

Recruiting and supporting short-break carers for children who are considered 'hard to place'

Family-based, short-break (shared care or respite care) services provide support services to disabled children or adults and their families, through linking them with families or individuals who can provide short breaks on a regular basis. While disabled children or adults experience new relationships, environments and activities, their families get 'time to themselves'. These services are often a critical support for families with disabled children. However, children and young people who have complex healthcare needs or 'challenging behaviour', and/or who come from minority ethnic families, are often not provided with short break services: they are 'hard to place'. This study by Beth Prewett investigated why short-break carers provided breaks for 'hard to place' children, and looked at their recruitment, assessment, training and support. It found:

- f** Short-break carers provided breaks for a variety of reasons. Many got involved because they knew a child or family who needed support.
- f** Most, but not all, short-break carers for children with complex healthcare needs or 'challenging behaviour' had professional or personal experience of disability.
- f** Most short-break carers said they enjoyed their role and were committed to and loved the children they were linked with.
- f** Short-break carers did not provide breaks for money, but there was concern that some people would not be able to afford to provide short breaks because of low payment. Many felt the payment did not reflect their skills, commitment, or the high expenses they incurred.
- f** Schemes felt lack of resources inhibited them from:
 - raising the profile of schemes within local communities;
 - pro-actively recruiting a diverse range of short-break carers;
 - providing appropriate training;
 - providing more constant support;
 - paying short-break carers appropriately;
 - providing equipment so that short breaks could continue as children grew larger and heavier.

Background

Recent reports from the Social Services Inspectorate have recognised that short break services are: "Almost universally regarded by parents as a critical service in supporting families within the community" (SSI 1998, **Removing barriers for disabled children**, Section 4.21). Quality Protects, the Government's three-year programme for transforming children's services in England, specifically promotes the increased provision of short-break services to disabled children and their families. In Wales, the **Children First** programme is committed to improving services for disabled children (specific sub-objectives are to be proposed shortly).

Around 10,000 children and their families currently benefit from short breaks (SSI 1998). The children have some time away from home in new environments, develop new relationships and experience new activities, while their parents have time to relax or spend time with their other children. Until recently short-break carers have primarily provided overnight care in their own home. The concept of short breaks is now broadening and schemes are increasingly providing day care, sitting and befriending services as well as in-home support.

However, the disabled children and their families most in need of short breaks are most likely to wait the longest. In a 1998 survey of 152 schemes, half as many children were waiting for services as were provided with services. There is a shortage of short-break carers, particularly from minority ethnic backgrounds. The children most likely to be waiting for services are those regarded as 'hard to place' because of their 'challenging behaviour' or complex healthcare needs (such as feeding by gastrostomy or nasogastric tubes, catheterisation or the administration of rectal diazepam for the control of epilepsy).

This study set out to investigate what motivates short-break carers for children regarded as 'hard to place', why they stop providing short breaks and how they are recruited, assessed, trained and supported.

Who provides short breaks for 'hard to place' children?

The short-break carers involved in this study included couples whose children had left home, couples with and without children and a few single people with or without children. The short-break carers selected were representative of the types of carers working with schemes and came from a variety of ethnic backgrounds. The majority of the 53 short-break carers provided overnight care while four single male carers provided day care.

The short-break carers loved children and were patient, understanding, dedicated and committed. They had a sense of humour and were able to work on their own and under pressure. Providing overnight short breaks was mainly seen by the carers as a role for women or couples/families. Single male short-break carers offering overnight care were either viewed with

suspicion by other short-break carers, or it was recognised that suitable men would be put off by the possibility of allegations of abuse and the predominantly female scheme environments. Short-break schemes could promote the positive inclusion of single men and younger carers in sitting and befriending services.

Experience is needed

The short-break carers usually had some experience with disabled children. They either:

- knew a child or family who required short breaks (some were relatives), or
- they had worked with disabled people professionally or as volunteers.

A few of the short-break carers had begun to provide short breaks without having had any experience of disability.

The carers believed providing short breaks for children who are 'hard to place' was not something that someone would do without some experience. They felt that people with the right characteristics could be provided with experience by short-break carers to enable them to become short-break carers for 'hard to place' children.

Motivations, rewards and satisfactions

The carers were motivated to provide short breaks because they enjoyed being with children and wanted to support families with a disabled child. They often knew a family whom they wanted to support. For some it was also an opportunity to give something back to the community. Others started providing short breaks so they could use their skills to benefit others. A small number linked their involvement to their religious beliefs.

The carers stressed that "caring is not for the money" but payments were important to those in low-paid employment or in receipt of state benefits. Some had given up professional roles, such as paediatric nursing or social work, to provide short breaks on a full-time basis.

The carers received great satisfaction and enjoyment from providing short breaks:

"The more you put in the more you get out."

"I like to feel I am helping to keep children at home, out of care, out of hospital... It's nice having the children come - I'll do it until I can't do it anymore."

They became committed to the children they cared for and developed a real, often loving, relationship with them. The short-break carers wanted the children to achieve their full potential. Carers continued to provide short breaks for long periods of time because of their relationships with the children.

Reasons for stopping

The main reason carers stopped providing short breaks was because of a change in their personal circumstances. In a few cases, poor relationships with the children's parents or the scheme workers resulted in the link ending. This highlights the importance of ongoing support by the short break schemes. Also, children with physical impairments often become too large to move easily, and short-break schemes often could not afford to supply the equipment required (e.g. hoists) to enable an otherwise successful link to continue.

Recruitment

The most successful recruitment method was word of mouth, whereby potential applicants are told about short breaks by other short-break carers, the families of a disabled child or scheme workers. The short-break carers had often not seen any recruitment materials in their local area. They felt that:

"People do not know there is a need."

Proactive recruitment of short-break carers was inhibited by lack of staff time and funding.

The carers believed that more people might provide short breaks if they were:

- Aware of the need;
- Educated about rather than afraid of disabled people; and
- Knew they did not have to have to be in a traditional family set-up (as implied by the term "family-based short breaks") to provide short-break services.

Good practice in recruiting carers

General recruitment strategies

- Use professional quality advertising with positive disability images
- Highlight the enjoyment, satisfaction and rewards for short-break carers
- Highlight the skills and experiences gained (relevant to many careers)
- Involve current short-break carers and users in raising awareness and recruiting new carers
- Increase the visibility of publicity materials

Targeting specific community groups

- Develop positive links with local communities
- Give talks at community groups and events
- Ensure that target groups (young people, black carers, single parents, etc) know that they are welcome
- Use appropriate images and community languages
- Employ scheme managers or workers from minority ethnic backgrounds
- Target people with relevant disability experience

Assessment

"It can be a bit daunting if you have never had any dealings with social services – wondering am I good enough?"

The assessment process was regarded as appropriately "rigorous" and "intrusive". Given society's concerns about child protection and the potential for unfounded allegations of abuse against male carers, the male carers received a more rigorous assessment which short-break carers and scheme co-ordinators felt to be justified.

Assessment could involve discussion of painful elements in their personal history, and was felt to require a high level of self-confidence from the applicant. The interpersonal skills of the assessing social worker were of paramount importance in this process.

Over a third of the short-break carers stated that their assessments took more than six months. Scheme staff linked this to time needed for police checks and a lack of staff time to fulfil their multi-faceted role in recruiting, assessing, training and supporting carers. Applicants could perceive this delay as implying a lack of interest from schemes.

Training and support

Preparatory training was provided in groups, individually or a mix of both and courses lasted different lengths of time. Short-break carers' views on the quality of this training varied immensely. Preparatory training was felt important in enabling carers to gain an insight into the role, and to establish appropriate attitudes and understanding about disability. It also provided an opportunity for meeting other short-break carers. However, a number were 'excused' from this mandatory training because they or their partner had sufficient prior experience or knowledge.

Ongoing training was also provided on an 'as and when basis' and also varied in quality. Again, some short-break carers did not attend because they felt that they already had the relevant knowledge. The provision of ongoing training was inhibited by a shortage of short-break carers and scheme workers' lack of time.

The possible accreditation or certification of training was felt to be a positive step, especially for those interested in gaining experience relevant to a future career.

Short-break carers' relationships with scheme workers were primarily recorded as good and appropriate. Between reviews, most schemes provided support on an *ad hoc* basis. Short-break carers were expected to contact the scheme if they had any concerns. While this 'as and when' relationship suited most, a minority felt they would have benefited from more ongoing support. Scheme workers would not necessarily be aware of difficulties

short-break carers were experiencing which could lead to the breakdown of links.

Only a third of the short-break carers knew of a support group. Long distances between short-break carers inhibited the development of support groups in rural areas, while low levels of attendance in some schemes led to the decision that they were not cost-effective.

Payments

The way that short-break carers were paid was inconsistent. They were mainly reimbursed their expenses with an additional reward element. Some were paid an enhanced rate; some were paid a retainer; others were paid a fee for their full-time services. There was often a lack of clarity about what the payments were for. The short-break carers were dissatisfied with the payments they received. They felt that the payments did not respect their skills and dedication:

"The money is no good at all, it needs complete review. We're either a valuable resource or we're not."

The payments often did not cover the expense of providing short breaks for a severely disabled child. The carers also felt that the low level of payments could prevent some potential carers from providing short breaks, especially if they were on low incomes. However, for others, the low level of payments provided a chance to generate income without affecting state benefits.

Conclusion

Short-break carers are skilled, dedicated and provide an often essential service for families with disabled children living in the community. However, there is a severe shortage of people to provide this service for disabled children and young people from minority ethnic families and/or who have complex health care needs or 'challenging behaviour'. Evidence from this study suggests the need:

- At a **national** level to raise awareness of the pressing need for short-break carers and the essential support these services provide to families with disabled children in the community.
- At the **local** level, to identify more resources to enable schemes to be proactive in outreach and recruitment; provide better support; pay short-break carers appropriately; and purchase essential equipment so short breaks do not automatically end when a child grows larger and heavier.

About the study

Fifty-three short-break carers took part in 41 interviews about why they became short-break carers, how they were recruited, trained, assessed and how they are currently supported. They provided short breaks for 93 children who were regarded as 'hard to place' because of their severe or multiple impairments, complex healthcare needs or 'challenging behaviour'. The short-break carers represented seven schemes of varying sizes (two in rural areas, two in towns and three in metropolitan areas) which had either experienced success or particular difficulty in recruiting short-break carers for children who are 'hard to place' and/or from minority ethnic backgrounds. Interviews with their scheme co-ordinators were also undertaken as well as a brief questionnaire (returned by 13 former short-break carers from the schemes) to learn why people stop providing short breaks.

How to get further information

The full report, *Committed to caring: The views of short break carers for children, who are 'hard to place'*, by Beth Prewett is published for the Foundation by YPS (ISBN 1 902633 85 7, price £15.95).