

Short breaks for disabled children

Briefing Paper No. 2 – The range of short breaks



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The purpose of this Briefing Paper

This is one of a series of briefing papers produced to help local authorities, providers and families work together to improve the range and quality of short breaks for disabled children.

The Centre for Disability Research at Lancaster University (CeDR) and National Development Team for Inclusion (NDTi) were commissioned by the Department for Education (DfE) in 2009 to evaluate the impact of the short breaks Pathfinder initiative. The full reports were published in 2010 and 2011 (Hatton et al., 2011, Greig et al., 2010, Welch et al., 2010, Langer et al., 2010). The evaluation identified some key issues that needed particular attention. DfE asked NDTi and CeDR to produce four Briefing Papers as short summaries of the key actions that the research evidence indicates should be taken by local authorities, providers and families in order to improve short breaks provision and the experiences of children, young people and families.

This Briefing Paper (No 2 of 4) highlights a number of actions and outputs that can result in improved outcomes.

Definition of the issue

The term 'short breaks' is used to describe a wide range of services for disabled children and their families including those which have often been referred to as 'respite'. Having a wide range of short breaks available is important because of the diversity of families who need to use short breaks (Welch et al., 2010). Short breaks services can differ significantly on a number of dimensions, including: the duration and timing of the break, the type of activity involved, the location or setting for the break, who provides the break, how the break is organised, and whether the disabled child or the wider family take part.

In this briefing paper we summarise evidence about how families have benefited from a wider range of short breaks and describe what would be effective practice in this area.

What does government policy say about delivering a range of services?

- Recent increases in resources allied to policy trends have resulted in the range of short break services offered to families becoming more diverse (Holmes et al., 2010).
- The Department for Education (DfE, 2011c) has outlined its aspiration to make a wider range of short breaks available as part of its aim to increase parental choice and to meet the needs of families with disabled children. In addition continued investment of over £800 million between 2011 and 2015 as part of the Early Intervention Grant has been announced.

- Regulation four of the Breaks for Carers of Disabled Children Regulations 2011 (DfE, 2011a), which came into force on 1st April 2011, stipulates that local authorities have a duty to provide a range of services that will assist carers in continuing to provide care or in providing care more effectively. The range of short break services that are identified in the legislation are:
 - day-time care in the homes of disabled children or elsewhere
 - overnight care in the homes of disabled children or elsewhere
 - educational or leisure activities for disabled children outside their homes
 - services available to assist carers in the evenings, at weekends and during the school holidays
- Advice provided by the Department for Education (DfE, 2011b) to support local authorities in implementing these duties contains a clear statement that local authorities have a duty to provide a range of services which will:
 - ensure that the needs of different types of carers are taken into account
 - be available as needed during the day, night, at weekends and during the school holidays
- This advice states that as well as providing a range of short break services, local authorities must publish a statement of their short break services by October 2011. This statement should include how the range of services provided by the local authority will meet the needs of families with disabled children in their area.
- Furthermore, local authorities should work in partnership with health services to ensure that they understand the range of short break services in their area.

What the Short Breaks Evaluation found out about delivering a range of short break services

Local authorities and partners were delivering a range of short breaks services, aiming to address the diverse needs of the populations that they served. In most local authorities this provision was accompanied by ongoing efforts to establish and respond to the expressed needs of these populations. In some local authorities additional efforts were being made to investigate the needs and aspirations of groups or communities that were felt to have been less well served previously, such as minority ethnic communities or certain age groups of children.

The successful Pathfinders undertook the following to support the provision of a range of short breaks:

- **Pathfinders developed a range of short breaks based on an implicit objective of promoting resilience in the family unit, as a whole.** It was seen to be imperative to develop a range of options which might be targeted at different family members, including siblings and extended family; *what works for Mum may not prove helpful to Dad*. Successful Pathfinders ensured that options were available for soft-play and outdoor recreation for pre-school as well as supporting teenagers to get together at an evening youth

group, either to take part in something active and healthy or simply make new friends and having some fun worrying the staff by doing something unhealthy!

- **Pathfinders actively listened to the views of young people and their families** when planning (and commissioning) the range and type of services that were delivered. In this 'listening' the successful Pathfinders also made interesting and new suggestions about activities or experiences that were perhaps beyond the envisaged expectations of disabled young people and their families. Most Pathfinders supported some form of annual parent forum which provided opportunities to discuss short breaks and gather views and experiences. In one such forum, parents were asked to vote for their favoured option from a menu of potential developments in their locality. Another Pathfinder worked with a group of young adults who had direct experience of receiving short breaks to undertake an extensive piece of market research with young people in schools. The findings from this research were used to inform the shape of service provision that was subsequently developed.
- **Pathfinders found that a flexible, perhaps less prescriptive commissioning process enabled 'new' providers to put forward suggestions** and proposals that were informed by their extensive experience with the wider community. Often such non-traditional providers came with fresh ideas and perspectives and both energised and challenged existing providers. In one Pathfinder, for example, a number of mainstream youth agencies found that they were able to offer a great deal of exciting community based activities to disabled young people. This included some challenging overnight trips away battling the elements on adapted bicycles, building muscles and character!
- **Pathfinders made a good range of options available and worked hard to ensure that individuals, families, groups and agencies were aware** of how to go about accessing these services quickly and easily, often without the need for an extensive assessment process. Pathfinders informed parents through newsletters, websites and information days and other events. Successful Pathfinders ensured that a wide range of health and social care practitioners were well informed about the emerging range of options available, and developed application or proportionate assessment processes that these practitioners could use to help families find a simple route into services. One Pathfinder used an annual carers event to host a 'market place' demonstration of the potential options in their area. Service providers presented colourful exhibits, photos and testimonies which highlighted what they had to offer and offered parents and practitioners the opportunity to find out more about each option and get a feel for what might work best for their son or daughter.
- **Pathfinders created and publicised opportunities for individuals, families and groups that went beyond the standardised list of options.** These opportunities might be secured using Direct Payments or a Personal Budget and many local authorities initiated a kind of 'participation' fund to meet specific or one-off needs and requests. Such funds might have paid, for example, for a dedicated worker to ensure that young people were able to take part in mainstream activities with their friends or siblings.

Most Pathfinders developed a funding system and support mechanism to enable families to enjoy a holiday together (with paid support) or a break apart. Other Pathfinders enabled parents and young people to enjoy high quality short breaks through providing different forms of equipment such as wheelchair equipment, as well as more health related facilities. One Pathfinder provided an adapted tricycle for a young girl which both allowed her to play with her friends in the park and at the same time

helped mum or dad to enjoy a well-earned sit down. Another Pathfinder provided one family with a laptop to help their son explore cyber space (safely) and leave his mum to catch up with other jobs or simply take some time for herself. In another area funds were used to buy a portable sports suite which featured a number of pieces of equipment adapted for wheelchair users.

- **Successful Pathfinders managed to present a balanced message concerning the nature of short breaks in their area.** This message both encouraged a flexible and creative re-interpretation of short breaks, whilst still being clear and straightforward with parents about new possibilities which went beyond traditional approaches to 'respite' care. In effect, the successful sites acknowledged that parents (and perhaps practitioners) could easily become confused about what was potentially available and therefore devoted significant attention to developing a clear and consistent message.
- **Pathfinders targeted a range of mainstream community services to help them to offer more suitable environments** for disabled young people and their family and friends. Successful sites devoted much time and energy to creating new partnerships with agencies that had not previously been closely involved with health and social care projects. In one site, for example, the Pathfinder team worked intensively in a project with a local leisure centre to assist them in developing a range of indoor and outdoor facilities and services that would be of great benefit. The involvement of the Pathfinder team further enabled the active participation of local disabled young people and their families in the overall development of the facilities. A number of new partnerships emerged which had the potential to improve mainstream services over and beyond the timescale of the Pathfinder pilot.
- **Pathfinders created streamlined, yet robust, systems to collect people's views about the strengths and limitations of the support services they had received.** These customer satisfaction tools were used effectively to shape future developments and to help to keep providers focused on delivering high quality outcomes.

Checklist for Effective Practice

From this evidence a consistent range of options or outputs emerged. Effective practice is likely to result in the following menu of options. Commissioners might benefit from comparing the range of options highlighted below with what is offered in their locality.

1. Availability - short breaks are offered:
 - During the day
 - During the evening
 - Overnight
 - During the weekend
 - Over more than one night
 - For short activities or breaks (1-2 hours)
 - For longer periods and perhaps days / trips away
 - Seasonally – particularly over summer holidays (play schemes) and other vacation periods

2. A range of settings are offered:
 - At home
 - In another family home or approved care worker / foster carers
 - In a school or 'after school' environment
 - Within an activity group organised by a community children's or youth agency
 - In the community taking part in individualised activities or experiences
 - Within an activity group that is targeted at a specific group, therefore offering specialist support and facilities
 - In a specialist residential facility

3. A range of activities are offered:
 - Sports and play
 - Music and arts
 - Friendship and socialising ('just chilling with my mates')
 - Getting out and about shopping, visiting, going to the cinema
 - Learning to speak up and developing confidence
 - Opportunities to meet others 'in the same boat', such as parents social events / meetings

4. Activities are offered to:
 - Individual young people
 - Groups of young people
 - Specific groups of young people e.g. people on the autistic spectrum
 - Young people and their siblings and friends
 - Parents with their children
 - Parents without their children

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The following may also be of interest

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