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The Impact of short breaks on families with a disabled child over time: The second report from the quantitative study

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The views expressed in this report are those of the authors and do not necessarily reflect those of the Department for Education. The authors can be contacted through the following website or postal address

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Acknowledgements

As with the first report from the quantitative element of this study we owe a huge debt of gratitude to the children, parents and carers who participated in the research. Once again they have been very generous with their time and attention, they continue to be interested in the subject matter and very keen to ensure that their experiences are shared in order to help improve services for other families. We also remain indebted to local authority colleagues who have continued to support the research in many ways, in particular by helping us to access families. We would again like to thank members of the research policy steering group who have continued to review and support the progress of the research.

It is our sincere hope that we have been able to capitalise on all of the help given to us and that the research will provide information that is timely, relevant, rigorous and robust. We aim to ensure that the various outputs from the research will be suited to the needs of decision makers and all those involved in delivering services for families with disabled children.

Executive Summary

The study

This report presents the findings of a longitudinal survey into the impact of short breaks on disabled children and their families. The study is the final element of a programme of research commissioned by the Department for Education (formerly the Department for Children, Schools and Families) and carried out by the Centre for Disability Research (CeDR) at Lancaster University in partnership with the National Development Team for Inclusion (NDTi).

In commissioning this research the Department had two aims; the first was to commission a programme evaluation of the then AHDC Short Break Pathfinder programme; the second 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 Department intended that the research findings would be used to improve the provision and commissioning of short breaks at a local level, to provide information to underpin advice to local authorities, and to inform national policy. The research began in the summer of 2009.

Other outputs from this programme of research include the following reports which are available from the DfE Publications website:

- The Impacts of Short Break Provision on Disabled Children and Families: An International Literature Review (Robertson et al., 2010);
- A Report on Themes Emerging from Qualitative Research into the Impact of Short Break Provision on Families with Disabled Children (Langer et al., 2010);
- The Impact of Short Breaks on Families with a Disabled Child: Report One of the Quantitative Phase (Welch et al., 2010);
- Short Breaks Pathfinder Evaluation (Greig et al., 2010a).

In addition four Briefing Papers for commissioners and providers of short break services have been prepared and are available from the NDTi and CeDR websites; details of these can be found in the bibliography of this report.

This report adds a longitudinal dimension to the findings reported to date, by examining continuity and change in the usage of short breaks over a 10-month period and the ongoing impact of short breaks as reported by the families who use them.

Follow-up questionnaires for main carers were sent to 349 families who had taken part in the survey at Time 1. 214 (61%) main carer questionnaires were returned before the analysis for this report began. The mean interval between return of the questionnaires at Time 1 and Time 2 was 10 months. Main carer questionnaires returned after the deadline for analysis, along with questionnaires from additional carers, children who use short breaks and siblings will be reported-on in other publications.

Quantitative analysis of the data used SPSS software to identify changes in usage of short breaks over time, and factors associated with short break usage and family outcomes over time. Qualitative analysis of textual data used QSR Nvivo 8 software to identify thematic changes in what families told us about short breaks at Time 2.

Family experiences of short breaks

The first set of questions we asked concerned change and continuity in families' experiences of short breaks over the 10 months from Time 1 to Time 2.

There was no overall change in the total number of hours of short breaks received by families from Time 1 to Time 2, but there was evidence of some reductions in short break services and funding. From Time 1 to Time 2 there were reductions in:

- the range of types of short break used by families;
- the number of families using sports/arts/crafts leisure short breaks (which dropped by one-third from 110 families at Time 1 to 74 families at Time 2);
- and the number of families getting NHS funding for short breaks (which halved from 22 families at Time 1 to 11 families at Time 2).

These reductions were being replaced by some families with private/self-funded short breaks; the number of families privately funding short breaks almost doubled from 33 families at Time 1 to 62 families at Time 2. However, these reductions were not being replaced by unpaid carers for short breaks; the number of families using unpaid carers for short breaks more than halved from 44 families at Time 1 to 20 families at Time 2.

The broader changes outlined above do not show the considerable fluctuation in short break usage experienced by most of the families in this study; over 70% of families reported that their total hours of short breaks had changed (either upwards or downwards) by more than 100 hours per year over the 10 months from Time 1 to Time 2. Furthermore, these changes in the amount of short breaks received by families were not predicted by any characteristics of children or families at Time 1, suggesting that these changes in short break allocation were not strongly determined by the needs of children or families. In this study, there was also some evidence of systematic differences in short break provision dependent on service-defined transition points (such as transition between primary and secondary school or beyond education) rather than dependent on the needs of the family.

Family usage of more total hours of short breaks at Time 2, and of centre-based short breaks and daytime/evening short breaks provided in the family home by a paid carer at Time 2, were almost exclusively predicted by certain characteristics of the disabled child at Time 1; these characteristics clustered around older children with more complex health and physical needs and severe learning disabilities. Other factors reported by carers as important influences on their capacity to cope, such as child problematic behaviour and high levels of carer stress, were not predictive of family usage of short breaks in total (or any type of short break) at Time 2.

Taken together, these findings reinforce carers' experiences of short breaks as being allocated on a somewhat arbitrary basis and subject to change at short notice, with carers having little sense of a clear entitlement to a minimum quantity and quality of short break support. While some types of short break such as centre-based short breaks are clearly allocated on the basis of an important set of child needs (more complex health and physical needs and severe learning disabilities), other crucial family and child needs (such as carer distress and child problematic behaviour) do not seem to be used in allocating short breaks.

These findings also support the serious concerns expressed by many carers about short break support being reduced or withdrawn; over this 10-month period NHS funding and specific types of short break support had been withdrawn from many families, with a big increase in families paying for some short breaks themselves. Furthermore, many carers reported receiving notice of future reductions or withdrawal of short break services which would not yet show up in our quantitative data. Given the importance of properly qualified and skilled short break carers to the family carers in this study, unpaid carers are unlikely to compensate for these reductions; indeed family carers had reduced their usage of unpaid carers for short breaks from Time 1 to Time 2.

Carers at both time points reported high levels of satisfaction with the providers of short break services for their family. They were less satisfied with the systems that surrounded short breaks, including how eligibility for short breaks was assessed, the range and amount of short breaks available, the flexibility of short breaks and the availability of short breaks in emergencies. Whether or not carers were satisfied with short breaks at Time 2 depended little on family needs and circumstances at Time 1; however, carers using overnight short breaks provided by a paid carer away from the family home at Time 1 were more satisfied with short break providers at Time 2.

Outcomes for carers and households

We explored continuity and change in several outcomes for the main carers and for households, principally economic outcomes and carer health and well-being outcomes.

Carer and household economic indicators (main carer employment; household employment; family money worries) remained stable from Time 1 to Time 2; at Time 2 just over half of main carers (52%) were in some form of employment. Main carers and households having someone in paid employment at Time 2 were predicted by socio-economic indicators at Time 1 (more carer education; less neighbourhood deprivation), and also by aspects of the disabled child (older children with better relationships with siblings and requiring less overnight supervision) and one type of short break provision (short breaks with a paid carer during the daytime/evening in the family home). Family worries about money at Time 2 were unsurprisingly predicted by a range of socio-economic indicators and carer psychological distress at Time 1; in addition families receiving a greater quantity and a wider range of short breaks at Time 1 reported fewer worries about money at Time 2.

Clearly, short breaks have a direct positive impact on how families perceive they are managing financially. Short breaks more effectively matched to family needs (for example in providing overnight short breaks for children with more problematic behaviour, providing short breaks that would support the employment of main carers acting as lone parents, considering the socio-economic circumstances of families when allocating short breaks) could assist in improving economic outcomes for families.

In terms of main carer health and wellbeing, there were no changes from Time 1 to Time 2 in carer levels of psychological distress, carer life satisfaction or carers' sense of positive gains as result of having a disabled child. However, the self-reported health of main carers worsened from Time 1 to Time 2; the percentage of carers reporting their health as fair/bad/very bad increased from 35% at Time 1 to 47% at Time 2. A broad range of factors at Time 1 predicted health and well-being outcomes for carers at Time 2. In terms of factors associated with the disabled child, aspects of child problematic behaviour and health rather than the child's levels of physical or learning disabilities predicted carer psychological distress at Time 2; few child factors predicted other carer outcomes. Household socio-economic indicators at Time 1 (neighbourhood deprivation, household hardship and family management of finances) predicted all the carer health and well-being indicators we analysed. Finally, family usage of short breaks at Time 1 had a direct positive impact on the health and well-being of carers at Time 2; families using more total hours and a wider range of short breaks at Time 1 were more likely to have carers with lower levels of psychological distress, higher levels of life satisfaction and better health at Time 2.

In addition to these direct impacts of short breaks, short breaks also had a buffering effect for main carers. Family usage of more hours of short breaks buffered the impact of the child's psychological difficulties on the carer's psychological distress; and also buffered the impact of family socio-economic circumstances on the self-reported health of carers.

Taken together, these findings suggest that short breaks have both a direct positive impact on the health and wellbeing of carers, and buffer the impact of important stressors on carers' health and well-being. These findings reinforce the experiences of carers about the importance of short breaks to their health and well-being and their capacity to continue caring effectively for their disabled child. These findings also raise issues about the targeting of short breaks – they clearly have beneficial impacts on carer health and well-being and help carers to be more resilient in the face of other stressors, yet short breaks do not seem to be allocated on the basis of the needs or circumstances of family carers. These findings also reinforce carers' views that the quantity and range of short breaks are crucial if short break supports are to have a meaningful impact on family life.

Consistent with much previous research, carers reported wanting short breaks that were sufficient in duration and quantity throughout the year (and often overnight to allow carers to have a real sense of a break), available at times when families really needed them (such as school holidays), funded to a level that enabled the employment of qualified, skilled and suitable short break carers, local, genuinely accessible to groups of disabled children often explicitly or tacitly excluded from short break provision (such as children with ASD, children with complex medical needs and children with challenging behaviour), and that struck the right balance between predictability and flexibility (particularly in response to family emergencies). While more personalised short break supports via personal budgets may be a vehicle for families to ensure that short breaks meet these requirements, such personal budgets would have to be paid at a sufficient level to enable carers to choose short break supports they trust, rather than having to make trade-offs between quantity vs quality short break support, and there would have to be a sufficient range of short break services available for families to choose from.

Again consistent with previous research, many carers expressed concerns about the processes surrounding the assessment, allocation and review of short break provision. In the main, carers did not feel secure in their entitlement to and/or eligibility for short break services and were not confident that their existing level of short break service would be maintained, let alone increased. For many carers, gaining short breaks seemed to be the end result of a long struggle or the result of a family crisis, rather than the result of an assessment of the family's needs designed to prevent future family crises. Bureaucracy (particularly surrounding direct payments) and reviews of family needs that were infrequent, absent, arbitrary or not responsive to the changing needs of children and families were also frequently mentioned by carers.

Outcomes for disabled children and siblings

We explored continuity and change over time in a wide range of outcome indicators for the disabled child, including health, behaviour and well-being indicators and other indicators of service usage, progress at school and future prospects as rated by carers.

There was a general pattern of stability in child outcomes from Time 1 to Time 2, although there was an improvement in children’s total psychological difficulties (as measured by the SDQ) over this time period. This pattern of general stability generally reinforced carers’ reports of continuity and change in their child over this time period, although a minority of carers (14%) reported changes or refinements to diagnoses associated with their disabled child between Time 1 and Time 2. Whilst for some carers the increasing age of their child was associated with deteriorating physical and mental health and greater difficulties in managing the child’s behaviour, this was balanced by other carers reporting improvements over time in their child’s behaviour, confidence, independence and maturity. Whilst such changes in the disabled child over time may come ‘under the radar’ of service assessment systems, they are clearly important to families and suggest the need for carers to be able to initiate reviews and re-appraisals of short break support as the child’s needs change.

The health, psychological difficulties and family/peer relationships of the disabled child at Time 2 were almost exclusively predicted by similar characteristics of the disabled child at Time 1. Disabled children were more likely to have poorer outcomes in these areas at Time 2 if the child had an autistic spectrum disorder, showed a range of psychological difficulties and challenging behaviours, had more complex health needs, had a severe learning disability, had poorer relationships with siblings and consequently required more supervision. Few factors concerning the main carers, the household or short breaks at Time 1 predicted these child outcomes at Time 2.

Similar child factors at Time 1 predicted other disabled child outcomes at Time 2, including child usage of a greater range of other child-oriented services, carer reports of better child progress at school, and carer perceptions of brighter future prospects for the disabled child. However, other factors also consistently predicted these child outcomes, including main carers reporting lower levels of psychological distress and families living in less deprived neighbourhoods. Greater carer satisfaction with short break providers and with systems surrounding short breaks at Time 1 also predicted better child outcomes in these areas at Time 2.

Outcomes for siblings were relatively stable from Time 1 to Time 2. Overall, better health and behavioural outcomes for siblings at Time 2 tended to be predicted by similar factors related to siblings at Time 1; although better household financial circumstances were also associated with improved outcomes for siblings.

Taken together these findings suggest that short breaks have little direct impact on the health and behaviour of the disabled child (or the sibling), an unsurprising finding given that short breaks are not primarily designed to achieve these outcomes. However, short breaks do seem to have an impact on how positive carers feel about the future for their disabled child, and as outlined above short breaks do buffer the impact of child behavioural difficulties on carer psychological distress. Some carers’ accounts did suggest a more direct link between short breaks and child outcomes, with stable, sufficient and high quality short breaks associated with increasing child confidence and maturity, and instability or reductions in short breaks associated with increasing child anxiety and problematic behaviours.

Whether directly or indirectly, it seems that short breaks have a role to play in reducing the impact of the child's difficulties on the well-being of carers. These findings also confirm that the central purpose of short breaks is to improve outcomes for family carers. Whilst it is clearly important that the disabled child enjoys the short break with short break carers in environments that families trust, the central function of short breaks is to offer the carer a meaningful break. The accounts of many of the carers in this study seem to describe 'short breaks' that, however enjoyable for the child, do not meet this central function as far as carers are concerned.

Policy and practice implications

The discussion above outlines many implications of this study's findings for policymakers, local authorities and those delivering short break supports. A final list of implications for policymakers and others are presented here.

- Short breaks have a positive direct impact on the health and wellbeing of family carers, and also act to buffer the impact of other stressors on family carers. Clearly, the government policy direction of continued investment in short breaks is strongly supported by these findings. However, the role of the NHS in funding short breaks urgently needs clarification.
- This research reaffirms that the central purpose of short breaks is to provide a meaningful break for family carers to maintain and improve their health, wellbeing and economic circumstances. To achieve this central purpose current patterns of short break allocation and provision need to be revised:
    - The allocation of short breaks should be based on careful assessment and regular review of the needs of the whole family (including assessment of carer health and well-being, child challenging behaviour and the family's financial circumstances) rather than solely on the health needs and level of disability of the disabled child.
    - Short breaks should be designed to actually provide a meaningful break for families; unless they are supporting carer employment (e.g. holiday clubs or after-school activities) short breaks of very short duration are unlikely to provide such a meaningful break for family carers.
    - It is crucial that Education, Care and Health plans proposed for 2014 consider the needs of the whole family and include explicit plans around short breaks for family carers.
- Family carers need to feel a sense of security in their entitlement to and eligibility for short breaks. In this study there was evidence of some withdrawal of short break funding and short break services, substantial fluctuations in short break support, and carer reports of changes being made at short notice and in ways that felt very arbitrary to them:
    - Families should routinely receive clear and comprehensive information about entitlement/eligibility for short breaks, and the range and quantity of short breaks available locally. For individual families, this will require more individualised and detailed information than the Statement required of local authorities by October 2011.

    - Service-defined transition points (e.g. from primary to secondary school) should not have a major impact on the short breaks used by families, unless families themselves consider that such transitions require changes to short break supports for their family.
    - Assessment and review processes should become simpler and more transparent, with family initiated review and reassessment becoming routinely available.
- The widespread implementation of personal budgets for families with a disabled child could help family carers address many of the concerns they express about how short breaks are delivered. For these personal budgets to be effective for families, the following issues will need to be addressed:
    - The personal budget will need to be at a sufficient level to enable carers to choose a sufficient quantity of short break supports they trust, rather than having to make trade-offs between quantity vs quality short break support, especially as families are understandably very reluctant to use unpaid or unskilled short break carers.
    - Families will need excellent and up to date information to make informed decisions about which short breaks to use.
    - Planned commissioning of a sufficient quantity and range of short break services will be needed, by local authorities working closely with families, to enable families to have a meaningful choice of short break options.
    - Processes for allocating and administering personal budgets need to be as simple and free of restrictions as possible, with support in the use of personal budgets available for all those families who want it.

1 Introduction

1.1 Policy and research context

The Centre for Disability Research (CeDR) at Lancaster University in partnership with the National Development Team for Inclusion (NDTi) were commissioned by the Department for Education (then the Department for Children, Schools and Families) to conduct 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'. In commissioning this research the Department had two aims; the first was to commission a programme evaluation of the AHDC Short Break Pathfinder programme; the second 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 Department intended that the research findings would be used to improve the provision and commissioning of short breaks at a local level, to provide information to underpin advice to local authorities, and to inform national policy. The research began in the summer of 2009. In order to be relevant to emerging policy and practice as well as to inform longer term debates the research had staged deadlines for different components of the research programme, including a programme evaluation of the Pathfinder programme (Greig et al., 2010a, b) a comprehensive review of the international research concerning short breaks (Robertson et al., 2010) a qualitative study of the impact of short breaks on families (Langer et al., 2010) and a quantitative survey of families using short breaks to assess the impact of short breaks on families (Welch et al., 2010). 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 contributes to the overall research programme. This report is the second report of the quantitative element of the impact study and comprises findings from follow-up questionnaires sent to families who had previously taken part in the study (See Welch et al., 2010).

The original policy and research context of this study was detailed in the first report from the quantitative element of the study (Welch et al., 2010). Since that time the new coalition Government has affirmed its commitment to short breaks, including through the announcement of £800 million further funding over a four year period (DfE, 2010), through legislation which places a duty on local authorities to provide short breaks (DfE, 2011a) and through the SEN Green Paper which includes proposals for continued provision of short breaks (DfE, 2011c). Data recently reported by the Department for Education (DfE, 2011d) from local authorities suggested that local authorities are planning to increase their spending on short breaks in 2011-2012 by 21% compared to 2010-2011.

In addition the Department for Education has provided new non-statutory advice for local authorities in respect of short breaks which details who should be considered for access to short breaks and the range of breaks that should be provided (DfE, 2011b). The advice also provides further details about how local authorities should meet the new duty to publish a 'Short Breaks Services Statement' from October 2011. Within these documents several clear policy themes are evident, for example there is a strong theme towards participation and involvement, for example the advice document discusses how local parents and carers, children and young people should be consulted, enabled to participate in decision-making and involved in the preparation of the Short Breaks Services Statement. Another clear policy theme is the promotion of choice, flexibility and personalisation, such as through the increased use of personal budgets and direct payments and increasing the range of provision to include short breaks which are available at different times, in different locations and delivered by different providers. A further policy theme is the improvement of partnership working, in particular between local authorities, health services and a range of short break providers in order to increase the effectiveness of services.

1.2 What this report contains and what questions it addresses

In addition to the first quantitative report described above a number of other reports and articles are available from earlier elements of this study. This includes output from an international review of evidence about short breaks (Robertson et al., 2010, Robertson et al., 2011), reports from a realist evaluation of the short break pathfinder programmes (Greig et al., 2010a, b) and reports from the qualitative elements of the study (Collins et al., 2009, Langer et al., 2010). A number of journal articles and papers focussed on specific aspects of short break services are also in preparation, including papers addressing family factors associated with short break use, family views on short break care workers, a consideration of the perceptions of children using short breaks and those of their parents, the transport issues in the use of short breaks and the use of direct payments to fund short breaks.

This report describes the findings from a follow-up survey of families taking part in a longitudinal study of the impact of short breaks. Time 1 and Time 2 were planned to take place approximately 12 months apart, with the former taking part in the early months of 2010. Due to late returns of some responses at Time 1, this time period was in practice slightly reduced; the mean difference achieved between Time 1 and Time 2 was 0.83 yrs, approximately 10 months.

This report does not repeat the cross-sectional analyses reported at Time 1 (Welch et al., 2010), rather this report focuses on questions about how different families' experience of short breaks has changed over the period and which factors predict short break usage and outcomes for carers, households, disabled children and siblings Time 2. In addition we are able to examine the experiences of families in different circumstances to understand how short breaks have impacted on them.

In general terms the research aims to answer the following questions.

- Have the characteristics of families and family members using short breaks changed from Time 1 to Time 2?
- Have patterns of short break usage, short break funding and carer satisfaction with short breaks changed from Time 1 to Time 2?
- Which factors at Time 1 predict short break usage, short break funding and carer satisfaction with short breaks at Time 2?
- Have outcomes for main carers, households, the disabled child and their siblings changed from Time 1 to Time 2?
- Which factors at Time 1, including family usage of short breaks, predict outcomes for main carers, households, the disabled child and their siblings at Time 2?
- What contribution do various short breaks make to outcomes for carers, children and families?
- What changes do carers identify in terms of the outcomes they and their family obtain from short breaks at Time 2?
- What changes do carers identify in terms of their family's experience of using short breaks at Time 2?
- Do carers report improvements in short break services from Time 1 to Time 2?

2 Method

2.1 Outline

The quantitative elements of the impact study were initially designed to comprise a detailed longitudinal cohort study and a larger cross-sectional survey. The first quantitative report (Welch et al., 2010) includes detailed discussion of the study design, ethical issues, sampling processes, materials and measures and the analytic strategies used and so these discussions are not repeated here.

As the response rate from the first iteration of the longitudinal cohort survey was lower than had been hoped, it was decided that families who had taken part in the cross-sectional survey at Time 1 would also be invited to take part at Time 2 along with those families who had originally been recruited to the longitudinal cohort. Families were given the opportunity to opt out before questionnaires were sent; four families contacted the researchers to do so for various reasons. Before any follow-up contact with families was made local authorities notified us of a small number of families who they felt should not be approached, for example due to the death of a child or a child being taken into care.

Time 2 follow-up questionnaires were sent to 120 families from the longitudinal cohort, 227 families from the cross-sectional sample and a further two families who had expressed an interest in taking part. Thus a total of 349 follow-up questionnaires were sent at Time 2.

2.2 Procedure at Time 2

2.2.1 Materials and measures

At Time 1, questionnaires for the longitudinal cohort were prepared for the main carer, additional carer, the disabled child using short breaks and siblings. The measures used in these Time 1 questionnaires assessed various aspects of parent / carer wellbeing, child wellbeing, child relationships, family composition, family economic context, and use and experience of short breaks (see Appendix A for a summary). The measures and questions used in the Time 2 questionnaire were largely identical to those used at Time 1 to facilitate analysis of change over time (see Appendix A). To reduce the length of the questionnaire some background questions already collected at Time 1 were removed (e.g. gender, date of birth) and some other questions were reworded to detect any changes since Time 1 rather than repeat a full description (e.g. household composition, qualifications). The format and structure of the question concerning types of short breaks used was altered in response to feedback from Time 1 respondents. Also in response to comments from carers at Time 1, a small number of items were added to collect further information on areas of interest (see below). Examples of the follow-up questionnaires used at Time 2 are available on request from the authors.

2.2.1.1 Changes in child's diagnoses and condition

Respondents to the main carer questionnaire were asked to indicate whether there had been changes to the child's diagnoses or other significant changes in their child's condition since Time 1. If changes were noted respondents were asked to respond to open questions asking them to describe these changes.

2.2.1.2 Child's communication methods

In response to issues identified by carers at Time 1, a question was added that asked main carers to indicate which of a number of communication methods their child uses regularly and to write in other communication methods used by their child.

2.2.1.3 Information about short breaks, received from local authorities

Six questions were added concerning the information about short breaks made available to respondents from their local authority This section included three questions taken from component parts of the Measure of Process of Care scale (MPOC) (King et al., 1995). Three further questions following the same format were formulated specifically for this study; based on issues raised by carers at Time 1. This set of six questions was incorporated into the main carer's questionnaire.

2.2.1.4 Satisfaction with assessment

A question was added to ascertain carers' satisfaction with the way in which their family's entitlement to short breaks was assessed. The question was compiled following the same format as existing questions assessing satisfaction with other aspects of short breaks and included with that question set in the questionnaires for both main carers and additional carers.

2.2.2 Sample and response

Time 2 follow-up questionnaires were sent to 349 families. Non-responding families were sent one reminder letter after four weeks and then a further reminder after a further four weeks. These reminder letters included reply slips by which families could let the research team know whether or not they intended to take part and whether they required any assistance. For those families indicating that they did not intend to take part the most common reason given was that they no longer used short break services and consequently felt it inappropriate. For families who had opted to respond by telephone interview at Time 1 attempts were also made at Time 2 to contact them in this way. Some opted again to have a telephone interview, others opted to complete the questionnaire themselves and return it by post and the remainder indicated their intention to withdraw from the study.

In total at Time 2, 214 (61%) families returned questionnaires before analysis for this report commenced. Responses received after this point will be incorporated for further analyses and reported elsewhere. In addition completed questionnaires were received from 49 additional carers, 56 children using short breaks and 71 siblings; findings from these will be reported elsewhere. The interval between the return of Time 1 and Time 2 questionnaires was recorded for each respondent family; this ranged from 0.43 years to 1.09 years, with a mean difference of 0.83 years (10 months).

Time 2 responders were compared with non-responders using a number of variables from Time 1 in order to ascertain how representative Time 2 responders were of the Time 1 sample[a]. The full results of these analyses are presented in Appendix B.

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[a] Due to the number of statistical tests, a significance level of $p<0.01$ was used for these analyses

Of the 54 comparisons between Time 2 responders and non-responders on Time 1 variables, 4 were significant at p<0.01. Carers who returned questionnaires at Time 2 were more likely than carers who did not return questionnaires at Time 2 to have a disabled child with behavioural difficulties and lower prosocial behaviour according to the SDQ, and more likely to be receiving more total hours of short breaks and more hours of short breaks provided by unpaid carers.

2.2.3 Analytic strategy

Our aim in this report is to focus on changes over time and factors predicting change, rather than to repeat the cross-sectional analyses of the Time 1 findings (Welch et al., 2010). In this report the quantitative analyses focus on identifying changes between Time 1 and Time 2, and examining factors which predict outcomes for carers, children and families at Time 2. As at Time 1, SPSS software was used for these non-parametric analyses. Qualitative analysis of textual responses focus on what families told us about change over time and any significant changes in themes that are identifiable in Time 2 responses; QSR Nvivo 8 software was used to support these analyses. Two researchers were jointly involved in identifying themes in the qualitative data and coding at Time 2. These researchers reviewed the process on a regular basis and reviewed samples of each other's coding.

The analyses reported here focus on data collected from main carers, as we have substantial data from the same people at both time points to allow analysis of change over time. Time 2 data from additional carers, disabled children and their siblings includes significant data from new respondents (those who did not complete questionnaires at Time 1). These data will be used by pooling them with Time 1 data to generate larger composite samples for analyses and publications looking in detail at these groups.

3 Family context

In this section of the report, we will describe changes in family circumstances and family needs from Time 1 to Time 2 as reported by carers.

3.1 Change and continuity in the child's diagnoses and reported condition

Carers described a number of changes in their disabled child's diagnoses and condition. Whilst it is not suggested that the changes in the child's diagnoses and condition should be attributed to short break usage they do illustrate how quickly the needs of the child and family can change over time, and how both the quantity and type of short breaks need to keep pace with these changes to continue to meet the needs of children and families.

3.1.1 Family context, changes in child's diagnoses

Most carers (86%, n=182) reported that the diagnoses they had reported at Time 1 had not changed. Those that reported a change in diagnosis named a wide range of health, developmental, sensory and behavioural conditions, with some descriptions being very specific and others more general. Examples are provided in Table 1 below; for most these were new additional diagnoses, for others they were refinements of earlier diagnoses.

Table 1. Examples of changes in diagnoses reported at Time 2.

Epilepsy[1] Photosensitive epilepsy Tumours in kidneys Kidney problems Enuresis Tonsillitis Helicobacter Pylori Autistic Spectrum Disorder (ASD) Pathological Demand Avoidance Syndrome (PDA) Attention Deficit Hyperactivity Disorder (ADHD) Obsessive Compulsive Disorder (OCD) Dyslexia Scoliosis Hip problems Registered blind Pigmentation in eyes, developing blindness Behavioural problems Sleeping difficulties Having tests for cause of mobility problems Genetic tests revised original diagnosis
Notes [1] Condition underlined if two or more carers report this change

3.1.2 Family context, changes in child's condition

More than half (60%, n=127) of families stated that their child's condition had not changed significantly over the last year; 40%, (n=86) reported that significant changes had occurred over the last year. Most carers reporting change (78%, n=66) noted changes which were negative overall. A small number of carers did note improvements in their child's condition, most often these were attributed to the child's maturation. Changes reported by carers are examined in more detail below.

3.1.2.1 Changes in child's physical health

Many of these families described changes in their child's physical health. These included emerging or worsening orthopaedic problems such as frequent dislocations, spinal and rib problems, limb problems and resultant effects on mobility and problems associated with orthopaedic surgery and treatment (managing pain, caring for child in a body cast, increased need for parents to perform physiotherapy tasks etc). Surgical operations and forthcoming surgery had particular resonance for several families, descriptions included *'major surgery needed'* and *'had life-threatening surgery'*. A small number of families reported that following surgery and convalescence their child's condition had improved.

Emerging or increased problems with epilepsy were also reported by several families; these included a greater number or severity of seizures, continued deterioration in their child's cognitive functions attributed to epilepsy and problems with anti-convulsive medication; however a small number of families did report that changes in epilepsy medication had improved their child's condition.

A number of children had developed other new conditions over the last year, these included diabetes, myoclonus (tremors / jerks), cyclical vomiting syndrome, irritable bowel syndrome, food intolerances and tumours. Some families noted that other aspects of their child's physical health had deteriorated, such as greater frailty, greater susceptibility to infection, greater reliance on oxygen, more sores, worsening incontinence, losing the ability to swallow and increased spasticity / rigidity. Worsening sensory impairments were noted by a small number of families, in particular deteriorating sight and hearing; in turn these issues were linked to greater frustration and communication difficulties. A small number of families noted that the only remaining treatment for their child was palliative care.

3.1.2.2 Changes in child's mental health, behaviour and cognitive function

Many families described their child's deteriorating mental health or problematic behaviour. Several families reported that their child had experienced increased anxiety, stress, paranoia, tearfulness or frustration. Several carers reported that their child had developed greater problems with sleeping, eating, self-harming and obsessive thoughts or compulsive behaviours. Many families described deterioration in behaviour which became more challenging, demanding, volatile and in many cases aggressive or violent; many carers suggested that these changes had a significant impact on their ability to cope with (and care for) their child. A small number of carers reported that their child had more problems with learning or memory.

A small number of carers noted modest but significant improvements in behaviour, confidence, independence and 'maturity' over the year. Similarly a small number of carers reported improvements in communication skills (e.g. started using PECS or Makaton) or that their child was developing a greater awareness of the family and the environment.

3.1.2.3 Changes attributed to child’s aging

Many carers described how the child’s growth made it more difficult to care for their child, for example children were heavier and more difficult to lift, dress, change or handle. Furthermore as a result of being larger and taller some children were able to reach or access more areas and were consequently exposed to more hazards. Many children with challenging or violent behaviour were significantly more difficult to control because of their increasing size, in some cases children were now said to be bigger and stronger than their carers.

In many cases carers explained changes in their child as being due to approaching or going through adolescence and puberty; in particular increases in aggression, temper, wilfulness, moodiness and self-harm were often attributed to puberty.

3.2 Changes and continuity in family contexts

3.2.1 Household context

The composition of households at Time 2 remained broadly similar to that at Time 1. As at Time 1 households ranged in size from two to 14 members, the mean number of members was 3.9 (s.d 1.17). As at Time 1 most households at Time 2 (88%, n=187) contained between three and five members. Main carer respondents were asked to indicate whether anyone had left the household and whether anyone had joined the household. Seventeen families (8%) indicated that someone had left, these people were most often siblings of the disabled child, a small number of parents had also left households. Nine (4%) carers indicated that someone had joined the household these people included parents, step parents, siblings of the disabled child (including new babies) and other relatives.

There were no significant changes between Time 1 and Time 2 in terms of marital status, lone parenting and whether or not the household contained more than one disabled child.

3.2.2 Carer and partner qualifications

10% (n=21) of carers reported gaining a qualification during the last year. These qualifications ranged in level from basic skills (e.g. NVQ Level 1) through to higher degree and higher professional levels. Most qualifications were vocational and usually linked to the current occupation of the respondent. Five carers reported that their partner had gained a qualification in the last year, these qualifications ranged from NVQ level 3 through to higher professional qualifications, as in the case of carers these qualifications were linked to current occupation.

3.2.3 Carer and partner employment

The proportions of main carers and partners working part-time and full-time are very similar at Time 1 and Time 2. Furthermore there were no statistically significant differences between main carers’ or main carer’s partners’ overall employment status from Time 1 to Time 2 indicating stability in employment patterns over this time period.

4 Short breaks

4.1 Short break usage over time

We investigated patterns of family usage of short breaks from Time 1 to Time 2 in several ways to build up a picture of continuity and change in family usage of short breaks over this relatively short time period. Because of the relatively large sample size and the number of statistical tests conducted, the statistical significance level was set at p<0.01 for all statistical tests.

4.1.1 Overall usage of short breaks

We used two indicators to investigate continuity and change in the short breaks used by families overall; the number of different types of short breaks used by families and the total number of hours of short breaks used by families.

Family usage of eight specific types of short break were summed to produce an indicator of the range of short break types used by families at Time 1 and Time 2. As Table 2 below shows, at Time 1 families were using an average 2.44 different types of short break, with 7.5% of families not using any type of short break. At Time 2, families were using an average of 2.13 different types of short break, with 10.7% not using any types of short break. These findings indicate a statistically significant reduction in the range of short breaks used from Time 1 to Time 2.

Table 2 Range of short break types and total hours of short breaks used by families at Time 1 and Time 2

Indicator	Time 1	Time 2	Magnitude (and direction) of change (Wilcoxon test)
Range of short breaks types used (n=214)			
Mean (s.d.)	2.44 (1.53)	2.13 (1.31)	z=-2.86, n=214, p=0.004
Median	2.00	2.00	
Range	0 – 7	0 – 6	Reduction in range of short break types used T1 > T2
Families using no short breaks	16 (7.5%)	23 (10.7%)	
Total number of short break hours used per year (T1 n=188; T2 n=212)			
Mean (s.d.)	591 (660)	668 (708)	z=1.76, n=187, p=0.079
Median	360	455	
Range	0 - 4290	0 - 4935	

Table 2 also shows that there was no statistically significant change in the total number of short break hours used by families from Time 1 to Time 2. However, the median hours used of 360 hours per year at Time 1 and 450 hours per year at Time 2 conceal massive variation in the total hours of short breaks used by families across the sample.

Figure 1 shows the total number of hours of short breaks used by families at Time 2, broken down into 100-hour per year bands. As Figure 1 shows, the range of hours of short breaks used by families is huge, with most families using less than 400 hours of short breaks per year.

Figure 1 Total hours per year of short breaks used by families at Time 2

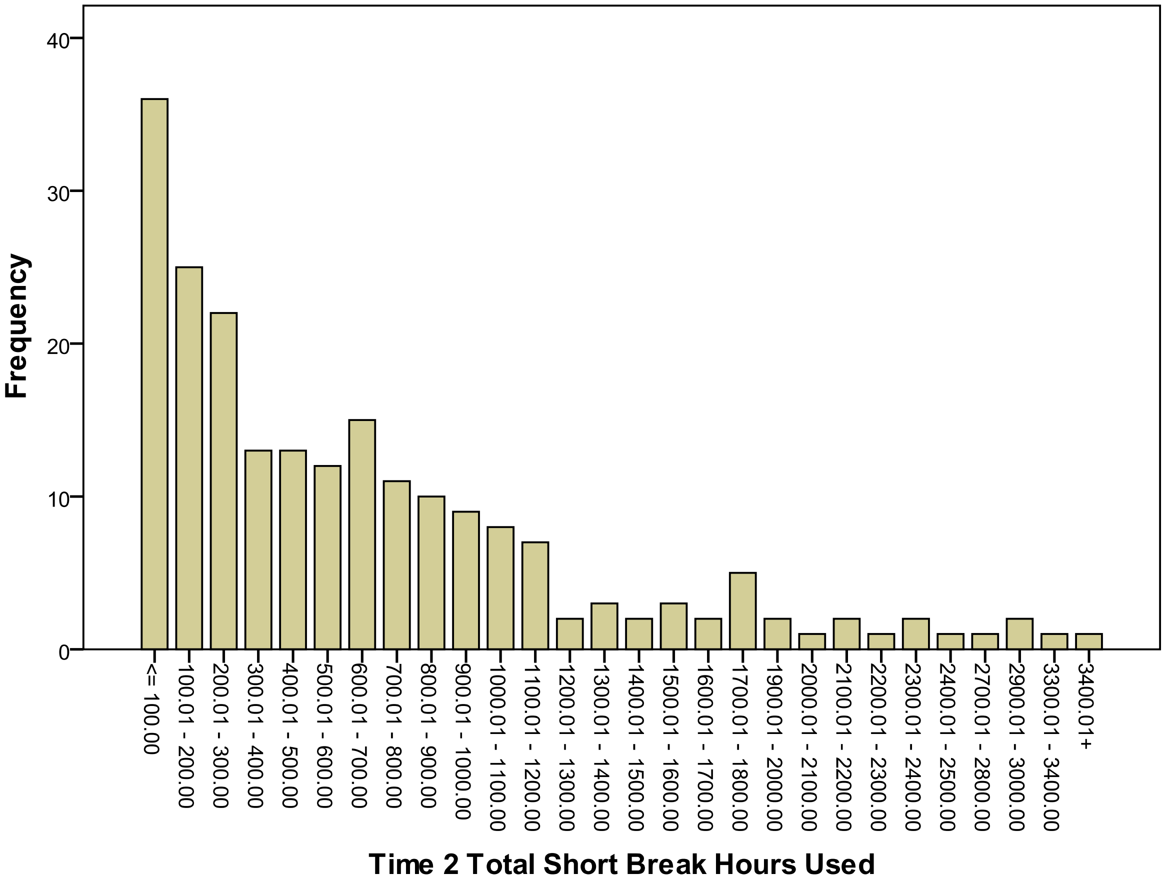
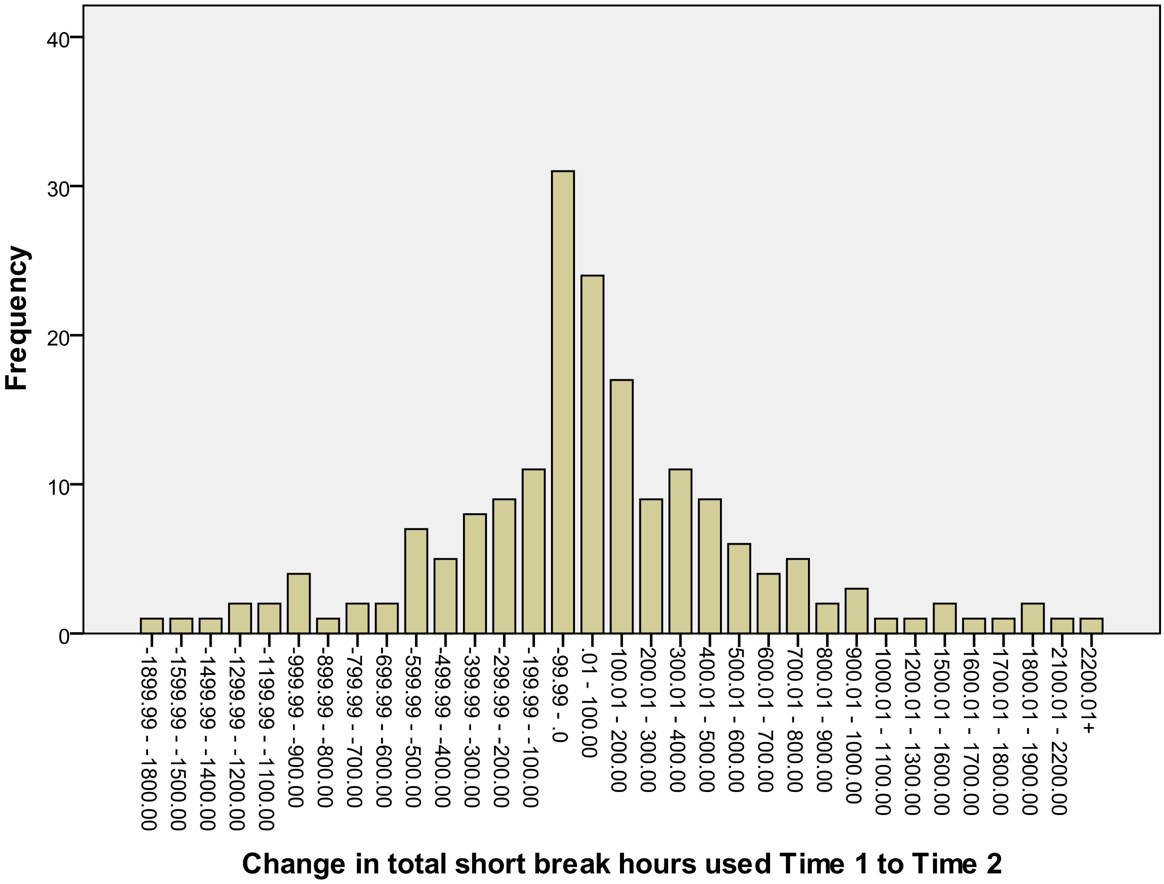


Figure 2 shows changes in the total number of short break hours used by families from Time 1 to Time 2. As Figure 2 shows, relatively few families reported stability in the number of hours of short breaks they used from Time 1 to Time 2; only 29% of families reported increases or decreases of less than 100 hours per year in their short break usage over the ten month period. Although the overall median change in total short break hours was near to zero (median change +34 hours per year), there were many cases of extreme change, including increases in short break hours of up to 2,277 hours per year balanced by reductions in short break hours of 1,896 hours per year.

Figure 2 Change in total number of short break hours used per year by families Time 1 to Time 2



4.1.2 Usage of specific types of short breaks

As well as investigating continuity and change in overall short break usage, we also explored continuity and change in the number of families using particular types of short break from Time 1 to Time 2. For each type of short break there were four possibilities:

- Families had not used the short break at Time 1 or Time 2
- Families had used the short break both at Time 1 and Time 2
- Families had not used the short break at Time 1 but had started using it at Time 2
- Families had been using the short break at Time 1 but had stopped using it at Time 2

Table 3 presents this information for eight specific types of short break.

As Table 3 shows, at Time 2 the types of short break most commonly used by families were centre-based short breaks (98 families, 46%) and short breaks where a paid carer spent some time with the disabled child away from the family home (but not overnight; 90 families; 42%). Other commonly used short breaks at Time 2 were leisure short breaks, both of the sports, arts/crafts, play variety (74 families; 35%) and of the variety based around school hours/holidays (74 families; 35%), and short breaks where a paid carer spent some time in the family home (but not overnight; 70 families; 33%).

From Time 1 to Time 2, there were significant reductions in the number of families using sports, arts/crafts, play-type leisure short breaks (from 110 families at Time 1 to 74 families at Time 2) and in the number of families using family/friends as unpaid short break carers (from 44 families at Time 1 to 20 families at Time 2). Even when there were no overall changes in short break usage from Time 1 to Time 2, Table 3 shows considerable fluctuations in family usage of all types of short break over the 10 months from Time 1 to Time 2.

Table 3 Family usage of specific types of short breaks at Time 1 and Time 2

Type of Short Break	Number (percentage) of families		Magnitude and direction of change (McNemar test)
Leisure Short Break (sports, arts/crafts, play)	No T1 and T2 Yes T1 and T2 No T1 > Yes T2 Yes T1 > No T2 Total usage at T1 Total usage at T2	77 (36%) 47 (22%) 27 (13%) 63 (29%) 110 (51%) 74 (35%)	Chi-square=13.61, n=214, p<0.001 Significant reduction in number of families using leisure short breaks T1 > T2
Leisure Short Break (after-school clubs, extended school clubs, school holiday clubs)	No T1 and T2 Yes T1 and T2 No T1 > Yes T2 Yes T1 > No T2 Total usage at T1 Total usage at T2	114 (53%) 41 (19%) 33 (15%) 26 (12%) 67 (31%) 74 (35%)	Chi-square=0.61, n=214, p=0.44 No change in number of families using leisure (school-related) short breaks T1 > T2
Centre-based Short Break (including overnight)	No T1 and T2 Yes T1 and T2 No T1 > Yes T2 Yes T1 > No T2 Total usage at T1 Total usage at T2	96 (45%) 76 (36%) 22 (10%) 20 (9%) 96 (45%) 98 (46%)	Chi-square=0.02, n=214, p=0.88 No change in number of families using centre-based short breaks T1 > T2
Daytime Paid Carer Short Break – Away from the family home	No T1 and T2 Yes T1 and T2 No T1 > Yes T2 Yes T1 > No T2 Total usage at T1 Total usage at T2	93 (43%) 53 (25%) 37 (17%) 31 (14%) 84 (39%) 90 (42%)	Chi-square=0.37, n=214, p=0.54 No change in number of families using daytime paid carer short breaks away from the family home T1 > T2
Daytime Paid Carer Short Break – In the family home	No T1 and T2 Yes T1 and T2 No T1 > Yes T2 Yes T1 > No T2 Total usage at T1 Total usage at T2	134 (63%) 46 (21%) 24 (11%) 10 (5%) 56 (26%) 70 (33%)	Chi-square=4.97, n=214, p=0.030 No change in number of families using daytime paid short breaks in the family home T1 > T2
Overnight Paid Carer Short Break – Away from the family home	No T1 and T2 Yes T1 and T2 No T1 > Yes T2 Yes T1 > No T2 Total usage at T1 Total usage at T2	172 (80%) 17 (8%) 8 (4%) 17 (8%) 34 (16%) 25 (12%)	n=214, exact p=0.11 No change in number of families using overnight paid carer short breaks away from the family home T1 > T2

Type of Short Break	Number (percentage) of families		Magnitude and direction of change (McNemar test)
Overnight Paid Carer Short Break – In the family home	No T1 and T2 Yes T1 and T2 No T1 > Yes T2 Yes T1 > No T2 Total usage at T1 Total usage at T2	204 (95%) 3 (1%) 1 (0%) 6 (3%) 9 (4%) 4 (2%)	n=214, exact p=0.13 No change in number of families using overnight paid carer short breaks in the family home T1 > T2
Any Unpaid Carer (family or friend) Short Break	No T1 and T2 Yes T1 and T2 No T1 > Yes T2 Yes T1 > No T2 Total usage at T1 Total usage at T2	160 (75%) 10 (5%) 10 (5%) 34 (16%) 44 (21%) 20 (9%)	Chi-square=12.02, n=214, p=0.001 Significant reduction in number of families using unpaid carer short breaks T1 > T2

Table 4 below presents data on the number of hours used by families for each specific type of short break at Time 1 and Time 2. Because the numbers of families using specific types of short break varied, these statistics are for all families using the specific type of short break at a specific time point. The numbers of families represented in Table 4 may also be smaller than in Table 3 as some families reported that they used a specific type of short break without specifying the number of hours for which they used that short break.

For those families who were using the same type of short break at Time 1 and Time 2, we also investigated whether there were any changes in the number of short break hours that families were using for each type of short break (see the final column of Table 4).

As Table 4 shows, there were different patterns of average hours associated with usage of different types of short break, although again there was massive variation in the number of hours that families received within each specific type of short break. At Time 2, usage of centre-based short breaks (median 582 hours per year used by 98 families), paid carer short breaks overnight in the family home (median 950 hours per year used by 4 families) and paid carer short breaks overnight away from the family home (median 288 hours per year used by 25 families) had the highest number of hours attached to them. For all other types of short breaks, all of which did not involve overnight support, the average number of hours received per year per family was similar and at a lower level (median 82 – 150 hours per year).

For those families using each specific type of short break at Time 1 and Time 2, Table 4 shows that there were no statistically significant changes in the number of hours used by families from Time 1 to Time 2.

Table 4 Number of hours of specific types of short break at Time 1 and Time 2

Indicator	Time 1	Time 2	Magnitude (and direction) of change (Wilcoxon test)
Leisure Short Break (sports, arts/crafts, play)	N=88	N=74	z=1.28, n=40, p=0.20 No change in the number of hours of sports/arts/crafts/leisure short breaks received by families T1 > T2
Mean (s.d.)	94.8 (75.1)	138.2 (119.0)	
Median	80.0	105.3	
Range	1 – 360	9 – 690	
Leisure Short Break (after-school clubs, extended school clubs, school holiday clubs)	N=59	N=74	z=1.67, n=35, p=0.10 No change in the number of hours of school-related leisure short breaks received by families T1 > T2
Mean (s.d.)	100.8 (73.5)	119.9 (98.0)	
Median	80.0	82.0	
Range	4 - 360	6 – 475	
Centre-based Short Break (including overnight)	N=80	N=98	z=1.96, n=61, p=0.05 No change in the number of hours of centre-based (including overnight) short breaks received by families T1 > T2
Mean (s.d.)	558.0 (480.6)	682.9 (494.8)	
Median	474.0	582.0	
Range	36 – 2214	24 – 2400	
Daytime Paid Carer Short Break – Away from the family home	N=70	N=90	z=-0.36, n=45, p=0.72 No change in the number of hours of daytime paid carer (away from home) short breaks received by families T1 > T2
Mean (s.d.)	199.0 (205.7)	200.6 (219.2)	
Median	150.0	150.0	
Range	8 – 1300	6 – 1680	
Daytime Paid Carer Short Break – In the family home	N=47	N=69	z=-0.48, n=41, p=0.63 No change in the number of hours of daytime paid carer (in the home) short breaks received by families T1 > T2
Mean (s.d.)	203.0 (241.4)	241.4 (264.6)	
Median	156.0	150.0	
Range	4 – 1500	4.5 – 1288	
Overnight Paid Carer Short Break – Away from the family home	N=26	N=25	Z=-1.2, n=13, p=0.24 No change in the number of hours of overnight paid carer (away from the home) short breaks received by families T1 > T2
Mean (s.d.)	352.1 (263.2)	382.8 (390.7)	
Median	252.0	288	
Range	10 – 1076	12 – 1680	

Indicator	Time 1	Time 2	Magnitude (and direction) of change (Wilcoxon test)
Overnight Paid Carer Short Break – In the family home Mean (s.d.) Median Range	N=6 1576.3 (1320.1) 1911.0 2 – 3270	N=4 1405.8 (1717.9) 950.0 48 – 3675	Test statistic cannot be reliably calculated (n=2)
Any Unpaid Carer (family or friend) Short Break Mean (s.d.) Median Range	N=33 305.0 (427.3) 200.0 9 - 2000	N=20 287.0 (365.7) 111.0 12 - 1200	Test statistic cannot be reliably calculated (n=5)

4.2 Short break funding over time

4.2.1 Changes in funding for short breaks

As well as investigating short break usage, we also explored continuity and change in how short breaks were funded from Time 1 to Time 2. For each source of funding there were four possibilities:

- Families had not received funding from this source at Time 1 or Time 2
- Families had received funding from this source at both at Time 1 and Time 2
- Families had not received funding from this source at Time 1 but had started getting funding from this source at Time 2
- Families had been getting funding from this source at Time 1 but had stopped getting it at Time 2

Table 5 presents this information for five sources of short break funding.

At Time 2, by far the most common source of funding for short breaks was the local authority (140 families; 75%), with significant numbers of families at Time 2 reporting getting direct payments for short breaks (71 families; 38%), using private/self-funding arrangements for short breaks (62 families; 33%) and getting funding for short breaks from other sources (e.g. charities) (42 families; 22%). By Time 2, only a small minority of families were getting NHS funding for short breaks (11 families; 6%).

Table 5 also presents information on changes in funding for short breaks from Time 1 to Time 2. As Table 5 shows, there was a statistically significant reduction in the number of families getting NHS funding for short breaks from Time 1 to Time 2 (from 22 families at Time 1 to 11 families at Time 2), and a statistically significant increase in the number of families using private/self-funding arrangements for short breaks (from 33 families at Time 1 to 62 families at Time 2). There were no changes in the number of families getting local authority funding or direct payments for short breaks from Time 1 to Time 2.

Table 5 Sources of funding for short breaks at Time 1 and Time 2

Source of Funding	Number (percentage) of families		Magnitude and direction of change (McNemar test)
NHS funding	No T1 and T2	163 (87%)	n=187, exact p=0.007 Significant reduction in number of families getting NHS funding for short breaks T1 > T2
	Yes T1 and T2	9 (5%)	
	No T1 > Yes T2	2 (1%)	
	Yes T1 > No T2	13 (7%)	
	Total funding at T1	22 (12%)	
	Total funding at T2	11 (6%)	
Local authority funding	No T1 and T2	25 (13%)	Chi-square=1.56, n=186, p=0.21 No change in number of families getting local authority funding for short breaks T1 > T2
	Yes T1 and T2	109 (59%)	
	No T1 > Yes T2	31 (17%)	
	Yes T1 > No T2	21 (11%)	
	Total funding at T1	130 (70%)	
	Total funding at T2	140 (75%)	
Direct payments	No T1 and T2	108 (57%)	Chi-square=2.70, n=189, p=0.10 No change in number of families getting direct payments for short breaks T1 > T2
	Yes T1 and T2	51 (27%)	
	No T1 > Yes T2	20 (11%)	
	Yes T1 > No T2	10 (5%)	
	Total funding at T1	61 (32%)	
	Total funding at T2	71 (38%)	
Private/self funding	No T1 and T2	110 (59%)	Chi-square=12.85, n=188, p<0.001 Significant increase in number of families using private/self-funding sources for short T1 > T2
	Yes T1 and T2	17 (9%)	
	No T1 > Yes T2	45 (24%)	
	Yes T1 > No T2	16 (9%)	
	Total funding at T1	33 (18%)	
	Total funding at T2	62 (33%)	
Other source of funding	No T1 and T2	135 (70%)	Chi-square=4.17, n=193, p=0.04 No change in number of families getting other sources of funding for short breaks T1 > T2
	Yes T1 and T2	11 (6%)	
	No T1 > Yes T2	31 (16%)	
	Yes T1 > No T2	16 (8%)	
	Total funding at T1	27 (14%)	
	Total funding at T2	42 (22%)	

4.2.2 Short break funding and short break usage at Time 2

Given changes in patterns of funding and short break usage over time, we explored associations between sources of funding for short breaks and family usage of specific types of short breaks at Time 2. Because families did not report to us how each type of short break they used was funded, we can only investigate broad associations between funding source and short break usage – i.e. are families getting funding from a specific funding source more or less likely to use a specific type of short break than families not getting funding from that specific funding source.

Table 6 presents the findings of the statistical tests conducted to investigate these associations. Due to the small number of families using paid carers for overnight short breaks in the family home, statistical tests could not be conducted for usage of this type of short break. We also did not conduct statistical tests concerning usage of unpaid family/friend carers for short breaks, as this type of short break is by definition unfunded.

We can summarise the findings from Table 6 as follows:

- Families receiving NHS funding for short breaks are more likely to be using centre-based (including overnight) short breaks and daytime short breaks involving a paid carer in the family home.
- Families receiving local authority funding for short breaks are more likely to be using school-related leisure short breaks, centre-based (including overnight) short breaks and daytime short breaks involving a paid carer in the family home.
- Families using direct payments to fund short breaks are more likely to be using daytime short breaks involving a paid carer away from the family home and daytime short breaks involving a paid carer in the family home.
- Families using private arrangements/self-funding to fund short breaks are more likely to use both types of leisure short breaks.

Table 6 Associations between sources of funding and short break usage at Time 2

Source of Funding	Number (%) of families getting funding who use the short break	Number (%) of families not getting funding who use the short break	Magnitude and direction of change (Fisher's exact test)
NHS Funding			
Leisure – sports/arts/play	2 (18.2%)	71 (37.6%)	n=200, p=0.33
Leisure – school-related	5 (45.5%)	68 (36.0%)	n=200, p=0.53
Centre-based	10 (90.9%)	86 (45.5%)	n=200, p=0.004*
Daytime paid carer out of home	4 (36.4%)	86 (45.5%)	n=200, p=0.39
Daytime paid carer in home	9 (81.8%)	60 (31.7%)	n=200, p=0.001*
Overnight paid carer away	0 (0.0%)	25 (13.2%)	n=200, p=0.37
Local Authority Funding			
Leisure – sports/arts/play	60 (40.8%)	13 (24.5%)	n=200, p=0.045
Leisure – school-related	64 (43.5%)	9 (17.0%)	n=200, p<0.001**
Centre-based	86 (58.5%)	10 (18.9%)	n=200, p<0.001**
Daytime paid carer out of home	72 (49.0%)	18 (34.0%)	n=200, p=0.08
Daytime paid carer in home	59 (40.1%)	10 (18.9%)	n=200, p=0.007*
Overnight paid carer away	21 (14.3%)	4 (7.5%)	n=200, p=0.24
Direct payments			
Leisure – sports/arts/play	27 (36.5%)	46 (35.9%)	n=202, p=1.00
Leisure – school-related	30 (40.5%)	44 (34.4%)	n=202, p=0.45
Centre-based	35 (47.3%)	62 (48.4%)	n=202, p=0.89
Daytime paid carer out of home	44 (59.5%)	46 (35.9%)	n=202, p=0.002*
Daytime paid carer in home	43 (58.1%)	26 (20.3%)	n=202, p<0.001**
Overnight paid carer away	10 (13.5%)	15 (11.7%)	n=202, p=0.83
Private/self funding			
Leisure – sports/arts/play	39 (58.2%)	35 (26.1%)	n=201, p<0.001**
Leisure – school-related	34 (50.7%)	39 (29.1%)	n=201, p=0.003*
Centre-based	31 (46.3%)	66 (49.3%)	n=201, p=0.77
Daytime paid carer out of home	32 (47.8%)	58 (43.3%)	n=201, p=0.55
Daytime paid carer in home	23 (34.3%)	46 (34.3%)	n=201, p=1.00
Overnight paid carer away	8 (11.9%)	17 (12.7%)	n=201, p=1.00
Other source of funding			
Leisure – sports/arts/play	21 (47.7%)	53 (33.1%)	n=204, p=0.08
Leisure – school-related	22 (50.0%)	52 (32.5%)	n=204, p=0.036
Centre-based	25 (56.8%)	72 (45.0%)	n=204, p=0.18
Daytime paid carer out of home	21 (47.7%)	69 (43.1%)	n=204, p=0.61
Daytime paid carer in home	22 (50.0%)	47 (29.4%)	n=204, p=0.012
Overnight paid carer away	7 (15.9%)	18 (11.3%)	n=204, p=0.44

Statistical significance, *p<0.01; **p<0.001

4.3 Short break satisfaction over time

4.3.1 Carer satisfaction with short breaks

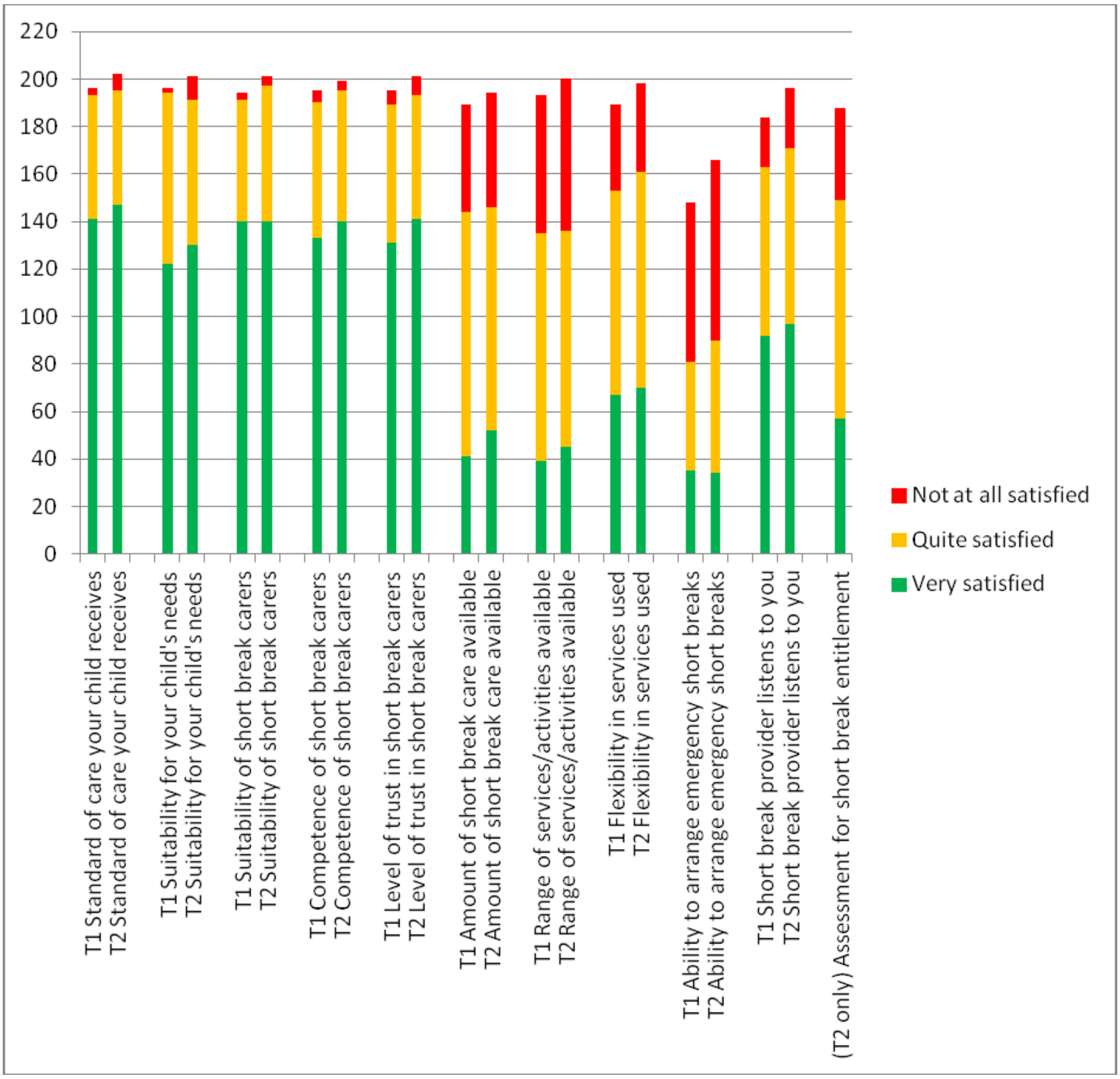
At both Time 1 and Time 2, we asked main carers about their satisfaction with 10 different aspects of short breaks. At Time 2, in response to main carers' accounts at Time 1, we added an additional question about carer satisfaction with how eligibility assessments for short breaks were conducted.

Figure 3 below presents main carer responses to each satisfaction question at Time 1 and Time 2. As Figure 3 shows (supported by statistical testing using Wilcoxon's tests), main carer satisfaction with every aspect of short breaks did not change significantly from Time 1 to Time 2.

At both time points, main carers reported very high levels of satisfaction with all aspects of short break provision, including the standard and suitability of short breaks, the suitability, competence and trustworthiness of short break carers, and the extent to which short break providers listen to carers' views. For later analyses, we summed these questions together into an overall measure of carer satisfaction with short break providers.

Lower levels of satisfaction were reported concerning the amount, range and flexibility of short break services available, the assessment process for determining eligibility for short breaks, and the capacity to arrange emergency short break cover. For later analyses, we summed these questions together (except the eligibility assessment question) into an overall measure of carer satisfaction with the systems surrounding access to short break provision.

Figure 3 Main carer satisfaction with short breaks at Time 1 and Time 2



At Time 1 and Time 2, we also asked main carers whether their families' experiences of using short breaks had improved in the past 12 months.

- At Time 1, 88 families (45%) reported that short break services had improved, 69 families (36%) reported that they had not improved and 37 families (19%) reported that they didn't know.
- At Time 2, 62 families (32%) reported that short break services had improved, 88 families (45%) reported that they had not improved and 44 families (23%) reported that they didn't know.

4.3.2 Short break usage and satisfaction with short breaks at Time 2

First, we investigated overall associations between family short break usage and carer satisfaction with short breaks at Time 2 by calculating Spearman's correlations between each carer satisfaction question and two indicators of overall short break usage; the total number of hours of short break support received by families and the range of different types of short break used by families.

The total number of short break hours used by families at Time 2 was significantly positively associated with greater carer satisfaction with the following aspects of short breaks[b]:

- The standard of care the child receives (r=-0.22, n=200, p=0.002)
- The range of services/activities available to your family (r=-0.21, n=198, p=0.003)
- The extent to which short break providers listen to your views (r=-0.23, n=194, p=0.001)
- The assessment process for determining eligibility for short breaks (r=-0.24, n=187, p=0.003)

The range of short break services used by families at Time 2 was not associated with any aspect of carer satisfaction with short breaks.

We also investigated associations between carer satisfaction with short breaks at Time 2 and the change in the total number of hours of short breaks used by families from Time 1 to Time 2. There were no associations between changes in short break hours from Time 1 to Time 2 and any dimensions of carer satisfaction with short breaks at Time 2.

Finally, we explored whether family usage of specific types of short break at Time 2 were associated with overall carer satisfaction with short break providers and overall carer satisfaction with the systems surrounding access to short break provision at Time 2. Family usage of only one type of short break, overnight paid carer short breaks away from the family home, was associated with greater overall carer satisfaction with short break providers (U=1581.5, n=197, p=0.006).

4.4 Time 1 Factors predicting short break outcomes at Time 2

Given a pattern of substantial fluctuations in short break usage over the ten months from Time 1 to Time 2, we wanted to investigate whether any child, carer or household factors at Time 1 predicted both family usage of short breaks at Time 2 and overall changes in short break usage from Time 1 to Time 2. This is a way of investigating whether changes in short break usage from Time 1 to Time 2 are the result of short break allocations being targeted

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[b] The negative r values in these correlations indicate a relationship between greater satisfaction and greater number of hours because higher levels of satisfaction were coded with lower numbers.

on the basis of the needs of the disabled child and/or their families – if such needs-based allocation of short breaks was happening we would expect to see disabled children and families in greater need at Time 1 getting greater access to short breaks at Time 2.

We conducted a number of univariate analyses to determine which child, carer, household and short break factors at Time 1 were associated with various short break outcomes at Time 2. Given the large number of variables in the analyses we report only those which were significant at the p=<0.01 level. These analyses are reported in full in Appendix C and summarised in Figures 4 and 5 below. Figures 4 and 5 show only those variables where a significant association was observed.
Figure 4 shows that, despite considerable fluctuation over time, family usage of many types of short break service at Time 2 was not predicted by any factors at Time 1. This suggests that changes in short break allocation are not firmly based on child or family needs.

- Greater family usage of short breaks at Time 2 was principally predicted by factors concerned with the disabled child at Time 1. Families receiving more total hours of short breaks at Time 2, and families using centre-based and daytime/evening paid carer short breaks in the family home at Time 2 were more likely at Time 1 to have an older disabled child with severe learning disabilities and complex health needs but fewer emotional difficulties.
- Families getting NHS or local authority funding for short breaks at Time 1 and who were using a wider range of other child-oriented services were also more likely to receive more total hours of short break support at Time 2.
- Families using unpaid carers for short breaks at Time 2 were more likely at Time 1 to have a disabled child showing more prosocial behaviour and less hyperactivity.

Figure 5 shows that very few factors at Time 1 predicted whether families were receiving funding from various sources for short breaks at Time 2.

- Families receiving NHS funding for short breaks at Time 2 were more likely at Time 1 to have a disabled child with more complex health needs, and to be less worried about money.
- Families receiving local authority funding for short breaks at Time 2 were more likely at Time 1 to have a disabled child showing lower levels of prosocial behaviour.
- Finally, families receiving direct payments for short breaks at Time 2 were more likely at Time 1 to be using a wider range of other child-oriented services.

Figure 5 also shows that few factors at Time 1 predicted carer satisfaction with short breaks at Time 2.

- Greater carer satisfaction with short break providers at Time 2 was predicted by families using overnight short breaks with a paid carer away from the family home and main carers reporting greater satisfaction with life at Time 1.
- Greater carer satisfaction with the systems surrounding short breaks at Time 2 was predicted by families using overnight short breaks with a paid carer away from the family home and families getting more total hours of short break support at Time 1.

Figure 4 Time 1 Factors predicting short break usage outcomes at Time 2

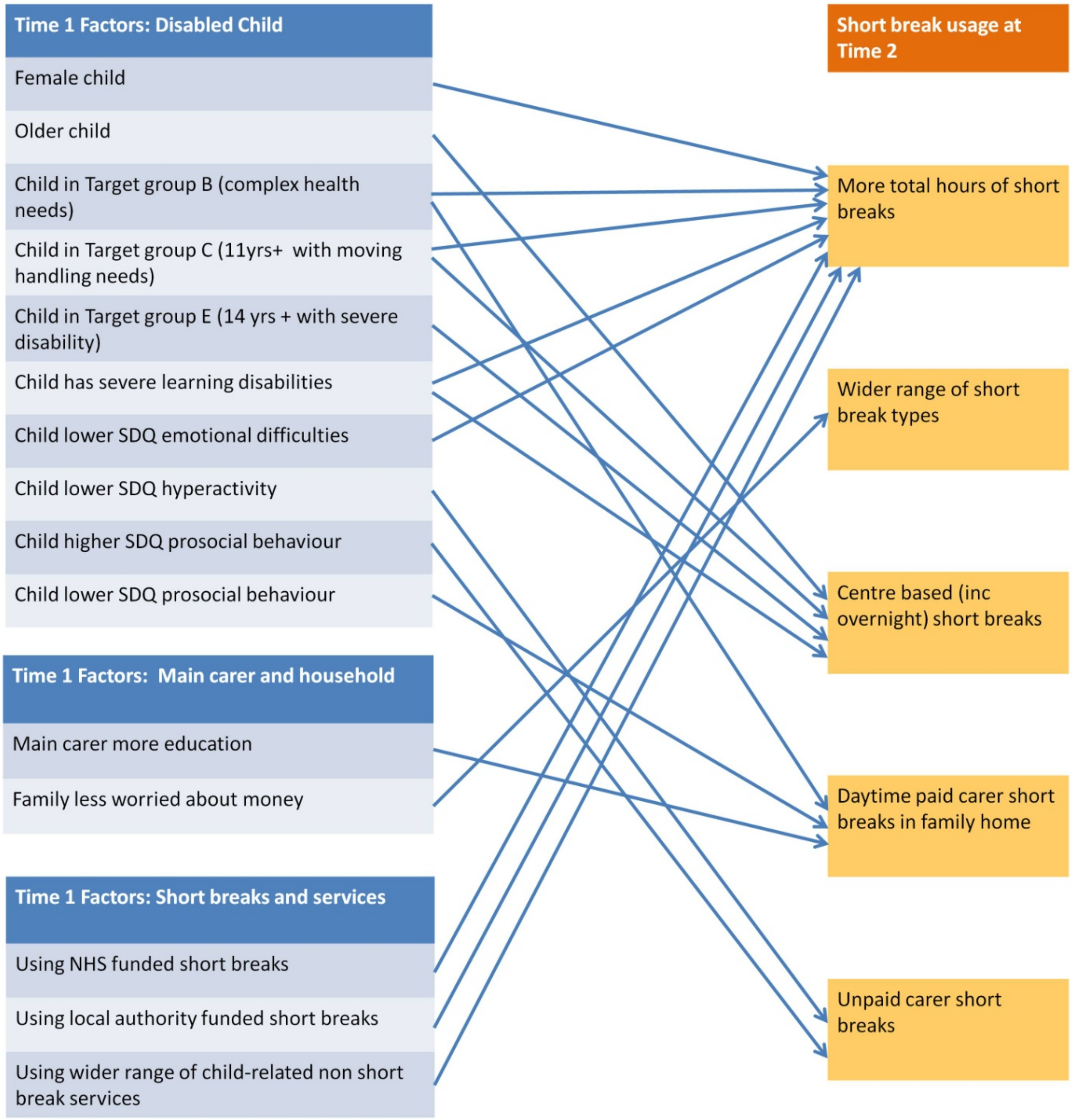
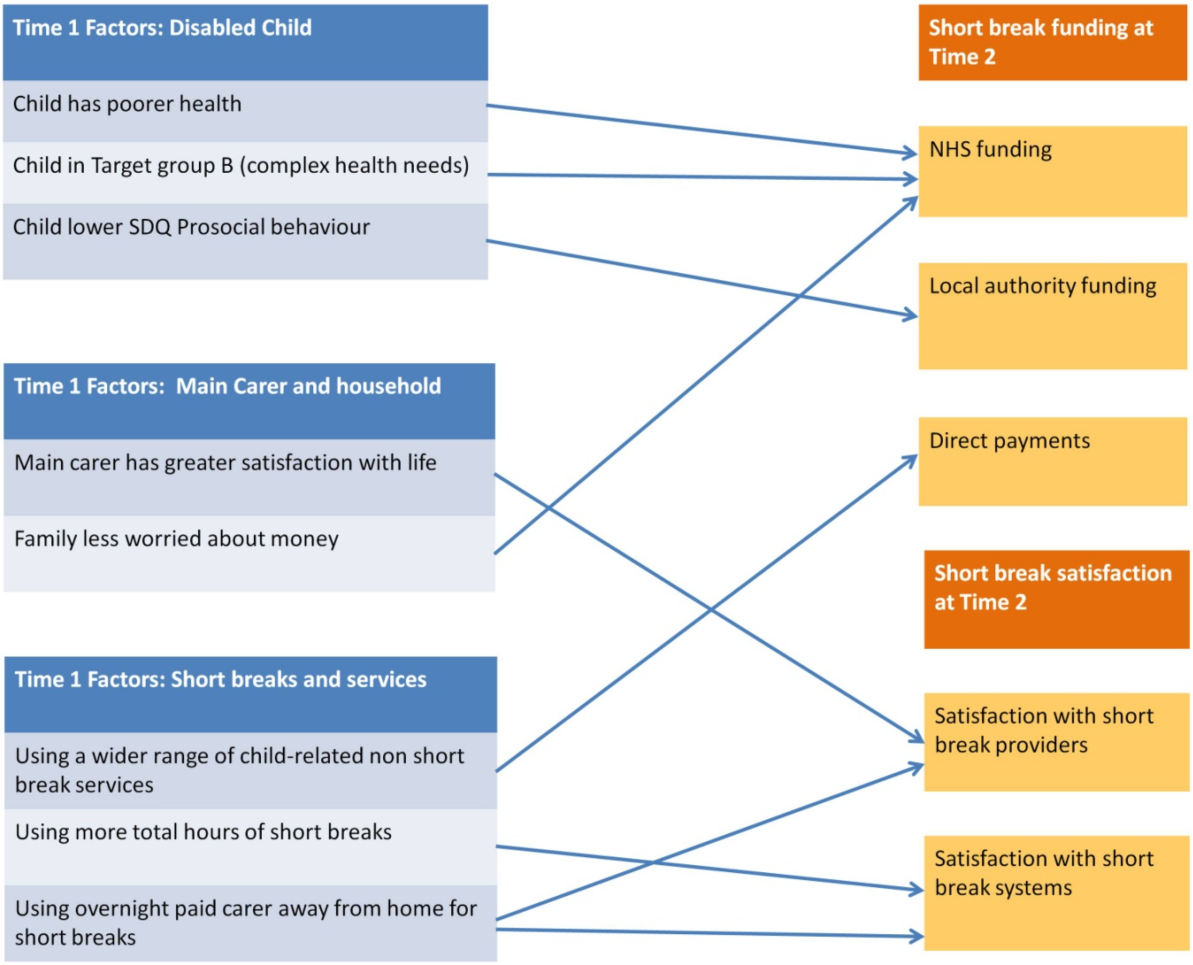


Figure 5 Time 1 Factors predicting short break funding and satisfaction outcomes at Time 2



4.5 Children’s ages and short break usage

Figures 6 to 8 present data on the relationship between the use of short breaks (in terms of mean total hours used) and the age of the disabled child, primarily to explore potential changes in short breaks across transition points in other services for the disabled child/young person. Data from children and young people younger than 5 years and older than 20 years were excluded due to there being insufficient children in these groups. The graphs show that the total amount of short break hours used appears to be patterned across different ages of child. There are relatively small numbers of children in each group and the error bars show these patterns should be considered tentative.

Figure 6 Mean hours used at Time 1 for different ages of child and young person

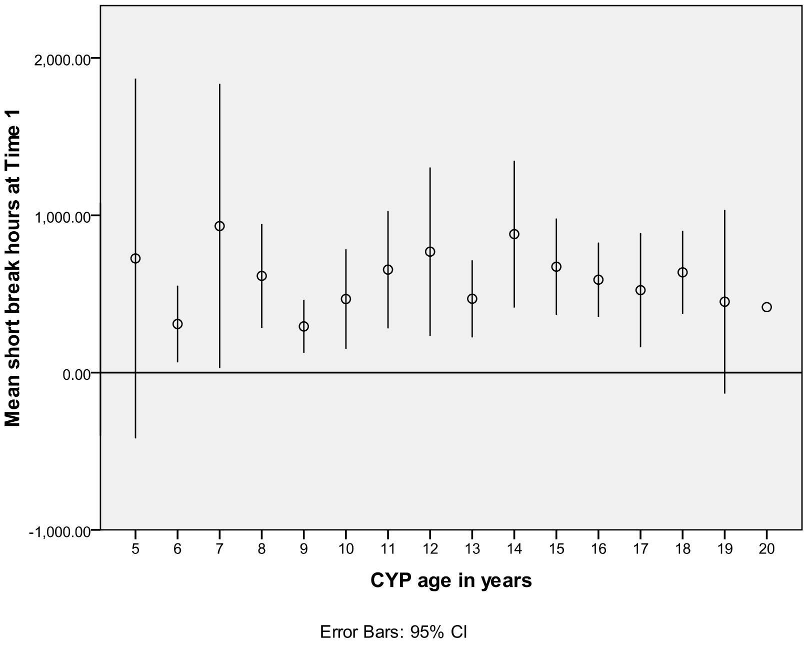
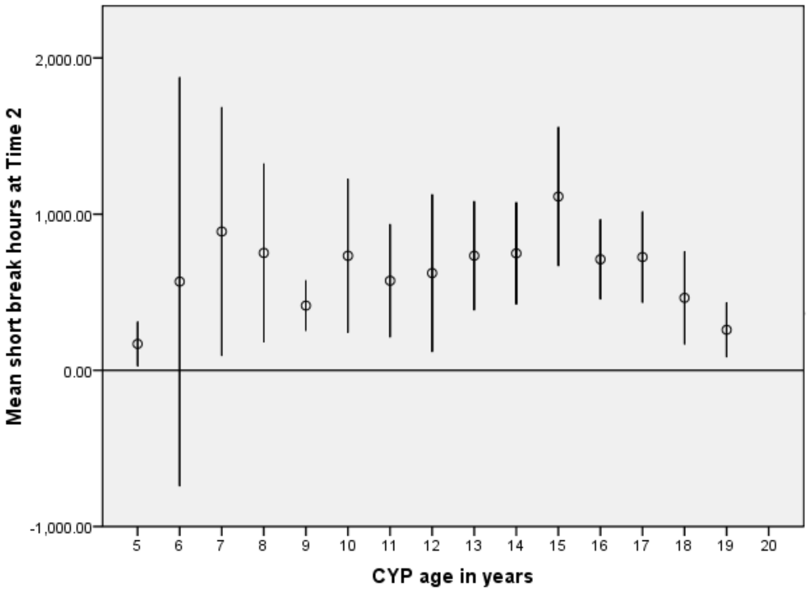


Figure 6 shows that at Time 1, during the infant years (5-7) the mean total hours of short breaks used was highest for children aged 7, during the primary years (7-11) mean total hours of short breaks decline somewhat and during secondary years (11-16) mean hours generally rise until 14-15 years after which they fall. Children aged 9 appear to use slightly less hours than might be expected, this may potentially be due to the fact that some types of childcare have accepted children up to the age of 8 and that these children may have left breaks provided in these settings but not yet begun to fully access other breaks available.

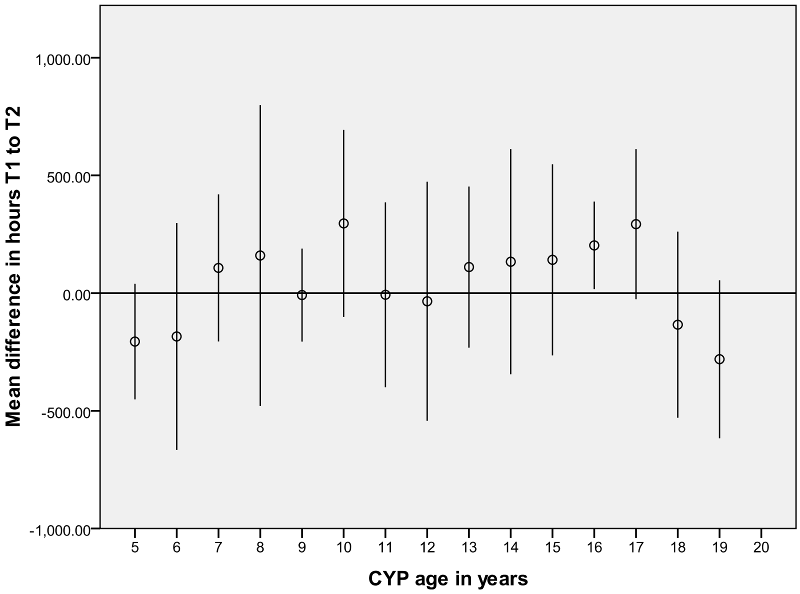
Figure 7 Mean hours used at Time 2 for different ages of child and young person



Error Bars: 95% CI

Figure 7 shows that at Time 2 the pattern is broadly similar to Time 1, except at late primary (10 years) where the mean total hours of short breaks increase prior to transition to secondary school. This particular cohort, who would mostly have been aged 9 at Time 1, were previously (at Time 1) using less hours on average than children in adjacent cohorts, suggesting that this cohort of children experienced particular increases between Time 1 and Time 2.

Figure 8 Mean differences in total hours of short breaks between Time 1 and Time 2 for different ages of children and young people



Error Bars: 95% CI

Figure 8 shows that over the 10 months from Time 1 to Time 2 changes in the total hours of short breaks used at each year of age also appears to be patterned. Children in the early infant years at Time 2 (5 and 6 yrs) used fewer hours of short breaks at Time 2 than they had at Time 1. Children in the remainder of infant and primary years (with the exception of age 9) generally gained hours over this period, with the largest gains for children aged 10 years. Children at or recently following transition to secondary school neither gained nor lost hours from Time 1 to Time 2. Children and young people aged from 13 to 17 gained hours during this period with the largest gains being experienced by young people aged 17 at Time 2. Finally, young people aged 18-19 years at Time 2 showed substantial decreases in the mean total hours of short breaks received by the family.

Taken together these results suggest that children's use of short breaks may be influenced to some extent by their age and stage of schooling. Many families drew attention to actual or anticipated falls in short break entitlement at age 18 years. These results suggest that other points of transition, in particular primary to secondary school, or between different types of childcare and short break may also influence a child's entitlement to, access to or uptake of short breaks. Further research would be required to confirm these results.

4.6 Changes in short breaks, qualitative evidence

4.6.1 Short break resource issues; sustainability and sufficiency

4.6.1.1 Sustainability

During the analysis of textual data from open questions a number of themes initially identified at Time 1 became more prominent and a small number or new themes were identified; for example at Time 2 many more families reported anxieties about the sustainability of services or cited evidence of 'cuts' than had done so at Time 1.

Many families talked about their fear that the services they relied upon would be cut back they feared this would be detrimental to their child and to their ability to cope and to care for their child. Often these fears were specific and related to a particular named service as in the examples below.

The playscheme run by [national charity] is a great success. However their contract is renewed every 3 years (this March 2011) and it is uncertain if this will continue. This is extremely worrying. (Main Carer)

We requested an increase in number of respite nights but were turned down. We were told that we should be lucky we are not having our allocation reduced. (Main Carer)

At other times these fears were more generalised and related to overall short break provision, for example many carers explained that they worried about prevailing funding constraints and the effects these would have on the availability of short breaks. Also when responding to a question asking what would now improve services many carers explained that they would like to be relieved of the worry that funding for breaks would be significantly reduced or withdrawn. The following quote is typical of these comments. These general anxieties about short breaks were very intense for some carers.

[What would improve services?] Knowing that Government cuts are not going to affect families like ours. It is a source of great anxiety about the future welfare of our son. (Main Carer)

As at Time 1 several carers asserted that without short breaks their family would not be able to cope or continue to care for their disabled child. As at Time 1 some carers used a cost-saving argument, asserting that if their child was taken into care then the costs to the public purse would be much higher than by providing appropriate short breaks to enable them to continue to care at home.

Services for disabled children have never been anywhere near adequate, but with the current cut backs we have a very dangerous situation (and unfair) that can only result in many children going into full-time care (or worse) as parents / carers can no longer cope. (Main Carer)

Some families cited examples where they had already been notified of service closures or where the frequency or duration of their breaks had been reduced. When carers described the explanation that they had been given by service providers it was usually concerned with funding rather than other issues. A few of these families highlighted this by enclosing copies of letters from services advising them of impending funding cuts and closures. The following comments are typical.

Not to cut after school club, family weekend stay and summer holiday play schemes which we have just received letters telling us this is going to happen this year... (Main Carer)

The local authority cut my son's package in the last six months, removing [service name] support fortnightly from him for funding reasons. (Main Carer)

Fifty (23%) families volunteered a statement about their concerns with service reductions or sustainability; a quantitative variable was generated to allow these families to be compared with others.

4.6.1.2 Sufficiency

In open responses at Time 2 a greater proportion of families than at Time 1 also offered comments about the insufficiency of short break services. Breaks were reported to be insufficient in a number of different ways. Whilst many of these issues had been raised at Time 1, the general strength of feeling appears to be greater in this regard at Time 2. Carers who felt that there were insufficient breaks available to them were also somewhat more likely to have worries about service sustainability. It is likely that families who do not feel that their need for short breaks is being adequately met are especially likely to be concerned about service cuts. Sufficiency was discussed in a number of different ways, including the following.

Generally insufficient - A great many carers simply stated that they needed more breaks, more frequent breaks, more regular breaks or that there should be more funding for breaks.

In terms of hours – Many carers explained that very short breaks (generally 2 hours or less) were rather ineffective as breaks for carers as they did not provide sufficient time to undertake other activities. This was often confounded by the time taken to transport the child to and from the short break. However many families continued to use these breaks because they felt that the activities were enjoyed by (or beneficial to) their child.

For specific groups of children – Many families explained that there were insufficient breaks available that were suitable for the needs of their child. Many groups of children were mentioned, including children with ASD, older children / teenagers, children with complex medical needs and children with challenging behaviour. Some families noted that whilst the need for breaks was increasing as the child got older they felt there were insufficient breaks to meet those future needs. Several families explained that they found it difficult to find appropriate short break carer workers, some went on to explain that this was either because there were insufficient people with the right qualifications and experience or because the wages they were able to offer (through direct payments for example) did not appropriately remunerate candidates with higher levels of skill, qualification or experience.

At certain times– Many parents stated that breaks were insufficient during school holidays as carers then had to care for (and occupy) a child all day, every day. This was seen as especially stressful and additionally interfered with other commitments such as employment. Some parents also mentioned that there was insufficient availability of short breaks before and after school and during weekends.

Overnight breaks – Some families needing overnight breaks indicated that the number of nights was insufficient given the demands of caring for their child. Some of these families wished for a periodic week-long break to enable them to take a holiday. However some families that needed overnight breaks were unable to secure any at all.

To meet growing demand – Many families suggested that breaks were insufficient to meet demand for the services, some noting that as short breaks became more popular there has been more competition for places. Some families had been on lengthy waiting lists for a break. Some had also experienced a reduction in the services they used as these became ‘rationed’ due to increased demand. Ironically some carers felt that increasing demand was in part due to improvements in the quality or appropriateness of services offered.

Location of breaks – Some parents noted that there were insufficient opportunities for their child to have a suitable break near their home. This impacted on travel time and consequently the efficacy of the break for parents who had to transport their child.

In terms of funding – Some parents noted that there was insufficient funding available to cover all the costs of a short break, their own ability to pay then limited the amount of breaks they were able to access.

Range of breaks – Some parents noted that there was an insufficient range of breaks with little choice available. They suggested that breaks should be more creative and delivered in a wider range of facilities. This included use of support workers to enable children to better access mainstream opportunities in universal provision.

For family circumstances – Some families mentioned that breaks were not sufficiently available in emergencies such as at times of illness. Some families noted that there were insufficient breaks in the early days following a diagnosis. A small number of families also noted a lack of provision for siblings.

Sufficient services – Some carers mentioned that they were now happy with the amount of short breaks they currently received, a few of these carers qualified these comments with concerns that this level of provision may not be maintained or that if their needs changed in future these may not be met.

Ninety-nine (46%) families described some concern about the insufficiency of breaks; a quantitative variable was generated to allow these families to be compared with others.

4.6.2 Short break information processes

At Time 1 many families indicated that there was a lack of information about short breaks, eligibility for short breaks and how to access them. Families also suggested that the information they received was not in a suitable format, did not provide all the information required and sometimes arrived too late. At Time 2 a set of six questions were incorporated to measure carers' feelings about the information provided by their local authority. Responses to these are reported below in Table 7.

Table 7 Extent of carer's agreement with information statements

Aspect	Not at all	To a small or moderate extent	To a fairly great or great extent
LA gives me information about the types of short break services offered	44 (21%)	112 (54%)	53 (25%)
LA provides information which is clear and easy to understand	36 (18%)	107 (52%)	62 (30%)
LA provides information which tells me everything I need to know	59 (29%)	92 (46%)	51 (25%)
LA lets me choose when to receive information and the type of information I want	78 (39%)	93 (47%)	27 (14%)
LA has information available in various forms (written booklets, telephone line, kits, videos etc.)	44 (24%)	96 (52%)	46 (25%)
LA provides advice on how to get further information or to contact other parents and carers	61 (30%)	105 (52%)	35 (18%)

Respondents were most likely to express small or moderate levels of agreement with information statements. The statement with the highest levels of disagreement related to the extent to which the local authority let them choose when to receive the information and what type of information they wanted. These findings suggest that whilst parents receive some information which is clear and to some extent meets their needs, many find that the information does not tell them everything they need to know and is not fully responsive to their needs.

178 main carer responses about each aspect of information provided by the local authority were summed to produce an index score. The possible range of the index score was between zero and 36, with 36 representing maximum agreement with all the statements and zero representing no agreement with any statement. Scores on this index ranged from zero to 24, the mean being 9.02 (s.d. 6.5). This indicates that main carers were most likely to express between small and moderate amounts of agreement with the statements about the provision of short breaks information overall.

A series of chi square tests were conducted in order to explore characteristics associated with main carer disagreement with the statements about short breaks. The characteristics examined included those associated with the child using short breaks, the local authority and the family's experience of using short breaks. The results are reported in Table 8 below.

Table 8 Characteristics associated with agreement with information statements

Characteristic	
Main carer information index - not at all agreed (0) * all other levels of agreement (1)	
Child using short breaks characteristic:	
Child age (0-16 * >16)	(n=214, p=.630, 1-tailed Fisher's Exact Test)
Child age (0-18 * >18)	(n=211, p=.457, 1-tailed Fisher's Exact Test)
Child's gender (male * female)	(n=213, p=1.00, 2-tailed Fisher's Exact Test)
Family experience of using short breaks characteristic:	
Total number of short break hours received in a year (0-50 * >50)	(n=214, p=.191, 2-tailed Fisher's Exact Test)
Direct Payments used to pay for short breaks (yes * no)	(n=211, p=.0.03, 2-tailed Fisher's Exact Test)
Perceptions of Local authority provision:	
Local Authority	(n=214, df=22, p=.631 Pearson's Chi Square)

As Table 8 shows none of the characteristics examined were found to be significantly associated with disagreement on the main carer information index. This suggests that disagreement with these statements is less related to the characteristics of the recipient of the information or to the information provider, but more to the nature of the information itself, which as noted in a previous report (Langer et al., 2010) is diverse and fragmentary in nature. Local authorities appear to have some work still to do in ensuring the information they provide is appropriate and useful to disabled children and their families.

In their responses to open questions at Time 2, main carers indicated that they continued to have different uses and needs for short break information. Some carers suggested that the quality of contact or communication with the local authority was an important indicator of their overall experience of short break provision.

Parents also suggested that they wanted information about what their child had been doing during a short break activity. Two parents reported positively about this, suggesting that it occurred as a result of an informal arrangement with the short break carers. As noted in the first quantitative report (Welch et al., 2010), information continued to be crucial to family forward planning so that short break activities could be integrated into the family's schedule.

A small number of parents noted that there had been improvements in the quality of information about short breaks provided. However a larger number of parents continued to express concern at the lack of information from or communication with the local authority. In some cases, this concern was accompanied by a perception that things had not changed. One particular carer reported that they were not able to access a short break activity for their child because they struggled to understand English.

The provision of information is crucial both to access to short breaks and to their beneficial impact, therefore local authorities need to give information a similar level of attention as the presence of resources, facilities and trained staff.

Things seem very much the same, lack of resources, lack of facilities, suitably trained staff and information. (Main carer)

He goes to a local respite care home, locally run (not private). Staff are good, he seems to enjoy it. On request they give me copies of his daily notes and text me each evening to say how he is or what he has been up to. (Main carer)

We are now able to plan our family activities including a short visit to a cafe because we know times and duration of the short breaks, especially the chillout and football club. (Main carer)

4.6.3 The short break assessment process

In response to concerns about assessment expressed at Time 1 a further question was added to the Time 2 carers questionnaires about respondents' levels of satisfaction with the way in which their family's entitlement to short breaks was assessed. 30% (n=57) of main carers were very satisfied with a further 49% (n=92) being quite satisfied, 21% (n=39) were not at all satisfied with this aspect of short breaks.

Some carers added comments about good experiences of assessment.

Social worker excellent. Really listened to our needs and made appropriate recommendations... The short breaks is the perfect respite for our family as a whole as we are all happy with the level we receive and the social worker has helped us to make it appropriate for [name] and not just 'a disabled child'. (Main carer)

Families who reported problems with assessments cited a number of issues similar to those raised at Time 1, Many used language of conflict for example speaking in terms of **"fighting"** or **"battling"** to get services.

Unless you go kicking and screaming at social services there is very little offered. (Main Carer)

Some families suggested that these battles had become regular events at reviews. Some carers explained that they had been obliged to fight over an extended period of time to get services or that they had to appeal against decisions that were made. As at Time 1, some carers described being ignored by social care. These experiences are problematic in themselves, but they also suggest that families who are willing and able to assertively and doggedly pursue services may be more likely to eventually have their needs met than families who do not have the capacity to do so.

Our short breaks has improved but only because we have finally been awarded our sitting service back, we had it taken away for no reason and it took us 9 months of fighting social services and the official complaint to get them to listen to us and award it back. (Main Carer)

That it's very difficult to get, have to wait a long time. At reviews they question if I still need it, that they might try and take it away. This worries me. (Main Carer)

A number of carers suggested that they felt it was not until they were seen to be **"exhausted", "unable to cope"** or on the **"brink of a break down"** that short breaks were put in place.

Other carers felt that entitlement was decided on criteria which were not relevant, not supported by evidence, contradictory or perverse. Examples include –

- breaks being withdrawn as the child or family had seemed happier and more settled since breaks had been introduced,
- breaks being reduced so that care-workers could have a break from the demands of caring,
- 'sitting' being terminated at age 13 yrs as the child was now too old for babysitting,
- packages of breaks from more than one provider being ruled out because it was not thought beneficial to have more than one provider involved,
- children receiving short breaks because of their behavioural problems being excluded from breaks because of problematic behaviour.

Finally a small number of carers commented that assessment processes themselves were excessive and used resources which should have been used for the provision of short breaks.

Currently short breaks services are grossly under-funded at point of service delivery. Money is wasted on assessment for eligibility and bureaucracy. Please tell Government to put money into services. (Main Carer)

4.6.4 Short break processes for direct payments

As at Time 1, Time 2 responses suggested that families valued highly the benefits of direct payments, particularly in respect of flexibility and feeling '**in-control'** of their breaks. Flexibility to be able to arrange breaks at times of greatest benefit continued to be a particular gain cited by many respondents. However some families continued to experience problems with bureaucracy and many remained fearful of taking responsibility for managing direct payments. The following quote is typical of these families.

The responsibility / paper work for direct payments is a time consuming drain on our otherwise precious time. A burden we can do without. (Main Carer)

Other families continued to have difficulties finding and keeping suitable care workers who they felt were appropriately trained, experienced and able to care for their child. This constraint both limited the choice parents had when choosing staff and at times meant that no care worker could be found and consequently no break could be arranged. A small number of families continued to report frustration with the limits placed upon what direct payments could be used for, for example paying wages but not other costs associated with a short break activity (entry fees, refreshments etc).

4.6.5 Short break areas identified by carers as needing improvement at Time 1

At Time 1 families were asked an open question about what would improve short break services. Based on responses to this and other open questions at Time 2 we looked for evidence to suggest whether or not these improvements had occurred during the 10 months from Time 1 to Time 2 and whether these issues were still problematic at Time 2. In the discussion below it is not our intention to repeat a full analysis of each theme, rather to highlight evidence of change or continuity over time.

4.6.5.1 Improvement of short breaks for named groups

A number of families at Time 1 had identified groups of children whose needs were not being fully met. The groups identified overlapped to some extent with the Aiming High target groups in that they included children with autistic spectrum disorders, children with complex health needs and children in their teenage years. Other groups mentioned included children under the age of 8 years and children without learning disabilities who used wheelchairs. Whilst the situation varies greatly from family to family at Time 2; there was continued evidence to suggest that some children in each of the areas described at Time 1 still did not have access to short breaks which met their particular needs. The quotes below gathered at Time 2 provide typical examples.

The out of bound course was more suitable to children with physical disabilities rather than ASD but was still enjoyable, helpful. (Main carer)

[What would improve your short breaks?] ***A new respite unit for children with autism and extremely challenging behaviour in our county. (Main carer)***

We desperately need more overnight respite care. As our son is often ill, we frequently are unable to access overnight stays. His behaviour also means that few places are willing to accept him. Ironically, the more severe the child's medical problems, are, the fewer options are available to that family. (Main carer)

Need more access to breaks in the early days when [child] was a baby / toddler. Lots of breaks only accept children over 8 years which [child] is now. (Main carer)

[Child] is a regular nine year old girl with a physical difficulty. She always gets grouped with children with learning difficulties which she finds challenging... (Main carer)

May include high proportion of autism / learning disabled – not able to interact, may be only wheelchair user present. (Main carer)

4.6.5.2 Improvement of named types of short breaks

At Time 1 carers had also detailed several types of break which were not sufficient in their area. These included overnight breaks, and breaks which took place before school, after school and during school holidays. In respect of overnight care at Time 2, there was some evidence that this had improved for some families, however many other families described problems with accessing overnight care in sufficient quantities or that was appropriate to their needs. In respect of breaks which fitted around school times at Time 2, the situation was similar to Time 1. Some families had been able to access more or improved holiday care but most families who commented on this area described continued or worsening problems. A selection of quotes below highlights both of these areas.

After several years and many battles, our short break 'package' has become suitable as they finally reflect the need we have: My son does not sleep so we now have a good amount of overnight breaks. Caring is much more intensive in the school holidays and we now have adequate help then. (Main carer)

We have reached 'crisis' point on a few occasions in the past, mainly due to lack of sleep due to [Child's] difficulty in getting to sleep and staying asleep. There has to be a way forward to help families before they get to this stage. WE NEED MORE RESPITE. (Main carer)

There is still an insufficient availability, in particular overnight respite. (Main carer)

Overnight respite – My county have no units suitable that would take my son; so we travelled 55 miles to a unit who said they could meet his needs, only to find they admitted they couldn't. (Main carer)

[What would improve?] ***Choice. To be able to access overnight care away from the family home. To be able to access local after school and holiday care provision away from the home. (Main carer)***

I would like more help in school holidays. It looks like the Easter playscheme is cut to 4 days over 2 weeks instead of 6 days last year and previous years. (Main carer)

[What would improve?] ***More availability during the school holidays, as this is the time when they are most appreciated. (Main carer)***

There are limited resources in [local authority]. There are no centres that provide day care provision for disabled children during the school holidays. This prevents us from being able to work. (Main carer)

It is getting more and more difficult to find appropriate activities during the holidays on the days that I work. I have considered giving up my job but somehow manage to wing it. (Main carer)

I found it very difficult to find Holiday care for [Child] as she is 14 years old and many schemes were not OFSTEDed up to this age and refused to take her. I work for [large

public sector organisation] and even their holiday care stopped at 13 yrs. (Main carer)

Happy with services available, however would like more breakfast / afterschool facilities which would help when trying to work and care for disabled child. Maybe financial assistance to help with this. (Main carer)

4.6.5.3 Improving the flexibility of short breaks

Another area which Time 1 carers suggested should be improved was related to the flexibility of short break services in terms of choice, timing of the break, timing of dropping off and collection, availability of breaks at short notice when unexpected needs arose and the availability of information in advance to allow planning of holidays and other longer term plans. At Time 2 some families reported that services were flexible and described the positive difference that this made, one carer illustrated the importance of flexibility by explaining that this was sometimes even traded against the quality of care. Some families achieved flexibility by combining different types of breaks or by using direct payments. However many families continued to describe how the inflexibility of short breaks presented problems. A number of quotes below are used to illustrate these points.

The breaks fitted and suited my needs as well as my child's, weekends were very flexible. Transport to and from carer's home provided by carer. Very flexible regarding our holiday allocation (5 nights extra to w/e allocation) and would fit in with family regarding times and dates etc. (Main carer)

Sometimes we have used direct payments person because again, just grateful for their flexibility / helpfulness as opposed to good skills with our daughter. (Main carer)

The short breaks taken individually are unsuitable. It is the combination of different forms of short breaks that have made them suitable. e.g. Direct payments do not allow overnight respite and we need our son to be out of the house in order to get a break from his behaviour and sleep disorder. (Main carer)

[What would improve?] ***More. Better organising of sitting service, not so last minute with confirmation – more flexible/ spontaneous? (Main carer)***

Short breaks have to be booked weeks/months in advance and particularly over the winter are often cancelled at short notice... [What would improve?] ***More flexibility and the ability to book time at much shorter notice. (Main carer)***

[In what ways unsuitable?] ***Early start and early finish. You can't choose the days you want. Not too flexible. (Main carer)***

They finished the moment my son was 18, there was no flexibility to allow a smooth transition to adult services. (Main carer)

4.6.5.4 Improving assessments for short break eligibility

Some families at Time 1 suggested that breaks would be improved by better assessments which were more streamlined and which took more account of the whole family rather than just focussing on the needs of the disabled child. At Time 2 the situation was again mixed with some carers reporting good experiences but many experiencing difficulties, these are discussed in more detail in section 4.6.3.

4.6.5.5 Improvement of facilities for short breaks

At Time 1 some families identified issues related to facilities which required improvement, both in terms of facilities that needed to be changed and in terms of better use of existing specialist facilities. At Time 2 although these difficulties were still evident with some families, there were increased numbers of families who reported improvements to facilities, in particular in terms of new buildings and centres. These improvements tended to be in facilities for children rather than facilities for carers.

Although [Child] enjoys the afterschool gym club I have to stay while she is there and there are no facilities for carers to go and have a coffee, sit down etc so it's not much of a break for me, also I am often the only male carer there. (Main carer)

A new unit has opened which is now autism specific. [Child] is much keener to go now. The building is more suitable and has more space. It has a low arousal environment and the staff have been specifically selected to work with autistic children and are enthusiastic and well trained. (Main carer)

Very similar to last year, one way in which it is likely to improve very soon is better facilities at the respite centre as they are having an extension built with 'aiming high' money. The bedroom [Child] will sleep in is purpose built and she will have access to en-suite bathroom facilities. (Main carer)

[Child] was becoming bored with the respite unit but they have just built a fantastic new one, she has been for an introductory tea time visit and is really looking forward to the first overnight stay this coming week. (Main carer)

[What would improve?] ***Respite / overnight unit open every day. At the moment 1/3 rd of the time it is shut and there's a waiting list. I think this is an awful waste... It has fantastic facilities that are just wasted. (Main carer)***

4.6.5.6 Improving transport and short break location

At Time 1 families drew attention to issues of transport for breaks and to the location of services. Whilst some carers reported improvements at Time 2 with transport arrangements or provision of local breaks, many others continued to report difficulties with the duration, length and expense of their journeys to access short breaks. Some carers reported not accessing breaks which would otherwise have been suitable because of transport issues. A common theme at both Time 1 and Time 2 was that transporting a child to and from a break could counter-balance any benefit that carers might otherwise have gained. In one case a carer was completing a journey nearing 2 hours so that their child could enjoy a swimming club with 30 minutes in the water. A range of examples of statements about transport are given below.

[Care worker] now provides transport to and from home... a huge help to me as a single parent. (Main carer)

Any short break under 2 hours benefits my child but picking up with [City] traffic

sometimes puts a strain on parents / carers.... I must emphasise that any short break less than two hours is difficult to benefit the family – by the time the child is taken to the place of short break, it will nearly time to go back to pick him up. Very unsettling for parent / carer, even to go shopping with that period is difficult. (Main carer)

There have been changes to the holiday play scheme we used to travel 20 mins, but now we have to travel 1 hour, because of the distance and the timing of the playscheme 10-3, it limits what we can do. We used to use the scheme once a week in the holidays but now we do not use it as much. (Main carer)

We live in a rural area, twenty miles from our main town, I feel we have significantly less opportunity available to us because of our location. (Main carer)

4.6.5.7 Improving transition to adult services

Families of older children at Time 1 suggested that improvement was needed in the processes for transition from children's services to adult services. At Time 2 a small number of carers related successful transitions, for example to residential colleges. But in the main as at Time 1 there were problems with transition or a notable fear of transition, indeed it seems that even more families shared this concern as the cohort was getting older. Carers were often very fearful on a number of fronts, whether they would receive breaks, whether they would receive the same quantity of breaks and whether breaks would be suitable. When thinking about this transition, carers often described their feelings using phrases such as worry, fear, dread and concern. Of the many comments in this area we have reproduced only a small number as an illustrative sample.

We have only 3 more months of short breaks with children's services (respite care) and are absolutely dreading entering adult services when our child becomes 18 in [Date]. A great amorphous space where adults of all ages from 18+ will be lumped together. I fear she will lose out on being with her own age peers and the cuts mean there will be given even less services to go around. We always have to fight for everything. (Main carer)

Our greatest concern is that our child is approaching 'transition' to adulthood, we are worried what, if any short break provision will be available. Just because a child reaches a certain age does not mean that the needs of the child or the family change in any way. (Main carer)

[Child] left his last respite facility as he was 18. The only places available are all with elderly people and I don't think it's suitable for him. He worries constantly about going the age gap is too great. (Main carer)

Up until 18 we used short breaks event holiday and they were excellent, since turning 18 there doesn't seem to be anything available. We already have to travel to find youth clubs and other groups to attend. (Main carer)

4.6.5.8 Improvement through the short breaks workforce

In addition some families at Time 1 felt that the short break workforce needed to be further developed in terms of numbers, availability, training, skills and knowledge. As at Time 1, Time 2 respondents underlined the importance of having the right carers with many explaining that this had made a significant difference to the quality of care, their child's enjoyment and the amount of trust parents could place in the carer. Good carers were seen as fundamental to good care and were at times regarded as important 'members' of the family. However as at Time 1 some families found that finding suitable staff was very difficult or that the staff who were available did not have the right qualities (attitude, ethos, qualifications, skills and experience). This meant that suitable care was either not available or inconsistent.

In addition a small number of families at Time 2 related instances when the care provided to their child had been very poor or when the behaviour of care-workers had been inappropriate - in these situations families had withdrawn their child from the situation. This small selection of quotes from Time 2 illustrates some of the more problematic issues raised by carers.

On the whole it is actually very difficult to find someone to do direct payments at home, when we need them... so we have had lots of gaps. (Main carer)

Direct payments – I was given money to a pay a carer to take my son on outings. Because of his extremely complex and challenging behaviour I find it too difficult to find carers who will work with him. (Main carer)

To achieve this, high quality care is needed that parents and users are confident and able to trust. I have not yet been able to find PAs that I can confidently leave my son with unless myself or husband are there for support. (Main carer)

Help within the home was tried with local authority staff for help in the mornings prior to school. Staff were untrained, unable to feed (no training) unable to dress (no lifting policy) unable to give medications (not allowed) after 6 months, situation unchanged, abandoned service. (Main carer)

We have been informed today that the agency providing our child with support can no longer continue as they have not got the resources and nor do they feel they are offering a person centered care package. Therefore we no longer have support! (Main carer)

We stopped using [National Charity] carers as they told me that their carers were unable to cope with our son. After doing some research I found that none of their carers have any qualifications in childcare and no training for autism... This organisation send out staff who have no qualifications in childcare to look after severely disabled children and receive funding for this and receive referrals from social services. There is a huge flaw in the system; our children deserve to be looked after by trained carers. (Main carer)

Carers are often very rough and uneducated and were making inappropriate remarks about my children... This subject is far too complex to just throw simplistic answers. It is not just the disabled child who needs to be considered but their family, culture, community etc. (Main carer)

4.6.5.9 Improving the additionality of short breaks

At Time 1 a small number of respondents drew particular attention to the fact that many of the services offered to families with disabled children as a 'short break' could be viewed as services which should be available to all children; so that some short break provision did not provide the family with something additional to address their additional needs, instead they provided partial compensation for the inaccessibility of other services. At Time 2 there was not sufficient evidence about whether or not this issue was still a concern for families.

4.6.5.10 Improving services for siblings of disabled children

Finally at Time 1 small numbers of respondents also raised concerns about the insufficiency of services for siblings of disabled children. Whilst the impact on siblings of having a disabled brother or sister and the benefits of short breaks for siblings continued to be widely discussed by carers at Time 2, there is not enough evidence to suggest that carers' concerns about the inadequacy of specific services for siblings have changed or continue at Time 2.

5 Main carers

5.1 Outcomes for main carers over time

The collection of information from main carers at two time points 10 months apart allowed us to investigate change and continuity in selected main carer outcomes over this time period. It also allowed us to explore the potential impact of short breaks on carer outcomes by investigating which factors at Time 1, including family usage of short breaks and carer satisfaction with short breaks, were associated with carer outcomes at Time 2. It is important to note that at Time 1 some questions were only asked to a subsample of families – although these questions were asked to all families at Time 2, this means that some changes over time need to be interpreted with caution.

5.1.1 Changes in carer outcomes from Time 1 to Time 2

We investigated change and continuity in several indicators that could be considered as outcomes for main carers. These included:

- Economic indicators (main carer and household employment, main carer reports of worrying about money, main carer reports of how well the family was managing financially);
- Indicators of health and wellbeing (main carer self-reported health, main carer psychological distress as measured by the K6, main carer life satisfaction, main carer perception of positive gains associated with their disabled child).

Table 9 presents the economic indicators for main carers at Time 1 and Time 2. As Table 11 shows, at Time 2 just over half of main carers (52%) were in some form of employment, largely part-time (82 carers) rather than full-time (29 carers). Overall, at Time 2 most households (77%) had at least one employed adult. In terms of family perceptions of their finances at Time 2, most families reported worrying about money only sometimes or never (58%) and most families felt that financially they were managing at least alright (81%).

Table 9 also shows that there was a high degree of stability in the employment and financial circumstances of families from Time 1 to Time 2, with no significant changes over time and little apparent fluctuation.

Table 9 Changes in main carer and family economic outcomes from Time 1 to Time 2

Indicator	Time 1	Time 2	Magnitude (and direction) of change
Main carer employment	N=212	N=214	n=212, Sign test exact p=0.72
Full-time	n=26 (12.3%)	n=29 (13.6%)	
Part-time	n=81 (38.2%)	n=82 (38.3%)	No change in main carer employment T1 > T2
None	n=105 (49.5%)	n=103 (48.1%)	
Any adult in household employed	N=212	N=214	N=212, McNemar p=0.39
Yes	n=167 (78.8%)	n=165 (77.1%)	No change in household employment T1 > T2
No	n=45 (21.2%)	n=49 (22.9%)	
Family worries about money in last few weeks	N=212	N=213	Wilcoxon z=-1.01, n=212, p=0.31
Almost all the time	n=30 (14.2%)	n=33 (15.5%)	No change in family worries about money T1 > T2
Quite often	n=60 (28.3%)	n=61 (28.6%)	
Only sometimes	n=85 (40.1%)	n=87 (40.8%)	
Never	n=37 (17.5%)	n=32 (15.0%)	
How well is the family managing financially	N=212	N=213	Wilcoxon z=-0.48, n=212, p=0.63
Manage very well	n=32 (15.1%)	n=27 (12.7%)	No change in how families are managing financially T1 > T2
Manage quite well	n=60 (28.3%)	n=63 (29.6%)	
Get by alright	n=78 (36.8%)	n=79 (37.1%)	
Don't manage very well	n=6 (2.8%)	n=10 (4.7%)	
Have some financial difficulty	n=32 (15.1%)	n=31 (14.6%)	
In deep financial trouble	n=4 (1.9%)	n=3 (1.4%)	

Table 10 presents the health and well-being indicators for main carers at Time 1 and Time 2. As Table 10 shows, at Time 2 just over half of main carers reported themselves to be in good or very good health (52%). Also at Time 2, a minority of main carers (16%) scored above the standard K6 threshold to indicate clinically significant levels of psychological distress.

As Table 10 also shows, main carer self-reported health substantially worsened from Time 1 to Time 2, with fewer carers reporting their health as very good and more carers reporting their health as fair or bad. Main carer psychological distress, life satisfaction and perception of positive gains associated with their disabled child, however, showed no significant changes from Time 1 to Time 2.

Table 10 Changes in carer health and well-being outcomes from Time 1 to Time 2

Indicator	Time 1	Time 2	Magnitude (and direction) of change
Main carer self-reported health	N=213	N=214	Wilcoxon z=-4.96, n=213, p<0.001 Main carer self-reported health poorer from T1 > T2
Very good	n=40 (18.8%)	n=19 (8.9%)	
Good	n=98 (46.0%)	n=93 (43.5%)	
Fair	n=64 (30.0%)	n=80 (37.4%)	
Bad	n=8 (3.8%)	n=19 (8.9%)	
Very bad	n=3 (1.4%)	n=3 (1.4%)	
Main carer psychological distress (K6)	N=208	N=208	
Mean (s.d.)	7.04 (5.10)	7.38 (5.03)	Change in K6 score Wilcoxon z=-1.38, n=208, p=0.17
Median	7.00	7.00	
Range	0 – 22	0 – 21	
Number (%) above threshold for psychological distress	N=35 (16.5%)	N=34 (15.9%)	Change in K6 threshold n=208, McNemar exact p=0.39 No change in main carer psychological distress T1 > T2
Main carer life satisfaction	N=211	N=214	Wilcoxon z=-0.03, n=211, p=0.97
Mean (s.d.)	5.93 (2.15)	5.94 (2.08)	Higher score=more life satisfaction
Median	6.00	6.00	No change in main carer life satisfaction T1 > T2
Range	1 - 10	1 - 10	
Main carer perception of positive gains	N=76	N=213	Wilcoxon z=-1.06, n=76, p=0.29
Mean (s.d.)	11.95 (4.40)	12.55 (4.74)	Higher score=more positive gains No change in carer perception of positive gains T1 > T2
Range	6 - 30	6 - 30	

5.2 Time 1 Factors predicting outcomes for main carers at Time 2

For each of the main carer economic, health and wellbeing outcomes described above, we conducted univariate analyses to determine which factors at Time 1 predicted each outcome at Time 2, again using a significance level of $p<0.01$. These analyses are reported in full at Appendix D and are summarised below in Figures 9 and 10.

Figure 9 shows that a wide range of factors at Time 1 predicted economic outcomes at Time 2. Factors concerning main carers and households at Time 1 were generally more predictive of carer outcomes than factors concerning the disabled child, and factors concerning short break usage at Time 1 predicted a wide range of carer and household outcomes at Time 2.

- Main carers in employment at Time 2 were more likely to have an older disabled child with better relationships with siblings at Time 1. Male main carers were more likely to be in full-time employment and female main carers were more likely to be in part-time employment.

- Households with any adult in employment at Time 2 were more likely at Time 1 to have a disabled child needing less supervision at night, to be living as a two-parent family in a less deprived neighbourhood, to have main carers with more education and greater satisfaction with life, and to be using short breaks with a paid carer in the family home during daytimes and evenings.
- Families with fewer money worries at Time 2 were more likely at Time 1 to have a disabled child needing less supervision at night, to be living as a two-parent family in a less deprived neighbourhood and to be managing better financially with less hardship, and to have a main carer not experiencing clinically significant psychological distress. Families with fewer money worries at Time 2 were also more likely at Time 1 to receive more total hours of short breaks, a wider range of short breaks, and to be using daytime/evening short breaks with paid carers both in and away from the family home.

Figure 10 shows that a similarly wide range of factors at Time 1 predicted carer health and wellbeing at Time 2. Factors concerning main carers and households at Time 1 were generally more predictive of carer outcomes than factors concerning the disabled child, and factors concerning short break usage at Time 1 predicted a wide range of carer and household outcomes at Time 2.

- Main carers reporting better self-reported health at Time 2 were more likely at Time 1 to have a disabled child in better health, to not have a longstanding illness/disability or clinically significant psychological distress themselves, and to be in better financial circumstances. They were also more likely to receive more total hours of short breaks, a wider range of short breaks, and to be using daytime/evening short breaks with paid carers away from the family home.
- Main carers reporting lower levels of psychological distress at Time 2 were more likely at Time 1 to have a disabled child in better health, with fewer challenging behaviours and with better relationships with siblings, and to be in better financial circumstances. They were also more likely to receive more total hours of short breaks, a wider range of short breaks, and to be using overnight short breaks with paid carers in the family home.
- Main carers reporting greater satisfaction with life at Time 2 were more likely at Time 1 to have a disabled child with better relationships with siblings, to not be experiencing clinically significant psychological distress, and to be in better financial circumstances, and to receive more total hours of short breaks, a wider range of short breaks. They were also more likely to be using overnight short breaks with paid carers away from the family home, and to be more satisfied with the systems surrounding short breaks.
- Main carers reporting more positive gains associated with having a disabled child at Time 2 were less likely at Time 1 to have a child with an autistic spectrum disorder and to be living in a deprived neighbourhood,
- Moderator analyses also showed that family usage of more hours of short breaks had a buffering effect for main carers; in reducing the impact of child psychological difficulties on carer psychological distress and in reducing the impact of family money worries on carer self-reported health.

Figure 9 Time 1 Factors predicting economic outcomes at Time 2

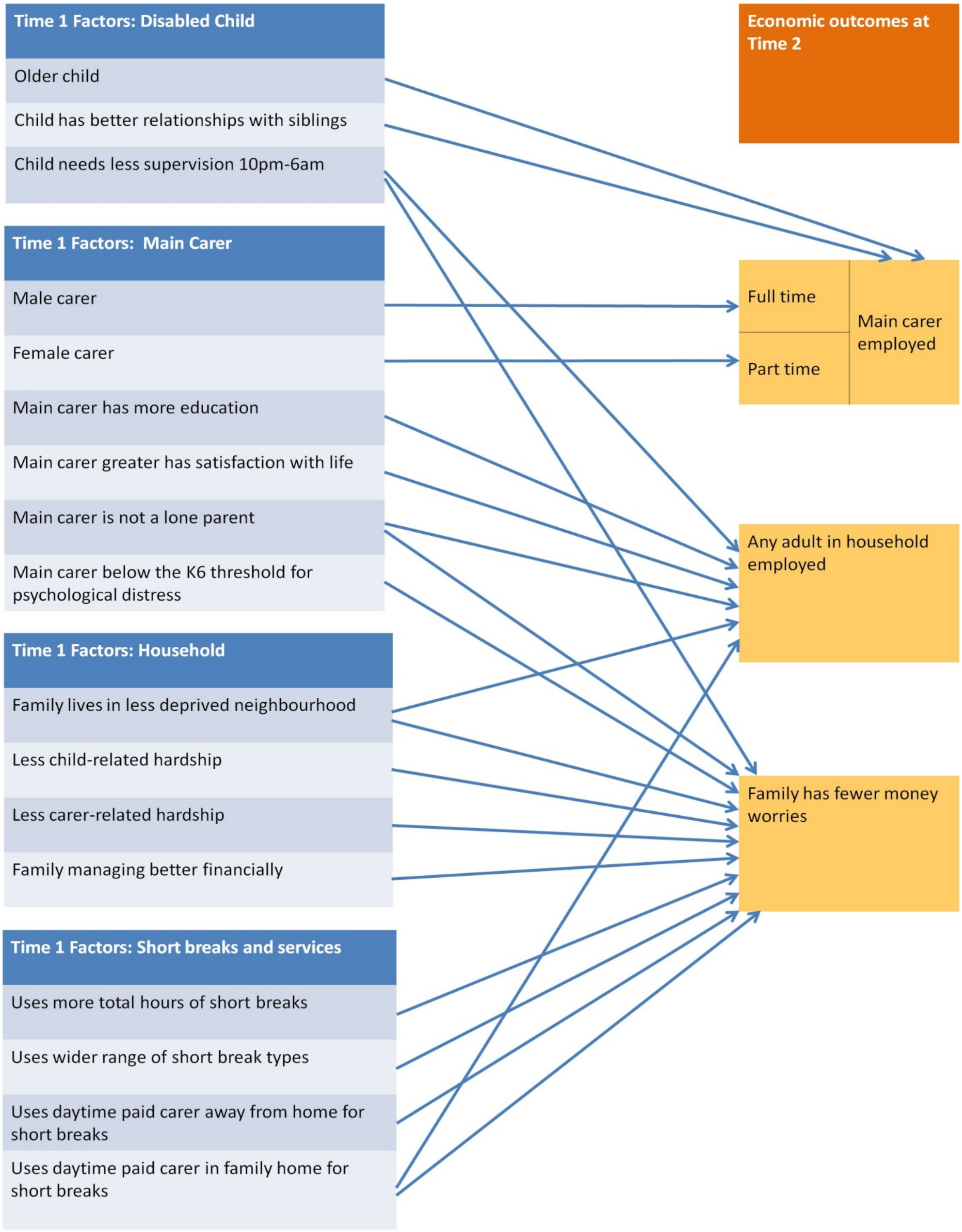
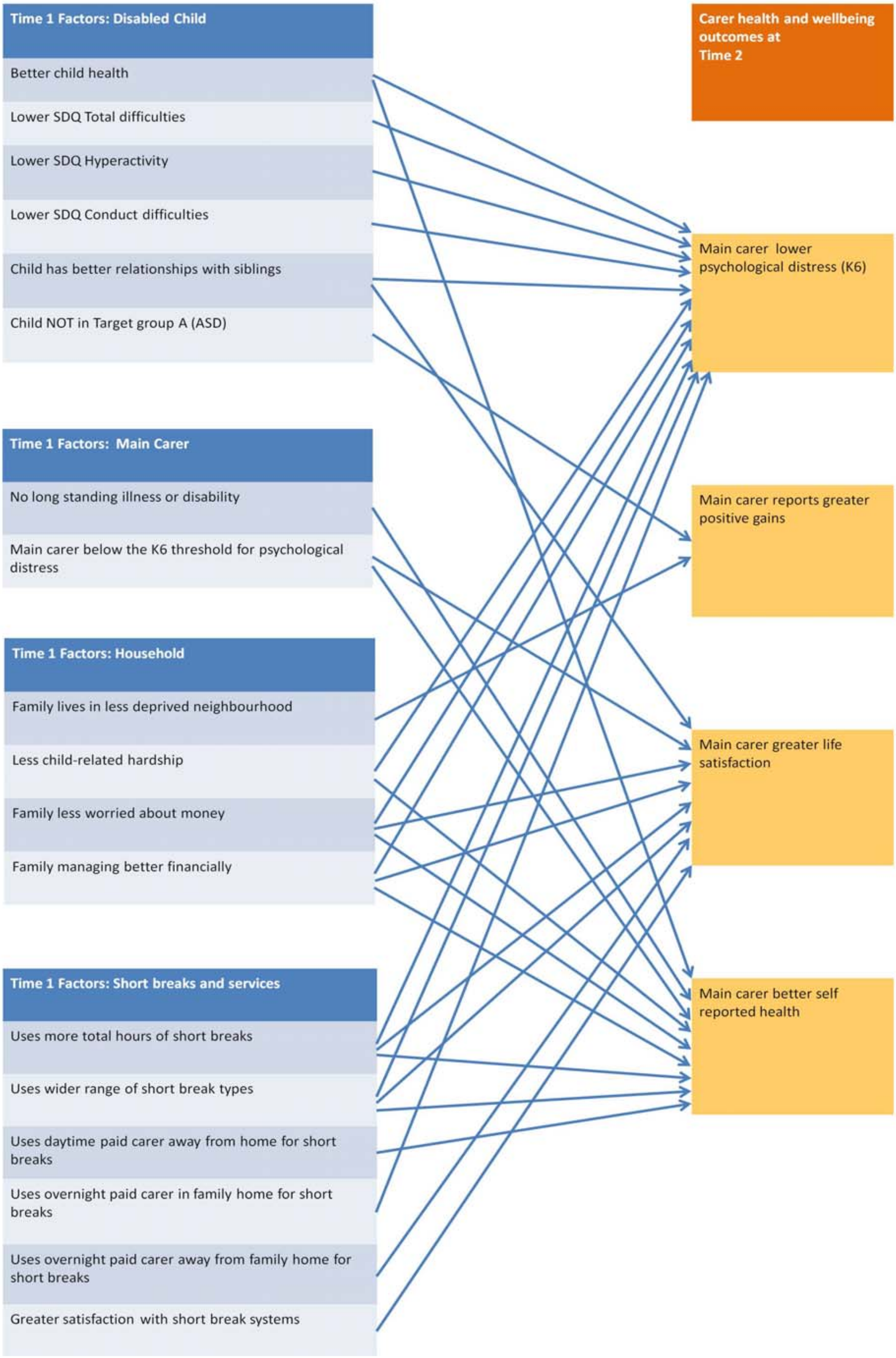


Figure 10 Time 1 Factors predicting carer health and wellbeing outcomes at Time 2



5.2.1 The buffering effects of short breaks for main carers

As Figure 10 has shown, short breaks, along with many other characteristics of children and families, have a direct impact on health and wellbeing outcomes for main carers.

However, it is often claimed that short breaks can have a buffering effect for carers, in effect reducing the impact of other stressors on the health and wellbeing of carers. We investigated whether short breaks had such a buffering effect in two areas where short breaks might be expected to act as a buffer.

First, we investigated whether short breaks had a buffering effect on the well-established relationship between child psychological difficulties and carer psychological distress. Table 11 below presents the results of a multiple regression, using Time 2 carer psychological distress as the independent variable and three Time 1 variables as potential predictor variables – total child psychological difficulties according to the SDQ, total hours of short breaks used by the family, and an interaction term for these two variables. Table 11 shows that child difficulties at Time 1 and the total hours of short breaks used by families at Time 1 both predict lower carer psychological distress at Time 2. In addition, the interaction term is also highly significant, indicating that family usage of short breaks moderates the impact of child psychological difficulties on carer psychological distress. In other words, family usage of more hours of short breaks acts as a buffer against the impact of child psychological difficulties on carers' psychological distress.

Second, we investigated whether short breaks had a buffering effect on the equally well-established relationship between household finances (assessed here using family worries about money) and carer health. Table 11 also shows the results of a similar multiple regression analysis with similar findings; family usage of more hours of short breaks buffers the impact of family worries about money on carer self-reported health.

Table 11 Moderator analyses

Regression 1 - Independent Variable: Time 2 carer psychological distress (K6) F=10.18; df=3,138; p<0.001. Adj R^2=0.163			
Predictor variable	*Beta*	*t*	*Significance*
Constant		0.889	0.376
T1 total hours of short breaks used	-0.596	-2.465	0.015
T1 total child difficulties (SDQ)	0.490	4.916	<0.001
SDQ x short breaks interaction term	-0.811	-3.324	0.001
Regression 2 - Independent Variable: Time 2 carer self-reported health F=6.99; df=3,183; p<0.001. Adj R^2=0.088			
Predictor variable	*Beta*	*t*	*Significance*
Constant		16.28	<0.001
T1 total hours of short breaks used	-0.493	-2.265	0.025
T1 family worries about money	-0.387	-4.301	<0.001
Money worries x short breaks interaction term	0.463	2.031	0.044

5.3 Changes in outcomes for main carers, qualitative evidence

An inspection of main carer responses to the open questions found few differences in carers' descriptions of outcomes at Time 1 and Time 2. This suggests that the outcomes for main carers reported at Time 1, including the opportunity to rest, relax and recuperate, to catch up on jobs, to focus upon partner relationships and to return to or maintain employment, were also present at Time 2.

Changes in outcomes that were reported between Time 1 and Time 2 tended to be associated with changes in short break provision. In these cases, negative outcomes included increased family stress, longer amounts of time spent travelling in order to attend short breaks and difficulties in taking up and using short breaks.

We have a good balance of daytime, holiday and overnight care but since last questionnaire we have had the befriender/sitter hours cut and turned into 'sitting' only and have been refused a permanent increase in overnight stays, despite an increase in daughter's difficult behaviour and increase in stress on family. (Main carer)

We now have to do a lot of travelling to access the holiday play scheme following changes to the service last year. (Main carer)

[Child's] current respite home is closing, it is merging with another respite home which...is not in our home town. Currently children who have home to school transport are taken from school to respite home ...as a gesture of goodwill. We have been told that this will not happen when they move. This will mean that we will not be able to use all our respite as we would not be able to pick up our son and get him to school and then get to work. (Main carer)

Although it is not always clear whether changes in reported outcomes have occurred as a result of short break provision, any change in provision that leads to a failure to meet the family's needs is likely to lead to an increase in perceived negative outcomes or a reduction in positive outcomes.

These findings indicate that main carer 's accounts of changes in outcomes are mostly attributed to by the carers changes in the provision of short breaks. Furthermore, where short break provision is stable, outcomes for main carers continue to be predominantly positive. However, changes to short breaks such as reductions in availability may lead some main carers to report negative outcomes, especially for the family's ability to absorb the practical and emotional consequences of such change.

6 Disabled children

6.1 Outcomes for disabled children over time

We investigated change and continuity in several indicators that could be considered as outcomes for the disabled child. These included:

- Health, well-being and behavioural indicators (child health; a range of child difficulties and positive behaviours according to the SDQ);
- Other indicators (child use of a range of services; carer perception of child progress at school; carer perceptions of various aspects of the child's present and future according to the TDRWQ).

Table 12 presents the health, well-being and behavioural indicators for disabled children at Time 1 and Time 2. Table 12 shows that overall there was stability in these child outcomes from Time 1 to Time 2 (child health; a range of child difficulties and positive behaviours), although children's total difficulties according to the SDQ did decrease from Time 1 to Time 2.

Table 13 presents the other indicators for the disabled child at Time 1 and Time 2. Table 13 shows that overall there was stability in these child outcomes (child use of a range of services; carer perception of child progress at school; carer perceptions of various aspects of the child's present and future), with none of these indicators changing from Time 1 to Time 2.

Table 12 Changes in health, well-being and behavioural outcomes for the disabled child from Time 1 to Time 2

Indicator	Time 1	Time 2	Magnitude (and direction) of change
Child health Mean (s.d.) Range	N=212 2.02 (0.80) 1 - 5	N=213 1.99 (0.83) 1 - 5	Wilcoxon z=-0.71, n=211, p=0.48 No change in child health T1 > T2
Child SDQ: total difficulties Mean (s.d.) Range	N=159 18.57 (5.94) 4 - 33	N=131 17.76 (6.43) 1 - 33	Wilcoxon z=-2.57, n=117, p=0.010 Decrease in child SDQ total difficulties T1 > T2
Child SDQ: hyperactivity Mean (s.d.) Range	N=192 7.02 (2.42) 1 – 10	N=174 7.06 (2.49) 0 - 10	Wilcoxon z=0.11, n=164, p=0.92 No change in child SDQ hyperactivity T1 > T2
Child SDQ: emotional difficulties Mean (s.d.) Range	N=183 3.48 (2.52) 0 - 10	N=162 3.46 (2.69) 0 - 10	Wilcoxon z=-1.37, n=147, p=0.17 No change in child SDQ emotional difficulties T1 > T2
Child SDQ: conduct problems Mean (s.d.) Range	N=187 2.63 (1.72) 0 - 10	N=169 2.49 (1.80) 0 - 10	Wilcoxon z=-2.11, n=160, p=0.035 No change in child SDQ conduct problems T1 > T2
Child SDQ: peer problems Mean (s.d.) Range	N=189 5.20 (2.07) 1 - 9	N=167 4.97 (2.21) 0 - 10	Wilcoxon z=-2.30, n=152, p=0.021 No change in child SDQ peer problems T1 > T2
Child SDQ: prosocial behaviour Mean (s.d.) Range	N=185 3.79 (3.02) 0 - 10	N=165 4.32 (3.09) 0 - 10	Wilcoxon z=1.93, n=154, p=0.053 No change in child SDQ prosocial behaviour T1 > T2

Table 13 Changes in service use, school progress and carer perceptions of the child's future for the disabled child from Time 1 to Time 2

Indicator	Time 1	Time 2	Magnitude (and direction) of change
Range of child-related services accessed by child Mean (s.d.) Range	N=210 7.03 (3.19) 1 - 15	N=209 6.46 (2.80) 0 - 16	Wilcoxon z=-2.55, n=205, p=0.011 No change in range of child-related services accessed by child T1 > T2
Carer perceptions of child progress at school Mean (s.d.) Range	N=77 1.46 (0.35) 1 – 2.67	N=209 1.53 (0.39) 1 - 3	Wilcoxon z=1.66, n=74, p=0.10 No change in carer perceptions of child progress at school T1 > T2
TDRWQ: Positive futures Mean (s.d.) Range	N=78 8.69 (3.38) 4 - 17	N=204 9.06 (3.58) 4 - 20	Wilcoxon z=-0.10, n=75, p=0.92 No change in carer perception of positive future for child T1 > T2
TDRWQ: Financial independence Mean (s.d.) Range	N=78 3.73 (2.12) 2 - 10	N=209 3.75 (1.97) 2 - 10	Wilcoxon z=-0.17, n=75, p=0.86 No change in carer perception of child's prospects for future financial independence T1 > T2
TDRWQ: Community resources Mean (s.d.) Range	N=78 5.47 (1.82) 2 - 9	N=205 5.57 (1.74) 2 – 10	Wilcoxon z=-0.79, n=74, p=0.043 No change in carer perceptions of continuing access to community resources to support child T1 > T2
TDRWQ: Sibling relationships Mean (s.d.) Range	N=159 22.76 (5.29) 7 - 33	N=154 23.14 (5.52) 7 - 35	Wilcoxon z=0.72, n=142, p=0.48 No change in carer perceptions of child - sibling relationships T1 > T2
TDRWQ: Family relations Mean (s.d.) Range	N=78 10.79 (2.39) 5 - 15	N=203 10.51 (2.41) 4 - 15	Wilcoxon z=-1.17, n=73, p=0.24 No change in carer perception of child – family relations T1 > T2

6.2 Time 1 Factors predicting outcomes for disabled children at Time 2

For each of the outcomes for the disabled child described above, we conducted univariate analyses to determine which factors at Time 1 predicted each child outcome at Time 2, using a significance level of p<0.01. The full analyses are presented in Appendix E and are summarised below in Figures 11 to 14.

Figure 11 presents the Time 1 factors predicting selected health and wellbeing outcomes for the disabled child at Time 2 (see Appendix E for details of all the outcomes). Time 1 factors predicting health and wellbeing outcomes for the disabled child at Time 2 most commonly concerned aspects of the health, needs and behaviours of the disabled child at Time 1.

- Disabled children in better health at Time 2 were at Time 1 less likely to have complex health needs, likely to need less supervision during the day and were older.
- Disabled children with fewer total difficulties and greater prosocial behaviour according to the SDQ at Time 2 were at Time 1 more likely to be older and female, less likely to have autistic spectrum disorder, complex health needs or severe learning disabilities, and were less likely to need supervision, less likely to have a range of challenging behaviours and more likely to have better relationships with peers and siblings. Other Time 1 predictive factors included main carers not having clinically significant psychological distress, household being in better financial circumstances, and carers being more satisfied with systems surrounding short breaks.

Figure 12 presents the Time 1 factors predicting outcomes for the disabled child at Time 2 concerning school and other services. Time 1 factors predicting these outcomes for the disabled child at Time 2 most commonly concerned aspects of the health, needs and behaviours of the disabled child at Time 1.

- Disabled children reported by their carers to be making better progress at school at Time 2 were at Time 1 older, in better health, and showed fewer challenging behaviours and greater prosocial behaviour.
- Disabled children using a wider range of child-oriented services at Time 2 were at Time 1 more likely to be in poorer health and to have moving and handling needs, less likely to have an autistic spectrum disorder, more likely to need supervision during the day, and more likely to have families getting short breaks from a paid carer in the daytime in the family home.
- Disabled children rated by their carers at Time 2 to be getting better access to community resources were at Time 1 more likely to show fewer total psychological difficulties and more prosocial behaviour according to the SDQ, to have carers acting as lone parents with lower psychological distress in better financial circumstances, and to have carers not using NHS funded short breaks but more satisfied with both short break providers and the systems surrounding short breaks.

As Figure 13 shows, similar child and main carer factors at Time 1 predicted the disabled child having better relationships with their siblings and their family at Time 2 were similar factors. For example, as expected, better scores on the SDQ prosocial subscale predicted better relationships with family members and lower scores on the SDQ peer difficulties subscale predicted better relationships with siblings.

Figure 14 presents the Time 1 factors predicting future-oriented outcomes for the disabled child at Time 2.

- These outcomes for the disabled child at Time 2 were predicted by a broader range of factors at Time 1, including lower levels of child challenging behaviour and greater child prosocial behaviour, main carers not having clinically significant levels of psychological distress, households being in better financial circumstances, and a range of factors concerning short breaks. Carers reporting better future prospects for their disabled child at Time 2 were less likely to be getting NHS funding for short breaks, and were more satisfied with both short break providers and the systems surrounding short breaks.

Figure 11 Time 1 Factors predicting child health and wellbeing outcomes at Time 2.

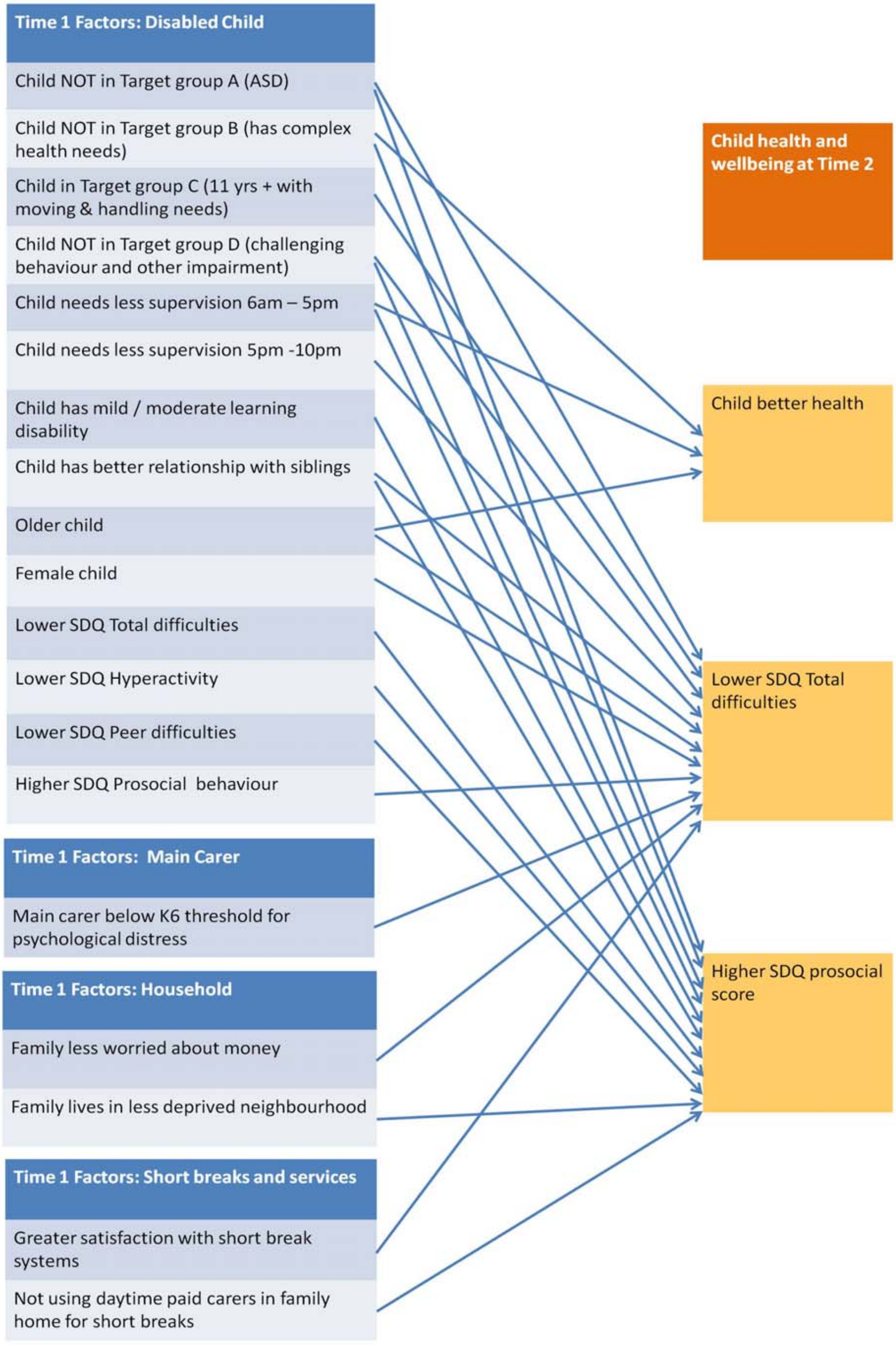


Figure 12 Time 1 Factors predicting child school and services outcomes at Time 2.

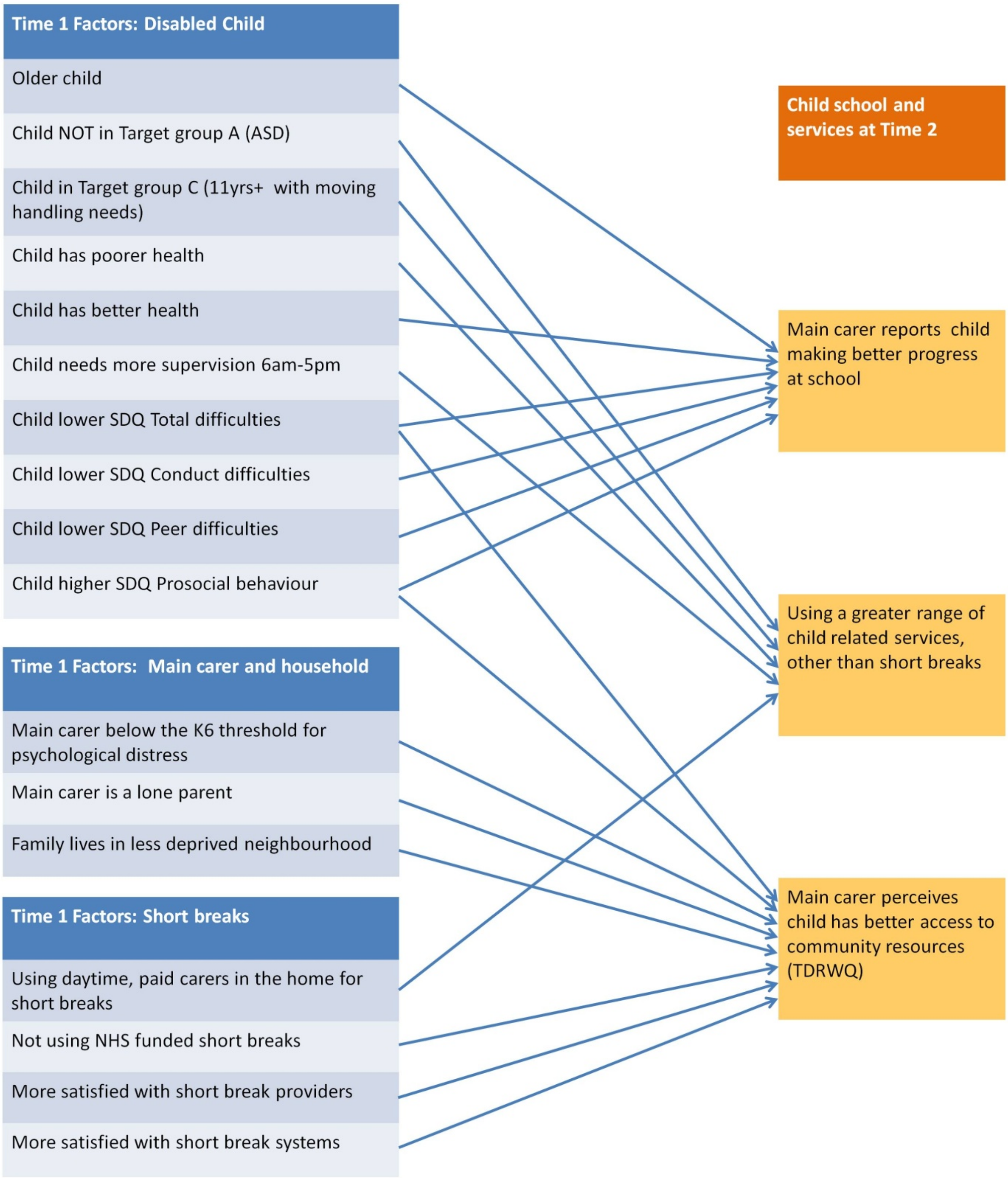


Figure 13 Time 1 factors predicting child relationships outcomes at Time 2.

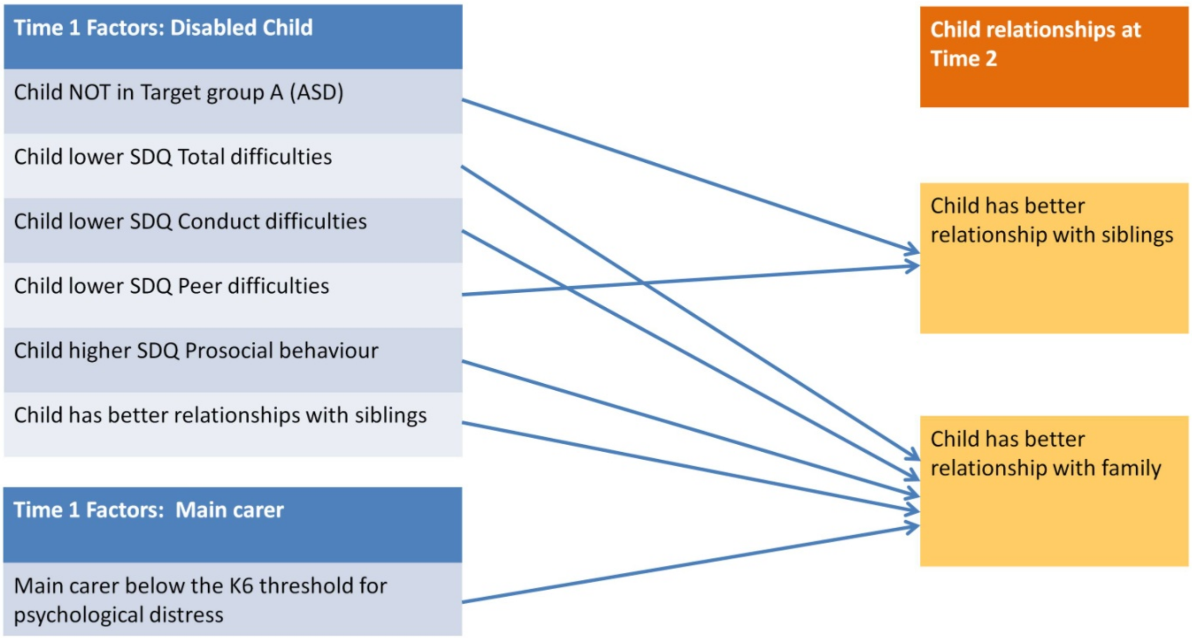
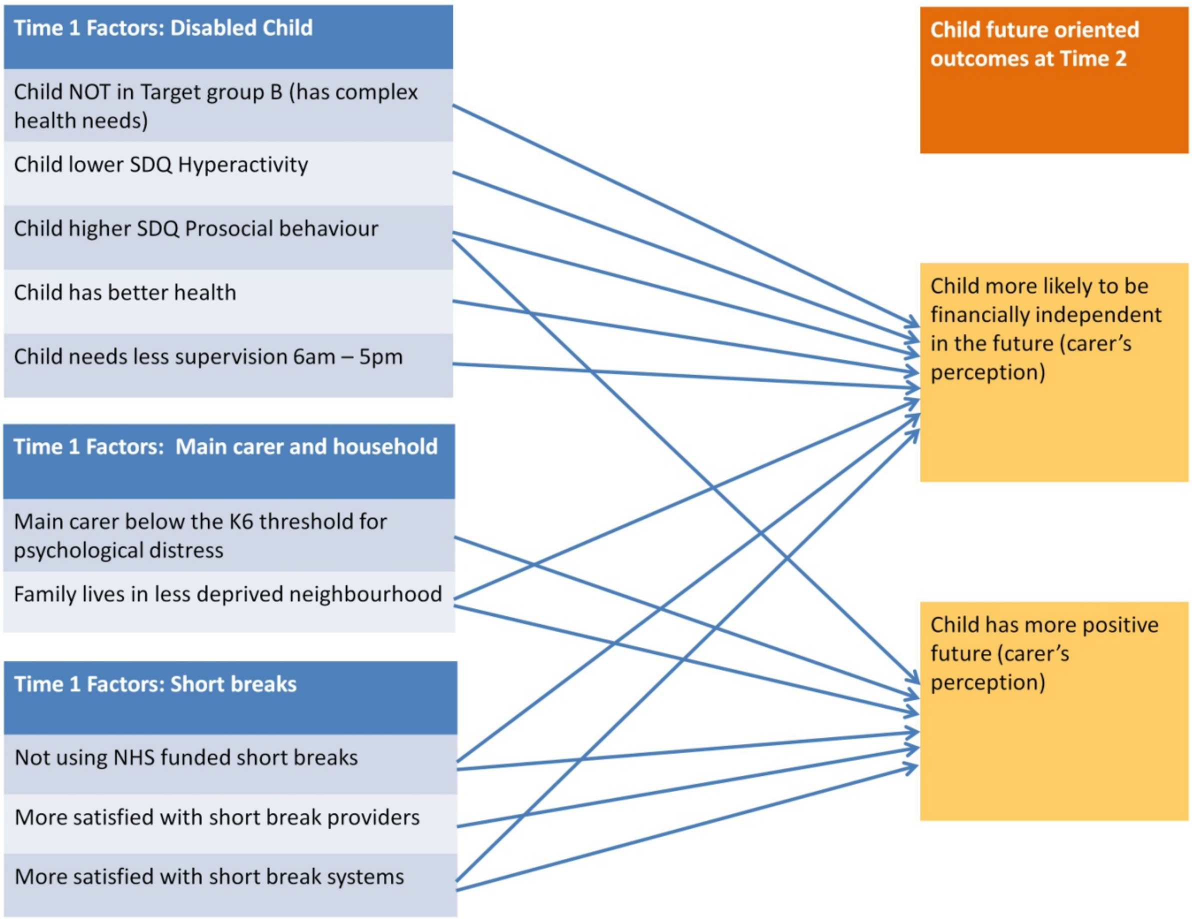


Figure 14 Time 1 Factors predicting child future oriented outcomes at Time 2.



6.3 Changes in outcomes for disabled children, qualitative evidence

Few main carers reported changes in outcomes, as a result of using short breaks, for their disabled child between Time 1 and Time 2 in their responses to the open questions. This suggests that the outcomes that carers reported at Time 2 are similar to those reported at Time 1 and include the child developing their self-esteem and confidence, becoming more independent and having increased opportunities to socialise with other children.

Positive changes in outcomes for disabled children that were reported by main carers tended to involve general remarks about their child's tendency to gradually develop specific attributes or skills, for example, gaining in confidence or becoming more independent as a result of using short breaks over a period of time. Some carers also identified positive changes in the way that their child had grown to enjoy short breaks after an initial period of being reluctant to attend.

[Child] is becoming more and more confident and is forging deeper bond with her carers at respite. (Main carer)

[Child] is much happier to go to respite than last year, he is improving his cooking skills all the time. (Main carer)

[Child] is much more confident. When he first started using short breaks he used to cry, now he can't wait to go and enjoys spending time with his peers, he has a lot more independence and does more things for himself. (Main carer)

One negative change in outcome was reported by a main carer

Since receiving care within our home instead of in a children's residential unit our child has shown signs of distress when being cared for by agency staff. Examples – obsessed with specific areas of the house, crying and wailing, generally not being himself. (Main carer)

In this case the change in outcome for the disabled child was attributed to a change in the nature of the short break provision they received. This reflects the finding in the previous section that examined qualitative evidence on outcomes for main carers which suggested that negative changes in outcomes tend to be reported in association with changes in the short break provision that disabled children and their families receive.

This suggests that where short break provision remains stable parents are likely to report gradual improvements in outcomes related to independence and confidence and the acquisition of new skills. In contrast negative changes tend to be reported in the context of changes to short break provision.

7 Siblings

7.1 Outcomes for siblings over time

We investigated change and continuity in selected indicators that could be considered as outcomes for siblings of the disabled child. These included:

- Health, well-being and behavioural indicators (sibling health; total sibling difficulties and prosocial behaviour according to the SDQ);
- Carer perception of sibling progress at school.

It is also important to note that relationships between the disabled child and their sibling are covered in the section on outcomes for the disabled child.

Table 14 presents these sibling outcome indicators at Time 1 and Time 2. Table 14 shows that overall there was stability in these sibling outcomes from Time 1 to Time 2, although it is important to recognise that the SDQ and carer perceptions of school progress for siblings questions were only asked of a subset of main carers at Time 1.

Table 14 Changes in sibling outcomes from Time 1 to Time 2

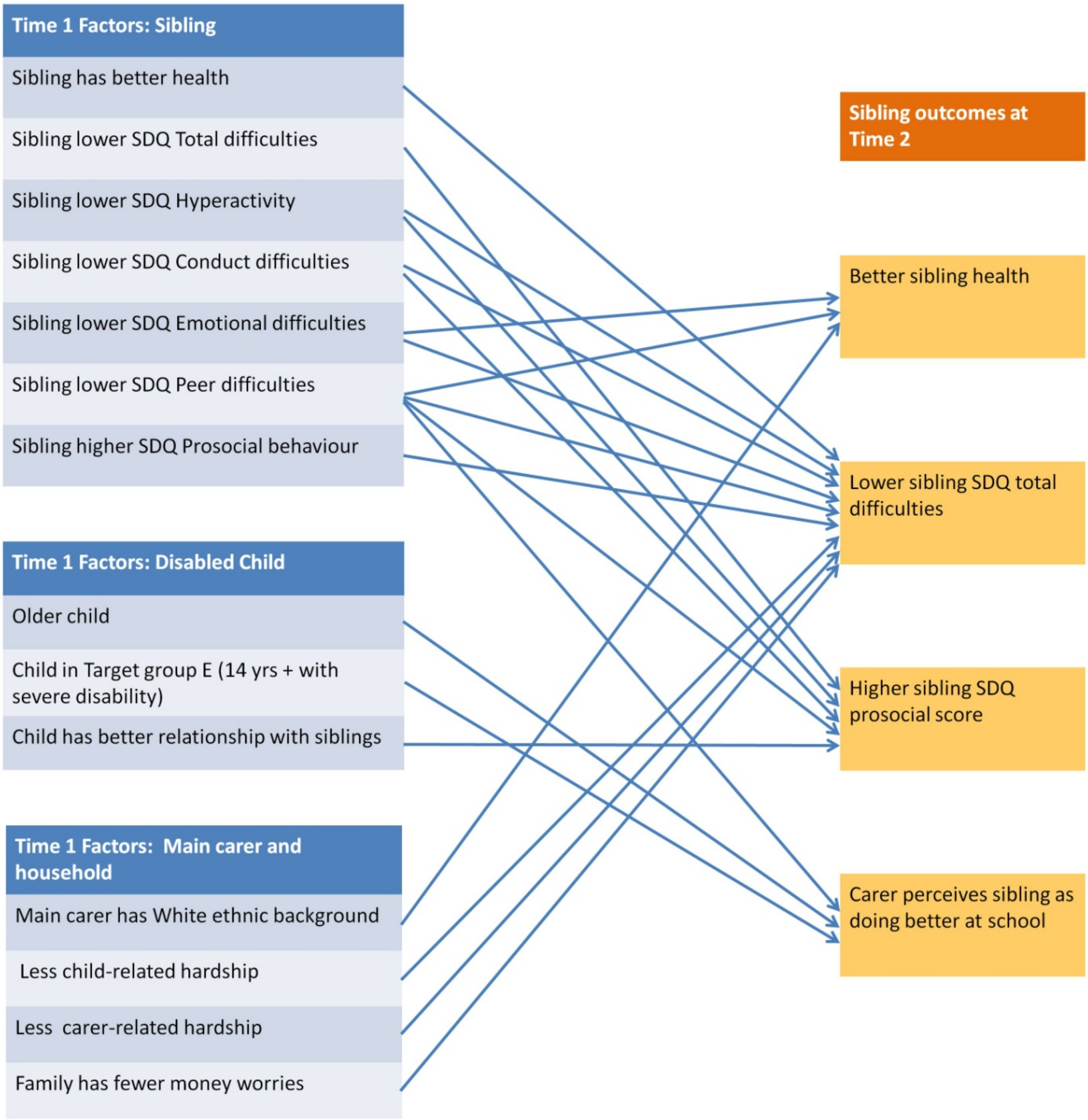
Indicator	Time 1	Time 2	Magnitude (and direction) of change
Sibling health	N=163	N=162	Wilcoxon z=-0.64, n=152, p=0.53
Mean (s.d.)	1.54 (0.70)	1.47 (0.65)	
Range	1 - 4	1 - 4	No change in sibling health T1 > T2
Sibling SDQ: total difficulties	N=43	N=134	Wilcoxon z=-0.36, n=39, p=0.72
Mean (s.d.)	8.98 (7.73)	7.81 (6.78)	No change in sibling SDQ total difficulties
Range	0 - 29	0 – 30	T1 > T2
Sibling SDQ: prosocial behaviour	N=49	N=156	Wilcoxon z=-1.45, n=47, p=0.15
Mean (s.d.)	7.98 (2.45)	7.96 (2.71)	No change in sibling prosocial behaviour
Range	1 - 10	0 - 10	T1 > T2
Carer perceptions of sibling progress at school	N=49	N=210	Wilcoxon z=0.44, n=48, p=0.66
Mean (s.d.)	1.32 (0.44)	1.32 (0.42)	No change in carer perceptions of sibling
Range	1 – 2.67	1 - 3	progress at school T1 > T2

7.2 Time 1 Factors predicting outcomes for siblings at Time 2

For each of the sibling outcomes described above, we conducted univariate analyses to determine which factors at Time 1 predicted each outcome at Time 2, again using a significance level of $p<0.01$. These analyses are reported in full at Appendix F and are summarised below in Figure 15.

As Figure 15 shows, better sibling health, lower sibling psychological difficulties, greater sibling prosocial behaviour and better sibling progress at school (as rated by carers) at Time 2 were unsurprisingly largely predicted by better sibling health, improved sibling behaviour and better sibling relationships with the disabled child at Time 1. Other Time 1 factors predictive of improved sibling outcomes at Time 2 included the disabled child being older and households being in better financial circumstances.

Figure 15 Time 1 Factors predicting sibling outcomes at Time 2.



7.3 Changes in outcomes for siblings, qualitative evidence

No further reported outcomes or changes in outcomes for siblings were identified at Time 2 in the main carer responses to the open questions. This suggests that outcomes identified in main carer responses at Time 1, such as siblings having more of their parents' attention and time, being able to spend more time with their friends and having a break from their disabled brother or sister continue to be relevant at Time 2.

At Time 2 a small number of main carers reported that they wanted to be able to spend more time with their other child or children and that this could be achieved by increasing the amount of short breaks that were available to them.

More breaks would be great as we could focus on the other kids more (Main Carer)

Allocation of more hours! To enable us to have more time away with our other children or by ourselves (Main carer)

8 Discussion and policy implications

This report presents a picture of continuity and change over a 10-month period in the lives of over 200 families with a disabled child, focusing in particular on continuity and change in families' experiences of short breaks and how short breaks impact on carer, child and sibling outcomes. We concentrate here on quantitative and qualitative analyses of the substantial information given to us by 214 main carers of a disabled child at two time points, as these data provide the most comprehensive perspective on continuity and change in families' lives. We want to thank these 214 carers and other family members who gave us considered and insightful responses, and who were motivated by their desire to help shape short break services into provision which is safe, sustainable, effective, fair and appropriate to family needs.

In this section we discuss some of the key findings of the research and their implications for policy and practice.

8.1.1 Family experiences of short breaks

The first set of questions we asked concerned change and continuity in families' experiences of short breaks over the 10 months from Time 1 to Time 2. There was no overall change in the total number of hours of short breaks received by families from Time 1 to Time 2, but there was evidence of some reductions in short break services and funding. From Time 1 to Time 2 there were reductions in the range of types of short break used by families, the number of families using sports/arts/crafts leisure short breaks (which dropped by one-third from 110 families at Time 1 to 74 families at Time 2), and the number of families getting NHS funding for short breaks (which halved from 22 families at Time 1 to 11 families at Time 2). These reductions were being replaced by some families with private/self-funded short breaks; the number of families privately funding short breaks almost doubled from 33 families at Time 1 to 62 families at Time 2. However, these reductions were not being replaced by unpaid carers for short breaks; the number of families using unpaid carers for short breaks more than halved from 44 families at Time 1 to 20 families at Time 2.

The broader changes outlined above do not show the considerable fluctuation in short break usage experienced by most of the families in this study; over 70% of families reported that their total hours of short breaks had changed (either upwards or downwards) by more than 100 hours per year over the 10 months from Time 1 to Time 2. Furthermore, these changes in the amount of short breaks received by families were not predicted by any characteristics of children or families at Time 1, suggesting that these changes in short break allocation were not strongly determined by the needs of children or families. In this study, there was also some evidence of systematic differences in short break provision dependent on service-defined transition points (such as transition between primary and secondary school or beyond education) rather than dependent on the needs of the family.

Family usage of more total hours of short breaks at Time 2, and of centre-based short breaks and daytime/evening short breaks provided in the family home by a paid carer at Time 2, were almost exclusively predicted by certain characteristics of the disabled child at Time 1; these characteristics clustered around older children with more complex health and physical needs and severe learning disabilities. Other factors reported by carers as important influences on their capacity to cope, such as child problematic behaviour and high levels of carer stress, were not predictive of family usage of short breaks in total (or any type of short break) at Time 2.

Taken together, these findings reinforce carers' experiences of short breaks as being allocated on a somewhat arbitrary basis and subject to change at short notice, with carers having little sense of a clear entitlement to a minimum quantity and quality of short break support. While some types of short break such as centre-based short breaks are clearly allocated on the basis of an important set of child needs (more complex health and physical needs and severe learning disabilities), other crucial family and child needs (such as carer distress and child problematic behaviour) do not seem to be used in allocating short breaks.

These findings also support the serious concerns expressed by many carers about short break support being reduced or withdrawn; over this 10-month period NHS funding and specific types of short break support had been withdrawn from many families, with a big increase in families paying for some short breaks themselves. Furthermore, many carers reported receiving notice of future reductions or withdrawal of short break services which would not yet show up in our quantitative data. Given the importance of properly qualified and skilled short break carers to the family carers in this study, unpaid carers are unlikely to compensate for these reductions; indeed family carers had reduced their usage of unpaid carers for short breaks from Time 1 to Time 2.

Carers at both time points reported high levels of satisfaction with the providers of short break services for their family. They were less satisfied with the systems that surrounded short breaks, including how eligibility for short breaks was assessed, the range and amount of short breaks available, the flexibility of short breaks and the availability of short breaks in emergencies. Whether or not carers were satisfied with short breaks at Time 2 depended little on family needs and circumstances at Time 1. However, carers using overnight short breaks provided by a paid carer away from the family home at Time 1 were more satisfied with short break providers at Time 2.

8.1.2 Outcomes for carers and households

We explored continuity and change in several outcomes for the main carers and for households, principally economic outcomes and carer health and well-being outcomes.

Carer and household economic indicators (main carer employment; household employment; family money worries) remained stable from Time 1 to Time 2; at Time 2 just over half of main carers (52%) were in some form of employment. Main carers and households having someone in paid employment at Time 2 were predicted by socio-economic indicators at Time 1 (more carer education; less neighbourhood deprivation), and also by aspects of the disabled child (older children with better relationships with siblings and requiring less overnight supervision) and one type of short break provision (short breaks with a paid carer during the daytime/evening in the family home). Family worries about money at Time 2 were unsurprisingly predicted by a range of socio-economic indicators and carer psychological distress at Time 1; in addition families receiving a greater quantity and a wider range of short breaks at Time 1 reported fewer worries about money at Time 2.

Clearly, short breaks have a direct positive impact on how families perceive they are managing financially. Short breaks more effectively matched to family needs (for example in providing overnight short breaks for children with more problematic behaviour, providing short breaks that would support the employment of main carers acting as lone parents, considering the socio-economic circumstances of families when allocating short breaks) could assist in improving economic outcomes for families.

In terms of main carer health and wellbeing, there were no changes from Time 1 to Time 2 in carer levels of psychological distress, carer life satisfaction or carers' sense of positive gains as result of having a disabled child. However, the self-reported health of main carers worsened from Time 1 to Time 2; the percentage of carers reporting their health as fair/bad/very bad increased from 35% at Time 1 to 47% at Time 2.

A broad range of factors at Time 1 predicted health and well-being outcomes for carers at Time 2. In terms of factors associated with the disabled child, aspects of child problematic behaviour and health rather than levels of physical or learning disabilities predicted carer psychological distress at Time 2; few child factors predicted other carer outcomes. Household socio-economic indicators at Time 1 (neighbourhood deprivation, household hardship and family management of finances) predicted all the carer health and well-being indicators we analysed. Finally, family usage of short breaks at Time 1 had a direct positive impact on the health and well-being of carers at Time 2; families using more total hours and a wider range of short breaks at Time 1 were more likely to have carers with lower levels of psychological distress, higher levels of life satisfaction and better health at Time 2.

In addition to these direct impacts of short breaks, short breaks also had a buffering effect for main carers. Family usage of more hours of short breaks buffered the impact of the child's psychological difficulties on the carer's psychological distress; and also buffered the impact of family socio-economic circumstances on the self-reported health of carers.

Taken together, these findings suggest that short breaks have both a direct positive impact on the health and wellbeing of carers, and buffer the impact of important stressors on carers' health and well-being. These findings reinforce the experiences of carers about the importance of short breaks to their health and well-being and their capacity to continue caring effectively for their disabled child. These findings also raise issues about the targeting of short breaks – they clearly have beneficial impacts on carer health and well-being and help carers to be more resilient in the face of other stressors, yet short breaks do not seem to be allocated on the basis of the needs or circumstances of family carers. These findings also reinforce carers' views that the quantity and range of short breaks are crucial if short break supports are to have a meaningful impact on family life. Consistent with much previous research, carers reported wanting short breaks that were:

- sufficient in duration and quantity throughout the year (and often overnight to allow carers to have a real sense of a break);
- available at times when families really needed them (such as school holidays);
- funded to a level that enabled the employment of qualified, skilled and suitable short break carers;
- local;
- genuinely accessible to groups of disabled children often explicitly or tacitly excluded from short break provision (such as children with ASD, children with complex medical needs and children with challenging behaviour);
- that struck the right balance between predictability and flexibility (particularly in response to family emergencies).

While more personalised short break supports via personal budgets may be a vehicle for families to ensure that short breaks meet these requirements, such personal budgets would have to be paid at a sufficient level to enable carers to choose short break supports they trust, rather than having to make trade-offs between quantity vs quality short break support, and there would have to be a sufficient range of short break services available for families to choose from.

Again consistent with previous research, many carers expressed concerns about the processes surrounding the assessment, allocation and review of short break provision. In the main, carers did not feel secure in their entitlement to and/or eligibility for short break services and were not confident that their existing level of short break service would be maintained, let alone increased. For many carers, gaining short breaks seemed to be the end result of a long struggle or the result of a family crisis, rather than the result of an assessment of the family's needs designed to prevent future family crises. Bureaucracy (particularly surrounding direct payments) and reviews of family needs that were infrequent, absent, arbitrary or not responsive to the changing needs of children and families were also frequently mentioned by carers.

8.1.3 Outcomes for disabled children and siblings

We explored continuity and change over time in a wide range of outcome indicators for the disabled child, including health, behaviour and well-being indicators and other indicators of service usage, progress at school and future prospects as rated by carers.

There was a general pattern of stability in child outcomes from Time 1 to Time 2, although there was an improvement in children's total psychological difficulties (as measured by the SDQ) over this time period. This pattern of general stability generally reinforced carers' reports of continuity and change in their child over this time period, although a minority of carers (14%) reported changes or refinements to diagnoses associated with their disabled child between Time 1 and Time 2. Whilst for some carers the increasing age of their child was associated with deteriorating physical and mental health and greater difficulties in managing the child's behaviour, this was balanced by other carers reporting improvements over time in their child's behaviour, confidence, independence and maturity. Whilst such changes in the disabled child over time may come 'under the radar' of service assessment systems, they are clearly important to families and suggest the need for carers to be able to initiate reviews and re-appraisals of short break support as the child's needs change.

The health, psychological difficulties and family/peer relationships of the disabled child at Time 2 were almost exclusively predicted by similar characteristics of the disabled child at Time 1. Disabled children were more likely to have poorer outcomes in these areas at Time 2 if the child had an autistic spectrum disorder, showed a range of psychological difficulties and challenging behaviours, had more complex health needs, had a severe learning disability, had poorer relationships with siblings and consequently required more supervision. Few factors concerning the main carers, the household or short breaks at Time 1 predicted these child outcomes at Time 2.

Similar child factors at Time 1 predicted other disabled child outcomes at Time 2, including child usage of a greater range of other child-oriented services, carer reports of better child progress at school, and carer perceptions of brighter future prospects for the disabled child. However, other factors also consistently predicted these child outcomes, including main carers reporting lower levels of psychological distress and families living in less deprived neighbourhoods. Greater carer satisfaction with short break providers and with systems surrounding short breaks at Time 1 also predicted better child outcomes in these areas at Time 2.

Outcomes for siblings were relatively stable from Time 1 to Time 2. Overall, better health and behavioural outcomes for siblings at Time 2 tended to be predicted by similar factors related to siblings at Time 1; although better household financial circumstances were also associated with improved outcomes for siblings.

Taken together these findings suggest that short breaks have little direct impact on the health and behaviour of the disabled child (or the sibling), an unsurprising finding given that short breaks are not primarily designed to achieve these outcomes. However, short breaks do seem to have an impact on how positive carers feel about the future for their disabled child, and as outlined above short breaks do buffer the impact of child behavioural difficulties on carer psychological distress. Some carers' accounts did suggest a more direct link between short breaks and child outcomes, with stable, sufficient and high quality short breaks associated with increasing child confidence and maturity, and instability or reductions in short breaks associated with increasing child anxiety and problematic behaviours.

Whether directly or indirectly, it seems that short breaks have a role to play in reducing the impact of the child's difficulties on the well-being of carers. These findings also confirm that the central purpose of short breaks is to improve outcomes for family carers. Whilst it is clearly important that the disabled child enjoys the short break with short break carers in environments that families trust, the central function of short breaks is to offer the carer a meaningful break. The accounts of many of the carers in this study seem to describe 'short breaks' that, however enjoyable for the child, do not meet this central function as far as carers are concerned.

8.1.4 Policy and practice implications

The discussion above outlines many implications of this study's findings for policymakers, local authorities and those delivering short break supports. A final list of implications for policymakers and others will be presented here.

- Short breaks have a positive direct impact on the health and wellbeing of family carers, and also act to buffer the impact of other stressors on family carers. Clearly, the government policy direction of continued investment in short breaks is strongly supported by these findings. However, the role of the NHS in funding short breaks urgently needs clarification.
- This research reaffirms that the central purpose of short breaks is to provide a meaningful break for family carers to maintain and improve their health, wellbeing and economic circumstances. To achieve this central purpose current patterns of short break allocation and provision need to be revised:
    - The allocation of short breaks should be based on careful assessment and regular review of the needs of the whole family (including assessment of carer health and well-being, child challenging behaviour and the family's financial circumstances) rather than solely on the health needs and level of disability of the disabled child.
    - Short breaks should be designed to actually provide a meaningful break for families; unless they are supporting carer employment (e.g. holiday clubs or after-school activities) short breaks of very short duration are unlikely to provide such a meaningful break for family carers.
    - It is crucial that Education, Care and Health plans proposed for 2014 consider the needs of the whole family and include explicit plans around short breaks for family carers.

- Family carers need to feel a sense of security in their entitlement to and eligibility for short breaks. In this study there was evidence of some withdrawal of short break funding and short break services, substantial fluctuations in short break support, and carer reports of changes being made at short notice and in ways that felt very arbitrary to them:
    - Families should routinely receive clear and comprehensive information about entitlement/eligibility for short breaks, and the range and quantity of short breaks available locally. For individual families, this will require more individualised and detailed information than the Statement required of local authorities by October 2011.
    - Service-defined transition points (e.g. from primary to secondary school) should not have a major impact on the short breaks used by families, unless families themselves consider that such transitions require changes to short break supports for their family.
    - Assessment and review processes should become simpler and more transparent, with family initiated review and reassessment becoming routinely available.
- The widespread implementation of personal budgets for families with a disabled child could help family carers address many of the concerns they express about how short breaks are delivered. For these personal budgets to be effective for families, the following issues will need to be addressed:
    - The personal budget will need to be at a sufficient level to enable carers to choose a sufficient quantity of short break supports they trust, rather than having to make trade-offs between quantity vs quality short break support, especially as families are understandably very reluctant to use unpaid or unskilled short break carers.
    - Families will need excellent and up to date information to make informed decisions about which short breaks to use.
    - Planned commissioning of a sufficient quantity and range of short break services will be needed, by local authorities working closely with families, to enable families to have a meaningful choice of short break options.
    - Processes for allocating and administering personal budgets need to be as simple and free of restrictions as possible, with support in the use of personal budgets available for all those families who want it.

9 Lists of tables and figures

9.1.1 Tables

9.1.2 Figures

10 Bibliography

BUHRMESTER, D. & FURMAN, W. 1990. Perceptions of sibling relationships during middle childhood and adolescence. *Child Development,* 61**,** 1387-1398.

CEDR AND NDTI 2011a. Short breaks for disabled children; Briefing Paper 1 Commissioning. Lancaster Centre for Disability Research, Lancaster University and the National Development Team for Inclusion. http://www.lancs.ac.uk/shm/research/projects/short_breaks/outputs/index.php.

CEDR AND NDTI 2011b. Short breaks for disabled children; Briefing Paper 2 The Range of Short Breaks. Lancaster Centre for Disability Research, Lancaster University and the National Development Team for Inclusion. http://www.lancs.ac.uk/shm/research/projects/short_breaks/outputs/index.php.

CEDR AND NDTI 2011c. Short breaks for disabled children; Briefing Paper 3 Family Participation. Lancaster Centre for Disability Research, Lancaster University and the National Development Team for Inclusion. http://www.lancs.ac.uk/shm/research/projects/short_breaks/outputs/index.php.

CEDR AND NDTI 2011d. Short breaks for disabled children; Briefing Paper 4 Personalised funding. Lancaster Centre for Disability Research, Lancaster University and the National Development Team for Inclusion. http://www.lancs.ac.uk/shm/research/projects/short_breaks/outputs/index.php.

CENSUS 2011. *Census for England and Wales*, http://www.ons.gov.uk/census/2011-census/index.html (Last accessed May 2011).

CHAMBA, R., AHMAD, W., HIRST, M., LAWTON, D. & BERESFORD, B. 1999. *On the edge: Minority Ethnic Families Caring For A Severely Disabled Child,* Bristol, The Policy Press.

COLLINS, M., LANGER, S., WELCH, V., WELLS, E., HATTON, C., ROBERTSON, J. & EMERSON, E. 2009. An initial report on preliminary themes emerging from qualitative research into the impact of short break provision on families with disabled children. Lancaster: Centre for Disability Research (CeDR). Lancaster University

CWI 2009. Child Well-being Index 2007 ('CWI 2009'). http://www.communities.gov.uk/publications/communities/childwellbeing2009 (Last accessed May 2011). London: Department of Communities and Local Government.

DFE. 2010. *Government announces £800 million to support families. Press Notice. http://www.education.gov.uk/childrenandyoungpeople/sen/a0070302/government-announces-800-million-to-support-families (Last accessed May 2011)* [Online]. Department for Education. [Accessed].

DFE 2011a. Children and Young Persons England: The Breaks for Carers of Disabled Children Regulations. http://www.legislation.gov.uk/uksi/2011/707/made (Accessed August 2011). London: Department for Education.

DFE 2011b. Short Breaks for Carers of Disabled Children: Advice for Local Authorities. London: Department for Education. http://media.education.gov.uk/assets/files/pdf/s/short%20breaks%20-%20advice%20for%20local%20authorities.pdf (Accessed August 2011).

DFE 2011c. Support & aspiration: A new approach to special educational needs and disability. A consultation. London: Department for Education. The Stationery Office. http://www.official-documents.gov.uk/document/cm80/8027/8027.pdf.

DFE 2011d. Benchmarking tables of LA planned expenditure: 2011-2012. London: Department for Education. http://www.education.gov.uk/researchandstatistics/statistics/recentreleases/a00197971/benchmarking-2011-12

FACS 2005. Families and Children Study. http://surveynet.ac.uk/sqb/surveys/facs.asp (Last accessed May 2011). Survey Resources Network.

GLIDDEN, L. & JOBE, B. 2007. Measuring parental daily rewards and worries in transition to adulthood. . *Am. J. Mental Retardation,* 112**,** 275-288.

GOODMAN, R. 2001. Psychometric Properties of the Strengths and Difficulties Questionnaire. *Journal of American Academy of Child and Adolescent Psychiatry,* 40.

GREIG, R., CHAPMAN, P., CLAYSON, A., GOODEY, C. & MARSLAND, D. 2010a. Short Breaks Pathfinder Evaluation. Research Report DFE-RR062. https://www.education.gov.uk/publications/standard/publicationdetail/page1/DFE-RR062 (Accessed August 2011). London: Department for Education & National Development Team for Inclusion.

GREIG, R., CHAPMAN, P., CLAYSON, A., GOODEY, C. & MARSLAND, D. 2010b. Short Breaks Pathfinder Evaluation; Interim Report - End of Phase One. https://www.education.gov.uk/publications/eOrderingDownload/DCSF-RR223.pdf (Last accessed May 2011). London: Department for Children, Schools and Families and National Development Team for Inclusion.

HATTON, C., AZMI, S., CAINE, A. & EMERSON, E. 1998. Informal carers of adolescents and adults with learning difficulties from the South Asian communities: family circumstances, service support, and carer stress. *British Journal of Social Work,* 28**,** 821-837.

HSE 2006. Health Survey for England. http://surveynet.ac.uk/sqb/surveys/hse.asp (Last accessed May 2011). Survey Resources Network.

ID 2007. Indices of Deprivation (at Lower Layer Super Output Areas). http://www.communities.gov.uk/publications/communities/indiciesdeprivation07 (Last accessed May 2011). London: Department of Communities and Local Government.

KESSLER, R., ANDREWS, G., COLPE, L., HIRIPI, E., MROCZEK, D., NORMAND, L., WALTERS, E. & ZASLAVSKY, A. 2002. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine,* 32**,** 959-976.

KING, S., ROSENBAUM, P. & KING, G. 1995. The Measure of Processes of Care. MPOC. A Means to Assess Family-Centred Behaviours of Health Care Providers. http://www.canchild.ca/en/measures/mpoc56_mpoc20.asp (Last accessed May 2011). Hamilton, ON, Canada: Canchild Centre for Childhood Disability Research, Institute for Applied Health Sciences, McMaster University.

LANGER, S., COLLINS, M., WELCH, V., WELLS, E., HATTON, C., ROBERTSON, J. & EMERSON, E. 2010. A report on themes emerging from qualitative research into the impact of short break provision on families with disabled children. Research Report DCSF - RR221 London: Department for Children Schools and Families. https://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-RR221 (Accessed August 2011).

MCGILL, P. & HONEYMAN, G. 2009. Survey of short break usage amongst families of children and adults with learning disabilities and challenging behaviour. Challenging Behaviour Foundation and Tizard Centre, University of Kent.

MCS 2003/05. Millennium Cohort Study 2003-2005. http://surveynet.ac.uk/sqb/surveys/mcs.asp (Last accessed May 2011). Survey Resources Network.

PIT-TEN CATE, I. 2003. *Family adjustment to disability and chronic illness in children. http://www.theses.com/idx/scripts/it3.asp?xml=Z:\index\idx\docs\all\53\it00469183.htm&subfolder=/search (Last accessed May 2011).* Unpublished doctoral thesis. University of Southampton.

ROBERTSON, J., HATTON, C., EMERSON, E., WELLS, E., COLLINS, M., LANGER, S. & WELCH, V. 2010. The impacts of short breaks provision on disabled children and families: an international literature review. DCSF-RR222. London: Department for Education. https://www.education.gov.uk/publications/standard/publicationdetail/page1/DCSF-RR222

(Accessed August 2011).

ROBERTSON, J., HATTON, C., WELLS, E., COLLINS, M., LANGER, S., WELCH, V. & EMERSON, E. 2011. The Impacts of short break provision on families with a disabled child: an international literature review. *Health and Social Care in the Community,* doi: 10.1111/j.1365-2524.2010.00977.x.

WATSON, D. & CLARK, L. 1988. Development and Validation of Brief Measures of Positive and Negative Affect. *Journal of Personality and Social Psychology,* 55**,** 1063-1070.

WELCH, V., HATTON, C., WELLS, E., COLLINS, M., LANGER, S., ROBERTSON, J. & EMERSON, E. 2010. The Impact of Short Breaks on Families with a Disabled Child; Report One of the Quantitative Phase. Research Report DFE-RR063. London: Department for Education. https://www.education.gov.uk/publications/RSG/AllRsgPublications/Page9/DFE-RR063 (Accessed August 2011).

11 Appendices

11.1 Appendix A Measures used at Time 1 and Time 2

Further discussion of these measures can be found in the first quantitative report (Welch et al., 2010)

Table 15 Summary of measures of parent and carer well-being

	Incorporated into questionnaire(s)					
Measure	**LS MC**	**LS AC**	**LS CYP**	**LS Sib**	**CS MC**	**Time 2**
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.

Table 16 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**	**Time 2**
Items formulated to ascertain basic information about disabled child (diagnoses, assessments etc)	✓				✓	✓a
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. a, item altered to detect change.

Table 17 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**	**Time 2**
Items investigating household composition items adapted from Millennium Cohort Study (MCS, 2003/05)	✓				✓	✓a
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, item altered to detect change.

Table 18 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**	**Time 2**
Items and adapted items exploring types of breaks used and their suitability from previous survey of short break use (McGill and Honeyman, 2009)	✓				✓	✓b
Items for this study identifying funding for short breaks and whether direct payments were received for other purposes	✓				✓	✓b
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. .b, item adapted in response to feedback.

11.2 Appendix B Comparison of T2 responders and non-responders

Table 19 T2 responders / T1 responders, 2x2 categorical variables

T1 Variables	T2 % Y/ % N	Odds Ratio (95% confidence interval)	n	Statistic Significance
Carer gender male	7 / 12	0.50 (0.24 – 1.1)	352	χ^2 *p*= 0.07
Disabled child's gender male	63 / 64	0.97 (0.62 – 1.5)	352	χ^2 *p*= 0.90
Carer a lone parent	21 / 25	0.80 (0.48 – 1.3)	350	χ^2*p*= 0.39
Family contains more than one disabled child	10 / 14	0.72 (0.37 – 1.4)	347	χ^2 *p*= 0.32
English and other language spoken at home	5 / 10	2.1 (0.92 – 4.7)	213	χ^2 *p*= 0.08
Carer reports literacy or numeracy problems	2 / 5	0.36 (0.10 – 1.3)	348	FET *p*= 0.12
Household has no one in employment	21 / 29	1.6 (0.94 – 2.5)	348	χ^2 *p*= 0.08
Carer has long standing illness or disability	46 / 46	1.0 (0.66 – 1.6)	350	χ^2 *p*= 0.94
Carer is not White British	8 / 14	1.9 (0.93 – 3.7)	348	χ^2 *p*= 0.75
Carer does not belong to a religion	10 / 11	0.90 (0.45 -1.8)	353	χ^2 *p*= 0.77
Child does not receive DLA	0 / 3	N/A	350	FET *p*= 0.024
Family not currently using short breaks	9 / 16	1.9 (1.0 – 3.7)	353	χ^2 *p*= 0.045
Uses direct payments for short breaks	33 / 25	1.4 (0.86 -2.4)	318	χ^2 *p*= 0.17
Uses direct payments for other services	20 / 14	1.5 (0.80 – 2.8)	313	χ^2 *p*= 0.21
Carer reported suitable breaks	95 / 94	1.2 (0.44 – 3.2)	296	χ^2 *p*= 0.72
Carer reported unsuitable breaks	29 / 26	1.1 (0.64 – 1.9)	278	χ^2 *p*= 0.71
Carer reported improvement in breaks -12m	56 / 51	1.3 (0.74 – 2.1)	246	χ^2 *p*= 0.41
Child in target group A	53 / 39	0.57 (0.37 - 0.88)	346	χ^2 *p*= 0.012
Child in target group B	22 / 24	1.08 (0.65 – 1.9)	348	χ^2 *p*= 0.77
Child in target group C	22 / 24	1.1 (0.66 – 1.9)	348	χ^2 *p*= 0.69
Child in target group D	73 / 56	0.47 (0.30 - 0.75)	343	χ^2 *p*= 0.001*
Child in target group E	33 / 32	0.95 (0.60 -1.5)	344	χ^2 *p*= 0.83
Child in TDC priority group A	80 / 62	0.41 (0.26 - 0.67)	342	χ^2 *p*= 0.000*
Child in TDC priority group B	34 / 35	1.0 (0.65 – 1.6)	348	χ^2 *p*= 0.91
Notes Calculations for 2 x 2 tables. χ^2= Pearson Chi-Square, FET = Fisher's Exact Test (reported here if one or more cell has expected count less than 5), *significant at *p*=<0.01				

Table 20 T2 responders / T1 responders, ordinal and interval variables

T1 Variables	T2 Yes	T2 No	Effect Size	n	Statistic Significance
Frequency of supervision 6am-5pm	x̄ = 1.35 (sd=0.58)	x̄ = 1.45 (sd=0.71)	-0.15	352	U = 14046 *p* = 0.32
Frequency of supervision 5pm – 10pm	x̄ = 1.61 (sd=0.74)	x̄ = 1.67 (sd=0.08)	-0.08	352	U = 14329 *p* = 0.57
Frequency of supervision 10pm – 6am	x̄ = 2.58 (sd=1.02)	x̄ = 2.77 (sd=1.04)	-0.18	351	U = 13200 *p* = 0.08
Age (yrs,) short break child	x̄ = 12.0 (sd=4.08)	x̄ = 11.7 (sd=4.32)	0.05	347	U = 14030 *p* = 0.72
Number of target groups child belongs to	x̄ = 2.01 (sd=1.14)	x̄ = 1.72 (sd=1.23)	0.25	348	U = 12316 *p* = 0.017
General health, short break child	x̄ = 2.02 (sd=0.80)	x̄ = 2.20 (sd=0.85)	-0.22	349	U = 12943 *p* = 0.06
SDQ total difficulties score, child	x̄ = 18.57 (sd=5.94)	x̄ = 17.5 (sd=7.60)	-0.16	259	U = 7033 *p* = 0.12
SDQ prosocial score, child	x̄ = 3.79 (sd=3.02)	x̄ = 4.94 (sd=3.21)	-0.37	298	U = 8292 *p* = 0.003*
Age (yrs), main carer	x̄ = 45.1 (sd=6.74)	x̄ = 43.9 (sd=6.80)	0.18	343	U = 12774 *p* = 0.18
General health, carer	x̄ = 2.23 (sd=0.85)	x̄ = 2.36 (sd=0.88)	-0.16	350	U = 13420 *p* = 0.17
K6 score carer, carer	x̄ = 7.04 (sd=5.10)	x̄ = 7.12 (sd=4.58)	-0.02	338	U = 13168 *p* = 0.69
Life satisfaction score, carer	x̄ = 5.93 (sd=2.15)	x̄ = 5.85 (sd=1.87)	0.05	344	U = 13505 *p* = 0.55
Positive gains score, carer	x̄ = 11.94 (sd=4.40)	x̄ = 11.1 (sd=2.98)	0.21	114	U = 1303 *p* = 040
TDRWQ total score	x̄ = 51.9 (sd=8.82)	x̄ = 54.0 (sd=11.9)	-0.20	78	U = 574 *p* = 0.35
Educational level, carer	x̄ = 2.16 (sd=1.08)	x̄ = 2.35 (sd=1.31)	-0.16	345	U = 13384 *p* = 0.38
Educational level, partner	x̄ = 2.37 (sd=1.34)	x̄ = 2.29 (sd=1.27)	0.07	93	U = 895 *p* = 0.90
Educational level, highest in household	x̄ = 1.87 (sd=0.96)	x̄ = 2.00 (sd=0.97)	-0.14	117	U = 135 *p* = 0.44
Household, number of people	x̄ = 3.93 (sd=1.17)	x̄ = 4.26 (sd=1.52)	-0.25	352	U = 13004 *p* = 0.044
Money worries in last few weeks	x̄ = 2.61 (sd=0.94)	x̄ = 2.49 (sd=0.96)	0.13	348	U = 13364 *p* = 0.23
How managing financially	x̄ = 2.80 (sd=1.29)	x̄ = 3.06 (sd=1.38)	-0.20	348	U = 12873 *p* = 0.08
Employment score for household	x̄ = 1.81 (sd=1.19)	x̄ = 1.65 (sd=1.29)	0.13	348	U = 13360 *p* = 0.23
Satisfaction with short breaks, mean for carer	x̄ = 1.63 (sd=0.43)	x̄ = 1.63 0.46(sd=)	0.20	314	U = 11467 *p* = 0.90
Hours of short breaks - total	x̄ = 644 (sd=665)	x̄ = 442 (sd=454)	0.36	271	U = 6887 *p* = 0.009*
Hours of short breaks - leisure and play	x̄ = 121	x̄ = 128	-0.07	178	U = 3590

T1 Variables	T2 Yes	T2 No	Effect Size	n	Statistic Significance
	(sd=93.1)	(sd=109)			*p* = 0.99
Hours of short breaks - overnight	x̄ = 655 (sd=599)	x̄ = 481 (sd=505)	0.31	144	U = 1716 *p* = 0.027
Hours of short breaks – non-centre	x̄ = 401 (sd=554)	x̄ = 281 (sd=348)	0.26	165	U = 2547 *p* = 0.041
Hours of short breaks – at a centre	x̄ = 558 (sd=481)	x̄ = 425 (sd=504)	0.27	117	U = 1130 *p* = 0.040
Hours of short breaks - unpaid	x̄ = 305 (sd=427)	x̄ = 116 (sd=214)	0.56	61	U = 234 *p* = 0.001*
IMD 07 rank	x̄ = 17786 (sd=8595)	x̄ = 16336 (sd=8464)	0.17	349	U = 13080 *p* = 0.12
CWI 09 rank	x̄ = 14379 (sd=8547)	x̄ = 16173 (sd=8386)	-0.21	349	U = 12730 *p* = 0.06
CWI 09 material domain rank	x̄ = 14321 (sd=8734)	x̄ = 16333 (sd=8612)	-0.23	349	U = 12590 *p* = 0.039
CWI 09 health / disability domain rank	x̄ = 17894 (sd=8917)	x̄ = 18602 (sd=9316)	-0.08	349	U = 13778 *p* =0.44
Notes Effect Size Cohen's *d*, U = Mann-Whitney U, *significant at *p*=<0.01					

11.3 Appendix C Time 1 Factors predicting short break outcomes at Time 2

11.3.1 Time 1 Factors predicting short break usage at Time 2

11.3.1.1 Time 1 Factors predicting short break usage at Time 2 and changes in short break usage from Time 1 to Time 2

Given a pattern of substantial fluctuations in short break usage over the ten months from Time 1 to Time 2, we wanted to investigate whether any child, carer or household factors at Time 1 predicted both family usage of short breaks at Time 2 and overall changes in short break usage from Time 1 to Time 2. This is a way of investigating whether changes in short break usage from Time 1 to Time 2 are the result of short break allocation being targeted on the basis of the needs of the disabled child and/or their families – if such needs-based allocation of short breaks was happening we would expect to see disabled children and families in greater need at Time 1 getting greater access to short breaks at Time 2.

11.3.1.2 Time 1 Factors predicting overall usage of short breaks at Time 2 and overall change in short break usage from Time 1 to Time 2

The first way we explored this issue was to conduct univariate analyses to determine which child, carer and household factors at Time 1 were associated with overall indicators of short break usage by Time 2; the range of short break types used at Time 2, the total hours of short breaks used by families at Time 2, and changes in the total hours of short breaks used by families from Time 1 to Time 2.

Table 21 shows that family usage of a wider range of short breaks used at Time 1 was associated with family usage of a wider range of short breaks at Time 2. Families less worried about money at Time 1 were more likely to use a wider range of short break types at Time 2.

Table 21 Time 1 Factors predicting the range of short break types used at Time 2

Factors predicting the range of short break types used by families at Time 2		Test statistics
Range of short break types used at Time 1		Spearman's rho=0.45, n=212, p<0.001
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1	Family less worried about money	Spearman's rho=0.18, n=212, p=0.01
Short break usage and funding at Time 1		

Table 22 shows that families using more total hours of short breaks at Time 1 were more likely to use more total hours of short breaks at Time 2. A wide range of child factors at Time 1 were associated with families getting more total hours of short breaks at Time 2: families with a female disabled child; in Target Groups B, or C; with severe/profound learning disabilities; with lower emotional difficulties according to the SDQ; and receiving a wider range of other child services. Finally, families getting NHS funding and/or local authority funding for short breaks at Time 1 were more likely to be using more total hours of short breaks at Time 2.

Table 22 Time 1 Factors predicting the total hours of short breaks used by families at Time 2

Factors predicting the total hours of short breaks used by families at Time 2		Test statistics
Total hours of short break hours used at Time 1		Spearman's rho=0.55, n=187, p<0.001
Disabled child factors at Time 1	Female child	Mann-Whitney U=4064, n=211, p=0.009
	Child in Target Group B	Mann-Whitney U=2601, n=210, p=0.001
	Child in Target Group C	Mann-Whitney U=2427.5, n=210, p<0.001
	Child with severe LD	KW chi-square=12.95, df=3, n=199, p=0.005
	Child lower SDQ emotional difficulties	Spearman's rho=-0.20, n=182, p=0.006
	Child receives greater range of other services	Spearman's rho=0.25, n=209, p<0.001
Main carer factors at Time 1		
Household factors at Time 1		
Short break funding at Time 1	Family gets NHS funding for short breaks	Mann-Whitney U=1253, n=194, p=0.005
	Family gets local authority funding for short breaks	Mann-Whitney U=2909, n=193, p=0.005

11.3.2 Time 1 Factors predicting change in short break usage, Time 1 to Time 2

Table 23 shows that no factors at Time 1 were associated with positive changes in the total hours of short breaks received from Time 1 to Time 2.

Table 23 Time 1 Factors predicting change in total hours of short breaks from Time 1 to Time 2

Factors predicting positive change in total hours of short breaks used by families from Time 1 to Time 2		Test statistics
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1		

Family usage and funding of short breaks at Time 1		

11.3.3 Time 1 Factors predicting usage of specific short break types at Time 2

As well as investigating factors predicting overall short break usage at Time 2, we also explored which Time 1 factors predicted family usage of specific types of short break at Time 2. This was to investigate whether usage of specific types of short breaks at Time 2 was associated with specific profiles of child and family needs at Time 1.

Table 24 shows that the only Time 1 factor predicting family usage of sports/arts/crafts/play leisure short breaks at Time 2 was family usage of this type of short break at Time 1.

Table 24 Time 1 Factors predicting family usage of sports/arts/crafts/sports leisure short breaks at Time 2

Factors predicting family usage of sports/arts/crafts/play leisure short breaks at Time 2		Test statistics
Family usage of sports/arts/crafts/play leisure short breaks at Time 1		Spearman's rho=0.18, n=214, p=0.010
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1		

Table 25 shows that only family usage of this type of short break at Time 1 predicted family usage of school-related short breaks at Time 2.

Table 25 Time 1 Factors predicting family usage of after-school/holiday club leisure short breaks at Time 2

Factors predicting family usage of after-school / holiday club leisure short breaks at Time 2		Test statistics
Family usage of after-school/holiday club leisure short breaks at Time 1		Spearman's rho=0.38, n=214, p<0.001
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1		

Table 26 shows that family usage of centre-based short breaks at Time 1 was strongly associated with family usage of this type of short break at Time 2. Several Time 1 factors related to the disabled child also predicted family usage of centre-based short breaks at Time 2: the child being older, the child being in Target Groups C or E, and the child having severe/profound learning disabilities.

Table 26 Time 1 Factors predicting family usage of centre-based (including overnight) short breaks at Time 2

Factors predicting family usage of centre-based (including overnight) short breaks at Time 2		Test statistics
Family usage of centre-based (including overnight) short breaks at Time 1		Spearman's rho=0.60, n=214, p<0.001
Disabled child factors at Time 1	Older child age	Mann-Whitney U=3982, n=211, p<0.001
	Child in Target Group C	n=212, Fisher's exact p<0.001
	Child in Target Group E	n=211, Fisher's exact p<0.001
	Child with severe LD	n=201, chi-square=20.34, df=3, p<0.001
Main carer factors at Time 1		
Household factors at Time 1		

Table 27 shows that only family usage of this type of short break at Time 1 predicted family usage of daytime short breaks with a paid carer away from the family home at Time 2.

Table 27 Time 1 Factors predicting family usage of daytime short breaks with a paid carer away from the family home at Time 2

Factors predicting family usage of daytime short breaks with a paid carer away from the family home at Time 2		Test statistics
Family usage of daytime short breaks with a paid carer away from the family home at Time 1		Spearman's rho=0.34, n=214, p<0.001
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1		

Table 28 shows that only family usage of this type of short break at Time 1 was predictive of family usage of overnight short breaks with a paid carer away from the family home at Time 2.

Table 28 Time 1 Factors predicting family usage of overnight short breaks with a paid carer away from the family home at Time 2

Factors predicting family usage of overnight short breaks with a paid carer away from the family home at Time 2		Test statistics
Family usage of overnight short breaks with a paid carer away from the family home at Time 1		Spearman's rho=0.52, n=214, p<0.001
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1		

Table 29 shows that family usage of daytime short breaks with a paid carer in the family home at Time 1 was highly associated with family usage of this type of short break at Time 2. In addition, child factors at Time 1 included the child being in Target Group B, the child being in more target groups, the child being in TDC Priority Group B and the child having lower prosocial behaviour according to the SDQ. The only main carer factor at Time 1 was the main carer having more education.

Table 29 Time 1 Factors predicting family usage of daytime short breaks with a paid carer in the family home at Time 2

Factors predicting family usage of daytime short breaks with a paid carer in the family home at Time 2		Test statistics
Family usage of daytime short breaks with a paid carer in the family home		Spearman's rho=0.63, n=214, p<0.001
Disabled child factors at Time 1	Child in Target Group B Child lower SDQ prosocial behaviour	n=212, Fisher's exact p=0.003 Mann-Whitney U=2468.5, n=185, p=0.002
Main carer factors at Time 1	Main carer more education	Mann-Whitney U=3308.5, n=211, p<0.001
Household factors at Time 1		

Table 30 shows that, apart from family usage of unpaid carers for short breaks at Time 1, only two child factors at Time 1 predicted family usage of unpaid carers (family/friends) for short breaks at Time 2, the child having lower hyperactivity and more prosocial behaviours according to the SDQ.

Table 30 Time 1 Factors predicting family usage of unpaid carers (family/friends) for short breaks at Time 2

Factors predicting family usage of unpaid carers (family/friends) for short breaks at Time 2		Test statistics
Family usage of unpaid carers (family/friends) for short breaks at Time 1		Spearman's rho=0.23, n=214, p<0.001
Disabled child factors at Time 1	Child lower SDQ hyperactivity Child higher SDQ prosocial behaviour	Mann-Whitney U=824, n=192, p=0.006 Mann-Whitney U=821, n=185, p=0.009
Main carer factors at Time 1		
Household factors at Time 1		

11.3.4 Time 1 Factors predicting sources of funding for short breaks at Time 2

Using the same analytic procedure as above, we investigated which factors at Time 1 were associated with families receiving/using various sources of funding for short breaks at Time 2. Given the fluctuations in funding for short breaks from Time 1 to Time 2, this was to investigate whether NHS, local authority, direct payments or other sources of funding at Time 2 were being allocated on the basis of greater child and/or family needs. We also investigated which child and family factors at Time 1 were associated with families using private/self-funding for short breaks at Time 2.

Table 31 shows that families getting NHS funding for short breaks at Time 1 was associated with families getting this source of funding for short breaks at Time 2. In addition, families with a child in Target Group B and/or in poorer health at Time 1 were more likely to be getting NHS funding at Time 2. Families who were less worried about money at Time 1 were also more likely to be getting NHS funding for short breaks at Time 2.

Table 31 Time 1 Factors predicting family getting NHS funding for short breaks at Time 2

Factors predicting family getting NHS funding for short breaks at Time 2		Test statistics
Family getting NHS funding for short breaks at Time 1		Spearman's rho=0.54, n=176, p<0.001
Disabled child factors at Time 1	Child in Target Group B Poorer child health	n=198, Fisher's exact p<0.001 Mann-Whitney U=422.5, n=198, p<0.001
Main carer factors at Time 1		
Household factors at Time 1	Family less worried about money	Mann-Whitney U=551.5, n=198, p=0.006

Table 32 shows that, apart from a moderate association with families getting this type of funding at Time 1, getting local authority funding for short breaks at Time 2 was associated with one child factor, the child having lower prosocial behaviour according to the SDQ.

Table 32 Time 1 Factors predicting family getting local authority funding for short breaks at Time 2

Factors predicting family getting local authority funding for short breaks at Time 2		Test statistics
Family getting local authority funding for short breaks at Time 1		Spearman's rho=0.30, n=186, p<0.001
Disabled child factors at Time 1	Child lower SDQ prosocial behaviour	Mann-Whitney U=2129.5, n=175, p=0.002
Main carer factors at Time 1		
Household factors at Time 1		

Table 33 shows that there was a strong association between families using direct payments to fund short breaks at Time 1 and at Time 2. Beyond this, one child factor predicted family usage of direct payments for short breaks at Time 2, the child using a wider range of other child-related health, social and welfare supports.

Table 33 Time 1 Factors predicting family using direct payments for short breaks at Time 2

Factors predicting family using direct payments for short breaks at Time 2		Test statistics
Family using direct payments for short breaks at Time 1		Spearman's rho=0.66, n=189, p<0.001
Disabled child factors at Time 1	Child receives greater range of other services	Mann-Whitney U=3592, n=201, p=0.008
Main carer factors at Time 1		
Household factors at Time 1		

Table 34 shows a moderate association between family usage of private self-funding for short breaks at Time 1 and Time 2; no Time 1 factors predicted family usage of private/self-funding at Time 2.

Table 34 Time 1 Factors predicting family using private/self-funding for short breaks at Time 2

Factors predicting family using private/self-funding for short breaks at Time 2		Test statistics
Family usage of unpaid carers (family/friends) for short breaks at Time 1		Spearman’s rho=0.18, n=188, p=0.012
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1		

Table 35 shows a moderate association between family usage of other funding sources for short breaks at Time 1 and Time 2; no other factors predicting family usage of other sources of funding for short breaks at Time 2.

Table 35 Time 1 Factors predicting family using other sources of funding for short breaks at Time 2

Factors predicting family using other sources of funding for short breaks at Time 2		Test statistics
Family usage of unpaid carers (family/friends) for short breaks at Time 1		Spearman’s rho=0.19, n=193, p=0.01
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1		

11.3.5 Time 1 Factors predicting carer satisfaction with short breaks at Time 2

To investigate which Time 1 factors predicted carer satisfaction with short breaks at Time 2, we used the two summed indicators of carer satisfaction described earlier: overall carer satisfaction with short break providers and overall carer satisfaction with the systems surrounding access to short break provision.

Table 36 shows that two factors at Time 1 were predictive of carer satisfaction with short break providers at Time 2. Apart from carer satisfaction with short break providers at Time 1, carers reporting greater satisfaction with life at Time 1 and families using overnight paid carer short breaks away from the family home at Time 1 were associated with greater carer satisfaction with short break providers at Time 2.

Table 36 Time 1 Factors predicting carer satisfaction with short break providers at Time 2

Factors predicting carer satisfaction with short break providers at Time 2		Test statistics
Carer satisfaction with short break providers at Time 1		Spearman’s rho=0.42, n=186, p<0.001
Disabled child factors at Time 1		
Main carer factors at Time 1	Carer greater satisfaction with life	Spearman’s rho=-0.26, n=194, p<0.001
Household factors at Time 1		
Short break usage and funding at Time 1	Family using overnight paid carer short breaks away from the family home	Mann-Whitney U=1912, n=197, p=0.008

Table 37 shows the factors at Time 1 predictive of carer satisfaction with the systems surrounding short breaks at Time 2. Carer satisfaction with the systems surrounding short breaks, families using more total hours of short break support and carers using overnight paid carer short breaks away from the family home and were associated with greater carer satisfaction with the systems surrounding short breaks at Time 2.

Table 37 Time 1 Factors predicting carer satisfaction with systems surrounding short breaks at Time 2

Factors predicting carer satisfaction with systems surrounding short breaks at Time 2		Test statistics
Carer satisfaction with systems surrounding short breaks at Time 1		Spearman’s rho=0.49, n=154, p<0.001
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1		
Short break usage and funding at Time 1	More total hours of short breaks received Family using overnight paid carer short breaks away from the family home	Spearman’s rho=-0.26, n=141, p=0.002 Mann-Whitney U=1304, n=163, p=0.002

11.4 Appendix D Time 1 Factors predicting outcomes for carers at Time 2

11.4.1 Time 1 factors predicting carer economic and support outcomes at Time 2

For each of the economic outcomes for main carers described above, we conducted univariate analyses to determine which factors at Time 1 predicted each carer economic and support outcome at Time 2, using a significance level of p<0.01.

First, Table 38 shows which factors at Time 1 were associated with main carer employment status at Time 2 (broken down into full-time, part-time, and not employed). As Table 38 shows, main carer employment status at Time 1 was highly predictive of main carer employment status 10 months later at Time 2. In terms of factors relating to the disabled child, main carers were more likely to be employed at Time 2 (and especially in part-time employment) if their children were older at Time 1, with particularly low rates of employment if the child was aged 5-7 at Time 1. Main carers were more likely to be in employment (and especially part-time employment) at Time 2 if their disabled child and siblings had better relationships with each other at Time 1. In terms of factors related to the main carer, male main carers were more likely to be in full-time employment and female main carers were more likely to be in part-time or no employment. No factors concerning short break usage or funding at Time 1 predicted main carers being in employment at Time 2.

Table 38 Time 1 Factors predicting main carer employment at Time 2

Time 1 factors predicting main carer employment at Time 2		Test statistics
Main carer employment at Time 1		Spearman's rho=0.77, n=212, p<0.001
Disabled child factors at Time 1	Older child age (esp for PT employment)	KW chi-square=13.43, df=2, n=211, p=0.001
	Child age band Less employment child age 5-7 Increasing PT and FT employment as child gets older	Chi-square=24.37, df=12, n=211, p=0.008
	Disabled child and siblings have better relationship	KW chi-square=11.31, n=159, p=0.003
Main carer factors at Time 1	Main carer gender Male more likely FT Female more likely PT or no employment	Chi-square=11.01, df=2, n=213, p=0.004
Household factors at Time 1		
Short break usage and funding at Time 1		

We conducted a similar analysis to investigate which factors at Time 1 predicted any adult in the household being in employment at Time 2 (see Table 39). Again, Table 39 shows there was a very strong association between household employment at Time 1 and Time 2. In terms of Time 1 factors relating to the disabled child, children needing less supervision from 10pm to 6am predicted household employment at Time 2. There was also likely to be someone in the household in employment at Time2 if the main carer had more education at Time 1, if the main carer reported greater life satisfaction at Time 1, if the main carer at Time 1 was living as part of a couple and not as a lone parent, and if families lived in less deprived neighbourhoods. Finally, at Time 1 families using daytime paid carer short breaks inside the family home were more likely to have someone in employment in the household at Time 2.

Table 39 Time 1 Factors predicting whether any adult in the household is in employment at Time 2

Time 1 factors predicting any adult in household in employment at Time 2		Test statistics
Any adult in household in employment at Time 1		Spearman's rho=0.84, n=212, p<0.001
Disabled child factors at Time 1	Child needs less supervision 10pm – 6am	Mann-Whitney U=3015, n=212, p=0.008
Main carer factors at Time 1	Main carer more education	Mann-Whitney U=2989.5, n=211, p=0.009
	Main carer greater life satisfaction	Mann-Whitney U=2990.5, n=211, p=0.008
	Main carer living as part of a couple	n=193, Fisher's exact p=0.009
	Main carer not living as a lone parent	n=212, Fisher's exact p=0.009
Household factors at Time 1	House in less deprived neighbourhood (IMD)	Mann-Whitney U=3020, n-213, p=0.008
	House in less deprived neighbourhood (CWI Health & Disability)	Mann-Whitney U=2894, n=213, p=0.003
Short break usage and funding at Time 1	Daytime paid carer short breaks in the home	n=214, Fisher's exact p=0.003

In addition to investigating employment status, we also explored two indicators of how families perceived their current financial position. Table 40 shows Time 1 factors predictive of families reporting fewer worries about money at Time 2. Again, there is a strong association between family money worries at Time 1 and Time 2. One Time 1 factors relating to the disabled child that predicted fewer family money worries at Time 2 was the child needing less supervision from 10pm to 6am. Main carers reporting fewer family money worries at Time 2 were more likely to be living as part of a couple at Time 1, less likely to be living as a lone parent, and more likely to be scoring under the K6 threshold for clinically significant psychological distress at Time 1. Unsurprisingly, families reporting fewer money worries at Time 2 were at Time 1 more likely to be living in less deprived neighbourhoods, to report less child and main carer-related hardship, and to be managing better financially. Finally, a number of factors concerning short break usage at Time 1 predicted fewer family money worries at Time 2. Families reporting fewer money worries at Time 2 received more total hours of short breaks and a greater range of short breaks at Time 1, and were more likely to be using daytime paid carers for short breaks both in and away from the family home at Time 1.

Table 40 Time 1 Factors predicting fewer family worries about money at Time 2

Time 1 factors predicting fewer family worries about money at Time 2		Test statistics
Fewer family worries about money at Time 1		Spearman’s rho=0.68, n=211, p<0.001
Disabled child factors at Time 1	Child needs less supervision 10pm – 6am	Spearman’s rho=0.19, n=211, p=0.005
Main carer factors at Time 1	Main carer living as part of a couple	Mann-Whitney U=2443, n=192, p=0.008
	Main carer not living as a lone parent	Mann-Whitney U=2749.5, n=211, p=0.007
	Main carer scoring below K6 threshold for psychological distress	Mann-Whitney U=2133, n=211, p=0.002
Household factors at Time 1	House in less deprived neighbourhood (IMD)	Spearman’s rho=0.20, n=212, p=0.003
	House in less deprived neighbourhood (CWI)	Spearman’s rho=-0.20, n=212, p=0.003
	Less child-related household hardship	Spearman’s rho=-0.25, n=213, p<0.001
	Less carer-related household hardship	Spearman’s rho=-0.25, n=213, p<0.001
	Family managing better financially	Spearman’s rho=-0.66, n=211, p<0.001
Short break usage and funding at Time 1	More total hours of short breaks received	Spearman’s rho=0.22, n=187, p=0.002
	Greater range of short break types received	Spearman’s rho=0.25, n=213, p<0.001
	Family using daytime short breaks with paid carers away from the home	Mann-Whitney U=4216, n=213, p=0.004
	Family using daytime short breaks with paid carers in the home	Mann-Whitney U=3332.5, n=213, p=0.005

Table 41 shows that the Time 1 factors predictive of families reporting managing better financially at Time 2 were broadly similar to those reported for fewer family money worries. Again, there is a strong association between family financial management at Time 1 and Time 2. Unsurprisingly, families reporting managing better financially at Time 2, at Time 1 were more likely to be living in less deprived neighbourhoods, to report less child and main carer-related hardship, and to have fewer money worries. Finally, families reporting fewer money worries at Time 2 were more likely to be using daytime paid carers for short breaks both in the family home at Time 1.

Table 41 Time 1 Factors predicting families managing better financially at Time 2

Time 1 factors predicting families managing better financially at Time 2		Test statistics
Family managing better financially at Time 1		Spearman's rho=0.69, n=211, p<0.001
Disabled child factors at Time 1		
Main carer factors at Time 1		
Household factors at Time 1	House in less deprived neighbourhood (IMD)	Spearman's rho=-0.24, n=212, p<0.001
	House in less deprived neighbourhood (CWI)	Spearman's rho=0.23, n=212, p=0.001
	Less child-related household hardship	Spearman's rho=0.25, n=213, p<0.001
	Less carer-related household hardship	Spearman's rho=0.26, n=213, p<0.001
	Family less worried about money	Spearman's rho=-0.63, n=211, p<0.001
Short break usage and funding at Time 1	Family using daytime short breaks with paid carers in the home	Mann-Whitney U=2994.5, n=213, p<0.001

11.4.2 Time 1 Factors predicting carer health and well-being outcomes at Time 2

We investigated Time 1 factors predicting a range of main carer health and well-being outcome indicators at Time 2, including self-reported health, psychological distress, satisfaction with life, and the carer reporting positive gains associated with having a disabled child.

Table 42 shows Time 1 factors associated with better main carer self-reported health at Time 2 – as expected there was a significant association between carer self-reported health at Time 1 and Time 2. The only predictive factor concerning the disabled child was better carer-reported child health at Time 1 predicting better self-reported carer health at Time 2. Main carers reporting no longstanding illness/disability at Time 1 and main carers scoring below the K6 threshold for clinically significant psychological distress at Time 1 were more likely to self-report better health at Time 2, as were families reporting less hardship, fewer money worries and managing better financially at Time 1. Finally, families receiving more total hours of short breaks at Time 1, receiving a greater range of short breaks at Time 1, and using paid carers for daytime short breaks away from the family home at Time 1 were more likely to report better main carer health at Time 2.

Table 42 Time 1 Factors predicting main carer better self-reported health at Time 2

Time 1 factors predicting main carer better self-reported health at Time 2		Test statistics
Main carer better self-reported health at Time 1		Spearman's rho=0.56, n=213, p<0.001
Disabled child factors at Time 1	Child better health	Spearman's rho=0.28, n=212, p<0.001
Main carer factors at Time 1	No main carer longstanding illness/disability	Mann-Whitney U=3335, n=211, p<0.001
	Main carer scoring below K6 threshold for psychological distress	Mann-Whitney U=1664, n=212, p<0.001
Household factors at Time 1	Less child-related household hardship	Spearman's rho=0.19, n=214, p=0.005
	Family less worried about money	Spearman's rho=-0.27, n=212, p<0.001
	Family managing better financially	Spearman's rho=0.31, n=212, p<0.001
Short break usage and funding at Time 1	More total hours of short breaks received	Spearman's rho=-0.21, n=188, p=0.004
	Greater range of short break types received	Spearman's rho=-0.18, n=214, p=0.008
	Family using daytime short breaks with paid carers away from the home	Mann-Whitney U=4352, n=214, p=0.007

We investigated Time 1 factors associated with main carer psychological distress at Time 2 in two ways. First, we explored factors predicting Time 1 scores on the K6 measure of psychological distress (see Table 43). Second, we explored factors predicting whether main carers were above or below the threshold for clinically significant psychological distress using the K6 measure at Time 2 (see Table 45).

Table 43 shows a wide range of Time 1 factors associated with carer lower psychological distress on the K6 scale at Time 2, including a very strong association between main carer psychological distress at Time 1 and Time 2. At Time 1, if the disabled child was in better health, having better relationships with siblings, and experiencing fewer problems according to the SDQ in terms of total difficulties, hyperactivity, and/or conduct problems, then the main carer was likely to report lower psychological distress at Time 2. Less household hardship and money worries and households reporting fewer problems managing financially at Time 1 also predicted lower carer distress at Time 2. Several factors relating to short break usage were associated with lower carer psychological distress at Time 2. At Time 1, families receiving more total hours of short breaks, a wider range of short break types, and/or using overnight short breaks with a paid carer in the family home, were all associated with lower main carer psychological distress at Time 2.

Table 43 Time 1 Factors predicting main carer greater psychological distress (K6 score) at Time 2

Time 1 factors predicting main carer lower psychological distress (K6 score) at Time 2		Test statistics
Main carer lower psychological distress at Time 1		Spearman's rho=0.73, n=203, p<0.001
Disabled child factors at Time 1	Child lower SDQ total difficulties	Spearman's rho=0.29, n=154, p<0.001
	Child lower SDQ hyperactivity	Spearman's rho=0.23, n=187, p=0.002
	Child lower SDQ conduct problems	Spearman's rho=0.26, n=182, p=0.001
	Better child health	Spearman's rho=0.25, n=206, p<0.001
	Better child relationship with siblings	Spearman's rho=-0.27, n=154, p=0.001
Main carer factors at Time 1		
Household factors at Time 1	Less child-related household hardship	Spearman's rho=0.18, n=208, p=0.009
	Family less worried about money	Spearman's rho=-0.29, n=206, p<0.001
	Family managing better financially	Spearman's rho=0.28, n=206, p<0.001
Short break usage and funding at Time 1	More total hours of short breaks received	Spearman's rho=-0.26, n=184, p<0.001
	Wider range of short break types received	Spearman's rho=-0.19, n=208, p=0.007
	Family using overnight short breaks with a paid carer in the family home	Mann-Whitney U=423.5, n=208, p=0.007

Table 44 shows a similar range of Time 1 factors associated with carers scoring below the threshold on the K6 scale at Time 2 indicating no clinically significant psychological distress, including a very strong association between main carer psychological distress at Time 1 and Time 2. At Time 1, if the disabled child was in better health, and experiencing fewer problems according to the SDQ in terms of total difficulties, hyperactivity, and/or conduct problems, then the main carer was more likely to report not experiencing clinically significant levels of psychological distress at Time 2. Two carer factors at Time 1, the carer reporting better health and greater levels of life satisfaction, were associated with carers not experiencing clinically significant psychological distress at Time 2, with fewer money worries and households reporting managing better financially at Time 1 also predictive. Finally, families receiving more total hours of short breaks were associated with main carers not reporting clinically significant psychological distress at Time 2.

Table 44 Time 1 Factors predicting main carer scoring above K6 threshold for clinically significant psychological distress at Time 2

Time 1 factors predicting main carer scoring below K6 threshold for clinically significant psychological distress at Time 2		Test statistics
Main carer scoring below K6 threshold at Time 1		Spearman's rho=0.46, n=212, p<0.001
Disabled child factors at Time 1	Child lower total SDQ difficulties	Mann-Whitney U=1085.5, n=159, p=0.01
	Child lower SDQ hyperactivity	Mann-Whitney U=1664, n=192, p=0.01
	Child lower SDQ conduct problems	Mann-Whitney U=1408.5, n=187, p=0.002
	Better child health	Mann-Whitney U=2319.5, n=212, p=0.002
Main carer factors at Time 1	Main carer better self-reported health	Mann-Whitney U=1743, n=213, p<0.001
	Main carer greater life satisfaction	Mann-Whitney U=1359.5, n=211, p<0.001
Household factors at Time 1	Family less worried about money	Mann-Whitney U=2059, n=212, p=0.002
	Family managing better financially	Mann-Whitney U=2121, n=212, p=0.004
Short break usage and funding at Time 1	More total hours of short breaks received	Mann-Whitney U=1497, n=188, p=0.010

The next main carer health and well-being indicator we investigated was main carer satisfaction with life in general (see Table 45). As Table 46 shows, main carer life satisfaction at Time 1 and Time 2 were strongly associated. Only one factor relating to the disabled child at Time 1, the child and siblings having better relationships, predicted greater carer life satisfaction at Time 2. Main carers scoring below the K6 threshold for clinical distress at Time 1 were more likely to report greater life satisfaction at Time 2. Households with fewer money worries and feeling they were managing better financially at Time 1 predicted greater carer satisfaction with life at Time 2. Finally, several factors relating to short break usage and funding at Time 1 were associated with main carer greater life satisfaction at Time 2. Families receiving more hours of short breaks, families using a wider range of short break types, families using paid carers for short breaks away from the family home overnight, and families who were more satisfied with the systems surrounding short breaks at Time 1, all predicted greater carer satisfaction with life at Time 2.

Table 45 Time 1 Factors predicting main carer greater life satisfaction at Time 2

Time 1 factors predicting main carer greater life satisfaction at Time 2		Test statistics
Main carer greater life satisfaction at Time 1		Spearman's rho=0.75, n=211, p<0.001
Disabled child factors at Time 1	Child better relationship with siblings	Spearman's rho=0.29, n=159, p<0.001
Main carer factors at Time 1	Main carer scoring below K6 threshold for psychological distress	Mann-Whitney U=2298.5, n=211, p=0.013
Household factors at Time 1	Family less worried about money	Spearman's rho=0.36, n=212, p<0.001
	Family managing better financially	Spearman's rho=-0.38, n=212, p<0.001
Short break usage and funding at Time 1	More total hours of short breaks received	Spearman's rho=0.20, n=188, p=0.005
	Greater range of short break types received	Spearman's rho=0.21, n=214, p=0.002
	More carer satisfaction with systems surrounding short breaks	Spearman's rho=-0.29, n=195, p<0.001
	Family using overnight short breaks with paid carers away from the home	Mann-Whitney U=2084.5, n=214, p=0.003

Table 46 shows the range of Time 1 factors associated with the main carer reporting more positive gains in their own lives as a result of having a disabled child. As Table 46 shows, children not in Target Group A were associated with main carers reporting more positive gains at Time 2, as were families living in less deprived neighbourhoods.

Table 46 Time 1 Factors predicting carer perception of more positive gains associated with their disabled child at Time 2

Time 1 factors predicting carer perception of more positive gains at Time 2		Test statistics
Main carer more positive gains at Time 1		Spearman’s rho=0.62, n=76, p<0.001
Disabled child factors at Time 1	Child not in Target Group A	Mann-Whitney U=3622.5, n=200, p=0.001
Main carer factors at Time 1		
Household factors at Time 1	House in less deprived neighbourhood (CWI)	Spearman’s rho=-0.18, n=212, p=0.007
Short break usage and funding at Time 1		

11.5 Appendix E Time 1 Factors predicting disabled child outcomes at Time 2

For each of the outcomes for the disabled child described above, we conducted univariate analyses to determine which factors at Time 1 predicted each child outcome at Time 2, using a significance level of $p<0.01$.

Table 47 shows which Time 1 factors predicted better health for the disabled child at Time 2. As Table 47 shows, child health at Time 1 and Time 2 were strongly associated. The only other Time 1 factors associated with better child health at Time 2 were factors concerning the disabled child; children with better health at Time 2 were older, not in Target Group B and needed less supervision from 6am to 5pm.

Table 47 Time 1 Factors predicting better child health at Time 2

Time 1 factors predicting better child health at Time 2		Test statistics
Better child health at Time 1		Spearman's rho=0.65, n=211, p<0.001
Disabled child factors at Time 1	Older child Child not in Target Group B Child needs less supervision 6am – 5pm	Spearman's rho=-0.30, n=210, p<0.001 Mann-Whitney U=2905, n=211, p=0.009 Spearman's rho=-0.23, n=212, p=0.001
Main carer factors at Time 1		
Household factors at Time 1		
Short break usage and funding at Time 1		

Table 48 shows Time 1 factors predicting lower total child difficulties on the SDQ scale at Time 2 for the disabled child (specific SDQ difficulties at Time 1 were not included in this analysis, as together they constitute SDQ total difficulties). As Table 48 shows, child SDQ total difficulties at Time 1 were highly predictive of lower child SDQ total difficulties at Time 2. A wide range of child factors at Time 1 were associated with lower SDQ total difficulties at Time 2, including: older children, female children, children in Target Group C but not in Target Groups A or D), children with higher SDQ prosocial behaviour, children needing less supervision from 5pm to 10pm, and children with better sibling relationships. In terms of carer and household factors at Time 1, main carers scoring below the K6 threshold for psychological distress, families who were less worried about money and families who were managing better financially were all associated with their disabled child having fewer SDQ total difficulties at Time 2. Finally, lower child SDQ total difficulties at Time 2 was predicted by carers reporting greater satisfaction with the systems surrounding short breaks at Time 1.

Table 48 Time 1 Factors predicting lower child SDQ total difficulties at Time 2

Time 1 factors predicting lower child SDQ total difficulties at Time 2		Test statistics
Lower child SDQ total difficulties at Time 1		Spearman's rho=0.84, n=117, p<0.001
Disabled child factors at Time 1	Older child age	Spearman's rho=-0.23, n=128, p=0.009
	Female child	Mann-Whitney U=1240.5, n=130, p=0.002
	Child not in Target Group A	Mann-Whitney U=863.5, n=127, p<0.001
	Child in Target Group C	Mann-Whitney U=823.5, n=129, p=0.004
	Child not in Target Group D	Mann-Whitney U=867.5, n=128, p<0.001
	Higher child SDQ prosocial behaviour	Spearman's rho=-0.28, n=123, p=0.002
	Child needs less supervision 5pm – 10pm	Spearman's rho=-0.25, n=130, p=0.005
	Child better TDRWQ relationships with siblings	Spearman's rho=-0.35, n=99, p<0.001
Main carer factors at Time 1	Main carer below K6 threshold psychological distress	Mann-Whitney U=654.5, n=129, p=0.005
Household factors at Time 1	Family less worried about money	Spearman's rho=0.26, n=129, p=0.003
	Family managing better financially	Spearman's rho=0.31, n=129, p<0.001
Short break usage and funding at Time 1	Greater carer satisfaction with systems surrounding short breaks	Spearman's rho=0.28, n=117, p=0.003

Table 49 shows Time 1 factors associated with the disabled child showing less hyperactivity according to the SDQ at Time 2. As Table 49 shows, child hyperactivity at Time 1 was highly predictive of child hyperactivity at Time 2. Other Time 1 disabled child factors predicting lower child hyperactivity at Time 2 included: older children, children in Target Group C but not in Target Groups A or D, lower child difficulties according to the SDQ (total difficulties, conduct problems, peer problems), higher child prosocial behaviour according to the SDQ, the child needing less supervision around the clock, and the disabled having better relationships with siblings. Fewer carer and household factors predicted children with lower hyperactivity at Time 2: the main carer reporting no longstanding illness/disability, the main carer below the K6 threshold for psychological distress, and the family managing better financially.

Table 49 Time 1 Factors predicting lower child SDQ hyperactivity at Time 2

Time 1 factors predicting lower child SDQ hyperactivity at Time 2		Test statistics
Lower child SDQ hyperactivity at Time 1		Spearman's rho=0.72, n=164, p<0.001
Disabled child factors at Time 1	Older child	Spearman's rho=-0.28, n=171, p<0.001
	Child not in Target Group A	Mann-Whitney U=2423, n=170, p<0.001
	Child in Target Group C	Mann-Whitney U=1716.5, n=172, p=0.009
	Child not in Target Group D	Mann-Whitney U=1401, n=171, p<0.001
	Lower child SDQ total difficulties	Spearman's rho=0.62, n=139, p<0.001
	Lower child SDQ conduct problems	Spearman's rho=0.37, n=159, p<0.001
	Lower child SDQ peer problems	Spearman's rho=0.35, n=160, p<0.001
	Higher child SDQ prosocial behaviour	Spearman's rho=-0.26, n=158, p=0.001
	Child needs less supervision 6am – 5pm	Spearman's rho=-0.35, n=173, p<0.001
	Child needs less supervision 5pm – 10pm	Spearman's rho=-0.29, n=173, p<0.001
	Child needs less supervision 10pm – 6am	Spearman's rho=-0.25, n=173, p=0.001
	Child better TDRWQ relationships with siblings	Spearman's rho=-0.32, n=133, p<0.001
Main carer factors at Time 1	Main carer no longstanding illness/disability	Mann-Whitney U=2695, n=171, p=0.003
	Main carer below K6 threshold psychological distress	Mann-Whitney U=1448, n=172, p=0.005
Household factors at Time 1	Family managing better financially	Spearman's rho=0.21, n=172, p=0.007
Short break usage and funding at Time 1		

Table 50 shows Time 1 factors associated with the disabled child showing fewer emotional difficulties according to the SDQ at Time 2. As Table 50 shows, child emotional difficulties at Time 1 were highly predictive of child emotional difficulties at Time 2. Other Time 1 disabled child factors predicting lower child emotional difficulties at Time 2 included: children in Target Group B or C but not in Target Group A, and lower child difficulties according to the SDQ (total difficulties, conduct problems, peer problems). No carer and household factors predicted children with lower emotional difficulties at Time 2, but families using centre-based (including overnight) short breaks at Time 1 were more likely to report their disabled child having fewer emotional difficulties at Time 2.

Table 50 Time 1 Factors predicting lower child SDQ emotional difficulties at Time 2

Time 1 factors predicting lower child SDQ emotional difficulties at Time 2		Test statistics
Lower child SDQ emotional difficulties at Time 1		Spearman’s rho=0.78, n=147, p<0.001
Disabled child factors at Time 1	Child not in Target Group A	Mann-Whitney U=1981.5, n=158, p<0.001
	Child in Target Group B	Mann-Whitney U=1020.5, n=160, p<0.001
	Child in Target Group C	Mann-Whitney U=1476, n=160, p=0.008
	Lower child SDQ total difficulties	Spearman’s rho=0.55, n=133, p<0.001
	Lower child SDQ conduct problems	Spearman’s rho=0.25, n=160, p<0.001
	Lower child SDQ peer problems	Spearman’s rho=0.28, n=150, p=0.001
Main carer factors at Time 1		
Household factors at Time 1		
Short break usage and funding at Time 1	Family using centre-based (inc overnight) short breaks	Mann-Whitney U=2372.5, n=162, p=0.006

Table 51 shows Time 1 factors associated with the disabled child showing fewer conduct problems according to the SDQ at Time 2. As Table 51 shows, child conduct problems at Time 1 were highly predictive of child conduct problems at Time 2. Other Time 1 disabled child factors predicting lower child conduct problems at Time 2 included: older children, children in Target Group E but not in Target Groups A or D, better child health, lower child difficulties according to the SDQ (total difficulties, hyperactivity, emotional difficulties, peer problems), greater child prosocial behaviour according to the SDQ, and better relationships between children and their siblings. Fewer carer and household factors predicted children with fewer conduct problems at Time 2: the main carer below the K6 threshold for psychological distress, the family reporting fewer money worries and the family managing better financially.

Table 51 Time 1 Factors predicting lower child SDQ conduct problems at Time 2

Time 1 factors predicting lower child SDQ conduct problems at Time 2		Test statistics
Lower child SDQ conduct problems at Time 1		Spearman's rho=0.72, n=160, p<0.001
Disabled child factors at Time 1	Older child	Spearman's rho=-0.22, n=166, p=0.004
	Child not in Target Group A	Mann-Whitney U==2395.5, n=165, p=0.001
	Child not in Target Group D	Mann-Whitney U=1396.5, n=166, p<0.001
	Child in Target Group E	Mann-Whitney U=2330.5, n=166, p=0.009
	Better child health	Spearman's rho=0.21, n=168, p=0.005
	Lower child SDQ total difficulties	Spearman's rho=0.67, n=139, p<0.001
	Lower child SDQ hyperactivity	Spearman's rho=0.41, n=156, p<0.001
	Lower child SDQ emotional difficulties	Spearman's rho=0.32, n=152, p<0.001
	Lower child SDQ peer problems	Spearman's rho=0.34, n=155, p<0.001
	Higher child SDQ prosocial behaviour	Spearman's rho=-0.23, n=155, p=0.003
	Child better TDRWQ relationships with siblings	Spearman's rho=-0.27, n=126, p=0.002
Main carer factors at Time 1	Main carer below K6 threshold psychological distress	Mann-Whitney U=1324, n=167, p=0.007
Household factors at Time 1	Family less worried about money	Spearman's rho=-0.21, n=167, p=0.008
	Family managing better financially	Spearman's rho=0.26, n=167, p=0.001
Short break usage and funding at Time 1		

Table 52 shows Time 1 factors associated with the disabled child showing fewer peer problems according to the SDQ at Time 2. As Table 52 shows, child peer problems at Time 1 were highly predictive of child peer problems at Time 2. Other Time 1 disabled child factors predicting lower child peer problems at Time 2 included: female children, children not in Target Group A, lower child difficulties according to the SDQ (total difficulties, hyperactivity, emotional difficulties, conduct problems), greater child prosocial behaviour according to the SDQ, and better relationships between children and their siblings. The only carer or household factor predicting children with fewer peer problems at Time 2 was main carers reporting themselves to be a lone parent at Time 1.

Table 52 Time 1 Factors predicting lower child SDQ peer problems at Time 2

Time 1 factors predicting lower child SDQ peer problems at Time 2		Test statistics
Lower child SDQ peer problems at Time 1		Spearman’s rho=0.73, n=152, p<0.001
Disabled child factors at Time 1	Female child	Mann-Whitney U=1976.5, n=166, p<0.001
	Child not in Target Group A	Mann-Whitney U=1464.5, n=163, p<0.001
	Lower child SDQ total difficulties	Spearman’s rho=0.52, n=137, p<0.001
	Lower child SDQ hyperactivity	Spearman’s rho=0.27, n=155, p=0.001
	Lower child SDQ emotional difficulties	Spearman’s rho=0.22, n=150, p=0.008
	Lower child SDQ conduct problems	Spearman’s rho=0.25, n=153, p=0.002
	Higher child SDQ prosocial behaviour	Spearman’s rho=-0.31, n=152, p<0.001
	Child better TDRWQ relationships with siblings	Spearman’s rho=-0.27, n=123, p=0.002
Main carer factors at Time 1	Main carer lone parent	Mann-Whitney U=1513.5, n=166, p=0.009
Household factors at Time 1		
Short break usage and funding at Time 1		

Table 53 shows Time 1 factors associated with the disabled child showing greater prosocial behaviour according to the SDQ at Time 2. As Table 53 shows, child prosocial behaviour at Time 1 was highly predictive of child prosocial behaviour at Time 2. Other Time 1 disabled child factors predicting greater child prosocial behaviour at Time 2 included: children not in Target Groups A, B or D, the child having mild/moderate learning disabilities, lower child difficulties according to the SDQ (total difficulties, hyperactivity, peer problems), the child needing less supervision from 6am to 5pm, and better relationships between children and their siblings. Children living in households in less deprived neighbourhoods and families not using daytime short breaks with paid carers in the family home at Time 1 were both associated with the child showing greater prosocial behaviour at Time 2.

Table 53 Time 1 Factors predicting higher child SDQ prosocial behaviour at Time 2

Time 1 factors predicting higher child SDQ prosocial behaviour at Time 2		Test statistics
Higher child SDQ prosocial behaviour at Time 1		Spearman's rho=0.79, n=154, p<0.001
Disabled child factors at Time 1	Child not in Target Group A	Mann-Whitney U=2021.5, n=162, p<0.001
	Child not in Target Group B	Mann-Whitney U=1236, n=163, p=0.004
	Child not in Target Group D	Mann-Whitney U=1538.5, n=162, p<0.001
	Child with mild/moderate learning difficulties	KW chi-square=11.01, df=2, n=147, p=0.004
	Lower child SDQ total difficulties	Spearman's rho=-0.31, n=131, p<0.001
	Lower child SDQ hyperactivity	Spearman's rho=-0.28, n=153, p<0.001
	Lower child SDQ peer problems	Spearman's rho=-0.39, n=150, p<0.001
	Child needs less supervision 6am – 5pm	Spearman's rho=0.23, n=164, p=0.003
	Child better TDRWQ relationships with siblings	Spearman's rho=0.30, n=125, p=0.001
Main carer factors at Time 1		
Household factors at Time 1	House in less deprived neighbourhood (CWI Material)	Spearman's rho=0.23, n=164, p=0.004
Short break usage and funding at Time 1	Family not using daytime short breaks with paid carers in the home	Mann-Whitney U=1606, n=165, p=0.001

Table 54 shows Time 1 factors associated with the disabled child using a greater range of child-oriented services at Time 2. As Table 54 shows, child usage of a wider range of child-oriented services at Time 1 and Time 2 were strongly associated. Other Time 1 disabled child factors predicting the child using a wider range of services at Time 2 included: children in Target Group C but not in Target Group A, poorer child health, and the child needing less supervision from 6am to 5pm. The only other factor associated with children using a wider range of services at Time 2 was family usage of daytime short breaks with paid carers in the family home.

Table 54 Time 1 Factors predicting child using greater range of child-oriented services at Time 2

Time 1 factors predicting child using greater range of services at Time 2		Test statistics
Child using greater range of services at Time 1		Spearman's rho=0.56, n=205, p<0.001
Disabled child factors at Time 1	Child not in Target Group A	Mann-Whitney U=3703.5, n=205, p<0.001
	Child in Target Group C	Mann-Whitney U=2663.5, n=207, p=0.003
	Poorer child health	Spearman's rho=0.19, n=207, p=0.007
	Child needs more supervision 6am – 5pm	Spearman's rho=-0.22, n=208, p=0.002
Main carer factors at Time 1		
Household factors at Time 1		
Short break usage and funding at Time 1	Family using daytime short breaks with paid carers in the home	Mann-Whitney U=3098, n=209, p=0.002

Table 55 shows Time 1 factors associated with carer perceptions of better child progress at school at Time 2. As Table 55 shows, carer perceptions of child progress at school at Time 1 and Time 2 were strongly associated. Other Time 1 disabled child factors predicting carer perceptions of better child progress at school at Time 2 included: better child health, lower child difficulties according to the SDQ (total difficulties, conduct problems, peer problems) and greater child prosocial behaviour according to the SDQ.

Table 55 Time 1 Factors predicting carer perception of better child progress at school at Time 2

Time 1 factors predicting better child progress at school at Time 2		Test statistics
Better child progress at school at Time 1		Spearman's rho=0.41, n=74, p<0.001
Disabled child factors at Time 1	Older child	Spearman's rho=-0.22, n=206, p=0.002
	Better child health	Spearman's rho=0.22, n=207, p=0.001
	Lower child SDQ total difficulties	Spearman's rho=0.26, n=156, p=0.001
	Lower child SDQ conduct problems	Spearman's rho=0.24, n=184, p=0.001
	Lower child SDQ peer problems	Spearman's rho=0.19, n=185, p=0.010
	Higher child SDQ prosocial behaviour	Spearman's rho=-0.21, n=182, p=0.005
Main carer factors at Time 1		
Household factors at Time 1		
Short break usage and funding at Time 1		

Table 56 shows the Time 1 factors predicting Time 2 carer perceptions that their disabled child will have a more positive future according to the TDRWQ. As Table 56 shows, carer perceptions of their child’s prospects for a positive future at Time 1 and Time 2 were strongly associated. A wide range of Time 1 factors predicted Time 2 carer perceptions of a more positive future for their disabled child, including: the child showing greater prosocial behaviour according to the SDQ, the main carer being below the K6 threshold for clinically significant psychological distress, the family living in a less deprived neighbourhood, the family not getting NHS funding for short breaks, and carers being more satisfied both with short break providers and the systems surrounding short breaks.

Table 56 Time 1 Factors predicting carer perceptions of a more positive future for the disabled child (TDRWQ) at Time 2

Time 1 factors predicting carer perception of more positive future for the child at Time 2		Test statistics
Carer perception of more positive future for the child at Time 1		Spearman’s rho=0.74, n=75, p<0.001
Disabled child factors at Time 1	Greater child SDQ prosocial behaviour	Spearman’s rho=0.23, n=179, p=0.002
Main carer factors at Time 1	Main carer below K6 threshold for psychological distress	Mann-Whitney U=1978, n=202, p=0.008
Household factors at Time 1	House in less deprived neighbourhood (CWI)	Spearman’s rho=0.24, n=203, p=0.001
Short break usage and funding at Time 1	Family not getting NHS funded short breaks	Mann-Whitney U=1198, n=186, p=0.010
	Carer more satisfied with short break providers	Spearman’s rho=-0.21, n=186, p=0.004
	Carer more satisfied with short break systems	Spearman’s rho=-0.25, n=185, p=0.001

Table 57 shows the Time 1 factors predicting Time 2 carer perceptions that their disabled child would reach financial independence according to the TDRWQ. As Table 57 shows, carer perceptions of their child's prospects for future financial independence at Time 1 and Time 2 were strongly associated. A wide range of Time 1 factors predicted Time 2 carer perceptions of future financial independence for their disabled child, including: the child not being in Target Group B, better child health, the child showing less hyperactivity and greater prosocial behaviour according to the SDQ, the family living in a less deprived neighbourhood, the family not getting NHS funding for short breaks, and carers being more satisfied with the systems surrounding short breaks.

Table 57 Time 1 Factors predicting carer perceptions of future financial independence for the disabled child (TDRWQ) at Time 2

Time 1 factors predicting carer perception of future financial independence for the child at Time 2		Test statistics
Carer perception of future financial independence for the child at Time 1		Spearman's rho=0.48, n=75, p<0.001
Disabled child factors at Time 1	Child not in Target Group B	Mann-Whitney U=2470.5, n=207, p<0.001
	Child lower SDQ hyperactivity	Spearman's rho=-0.22, n=187, p=0.003
	Greater child SDQ prosocial behaviour	Spearman's rho=0.22, n=178, p=0.003
	Child needs less supervision 6am – 5pm	Spearman's rho=0.25, n=208, p<0.001
	Better child health	Spearman's rho=-0.20, n=207, p=0.004
Main carer factors at Time 1		
Household factors at Time 1	House in less deprived neighbourhood (CWI Health & Disability)	Spearman's rho=0.18, n=208, p=0.010
Short break usage and funding at Time 1	Family not getting NHS funded short breaks	Mann-Whitney U=1149, n=191, p=0.002
	Carer more satisfied with short break systems	Spearman's rho=-0.19, n=190, p=0.010

Table 58 shows the Time 1 factors predicting Time 2 carer perceptions that their disabled child was accessing sufficient community resources according to the TDRWQ. As Table 58 shows, carer perceptions of their child's access to community resources at Time 1 and Time 2 were strongly associated. A wide range of Time 1 factors predicted Time 2 carer perceptions of access to community resources for their disabled child, including: the child showing fewer total difficulties and greater prosocial behaviour according to the SDQ, the main carer not living as part of a couple and living as a lone parent, the main carer being below the K6 threshold for clinically significant psychological distress, the family living in a less deprived neighbourhood, the family not getting NHS funding for short breaks, and carers being more satisfied both with short break providers and the systems surrounding short breaks.

Table 58 Time 1 Factors predicting carer perceptions of access to community resources for the disabled child (TDRWQ) at Time 2

Time 1 factors predicting carer perception of access to community resources for the child at Time 2		Test statistics
Carer perception of access to community resources for the child at Time 1		Spearman's rho=0.43, n=74, p<0.001
Disabled child factors at Time 1	Child lower SDQ total difficulties	Spearman's rho=-0.26, n=152, p=0.002
	Greater child SDQ prosocial behaviour	Spearman's rho=0.22, n=181, p=0.003
Main carer factors at Time 1	Main carer not living as part of a couple	Mann-Whitney U=2166.5, n=184, p=0.006
	Main carer living as a lone parent	Mann-Whitney U=2327.5, n=203, p=0.003
	Main carer below K6 threshold for psychological distress	Mann-Whitney U=2033.5, n=203, p=0.006
Household factors at Time 1	House in less deprived neighbourhood (CWI Health & Disability)	Spearman's rho=0.20, n=204, p=0.003
Short break usage and funding at Time 1	Family not getting NHS funded short breaks	Mann-Whitney U=1187.5, n=187, p=0.007
	Carer more satisfied with short break providers	Spearman's rho=-0.30, n=187, p<0.001
	Carer more satisfied with short break systems	Spearman's rho=-0.25, n=186, p=0.001

Table 59 shows the Time 1 factors predicting Time 2 carer perceptions of better relationships between the disabled child and their siblings according to the TDRWQ. As Table 59 shows, carer perceptions of child-sibling relationships at Time 1 and Time 2 were strongly associated. Beyond this only two Time 1 factors predicted Time 2 carer perceptions of better child-sibling relationships: the child not being in Target Group A and the child showing fewer peer problems according to the SDQ.

Table 59 Time 1 Factors predicting better child-sibling relationships (TDRWQ) at Time 2

Time 1 factors predicting better child-sibling relationships at Time 2		Test statistics
Better child-sibling relationships at Time 1		Spearman's rho=0.68, n=142, p<0.001
Disabled child factors at Time 1	Child not in Target Group A Lower child SDQ peer problems	Mann-Whitney U=1945.5, n=209, p=0.001 Spearman's rho= -0.36, n=135, p<0.001
Main carer factors at Time 1		
Household factors at Time 1		
Short break usage and funding at Time 1		

Table 60 shows the Time 1 factors predicting better child-sibling relationships at Time 2 according to the TDRWQ. As Table 60 shows, carer perceptions of child-family relations at Time 1 and Time 2 were strongly associated. Time 1 factors predicting Time 2 carer perceptions of better relations between the disabled child and the family included: the child showing fewer total difficulties, fewer conduct problems and greater prosocial behaviour according to the SDQ, the child having a better relationship with siblings according to the TDRWQ, and the main carer being below the K6 threshold for clinically significant psychological distress.

Table 60 Time 1 Factors predicting carer perceptions of relations between the disabled child and their family (TDRWQ) at Time 2

Time 1 factors predicting family relations for the child at Time 2		Test statistics
Carer perception of family relations for the child at Time 1		Spearman's rho=0.61, n=73, p<0.001
Disabled child factors at Time 1	Child lower SDQ total difficulties	Spearman's rho=-0.22, n=154, p=0.005
	Child lower SDQ conduct problems	Spearman's rho=-0.25, n=180, p=0.001
	Greater child SDQ prosocial Behaviour	Spearman's rho=0.22, n=178, p=0.003
	Child better relationship with siblings (TDRWQ)	Spearman's rho=0.25, n=151, p=0.002
Main carer factors at Time 1	Main carer below K6 threshold for psychological distress	Mann-Whitney U=1875.5, n=201, p=0.003
Household factors at Time 1		
Short break usage and funding at Time 1		

11.6 Appendix F Time 1 Factors predicting outcomes for siblings at Time 2

Table 61 presents Time 1 factors predicting better sibling health at Time 1. As Table 61 shows, sibling health at Time 1 was strongly associated with sibling health at Time 2. Two sibling factors at Time 1 predicted better sibling health at Time 2: lower sibling emotional difficulties and lower sibling peer problems according to the SDQ. In addition, main carers of White ethnicity were associated with better sibling health at Time 2.

Table 61 Time 1 Factors predicting better sibling health at Time 2

Time 1 factors predicting better sibling health at Time 2		Test statistics
Better sibling health at Time 1		Spearman's rho=0.50, n=152, p<0.001
Disabled child factors at Time 1		
Sibling factors at Time 1	Sibling lower SDQ emotional difficulties	Spearman's rho=0.45, n=48, p=0.001
	Sibling lower SDQ peer problems	Spearman's rho=0.38, n=47, p=0.008
Main carer factors at Time 1	Main carer White ethnicity	Mann-Whitney U=470, n=161, p=0.006
Household factors at Time 1		
Short break usage and funding at Time 1		

Table 62 presents Time 1 factors predicting lower sibling total difficulties according to the SDQ at Time 2. As Table 62 shows, sibling total difficulties at Time 1 were very strongly associated with sibling total difficulties at Time 2. Several sibling factors at Time 1 predicted lower sibling total difficulties according to the SDQ at Time 2: better sibling health, lower sibling difficulties according to the SDQ (hyperactivity, emotional difficulties, conduct problems, peer problems) and greater sibling prosocial behaviour according to the SDQ. In addition, households reporting less hardship, fewer money worries, and managing better financially at Time 1 were associated with lower sibling total difficulties according to the SDQ at Time 2.

Table 62 Time 1 Factors predicting lower sibling SDQ total difficulties at Time 2

Time 1 factors predicting lower sibling SDQ total difficulties at Time 2		Test statistics
Lower sibling SDQ total difficulties at Time 1		Spearman's rho=0.89, n=44, p<0.001
Disabled child factors at Time 1		
Sibling factors at Time 1	Better sibling health	Spearman's rho=0.25, n=127, p=0.004
	Sibling lower SDQ hyperactivity	Spearman's rho=0.78, n=41, p<0.001
	Sibling lower SDQ emotional difficulties	Spearman's rho=0.55, n=41, p<0.001
	Sibling lower SDQ conduct problems	Spearman's rho=0.64, n=42, p<0.001
	Sibling lower SDQ peer problems	Spearman's rho=0.76, n=41, p<0.001
	Sibling higher SDQ prosocial behaviour	Spearman's rho=-0.47, n=41, p=0.002
Main carer factors at Time 1		
Household factors at Time 1	Less child-related household hardship	Spearman's rho=0.26, n=134, p=0.002
	Less main carer-related household hardship	Spearman's rho=0.24, n=134, p=0.005
	Family fewer money worries	Spearman's rho=-0.23, n=132, p=0.008
	Family managing better financially	Spearman's rho=0.26, n=132, p=0.002
Short break usage and funding at Time 1		

Table 63 presents Time 1 factors predicting greater sibling prosocial behaviour according to the SDQ at Time 2. As Table 63 shows, sibling prosocial behaviour at Time 1 was strongly associated with sibling prosocial behaviour at Time 2. Several sibling factors at Time 1 predicted greater sibling prosocial behaviour at Time 2: lower sibling difficulties according to the SDQ (total difficulties, hyperactivity, conduct problems, peer problems). Greater child prosocial behaviour at Time 2 was also predicted by the disabled child and their sibling having a better relationship at Time 1.

Table 63 Time 1 Factors predicting higher sibling SDQ prosocial behaviour at Time 2

Time 1 factors predicting higher sibling SDQ prosocial behaviour at Time 2		Test statistics
Higher sibling SDQ prosocial behaviour at Time 1		Spearman's rho=0.73, n=47, p<0.001
Disabled child factors at Time 1	Disabled child and sibling better relationship TDRWQ	Spearman's rho=0.21, n=146, p=0.010
Sibling factors at Time 1	Sibling lower SDQ total difficulties	Spearman's rho=-0.70, n=41, p<0.001
	Sibling lower SDQ hyperactivity	Spearman's rho=-0.59, n=45, p<0.001
	Sibling lower SDQ conduct problems	Spearman's rho=-0.53, n=49, p<0.001
	Sibling lower SDQ peer problems	Spearman's rho=-0.55, n=46, p<0.001
Main carer factors at Time 1		
Household factors at Time 1		
Short break usage and funding at Time 1		

Table 64 presents Time 1 factors predicting carer perceptions of the sibling making better progress at school at Time 2. As Table 64 shows, sibling progress at school at Time 1 was strongly associated with sibling progress at school at Time 2. Carer perceptions of better sibling progress at school at Time 2 was associated with the disabled being older and/or being in Target Group E, and with the sibling showing fewer peer problems according to the SDQ at Time 1.

Table 64 Time 1 Factors predicting carer perception of better sibling progress at school at Time 2

Time 1 factors predicting better sibling progress at school at Time 2		Test statistics
Better sibling progress at school at Time 1		Spearman’s rho=0.69, n=48, p<0.001
Disabled child factors at Time 1	Older child Child in Target Group E	Spearman’s rho=-0.28, n=207, p<0.001 Mann-Whitney U=3591, n=207, p=0.002
Sibling factors at Time 1	Sibling lower SDQ peer problems	Spearman’s rho=0.44, n=47, p=0.002
Main carer factors at Time 1		
Household factors at Time 1		
Short break usage and funding at Time 1		

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