped it had a huge impact upon our family and I struggled to cope on a daily basis..."**
>
> **"Recently had a care assessment to see if Freddie might be able to experience a monthly overnight stay at carer's, it was turned down – I think because he is / nor I – eligible for more hours."**

Child factors included being turned down due to the highly complex nature of the child's needs; especially where these involved carers in undertaking procedures which were perceived as requiring a level of medical skill or training. Children were turned down on occasions as they were seen as too young to receive certain types of break, others were thought to be too old for a particular service, this included one child who became 'too old' whilst being on a waiting list for two years. Children were also turned down for certain breaks because of their behavioural problems or violence or because of their handling needs or lack of mobility. Some respondents further noted that the breaks that were on offer to them were unsuitable for their children due to the nature of their disabilities.

> **"The activities offered are not appropriate to my children – my daughter is in a wheel chair, can't walk, can't crawl, can't sit without support – they offer 2 hours trampolining with a 2-3 hours drive to use it and phone that morning to book in!"**
>
> **"Each time a new carer has been needed it has taken 2 years to find a suitable person. Twice she was turned down for being too much of a handful."**
>
> **"[Local charity] refused him because he can't weight bear – takes 2 people to lift him and the services there were not able to cope with his moving and handling needs which is wrong when this service was set up for disabled children – should be able to cope."**

Some respondents described being reluctant to use short breaks; this reluctance took several forms. Some respondents worried about whether the service would be able to cope with their child, some worried about the quality of the service offered, others did not want to admit they could not cope, others simply would have preferred to have been able to care for their child themselves.

> **"I had never used any form of overnight respite [until child was 18]. I was against using any sort of overnight service and was particularly worried about abuse. But because Karen developed severe uncontrolled epilepsy as well as having a profound and multiple learning disability – I was forced to use respite, because I was no longer physically able to cope. My ideas of respite have changed dramatically and I think the quality of care is well above average."**
>
> **"It is a huge fight to get adequate respite services and is really difficult having to open yourself up and admit you can't cope in order to get services and to constantly fight to get more services to met your family's needs."**
>
> **"He is [tall and heavy], he is very autistic and has very complex needs, no one who does not know him very well and his peculiarities can manage him. I don't think short break providers could cope with him."**
>
> **"I was apprehensive at first because she hadn't spent an overnight with anyone except family (mainly me!) but once I saw the difference it made to Rianne I realised that it was a much needed break for both of us."**
>
> **"I feel extremely guilty sending her yet I know that both myself and her younger sister need a break and a chance to do normal things."**

Univariate analyses and logistic regressions were used to examine factors associated with families being turned down for or excluded from short breaks (see Appendix C and Appendix D for details).

As Table 67 below shows, families were more likely to have been turned down for a short break at some point in the past if they lived in a less deprived area and if their child had more problems with peers. Children were more likely to have been excluded from a short break at some point if they had more complex health and physical needs and if they had more conduct problems.

Table 67 Factors associated with the family being turned down or excluded from short breaks, data from respondents to main carer questionnaires

Family experience	Wald (p)
Family ever turned down for short break for disabled child (n=262, % correct classification 78.2%-78.2%, Nagelkerke R^2=0.11)	
Child higher SDQ peer problems	11.89 (p=0.001)
Less deprived neighbourhood CWI Health & Disability Domain	6.37 (p=0.012)
Disabled child ever excluded from short break (n=260, % correct classification 90.4%-90.4%, Nagelkerke R^2=0.08)	
Child in TDC Priority Group B	5.34 (p=0.021)
Child higher SDQ conduct problems	8.77 (p=0.003)

4.3 Direct payments and short breaks

Respondents to both main carer questionnaires were asked whether they also received direct payments for services other than short breaks; 18.2% (n=55) indicated that they did. However when asked to describe what these services were, many respondents described the services they had already mentioned as being short breaks, this again confirms the difficulty of defining short break services. Other services for which families receive direct payments include personal assistants and extra help when bathing children, preparing for school or accessing recreational or social activities or for childcare whilst parents worked. The childcare element of child tax credit was seen by at least one respondent as being a direct payment; this suggests that as with ‘short break’ the term ‘direct payments’ is interpreted broadly by some people.

Respondents to the main carer questionnaire give detailed comments about their experiences of direct payments. Many families mentioned appreciating the aspects of choice and control that these bring, for example, respondents to the main carer questionnaires suggested that direct payments allowed them control over when short breaks took place, they were able to arrange hours and breaks that fitted in with their family and could ‘wrap’ these hours round other activities to ensure that these were fully integrated and as productive as possible. For example children could sometimes be collected at the end of a school day by a short break provider, stay overnight and be taken back to school by the carer, thus effectively extending the ‘break’ for the parent or carer by the length of two school days. This kind of flexibility was easier for families using direct payments. Direct payments were particularly useful when they were combined with other short breaks to provide flexibility around core provision.

> **“I have found direct payments to be extremely flexible, as my son has grown older we have easily been able to change / adapt the activities to suit his needs and interests. Having control of the direct payments means that I can do this easily and quickly without the need to review his care package every time he wants to change to another different activity.”**

> **“Fiona needs a place that she can go to and feel comfortable and secure as taking her out for long periods is difficult hence her overnight respite is essential to us. It is also useful to have flexibility of some direct payments to arrange other care / support as needed.”**

Direct payments were often flexible enough to be used in imaginative ways, for example for paying for a carer to join the family on trips or holidays, paying for care for siblings to allow a parent ‘one to one’ time with a disabled child or paying to enhance the environment of the family. However such administrative flexibility was not universal. Furthermore some respondents had become critically aware of differences between local authorities in the ways in which direct payments (and short breaks generally) were allocated or administered.

> **“I have found short breaks through the direct payment scheme excellent. I arrange breaks that suit Becky’s interests and at times that suit her as an individual and us as a family. On one occasion we took a carer with us on a weekend away [which] meant we could all have a break but still be together.”**

> **“We are using our short break funding to create and provide a sensory garden for our child...”**

> **“Moved house May 2009 from [Area 1] to [Area 2]... Direct payments in [Area 1] was a lot better.”**

Direct payments allowed the family greater choice and influence over selection of staff, providers and activities with many recruiting their own carers or negotiating directly with short break providers. This enabled them to assert their own priorities for example when selecting staff. Furthermore direct payments were one way in which families increased the influence that children had by overtly recognising their preferences for certain activities and for some by including them in decisions about carers.

> **“Having direct payments and having that control of how you spend your time and having the ability to resource a carer who is our choice of person, knowing she works with children with similar needs to Bradley really makes a difference...”**

Most families using direct payments were happy to do so; however a small number of families were more reluctant and used direct payments because they saw this as the only way to get services that met their needs.

> **“I would prefer not to have to use direct payments, but to take Penny to a setting / club and feel confident that she would receive appropriate care and support to enjoy the experience, as she really enjoys socialising.”**

Some respondents reported good experiences of direct payments processes with supportive systems from local authorities, however many reported difficulties in accessing and administering direct payments. Difficulties often focussed on problems with eligibility, assessment or paperwork and administration. Eligibility for direct payments was not clear for many respondents, some felt they had been given misinformation or that eligibility criteria were unfair.

> **"We did look into direct payments but was given different information from different people; nobody seemed to know what we needed to do, so in the end we just left it."**

> **"For direct payments, I was told erroneously that my child had to be in special school."**

> **"We have been turned down by social services four times. If we don't have a social worker we can't get direct payments. We have a child in a special school with autism and moderate learning difficulties and yet do not meet the criteria for social services involvement..."**

Assessment was complex and lengthy and reviews and reassessment could also cause difficulties.

> **"It takes a long time to get direct funding in place for breaks but once ours was set up we have not looked back. The initial assessment process was protracted and we had to almost reach breaking point to get assessed. [There was] more flexibility when Ben's behaviour worsened, the system was much more responsive and got extra hours quickly.**

> **"Direct payments have been very helpful. However when it runs out and social services give me a very hard time, I have to phone about 20 times until something happens, usually have to get a little cross or start complaining for messages to be passed on. When they finally approve the services for 3 months – it's already time to review it again."**

Administration of direct payments also caused difficulties for some families.

> **"The direct payment maze is just that. If it is difficult for myself, an articulate parent, what on earth is it like for others?"**

> **[What would improve short breaks?] "... direct payments process simplified - no lost paperwork causing delays with CRBs etc."**

> **"... and there is a lot of work for us administering direct payments."**

> **"Direct payments bureaucracy has been a pain in the bum"**

Finally respondents point out that for direct payments to be effective, suitable short break provision has to be available for families to use.

> **"Social services recently gave us [amount of money] as a holiday grant as we had not had any short breaks money. However we need so much equipment to cope with Samantha that we cannot find anywhere suitably adapted to go to. Simply giving us money is not going to solve our problems."**

As Table 66 above demonstrates, families were more likely to be using direct payments for short breaks if the child was younger and if the main carer was female, White British and educated to a higher level.

4.4 Short breaks and schools

Many respondents provided examples of short breaks that were integrated with schools. In some cases this was through provision of afterschool clubs located at the child's school and thus in a familiar setting often with familiar staff. These both met the child's needs and gave the parents and carers confidence that their child would be understood and receive appropriate care. In addition these arrangements were convenient for parents and carers as it did not require an additional transfer. However afterschool clubs were not always available and many respondents mentioned a lack of suitable childcare provision after school.

> **"Jane attends after school club at her special needs school. I did look into her attending a local childcare provider in the area when she was younger, but in the end chose not to send her as I felt that her needs would not be fully met."**
>
> **"There is a complete lack of after school care for disabled children. There is also a lack of holiday clubs. Which means that I am unable to work during the holidays and beyond 3pm as I have no options for childcare besides family members who are some distance from us."**

In some cases short break providers collected the child directly from school and took them back the following day.

> **"It works well during school times as he's collected straight from school but in the holiday time the travel eats into our respite time."**
>
> **"Our short breaks carer collects Ellen from school once a week and she stays overnight, and our carer takes her to school the next day."**

Other respondents provided examples of effective joint working and good communication between short break providers, schools and other people working with the child.

> **"Enjoys it a lot now but it took a while for him to accept. We are pleased we persevered. It has given him a degree of independence the service benefits from input from occupational therapist, learning disability nurse, psychologist and maintains close liaison with ourselves and school."**

4.5 The suitability of short breaks

The suitability (and unsuitability) of short breaks used by families was investigated using two separate questions since families may find some of the breaks (or aspects of breaks) to be suitable and others to be unsuitable. Respondents to both main carer questionnaires were first asked whether they found breaks they used suitable for their family and if so, were asked to describe the ways in which they were suitable. 88.9% (n=264) had found breaks to be suitable, 5.7% (n=17) had not found breaks to be suitable and 5.4% (n=16) did not know. Additional carer questionnaires also included this question, results were similar with 86.7% (n=13) indicating that they had found breaks to be suitable.

Respondents were asked to write in the reasons why they found their short breaks to be suitable, some explained what factors or characteristics made the breaks they used suitable and others highlighted the benefits that they accrued (benefits will be dealt with later in this report). Depending on each families' individual circumstances different things made breaks suitable for them, for example while it was important for some that breaks took place in the home, for others it was important that breaks took place away from the home. The factors that were most often mentioned are summarised in Figure 2 below.

Figure 2 Examples of factors which made breaks 'suitable' for families

The right staffing arrangements

- Sufficient staff, high adult to child ratio, staff are supervised, safeguards in place, CRB'd .

The right people

- Understanding, respectful, enthusiastic, capable, suitably qualified, experienced, flexible, trusted, known to family, know the child.

The right venue

- Home, away from home, at school, not too far away, homely, appropriate facilities, appropriately equipped, safe, outdoors.

The right systems and structures

- Duration, frequency, regularity, timing (holidays, nights, days), bookable, flexible, reviewed when need be.

The right care and activities

- Takes accounts of needs, wide range, appeals to child, facilitates socialisation, meets child's needs (including complex needs), adapts to changing needs, integrated into family life, age and stage appropriate, good communication, flexible / responsive.

Respondents to the main carer and the additional carer questionnaires were also asked whether they had found breaks to be unsuitable and if so, were asked in what ways they were unsuitable. 24.7% (n=70) had found breaks to be unsuitable, 68.6% (n=194) had not and 6.7% (n=19) did not know. Similarly respondents to the additional carer questionnaire were also asked this question and again the results were similar to those of the main carers with 26.7% (n=4) indicating that they had found breaks to be unsuitable.

Respondents were asked to write in why they found their breaks to be unsuitable. Many of their comments related to the same issues as those that made breaks suitable. Additional themes arose related to sufficiency, to the fact that whilst breaks may have been very suitable for the child they failed to provide 'a break' for the carer for various reasons and to the fact that some breaks were inherently expensive. These additional themes are illustrated by selected quotes below whilst the factors most often noted as making breaks unsuitable are summarised in Figure 3 below.

> **"Tried holiday breaks before as a family – the adapted ones are too expensive (should be more affordable) and otherwise they are not adapted for his needs. Everything costs too much money if it fits his needs (overnight stay in an adapted bungalow which catered very well for Phil cost us £800)"**
>
> **"Some of the leisure breaks such as sports and games are too far away and also I have found it difficult to get 1:1 support and have often ended up going myself and being the support, so Debbie enjoys the activity but I don't get a break."**
>
> **"Difficult, not a true break – because of manual handling a parent has to stay to help child transfer to the bikes she enjoys. Bowling –Lauren is independent of parents but by the time I have got to destination there is little time before pick-up again."**
>
> **"We were offered the help of another family to have Ian for occasional weekends – but Social Services never found a family. Basically, there is a gross lack of suitable short breaks for Ian and he desperately needs to make friends and have a life away from home. Also we are desperate for respite."**
>
> **"We would prefer 1 weekend every 6 weeks as James doesn't sleep, even my doctor wrote to the Lead Professional and asked and she laughed and said 'NO WAY!'."**
>
> **"We get 4 hours per month. Pam cannot do anything for herself. She is profoundly disabled. What is offered is very inadequate and does not really help."**
>
> **"I have only ever been offered 4 hours a week and that is only in the last 12 months, so it is inadequate. Before this period my mum was Daniel's carer if I decided I needed a break, but my dad has had a stroke. Also I used to get help from my older sons but they are both at uni now so I have no help."**
>
> **"Some of the pathfinder short breaks have been too short in length... swimming club is good but you can't drop them off and leave them, you have to get them ready etc."**
>
> **"Parents are not offered respite to suit them. The choice is – attend an organised short break (if it is not fully booked) or nothing. Events are not always age or ability appropriate, not suitable for children with ASD, or those with challenging behaviour, or complex health needs."**

Figure 3 Examples of factors which made breaks ‘unsuitable’ for families

The wrong staffing arrangements

- Lone workers with vulnerable children, staff not supervised, no replacement staff available when someone leaves.

The wrong people

- Patronising, do not understand child's needs, poor relationship, no trust, unreliable, disinterested, do not have right skills (AAC, signing, VOCA etc), do not have experience or training, refuses certain activities.

The wrong venue

- Home - Our house is too small for us and a carer, invasion of privacy, child remains in earshot, don't trust carer alone in my home. Away - child would prefer to be cared for at home.

Wrong systems & structures

- Not flexible, can't prebook, allocated times, can't get dates needed, no evening s /weekends, cancelled and rebooked weeks later, 2 children breaks do not coincide, bureaucratic processes, too expensive.

The wrong care and activities

- Not with suitable peers (age, needs, abilities), unsuitable activities for child's needs, boring, not challenging, understimulating, problems with food, problems with travel or location.

Not sufficient

- Not enough hours, no overnights, no evenings or weekends, can't go away, grandparents can't cope with longer than one day.

Not a break for carer

- Just too short, have to stay with child to support them, too far away, have to transport child, extensive travel required, child and carer keep us awake, good for child but not a break for the carer, worry about care of child.

4.6 Satisfaction with short breaks

Respondents to both main carer questionnaires were asked to indicate their level of satisfaction with 10 aspects of short break services. Some of these aspects related to the people involved in caring, including their suitability, competence and how well they listen to parent's views. Other aspects related to the care received including its suitability for the child's needs and the standard of care. Finally a number of aspects related to the processes of arranging short breaks these included the amount of care available, the range of services and activities, the flexibility of services used and the ability to arrange short beaks in an emergency. There were marked differences in satisfaction levels between these three areas with aspects relating to carers tending to have very high rates of satisfaction and aspects related to processes involved tending to have somewhat lower rates of satisfaction. A number of respondents explained that they felt unable to answer in relation to the ability to arrange emergency care as this situation had not yet arisen for them. The results are summarised in Table 68 below.

Table 68 Satisfaction with aspects of short breaks – percentages, respondents to main carer questionnaires

Aspect	Very satisfied	Quite satisfied	Not at all satisfied	Base
Suitability of the people who look after your child	73.8	24.8	1.3	298
The standard of care your child receives	73.3	24.7	2.0	300
Competence of the people who look after your child	71.0	26.3	2.7	297
The level of trust you can place in the people who look after your child	69.2	27.4	3.3	299
The suitability for your child's needs	64.9	32.4	2.7	299
The extent to which your short break provider listens to your views	50.5	37.1	12.4	283
The flexibility in services used	34.4	44.0	21.6	291
The ability to arrange emergency short breaks	24.0	31.0	45.0	229
The range of services / activities available	20.9	47.6	31.4	296
The amount of short break care available	20.3	52.2	27.5	291

These 10 satisfaction items were included on the additional carer questionnaires. The numbers of respondents was small (15) and whilst in general terms additional carers were somewhat less satisfied than main carers, the pattern of findings was broadly similar with the lowest levels of satisfaction for the amount and range of care and the ability to arrange breaks at short notice.

Univariate analyses and logistic regressions were used to examine factors associated with the main carer satisfaction with various aspects of short breaks (see Appendix C and Appendix D for details).

As Table 69 below shows, main carers were more satisfied with the amount and range of short breaks available if their child was in Target Group E (aged 14+ and in one of the other target groups), if they lived in a more deprived area and if they received more total hours of short break support. Main carers were more satisfied with the standard and suitability of short break care provided if they received more total short break hours, overnight short breaks and if their child reported more prosocial behaviour. Main carers were more satisfied with the people acting as short break carers (satisfaction with suitability, competence and trust concerning short break carers) if their child used overnight short breaks, carers were White British and families lived in more deprived areas. Main carers were more satisfied with the flexibility of short breaks if they received more total hours of short break support, if their child needed less supervision in the evening and if the carer was educated to a lower level. Main carers were more satisfied with their ability to arrange emergency short break support if their child was a young adult (aged 17-19) and if they were using overnight short breaks. Main carers were more satisfied with the extent to which short break providers listened to them if they used overnight short breaks, if their child was reported as showing fewer behavioural needs and more prosocial behaviour, if their child needed less supervision in the evening and if the carer was White British.

Overall, carer satisfaction with short breaks was associated with the total number of hours of short break support received and with the child showing more prosocial behaviour. Across all aspects of carer satisfaction, the carers most broadly associated with greater carer satisfaction were the family using overnight short breaks (associated with 6 aspects of carer satisfaction), the family living in a more deprived area (associated with 4 aspects of carer satisfaction), the total number of hours of short breaks received (associated with 3 aspects of carer satisfaction), the main carer being White British (associated with 3 aspects of carer satisfaction) and the child requiring less supervision in the evenings (associated with 3 aspects of carer satisfaction).

Table 69 Factors associated with main carer satisfaction with short breaks

Satisfaction with short breaks	Wald (p)
Short breaks have improved in last 12 months (n=204, % correct classification 55.4%-59.8%, Nagelkerke R^2=0.05)	
Child total hours of short breaks used	5.98 (p=0.015)
Main carer satisfaction with standard of care the child receives (median split, n=148, % correct classification 70.3%-75.7%, Nagelkerke R^2=0.29)	
Child higher SDQ prosocial behaviour	15.75 (p<0.001)
Child total hours of short breaks used	12.07 (p=0.001)
Main carer satisfaction with suitability of short breaks for their child (median split, n=160, % correct classification 60.6%-63.1%, Nagelkerke R^2=0.10)	
Child uses overnight short breaks	11.19 (p=0.001)
Main carer satisfaction with suitability of the people who look after their child (median split, n=247, % correct classification 74.1%-75.7%, Nagelkerke R^2=0.11)	
White British main carer	5.86 (p=0.015)
More deprived neighbourhood CWI Health & Disability Domain	5.96 (p=0.015)
Child uses overnight short breaks	9.00 (p=0.003)
Main carer satisfaction with the competence of the people who look after their child (median split, n=293, % correct classification 70.6%-72.4%, Nagelkerke R^2=0.10)	
White British main carer	5.80 (p=0.016)
Family has one disabled child	5.49 (p=0.019)
Child uses overnight short breaks	7.88 (p=0.005)
Main carer satisfaction with the level of trust they can place in short break carers (median split, n=216, % correct classification 70.4%-72.7%, Nagelkerke R^2=0.11)	
Child needs less supervision 5pm-10pm	5.22 (p=0.022)
More deprived neighbourhood CWI Health & Disability Domain	5.40 (p=0.020)
Child uses overnight short breaks	9.28 (p=0.002)
Main carer satisfaction with the amount of short term care available (median split, n=222, % correct classification 80.6%-81.1%, Nagelkerke R^2=0.15)	
Child in Target Group E	9.11 (p=0.003)
More deprived neighbourhood CWI	12.21 (p<0.001)
Main carer satisfaction with the range of short breaks available (median split, n=151, % correct classification 82.1%-82.8%, Nagelkerke R^2=0.18)	
Child in Target Group E	5.40 (p=0.020)
More deprived neighbourhood CWI	5.97 (p=0.015)
Child total hours of short break used	4.27 (p=0.039)
Main carer satisfaction with the flexibility of short break services (median split, n=223, % correct classification 65.9%-65.5%, Nagelkerke R^2=0.11)	
Child needs less supervision 5pm-10pm	7.44 (p=0.006)
Main carer lower level of education	5.56 (p=0.018)
Child total hours of short breaks used	7.51 (p=0.006)
Main carer satisfaction with their ability to arrange emergency short breaks if/when needed (median split, n=151, correct classification 78.8%-82.1%, Nagelkerke R^2=0.29)	
Child age 17-19	12.00 (p=0.062)
Child uses overnight short breaks	5.67 (p=0.017)
Main carer satisfaction with the extent to which break providers listen to the family's views (median split, n=143, correct classification 53.8%-75.5%, Nagelkerke R^2=0.38)	
Child higher SDQ prosocial behaviour	7.20 (p=0.007)
Child lower SDQ total difficulties	9.16 (p=0.002)
Child needs less supervision 5pm-10pm	4.67 (p=0.031)
White British main carer	3.62 (p=0.057)
Child uses overnight short breaks	11.67 (p=0.001)

Satisfaction with short breaks	Wald (p)
Main carer overall satisfaction with short breaks (median split, n=153, correct classification 51.0%-60.8%, Nagelkerke R^2=0.18)	
Child higher SDQ prosocial behaviour	9.15 (p=0.002)
Child total hours of short breaks used	11.49 (p=0.001)

4.7 Carer's perceptions of recent improvements

Respondents to the main carer questionnaires of both studies were asked to indicate whether over the last 12 months their family's experience of short breaks had improved; 43.7% (n=129) indicated that it had, 36.9% (n=109) indicated that it had not, with a further 19.3% (n=57) indicating that they did not know. Respondents were asked to describe the ways in which their experience of using short breaks had improved or not improved and further to describe what would improve the short break services available to their family. Additional carers were also asked this question, the results were similar with 46.7% (n=7) indicating that they felt their family's experience of short breaks had improved.

As Table 69 above shows, the only factor strongly associated with main carer perceptions of improvement was whether they received more hours in total of short break provision.

Respondents to the carer questionnaires wrote in explanations of how their short breaks had improved or not improved. Some of these related to the benefits that they received and these will be described later in this report. Many wrote in that their breaks had stayed the same, sometimes this was because they were already very good. Respondents also reported a wide range of different improvements and some things which they viewed as setbacks. This again suggests a diversity of experience with various families having contrasting experiences. Improvements and setbacks and are summarised in Figure 4 below.

Figure 4 Examples of improvements and setbacks noted by respondents

Improved family situation

- More confident to leave child, child more confident and settled , now more carers within the family (older siblings, grandparents etc).

Improved staffing and people

- Staff more highly trained, listen more to child, understand child better, now have a stable team of carers.

Improved systems & structures

- More flexible, can prebook, know about the whole year, better communication, better information, help with paperwork, access to direct payments, allocated a social worker, improved assessments, short break services are more established and seem more permanent.

Improved care and activities

- Better range of actives, meeting needs better, more appropriate to child, more for teens, more for children with complex needs, more for children with ASD, new and better facilities, carers now have suitable transport.

Improved sufficiency

- More hours, more direct payments, more often, more overnights, more evenings or weekends, more family able to help.

Setbacks

- Reduced hours, funding withdrawn, reduced range , services threatenned with closure, less flexible, poorer communication, no suitable provision, AHDC services not developed as promised, prices drastically increased (childminder), lack of adequate care, gaps in services (for specific ages, or complex needs).

4.8 Further potential improvements

Respondents were also asked to write in what would improve short break services that were available to them. Again there was a wide range of different responses but a number of themes could be identified. Many families felt that the main improvement required was increased availability of short breaks which would result both in more frequent breaks and longer breaks. When describing where greater availability of breaks was required the following areas were mentioned by many families, there is some overlap with AHDC target groups. Some of the areas described appear to possibly be childcare rather than purely short breaks.

- Children with ASD
- Children with severe and complex needs
- Older children and young people (14-25 years)
- Younger children (preschool – 8 years)
- Overnight care (away from home and at home)
- After school care
- School holiday care

Another area frequently mentioned as a potential improvement was that of information about short breaks. Respondents stated that they needed information which was available regularly and was available as soon as their child had a diagnosis or an identified need. In particular families wanted concise, transparent information which clearly described –

- Eligibility for breaks
- The range of breaks available
- How to access short breaks

Another area where several respondents felt more provision was needed was in services for children who use wheelchairs. This included more active groups and sporty groups. Children with physical disabilities were often using short breaks with mixed groups of children who had a wide variety of needs. Some carers of children with physical disabilities thought that their children would prefer to be able to access some groups which did not include a high proportion of children with learning or behaviour disabilities.

Several respondents were particularly concerned about transition to adult services and felt that information, support and planning for transition was an area which could be improved.

Communication with providers was a further area where some families felt breaks could improve. In particular better communication about the child’s needs, likes and dislikes as well as feedback about what had happened during the break or activity.

Many respondents mentioned that assessment processes needed improvement. This would include speeding up processes and making them simpler (including better interagency working and use of ‘in common’ paperwork). A particular improvement would be for assessments to focus more on the needs of the whole family, including parents, other carers and siblings rather than focussing only on the needs of the disabled children.

Many respondents also mentioned scope for improvements to existing facilities or a requirement for new facilities. This included facilities such as adapted bungalows, respite homes and family centres and included facilities which families could access together with their disabled child. In particular respondents suggested making existing specialist facilities such as sensory rooms and pools located in special schools more available to families.

A number of respondents were concerned with issues of equality and equity. In particular they felt that irrespective of short break provision disabled children should have the same level of access as non-disabled children to childcare (including afterschool, breakfast and holiday clubs) and to leisure facilities. One respondent for example mentioned the importance of educating workers in mainstream provision about the needs of disabled children. Respondents were also concerned that short break eligibility criteria should be made more transparent and should be defined nationally to ensure equal access to services irrespective of local authority area.

Respondents thought that more consideration should be given to transport issues. A number of solutions were described, these including integrating transport with the short break services (e.g. the child being collected from home), reimbursing petrol money to parents for transporting their child to the short break and ensuring that more short breaks took place nearer to home.

Staffing issues were also mentioned by many respondents as having potential improvements, this included increasing the numbers of staff available, increasing the adult to child ratio and provision of more appropriate training for staff. Particular skills that some staff needed to develop were mentioned, these included better understanding the needs of children with severe and complex disabilities (e.g. supporting eating and feeding) and improved skills in communicating with and listening to children and their parents. The use of existing workers (often from schools) who already knew the child was thought by some parents to be ideal.

Many respondents suggested that greater flexibility in short break provision would be a marked improvement. Several ways in which this could be achieved were described including –

- Ability to choose and control the timing of a break rather than take what is offered
- More flexibility over drop-off and collection times
- Ability to arrange breaks at short notice if required
- Availability of a calendar or menu of short breaks (e.g. covering 6 months or a year)
- Greater access to direct payments or individual budgets

Other areas which could be improved included reduction in the cost of some short breaks, provision for siblings of children with disabilities, provision of more outdoors activities and provision of ‘conductive education’.

Finally one area where respondents hoped for improvement was in the sustainability and continuity of short breaks. Several respondents described considerable anxiety that they would lose their short breaks or their breaks would be reduced, due to loss of funding or as the result of a harsher reassessment of their needs.

4.9 Children and young people's opinions of their short breaks

Respondents to the child or young person using short breaks questionnaire were asked to indicate how much they had enjoyed the breaks they used on a three point scale from 'enjoyed it a lot' to 'did not enjoy it at all'. They were asked to do this for their most recent short breaks and more generally for other short breaks they had used (if they had used more than one type). The results are summarised in Table 70 below.

Table 70 Children's views as to whether they had enjoyed their short breaks, respondents to longitudinal study children or young person using short breaks questionnaires

	Enjoyed it a lot	Enjoyed it a little	Did not enjoy it at all
The last short break you had	84.6% (n=22)	11.5% (n=3)	3.8% (n=1)
Other short breaks you have had	94.7% (n=18)	5.3% (n=1)	0%

Children were asked to write in things they had liked and not liked about their breaks. All children made a comment about what they liked. These comments most frequently related to three themes 1) Activities, 2) Relationships and less often 3) Confidence / Independence. Activity comments included a wide range of play, craft, sports and recreational activities, often referring to enjoyment of relatively simple activities (see Figure 5). Relationship comments focused on aspects of good relationships with short break carers and opportunities to be with their friends (see Figure 6). Confidence/independence comments focused on being away from home and trying new things (see Figure 7).

Figure 5 Examples of things children enjoyed about their breaks (activity theme)

“Doing art, seeing films, walking and feeding the swans.”

“Playing, listening, writing and cutting.”

“... drawing, painting and colouring”

“Going to the park, playing with Jamie and John, jigsaw, watching videos, playing games.”

“Camping...”

“Playing on the beach, going to the zoo.”

“Watching TV and playing on the Wii...”

“We went to the aquarium in [location] and played on Wii sports on Aunty Alison’s TV.”

“Got to go on the bus to watch cranes loading the boats....”

“Having a drink of orange and a biscuit.”

“I got KFC.”

“Cooking.”

“Every week is different.”

“Played games, walked about and stuff, liked it.”

“Played in the park, took dog for a walk, had Sunday lunch at a pub.”

“Skiing and playing with Chris.”

“Swimming, archery, canoeing, zip-wire, walking in the woods, disco, big floor puzzle, karaoke.”

“We go to galleries and look at pictures because I am doing art at school.”

“The show.”

“Speech work.”

“Being spoilt and pampered ...”

“I won every game at Wii, cause Naaz was no good at it.”

Figure 6 Examples of things children enjoyed about their breaks (relationships theme)

“I was with my friend.”

“...had friends.”

“Being with my friends.”

“Making friends with Taylor.”

“... socialising with other young persons.”

“We play and we counted how many times I went down the slide.”

“I like going to the cinema with Jenny [carer].”

“I liked being with Ann [carer].”

“Adrian [carer] was just a good friend and it felt great to be with him.”

“The staff were kind.”

“The staff were supportive and I enjoyed doing something different.”

“We had cake because it was somebody’s birthday and it made them happy.”

Figure 7 Examples of things children enjoyed about their breaks (confidence / independence theme)

“[enjoyed] Being away from home.”

“Had my own bedroom and bathroom, lots of activities...”

“Trying new things.”

“Stay up late! Time away from mum and dad.”

“The staff don’t treat me as a five year old (I am 12).”

Fewer children were able to provide a comment about what they did not like about their breaks, many entering ‘nothing at all’ or similar comments. Examples of comments about things they did not enjoy are given below in Figure 8, again activity, relationship and independence themes are discernable.

Figure 8 Examples of things children did not like about their short breaks (all themes)

“Naaz [Wii opponent] got better and better and better.”

“Dancing.”

“Strange places.”

“Noise!”

“Noise and swings.”

“Lots of people.”

“Falling over.”

“I bumped my knee on the ‘wave’ toy.”

“Some of the other boys play ‘tag’ and I don’t want to play when they ask me to join in.”

“Helen [carer] was late and I missed the film I wanted to see.”

“Not always keen on all members of staff, [I have] my favourites.”

“Coming home, I have too much fun.”

Children were also asked whether they would like to have more or less short breaks than they currently have. Most children wanted to have more short breaks, the results are summarised in Table 71 below.

Table 71 Children’s views as to whether they would like more or less short breaks, respondents to longitudinal study children or young person using short breaks questionnaires

	Frequency	Percent
Lots more	12	46.2
A few more	8	30.8
About the same	5	19.2
A few less	1	3.8
Lots less	0	0.0

Children using short breaks were further asked to write in what they would like their next short break to be like. Most mentioned particular venues they would like to go to or activities they would like to take part in, some mentioned people they would like to spend time with such as a named carer or a grandparent. Venues and activities mentioned can be summarised as those that have a physical activity theme (football, cycling, swimming, trampolining, dance, skiing etc), an outdoors theme (beach, woods, rivers, mountains, parks etc), an animal theme (zoos and farms), a play theme (play schemes, theme parks, lazer games) or a leisure theme (cinema, eating out etc).

Respondents to the children or young people using short break questionnaire were asked to indicate whether they had experienced two specific benefits, ‘trying new things’ and ‘making new friends’. The findings suggest that many children do receive these benefits, these are summarised in Table 72 below.

Table 72 Specific benefits for children using short breaks, respondents to longitudinal study children or young person using short breaks questionnaires

	Yes	No
Has having short breaks helped you to try new things?	88.0% (n=22)	12.0% (n=3)
Has having short breaks helped you to make new friends?	84.0% (n=21)	16.0% (n=4)

4.10 Siblings’ opinions of short breaks

The siblings of children using short breaks were asked to write in which type of break is best in their opinion. Many of these comments named activities, some giving an explanation of why these were best. Of particular note is the fact that 11 comments made reference to breaks where their brother or sister stayed away overnight suggesting that some siblings perceive particular benefits from these kinds of break. It is also notable that siblings were concerned that the child using short break should be safe and should enjoy their break. Selected quotes are given below in Figure 9.

Figure 9 Examples of comments about which breaks siblings thought were best

“[Named charity] afterschool club because its longer and she has more fun”

“[Named local blind charity] because she enjoys it a lot and I like it when she enjoys things. I am happy when she is happy.”

“Overnight because she is nice and safe.”

“Something fun / suitable for my brother.”

“They are all good in individual ways. In terms of respite care for my parents, the residential breaks are good as he is away for a few days, so they can continue with their full time work. But he enjoys the both equally, so really that’s the important thing.”

“When he goes to a residential house sometimes my parents and I have more time together – it sounds selfish I know!”

Siblings were also asked what they liked and disliked about their brother or sister having short breaks. The responses given mainly fall into four themes, 1) a rest or a break (from caring or demanding behaviour), 2) removal of usual limits or constraints on activity, 3) spending more time with parents or getting more attention from them and 4) the fact that their brother or sister has an enjoyable time. Selected quotes are given below in Figures 10, 11, 12 and 13.

Figure 10 Examples of things siblings enjoy about their brother or sister having short breaks (rest / break theme)

"Because it gives me a break."

"No fusses, quiet uninterrupted conversation, no smelly nappies, not being woken at 5am. (Fusses include: tantrums, throwing, scratching, screaming)."

"Things are easier."

"I get a break from him and more attention."

"Mum and dad get a break and we get to go out."

Figure 11 Examples of things siblings enjoy about their brother or sister having short breaks (fewer constraints theme)

"... it means me and my parents can do something and not have to dash back."

"I get to do things with my mum and dad that I can't usually do."

"It gives me a chance to do things that we can't do with Kyle."

"I get to invite my friends over more."

"I like spending time with my mum without Christine. We mostly go shopping but sometimes we go to the cinema and then out for a meal. We can't do this when Christine is around."

"We can go out and do some of the things that we can't do at the weekends when Rachel is at home..."

"Can do things I can't with him, spend more time with my family."

"I would feel embarrassed if she is around on holiday..."

Figure 12 Examples of things siblings enjoy about their brother or sister having short breaks (parental time and attention theme)

"I get all mum and dad's attention."

"Spending time alone with my mum and dad."

"I get to do drawing with mum and dad."

"I have special one to one time with my mum and dad."

"I get more time with my mum and dad, like doing homework and playing games."

"Yes, my mum and dad take me shopping and / or for tea."

"Spending time with mam and dad and going out for tea."

"I get more time with the rest of my family."

Figure 13 Examples of things siblings enjoy about their brother or sister having short breaks (activity is enjoyed by brother or sister theme)

“He enjoys it and it gives him a different surrounding...”

“He has fun and gets to meet new people that he otherwise can’t, because he cannot go out and meet his mates like I can...”

“It gives her a chance to socialise with more people who are disabled.”

Siblings of children using short breaks were also asked what they disliked about their brother or sister having short breaks, many simply stated ‘nothing’ or similar. The other comments received fall into four main themes, 1) Worry or concern for their brother or sister, 2) missing their brother or sister, 3) feeling guilty, 4) feeling excluded from the activities their brother or sister was enjoying (see Figures 14, 15, 16 and 17).

Figure 14 Examples of things siblings don’t like about their brother or sister having short breaks (worry for brother or sister theme)

“I always worry in case she has a seizure or hurts herself.”

“... I worry he won’t eat as he’s quite fussy. Also he’s quite quiet when he’s around lots of people, so it’s a worry that no one’s paying him any attention!”

Figure 15 Examples of things siblings don’t like about their brother or sister having short breaks (missing brother or sister theme)

“I miss him and everything seems quiet when he’s gone.”

“I miss Sam a little.”

“Too quiet.”

“Yes, mum gets upset about him going and I miss him at times.”

Figure 16 Examples of things siblings don’t like about their brother or sister having short breaks (feeling guilty theme)

“Sometimes if we do something I think she would like.”

“That sometimes we have to go on holiday and leave her.”

“I don’t like it when he cries because it makes me sad and I miss him at the table at tea time”

Figure 17 Examples of things siblings don't like about their brother or sister having short breaks (feeling excluded theme)

"Daisy has fun and I stay at home with mum and dad doing homework and stuff."

"I think he just gets spoilt."

"I always have to go around with him and help quite a lot." [sibling accompanies child on break]

Siblings of children using short breaks were asked to write in the benefits that they get from their brother or sister using short breaks. The benefits written in are summarised below in Figure 18 together with an indication of how many siblings mentioned each type of benefit.

Figure 18 Benefits mentioned by respondents to longitudinal study sibling questionnaires

- **Able to enjoy activities which are usually not possible with sibling present (9 siblings)**
- **More time with parents or family (7 siblings)**
- **More attention from parents (6 siblings)**
- **More sleep, rest, quiet or relaxation (5 siblings)**
- **Able to have friends round (for tea or sleepovers) (4 siblings)**
- **Change to routines (bedtimes, getting back at a certain time, being quiet, doing my own thing) (4 siblings)**
- **Knowing that brother or sister is enjoy themselves (3 siblings)**
- **Able to go on holiday (3 siblings)**
- **Less trouble from sibling / not having to look after sibling (2 siblings)**

Siblings were also asked to respond to a four questions about specific benefits they may get from their brother or sister using short breaks, the results are summarised below in Table 73. These seem to confirm that sibling often get to try new things, spend more time with their parents and get more time to themselves, however they do not confirm that siblings often get to make new friends because of their brother or sister's short breaks.

Table 73 Specific benefits for respondents to longitudinal study sibling questionnaires

When your brother or sister has a short break do you get...	Yes	No
...to try new things?	92.6% (n=25)	7.4% (n=2)
...to make new friends?	29.6% (n=8)	70.4% (n=19)
...more time to yourself?	81.5% (n=22)	18.5% (n=5)
...to spend more time with your parents?	88.9% (n=24)	11.1% (n=3)

Siblings were asked to write in what they would like their brother or sister's next short break to be like. Most (18) siblings mentioned the importance of their brother or sister having fun or enjoying themselves, many of these children gave specific ideas for suitable activities. 6

siblings mentioned that they would like their brother or sister's short breaks to be longer than they currently are. 2 siblings wrote in that they would like the breaks to stay the same.

Siblings were specifically asked whether they would like their brother or sister to have more or less breaks than they currently had. Most would like their brother or sister to have more breaks than they currently do. The results are summarised in Table 74 below.

Table 74 Sibling's views as to whether they would like their brother or sister to have more or less breaks, respondents to longitudinal study sibling questionnaires

	Frequency	Percent
Lots more	6	22.2
A few more	15	55.6
About the same	5	18.5
A few less	1	3.7
Lots less	0	0.0

5 Factors associated with outcomes for main carers and partners

This section discusses which factors are associated with a range of outcomes, largely for main carers but in some of the qualitative analyses for partners and more general household functioning as well. As the quantitative analyses are drawn from cross-sectional survey data collected at a single point in time and as family systems are complex and transactional in their influences, the quantitative analyses cannot be used to definitively make judgements on the impact of short breaks and other factors on outcomes for main carers and partners. However, the quantitative analyses conducted on the whole sample can determine which factors were most robustly associated with a range of outcomes for main carers. These analyses are complemented by the qualitative analyses, which summarise carers' views of the impact of short breaks on various aspects of their lives.

5.1 The health and well-being of main carers: quantitative analyses

Univariate analyses and logistic regressions were used to examine factors associated with four aspects of the health and well-being of main carers.

Table 75 Factors associated with main carer self-reported good general health, data from respondents to main carer questionnaires

Factors associated with good general health	
Univariate Associations (*p<0.05; **p<0.01)	
Child characteristics:	**Short break usage:**
Child lower SDQ total difficulties**	
Child lower SDQ emotional symptoms**	**Short break family experience/satisfaction:**
Child lower SDQ conduct problems**	
Child needs less supervision 10pm-6am*	
Child better general health**	
Carer characteristics:	
Main carer not long-standing illness/disability**	
Main carer working PT or FT*	
Household characteristics:	
Less hardship – items for disabled child*	
Fewer money worries**	
Managing better financially**	
Fewer debt problems**	
Logistic Regression	
Main carer self-reported good general health (Very Good and Good vs. Fair, Bad and Very Bad) (n=244, % correct classification 65.6%-77.0%, Nagelkerke R^2=0.41)	**Wald (p)**
Child better general health	45.61 (p<0.001)
Main carer not longstanding illness/disability	14.83 (p<0.001)
Household managing better financially	44.95 (p<0.001)

Table 75 above summarises the findings concerning main carer self-reported general health. As the univariate analyses show, better self-reported main carer health was associated with better child general health and behaviour, the main carer not reporting longstanding health/disability and the main carer being in employment and families managing better financially.

The logistic regression showed that three factors were very strongly associated with main carer self-reported good general health: the child being in better general health, the household managing better financially and the carer not reporting a longstanding illness or disability. No aspects of short break usage, funding, or satisfaction, were associated with main carer self-reported general health in either the univariate analysis or the logistic regression. Because of a potential overlap in the constructs of main carer self-reported health and main carer self-reported long-standing illness/disability, the logistic regression was run again without main carer long-standing illness/disability as a potential independent variable. This logistic regression reported that both child better health and the household managing better financially were still the factors most strongly associated with main carer self-reported general health; child lower emotional symptoms on the SDQ replaced long-standing illness/disability as the third factor associated with better carer self-reported general health.

Table 76 below summarises the findings concerning the main carer's usage of adult-focused health and welfare services in the last 3 months. The univariate analyses show that main carers using fewer adult-focused services were older, employed and did not report long-standing illness/disability and their children were older, had fewer conduct problems and were less likely to be in Target Group A (ASD); they were also more likely to be using local authority-funded short breaks. The logistic regression showed two factors having relatively weak associations with main carer usage of a narrower range of adult-focused services; the main carer not reporting long-standing illness/disability and the disabled child being older. Because of a potential overlap in the constructs of main carer usage of adult-focused services and main carer self-reported long-standing illness/disability, the logistic regression was run again without main carer long-standing illness/disability as a potential independent variable. This logistic regression reported that older child age was still most strongly associated with main carer usage of a narrower range of adult-focused services; child lower conduct problems on the SDQ replaced long-standing illness/disability as the second factor associated with better carer usage of a narrower range of adult-focused services.

Table 76 Factors associated with main carer usage of a narrower range of adult-focused health and welfare services in the last 3 months, data from respondents to main carer questionnaires

Factors associated with main carer using a narrower range of adult-focused health and welfare services in the last 3 months	
Univariate Associations (*p<0.05; **p<0.01)	
Child characteristics: Child older than 7* Older child** Child not in Target Group A* Child lower SDQ conduct problems*	**Short break usage:** Child uses local authority-funded short breaks* **Short break family experience/satisfaction:**
Carer characteristics: Older main carer** Main carer not long-standing illness/disability* Main carer working PT or FT*	
Household characteristics:	
Logistic Regression	

Main carer usage of a narrower range of adult-focused health and welfare services in the last 3 months (no services used vs. at least one service used)	**Wald (p)**
(n=272, % correct classification 61.0%-62.9%, Nagelkerke R^2=0.07)	
Older child	8.18 (p=0.004)
Main carer not longstanding illness/disability	5.95 (p=0.015)

Table 77 below summarises the findings concerning main carer psychological distress as measured using the K6 scale. The univariate analyses show that older main carers with no long-standing illness/disability, with disabled children in better health and with fewer behavioural needs, living as couples in households managing better financially, were likely to report lower levels of psychological distress. These analyses also showed that main carers in families using centre-based short breaks who were more satisfied with several aspects of short breaks reported lower levels of psychological distress. The logistic regression shows that three factors were strongly associated with below-threshold levels of main carer psychological distress: the main carer not reporting a longstanding illness/disability, the child having fewer behavioural difficulties and the household managing better financially.

Table 77 Factors associated with main carer lower psychological distress, data from respondents to main carer questionnaires

Factors associated with main carer lower psychological distress

Univariate Associations (*p<0.05; **p<0.01)

Child characteristics:
Child not in Target Group D*
Child lower SDQ total difficulties**
Child lower SDQ hyperactivity**
Child lower SDQ emotional symptoms**
Child lower SDQ conduct problems**
Child lower SDQ peer problems**
Child needs less supervision 6am-5pm*
Child better general health*

Carer characteristics:
Older main carer**
Main carer not long-standing illness/disability**

Household characteristics:
Main carer living in household as couple**
Main carer not a lone parent**
Less hardship – items for disabled child*
Fewer money worries**
Managing better financially**
Fewer debt problems**

Short break usage:
Child uses centre-based short breaks**

Short break family experience/satisfaction:
Satisfaction: range of short breaks**
Satisfaction: amount of short breaks*
Satisfaction: emergencies*
Satisfaction: short breaks overall*

Logistic Regression

Main carer lower psychological distress on the K6 scale (below K6 threshold<13 vs. above K6 threshold>=13)	**Wald (p)**
(n=154, % correct classification 87.0%-90.9%, Nagelkerke R^2=0.36)	
Child lower SDQ total difficulties	12.69 (p<0.001)
Main carer not longstanding illness/disability	4.79 (p=0.029)
Household managing better financially	9.17 (p=0.002)

Table 78 below summarises the findings concerning main carer satisfaction with life. The univariate analyses show that main carers without longstanding illness/disability who are employed, married and living as a couple in a more affluent household report greater satisfaction with life. These carers also have children with better general health, fewer complex health needs and fewer behavioural needs, requiring less intensive supervision and they are more satisfied with a wide range of aspects of short break support. The logistic regression show that two factors are moderately associated with greater main carer satisfaction with life: the household managing better financially and main carers reporting that they need fewer essential items for their disabled child. Because of a potential overlap in the constructs of main carer psychological distress and main carer self-reported long-standing illness/disability, the logistic regression was run again without main carer long-standing illness/disability as a potential independent variable. This logistic regression reported that both child lower total difficulties on the SDQ and the household managing better financially were still the factors most strongly associated with main carer lower psychological distress; no additional factors replaced main carer long-standing illness/disability in the logistic regression.

Table 78 Factors associated with main carer greater satisfaction with life, data from respondents to main carer questionnaires

Factors associated with main carer greater satisfaction with life	
Univariate Associations (*p<0.05; **p<0.01)	
Child characteristics:	**Short break usage:**
Child not in Target Group B**	
Child lower SDQ total difficulties**	**Short break family experience/satisfaction:**
Child lower SDQ emotional symptoms**	Satisfaction: short breaks overall**
Child lower SDQ conduct problems**	Satisfaction: range of short breaks**
Child lower SDQ peer problems*	Satisfaction: amount of short breaks*
Child needs less supervision 6am-5pm*	Satisfaction: flexibility*
Child needs less supervision 5pm-10pm*	Satisfaction: emergencies*
Child needs less supervision 10pm-6am*	Satisfaction: providers listen*
Child better general health**	
Carer characteristics:	
Main carer not long-standing illness/disability**	
Main carer working PT or FT*	
Household characteristics:	
Main carer living in household as couple**	
Main carer not a lone parent**	
Main carer married*	
Less hardship – items for disabled child*	
Fewer money worries**	
Managing better financially**	
Fewer debt problems**	
Logistic Regression	
Main carer greater satisfaction with life (median split, n=152, % correct classification 56.6%-64.5%, Nagelkerke R^2=0.17)	**Wald (p)**
Household less hardship – items for the disabled child	4.19 (p=0.041)
Household managing better financially	16.13 (p<0.001)

5.2 Impact on main carer health and wellbeing: qualitative analysis

Respondents also wrote in comments related to the impact of short breaks on their own well-being. A major theme of these was that of rest, relaxation and recuperation. Respondents described the ability to have a break from the physical and emotional aspects of caring, being constantly alert and 'on duty', a break from worry and from constant planning. They reported being able to engage in simple pleasurable activities in peace such as having a bath, reading a book, going for a walk, having a meal out, visiting the cinema or socialising, many respondents mentioned being able to catch up on sleep. As a result respondents reported feeling less stressed, tired and worn out and more able to think clearly after a short break. Many respondents used phrases such as 'recharge my batteries' to describe the impact of short breaks and some further suggested that this enabled them to be ready to cope with the child when they returned.

> **"Very happy with short break care received. It is very important that families have break from caring, and have chance to recharge batteries. This helps you to be able to cope in between."**
>
> **"To know my child is comfortable and happy and gives us time to catch up on sleep and relax."**
>
> **"... break away from disabled child allows relaxation and sleep and a break from the stresses of full time care, also can do physical activities without feeling guilty."**
>
> **"A rest. Time out... Eases the stress, give you a chance to regroup your thoughts. "**
>
> **"We get peace and quiet, he is very talkative and gets frustrated – it is so calm, sometimes I just sit there in the quiet."**

A number of respondents described feeling healthier, happier and being able to be more loving as a parent.

> **"Rest, relation and me time. Holidays, time to recharge batteries. Enjoy some normal activities without worrying about wheelchair access/changing/feeding etc. Maintain your own good health due to rest."**
>
> **"Time for ourselves and other children recharge our batteries, therefore our stresses lessened and more loving, attentive parents towards Stephen."**

Many respondents also commented on the way that short breaks impact on their daily lives, simplifying tasks and allowing them to catch up on chores and household duties such as shopping, cleaning, decorating and gardening.

> **"...We can do things like clean her sensory equipment / lights, if we need to paint we have to do it then as she has respiratory problems, we can mow the lawn which is hard when she's home. We can do things that other families take for granted, like washing the car."**
>
> **"...and I can just get on with my housework or go shopping!"**
>
> **"An opportunity to complete pressing overdue tasks e.g. decorating in the home or tending an overgrown garden!"**

5.3 Impact on social participation, main carers and partners: qualitative analysis

Many respondents to the carer questionnaires wrote in comments relating the positive impacts of short breaks on their contact with social and familial networks and on opportunities for engagement with their communities. This was particularly true for respondents of children who had overnight breaks and breaks away from the family. Some report feeling less lonely as a result of short breaks.

> **"It gives me a break from looking after my daughter who requires 24 hour care and gives me a chance to go out and visit friends on the respite weekends."**
>
> **"Overnight respite means we can do things as a family – visit friends and family, go out for meals, go to events."**
>
> **"A few unbroken night's sleep. An opportunity to have a night away from home, an evening out or just visit friends. An opportunity to visit our other children who no longer live at home nor in the locality."**
>
> **"Catching up on sleep and having a night out with friends, so you don't feel as lonely."**

A small number of respondents also noted benefits from meeting up with other families during short break activities.

> **"Being the family with a child with a disability can be very isolating both for the child and the parents, as there is no 'school gate' meeting time. The [project] allows the families to socialise with each other when this would not normally occur – both children and adults."**

5.4 Impact on main carers' relationships with partners: qualitative analysis

Respondents to the carer questionnaires stressed the importance of being able to spend more time focussing on their relationship with their partner. This was described as being of particular importance as the strains and stresses of raising a child with disabilities was seen as likely to cause or exacerbate problems in relationships between partners.

> **"Short breaks are the only thing that has enabled me to cope with the demands of bringing up a disabled child and to keep a relationship with my husband 'stable'. Without short breaks I am sure that either my husband, myself or child would not be at home."**
>
> **"When you have a demanding child with special needs you stop focusing on other members of the household and of course yourself. We love our son dearly but since having him it has had a huge impact on our relationship as husband and wife..."**
>
> **"I cannot emphasise enough the importance of short breaks in enabling families to cope with the demands of caring for a disabled child. I strongly believe that the chance to spend uninterrupted 'normal' time together has been fundamental in maintaining my marriage. At times it has been our only opportunity to have any social life."**
>
> **"We all love her very much but it is a massive strain and caused a split in my marriage."**

> **“Having three children all of whom have SEN and special needs, I don’t get no help except for Harry, is this because he is the worst? My husband and I don’t get no time to our self and it is beginning to break us up.”**

5.5 Impact on main carer employment: qualitative analysis

Comments given by respondents to the carer questionnaires suggest that receipt of short breaks had enabled some carers to return to work and others to continue in work or to attend training for work. In turn some respondents identify work as having positive impacts for example on financial security, self-esteem and in some cases access to support; however other respondents also note some negative impacts of work such as having less time and energy for caring. Whilst short breaks do appear to be helping some carers to work many respondents feel strongly that short breaks are effectively being used to compensate for shortcomings in the availability and suitability of childcare for children with disabilities.

> **“Short breaks after school enable us to continue in paid employment, as there is no local after school provision available unless my child has 1:1 Worker and no childminder will accept our child.”**
>
> **“Short breaks should be what is over and above what able-bodied children can access... The thinking should be that <u>all</u> children and families have a right to childcare and <u>some</u> children have a right to ‘short breaks’.”**

5.6 Impact on the family unit: qualitative analysis

Respondents to the carer questionnaires frequently described the way that short breaks, or the lack of them, impacted on the family as a whole. In particular they noted positive impacts on family cohesion and resilience.

> **“...Once the short break had been suspended our family really struggled to cope and I had to appeal against the decision.”**
>
> **“Without regular breaks I am sure the entire family would find the day to day stress impossible to cope with, and I am certain the other children would end up with ‘issues’ if they never had the chance to be put first. I am also certain that marriages would collapse if short breaks were not available.”**
>
> **“I find it crucial in managing to cope with the demands of caring for a disabled child and feel that short breaks have held our family together.”**
>
> **“The help I was given by short breaks has helped to alleviate my frustration and therefore enabled me to cope with my son’s difficulties and he has calmed down. Also it has helped our relationship and helped us to more forwards.”**

Many respondents described their family as approaching ‘breaking point’, stating that short breaks prevented this from happening. Others referred to short breaks as a ‘life line’ or ‘life saver’.

> **“[We] are now coping better with his challenging behaviour when he comes home, whereas before short breaks the family was at breaking point.”**

> **"Short breaks have prevented our family from reaching breaking point, knowing that Dave enjoys his break too is essential to our peace of mind as a family."**

> **"It is hard to imagine how I would cope on my own now with Jonathan if I didn't get these breaks. I thought they were valuable for all the family in the past, but now they are certainly my lifeline to rest, recuperation and some kind of social with girl friends."**

> **"Short breaks has been a life saver for our family, we were really struggling to cope (especially me). We all have the most wonderful relationship with our carer and her family."**

Several respondents felt that receiving short breaks made the difference between the family being able to continue to provide care for their child and the child having to be cared for elsewhere.

> **"Estelle's link family are my lifeline. If I didn't have a link family I won't be able to cope with Estelle's 24/7 needs. She would have been given up for foster care."**

> **"Having people who know your child well and that you trust to keep them safe and give them a good time allows you to totally relax and enjoy your 'child free' time. Take this away or start cutting hours would be a recipe for disaster and cost local authorities a fortune, because parents like us wouldn't be able to cope and many more parents would be asking for their children to be in permanent or shared care."**

> **"My family (my wife, two daughters and dog) all find the short breaks an incredible relief (to be frank) it's basically time for the four of us to enjoy each other's company, Marsha demands and receives most of the attention, for Marsha's placement to continue in our home we need the breaks, sounds awful, but as a family we go through hell with Marsha's anti-social behaviours."**

6 Factors associated with outcomes for disabled children

This section discusses which factors are associated with a range of outcomes for disabled children. As the quantitative analyses are drawn from cross-sectional survey data collected at a single point in time and as family systems are complex and transactional in their influences, the quantitative analyses cannot be used to definitively make judgements on the impact of short breaks and other factors on outcomes for the disabled child. However, the quantitative analyses conducted on the whole sample can determine which factors were most robustly associated with a range of outcomes for disabled child. These analyses are complemented by the qualitative analyses, which summarise carers' and children's views of the impact of short breaks on various aspects of their disabled child's lives.

It should be noted that some respondents to the carer questionnaires felt that whilst there may be other benefits short breaks they were not able to say that breaks would have a direct influence how their child changed or developed. There were three different types of explanation for this 1) the carer's perception of the child's capacity to change, particularly where the child had profound disabilities, 2) the difficulty attributing change to short breaks rather than to the child's maturation, their wider environment or their use of other services and activities, 3) the fact that some families had only recently started using breaks or had used relatively few short breaks.

> **"This is very hard to answer as it's difficult to link changes/development in Caroline to short breaks compared with other factors. However I suspect little of their development is the direct result of short breaks."**
>
> **"None really. Frankie is a very social young man who adapts well. It is difficult to say what leads to this and is probably a mixture of several factors, school, short breaks, family etc."**

6.1 The health of the child using short breaks: quantitative analysis

Univariate analyses and logistic regressions were used to examine factors associated with two aspects of the health of the child using short breaks.

Table 79 below summarises the findings concerning the general health of the disabled child as reported by the main carer. The univariate analyses show that better general health was reported for older children, children not in Target Groups identified as having complex health needs and children requiring less intensive supervision, although they were more likely to show problems with peers. Main carers of children in better general health were also older, did not report a long-standing illness/disability themselves and were more likely to be living as a couple and not as a lone parent in households in less deprived areas with better finances. No aspect of short break usage, funding, or carer satisfaction was associated with child general health. The logistic regression showed that five factors were moderately associated with better child general health: the child being older, being in Target Group A (ASD) and needing less supervision overnight, the main carer not reporting a long-standing illness/disability and the household reporting a better financial situation.

Table 79 Factors associated with the (good) general health of the disabled child, data from respondents to main carer questionnaires

Factors associated with disabled child better general health	
Univariate Associations (*p<0.05; **p<0.01)	
Child characteristics:	**Short break usage:**
Older child**	
Child in Target Group A**	**Short break family experience/satisfaction:**
Child not in Target Group B**	
Child in TDC Priority Group A*	
Child not in TDC Priority Group B**	
Child higher SDQ peer problems**	
Child needs less supervision 6am-5pm**	
Child needs less supervision 5pm-10pm**	
Child needs less supervision 10pm-6am**	
Carer characteristics:	
Older carer	
Main carer not long-standing illness/disability**	
Household characteristics:	
Main carer living in household as couple*	
Main carer not a lone parent**	
Main carer manage finances better**	
Main carer fewer debt problems**	
Less deprived neighbourhood IMD*	
Less deprived neighbourhood CWI*	
Less deprived neighbourhood CWI M*	
Logistic Regression	
Disabled child good general health (Very Good and Good vs. Fair, Bad and Very Bad) (n=251, % correct classification 70.9%-75.3%, Nagelkerke R^2=0.20)	**Wald (p)**
Child in Target Group A	9.82 (p=0.002)
Child needs less supervision 6am-5pm	5.37 (p=0.021)
Older child	4.36 (p=0.037)
Main carer not longstanding illness/disability	7.42 (p=0.006)
Household managing finances better	5.37 (p=0.02)

Table 80 below summarises the findings concerning the disabled child's usage of a range of other education, health and welfare services in the last 3 months as reported by the main carer. The univariate analyses show that many child factors were associated with the usage of other services, in particular younger children and girls with more complex physical and health needs in poorer health requiring more 24-hour supervision, but not older children with ASD. Relatively few main carer or household factors (the main carer not having a long-standing illness/disability, households reporting less hardship) were associated with the child accessing a wider range of services. Although main carer satisfaction with short breaks was not associated with the child accessing a wider range of child-focused services, several aspects of short break usage were, such as the child using a wider range of several types of short break service funded from a wider range of funding sources, including direct payments.

The logistic regression showed that three factors were moderately associated with the disabled child accessing a wider range of child-focused services in the last 3 months: the child not being in Target Group A (i.e. not having ASD), the child needing more supervision overnight and the child accessing a wider range of types of short break support.

Table 80 Factors associated with the disabled child's usage of a wider range of child-focused services in the last 3 months, data from respondents to main carer questionnaires

Factors associated with disabled child usage of a wider range of child-focused services in the last 3 months

Univariate Associations (*p<0.05; **p<0.01)

Child characteristics:
- Girl**
- Child aged under 5*
- Younger child**
- Child not in Target Group A**
- Child in Target Group B**
- Child in Target Group C**
- Child not in Target Group E*
- Child in TDC Priority Group B**
- Child lower SDQ peer problems*
- Child needs more supervision 6am-5pm**
- Child needs more supervision 5pm-10pm**
- Child needs more supervision 10pm-6am**
- Child poorer health**

Carer characteristics:
- Main carer long-standing illness/disability**

Household characteristics:
- Less hardship general household items*
- Less hardship items for main carer*

Short break usage:
- Child uses a wider range of short breaks*
- Child uses overnight short breaks**
- Child uses paid carer short breaks (not centre-based)**
- Child uses short breaks from a wider range of funding sources*
- Child uses local authority-funded short breaks*
- Child uses short breaks funded via direct payments*

Short break family experience/satisfaction:

Logistic Regression

Disabled child usage of a wider range of child-focused services for children in last 3 months (median split, n=191, % correct classification 57.1%-71.7%, Nagelkerke R^2=0.23)	**Wald (p)**
Child not in Target Group A	9.55 (p=0.002)
Child needs more supervision 10pm-6am	16.19 (p<0.001)
Child uses a wider range of short breaks	5.57 (p=0.018)

6.2 The well-being and behaviour of the child using short breaks: quantitative analysis

Univariate analyses and logistic regressions were used to examine factors associated with four aspects of the well-being and behaviour of the child using short breaks, all of them derived from the SDQ.

Table 81 below summarises the findings concerning the total difficulties of the disabled child as reported by the main carer in the SDQ. The univariate analyses show that disabled children reported as showing fewer difficulties on the SDQ scale were more likely to be older, less likely to be in Target Groups A or D (ASD and/or challenging behaviour) rather than in Targets Groups B or C (complex health and/or moving and handling needs) and to need less 24-hour supervision. Households of children with fewer total difficulties on the SDQ scale were more likely to report managing better financially. Children with lower total difficulties on the SDQ scale were more likely to use centre-based short breaks and less likely to use leisure short breaks and their main carers reported greater satisfaction with a wide range of aspects of short break support.

The logistic regression showed that five factors were moderately strongly associated with lower child total difficulties on the SDQ scale: the child not being in Target Groups A or D (ASD and/or challenging behaviour), the child being in Target Group E (aged 14+) and in TDC Priority Group B (more complex health and moving and handling needs) and the child using centre-based short breaks. Because some of the Target Groups children were placed in are likely to overlap with the construct of SDQ total difficulties, the logistic regression was run again without child Target Groups or TDC Priority Groups as potential independent variables. This logistic regression reported that the child using centre-based short breaks was still strongly associated with lower child SDQ total difficulties; two additional factors of child age (child aged under 8 or over 13) and the child needing less supervision in the evenings replaced child Target Group variables in the logistic regression.

Table 81 Factors associated with disabled child lower SDQ total difficulties, data from respondents to main carer questionnaires

Factors associated with disabled child lower SDQ total difficulties

Univariate Associations (*p<0.05; **p<0.01)

Child characteristics:
- Child aged under 8 or over 13**
- Older child
- Child not in Target Group A**
- Child in Target Group B**
- Child in Target Group C**
- Child not in Target Group D**
- Child in Target Group E**
- Child not in TDC Priority Group A**
- Child in TDC Priority Group B**
- Child needs less supervision 6am-5pm**
- Child needs less supervision 5pm-10pm**
- Child needs less supervision 10pm-6am*

Carer characteristics:

Household characteristics:
- Fewer money worries*
- Managing better financially*

Short break usage:
- Child does not use leisure short breaks*
- Child uses centre-based short breaks**

Short break family experience/satisfaction:
- More satisfaction: short breaks overall**
- More satisfaction: range of short breaks**
- More satisfaction: providers listen**
- More satisfaction: standard of care*
- More satisfaction: suitability of short break*
- More satisfaction: emergencies*

Logistic Regression

Disabled child lower SDQ total difficulties (median split, n=323, % correct classification 65.9%-72.4%, Nagelkerke R^2=0.31)	**Wald (p)**
Child not in Target Group A	10.28 (p=0.001)
Child not in Target Group D	16.62 (p<0.001)
Child in Target Group E	9.38 (p=0.002)
Child in Priority Group B	6.33 (p=0.012)
Child uses centre-based short breaks	3.84 (p=0.05)

Table 82 below summarises the findings concerning the emotional symptoms shown by the disabled child as reported by the main carer in the SDQ. The univariate analyses show that disabled children reported as showing fewer emotional symptoms on the SDQ scale were less likely to be in Target Groups A or D (ASD and/or challenging behaviour) rather than in Targets Groups B or C (complex health and/or moving and handling needs). Households of children with fewer emotional symptoms on the SDQ were more likely to report living in less deprived areas and main carers were less likely to be lone parents. Children with lower emotional symptoms on the SDQ were more likely to use more hours of short breaks overall and more hours of paid carer short breaks, more likely to use overnight and centre-based short breaks and their main carers reported greater satisfaction with two aspects of short break support.

The logistic regression showed that four factors were moderately associated with lower child emotional symptoms on the SDQ: the child not being in Target Group D (challenging behaviour), the child being in TDC Priority Group B (more complex health and moving and handling needs), the child using centre-based short breaks and the main carer being more satisfied with the extent to which short break providers listen to the family. Because some of the Target Groups children were placed in are likely to overlap with the construct of SDQ emotional symptoms, the logistic regression was run again without child Target Groups or TDC Priority Groups as potential independent variables. This logistic regression reported that the child using centre-based short breaks and the main carer being more satisfied with the extent to which short break providers listen to the family were still strongly associated with lower child SDQ emotional symptoms; no additional factors replaced child Target Group variables in the logistic regression.

Table 82 Factors associated with disabled child lower SDQ emotional symptoms, data from respondents to main carer questionnaires

Factors associated with disabled child lower SDQ emotional symptoms	
Univariate Associations (*p<0.05; **p<0.01)	
Child characteristics:	**Short break usage:**
Child not in Target Group A**	More total hours of short breaks*
Child in Target Group B**	Child uses overnight short breaks*
Child in Target Group C**	More hours of paid carer short breaks (not centre-based)*
Child not in Target Group D**	
Child not in TDC Priority Group A**	Child uses centre-based short breaks**
Child in TDC Priority Group B**	
	Short break family experience/satisfaction:
Carer characteristics:	More satisfaction: providers listen**
	More satisfaction: suitability of short break*
Household characteristics:	
Main carer not a lone parent*	
Less deprived neighbourhood CWI M*	
Logistic Regression	
Disabled child lower SDQ emotional symptoms	**Wald (p)**
(median split, n=240, % correct classification 60.4%-70.0%, Nagelkerke R^2=0.18)	
Child not in Target Group D	7.86 (p=0.005)
Child in TDC Priority Group B	6.93 (p=0.009)
Child uses centre-based short breaks	5.13 (p=0.023)
Main carer satisfaction: extent to which short break providers listen to the family	9.04 (p=0.003)

Table 83 below summarises the findings concerning the conduct problems shown by the disabled child as reported by the main carer in the SDQ. The univariate analyses show that disabled children reported as showing fewer conduct problems on the SDQ were more likely to be girls, more likely to be older, less likely to be in Target Groups A or D (ASD and/or challenging behaviour) rather than in Targets Groups B or C (complex health and/or moving and handling needs) and likely to be in fewer Target Groups. Main carers of children showing fewer conduct problems on the SDQ were less likely to report their own long-standing illness/disability and were more likely to be living in more financially deprived households. Children with lower conduct problems on the SDQ were more likely to use paid carer (non centre-based) short breaks and their main carers reported greater satisfaction with the extent to which short break providers listened to the family.

The logistic regression showed that four factors were moderately associated with lower child conduct problems on the SDQ: the child not being in Target Group D (challenging behaviour), the child being in TDC Priority Group B (more complex health and moving and handling needs), the child using paid carer (non centre-based) short breaks and the household having fewer money worries. Because some of the Target Groups children were placed in are likely to overlap with the construct of SDQ conduct problems, the logistic regression was run again without child Target Groups or TDC Priority Groups as potential independent variables. This logistic regression reported that the child using paid carer (non centre-based) short breaks and the household having fewer money worries were still strongly associated with lower child SDQ emotional symptoms; no additional factors replaced child Target Group variables in the logistic regression.

Table 83 Factors associated with disabled child lower SDQ conduct problems, data from respondents to main carer questionnaires

Factors associated with disabled child lower SDQ conduct problems

Univariate Associations (*p<0.05; **p<0.01)

Child characteristics:
Girl*
Older child*
Child not in Target Group A**
Child in Target Group B*
Child in Target Group C**
Child not in Target Group D**
Child in fewer Target Groups A-E*
Child not in TDC Priority Group A**
Child in TDC Priority Group B**
Child needs less supervision 6am-5pm**

Carer characteristics:
Main carer not long-standing illness/disability*

Household characteristics:
Fewer money worries**
Managing finances better**
More hardship – general household items*
More hardship – items for main carer*

Short break usage:
Child uses paid carer short breaks (not centre-based)**

Short break family experience/satisfaction:
More satisfaction: providers listen*

Logistic Regression

Disabled child lower SDQ conduct problems **(median split, n=272, % correct classification 74.6%-77.2%, Nagelkerke R^2=0.22)**	**Wald (p)**
Child not in Target Group D	11.74 (p=0.001)
Child in TDC Priority Group B	12.00 (p=0.001)
Household fewer money worries	10.16 (p=0.001)
Child uses paid carer (not centre-based) short breaks	4.61 (p=0.032)

Table 84 below summarises the findings concerning the hyperactivity shown by the disabled child as reported by the main carer in the SDQ. The univariate analyses show that disabled children reported as showing less hyperactivity on the SDQ were more likely to be older, less likely to be in Target Groups A or D (ASD and/or challenging behaviour) rather than in Targets Group C (moving and handling needs), likely to be in fewer Target Groups and to require less 24-hour supervision. Main carers of children showing less hyperactivity on the SDQ were older. Children with lower hyperactivity on the SDQ were more likely to use centre-based short breaks and their main carers reported greater satisfaction with the extent to which short break providers listened to the family.

The logistic regression showed that four factors were moderately strongly associated with lower child hyperactivity on the SDQ: the child not being in Target Group A (ASD) or D (challenging behaviour), the child being in Target Group E (14+) and the main carer being older. Because some of the Target Groups children were placed in are likely to overlap with the construct of SDQ hyperactivity, the logistic regression was run again without child Target Groups or TDC Priority Groups as potential independent variables. This logistic regression reported that the child needing less supervision in the evenings was the only factor strongly associated with lower child SDQ hyperactivity; no other factors were in the logistic regression.

Table 84 Factors associated with disabled child lower SDQ hyperactivity, data from respondents to main carer questionnaires

Factors associated with disabled child lower SDQ hyperactivity

Univariate Associations (*p<0.05; **p<0.01)

Child characteristics:
- Child aged under 5 or over 13**
- Older child**
- Child not in Target Group A**
- Child in Target Group C*
- Child not in Target Group D**
- Child in Target Group E**
- Child in fewer Target Groups A-E**
- Child not in TDC Priority Group A**
- Child in TDC Priority Group B**
- Child needs less supervision 6am-5pm**
- Child needs less supervision 5pm-10pm**
- Child needs less supervision 10pm-6am*

Carer characteristics:
- Older carer age*

Household characteristics:

Short break usage:
- More hours of centre-based short breaks**

Short break family experience/satisfaction:
- More satisfaction: providers listen*

Logistic Regression

Disabled child lower SDQ hyperactivity (median split, n=272, % correct classification 71.7%-77.2%, Nagelkerke R^2=0.31)	Wald (p)
Child not in Target Group A	16.20 (p<0.001)
Child not in Target Group D	22.63 (p<0.001)
Child in Target Group E	13.93 (p<0.001)
Older main carer age	8.10 (p=0.004)

6.3 Impact on well-being and behaviour, child using short breaks: qualitative analysis

Carers reported increases in children's self esteem and self confidence; these were marked for some children whilst for others these were small but important changes.

> **"It has allowed Christopher to have a social life, to interact with his peers and thus to develop his social skills and boost his confidence. He is now more willing to try new things and is not as devastated by failures, whether perceived or real. He is very slowly gaining acceptance of who he is and learning that that is not necessarily bad, just different and that is OK."**
>
> **"Self esteem is better, he used to say 'I'm ugly and I'm stupid' but now he does not say it anymore. His confidence is better."**
>
> **"It has definitely helped him – the external (male) voice of advice, the mentor, the confidence-booster – we are seeing the impact in his school performance (improved) and generally, in his developing maturity... even sometimes the glimmers of self-esteem!!"**
>
> **"He feels like he has a friend, and that someone values him for who he is – boosts his emotional well-being (knowing someone wants to spend time with him and be his friend, even if it is an adult)"**

Some respondents to the carer questionnaires reported that children had become more confident to separate from their main carers since they had started using short breaks, or that they had learned to trust other people to care for them.

> **"It took 12 months of weekly visits for my child to begin to feel confident to go with her carer. She still only just 'manages' to go to the carer (confidence wise) when circumstances change (e.g. not being taken from school, me not collecting) everything has to be exactly the same every occasion – But being reasonably confident to go when circumstances are as usual is a profound breakthrough – 'confidence' to do something without my presence."**
>
> **"He appears to go into the short break venue quite happily. Originally he stayed in a very small area and didn't venture from it. Now he explores many activities and areas and is becoming more confident and engaging with staff and even one or two children."**

Respondents to the carer questionnaires described how short breaks had helped to develop children's communications skills and how this was linked to their confidence and independence.

> **"Michael is becoming more confident in different settings and with different carers, his independence has improved and he has been able to communicate his needs to new carers quite well."**

“Sam is unable to speak, he uses signs so he can be very shy with new people. Going to [centre] each week has given him confidence that people are able to learn how he communicates and understand him.”

“The breaks have developed Douglas’s social skills and interactions, his communication skills have vastly improved and most importantly his confidence and independence have reached new heights.”

“As both children speak little both are having to communicate their needs. My eldest is now speaking a lot more due to the fact strangers will not understand, she is also trying to sign more and is developing a sense of independence.”

Many respondents also described an impact on children's level of independence, including for some increases in various life skills which helped them to be more independent.

> **"... Being away from home for any amount of time will encourage independent skills and will give the opportunity for youngsters to do things for themselves. They are encouraged to make choices and will start to experience a sense of responsibility and a sense of achievement. This develops children emotionally, giving them a sense of pride and boosting confidence."**
>
> **"Independence and confidence have definitely improved. He's learned some new skills – even if unwilling to use at home e.g. washing up!"**
>
> **"Learnt new skills i.e. learning to sit and eat at table, behaving better in the home, learning to stay at home rather than want to go out all the time, learning to behave in the shops/cafes."**
>
> **"He has increased his cooking skills."**
>
> **"He is able to do things for himself e.g. putting his clothes on since he started attending overnight breaks"**

Some carers also described a direct impact that short break activities have on their child's physical skills and abilities; sometimes this was related to specific skills such as swimming, skiing or trampolining, at other times it was related to more general physical skills.

> **"The short break we use is called [sporting activity]. It has helped a little with balance and co-ordination. She feels she can participate in a group more."**
>
> **"It has helped Daniel's motor skills and co-ordination by attending the sports club."**
>
> **"At hospice – good stimulation for him and have noticed some small changes in gross motor movements and alertness, it doesn't seem like a big change but thinking about my son's needs it really is."**
>
> **"Alongside this Johnny's posture and core stability has improved by his ability to take part in many sports. His gross motor skills are improving; this again is due to the sporting activities alongside the support given by the supporting adult staff."**

Respondents to the child or young person using short breaks questionnaires also wrote in comments that help to demonstrate the impact of short breaks on other health and well-being related skills and behaviours. These were covered in more detail in an earlier section of this report (Children and young people's opinions of their short breaks); but include increased access to various sports and other physical activities as well as opportunities for cooking and food related activities.

6.4 Factors associated with social participation by the child using short breaks: quantitative analysis

Univariate analyses and logistic regressions were used to examine factors associated with two aspects of social engagement by the child using short breaks, both of them derived from the SDQ.

Table 85 below summarises the findings concerning problems with peers shown by the disabled child as reported by the main carer in the SDQ. The univariate analyses show that disabled children reported as showing fewer peer problems on the SDQ were more likely to be girls, have severe/profound learning disability and were less likely to be in Target Groups A or D (ASD and/or challenging behaviour) rather than in Targets Group B or C (complex health and/or physical needs). Main carers of children showing fewer peer problems on the SDQ had lower levels of education. Children with fewer peer problems on the SDQ were less likely to use leisure short breaks and their main carers reported greater satisfaction with a wide range of aspects of short break provision.

The logistic regression showed that four factors were moderately strongly associated with fewer child peer problems on the SDQ: the child not being in Target Group A (ASD), the child being in Target Group C (physical needs), the child having severe/profound learning disability and the main carer reporting greater satisfaction with the range of short break supports available. Because some of the Target Groups children were placed in are likely to overlap with the construct of SDQ peer problems, the logistic regression was run again without child Target Groups, TDC Priority Groups or level of child learning disability as potential independent variables. This logistic regression reported that existing independent variables were replaced by two factors: the child not using leisure short breaks and main carer satisfaction with the extent to which the short break provider listens to the family.

Table 85 Factors associated with disabled child lower SDQ peer problems, data from respondents to main carer questionnaires

Factors associated with disabled child lower SDQ peer problems	
Univariate Associations (*p<0.05; **p<0.01)	
Child characteristics:	**Short break usage:**
Girl**	Child does not use leisure short breaks*
Child not in Target Group A**	Family turned down for short break**
Child in Target Group B**	
Child in Target Group C**	**Short break family experience/satisfaction:**
Child not in Target Group D**	More satisfaction: short breaks overall**
Child not in TDC Priority Group A**	More satisfaction: suitability of short break**
Child in TDC Priority Group B**	More satisfaction: range of short breaks**
Child severe/profound learning disability*	More satisfaction: flexibility of short breaks**
	More satisfaction: emergencies**
Carer characteristics:	More satisfaction: providers listen**
Main carer lower level of education*	More satisfaction: standard of care*
	More satisfaction: amount of short breaks*
Household characteristics:	
Logistic Regression	
Disabled child lower SDQ peer problems **(median split, n=189, % correct classification 61.4%-71.4%, Nagelkerke R^2=0.30)**	**Wald (p)**
Child not in Target Group A	24.22 (p<0.001)
Child in Target Group C	3.74 (p=0.053)
Child severe/profound learning disability	5.69 (p=0.058)
Main carer greater satisfaction with the range of short breaks available	5.97 (p=0.015)

Table 86 below summarises the findings concerning prosocial behaviour shown by the disabled child as reported by the main carer in the SDQ. The univariate analyses show that disabled children reported as showing greater prosocial behaviour on the SDQ were more likely to be older, to have mild/moderate learning disabilities, were less likely to be in Target Groups A, B or D (ASD, complex health needs and/or challenging behaviour) and were less likely to be in a wider range of Target Groups. Main carers of children showing greater prosocial behaviour on the SDQ were older, reported more hardship and lived in more deprived areas. Children with greater prosocial behaviour on the SDQ were more likely to have fewer overall hours of short break support and fewer hours of overnight or centre-based short breaks and were less likely to use paid carer (non centre-based) short breaks.

The logistic regression showed that five factors were strongly associated with greater child prosocial behaviour on the SDQ: the child being older, the child not being in Target Group A (ASD) or B (complex health needs), the household reporting more hardship and the main carer reporting greater satisfaction with the extent to which short break providers listen to the family. Because some of the Target Groups children were placed in are likely to overlap with the construct of SDQ prosocial behaviour, the logistic regression was run again without child Target Groups or TDC Priority Groups as potential independent variables. This logistic regression reported that the child being older, the household reporting more hardship and the main carer reporting greater satisfaction with the extent to which short break providers listen to the family were still strongly associated with higher child SDQ prosocial behaviour; the family living in a more deprived neighbourhood according to the Child Well-Being Index replaced child Target Group variables in the logistic regression.

Table 86 Factors associated with disabled child greater SDQ prosocial behaviour, data from respondents to main carer questionnaires

Factors associated with disabled child greater SDQ prosocial behaviour

Univariate Associations (*p<0.05; **p<0.01)

Child characteristics:
- Child aged 17 or over*
- Older child**
- Child with mild/moderate learning disabilities**
- Child not in Target Group A**
- Child not in Target Group B**
- Child not in Target Group D**
- Child in fewer Target Groups A-E**
- Child not in TDC Priority Group A**
- Child needs less supervision 6am-5pm**

Carer characteristics:
- Older main carer*

Household characteristics:
- More hardship general household items*
- More deprived neighbourhood IMD*
- More deprived neighbourhood CWI*
- More deprived neighbourhood CWI M*
- More deprived neighbourhood CWI H&D*

Short break usage:
- Fewer total hours of short breaks*
- Fewer hours of overnight short breaks*
- Child does not use paid carer short breaks (not centre-based)*
- Fewer hours of centre-based short breaks*

Short break family experience/satisfaction:
- More satisfaction: short breaks overall**
- More satisfaction: standard of care**
- More satisfaction: trust*
- More satisfaction: providers listen*

Logistic Regression

Disabled child higher SDQ prosocial behaviour (median split, n=221, % correct classification 86.9%-90.0%, Nagelkerke R^2=0.52)	**Wald (p)**
Older child	6.69 (p=0.01)
Child not in Target Group A	17.94 (p<0.001)
Child not in Target Group B	8.40 (p=0.004)
Household more hardship general household items	9.39 (p=0.002)
Main carer greater satisfaction: extent to which short break providers listen to family	4.51 (p=0.034)

6.5 Impact on social participation, children using short breaks: qualitative analysis

Respondents to the carer questionnaires frequently reported a positive impact on their child's social participation and further noted that their child's social participation might otherwise be very restricted.

> **"My daughter gets a break from being in the same 4 walls with the same 2 people. She has a life independently from us, she goes out on activities with a group of peers and carers she generally really likes. She has different opportunities and her world is a bigger place."**
>
> **"Steph has enjoyed 3 x 2 nights away to a caravan holiday, [theme park] and a weekend in a residential house with outings. Fantastic because Steph doesn't have friends and therefore doesn't get a chance to have fun with friends and peers away from family. Provided excellent opportunity to develop confidence and friendship away from home, develop social skills and have great fun."**

Respondents further highlight the impact that social participation has on their child's social skills and social confidence.

> **"Very confident and less lonely because he is mixing with children from his school and other schools on a social level."**

> **"More confident, more independent skills and has shown interest in peers her own age (closest to friendship) lovely to experience."**

> **"He has learned new social skills as he has to communicate with 'outsiders' (non-family) and make his wishes understood!"**

> **"We hope he will become more confident with the one to one leisure service he is starting, learn new social skills and become more independent and less lonely."**

Several respondents point out that short breaks provide valuable opportunities to mix with children who they feel are particularly suitable peers for their child (similar ages, similar needs etc).

> **"Couple of hours Saturday morning when Lynn uses hand-bikes and other adapted bikes with other children, some also wheelchair users. Gets exercise and meets other wheelchair users (her choice) from [local area]... Lynn attends mainstream school with few other wheelchair users like herself. At present she wants to be with people like herself – physically disabled, not learning disabled. Most children attending the local activities have learning disabilities."**

> **"...the youngsters to develop relationships and friendships (such an important part of respite) and us parents feel they are doing 'normal' activities that teenagers should be doing so removes the guilt from 'sending' them away – they actually want to go!"**

For some children social participation includes forming close relationships with their short break carers who become de facto friends.

> **"April's social life has improved markedly following recruitment of her personal assistant who takes her shopping, to the cinema and out and about with friends. She is happier and less socially isolated than she was previously."**

> **"As Pearl has got older, her needs have changed. Her peers have left her behind, friendships are difficult for any teenagers. Mandy (carer) gives Pearl her independence, somewhere without mum or brothers. I wish I had applied years ago. She enjoys going and doing her own thing."**

> **"Jeremy gains both through joining in activities and sports but also through socialising with his peers and friends, and also establishing relationships with other adults."**

7 Factors associated with outcomes for siblings

Because relatively small numbers of siblings completed the questionnaires, quantitative analysis of factors associated with the sibling experience cannot be completed. However Table 87 below summarises the findings concerning the disabled child's relationships with their siblings as reported by the main carer. The univariate analyses show that disabled children reported as showing better relationships with their siblings were more likely to be young adults, to have mild/moderate learning disabilities, were less likely to be in Target Groups A or D (ASD and/or challenging behaviour) and were more likely to be in Target Groups B or C (complex health and/or physical needs), were less likely to report a range of difficulties on the SDQ and were more likely to report prosocial behaviour on the SDQ. Main carers of children showing better relationships with siblings did not report a long-standing illness/disability and were more likely to be working full-time. Children with better relationships with their siblings were more likely not have been turned down or excluded from a short break, not to use leisure or non centre-based short breaks and their main carers were more likely to report greater satisfaction with the suitability and range of short breaks and with short breaks overall. The logistic regression showed that four factors were moderately strongly associated with better relationships with siblings: the child having fewer total difficulties on the SDQ, the child not being previously excluded from a short break, the main carer being in employment and the child not using leisure short breaks.

Table 87 Factors associated with disabled child better relationships with siblings, data from respondents to main carer questionnaires

Factors associated with disabled child better relationships with siblings

Univariate Associations (*p<0.05; **p<0.01)

Child characteristics:
Child aged 17 or over**
Child not in Target Group A**
Child in Target Group B**
Child in Target Group C*
Child not in Target Group D**
Child not in TDC Priority Group A**
Child in TDC Priority Group B**
Child lower SDQ total difficulties**
Child lower SDQ hyperactivity**
Child lower SDQ emotional symptoms**
Child lower SDQ conduct problems**
Child lower SDQ peer problems**
Child higher SDQ prosocial behaviour**
Child needs less supervision 6am-5pm*

Carer characteristics:
Main carer not long-standing illness/disability*
Main carer working FT**

Household characteristics:

Short break usage:
Family not previously turned down for short break**
Disabled child not previously excluded from short break**
Child does not use leisure short breaks**
Child does not use paid carer short breaks (not centre-based)**

Short break family experience/satisfaction:
More satisfaction: suitability of short breaks*
More satisfaction: range of short breaks*
More satisfaction: short breaks overall*

Logistic Regression

Disabled child better relationship with siblings (median split, n=177, % correct classification 66.7%-75.1%, Nagelkerke R^2=0.31)	**Wald (p)**
Child lower SDQ total difficulties	6.86 (p=0.009)
Main carer working FT or PT	3.23 (p=0.780)
Child not previously excluded from a short break	4.12 (p=0.042)
Child does not use leisure short breaks	13.76 (p<0.001)

7.1 Impact on siblings: qualitative analysis

Respondents to the carer questionnaires frequently wrote in descriptions of how receiving short breaks meant they and their partners could give more attention to brothers and sisters of children using short breaks, to give them more 'quality time' and for them to experience being 'put first'.

> **"Gives siblings the chance to have a break and get more parental attention ... although parents don't want to devote more attention to disabled child a lot of time you have to. So breaks give chance to catch up with these siblings and give individual attention."**
>
> **"Our younger son gets some exclusive 'quality' time with mum and dad without having always to cater for his brother's needs. We get some time in our home without Michael's constant noise and dominance of routine etc."**
>
> **"We are a very close family and my children have a great relationship. Oscar [sibling] is very understanding and kind to his sometimes very annoying sister and I think this relationship has developed so well as one night a week it was always Oscar's time and one weekend a month Becky went off [to] a respite home for a Saturday night."**

Siblings also benefited from the opportunity to experience a wider range of activities when their brothers and sisters were having a short break. There were three main ways in which this came about, some siblings were able to join-in the short break activities provided, some were provided with special activities for siblings whilst many were able to take part in activities with their families whilst their brother or sister was away at their short break.

> **"Extra support for disabled child is vital and is provided, siblings are included, so can go all together. Variety of activities – sport, art, music, theme parks..."**
>
> **"We visit a local children's hospice, it works well because we can all visit as a family ... Kate and her brother and sister enjoy time at [respite centre] with all the activities on offer... Siblings enjoy the same activities as Kate, art lessons, music sessions, visits to donkey sanctuaries."**
>
> **"Gives kids (siblings) a chance to be themselves away from disabled child, they are classed as young carers and have to grow up so quick – gives them a chance to be kids... they can meet like-minded children."**
>
> **"Siblings: they can enjoy time with parents doing the kind of things not possible when their sister is around. Doing more physically challenging experiences, age appropriate activities, 'grown up' conversations."**
>
> **"When Anne goes to respite I try to spend some quality time with her 12yr old sister Sherrie. Last time she went we had a 'girly' shopping trip and then went to the cinema."**
>
> **"The remaining children in the family have time to talk without being interrupted by a special needs sibling. Activities such as going out for family meals, are much less stressful and more enjoyable if they can happen when the short break is taking place."**

Some respondents to the carer questionnaires also stated that it was important for the well-being of siblings that they have a 'break' from their disabled brother or sister. Sometimes this provided respite from difficult behaviour and sometimes it provided a break from providing care for their brother or sister.

> **"Peter will sometimes vent his frustration on his older brother, both physically and verbally..."**

> **“In the past this short break facility gave us the opportunity to take our older non-disabled children on a much needed break away from their disabled siblings. Where their needs could be paramount and we would be a ‘normal’ family for a few days.”**
>
> **“Siblings also have a rest from the demands of the child – they can have good quality time with parents or can do normal activities which may otherwise be difficult.”**
>
> **“Our middle child loves his sister dearly but appreciated most the break from her – his room, time, parents’ time is his alone. He doesn’t have to creep around the house once Susie is in bed in order not to illicit a demanding cry for attention.”**

Respondents to the sibling questionnaire often wrote of their concern for and affection for their brother or sister who used short break, some described a link between their sibling’s well-being and their own. It is likely therefore that if disabled children are enjoying their short break, siblings will gain indirect benefits.

> **“I don’t like it when he cries because it makes me sad and I miss him at the table at tea time”**
>
> **“...she enjoys it a lot and I like it when she enjoys things. I am happy when she is happy.”**

A small number of respondents to the carer questionnaires also reported positive educational impacts for siblings. Often this was associated with opportunities for peace and quiet in the home.

> **“Allows for a calm, settled, quiet home for Felix’s sibling to do school work / revise for GCSEs.”**

Respondents to the carer questionnaires described a number of social benefits for the siblings of children using short breaks. These included the opportunity to socialise more with extended family, the opportunity to experience holidays and the opportunity to spend more ‘uninterrupted’ time with their existing friends.

> **“We apply for a nine night extended break each year so that we can take Isaac [sibling] on holiday without his sister.”**
>
> **“My daughter is able to have her friends round and to stay overnight.”**
>
> **“This allowed her younger brother Paul to have friends round...”**
>
> **“Even now that they [siblings] are adults the short-break enables us to visit them, meet their boyfriend / girlfriend, attend their celebrations etc.”**

8 Discussion and policy implications

This report covers many aspects of the lives of families and the use they have made of an increasingly complex array of short break provision. The information contained in the report is therefore necessarily detailed; furthermore it includes both numerical and verbal information resulting from quantitative and qualitative analyses. The contents of this report might therefore be regarded as being complex despite our attempts to make it clear and straightforward. Of paramount importance is that the report provides evidence and information which will help to inform policy-making and improve service delivery.

We have described the characteristics of families using short breaks and have demonstrated a number of significant associations between these characteristics, the use of short breaks and various outcomes for children, carers and other family members. Throughout the research we have also used the comments, explanations and descriptions given by respondents to gain insight into the impacts of short breaks. We have reproduced many of the respondents' comments in the report to illustrate particular points. These have not only been helpful in facilitating an understanding of what has been observed but have promoted a greater appreciation of the diversity of experiences and opinions.

The research programme is continuing with the second application of the longitudinal study which we hope will provide further measures of the ongoing impacts of short breaks for families with a disabled child.

The purpose of this section is not to repeat the findings presented in the earlier section, rather the aim is to draw out areas of particular interest for policymakers and also to note areas which might warrant further thought or investigation. Taking part in this study has enabled respondents to provide detailed information and comment on the short break services they have used. Whilst this inevitably involves a certain amount of constructive criticism this should not detract from the consistency with which families demonstrate the value that short breaks hold for them. Many rely heavily on short breaks and many express high levels of satisfaction with many aspects of short breaks. Similarly children using short breaks and their siblings are very positive about their breaks and identify many benefits that they receive. Carers are naturally careful and selective about services that look after their disabled child; their comments also show that they understand that resources are limited; recognise the needs of other families and ask for 'fair' access to services and clear eligibility criteria.

This research has demonstrated that families with disabled children are highly diverse in terms of various characteristics of the children, carers, other family members and family circumstances. Furthermore the situation within families can be fluid and changeable, many families experience changes in circumstances (e.g. employment, illnesses, births, marriages, separations, moving house, extended family and social networks). Even the most settled of families experience change as children mature, change schools and eventually move into adult services. This research has shown that these different characteristics are important in terms of how families use short breaks and in their opinions of the services they use.

Such diversity provides significant challenges to agencies planning and delivering short break services. Whilst it is important to have a good basic understanding of needs in a local area, each family is unique and will have changing needs over time. Consequently the availability of a wide range of different services appears to help families and they further benefit if services are as accommodating as possible.

Systems for accessing short breaks work best when they are simple and responsive; capable of taking account of a wide range of factors and open to finding flexible solutions for families. The study has identified many different types of breaks which are being used in diverse ways by different groups of families. Each different break is likely to provide particular benefits for different people within the family and there are clearly variations in the ways that different types of short break are allocated and used. This is important when considering the issue of flexibility in the delivery of short break support, as different families in different circumstances are likely to take a different view of the relative merits of flexibility versus other valued aspects of short break provision such as quantity, suitability, reliability and predictability.

Overall, overnight and centre-based short breaks provide families with more hours of short break support and are more likely to be used by older children with more complex disabilities, health needs and physical needs, but lower levels of actively challenging behaviour involving other people. This pattern suggests that these types of short breaks may be more ‘traditional’, long-standing forms of local authority-funded short break services that pre-date Aiming High for Disabled Children. However, they may not be optimally focused in terms of accepting younger children, children with more actively challenging behaviours, or children of family carers who require overnight or centre-based short breaks to improve their health and well-being. This may be particularly important given that the use of overnight short breaks was an important factor in several aspects of main carer satisfaction with short breaks.

In contrast, more innovative forms of short breaks such as leisure-based short breaks and non centre-based short breaks offered overall fewer hours of short break support to families of children who had less complex disabilities, health and physical needs, but who tended to show more actively challenging behaviour involving other people. These forms of short break support were more likely to be used by main carers with a greater level of education and more of these forms of support were used by main carers in circumstances where they were needed, such as lone parents. Again there are issues around how these short break services, many of which may have started or expanded with the advent of Aiming High For Disabled Children, are focused, for example in terms of their attractiveness for use by older children with more complex disabilities, health and physical needs and particularly in making sure that they are practically useful in terms of giving family carers slices of time that are actually useful to them.

Across almost all types of short breaks, aspects of families’ socio-economic circumstances came up as being related to access to short break support, with families in less financially and materially deprived circumstances having greater access to short break services. The issue of targeting short breaks support more effectively is particularly important here, as family economic and material disadvantage was also associated with a wide range of poor health and well-being outcomes for main carers and with poorer general health for the disabled child. Ensuring that decisions about access to short breaks are determined by a more balanced approach that takes into account the needs of the whole family (and also the behavioural needs of the disabled child) rather than primarily the disability, health and physical needs of the child, could help considerably in reducing current inequities in access to short break services.

In terms of family satisfaction with short breaks, having more hours of short break support overall and using overnight short breaks were robustly associated with a range of aspects of main carer satisfaction with short breaks. It is worth pointing out that overnight short breaks included centre-based, home-based and shared care short breaks in other families' homes. Of concern was that main carers from ethnic backgrounds other than White British were less satisfied with various aspects of the suitability of short break support and short break carers. It is crucial that local authorities and short break providers ensure that securing equity across ethnic groups moves beyond access to services (where there were no differences across ethnic groups) to consider the suitability of short break provision across ethnic groups.

Again, family socio-economic circumstances were consistently associated with a wide range of aspects of main carer satisfaction with short breaks. However, although families in more deprived circumstances tended to receive less short break support, they rated themselves as more satisfied with the short break support they did use and were more satisfied with both the amount and range of short break support available. It is unclear whether families in more deprived circumstances have lower expectations of short break support or are less assertive in making their views known for fear of losing the support they do have. It is certainly the case that families in less deprived circumstances were more likely to articulate shortcomings in short break supports and to suggest improvements. Agencies undertaking consultations will need to take particular care to include the opinions of the whole range of families using and needing short breaks including families in more materially and financially deprived circumstances, as these families may bring different views about current and desired future short break supports than more assertive families in more affluent circumstances.

Families have highlighted a number of groups of children they feel are less well served by short break services, the AHDC target groups identify some of these, a further group being young disabled children (under 8 years). Many respondents suggest that more access to overnight short breaks is needed. Families have also highlighted their concern that care for disabled children before and after school and during school holidays is insufficient. Families differ in their approach to such care, some seeing it primarily as 'childcare' and others being happy to use it as 'short break' care. Families who have responded to this study have clearly stated a belief that some disabled children do not have equal access to wider services including childcare and in some areas leisure services, some carers feel that short break services are unfairly being used to compensate for deficiencies in other services rather than to provide additional support. In policy terms, it is crucial that a consideration of short break support is integrated into wider considerations of family support taking the whole family as a focus. More personalised approaches to family support that allow the family to take a holistic view of their needs and design their support accordingly, without falling foul of artificial bureaucratic compartmentalisations of family support (short breaks vs. childcare is a particularly vexed issue for many families), may be one way of addressing this issue. Such an approach may also be helpful in helping families to find their preferred balance of short breaks services that are booked well in advance and provide predictability for the family versus an allocation for short break support that the family holds back to use flexibly at relatively short notice. However, there are likely to be significant challenges for local authorities in moving towards effectively targeted and equitable personalised support, as the findings concerning direct payments illustrate.

Short breaks funded via direct payments have been shown to have a number of advantages for families and are viewed positively by most carers. However, along with some examples of good practice, families have described difficulties in accessing and using direct payments. Furthermore families who currently use direct payments tend to be those with higher levels of education, White British carers, female carers and those who live in less deprived areas.

This suggests that some local authorities needs to consider how to extend the use of direct payments beyond assertive and relatively affluent families – these issues will become even more relevant as part of a broader personalisation agenda. First, information concerning direct payments needs to be made more readily accessible to all families. Second, direct payments must have the potential to be of sufficient size to enable families to invest in significant quantities of overnight and centre-based short breaks if that is what the family needs and wants. Third, the process of applying for, allocating, using and monitoring direct payments needs to be considerably simplified. Fourth, local authorities may need to offer additional support (either directly or via other agencies) to families in administering and managing their direct payment. Fifth, arbitrary rules concerning how direct payments allocations may be used may need to be reviewed and relaxed to ensure that families can use direct payments in ways that make sense for the family's functioning. Finally, local authorities will need to maintain a strategic development role to ensure that local markets for short break provision are delivering short breaks that are valued by families.

One further area of emerging interest is the gender differences noted in children using short breaks. These differences are marked in terms of the types of disabilities that children have, in terms of short breaks that are use and interestingly in terms of families' likelihood to respond to this survey. Further research to investigate the different needs, attitudes and opinions of boys, girls and their families may provide particularly useful information for those planning and delivering short breaks and other services.

An important finding for policy-makers is the near-invisibility of NHS-funded short break support for the families in this study. This may be because families were identified via local authorities rather than Primary Care Trusts, but comments from several families mentioned the difficulty of gaining support from the NHS for short breaks. Given current policy proposals around the replacement of many of the functions of PCTs with GP commissioning consortia, an important issue for policy-makers is to consider whether the NHS should retain a commissioning responsibility for short breaks for families with a disabled child and if so where that commissioning responsibility should best reside. With less ring-fencing of budgets and less top-down control over local authorities on the horizon, it will also be important for policymakers to consider how local authorities will be made accountable to their local communities of families with a disabled child on the effectiveness of their family support, to ensure that these families do not become invisible and fall through the net in terms of local authority-commissioned support.

Finally, there are clearly imbalances in short break support that represent a considerable challenge for policymakers and local authorities. Overnight and centre-based short break services are more likely to be used by older children with more complex disabilities, health and physical needs and it seems that family carers using these services are very satisfied with them and are unlikely to 'trade' some of these forms of support for more innovative leisure and non centre-based short breaks. Yet this may mean that these forms of short break support are effectively 'blocked' to younger children, children with more behavioural needs and family carers with more needs around their own health and well-being, who are currently more likely to use leisure and non centre-based short breaks. Unless there is to be a considerable expansion in overnight and centre-based short breaks, local authorities will have to manage very carefully a transition to more balanced profiles of short break support. This process will be made more challenging by the likelihood that the family carers using overnight and centre-based short breaks may be less likely to embrace processes such as direct payments or personalisation that could be used as tools to effect such a rebalancing.

Policymakers and local authorities will also need to consider such a rebalancing beyond the provision of ‘child’ services, as many young disabled people move into adulthood whilst still living with their family carers. Such a transition point is often felt as catastrophic by families as an array of family supports, including short breaks, are drastically reduced as their child officially becomes an adult, although the needs of the disabled young person and their family carers may change little over this transition point.

9 List of Tables

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11 Bibliography

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12 Appendices

12.1 Appendix A – Examples of introductory materials

Example text from local authority Covering Letter –

Local Authorities were asked to include a covering letter introducing the studies and were given some suggested text which they were free to adapt as they saw free. Most local authorities used the suggested text, some with a few additions.

Dear Parent or Carer,

We have been asked to tell you about an important national study involving families with a disabled child who is using short breaks. The research is being undertaken by the University of Lancaster and has been commissioned by the Department for Children, Schools and Families. It is designed to increase knowledge and understanding about the impacts that using short breaks has on families. This will be the largest study of its kind ever undertaken and will be influential in the future provision of short breaks.

This study is part of the evaluation of the Aiming High for Disabled Children programme. A number of families from different areas in England are being invited to take part. Some families will have lots of experience of using short breaks; others will be new to using them. The researchers need as many as possible of the families that are invited to take part to ensure that the research is comprehensive and robust.

Most people that take part will do so by completing a questionnaire, some may prefer to be interviewed. The enclosed information tells you more about what’s involved and who to contact if you have any questions.

Please note that we have not passed your name and address to the researchers. If you decide to take part you will first have to return the enclosed form in the FREEPOST envelope provided or telephone the researchers to give them your contact details.

Thank you for taking time to consider this study and if you do take part we hope that you find it both interesting and rewarding.

Yours sincerely

As appropriate

Example of invitation letter / information sheet from Centre for Disability Research, Lancaster University

Centre for Disability Research
CeDR

School of
Health & Medicine

LANCASTER
UNIVERSITY

Short breaks for families with a disabled child: Research Project Information

Dear Parent or Carer,
The Centre for Disability Research at Lancaster University, would like to invite you to take part in an important piece of research. Your council is one the areas across England that have some extra funding from the Government (the Department for Children, Schools and Families) to provide more short breaks to help families with a disabled child. The Government has funded us to investigate what impact short breaks have for families and whether it is making a difference to the lives of families.

What is a 'Short Break'?

'Short breaks' can be any type of extra care or activity given to a disabled child so that their usual carer or family can have a short break from looking after them.

Short breaks can happen anywhere (at home or away from home)
Short breaks can happen at any time of day or night
Short breaks can last for different lengths of time, from one hour, to several days
Short breaks can be part of mainstream provision or specially for disabled children and their families
The people providing the care are often paid (employed) carers, but sometimes they might be volunteers or members of wider family or friends
Short breaks can be fun, but one of the reasons for them is so that carers can have a bit of a break

A few examples

Sports, leisure, craft or play activities
After-school or holiday clubs
A short holiday, day trip or something similar
An overnight stay in a centre or a hospice
An overnight stay at the home of a carer or a relative such as a grandparent
Being looked after in the child's own home, during the day or during the night
Using direct payments to get some extra help to look after a child
The whole family taking part in an activity where there are extra carers on hand to help look after the child

Why are we inviting you to take part?

Your local authority identified your family as having used some kind of short break service and agreed to forward this letter to you. This could have been a service you use often or something you have used only once or twice. We don't have your contact details unless you chose to take part and return the enclosed form. We hope you will take part; we need to learn about people's experiences of using all kinds of short breaks, what has worked well and what could work better.

What's involved?

We are asking people to take part in this research by agreeing to complete a questionnaire now and again in one year. Your responses would be treated confidentially. We would use them, without naming you, to help improve short breaks for families with a disabled child across England. We would only share what you have told us if we thought that someone might get seriously hurt. If you would find completing a form difficult we can give you help, this could be help over the phone or face to face if need be. We could also translate the forms into other languages.

What kinds of questions will we ask?

This research builds on early research looking at the kinds of difference that using short breaks makes to people. Some families said that using short breaks makes a difference to their well-being, their child's education or their child's behaviour. Other families said it makes a difference to relationships in the family, how easy they find it to do other things or how much money the family have to spend. We ask some questions about all these areas as well as going into detail about what types of break you use, how you use them and what you think of them.

Would anyone else in your family like to take part?
We also have questionnaires for other adults and children in your household to see if short breaks make a difference for them. You can tell us if you think someone else might be interested. We appreciate that children might need extra support to decide whether to take part, and help to participate in the research project. Together with you, we will provide any extra support needed.

Do you have to take part?
No – you will have time to decide whether or not you take part in this research. Your decisions will not affect any services or support you receive, and you are free to stop taking part at any time without giving a reason. If you decide to stop you could ask us not to make any further use of information you have already given us.

What some other families said after taking part
"Questionnaire was good in taking into account how the whole family coped with the affect of disability"
"The questionnaire is a great way to survey exactly what families think"
"I am willing to help in any way with this research"

What should I do now?
When you are ready, please take a few moments to complete the enclosed form to let us know if you would like to take part, then return it to us in the freepost envelope.

If you would like to know more about the research look at the website or get in touch
http://www.lancs.ac.uk/shm/research/projects/short_breaks/
Vicki Welch, Centre for Disability Research, Division of Health Research, Bowland Tower East, Lancaster University, Lancaster. LA1 4YT☎01524 593301💻 v.welch@lancaster.ac.uk

If you have any complaints or reservations about the ethical conduct of this research please contact
Professor Chris Hatton, Division of Health Research, Bowland Tower East, Lancaster University, Lancaster. LA1 4YT. ☎ 01524 592823. 💻 chris.hatton@lancaster.ac.uk
Any issues you raise will be treated in confidence, investigated fully and you will be informed of the outcome.

Please keep this information for your future reference

Example of consent, preferences and contact details form

Centre for Disability Research
CeDR

School of
Health & Medicine

LANCASTER
UNIVERSITY

Short breaks study for families with a disabled child

If you would like to be involved please complete this form and return it in the freepost envelope.

1, Your Consent (main carer)

I have read and understood the enclosed information about the research project, and I would like to take part. I understand that I can change my mind at any time about taking part in this research. My services or support will not be affected. I understand that I don't have to answer a question if I don't want to. I understand that the researchers will write a report, which may include things I say, but my name will not be used. My personal information will not be shared with any other organisations except if the researcher feels that someone is at risk of serious harm or abuse.

Your Name	**Your Signature**	Date

2, Other household members

Would anyone else in your household like to take part? We are keen to hear the views of everyone in the household. As well as a main carer questionnaire we have short forms suitable for different people in your household. If you think they might like to take part we will send information and forms for them, so that they can decide whether or not to take part. Please tell us below how many of each you would like.

	How many?	Age(s) of child (so we send the best form for them)
Forms for additional adult carers		
Forms for a child who uses short breaks*		
Forms for other children who live in the household*		

*If you would like any children's forms to be sent please also complete and return the yellow consent form which gives your permission for researchers to contact your child(ren).

3, Accessibility

If <u>for any reason</u> it would be difficult for you to take part by postal questionnaire please tick this box. We will contact you to discuss other ways in which you can take part.

☐

Please complete your contact details on the following page

4, Your Contact Details

Your name
Your address (including postcode)
Your phone number(s)
Any special instructions for contacting you

Thank you. Please return this form in the freepost envelope provided.

Example of consent to approach child form (longitudinal study only)

Centre for Disability Research
CeDR

School of Health & Medicine

LANCASTER UNIVERSITY

Consent for Researchers to Approach Child(ren)

Only needed if you would like us to send a short form for any child(ren) in your household. Please complete a section for each child who might want to take part. Don't forget to sign at the bottom and return with the consent form in the freepost envelope.

Child 1

I give my consent for [Name of child who uses short breaks] to be invited to take part in the Short Breaks research project.

My relationship to this child is ________________________________ Their date of birth is___________________

Child 2

I give my consent for [Name of other child in household, e.g. a sister or brother] to be invited to take part in the Short Breaks research project.

My relationship to this child is ________________________________ Their date of birth is___________________

Child 3

I give my consent for [Name of other child in household, e.g. a sister or brother] to be invited to take part in the Short Breaks research project.

My relationship to this child is ________________________________ Their date of birth is___________________

Your details

Your name Your signature Date

Example of children's information (older child version)

Centre for Disability Research CeDR

School of Health & Medicine

LANCASTER UNIVERSITY

Hello,

We are researchers and we are interested in finding out about you and your family's experiences of Short Breaks.

You or your brother/sister has 'short breaks' where he/she does things without the rest of the family being there.

We want to find out if short breaks make life better for you and your family. We are going to ask lots of young people and their families about short breaks.

We will ask about what you like and what you don't like and whether the short breaks scheme makes a difference to your life and the life of your family.

We will send you a form to fill in. Everything you say will be kept private! The only time we will tell someone else what you say is if we think someone might get seriously hurt.

What you tell us might help to make short breaks better. Would you like to be one of the people that take part?

Nothing bad will happen if you say "No"

If you say "Yes" now you can still change your mind later.

Do you have any questions? We can arrange for someone to talk to you before you say "Yes" or "No".

If you want to speak to someone you can ring or email:

Emma on
☎01524 593808
💻 e.wells@lancaster.ac.uk

Vicki on
☎ 01524 592301
💻 v.welch@lancaster.ac.uk

If you are unhappy about the way this research is being done please contact –
Professor Chris Hatton, Division of Health Research, Bowland Tower East, Lancaster University, Lancaster. LA1 4YT. ☎ 01524 592823. 💻 chris.hatton@lancaster.ac.uk
What you say will be treated as private, it will be looked into and you will be told what happens.

Example of children’s consent form (older child’s version)

Centre for Disability Research
CeDR

School of
Health & Medicine

LANCASTER
UNIVERSITY

Short Breaks Study

Please write your name below, read the information carefully then when you have decided please tick a box and sign your name on the last page. To make sure that everyone understands about this research please ask an adult to watch you sign.

Consent Form For:____

The project has been explained to me.

I know I can change my mind and say “No” whenever I like.

I know that it is OK to say “No”.

I know that what I say will be written down or recorded.

I know that I can stop at any time.

I know that everything I say will be kept private, unless someone might get seriously hurt.

I know that my name will never be used in reports.

(please sign on the next page)

👍 Yes I want to take part in the project ☐

👎 No I don't want to take part in the project ☐

Please ask an adult to watch you sign the form.

Signed ____

Name of adult watching ____

Signed by adult watching ____

Date ____

If you want to ask anything

You can ring ☎

Vicki on 01524 593301

or

Emma on 01524 592808

Or email 💻

Vicki at v.welch@lancaster.ac.uk

Emma at e.wells@lancaster.ac.uk

12.2 Appendix B – The questionnaires

a) Longitudinal study – Main Carer Questionnaire

b) Longitudinal study – Additional Carer Questionnaire

c) Longitudinal study – Child or Young Person using Short Breaks Questionnaire

d) Longitudinal study – Sister or Brother of a Child or Young Person using Short Breaks Questionnaire

e) Cross-sectional study – Main Carer Questionnaire (Family Experiences Questionnaire)

NB Fonts, formatting etc have been changed where necessary to allow incorporation into this document.

Form 1

Main Carer

Your first name:

Office use only		
Code	Date rec.	Proc.

Introduction

Thank you for agreeing to help us with this study. Please answer as many questions as you can. This page shows some examples of the types of questions you will find.

Sometimes we ask you to choose an answer by ticking or marking a box like this -

	Very satisfied	Quite satisfied	Not satisfied
How satisfied are you with communications between you and the short break provider?	☐	☑	☐

Sometimes we give you a box and ask you to write in an answer like this -

What is the main difference between the services you use now and the ones you used in the past? (please write in)

As my daughter has got older she wants to be more active and get out more. At the moment she goes swimming and horse riding but a couple of years ago she wanted to stay at her carer's house and play inside.

Remember there are no 'right' or 'wrong' answers; we are really interested in your thoughts and your opinions.

Before you start, please write your first name on the front of this booklet (in the space provided) so we know who has completed this form.

Section 1 – Your household

In this section, we would like to find out a little bit about yourself, the disabled child who uses short breaks and the other members of your household.

1. Counting all adults and children how many people live in your household? ☐

2. What is your gender? (Please tick one box) Male ☐ Female ☐

3. What is your date of birth? (Please write in) ☐

4. What is the first name of the disabled child in your household who uses short breaks? If there is more than one child in your household who uses short breaks, please select the eldest. ☐

5. What is his/her gender? (Please tick one box) Male ☐ Female ☐

6. What is his/her date of birth? (Please write in) ☐

7. What is your relationship to this child? (Please tick one box)

Natural parent	☐	Step parent	☐
Adoptive parent	☐	Foster parent	☐

Other (please specify)

8. In the table below, please state the details of **all other adults** (18 years of age and above) who live in your home as regular members of your household

	Adult 2	**Adult 3**	**Adult 4**	**Adult 5**
First name				
Age (in years)				
Male				
Female				
Natural parent				
Step-parent/ partner of parent				
Adoptive parent				
Foster parent				
Other (please write in)				

Section 1 – Your household

			Gender (please tick one box)	Relationship to the child using short breaks named on page 3 (Please tick one box)

9. In the table below, please state the details of **all other children** (under the age of 18 years) who live in your home as regular members of your household:

		Child 2	**Child 3**	**Child 4**	**Child 5**
First name:					
Age					
Gender (please tick one box)	**Male**				
	Female				
Relationship to the child using short breaks named on page 3 **(please tick one box)**	**Natural brother**				
	Natural sister				
	Step-brother				
	Step-sister				
	Adopted brother				
	Adopted sister				
	Foster brother				
	Foster sister				
	Other (Please write in):				

Section 1 – Your household

10. What is your current marital status? (Please tick one box)

Legally separated	☐	Married, 1st and only marriage	☐	Remarried, 2nd or later marriage	☐
Single, never married	☐	Divorced	☐	Widowed	☐

11. Are you living with someone in your household as a couple? (Please tick one box) Yes ☐ No ☐

12. Do you consider yourself to be a lone parent? (Please tick one box) Yes ☐ No ☐

13. Do you have any other disabled children living with you? Yes ☐ No ☐

If yes, please state how many: ☐

Section 1 – Your household

14. What is your ethnic group? Please choose one section and then tick the box which best describes your ethnic group.

A. White:		**C. Asian/ Asian British:**	
British	☐	Indian	☐
Irish	☐	Pakistani	☐
	☐		☐
B. Mixed/ multiple ethnic groups:		Any other Asian/ Asian British background: Please state:	☐
	☐	**D. Black/ African/ Caribbean/ Black British:**	
White and Black African	☐	African	☐
White and Asian	☐	Caribbean	☐
Any other mixed/ multiple ethnic groups background Please state:	☐	Any other Black/ African/ Caribbean background: Please state:	☐
		hnic group	
			☐
			☐

15. Do you regard yourself as belonging to a particular religion? If so, which? (Please tick one box).

No religion ☐	Christian (no denomination) ☐	Roman Catholic ☐	Baptist ☐
Free Presbyterian ☐	Other Christian ☐	Methodist ☐	Hindu ☐
Muslim ☐	Sikh ☐	Buddhist ☐	Jew ☐
Church of England/ Ireland/ Anglican/ Episcopal ☐	United Reformed Church/ Congregational ☐	Presbyterian/ Church of Scotland ☐	Other, please state: ☐

16. What is the ethnic group of the child who uses short breaks? Please choose one section and then tick the box which best describes his/ her ethnic group.

A. White:	**C. Asian/ Asian British:**
British ☐	Indian ☐
Irish ☐	Pakistani ☐
☐	☐
B. Mixed/ multiple ethnic groups:	Any other Asian/ Asian British background: Please state: ☐
☐	**D. Black/ African/ Caribbean/ Black British:**
White and Black African ☐	African ☐
White and Asian ☐	Caribbean ☐
Any other mixed/ multiple ethnic groups background Please state: ☐	Any other Black/ African/ Caribbean background: Please state: ☐
	hnic group
	☐
	☐

Section 1 – Your household

17. Is English the language usually spoken at home? (Please tick one box)

Yes - English only	☐	Yes - English and other language	☐	No - Other languages only	☐

18. If applicable, which other languages are spoken at home? (Please tick one box)

Welsh	☐	Gaelic	☐	Urdu	☐	Punjabi	☐
Guajarati	☐	Hindi	☐	Bengali	☐	Sylheti	☐
Cantonese	☐	Somali	☐	Tamil	☐	Other, please state:	☐

Your education:

19. Please can you tell us, do you have any of the following qualifications? (Tick as many as apply)

Higher degree	☐	First degree	☐	Diplomas in Higher Education	☐
A/AS Levels	☐	O-Level/ GCSE Grades A-C	☐	GCSE Grades D-G	☐
Other academic qualifications	☐	None of these	☐		

20. Please can you tell us, do you have any of the following qualifications? (Tick all that apply):

Professional qualification at degree level	☐	Nursing or other medical qualifications	☐	NVQ/ SVQ/ GSVQ Level 3	☐
NVQ/ SVQ/ GSVQ Level 2	☐		☐		☐
Other vocational Qualifications	☐	None of these	☐		

21. Do problems with reading, writing, or maths make it difficult for you to manage day-to-day activities, like paying bills, writing letters, etc? (Please tick one box)

Yes ☐ No ☐

22. Since leaving school, have you ever been on courses to improve your reading or number skills?

(Please tick as many as apply)

Yes- reading ☐ Yes- number ☐ No- neither ☐

Your partner's education (if you do not have a partner living with you, please move on to Q27)**:**

23. Please can you tell us, does your partner have any of the following qualifications? (Tick as many as apply):

Higher degree	☐	First degree	☐	Diplomas in Higher Education	☐
A/AS Levels	☐	O-Level/ GCSE Grades A-C	☐	GCSE Grades D-G	☐
Other academic qualifications	☐	None of these	☐		

24. Please can you tell us, does your partner have any of the following qualifications? (Tick as many as apply):

Professional qualification at degree level	☐	Nursing or other medical qualifications	☐	NVQ/ SVQ/ GSVQ Level 3	☐
NVQ/ SVQ/ GSVQ Level 2	☐		☐		☐
Other vocational Qualifications	☐	None of these	☐		

25. Do problems with reading, writing, or maths make it difficult for your partner to manage day-to-day activities, like paying bills, writing letters, etc? (Please tick one box)

Yes ☐ No ☐

26. Since leaving school, has your partner ever been on courses to improve his/her reading or number skills?
(Please tick as many as apply)

Yes- reading ☐ Yes- number ☐ No- neither ☐

Your employment:

27. Which of these best describes you? (Please tick one box):

Looking after family full-time	☐	Working part-time	☐	Working full-time	☐
On government training scheme	☐	Looking for work	☐		☐

28. What is your present or last occupation? (Please write in) ☐

Your partner's employment (If you do not have a partner living with you, please move on to Q31)**:**

29. Which of these best describes your partner? (Please tick one box):

Looking after family full-time	☐	Working part-time	☐	Working full-time	☐
On government training scheme	☐	Looking for work	☐		☐

30. What is his / her present or last occupation? (Please write in) ☐

Section 2 - Expenditure

31. The table below contains a list of the sorts of things families have or would like to do, but which many people have difficulty finding the money for. Please indicate whether you have each item, would like it but cannot afford it, or do not want or need each item (tick one box per item).

	We have this	**We would like this but cannot afford it at the moment**	**We do not want / need this at the moment**
Do your family have...			
Good quality 'brand name' food for family meals on most days?	☐	☐	☐
	☐	☐	☐
New, not second hand clothes when you need them?	☐	☐	☐
	☐	☐	☐
Good quality 'brand name' clothes or shoes for you and your family?	☐	☐	☐
A celebration with presents, for friends and family on special occasions?	☐	☐	☐
Toys and sports gear for the children?	☐	☐	☐
Money for trips, holidays and outings, or going with gifts to parties?	☐	☐	☐
A one-week holiday away from home, not staying with relatives?	☐	☐	☐
	☐	☐	☐
A dishwasher?	☐	☐	☐
	☐	☐	☐
A home computer?	☐	☐	☐

32. Is there anything else that your child(ren) need(s) at the moment but which you just can't find the money for? (Please tick one box) Yes ☐ No ☐

33. If yes, what do your children need at the moment? (Please tick as many as apply).

Clothes	☐	Footwear	☐	School uniform	☐	Holidays/ days out/ trips	☐
Toys	☐	Bed/ new bed/ cot/ high chair	☐		☐	Other, please state:	☐

34. Is there anything else that you or your partner Yes ☐ No ☐

really need to buy at the moment, but which you just can’t find the money for? (Please tick one box):

35. If yes, what do you or your partner really need at the moment? (Please tick as many as apply)

Clothes	☐	Footwear	☐	Car	☐	Carpets/ curtains	☐
Bed/ bedding				Electrical equipment Or repairs			
Home improvements	☐	Other, please state:	☐				

36. How often would you say you have been worried about money during the last few weeks? (Please tick one box)

Almost all the time ☐ Quite often ☐ Only sometimes ☐ Never ☐

37. Taking everything together, which of these phrases best describes how you and your family are managing financially these days? (Please tick one box).

Manage very well	☐	Manage quite well	☐	Get by alright	☐
					☐

38. During the past 12 months, would you say your financial situation has...? (Please tick one box)

Got better ☐ Got worse ☐ Stayed more or less the same? ☐

39. Thinking back over the last 12 months, how often would you say you had trouble with debts that you found hard to repay? (Please tick one box)

Almost all the time ☐ Quite often ☐ Only sometimes ☐ Never ☐

Section 3 – Your health and wellbeing

40. How is your health in general? Would you say it was...(Please tick one box).

Very good ☐ Good ☐ Fair ☐ Bad ☐ Very bad ☐

41. Do you have any long-standing illness, disability or infirmity? By long-standing we mean anything that has troubled you for at least 3 months, or is expected to continue for the next 3 months? (Please tick one box)

Yes ☐ No ☐

If you answered ‘No’ please move on to question 44.

42. Could you please state these long-standing illnesses? (Please write in the box below).

43. Does this illness or disability/ do any of these illnesses or disabilities limit your activities in any way? (Please tick one box).

Yes ☐ No ☐

44. The following questions ask about how you have been feeling during the **past 30 days.** For each question, please tick the box that best describes how often you had this feeling.

During the past 30 days, how often did you feel...	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) ...nervous?	☐	☐	☐	☐	☐
b) ...hopeless?	☐	☐	☐	☐	☐
c) ...restless or fidgety?	☐	☐	☐	☐	☐
d) ...so depressed that nothing could cheer you up?	☐	☐	☐	☐	☐
e) ...that everything was an effort?	☐	☐	☐	☐	☐
f) ...worthless?	☐	☐	☐	☐	☐

Section 3 – Your health and wellbeing

45. The last six questions asked about feelings that might have occurred during the past 30 days. Taking them altogether, did these feelings occur more often in the past 30 days than is usual for you, about the same as usual, or less often than usual? (Please tick one box).

More often than usual			About the same as usual	**Less often than usual**		
A lot	Some	A little		A little	Some	A lot
☐	☐	☐	☐	☐	☐	☐

46. During the past 30 days, how many days were you totally unable to work or carry out your normal activities because of these feelings? (Please write in)

47. Not counting the responses in the question above, how many days in the past 30 days were you able to do only half or less of what you would normally have been able to do because of these feelings? (Please write in)

48. During the past 30 days, how many times did you see a doctor or other health professional about these feelings? (Please write in)

49. During the past 30 days, how often have physical health problems been the main cause of these feelings? (Please write in)

50. Here is a scale from 1 to 10 where ‘1’ means that you are completely dissatisfied and ‘10’ means that you are completely satisfied. Please tick the box which corresponds with how satisfied or dissatisfied you are about the way your life has turned out so far.

Completely dissatisfied									**Completely satisfied**
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Section 3 – Your health and wellbeing

51. The next few questions ask about how much having a disabled child impacts upon your way of thinking. Please tick the box that best describes how much you agree or disagree with each statement, when considering your disabled child who uses short breaks.

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
a) Since having this child I have grown as a person	☐	☐	☐	☐	☐
b) Having this child has helped me to learn new things/ skills	☐	☐	☐	☐	☐
c) Raising this child helps putting life into perspective	☐	☐	☐	☐	☐
d) Since having this child, my family has become closer to one another	☐	☐	☐	☐	☐
e) Since having this child I have become more determined to face up to challenges	☐	☐	☐	☐	☐
f) Since having this child I have a greater understanding of other people	☐	☐	☐	☐	☐

You and your friends:

52. In the past week, how often have you spent time with friends? (Please tick one box)

Every day ☐	3-6 times ☐	1-2 times ☐	Not at all ☐	No friends ☐

You and your partner (If you do not have a partner living with you, please move on to question 55)**:**

53. How often do you and your partner disagree over issues concerning your disabled child who uses short breaks? (Please tick one box).

More than once a day	Once a Day	Several times a week	Once a week	Less than once a week	Never	Cannot say
☐	☐	☐	☐	☐	☐	☐

54. Here is a scale from 1 to 7, where ‘1’ means that you are very unhappy and ‘7’ means that you are very happy. Please tick the box which corresponds with how happy or unhappy you are with your relationship, all things considered?

Completely dissatisfied						Completely satisfied
1	**2**	**3**	**4**	**5**	**6**	**7**
☐	☐	☐	☐	☐	☐	☐

Section 4 – Your child

In this section, we would like you to answer some questions about your disabled child who uses short breaks. There will be a section that will ask about other children who live in your household later.

55. Who has the main responsibility for caring for this child? (Please write in)

56. Does this child receive Disability Living Allowance (DLA)? (Please tick one box) Yes ☐ No ☐

57. Does this child have any diagnosed syndromes/ conditions? (Please tick one box and if yes, please write these in the box below). Yes ☐ No ☐

58. Do you feel that this child has any syndromes or conditions that have not been diagnosed? (Please tick one box and if yes, please write these in the box below). Yes ☐ No ☐

59. Is this child currently undergoing assessment for a syndrome or condition? (Please tick one box and if yes, please write these in the box below). Yes ☐ No ☐

Section 4 – Your child

60. Does this child have a learning disability? Yes ☐ No ☐
(Please tick one box)

If yes, what level of disability does this child have? (Please tick one box, if applicable)

Severe/ profound learning disability ☐ Moderate/ mild learning disability ☐ Learning disability (level not known) ☐

61. Please tick the areas in which your child who uses short breaks is affected as a result of his/ her disability. (Please tick all boxes that apply)

Mobility - uses help from a carer moving around inside or outside the home	☐
Mobility - uses equipment for moving around inside or outside the home (e.g. wheelchair, lift,	☐
Hand function – holding and touching	☐
	☐
Eating and drinking – has difficulty eating or drinking by him or herself or sickness or lack of appetite	☐
Medication – has difficulty taking medication or has side effects because of medication he/ she takes	☐
Incontinence – controlling the passage or urine and faeces	☐
	☐
Learning- having special educational needs	☐
	☐
Vision	☐
Behaviour – a condition resulting in the child being hyperactive or having short attention span or getting frustrated or behaving in a socially unacceptable manner	☐
Consciousness – fits and seizures	☐
	☐
Palliative care needs	☐
	☐

If your child is affected in any other way not stated in this question, please write in the box below:

Section 4 – Your child

	Almost constantly	Most of the time	Some of the time	Very little
62. How often does your child need supervision from	☐	☐	☐	☐
63. How often does your child need supervision from 5.00pm to 10.00pm?	☐	☐	☐	☐
	☐	☐	☐	☐

Your child's education (child who uses short breaks)

65. Does this child have a written statement of his/ her special educational needs? (Please tick box). Yes ☐ No ☐

66. Does this child attend...	Yes	No
a. Preschool or nursery	☐	☐
b. School	☐	☐
c. Further Education (6th form or college)	☐	☐

If none, please move onto Q68.

67. Below is a table of statements. Please read them carefully and tick the box that best describes how true (or not true) this is of your child who uses short breaks.

	Very True	Somewhat true	Not at all true
a) My child is progressing well	☐	☐	☐
b) School keeps me informed about my child's progress	☐	☐	☐
c) My child enjoys school	☐	☐	☐
d) School supports me as a parent	☐	☐	☐
e) Staff at the school do not understand my child	☐	☐	☐
f) School is unable to cope with my child	☐	☐	☐
g) School does not meet my child's needs	☐	☐	☐
h) My child has a good attendance record at school	☐	☐	☐

Your child's physical health (child who uses short breaks):

68. How is this child's health in general? Would you say it was...(Please tick one box).

Very good ☐ Good ☐ Fair ☐ Bad ☐ Very bad ☐

69. Other than the things you have already told us about, does this child have any long-standing illness or infirmity? By long-standing I mean anything that has they have had for at least three months or is expected to continue for the next 3 months? (Please tick one box)

Yes ☐ No ☐

If you answered 'No' to question 69 above, please move on question 72.

70. Could you please state these long-standing illnesses? (Please write in the box below).

71. Does this/ do these illnesses limit him/ her from joining in any other activity that is normal for his/ her age? (Please tick one box).

Yes ☐ No ☐

Your child's emotional and behavioural wellbeing (child who uses short breaks)

72. Below is a table of statements, please read them carefully and tick the most appropriate box that best describes how true (or not true) each statement is of your child who uses short breaks.

	Very true	Somewhat true	Not at all true
a) Restless, overactive, cannot stay still for long	☐	☐	☐
b) Constantly fidgeting or squirming	☐	☐	☐
c) Easily distracted, concentration wanders	☐	☐	☐
d) Thinks things out before acting	☐	☐	☐
e) Sees tasks through to the end, good attention span	☐	☐	☐
f) Often complains of headaches, stomach aches, or sickness	☐	☐	☐
g) Many worries, often seems worried	☐	☐	☐
h) Often unhappy, down-hearted or tearful	☐	☐	☐
i) Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
j) Many fears, easily scared	☐	☐	☐
k) Often has temper tantrums or hot tempers	☐	☐	☐
l) Generally obedient, usually does what adults request	☐	☐	☐
m) Often fights with other children or bullies them	☐	☐	☐
n) Often lies or cheats	☐	☐	☐
o) Steals from home, school or elsewhere	☐	☐	☐
p) Rather solitary, tends to play alone	☐	☐	☐
q) Has at least one good friend	☐	☐	☐
r) Generally liked by other children	☐	☐	☐
s) Picked on or bullied by other children	☐	☐	☐
t) Gets on better with adults than with other children	☐	☐	☐
u) Considerate of other people's feelings	☐	☐	☐
v) Shares readily with other children (treats, toys, pencils, etc.)	☐	☐	☐
w) Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
x) Kind to younger children	☐	☐	☐
y) Often volunteers to help others (parents, teachers, other children)	☐	☐	☐

Worries and rewards:

73. Below is a table of statements, please read them carefully and tick the box that best describes how much you agree with each one (in relation to your child who uses short breaks)

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a) I am excited by the prospects for my child's future	☐	☐	☐	☐	☐
b) I am optimistic about my child's adjustment to living outside the home	☐	☐	☐	☐	☐
c) My child will lead a fulfilled life	☐	☐	☐	☐	☐
d) I am optimistic that my child will have adequate social activities in the future	☐	☐	☐	☐	☐
e) I feel pleased that my child's school program will be good preparation for their future life	☐	☐	☐	☐	☐
f) I believe that there are lots of resources available in my child's community	☐	☐	☐	☐	☐
g) I am afraid my child will depend on me forever	☐	☐	☐	☐	☐
h) I worry that my child will never be self-supporting	☐	☐	☐	☐	☐
i) I feel that my child prefers friends over family	☐	☐	☐	☐	☐
j) I feel good because my child enjoys family activities	☐	☐	☐	☐	☐
k) I am sad that my child is missing out on important family interactions	☐	☐	☐	☐	☐

Section 5 – Your other children

In this section, we would like to find out a bit more about the siblings (brothers and sisters) of your child who uses short breaks.

- If this child has no siblings, please move on to ‘Section 6 – Your family’s use of short breaks on page 26.
- If this child has more than one sibling, please refer to the oldest sibling living in your household when answering the following questions.

Which child is this? Please write their first name here (sibling of child who uses short breaks). ☐

His/ her physical health (sibling of child who uses short breaks):

74. How is this child’s health in general? Would you say it was...(Please tick one box).

Very good ☐ Good ☐ Fair ☐ Bad ☐ Very bad ☐

75. Does this child have any long-standing illness, disability or infirmity? By long-standing I mean anything that has they have had for at least three months or is expected to continue for the next 3 months? (Please tick one box)

Yes ☐ No ☐

If you answered ‘No’ to question 75 above, please move on question 78.

76. Could you please state these long-standing illnesses? (Please write in the box below).

☐

77. Does this/ do these illnesses limit him/ her from joining in any other activity that is normal for his/ her age? (Please tick one box).

Yes ☐ No ☐

His/ her education (sibling of child who uses short breaks):

78. Below is a table of statements please read them carefully and tick the box that best describes how true (or not true) each statement is of this child.

	Very true	Somewhat true	Not at all true
a) My child is progressing well	☐	☐	☐
b) School keeps me informed about my child's progress	☐	☐	☐
c) My child enjoys school	☐	☐	☐
d) School supports me as a parent (or carer)	☐	☐	☐
e) Staff at the school do not understand my child	☐	☐	☐
f) School is unable to cope with my child	☐	☐	☐
g) School does not meet my child's needs	☐	☐	☐
h) My child has a good attendance record at school	☐	☐	☐

His/ her emotional and behavioural wellbeing (sibling of child who uses short breaks)
79. Below is a table of statements. Please read them carefully and tick the most appropriate box that best describes how true (or not true) each statement is of this child.

	Very true	Somewhat true	Not at all true
a) Restless, overactive, cannot stay still for long	☐	☐	☐
b) Constantly fidgeting or squirming	☐	☐	☐
c) Easily distracted, concentration wanders	☐	☐	☐
d) Thinks things out before acting	☐	☐	☐
e) Sees tasks through to the end, good attention span	☐	☐	☐
f) Often complains of headaches, stomach aches, or sickness	☐	☐	☐
g) Many worries, often seems worried	☐	☐	☐
h) Often unhappy, down-hearted or tearful	☐	☐	☐
i) Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
j) Many fears, easily scared	☐	☐	☐
k) Often has temper tantrums or hot tempers	☐	☐	☐
l) Generally obedient, usually does what adults request	☐	☐	☐
m) Often fights with other children or bullies them	☐	☐	☐
n) Often lies or cheats	☐	☐	☐
o) Steals from home, school or elsewhere	☐	☐	☐
p) Rather solitary, tends to play alone	☐	☐	☐
q) Has at least one good friend	☐	☐	☐
r) Generally liked by other children	☐	☐	☐
s) Picked on or bullied by other children	☐	☐	☐
t) Gets on better with adults than with other children	☐	☐	☐
u) Considerate of other people's feelings	☐	☐	☐
v) Shares readily with other children (treats, toys, pencils, etc.)	☐	☐	☐
w) Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
x) Kind to younger children	☐	☐	☐
y) Often volunteers to help others (parents, teachers, other children)	☐	☐	☐

Section 5 – Your other children

Relationships between your children:

80. In the following questions, we would like to find out more about how well your child who uses short breaks gets along with the sibling discussed in the previous section. Below is a table of statements looking at various aspects of sibling relationships. Please read them carefully and tick the box that best describes how much you agree with each one.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a) I am bothered that my children do not appreciate each other	☐	☐	☐	☐	☐
b) I worry that my child's siblings may come to resent him/ her	☐	☐	☐	☐	☐
c) I am glad that my children look out for one another	☐	☐	☐	☐	☐
d) I am concerned that my child will rely too heavily on his/her siblings	☐	☐	☐	☐	☐
e) I am pleased that my children seem to have a close relationship	☐	☐	☐	☐	☐
f) I worry that my child will not be able to rely on his/ her siblings	☐	☐	☐	☐	☐
g) I am optimistic that my children will help one another	☐	☐	☐	☐	☐

Section 6 – Your family's use of short breaks

In this section, we would like to find out a bit more about the types of short breaks used by your child, how much this child uses these services and your experiences and views with regards to the breaks.

81. Please choose the statement below that best describes your family's situation (please tick one box):

a) We currently receive short breaks	☐	c) We have never received short breaks but would like to have done	☐
b) We used to receive short breaks but no longer do	☐	d) We have never received short breaks but have never wanted them	☐

If you ticked answers 'c' or 'd' for Q81 above, please now go on to answer Q88 and Q89, and then go on to answer Q95 and all remaining questions after Q95.

Section 6 – Your family's use of short breaks

82. If you use short break services, please tick all that you use. For each service that you use, please tell us how often and for how long on average you use them in terms of per week, per month and number of hours.

Type of short break	Uses	How often and for how long?		Uses	How often and for how long?
A leisure break – Sports and games (e.g. football, swimming, horse riding)	☐			☐	
A leisure break - Arts and crafts	☐		An after school club, school holiday club, extended school or similar	☐	
A morning, afternoon, or evening break away from home with a paid carer (including childminders)	☐		An overnight break away from home with a paid carer (including childminders)	☐	
A morning, afternoon, or evening break away from home with an unpaid friend or family member (e.g. grandparent, aunt/uncle, family friend)	☐		An overnight break away from home with an unpaid friend or family member (e.g. grandparent, aunt/uncle, family friend)	☐	
A morning, afternoon, or evening break away from home in a centre or similar setting	☐		An overnight break away from home in a centre or similar setting	☐	
A morning, afternoon, or evening break in your home with a paid carer	☐		An overnight break in your home with a paid carer	☐	
A morning, afternoon, or evening break in your home with an unpaid friend or family member (e.g. grandparent, aunt/uncle, family friend)	☐		An overnight break in your home with an unpaid friend or family member (e.g. grandparent, aunt/uncle, family friend)	☐	
Other, please specify:					

83. Please tell us about any other short breaks that you use as a whole family, for example whether you get a holiday and for how long? (Please write in the box below)

84. How are your child's short breaks funded? (Please tick all that apply)

Through the health service	☐	Through social services	☐	Combination of health and social services	☐
By direct payments (or similar)	☐	Private arrangement (you pay)	☐	Don't know	☐

Other type of funding (please write in the box below)

85. Do you receive direct payments (or similar) for any other services? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, please state these other services (write in the box below):

86. When thinking about the short breaks your child uses (identified in questions 82 and 83), have you found them suitable for your family? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, in what ways were they suitable? (Please write in the box below).

87. When thinking about the short breaks you child uses (identified in questions 82 and 83), have you found them unsuitable for your family? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, in what ways were they unsuitable? (Please write in the box below):

88. Are you on a waiting list for a short break? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, how long have you been on the waiting list? (Please tick one box)

Less than 3 months	Less than 6 months	Less than a year	A year or more (please specify how long):
☐	☐	☐	☐

89. Have you been turned down, now or in the past for any short break service? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, what reasons were given? (Please write in the box below)

90. Has your child been excluded from a short break service, now or in the past? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, what reasons were given? (Please write in box below)

91. We would now like to find out how satisfied you are with various elements of the short breaks you and your family uses. In the table below, please read each statement carefully, and indicate how satisfied you are with each element by ticking the most appropriate box.

	Very satisfied	Quite satisfied	Not at all satisfied
a) Standard of care the child receives	☐	☐	☐
b) Suitability for the child's needs	☐	☐	☐
c) Suitability of the people who look after your child during short breaks	☐	☐	☐
d) Competence of the people who look after your child during short breaks	☐	☐	☐
e) The level of trust you feel you can place in the people who look after your child during short breaks.	☐	☐	☐
f) Amount of short term care available	☐	☐	☐
g) The range of services/ activities available to your family	☐	☐	☐
h) Flexibility in the services used (i.e. arranging, rearranging, cancelling breaks)	☐	☐	☐
i) The ability to arrange emergency short breaks if/when you need to	☐	☐	☐
j) The extent to which your short break provider listens to your views	☐	☐	☐

92. In what ways (if any) has your child changed/ developed as a direct result of using short breaks? (e.g. socially, learning new skills, levels of confidence and independence, etc)

93. Over the past 12 months, has your family's experience of using short break services improved? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

94. In the box below, please state the ways in which your family's experience of using short break services has improved or not improved:

95. What would improve the short break services available to you and your family? Please write in the box below:

96. Thinking about both adults and children what benefits do you think family members get from using short breaks? (You can draw on your own experience here if you wish).

97. The table below contains a list of services that **your child who uses short breaks** may or may not also use. Please indicate (by ticking all that apply) if they been used within the **last 3 months** and if so please write in how many times during the last 3 months (or your best estimate)

	Used?	How often?		Used?	How often?
	☐		Home teaching, portage, private tutor	☐	
Hospital out-patient	☐		Mainstream school	☐	
	☐		Special school	☐	
Psychiatrist	☐		Special education unit	☐	
	☐		Hospital education service	☐	
Community Psychiatric nurse	☐		Support from special needs teacher	☐	
Community learning disability nurse	☐		Dedicated teaching assistant/ learning support assistant	☐	
Educational Psychologist	☐		Connexions	☐	
Clinical Psychologist	☐		Home adaptations service (e.g. new ramps, lifts)	☐	
Speech Therapist	☐		Community equipment and wheelchair services	☐	
	☐		Advocate	☐	
Occupational therapist	☐		Social worker	☐	
	☐		Volunteer transport scheme	☐	
Alternative/ complementary health practitioner	☐		Childcare and play provision (where you leave your child)	☐	
Children's centre (Sure Start)	☐		Stay and play sessions for all families	☐	
Public transport	☐		Stay and play sessions for families with a disabled child	☐	

The table below contains a list of services that **you** may or may not also use (alone or with your child). Please indicate (by ticking all that apply) if they have been used within the **last 3 months** and if so please write in how many times during the last 3 months (or your best estimate)

	Used?	How often?		Used?	How often?
Job centre	☐		Parenting skills sessions for families with a disabled child (classes, training, etc)	☐	
Parents group for families with a disabled child (e.g. meeting and sharing experiences)	☐		Volunteer supporter (peer supporter, Home-Start volunteer or similar)	☐	
Parenting skills sessions for all families (classes, training, etc)	☐		Other supporter for your family	☐	

98. What other services do you and your family use regularly? (Please write in)

99. Is there anything that you would like to tell us about short breaks or the questionnaire? (Please write in the box below)

End of survey. Thank you for your support.

Extra questions

Please take a moment to answer these extra questions. Many thanks

X1

Thinking about the very first time your child had a short break (of any kind); what type of break was that?

X2

And how long ago was that; would you say it was ...	more than a year ago?	☐
		☐
	between six months and a year ago?	☐
		☐
	in the last three months?	☐

X3

And lastly, would you say that your child has had short breaks fairly regularly since then?	Yes	☐
	No	☐

Form 1b

Additional Carer

Your first name:

Office use only		
Code	Date rec	Proc

Introduction

Thank you for agreeing to help us with this study. Please answer as many questions as you can. This page shows some examples of the types of questions you will find.

Sometimes we ask you to choose an answer by ticking or marking a box like this –

	Very satisfied	Quite satisfied	Not satisfied
How satisfied are you with communications between you and the short break	☐	☑	☐

Sometimes we give you a box and ask you to write in an answer like this –

What is the main difference between the services you use now and the ones you used in the past? (please write in)

As this child has got older she wants to be more active and get out more. At the moment she goes swimming and horse riding but a couple of years ago she wanted to stay at her carer's house and play inside.

Remember there are no 'right' or 'wrong' answers; we are really interested in your thoughts and your opinions.

Before you start, please write your first name on the front of this booklet so we know who has completed this form.

Section 1 - Your thoughts, feelings and emotions

1. This question asks about how much living with a disabled child impacts upon your way of thinking and perceptions. For each statement, please tick the box that best describes how much you agree or disagree with each statement. When answering these questions, please refer to the child in your household who uses short breaks. If there is more than one child in your household, please select the eldest.

	Strongly agree	Agree	Not sure	Disagree	Strongly disagree
a) Since having this child I have grown as a person	☐	☐	☐	☐	☐
b) Having this child has helped me to learn new things/ skills	☐	☐	☐	☐	☐
c) Raising this child helps putting life into perspective	☐	☐	☐	☐	☐
d) Since having this child, my family has become closer to One another	☐	☐	☐	☐	☐
e) Since having this child I have become more determined to	☐	☐	☐	☐	☐
f) Since having this child I have a greater understanding of other people	☐	☐	☐	☐	☐

You and your friends:

2. In the past week, how often have you spent time with friends? (Please tick one box).

Every day ☐ 3-6 times ☐ 1-2 times ☐ Not at all ☐ No friends ☐

You and your partner: (if you do not have a partner please go to question 5)

3. How often do you and your partner disagree over issues concerning your disabled child who uses short breaks? (Please tick one box).

Never	More than once a day	Once a Day	Less than once a week	Once a week	Several times a week	Cannot say
☐	☐	☐	☐	☐	☐	☐

Section 1 - Your thoughts, feelings and emotions

4. Here is a scale from 1 to 7, where ‘1’ means that you are very unhappy and ‘7’ means that you are very happy. Please tick the box which corresponds with how happy or unhappy you are with your relationship, all things considered?

Completely dissatisfied 1	2	3	4	5	6	Completely satisfied 7
☐	☐	☐	☐	☐	☐	☐

Section 2 Your Child

5. Below is a table of statements relating to you and your child’s experiences of his/ her education, please read them carefully and tick the box that best describes how true (or not true) each statement is of your child.

If this child is not currently in education (preschool/ nursery, school, further education) please move on to question 6.

	Very true	Somewhat true	Not at all true
a) My child is progressing well	☐	☐	☐
b) School keeps me informed about my child’s progress	☐	☐	☐
c) My child enjoys school	☐	☐	☐
d) School supports me as a parent (or carer)	☐	☐	☐
e) Staff at the school do not understand my child	☐	☐	☐
f) School is unable to cope with my child	☐	☐	☐
g) School does not meet my child’s needs	☐	☐	☐
h) My child has a good attendance record at school	☐	☐	☐

Section 3 - Your worries and rewards

6. Below is a table of statements, please read them carefully and tick the box that best describes how much you agree with each one (in relation to your child who uses short breaks)

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a) I am excited by the prospects for my child's	☐	☐	☐	☐	☐
b) I am optimistic about my child's adjustment to living outside the home	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐
d) I am optimistic that my child will have adequate social activities in the future	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐
f) I believe that there are lots of resources available in my child's community	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐
h) I worry that my child will never be self-supporting	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐
j) I feel good because my child enjoys family activities	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐

Section 4 - Relationships between your children

7. In the following question, we would like to find out more about how well your disabled child who uses short breaks gets along with his/ her siblings (brothers or sisters). Below is a table of statements looking at various aspects of relationships, please read them carefully and tick the box that best describes how much you agree with each one.

If this child does not have any siblings, please move on to question 8.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a) I am bothered that my children do not	☐	☐	☐	☐	☐
b) I worry that my child's siblings may come to resent him/ her	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐
d) I am concerned that my child will rely too heavily on his/her siblings	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐
f) I worry that my child will not be able to rely on his/ her siblings	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐

Section 5 - Your family’s experience with short breaks

In this section, we would like to find out about your experiences and views with regards to the short breaks your child uses. If this child does not use any short breaks, please go on to answer Q14 and complete all remaining questions after Q14.

8. When thinking about the short breaks your child uses, have you found them suitable for your family? (Please tick one box)

Yes ☐ No ☐ Don’t know ☐

If yes, in what ways were they suitable? (Please state in the box below)

9. When thinking about the short breaks your child uses, have you found them unsuitable for your family? (Please tick one box)

Yes ☐ No ☐ Don’t know ☐

If yes, in what ways were they unsuitable? (Please write in the box below):

Section 5 - Your family's experience with short breaks

10. We would now like to find out how satisfied you are with various elements of the short breaks you and your family use. In the table below, please read each statement carefully, and indicate how satisfied you are with each element by ticking the most appropriate box.

	Very satisfied	Quite satisfied	Not at all satisfied
a) Standard of care the child receives	☐	☐	☐
b) Suitability for the child's needs	☐	☐	☐
	☐	☐	☐
d) Competence of the people who look after your child during short breaks	☐	☐	☐
	☐	☐	☐
f) Amount of short term care available	☐	☐	☐
	☐	☐	☐
h) Flexibility in the services used (i.e. arranging, rearranging, cancelling breaks)/ ability to fit breaks around lifestyle	☐	☐	☐
	☐	☐	☐
j) The extent to which your short break provider listens to your views.	☐	☐	☐

11. In what ways (if any) has your child changed/ developed as a direct result of using short breaks? (e.g. socially, learning new skills, levels of confidence and independence, etc)

Section 5 - Your family's experience with short breaks

12. Over the past 12 months, has your family's experience of using short break services improved?

Yes ☐ No ☐ Don't know ☐

13. In the box below, please state the ways in which your family's experience of using short break services has improved or not improved:

14. What would improve the short break services available to you and your family? Please write in the box below:

15. Thinking about both adults and children what benefits do you think family members get from using short breaks? (You can draw on your own experience here if you wish).

16. Is there anything that you would like to tell us about short breaks or the questionnaire? (Please write in the box below)

End of survey. Thank you for your support.

Form 2

Child or young person using short breaks

Your first name

Office use only		
Code	Date rec	Proc

Introduction

Thank you for agreeing to help us with this study. Please answer as many questions as you can.

Sometimes we ask you to choose an answer by ticking or marking a box like this -

	Hardly at all	Not much	Somewhat	Very much	Extremely much
How much do you like visiting friends' houses?	☐	☐	☑	☐	☐

Sometimes we give you a box and ask you to write in an answer like this -

What did you enjoy doing today? (please write in)

Going on a very long bike ride with my friends.

Remember we are interested in YOUR thoughts and YOUR answers, but you can get someone to help you read the form or help you fill it in.

Before you start please write your first name in the box on the front of the booklet so we know who has completed this form.

	Hardly at all	Not much	Somewhat	Very much	Extremely much
Some sisters and brothers do nice things f a o t	☐	☐	☐	☐	☐
How much does your brother/sister do nice things for you?	☐	☐	☐	☐	☐
Some sisters and brothers care about each other a lot, while other sisters and brothers don't care about each other that much. How much do you care about your brother/sister?	☐	☐	☐	☐	☐
How much does your brother/sister care about you?	☐	☐	☐	☐	☐
How much do you and your brother/sister get cross and argue with each other?	☐	☐	☐	☐	☐
How much do you and your brother/sister go places and do things together?	☐	☐	☐	☐	☐

	Me	We get about the same	Brother/sister
Who usually gets more attention from your parents, you or your brother or sister?	☐	☐	☐

	Hardly at all	Not much	Somewhat	Very much	Extremely much
How much do you and your friends go	☐	☐	☐	☐	☐
Some friends care about each other a lot, while some friends don't care about each other that much. How much do you care about your friends?	☐	☐	☐	☐	☐
How much do your friends care about	☐	☐	☐	☐	☐
Some friends do nice things for each other a lot, while some friends do nice things for each other a little. How much do you do nice things for your friends?	☐	☐	☐	☐	☐
How much do your friends do nice things	☐	☐	☐	☐	☐
How much do you and your friends get cross and argue with each other?	☐	☐	☐	☐	☐

	Like all	Like most	Like some	Like none	Don't know	Don't go to school
How do you feel about the time you spend at school?	☐	☐	☐	☐	☐	☐
How do you feel about your teachers?	☐	☐	☐	☐	☐	☐

	Very slightly or not at all	A little	Moderately (so-so)	Quite a bit	Extremely
Over the past few weeks how much have you felt proud (of yourself)?	☐	☐	☐	☐	☐
Over the past few weeks how much have you felt strong?	☐	☐	☐	☐	☐
Over the past few weeks how much have you felt excited?	☐	☐	☐	☐	☐
Over the past few weeks how much have you felt interested (in something)?	☐	☐	☐	☐	☐

Section 2 – Your school and your feelings

What was the last short break you had? (please write in)

	Enjoyed it a lot	Enjoyed it a little	Did not enjoy it at all
How much did you enjoy the last short break you had?	☐	☐	☐

Are there things you liked about your last short break? (please tell us about these things)

Section 2 – Your school and your feelings

Are there things you did not like about your last short break? (please tell us about these things)

Are there things you did not like about those short breaks? (please tell us about these things)

What other short breaks have you had? (please write in)

	Enjoy it a lot	Enjoyed it a little	Did not enjoy it at all
How much did you enjoy those short breaks?	☐	☐	☐

Are there things you liked about those short breaks? (please tell us about these things)

Section 2 – Your school and your feelings

	Lots more	A few more	About the same	A few less	Lots less
Would you like to have more or less short breaks than you do now?	☐	☐	☐	☐	☐

What would you like your next short break to be like? (please write in)

	YES	NO
Has having short breaks helped you to try new things (e.g. new activities)?	☐	☐
Has having short breaks helped you to make new friends?	☐	☐

	No help	A little help	Lots of help
How much help did you have with this form?	☐	☐	☐

Thank you for your time and help with this study

Form 3

Sister or brother of a child or young person using short breaks

Your first name

Office use only		
Code	Date reg.	Proc.

Introduction

Thank you for agreeing to help us with this study. Please answer as many questions as you can.

Sometimes we ask you to choose an answer by ticking or marking a box like this -

	Hardly at all	Not much	Somewhat	Very much	Extremely much
How much do you like visiting friends' houses?	☐	☐	☑	☐	☐

Sometimes we give you a box and ask you to write in an answer like this -

What did you enjoy doing today? (please write in)

Going on a very long bike ride with my friends.

Remember we are interested in YOUR thoughts and YOUR answers, but you can get someone to help you read the form or help you fill it in.

Before you start please write your first name in the box on the front of the booklet so we know who has completed this form.

Section 1 – Your brothers, sisters, and your friends

Thinking about your brother or sister who uses short breaks	Hardly at all	Not much	Somewhat	Very much	Extremely much
Some sisters and brothers do nice things	☐	☐	☐	☐	☐
How much does your brother/sister do nice things for you?	☐	☐	☐	☐	☐
Some sisters and brothers care about	☐	☐	☐	☐	☐
How much does your brother/sister care about you?	☐	☐	☐	☐	☐
How much do you and your brother/sister	☐	☐	☐	☐	☐
How much do you and your brother/ sister go places and do things together?	☐	☐	☐	☐	☐

	Me	We get about the same	Brother / sister
Who usually gets more attention from your	☐	☐	☐

Section 1 – Your brothers, sisters, and your friends

	Hardly at all	Not much	Somewhat	Very much	Extremely much
How much do you and your friends go	☐	☐	☐	☐	☐
Some friends care about each other a lot, while some friends don't care about each other that much. How much do you care about your friends?	☐	☐	☐	☐	☐
How much do your friends care about	☐	☐	☐	☐	☐
Some friends do nice things for each other a lot, while some friends do nice things for each other a little. How much do you do nice things for your friends?	☐	☐	☐	☐	☐
How much do your friends do nice things	☐	☐	☐	☐	☐
How much do you and your friends get cross and argue with each other?	☐	☐	☐	☐	☐

Section 2 – Your school and your feelings

	Like all	Like most	Like some	Like none	Don't know	Don't go to school
How do you feel about the time you spend at school?	☐	☐	☐	☐	☐	☐
How do you feel about your teachers?	☐	☐	☐	☐	☐	☐

	Very slightly or not at all	A little	Moderately (so-so)	Quite a bit	Extremely
Over the past few weeks how much have you felt proud (of yourself)?	☐	☐	☐	☐	☐
Over the past few weeks how much have you felt strong?	☐	☐	☐	☐	☐
Over the past few weeks how much have you felt excited?	☐	☐	☐	☐	☐
Over the past few weeks how much have you felt interested (in something)?	☐	☐	☐	☐	☐

Section 2 – Your school and your feelings

	YES	NO
Do you help to look after your brother or sister?	☐	☐

What types of short break does your brother/sister have? (please write in)

[If more than one type] Which type of short break is best in your opinion? (please write in)

Are there things you like about your brother or sister having short breaks? (please tell us about these things)

Are there things do you not like about your brother or sister having short breaks? (please tell us about these things)

What benefits do you get out of your brother or sister having short breaks? (please write in)

	YES	NO
When your brother/sister has a short break do you get to try	☐	☐
When your brother/sister has a short break do you get to make new friends?	☐	☐
When your brother/sister has a short break do you get more	☐	☐
When your brother/sister has a short break do you get to spend more time with your parents?	☐	☐

What would you like your brother or sister's next short break to be like? (please write in)

	Lots more	A few more	About the same	A few less	Lots less
Would you like your brother/sister to have	☐	☐	☐	☐	☐

	No help	A little help	Lots of help
How much help did you have with this form?	☐	☐	☐

Thank you for your time and help with this study.

Family Experiences Survey

Your first name:

Office use only		
Code	Date reg.	Proc.

Introduction

Thank you for agreeing to help us with this study. Please answer as many questions as you can. This page shows some examples of the types of questions you will find.

Sometimes we ask you to choose an answer by ticking or marking a box like this -

	Very satisfied	Quite satisfied	Not satisfied
How satisfied are you with communications between you and the short break provider?	☐	☑	☐

Sometimes we give you a box and ask you to write in an answer like this -

What is the main difference between the services you use now and the ones you used in the past? (please write in)

As my daughter has got older she wants to be more active and get out more. At the moment she goes swimming and horse riding but a couple of years ago she wanted to stay at her carer's house and play inside.

Remember there are no 'right' or 'wrong' answers; we are really interested in your thoughts and your opinions.

Before you start, please write your first name on the front cover so that we know who has completed this form.

Section 1 – Your household

In this section, we would like to find out a little bit about yourself, the disabled child who uses short breaks, and the other members of your household.

1. Counting all adults and children how many people live in your household? ☐

2. What is your gender? (Please tick one box) Male ☐ Female ☐

3. What is your date of birth? (Please write in) ☐

4. What is the first name of the disabled child in your household who uses short breaks? If there is more than one child in your household who uses short breaks, please select the eldest. ☐

5. What is his/her gender? (Please tick one box) Male ☐ Female ☐

6. What is his/her date of birth? (Please write in) ☐

7. What is your relationship to this child? (Please tick one box)

Natural parent	☐	Step parent	☐
Adoptive parent	☐	Foster parent	☐
Other (please specify)			

Section 1 – Your household

8. Apart from yourself, how many other adults (18 years or older) live in your home as regular members of your household? (Please write in)

9. Apart from the child using short breaks identified in question 4, how many other children (under the age of 18) live in your home as regular members of your household? (Please write in)

10. What is your current marital status? (Please tick one box)

Legally separated	☐	Married, 1st and only marriage	☐	Remarried, 2nd or later marriage	☐
Single, never married	☐	Divorced	☐	Widowed	☐

11. Are you living with someone in your household as a couple? (Please tick one box) Yes ☐ No ☐

12. Do you consider yourself to be a lone parent? (Please tick one box) Yes ☐ No ☐

13. Do you have any other disabled children living with you? Yes ☐ No ☐

If yes, please state how many:

14. What is your ethnic group? Please choose one section and then tick the box which best describes your ethnic group.

A. White:		**C. Asian/ Asian British:**	
British	☐	Indian	☐
Irish	☐	Pakistani	☐
	☐		☐
B. Mixed/ multiple ethnic groups:		Any other Asian/ Asian British background: Please state:	☐
	☐	**ribbean/ Black British:**	
White and Black African	☐	African	☐
White and Asian	☐	Caribbean	☐
Any other mixed/ multiple ethnic groups background Please state:	☐	Any other Black/ African/ Caribbean background: Please state:	☐
		hnic group	
			☐
			☐

Section 1 – Your household

15. Is English the language usually spoken at home? (Please tick one box)

Yes - English only ☐	Yes - English and other language ☐	No - Other languages only ☐

16. If applicable, which other languages are spoken at home? (Please tick as many as apply)

Welsh ☐	Gaelic ☐	Urdu ☐	Punjabi ☐
Guajarati ☐	Hindi ☐	Bengali ☐	Sylheti ☐
Cantonese ☐	Somali ☐	Tamil ☐	Other, please state: ☐

Section 2 – About you

Your education:

17. Please can you tell us, do you have any of the following qualifications? (Tick as many as apply)

Higher degree ☐	First degree ☐	Diplomas in Higher Education ☐
A/AS Levels ☐	O-Level/ GCSE Grades A-C ☐	GCSE Grades D-G ☐
Other academic qualifications ☐	Professional qualification at degree level ☐	Nursing or other medical qualifications ☐
NVQ/ SVQ/ GSVQ Level 3 ☐	NVQ/ SVQ/ GSVQ Level 2 ☐	☐
Trade apprenticeships ☐	Other vocational Qualifications ☐	None of these ☐

18. Do problems with reading, writing, or maths make it difficult for you to manage day-to-day activities, like paying bills, writing letters, etc? (Please tick one box)

Yes ☐ No ☐

Section 2 – About you

Your employment:

19. Which of these best describes you? (Please tick one box):

Looking after family full-time	☐	Working part-time	☐	Working full-time	☐
On government training scheme	☐	Looking for work	☐	Other, please state:	☐

20. What is your present or last occupation? (Please write in) ☐

Your partner's employment (If you do not have a partner living with you, please move on to question 23)**:**

21. Which of these best describes your partner? (Please tick one box):

Looking after family full-time	☐	Working part-time	☐	Working full-time	☐
On government training scheme	☐	Looking for work	☐	Other, please state:	☐

22. What is your present or last occupation? (Please write in) ☐

23. How often would you say you have been worried about money during the last few weeks? (Please tick one box)

Almost all the time	☐	Quite often	☐	Only sometimes	☐	Never	☐

24. Taking everything together, which of these phrases best describes how you and your family are managing financially these days? (Please tick one box).

Manage very well	☐	Manage quite well	☐	Get by alright	☐
Don't manage very well	☐	Have some financial difficulty	☐	In deep financial trouble	☐

Your Wellbeing and Health:

25. How is your health in general? Would you say it was... (Please tick one box).

Very good ☐ Good ☐ Fair ☐ Bad ☐ Very bad ☐

26. Do you have any long-standing illness, disability or infirmity? By long-standing we mean anything that has troubled you for at least 3 months, or is expected to continue for the next 3 months? (Please tick one box)

Yes ☐ No ☐ If you answered 'No' please move on to question 29.

27. Could you please state these long-standing illnesses? (Please write in the box below).

28. Does this illness or disability/ do any of these illnesses or disabilities limit your activities in any way? (Please tick one box).

Yes ☐ No ☐

29. The following questions ask about how you have been feeling during the **past 30 days.** For each question, please tick the box that best describes how often you had this feeling.

During the past 30 days, how often did you feel...	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) ...nervous?	☐	☐	☐	☐	☐
b) ...hopeless?	☐	☐	☐	☐	☐
c) ...restless or fidgety?	☐	☐	☐	☐	☐
d) ...so depressed that nothing could cheer you up?	☐	☐	☐	☐	☐
e) ...that everything was an effort?	☐	☐	☐	☐	☐

f) ...worthless?	☐	☐	☐	☐	☐

30. The last six questions asked about feelings that might have occurred during the past 30 days. Taking them altogether, did these feelings occur <u>more often</u> in the past 30 days than is usual for you, <u>about the same</u> as usual, or <u>less often</u> than usual? (Please tick one box).

More often than usual			About the same as usual	Less often than usual		
A lot	Some	A little		A little	Some	A lot
☐	☐	☐	☐	☐	☐	☐

31. During the past 30 days, how many days were you totally unable to work or carry out your normal activities because of these feelings? (Please write in)

32. Not counting the responses in the question above, how many days in the past 30 days were you able to do only half or less of what you would normally have been able to do because of these feelings? (Please write in)

33. During the past 30 days, how many times did you see a doctor or other health professional about these feelings? (Please write in)

34. During the past 30 days, how often have physical health problems been the main cause of these feelings? (Please write in)

35. Here is a scale from 1 to 10 where ‘1’ means that you are completely dissatisfied and ‘10’ means that you are completely satisfied. Please tick the box which corresponds with how satisfied or dissatisfied you are about the way your life has turned out so far

Completely dissatisfied									Completely satisfied
1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Section 3 – About your child

In this section, we would like you to answer some questions about your disabled child who uses short breaks. There will be a section that will account for other children who live in your household later.

36. Who has the main responsibility for caring for this child? (Please write in) ☐

37. Does this child receive Disability Living Allowance (DLA)? (Please tick one box) Yes ☐ No ☐

38. Does this child have any diagnosed syndromes/ conditions? (Please write these in the box below). Yes ☐ No ☐

☐

39. Does this child have a learning disability? (Please tick one box) Yes ☐ No ☐

If yes, what level of disability does this child have? (Please tick one box, if applicable)

Severe/ profound learning disability ☐ Moderate/ mild learning disability ☐ Learning disability (level not known) ☐

Your child's physical health:

40. How is this child's health in general? Would you say it was... (Please tick one box).

Very good ☐ Good ☐ Fair ☐ Bad ☐ Very bad ☐

41. Please state the areas in which this is affected as a result of his/ her disability. (Please tick all boxes that apply).

Mobility - uses help from a carer moving around inside or outside the home	☐
Mobility - uses equipment for moving around inside or outside the home (e.g. wheelchair, lift, hoist etc)	☐
Hand function – Holding and touching	☐
Personal care – washing, going to the toilet, dressing, etc.	☐
Eating and drinking – has difficulty eating or drinking by him or herself or sickness or lack of appetite	☐
Medication – has difficulty taking medication or has side effects because of medication he/ she takes	☐
Incontinence – controlling the passage or urine and faeces	☐
Communication – speaking and/ or understanding others	☐
Learning- having special educational needs	☐
Hearing	☐
Vision	☐
Behaviour – a condition resulting in the child being hyperactive or having short attention span or getting frustrated or behaving in a socially unacceptable manner	☐
Consciousness – fits and seizures	☐
Diagnosed with Autism, Asperger Syndrome or Autistic Spectrum Disorder (ASD)	☐
Palliative care needs	☐
Depression	☐

	Almost constantly	Most of the time	Some of the time	Very little
42. How often does your child need supervision from	☐	☐	☐	☐
43. How often does your child need supervision from 5.00pm to 10.00pm?	☐	☐	☐	☐
	☐	☐	☐	☐

Your child's emotional and behavioural wellbeing

45. Below is a table of statements, please read them carefully and tick the most appropriate box that best describes how true (or not true) each statement is of your child who uses short breaks.

	Very true	Somewhat true	Not at all true
a) Restless, overactive, cannot stay still for long	☐	☐	☐
b) Constantly fidgeting or squirming	☐	☐	☐
c) Easily distracted, concentration wanders	☐	☐	☐
d) Thinks things out before acting	☐	☐	☐
e) Sees tasks through to the end, good attention span	☐	☐	☐
f) Often complains of headaches, stomach aches, or sickness	☐	☐	☐
g) Many worries, often seems worried	☐	☐	☐
h) Often unhappy, down-hearted or tearful	☐	☐	☐
i) Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
j) Many fears, easily scared	☐	☐	☐
k) Often has temper tantrums or hot tempers	☐	☐	☐
l) Generally obedient, usually does what adults request	☐	☐	☐
m) Often fights with other children or bullies them	☐	☐	☐
n) Often lies or cheats	☐	☐	☐
o) Steals from home, school or elsewhere	☐	☐	☐
p) Rather solitary, tends to play alone	☐	☐	☐
q) Has at least one good friend	☐	☐	☐
r) Generally liked by other children	☐	☐	☐
s) Picked on or bullied by other children	☐	☐	☐
t) Gets on better with adults than with other children	☐	☐	☐
u) Considerate of other people's feelings	☐	☐	☐
v) Shares readily with other children (treats, toys, pencils, etc.)	☐	☐	☐
w) Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
x) Kind to younger children	☐	☐	☐
y) Often volunteers to help others (parents, teachers, other children)	☐	☐	☐

Section 4 – About your other children

We would now like to find out about the siblings (brothers or sisters) of your child who uses short breaks.

- If this child has no siblings, please move on to Q48.
- If this child has more than one sibling, please refer to the oldest sibling living in your household when answering the following questions.

His/ her physical health:

46. How is this child's health in general? Would you say it was... (Please tick one box).

Very good ☐ Good ☐ Fair ☐ Bad ☐ Very bad ☐

47. In the following questions, we would like to find out more about how well your child who uses short breaks gets along with the sibling discussed above. Below is a table of statements looking at various aspects of sibling relationships, please read them carefully and tick the box that best describes how much you agree with each one.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a) I am bothered that my children do not	☐	☐	☐	☐	☐
b) I worry that my child's siblings may come to resent him/ her	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐
d) I am concerned that my child will rely too heavily on his/her siblings	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐
f) I worry that my child will not be able to rely on his/ her siblings	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐

Section 5 – About your family's use and experience of short breaks

In this section, we would like to find out a bit more about the types of short breaks used by your child, how much this child uses these services, and your experiences and views with regards to these short breaks

48. Please choose the statement below that best describes your family's situation (please tick one box):

a) We currently receive short breaks	☐	c) We have never received short breaks but would like to have done	☐
	☐	d) We have never received short breaks but have never wanted them	☐

If you answered 'c' or 'd' to Q 48 above, please move on to answer Q55 and 56, and then go on to answer Q62 and all remaining questions after Q62.

49. If you use short break services, please tick all that you use. For each service, please tell us how often and for how long on average you use them per week, or per month and the number of hours.

Type of short break	Uses	How often and for how long?	Type of short break	Uses	How often and for how long?
A leisure break – Sports	☐		A leisure break – Play schemes and similar activities	☐	
A leisure break - Arts and crafts	☐		An after school club, school holiday club, extended school or similar	☐	
A morning, afternoon, or	☐		An overnight break away from home with a paid carer (including childminders)	☐	
A morning, afternoon, or evening break away from home with an unpaid friend or family member (e.g. grandparent, aunt/uncle, family friend)	☐		An overnight break away from home with an unpaid friend or family member (e.g. grandparent, aunt/uncle, family friend)	☐	
A morning, afternoon, or	☐		An overnight break away from home in a centre or similar setting	☐	
A morning, afternoon, or evening break in your home with a paid carer	☐		An overnight break in your home with a paid carer	☐	
A morning, afternoon, or	☐		An overnight break in your home with an unpaid friend or family member (e.g. grandparent, aunt/uncle, family friend)	☐	
Other, please specify:					

50. Please tell us about any other short breaks that you use as a whole family, for example whether

you get a holiday and for how long? (Please write in the box below)

51. How are your child's short breaks funded? (Please tick all that apply)

Through the health service	☐	Through social services	☐	Combination of health and social services	☐
By direct payments (or similar)	☐	Private arrangement (you pay)	☐	Don't know	☐

Other type of funding (please write in the box below)

52. Do you receive direct payments (or similar) for any other services? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, please state these other services (write in the box below):

Section 5 – About your family’s use and experience of short breaks

53. When thinking about the short breaks you use, have you found them suitable for your family? (Please tick one box)

Yes ☐ No ☐ Don’t know ☐

If yes, in what ways were they suitable? (Please write in the box below).

54. When thinking about the short breaks you use, have you found them unsuitable for your family? (Please tick one box)

Yes ☐ No ☐ Don’t know ☐

If yes, in what ways were they unsuitable? (Please write in the box below).

Section 5 – About your family's use and experience of short breaks

55. Are you on a waiting list for a short break? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, how long have you been on the waiting list? (Please tick one box)

Less than 3 months	Less than 6 months	Less than a year	A year or more (please specify how long):
☐	☐	☐	☐

56. Have you been turned down, now or in the past for any short break service? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, what reasons were given? (Please write in the box below)

Section 5 – About your family's use and experience of short breaks

57. Has your child been excluded from a short break service, now or in the past? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

If yes, what reasons were given? (Please write in box below)

58. In what ways (if any) has your child changed/ developed as a direct result of using short breaks? (E.g. socially, learning new skills, levels of confidence and independence, etc)

Section 5 – About your family's use and experience of short breaks

59. We would now like to find out how satisfied you are with various elements of the short breaks you and your family uses. In the table below, please read each statement carefully, and indicate how satisfied you are with each element by ticking the most appropriate box.

	Very satisfied	Quite satisfied	Not at all satisfied
a) Standard of care the child receives	☐	☐	☐
b) Suitability for the child's needs	☐	☐	☐
c) Suitability of the people who look after your child during short breaks	☐	☐	☐
d) Competence of the people who look after your child during short breaks	☐	☐	☐
e) The level of trust you feel you can place in the people who look after your child during short breaks.	☐	☐	☐
f) Amount of short term care available	☐	☐	☐
g) The range of services/ activities available to your family	☐	☐	☐
h) Flexibility in the services used (i.e. arranging, rearranging, cancelling breaks)/ ability to fit breaks around lifestyle	☐	☐	☐
i) The ability to arrange emergency short breaks when you need to	☐	☐	☐
j) The extent to which your short break provider listens to your views.	☐	☐	☐

60. Over the past 12 months, has your family's experience of using short break services improved? (Please tick one box)

Yes ☐ No ☐ Don't know ☐

Section 5 – About your family's use and experience of short breaks

61. In the box below, please state the ways in which your family's experience of using short break services has improved or not improved:

62. What would improve the short break services available to you and your family? Please write in the box below:

63. Thinking about both adults and children what benefits do you think family members get from using short breaks? (You can draw on your own experience here if you wish).

Section 5 – About your family's use and experience of short breaks

Other services you might use:

64. The table below contains a list of services that **your child who uses short breaks** may or may not also use. Please indicate (by ticking all that apply) if they been used within the **last 3 months** and if so please write in **how many times during the last 3 months** (or your best estimate)

	Used?	How often?		Used?	How often?
	☐		Home teaching, portage, private tutor	☐	
Hospital out-patient	☐		Mainstream school	☐	
	☐		Special school	☐	
Psychiatrist	☐		Special education unit	☐	
	☐		Hospital education service	☐	
Community Psychiatric nurse	☐		Support from special needs teacher	☐	
Community learning disability nurse	☐		Dedicated teaching assistant/ learning support assistant	☐	
Educational Psychologist	☐		Connexions	☐	
Clinical Psychologist	☐		Home adaptations service (e.g. new ramps, lifts)	☐	
Speech Therapist	☐		Community equipment and wheelchair services	☐	
	☐		Advocate	☐	
Occupational therapist	☐		Social worker	☐	
	☐		Volunteer transport scheme	☐	
Alternative/ complementary health practitioner	☐		Childcare and play provision (where you leave your child)	☐	
Children's centre (Sure Start)	☐		Stay and play sessions for all families	☐	
Public transport	☐		Stay and play sessions for families with a disabled child	☐	

The table below contains a list of services that **you** may or may not also use (alone or with your child). Please indicate (by ticking all that apply) if they have been used within the **last 3 months** and if so please write in **how many times during the last 3 months** (or your best estimate)

	Used?	How often?		Used?	How often?
Job centre	☐		Parenting skills sessions for families with a disabled child (classes, training, etc)	☐	
Parents group for families with a disabled child (e.g. meeting and sharing experiences)	☐		Volunteer supporter (peer supporter, Home-Start volunteer or similar)	☐	

Parenting skills sessions for all families (classes, training, etc)	☐		Other supporter for your family	☐	

65. Is there anything that you would like to tell us about short breaks or the questionnaire? (Please write in the box below)

End of survey. Thank you for your support.

12.3 Appendix C – Summary of univariate statistics

Appendix C: Summary of univariate statistics

Table C1: Factors associated with short break usage and funding: univariate associations

Child, carer and household factors associated with short break usage	Dimensions of short break usage	Dimensions of carer satisfaction with short breaks and carer/child outcomes associated with short break usage
General indicators of short break usage		
Child characteristics: Target Group B** Target Group D* Target Group E** TDC Priority Group B* In more Target Groups A-E** Severe/profound learning disability** Child lower SDQ emotional symptoms* Child lower SDQ prosocial behaviour* Child needs more supervision 6am-5pm** Child needs more supervision 5pm-10pm** **Carer characteristics:** **Household characteristics:** Fewer debt problems**	**Total hours of short breaks used**	**Main carer short break experience/satisfaction:** Short breaks improved in last 12 months** Satisfaction: standard of care** Satisfaction: suitability for child** Satisfaction: amount of short breaks** Satisfaction: range of short breaks** Satisfaction: flexibility of short breaks** Satisfaction: emergencies** Satisfaction: providers listen* Satisfaction: short breaks overall* **Main carer outcomes:** **Disabled child outcomes:** Lower SDQ emotional symptoms* Lower SDQ prosocial behaviour*

Child, carer and household factors associated with short break usage	Dimensions of short break usage	Dimensions of carer satisfaction with short breaks and carer/child outcomes associated with short break usage
Child characteristics: **Carer characteristics:** Main carer higher level of education* **Household characteristics:** Fewer money worries** Less hardship – items for disabled child*	**Total number of types of short breaks used**	**Main carer short break experience/satisfaction:** Satisfaction: standard of care** Satisfaction: trust** Satisfaction: suitability for child* Satisfaction: suitability of carers* Satisfaction: range of short breaks* Satisfaction: providers listen* Satisfaction: short breaks overall* **Main carer outcomes:** **Disabled child outcomes:** Use a wider range of other child services*
Child characteristics: Child higher SDQ peer problems** **Carer characteristics:** Main carer higher level of education* **Household characteristics:** Less deprived neighbourhood CWI H&D*	**Family ever turned down for short break for disabled child**	**Main carer short break experience/satisfaction:** **Main carer outcomes:** **Disabled child outcomes:** Poorer relationships with siblings**
Child characteristics: Target Group B* TDC Priority Group B* In more Target Groups A-E* Child higher SDQ conduct problems** Child needs more supervision 5pm-10pm* **Carer characteristics:** **Household characteristics:**	**Disabled child ever excluded from a short break**	**Main carer short break experience/satisfaction:** **Main carer outcomes:** **Disabled child outcomes:** Higher SDQ emotional symptoms** Child progressing less well at school** Poorer relationships with siblings*

Child, carer and household factors associated with short break usage	Dimensions of short break usage	Dimensions of carer satisfaction with short breaks and carer/child outcomes associated with short break usage
Child characteristics: Age 8-10, 14-16* Older child* In more Target Groups A-E* Severe/profound learning disability* **Carer characteristics:** Older main carer** Main carer higher level of education* **Household characteristics:** Less deprived neighbourhood - CWI H&D*	**Uses short breaks funded by local authority**	**Main carer short break experience/satisfaction:** **Main carer outcomes:** Use narrower range of health/welfare services for adults* **Disabled child outcomes:** Use a wider range of other child services*
Child characteristics: Age <5, 5-7* Younger child* Not Target Group E* **Carer characteristics:** Female main carer** White British main carer** Main carer higher level of education* **Household characteristics:** Less deprived neighbourhood – CWI M*	**Uses short breaks funded via direct payments**	**Main carer short break experience/satisfaction:** Short breaks improved in last 12 months* **Main carer outcomes:** **Disabled child outcomes:** Use a wider range of other child services*

Child, carer and household factors associated with short break usage	Dimensions of short break usage	Dimensions of carer satisfaction with short breaks and carer/child outcomes associated with short break usage
Child characteristics: Age 8-10, 17-19* TDC Priority Group B* **Carer characteristics:** Female main carer* Older main carer* Main carer higher level of education* **Household characteristics:** Carer and partner living in household* Fewer money worries* Less deprived neighbourhood – CWI* Less deprived neighbourhood – CWI M* Less deprived neighbourhood – CWI H&D** Less deprived neighbourhood – IMD**	**Uses short breaks funded from a wider range of funding sources**	**Main carer short break experience/satisfaction:** **Main carer outcomes:** **Disabled child outcomes:** Use a wider range of other child services**
Usage of specific types of short break support		
Child characteristics: Target Group A Not Target Group B* TDC Priority Group A** Not TDC Priority Group B* Child higher SDQ total difficulties* Child higher SDQ peer problems* **Carer characteristics:** **Household characteristics:**	**Uses leisure short breaks**	**Main carer short break experience/satisfaction:** Short breaks improved in last 12 months* Satisfaction: range of short breaks* **Main carer outcomes:** **Disabled child outcomes:** Higher SDQ total difficulties* Poorer relationships with siblings**
Child characteristics: Aged 8-10** Main carer not long-standing illness/disability* **Carer characteristics:** Not carer and partner living in household* Lone parent household** **Household characteristics:**	**Number of hours of leisure short breaks used**	**Main carer short break experience/satisfaction:** **Main carer outcomes:** **Disabled child outcomes:**

Child, carer and household factors associated with short break usage	**Dimensions of short break usage**	**Dimensions of carer satisfaction with short breaks and carer/child outcomes associated with short break usage**
Child characteristics: **Carer characteristics:** **Household characteristics:** Fewer money worries*	**Uses unpaid carers for short breaks**	**Main carer short break experience/satisfaction:** Disabled child previously excluded* **Main carer outcomes:** **Disabled child outcomes:**
Child characteristics: **Carer characteristics:** **Household characteristics:**	**Number of hours of unpaid carer short breaks used**	**Main carer short break experience/satisfaction:** **Main carer outcomes:** **Disabled child outcomes:**
Child characteristics: Girls** Age 14-16, 17-19** Target Group B* Target Group C** Target Group E** TDC Priority Group B** In more Target Groups A-E** Severe/profound learning disability** Child lower SDQ emotional symptoms* **Carer characteristics:** Main carer lower level of education* **Household characteristics:** Less hardship – general household items* Less deprived neighbourhood – CWI M** Less deprived neighbourhood – CWI H&D* Less deprived neighbourhood – IMD*	**Uses overnight short breaks**	**Main carer short break experience/satisfaction:** Satisfaction: standard of care** Satisfaction: suitability for child** Satisfaction: suitability of carers** Satisfaction: competence of carers** Satisfaction: range of short breaks** Satisfaction: emergencies** Satisfaction: provider listens** Satisfaction: short breaks overall** Satisfaction: trust* Satisfaction: amount of short breaks* **Main carer outcomes:** **Disabled child outcomes:** Lower SDQ emotional symptoms* Use a wider range of other child services**

Child, carer and household factors associated with short break usage	Dimensions of short break usage	Dimensions of carer satisfaction with short breaks and carer/child outcomes associated with short break usage
Child characteristics: Target Group C* Target Group E* In more Target Groups A-E** Severe/profound learning disability** Child lower SDQ prosocial behaviour* Child needs more supervision 5pm-10pm** **Carer characteristics:** **Household characteristics:** Fewer debt problems*	**Number of hours of overnight short breaks used**	**Main carer short break experience/satisfaction:** Short breaks improved in last 12 months* Satisfaction: standard of care* Satisfaction: amount of short breaks* Satisfaction: range of short breaks* **Main carer outcomes:** **Disabled child outcomes:** Lower SDQ prosocial behaviour**
Child characteristics: Child higher SDQ conduct problems** Child lower SDQ prosocial behaviour** **Carer characteristics:** Main carer long-standing illness/disability* Main carer higher level of education** Carer's partner higher level of education* **Household characteristics:** Less hardship – general household items* Less hardship – items for disabled child* Less deprived neighbourhood – CWI H&D* Less deprived neighbourhood – IMD*	**Uses paid carers (not centre-based) for short breaks**	**Main carer short break experience/satisfaction:** Family previously turned down for short break** **Main carer outcomes:** **Disabled child outcomes:** Higher SDQ conduct problems** Lower SDQ prosocial behaviour** Use a wider range of other child services** Poorer relationships with siblings*

Child, carer and household factors associated with short break usage	Dimensions of short break usage	Dimensions of carer satisfaction with short breaks and carer/child outcomes associated with short break usage
Child characteristics: TDC Priority Group B* Child lower SDQ emotional symptoms* **Carer characteristics:** **Household characteristics:**	**Number of hours of paid carer (not centre-based) short breaks used**	**Main carer short break experience/satisfaction:** Satisfaction: amount of short breaks** Satisfaction: flexibility** Satisfaction: short breaks overall** Satisfaction: standard of care* Satisfaction: range of short breaks* Satisfaction: emergencies* Satisfaction: providers listen* **Main carer outcomes:** **Disabled child outcomes:** Lower SDQ emotional symptoms*
Child characteristics: Age 14-16, 17-19** Target Group B** Target Group E** TDC Priority Group B** In more Target Groups A-E** Severe/profound learning disability** Child lower SDQ total difficulties** Child lower SDQ emotional symptoms** Child needs more supervision 6am-5pm** Child needs more supervision 5pm-10pm** **Carer characteristics:** Older main carer** Main carer lower level of education** **Household characteristics:** Fewer money worries** Managing better financially** Fewer debt problems**	**Uses centre-based short breaks**	**Main carer short break experience/satisfaction:** Satisfaction: standard of care** Satisfaction: amount of short breaks** Satisfaction: range of short breaks** Satisfaction: emergencies** Satisfaction: provider listens* Satisfaction: short breaks overall* **Main carer outcomes:** **Disabled child outcomes:** Lower SDQ total difficulties** Lower SDQ emotional symptoms** Child better progress at school* Child's school more responsive*

Child, carer and household factors associated with short break usage	Dimensions of short break usage	Dimensions of carer satisfaction with short breaks and carer/child outcomes associated with short break usage
Child characteristics: Age 14-16, 17-19* Older child* Target Group C* Target Group D* Target Group E** TDC Priority Group A* In more Target Groups A-E** Severe/profound learning disability** Child higher SDQ hyperactivity** Child lower SDQ prosocial behaviour* **Carer characteristics:** **Household characteristics:**	**Number of hours of centre-based short breaks used**	**Main carer short break experience/satisfaction:** Satisfaction: amount of short breaks** Satisfaction: provider listens** Satisfaction: suitability for child* Satisfaction: short breaks overall* **Main carer outcomes:** Lower psychological distress (K6)** Below threshold psychological distress (K6)* **Disabled child outcomes:** Higher SDQ hyperactivity** Lower SDQ prosocial behaviour*

* p<0.05; ** p<0.01

Table C2: Factors associated with family experience of and satisfaction with short breaks: univariate associations

Child, carer and household factors associated with short break experience/satisfaction with short breaks	Dimensions of short break usage associated with short break experience/satisfaction with short breaks	Dimension of family experience of and satisfaction with short breaks
Child characteristics: **Carer characteristics:** **Household characteristics:**	More total hours of short break support** Disabled child uses leisure short breaks* Disabled child more hours overnight short breaks* Short breaks funded via direct payments*	**Short breaks have improved in the last 12 months**
Child characteristics: Age 14-16, 17-19* Target Group E** TDC Priority Group A* In more Target Groups A-E* Lower SDQ total difficulties* Lower SDQ peer problems* Higher SDQ prosocial behaviour** **Carer characteristics:** White British main carer** Main carer lower level of education* **Household characteristics:** Family has one disabled child* Less hardship – items for disabled child* More deprived neighbourhood CWI H&D*	More total hours of short break support** Greater range of short break services** Disabled child uses overnight short breaks** Disabled child more hours overnight short breaks* Disabled child more hours paid carer short breaks (not centre-based)* Disabled child uses centre-based short breaks**	**Satisfaction with the standard of care the child receives**

Child, carer and household factors associated with short break experience/satisfaction with short breaks	Dimensions of short break usage associated with short break experience/satisfaction with short breaks	Dimension of family experience of and satisfaction with short breaks
Child characteristics: Target Group E* Lower SDQ total difficulties* Lower SDQ emotional symptoms* Lower SDQ peer problems** **Carer characteristics:** Main carer lower level of education* **Household characteristics:**	More total hours of short breaks** Greater range of short break services* Disabled child uses overnight short breaks** Disabled child more hours centre-based short breaks*	**Satisfaction with the suitability of short breaks for the child's needs**
Child characteristics: **Carer characteristics:** White British main carer** **Household characteristics:** More deprived neighbourhood CWI H&D*	Greater range of short break services* Disabled child uses overnight short breaks**	**Satisfaction with the suitability of the people who look after the child during short breaks**
Child characteristics: **Carer characteristics:** White British main carer** **Household characteristics:** Family has one disabled child* Less hardship – items for disabled child*	Disabled child uses overnight short breaks**	**Satisfaction with the competence of the people who look after the child during short breaks**
Child characteristics: Higher SDQ prosocial behaviour* Child needs less supervision 6am-5pm* Child needs less supervision 5pm-10pm* **Carer characteristics:** **Household characteristics:** More deprived neighbourhood CWI H&D**	Greater range of short break services** Disabled child uses overnight short breaks*	**Satisfaction with the level of trust carers can place on the people who look after the child during short breaks**

Child, carer and household factors associated with short break experience/satisfaction with short breaks	Dimensions of short break usage associated with short break experience/satisfaction with short breaks	Dimension of family experience of and satisfaction with short breaks
Child characteristics: Older child* Target Group E* In more Target Groups A-E* Lower SDQ peer problems* **Carer characteristics:** **Household characteristics:** More hardship – general household items* More hardship – items for carer* More deprived neighbourhood CWI** More deprived neighbourhood CWI M* More deprived neighbourhood CWI H&D* More deprived neighbourhood IMD*	More total hours of short break support** Disabled child uses overnight short breaks* Disabled child more hours overnight short breaks* Disabled child more hours paid carer short breaks (not centre-based)** Disabled child uses centre-based short breaks** Disabled child more hours centre-based short breaks**	**Satisfaction with the amount of short term care available**
Child characteristics: Target Group E* Lower SDQ total difficulties** Lower SDQ peer problems** **Carer characteristics:** Older main carer* Main carer not long-standing illness/disability* **Household characteristics:** More deprived neighbourhood CWI* More deprived neighbourhood CWI H&D*	More total hours of short break support** Greater range of short break services* Disabled child more hours of leisure short breaks* Disabled child uses overnight short breaks** Disabled child more hours overnight short breaks* Disabled child more hours paid carer short breaks (not centre-based)* Disabled child uses centre-based short breaks**	**Satisfaction with the range of short break supports available to the family**
Child characteristics: Lower SDQ peer problems* Child needs less supervision 5pm-10pm* **Carer characteristics:** White British main carer* Main carer lower level of education* **Household characteristics:**	More total hours of short break support** Disabled child more hours paid carer short breaks (not centre-based)**	**Satisfaction with the flexibility of short break services**

Child, carer and household factors associated with short break experience/satisfaction with short breaks	Dimensions of short break usage associated with short break experience/satisfaction with short breaks	Dimension of family experience of and satisfaction with short breaks
Child characteristics: Age 17-19* Target Group E* Lower SDQ total difficulties* Lower SDQ peer problems** **Carer characteristics:** **Household characteristics:**	More total hours of short break support** Disabled child uses overnight short breaks** Disabled child more hours paid carer short breaks (not centre-based)* Disabled child uses centre-based short breaks**	**Satisfaction with the ability to arrange emergency short breaks if/when needed**
Child characteristics: Older child* Not Target Group A* Target Group E** Lower SDQ total difficulties** Lower SDQ hyperactivity* Lower SDQ emotional symptoms** Lower SDQ conduct problems* Lower SDQ peer problems** Higher SDQ prosocial behaviour* Child needs less supervision 5pm-10pm* **Carer characteristics:** White British main carer* **Household characteristics:** Family managing worse financially*	More total hours of short break support** Greater range of short break services* Disabled child uses overnight short breaks** Disabled child more hours paid carer short breaks (not centre-based)* Disabled child uses centre-based short breaks* Disabled child more hours centre-based short breaks**	**Satisfaction with the extent to which short break providers listen to the family's views**
Child characteristics: Older child* Target Group E** Lower SDQ total difficulties** Lower SDQ peer problems** Higher SDQ prosocial behaviour** **Carer characteristics:** Main carer lower level of education* **Household characteristics:** More deprived neighbourhood CWI H&D**	More total hours of short break support** Greater range of short break services* Disabled child uses overnight short breaks** Disabled child more hours paid carer short breaks (not centre-based)** Disabled child uses centre-based short breaks* Disabled child more hours centre-based short breaks*	**Overall satisfaction with short breaks**

* $p<0.05$; ** $p<0.01$

Table C3: Factors associated with main carer and disabled child outcomes: univariate associations

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Main Carer Outcomes		
Child characteristics: Child lower SDQ total difficulties** Child lower SDQ emotional symptoms** Child lower SDQ conduct problems** Child needs less supervision 10pm-6am* Child better general health** **Carer characteristics:** Main carer not long-standing illness/disability** Main carer working PT or FT* **Household characteristics:** Less hardship – items for disabled child* Fewer money worries** Managing better financially** Fewer debt problems**	**Short break usage:** **Short break family experience/satisfaction:**	**Main carer self-reported general (good) health**

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Child not in Target Group D* Child lower SDQ total difficulties** Child lower SDQ hyperactivity** Child lower SDQ emotional symptoms** Child lower SDQ conduct problems** Child lower SDQ peer problems** Child needs less supervision 6am-5pm* Child better general health* **Carer characteristics:** Older main carer** Main carer not long-standing illness/disability** **Household characteristics:** Main carer living in household as couple** Main carer not a lone parent** Less hardship – items for disabled child* Fewer money worries** Managing better financially** Fewer debt problems**	**Short break usage:** Child uses centre-based short breaks** **Short break family experience/satisfaction:** Satisfaction: range of short breaks** Satisfaction: amount of short breaks* Satisfaction: emergencies* Satisfaction: short breaks overall* **Other services:** School more responsive*	**Main carer lower psychological distress (K6)**

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Child not in Target Group B** Child lower SDQ total difficulties** Child lower SDQ emotional symptoms** Child lower SDQ conduct problems** Child lower SDQ peer problems* Child needs less supervision 6am-5pm* Child needs less supervision 5pm-10pm* Child needs less supervision 10pm-6am* Child better general health** Child better progress at school* **Carer characteristics:** Main carer not long-standing illness/disability** Main carer working PT or FT* **Household characteristics:** Main carer living in household as couple** Main carer not a lone parent** Main carer married* Less hardship – items for disabled child* Fewer money worries** Managing better financially** Fewer debt problems**	**Short break usage:** **Short break family experience/satisfaction:** Satisfaction: short breaks overall** Satisfaction: range of short breaks** Satisfaction: amount of short breaks* Satisfaction: flexibility* Satisfaction: emergencies* Satisfaction: providers listen* **Other services:** School more responsive*	**Main carer greater satisfaction with life**
Child characteristics: Child older than 7* Older child** Child not in Target Group A* Child lower SDQ conduct problems* **Carer characteristics:** Older main carer** Main carer not long-standing illness/disability* Main carer working PT or FT* **Household characteristics:**	**Short break usage:** Child uses local authority-funded short breaks* **Short break family experience/satisfaction:**	**Main carer usage of a narrower range of health/welfare services for adults**
Disabled Child Outcomes		

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Child aged under 8 or over 13** Older child Child not in Target Group A** Child in Target Group B** Child in Target Group C** Child not in Target Group D** Child in Target Group E** Child not in TDC Priority Group A** Child in TDC Priority Group B** Child needs less supervision 6am-5pm** Child needs less supervision 5pm-10pm** Child needs less supervision 10pm-6am* Child better progress at school** **Carer characteristics:** **Household characteristics:** Fewer money worries* Managing better financially*	**Short break usage:** Child does not use leisure short breaks* Child uses centre-based short breaks** **Short break family experience/satisfaction:** More satisfaction: short breaks overall** More satisfaction: range of short breaks** More satisfaction: providers listen** More satisfaction: standard of care* More satisfaction: suitability of short break* More satisfaction: emergencies*	**Lower SDQ total difficulties**
Child characteristics: Child not in Target Group A** Child in Target Group B** Child in Target Group C** Child not in Target Group D** Child not in TDC Priority Group A** Child in TDC Priority Group B** **Carer characteristics:** **Household characteristics:** Main carer not a lone parent* Less deprived neighbourhood CWI M*	**Short break usage:** More total hours of short breaks* Child uses overnight short breaks* More hours of paid carer short breaks (not centre-based)* Child uses centre-based short breaks** **Short break family experience/satisfaction:** More satisfaction: providers listen** More satisfaction: suitability of short break*	**Lower SDQ emotional symptoms**

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Girl* Older child* Child not in Target Group A** Child in Target Group B* Child in Target Group C** Child not in Target Group D** Child in fewer Target Groups A-E* Child not in TDC Priority Group A** Child in TDC Priority Group B** Child needs less supervision 6am-5pm** Child better progress at school* **Carer characteristics:** Main carer not long-standing illness/disability* **Household characteristics:** Fewer money worries** Managing finances better** More hardship – general household items* More hardship – items for main carer*	**Short break usage:** Child uses paid carer short breaks (not centre-based)** **Short break family experience/satisfaction:** More satisfaction: providers listen*	**Lower SDQ conduct problems**

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Child aged under 5 or over 13** Older child** Child not in Target Group A** Child in Target Group C* Child not in Target Group D** Child in Target Group E** Child in fewer Target Groups A-E** Child not in TDC Priority Group A** Child in TDC Priority Group B** Child needs less supervision 6am-5pm** Child needs less supervision 5pm-10pm** Child needs less supervision 10pm-6am* **Carer characteristics:** Older carer age* **Household characteristics:** Partner higher level of education**	**Short break usage:** More hours of centre-based short breaks** **Short break family experience/satisfaction:** More satisfaction: providers listen*	**Lower SDQ hyperactivity**
Child characteristics: Girl** Child not in Target Group A** Child in Target Group B** Child in Target Group C** Child not in Target Group D** Child not in TDC Priority Group A** Child in TDC Priority Group B** Child severe/profound learning disability* **Carer characteristics:** Main carer lower level of education* **Household characteristics:**	**Short break usage:** Child does not use leisure short breaks* Family turned down for short break** **Short break family experience/satisfaction:** More satisfaction: short breaks overall** More satisfaction: suitability of short break** More satisfaction: range of short breaks** More satisfaction: flexibility of short breaks** More satisfaction: emergencies** More satisfaction: providers listen** More satisfaction: standard of care* More satisfaction: amount of short breaks*	**Lower SDQ peer problems**

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Child aged 17 or over* Older child** Child with mild/moderate learning disabilities** Child not in Target Group A** Child not in Target Group B** Child not in Target Group D** Child in fewer Target Groups A-E** Child not in TDC Priority Group A** Child needs less supervision 6am-5pm** **Carer characteristics:** Older main carer* **Household characteristics:** More hardship general household items* More deprived neighbourhood IMD* More deprived neighbourhood CWI* More deprived neighbourhood CWI M* More deprived neighbourhood CWI H&D*	**Short break usage:** Fewer total hours of short breaks* Fewer hours of overnight short breaks* Child does not use paid carer short breaks (not centre-based)* Fewer hours of centre-based short breaks* **Short break family experience/satisfaction:** More satisfaction: short breaks overall** More satisfaction: standard of care** More satisfaction: trust* More satisfaction: providers listen*	**Higher SDQ prosocial behaviour**

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Older child** Child in Target Group A** Child not in Target Group B** Child in TDC Priority Group A* Child not in TDC Priority Group B** Child higher SDQ peer problems** Child needs less supervision 6am-5pm** Child needs less supervision 5pm-10pm** Child needs less supervision 10pm-6am** Child better progress at school** **Carer characteristics:** Older carer Main carer not long-standing illness/disability** **Household characteristics:** Main carer living in household as couple* Main carer not a lone parent** Main carer manage finances better** Main carer fewer debt problems** Less deprived neighbourhood IMD* Less deprived neighbourhood CWI* Less deprived neighbourhood CWI M*	**Short break usage:** **Short break family experience/satisfaction:** **Other services:** Child's school more responsive*	**Disabled child general (good) health**

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Child aged 17 or over** Child not in Target Group A** Child in Target Group B** Child in Target Group C* Child not in Target Group D** Child not in TDC Priority Group A** Child in TDC Priority Group B** Child lower SDQ total difficulties** Child lower SDQ hyperactivity** Child lower SDQ emotional symptoms** Child lower SDQ conduct problems** Child lower SDQ peer problems** Child higher SDQ prosocial behaviour** Child needs less supervision 6am-5pm* **Carer characteristics:** Main carer not long-standing illness/disability* Main carer working FT** **Household characteristics:**	**Short break usage:** Family not previously turned down for short break** Disabled child not previously excluded from short break** Child does not use leisure short breaks** Child does not use paid carer short breaks (not centre-based)** **Short break family experience/satisfaction:** More satisfaction: suitability of short breaks* More satisfaction: range of short breaks* More satisfaction: short breaks overall*	**Disabled child good relationship with siblings**

Child, carer and household factors associated with main carer and disabled child outcomes	Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes	Main carer and child outcome
Child characteristics: Girl** Child aged under 5* Younger child** Child not in Target Group A** Child in Target Group B** Child in Target Group C** Child not in Target Group E* Child in TDC Priority Group B** Child lower SDQ peer problems* Child needs more supervision 6am-5pm** Child needs more supervision 5pm-10pm** Child needs more supervision 10pm-6am** Child poorer health** **Carer characteristics:** Main carer long-standing illness/disability** **Household characteristics:** Less hardship general household items* Less hardship items for main carer*	**Short break usage:** Child uses a wider range of short breaks* Child uses overnight short breaks** Child uses paid carer short breaks (not centre-based)** Child uses short breaks from a wider range of funding sources* Child uses local authority-funded short breaks* Child uses short breaks funded via direct payments* **Short break family experience/satisfaction:**	**Disabled child using wider range of child services**
Child characteristics: Child in Target Group C* Child in Target Group E* Child lower SDQ total difficulties** Child lower SDQ conduct problems* Child better general health** **Carer characteristics:** **Household characteristics:** Less hardship general household items* Main carer fewer money worries* Main carer manage finances better*	**Short break usage:** Child not previously excluded from short breaks** Child uses centre-based short breaks* **Short break family experience/satisfaction:** Satisfaction: range of short breaks*	**Main carer reports child progressing well at school**

Child, carer and household factors associated with main carer and disabled child outcomes	**Dimensions of short break usage and experience/satisfaction associated with main carer and disabled child outcomes**	**Main carer and child outcome**
Child characteristics: Child in more Target Groups A-E* Child in TDC Priority Group A* **Carer characteristics:** **Household characteristics:** Main carer fewer money worries** Main carer manage finances better**	**Short break usage:** Child uses centre-based short breaks* **Short break family experience/satisfaction:** Satisfaction: standard of care** Satisfaction: range of short breaks** Satisfaction: provider listens** Satisfaction: short breaks overall** Satisfaction: emergencies*	**Main carer reports child's school is responsive to child and family needs**

* p<0.05; ** p<0.01

12.4 Appendix D – Summary of logistic regressions

Appendix D: Summary of logistic regressions

Table D1: Factors associated with short break usage and funding: logistic regressions

Aspect of short break usage or funding	Wald (p)
Total hours of short breaks used (median split, n=202, % correct classification 53.0%-66.3%, Nagelkerke R^2=0.22)	
Child in Target Group E	24.65 (p<0.001)
Child lower SDQ prosocial behaviour	4.34 (p=0.037)
Child needs more supervision 6am-5pm	5.28 (p=0.022)
Total number of types of short breaks used (median split, n=282, % correct classification 57.8%-56.0%, Nagelkerke R^2=0.04)	
Main carer fewer money worries	7.23 (p=0.007)
Family ever turned down for short break for disabled child (n=262, % correct classification 78.2%-78.2%, Nagelkerke R^2=0.11)	
Child higher SDQ peer problems	11.89 (p=0.001)
Less deprived neighbourhood CWI Health & Disability Domain	6.37 (p=0.012)
Disabled child ever excluded from short break (n=260, % correct classification 90.4%-90.4%, Nagelkerke R^2=0.08)	
Child in TDC Priority Group B	5.34 (p=0.021)
Child higher SDQ conduct problems	8.77 (p=0.003)
Disabled child uses short breaks funded by the local authority (n=290, % correct classification 64.5%-69.7%, Nagelkerke R^2=0.09)	
Child in more Target Groups A-E	6.56 (p=0.01)
Older main carer	7.19 (p=0.007)
Less deprived neighbourhood CWI Health & Disability Domain	4.97 (p=0.026)
Disabled child uses short breaks funded via direct payments (n=296, % correct classification 70.6%-69.9%, Nagelkerke R^2=0.14)	
Younger child	5.05 (p=0.025)
Female main carer	5.07 (p=0.024)
White British main carer	6.70 (p=0.01)
Main carer higher level of education	5.06 (p=0.024)
Disabled child uses short breaks funded from a wider range of sources (median split, n=294, % correct classification 67.3%-67.3%, Nagelkerke R^2=0.13)	
Female main carer	4.42 (p=0.035)
Main carer higher level of education	18.60 (p<0.001)
Disabled child uses leisure short breaks (n=247, % correct classification 64.4%-66.0%, Nagelkerke R^2=0.06)	
Child in TDC Priority Group A	11.50 (p=0.001)
For disabled children using leisure short breaks, how many hours of leisure short breaks used (median split, n=159, % correct classification 50.3%-61.0%, Nagelkerke R^2=0.12)	
Main carer not long-standing health or disability	5.75 (p=0.016)
Lone parent household	8.37 (p=0.004)

Aspect of short break usage or funding	Wald (p)
Disabled child uses unpaid carers for short breaks (n=332, correct classification 75.6%-75.6%, Nagelkerke R^2=0.03)	
Household fewer money worries	5.60 (p=0.018)
For disabled children using unpaid carers for short breaks, how many hours of unpaid carers for short breaks used (median split, no variables univariately associated with this variable)	
Disabled child uses overnight short breaks (n=250, correct classification 52.8%-71.6%, Nagelkerke R^2=0.28)	
Girl	5.09 (p=0.024)
Child in Target Group C	7.64 (p=0.006)
Child in Target Group E	9.56 (p=0.002)
Child severe/profound level of learning disability	6.71 (p=0.082)
Less household hardship – general household items	3.71 (p=0.054)
Less deprived neighbourhood – CWI Material Domain	5.06 (p=0.025)
For disabled children using overnight short breaks, how many hours of overnight short breaks used (median split, n=102, correct classification 50.0%-69.6%, Nagelkerke R^2=0.24)	
Child severe/profound level of learning disability	10.87 (p=0.004)
Child lower SDQ prosocial behaviour	4.14 (p=0.042)
Disabled child uses paid carers (not centre-based) for short breaks (n=272, correct classification 59.2%-65.1%, Nagelkerke R^2=0.15)	
Child higher SDQ conduct problems	8.32 (p=0.004)
Main carer higher level of education	11.47 (p=0.001)
Less household hardship – general household items	9.83 (p=0.002)
For disabled children using paid carers (not centre-based) for short breaks, how many hours of overnight of paid carer short breaks used (median split, n=136, correct classification 58.8%-61.0%, Nagelkerke R^2=0.04)	
Child in TDC Priority Group B	3.87 (p=0.049)
Disabled child uses centre-based short breaks (n=216, correct classification 61.6%-73.6%, Nagelkerke R^2=0.18)	
Child in Target Group E	24.03 (p<0.001)
Child severe/profound learning disability	18.82 (p<0.001)
Child lower SDQ emotional symptoms	10.33 (p=0.001)
For disabled children using centre-based short breaks, how many hours of centre-based short breaks used (median split, n=76, correct classification 52.6%-73.7%, Nagelkerke R^2=0.31)	
Child in more Target Groups A-E	4.11 (p=0.043)
Child severe/profound learning disability	8.37 (p=0.015)

Table D2: Factors associated with family experiences of and satisfaction with short breaks: logistic regressions

Aspect of short break satisfaction	Wald (p)
Short breaks have improved in last 12 months (n=204, % correct classification 55.4%-59.8%, Nagelkerke R^2=0.05)	
Child total hours of short breaks used	5.98 (p=0.015)
Main carer satisfaction with standard of care the child receives (median split, n=148, % correct classification 70.3%-75.7%, Nagelkerke R^2=0.29)	
Child higher SDQ prosocial behaviour	15.75 (p<0.001)
Child total hours of short breaks used	12.07 (p=0.001)
Main carer satisfaction with suitability of short breaks for their child (median split, n=160, % correct classification 60.6%-63.1%, Nagelkerke R^2=0.10)	
Child uses overnight short breaks	11.19 (p=0.001)
Main carer satisfaction with suitability of the people who look after their child during short breaks (median split, n=247, % correct classification 74.1%-75.7%, Nagelkerke R^2=0.11)	
White British main carer	5.86 (p=0.015)
More deprived neighbourhood CWI Health & Disability Domain	5.96 (p=0.015)
Child uses overnight short breaks	9.00 (p=0.003)
Main carer satisfaction with the competence of the people who look after their child during short breaks (median split, n=293, % correct classification 70.6%-72.4%, Nagelkerke R^2=0.10)	
White British main carer	5.80 (p=0.016)
Family has one disabled child	5.49 (p=0.019)
Child uses overnight short breaks	7.88 (p=0.005)
Main carer satisfaction with the level of trust they can place in short break carers (median split, n=216, % correct classification 70.4%-72.7%, Nagelkerke R^2=0.11)	
Child needs less supervision 5pm-10pm	5.22 (p=0.022)
More deprived neighbourhood CWI Health & Disability Domain	5.40 (p=0.020)
Child uses overnight short breaks	9.28 (p=0.002)
Main carer satisfaction with the amount of short term care available (median split, n=222, % correct classification 80.6%-81.1%, Nagelkerke R^2=0.15)	
Child in Target Group E	9.11 (p=0.003)
More deprived neighbourhood CWI	12.21 (p<0.001)
Main carer satisfaction with the range of short breaks available (median split, n=151, % correct classification 82.1%-82.8%, Nagelkerke R^2=0.18)	
Child in Target Group E	5.40 (p=0.020)
More deprived neighbourhood CWI	5.97 (p=0.015)
Child total hours of short break used	4.27 (p=0.039)

Aspect of short break satisfaction	Wald (p)
Main carer satisfaction with the flexibility of short break services (median split, n=223, % correct classification 65.9%-65.5%, Nagelkerke R^2=0.11)	
Child needs less supervision 5pm-10pm	7.44 (p=0.006)
Main carer lower level of education	5.56 (p=0.018)
Child total hours of short breaks used	7.51 (p=0.006)
Main carer satisfaction with their ability to arrange emergency short breaks if/when needed (median split, n=151, correct classification 78.8%-82.1%, Nagelkerke R^2=0.29)	
Child age 17-19	12.00 (p=0.062)
Child uses overnight short breaks	5.67 (p=0.017)
Main carer satisfaction with the extent to which short break providers listen to the family's views (median split, n=143, correct classification 53.8%-75.5%, Nagelkerke R^2=0.38)	
Child higher SDQ prosocial behaviour	7.20 (p=0.007)
Child lower SDQ total difficulties	9.16 (p=0.002)
Child needs less supervision 5pm-10pm	4.67 (p=0.031)
White British main carer	3.62 (p=0.057)
Child uses overnight short breaks	11.67 (p=0.001)
Main carer overall satisfaction with short breaks (median split, n=153, correct classification 51.0%-60.8%, Nagelkerke R^2=0.18)	9.15 (p=0.002)
Child higher SDQ prosocial behaviour	11.49 (p=0.001)
Child total hours of short breaks used	

Table D3: Factors associated with outcomes for main carers: logistic regressions

Main carer outcome	Wald (p)
Main carer self-reported good general health (Very Good and Good vs Fair, Bad and Very Bad) (n=244, % correct classification 65.6%-77.0%, Nagelkerke R^2=0.41)	
Child better general health	45.61 (p<0.001)
Main carer not longstanding illness/disability	14.83 (p<0.001)
Household managing better financially	44.95 (p<0.001)
Main carer satisfaction lower psychological distress on the K6 scale (below K6 threshold<13 vs above K6 threshold>=13) (n=154, % correct classification 87.0%-90.9%, Nagelkerke R^2=0.36)	
Child lower SDQ total difficulties	12.69 (p<0.001)
Main carer not longstanding illness/disability	4.79 (p=0.029)
Household managing better financially	9.17 (p=0.002)
Main carer greater satisfaction with life (median split, n=152, % correct classification 56.6%-64.5%, Nagelkerke R^2=0.17)	
Household less hardship – items for the disabled child	4.19 (p=0.041)
Household managing better financially	16.13 (p<0.001)
Main carer usage of a narrower range of health/welfare services for adults in the last 3 months (no services used vs at least one service used, n=272, % correct classification 61.0%-62.9%, Nagelkerke R^2=0.07)	
Older child	8.18 (p=0.004)
Main carer not longstanding illness/disability	5.95 (p=0.015)

Table D4: Factors associated with outcomes for disabled children: logistic regressions

Disabled child outcome	Wald (p)
Disabled child lower SDQ total difficulties (median split, n=323, % correct classification 65.9%-72.4%, Nagelkerke R^2=0.31)	
Child not in Target Group A	10.28 (p=0.001)
Child not in Target Group D	16.62 (p<0.001)
Child in Target Group E	9.38 (p=0.002)
Child in Priority Group B	6.33 (p=0.012)
Child uses centre-based short breaks	3.84 (p=0.05)
Disabled child lower SDQ emotional symptoms (median split, n=240, % correct classification 60.4%-70.0%, Nagelkerke R^2=0.18)	7.86 (p=0.005)
Child not in Target Group D	6.93 (p=0.009)
Child in TDC Priority Group B	5.13 (p=0.023)
Child uses centre-based short breaks	9.04 (p=0.003)
Main carer satisfaction with the extent to which short break providers listen to the family	
Disabled child lower SDQ conduct problems (median split, n=272, % correct classification 74.6%-77.2%, Nagelkerke R^2=0.22)	11.74 (p=0.001)
Child not in Target Group D	12.00 (p=0.001)
Child in TDC Priority Group B	10.16 (p=0.001)
Household fewer money worries	4.61 (p=0.032)
Child uses paid carer (not centre-based) short breaks	
Disabled child lower SDQ hyperactivity (median split, n=272, % correct classification 71.7%-77.2%, Nagelkerke R^2=0.31)	
Child not in Target Group A	16.20 (p<0.001)
Child not in Target Group D	22.63 (p<0.001)
Child in Target Group E	13.93 (p<0.001)
Older main carer age	8.10 (p=0.004)
Disabled child lower SDQ peer problems (median split, n=189, % correct classification 61.4%-71.4%, Nagelkerke R^2=0.30)	
Child not in Target Group A	24.22 (p<0.001)
Child in Target Group C	3.74 (p=0.053)
Child severe/profound learning disability	5.69 (p=0.058)
Main carer greater satisfaction with the range of short breaks available	5.97 (p=0.015)
Disabled child higher SDQ prosocial behaviour (median split, n=221, % correct classification 86.9%-90.0%, Nagelkerke R^2=0.52)	6.69 (p=0.01)
Older child	17.94 (p<0.001)
Child not in Target Group A	8.40 (p=0.004)
Child not in Target Group B	9.39 (p=0.002)
Household more hardship general household items	4.51 (p=0.034)
Main carer greater satisfaction with the extent to which short break providers listen to the family	

Disabled child outcome	**Wald (p)**
Disabled child good general health (Very Good and Good vs Fair, Bad and Very Bad) (n=251, % correct classification 70.9%-75.3%, Nagelkerke R^2=0.20)	
Child in Target Group A	9.82 (p=0.002)
Child needs less supervision 6am-5pm	5.37 (p=0.021)
Older child	4.36 (p=0.037)
Main carer not longstanding illness/disability	7.42 (p=0.006)
Household managing finances better	5.37 (p=0.02)
Disabled child better relationship with siblings (median split, n=177, % correct classification 66.7%-75.1%, Nagelkerke R^2=0.31)	6.86 (p=0.009)
Child lower SDQ total difficulties	3.23 (p=0.780)
Main carer working FT or PT	4.12 (p=0.042)
Child not previously excluded from a short break	13.76 (p<0.001)
Child does not use leisure short breaks	
Disabled child usage of a wider range of other health/welfare services for children in last 3 months (median split, n=191, % correct classification 57.1%-71.7%, Nagelkerke R^2=0.23)	
Child not in Target Group A	9.55 (p=0.002)
Child needs more supervision 10pm-6am	16.19 (p<0.001)
Child uses a wider range of short breaks	5.57 (p=0.018)

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