

# SCIE RESEARCH BRIEFING

## SHORT BREAKS (RESPITE CARE) FOR CHILDREN WITH LEARNING DISABILITIES

**Definition of a briefing:** A SCIE research briefing is a summary of information on a particular topic to update practice at the health and social care interface. It is a concise document summarising the knowledge base in a particular area to act as a ‘launch pad’ or signpost to more in-depth material. It is produced through a clear methodology involving identification of a focused question, comprehensive searching of multiple sources and filtering of materials for quality.

**Definitions used in this briefing:** The term “short breaks” will be used throughout this briefing to emphasise that current thinking and policy in this area includes benefits for both children and carers. However, the term “respite care” is still used by some parents who also might regard its primary aim as giving them a break from caring.

<b>What is the issue?</b>	Short breaks are intended to have positive benefits for both children and carers (1, 2): children have the opportunity to have enjoyable experiences (3, 4) and socialise with others (5) whilst carers and siblings have the opportunity to relax (6), do other tasks (7) and spend time with family and friends (8). Short break services, of which there are over 400 in the UK (not Scotland) (9) include: sitting services, befriending services, youth clubs, play schemes, the use of outreach/sessional workers to stay with the child or take them out and overnight stays with carers or in care homes or hospital. Many service providers aim to provide a range of short break services (10), of differing lengths (11) reflecting the ages of the children and range of disability. Services must take into account the individual and unique nature of each child (10, 12) and be planned in conjunction with children and their families. It is important that the provision and use of short breaks is considered as an integral part of the substantial care provided by families (6).
<b>Why is it important?</b>	Support services must be provided to disabled children (classified as “children in need”) under the <i>Children Act</i> (1989) (13) and carers under the <i>Carers and Disabled Children Act</i> (2000) (14). There is also strong government support for short break services and their benefits through “ <i>Quality Protects</i> ” (15), “ <i>Choice Protects</i> ” (16), <i>Removing Barriers for Disabled Children Act</i> (1998 – s4.21) (17) and the <i>Disabled Children: Directions for their Future</i> report (1998) (18). However, short break services struggle with a lack of funding (9, 19), lengthy

	<p>waiting lists (1, 20, 21), moving and handling issues (4, 22) and difficulty in recruiting suitable short break carers (4). Many families use short break services in a crisis (23) and not in a planned way (24). As well as a need to consult children using the services (25, 26), the wishes of carers need to be acted upon: this includes the need for more services (12), more choice (2, 12, 27), more service flexibility (2, 9, 10), higher quality services (28, 29) family-based breaks (12, 30) and a move away from hospital-based breaks (10, 31). Short breaks can help to alleviate a major problem of carer stress (19, 32, 33), which is particularly acute for children with severe, multiple disabilities (34) although in a minority of instances, carer stress may actually increase (5, 31).</p>
<p><b>What does the research show?</b></p>	<p>Research confirms that along with waiting lists for short breaks, families are not getting as many short breaks as they would like nor breaks for as long as they would like. Children with complex health needs (1), “challenging” behaviour (35) and disabilities such as autistic spectrum disorders (36) are less likely to have short breaks (1), as well as boys and youngsters from mixed race or minority ethnic communities (35, 37), although some studies have found that severely disabled children use short break services more (34). Studies show that families prefer home-based breaks (30) to breaks in care homes or hospitals and would like more choice in the type of break available (11): short breaks during school holidays and in the form of play schemes are particularly popular with families (10, 31, 38). Research shows that minority ethnic children are more likely to be placed in institutions than family settings (39) and are more likely to be unaware of short break services (20), that low income families use a narrower range of services than other families (10) and that very young children are less likely to have short breaks (20, 30, 40). There is also evidence that whilst carers benefit from the use of short break services (33), this can be accompanied by feelings of guilt (6), loss (5), concerns about safety (12) and an increase in carer stress (6). There is also increasing consultation of children both about the services they would like to receive and their assessment of existing short break services (26). Some studies suggest that there is a lack of adapted housing, moving/handling issues and a lack of short break carers (4). Research examining the use of salaried carers to address carer recruitment problems found benefits including improved stability of placements, a greater level of commitment by carers and a more experienced pool of carers (35). However, there is some concern about existing research methodologies (20), including methodological flaws (33) and small sample sizes (8). Much of the literature is descriptive in nature (11) which is of value in exploring the viewpoints of children and their carers. More research is needed on the outcomes and benefits of short break services (11, 34, 41), the views of children using them (7, 10), the cost-benefits of different types of service (10, 11) and the development of effective models for short break care (32, 34).</p>
<p><b>What do I need to do?</b></p>	<ul style="list-style-type: none"> <li>• Be aware of local short break services and how to access them.</li> <li>• Obtain the resource pack “<i>I’ll Go First: The Planning and Review Toolkit for Use with Children with Disabilities</i>” intended to support social workers in consulting disabled children in short-term care. Details can be found at <a href="http://cnb-host4.clickandbuild.com/cnb/shop/tcs?listPos=&amp;productID=21&amp;search=&amp;op=catalogue-product_info-null&amp;prodCategoryID=8">http://cnb-host4.clickandbuild.com/cnb/shop/tcs?listPos=&amp;productID=21&amp;search=&amp;op=catalogue-product_info-null&amp;prodCategoryID=8</a></li> <li>• Look at the “<i>Quality Protects</i>” website at <a href="http://www.dfes.gov.uk/qualityprotects/">http://www.dfes.gov.uk/qualityprotects/</a></li> </ul>

<p><b>What are the implications?</b></p>	<p>An increase in funding and continuity of funding is needed to provide the variety of services required (29). To do this, service providers need to obtain accurate information on the numbers of children with complex health needs to assist in planning (31): this should mean that the substantial minority of families who do not use short break services at all can be identified. At a local level, services need to be developed and information about them disseminated to the families most likely to benefit (2, 31, 42). In particular, services need to be targeted to children from minority ethnic groups, low income households or large families to address current access inequalities (29) and increased provision of school holiday breaks. More trained carers (21) would help to reduce waiting lists and enabling them to have a paid and professional standing (4, 5) might allow quality issues to be addressed. Key worker support and guidance needs to reach as many as want it (2) to enable individual short break services and families to be matched correctly (31).</p>
<p><b>Who can I contact?</b></p>	<ul style="list-style-type: none"> <li>• Shared Care Network at <a href="http://www.sharedcarenetwork.org.uk">http://www.sharedcarenetwork.org.uk</a></li> <li>• Shared Care Scotland at <a href="http://www.sharedcarescotland.com">http://www.sharedcarescotland.com</a></li> <li>• Crossroads (providing “in the home care” for carers) at <a href="http://www.crossroads.org.uk/index.html">http://www.crossroads.org.uk/index.html</a></li> <li>• Valuing People Support Team at <a href="http://www.valuingpeople.gov.uk/">http://www.valuingpeople.gov.uk/</a></li> <li>• Learning Disability Task Force within the Department of Health at <a href="http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities/LearningDisabilitiesTaskforce/DisabilitiesTaskforceMembership/fs/en?CONTENT_ID=4001884&amp;chk=Drqkqg">http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities/LearningDisabilitiesTaskforce/DisabilitiesTaskforceMembership/fs/en?CONTENT_ID=4001884&amp;chk=Drqkqg</a></li> <li>• National Forum for people with learning disabilities at <a href="http://www.valuingpeople.org.uk/">http://www.valuingpeople.org.uk/</a></li> <li>• The Home Farm Trust at <a href="http://www.hft.org.uk/">http://www.hft.org.uk/</a></li> <li>• The Foundation for People with Learning Disabilities at <a href="http://www.learningdisabilities.org.uk/">http://www.learningdisabilities.org.uk/</a></li> </ul>
<p><b>Where can I find examples of innovative practice?</b></p>	<ul style="list-style-type: none"> <li>• Directories of short break schemes are available from: Shared Care Network at <a href="http://www.sharedcarenetwork.org.uk/scn/dynamic/scn21.shtml">http://www.sharedcarenetwork.org.uk/scn/dynamic/scn21.shtml</a></li> <li>• Sharing Value at <a href="http://www.sharingvalue.co.uk/">http://www.sharingvalue.co.uk/</a></li> <li>• The Audit Commission has produced two factsheets on short breaks: <ul style="list-style-type: none"> <li>• Factsheet 8a: Short Breaks at <a href="http://www.audit-commission.gov.uk/disabledchildren/factsheet8a.asp">http://www.audit-commission.gov.uk/disabledchildren/factsheet8a.asp</a></li> <li>• Factsheet 8b: Short Breaks and Childcare: Questions to Ask Before Placing Your Child at <a href="http://www.audit-commission.gov.uk/disabledchildren/factsheet8b.asp">http://www.audit-commission.gov.uk/disabledchildren/factsheet8b.asp</a></li> </ul> </li> <li>• St Michael’s House provides day and residential services to both children and adults in the Dublin area, including family-based respite (7). See the website at: <a href="http://indigo.ie/~smh/">http://indigo.ie/~smh/</a></li> <li>• Middlesborough social services and the Shaftesbury Society have worked in partnership to provide a wide range of community-based respite services. See: <a href="http://www.communitycare.co.uk/articles/article.asp?liarticleid=23911&amp;liSectionID=22&amp;sKeys=voluntary+value+added&amp;liParentID=26">http://www.communitycare.co.uk/articles/article.asp?liarticleid=23911&amp;liSectionID=22&amp;sKeys=voluntary+value+added&amp;liParentID=26</a></li> </ul>
<p><b>What are the views of users and users groups?</b></p>	<p>It is vital that disabled children are consulted about the services they receive (21), including the issue of quality in services (28) as services that respond directly to user and family needs have a greater chance of success (38). It is also important that efforts are made to consult children directly (25), through communication aids if necessary, rather than through the advocacy of family members (40). Research</p>

	<p>studies have shown that children appeared to enjoy short breaks with family carers (9, 43) and holiday schemes (23, 38) although a minority had unhappy experiences of residential short breaks (24, 25, 44), including acute homesickness (5). Four specific quality indicators in relation to short breaks were highlighted by children: opportunities to meet and make friends, having a variety of activities, opportunities to develop independence and having a break from their family (28). A group of parents identified the following issues as the most important: continuity of carer, consistency of service, concern about what will happen when children are older/grow up, the appropriateness of placements so that the individual is recognised, using the wealth of experience in family networks, the need for a directory of provision and the difficulties of schemes funded over a limited period. Good outcomes were stated as the child appearing happy, a reduction in carer stress, breaks given when needed and not cancelled, the continued use of known and trusted carers and offering a variety of experiences.</p>
<b>Resource sites</b>	<ul style="list-style-type: none"> <li>• See the Valuing People Support Team website for resources linked to “<i>Valuing People</i>” at <a href="http://www.valuingpeople.gov.uk/papers.htm">http://www.valuingpeople.gov.uk/papers.htm</a></li> <li>• The Learning Disabilities pages in the Department of Health website has a list of other sites of interest at <a href="http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities/WhatsNewWithinLearningDisabilities/fs/en?CONTENT_ID=4031682&amp;chk=ozmMhZ">http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities/WhatsNewWithinLearningDisabilities/fs/en?CONTENT_ID=4031682&amp;chk=ozmMhZ</a></li> <li>• See the National electronic Library for Learning Disabilities (NeLLD), part of the National electronic Library for Health at <a href="http://www.minervation.com/ld/">http://www.minervation.com/ld/</a></li> <li>• The Foundation for People with Learning Disabilities has a “Getting Help” section at <a href="http://www.learningdisabilities.org.uk/page.cfm?pagecode=GH">http://www.learningdisabilities.org.uk/page.cfm?pagecode=GH</a></li> <li>• The Department of Health “Integrated Children’s System” has a list of resources on involving disabled children at <a href="http://www.children.doh.gov.uk/integratedchildrenssystem/involving2.htm">http://www.children.doh.gov.uk/integratedchildrenssystem/involving2.htm</a></li> <li>• Search <a href="#">CareData</a> freely available via the <a href="#">Electronic Library for Social Care</a></li> <li>• Search <a href="#">ASSIA</a>.</li> </ul>
<b>Comments</b>	<p>Please address all comments, suggestions or ideas for improvement to the ScHARR Library at <a href="mailto:scharrlib@shef.ac.uk">scharrlib@shef.ac.uk</a></p>
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UK interview survey with 26 children and young people which includes material for people with learning disabilities.