
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 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.

Additional Information

The full report can be accessed at <http://www.education.gov.uk/publications/>
Further information about this research can be obtained from
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This research report was commissioned before the new UK Government took office on 11 May 2010. As a result the content may not reflect current Government policy and may make reference to the Department for Children, Schools and Families (DCSF) which has now been replaced by the Department for Education (DFE).

The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.