

Committed to caring

**The views of short break carers for children who are
'hard to place'**

Beth Prewett

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Glossary

BAAF Form F

The assessment form usually used to assess potential foster carers.

Befriending

One-to-one peer relationship with a short break carer enabling users to access local leisure facilities.

Domiciliary care

Short breaks provided in the user's home, which can include personal care.

Link

A term to describe the relationship between a short break carer and the disabled child and their family who are provided with short breaks.

Link worker

The scheme worker responsible for matching/linking users with short break carers. This worker also supports the short break carers.

Retainer

Payment made to short break carers to retain their services.

Short break carer

A carer who provides short breaks, often in their own home. Also known as shared carers, family link carers, or respite carers.

Short break services

Services that provide short breaks for users and their families/long-term carers. Shared care is a term often used by schemes providing short breaks. Schemes are also known as shared care, respite services or family link services.

Sitting

Short breaks provided in or from the user's home.

1 What are short breaks?

Short-term break or respite care are services that give disabled people and their carers a break from the usual routine of daily life. Short-term breaks for people with learning disabilities and family carers is one way of getting more of an 'ordinary life'. Most other people get a chance to get away from their daily routine; many people with learning disabilities and many carers do not get a break now or envisage being able to get a break in the future. (Mencap, 1999, p. 3)

Family based breaks are services that link disabled children and adults with families, couples or individuals who are willing to offer occasional care. The amount of care provided can vary from a few hours a week to several days each month. A small number of schemes offer more regular care, perhaps a few days each week, for children with complex or more demanding needs.

Short break services have been recognised by the Social Services Inspectorate (SSI), and in the Government's Quality Protects Programme for transforming children's services, as essential family support. *Removing Barriers for Disabled Children* (Department of Health Social Services Inspectorate, 1998a) and *Disabled Children – Directions for their Future* (Department of Health Social Services Inspectorate, 1998b) both recognise that short breaks are a critical service for supporting families within the community.

According to *Disabled Children – Directions for their Future* (Department of Health Social Services Inspectorate, 1998b), approximately 10,000 children and young people in the UK currently use this kind of service – a service which, in one young person's words, provides:

A mini-break for me from my family and a mini-break for my family from me. (Young person, in Prewett, 1999, p. 9)

Short break services provide a break for all the members of the family and in so doing often make it easier for them to stay together as a family. Short breaks provide time for parents to recharge their batteries and to spend quality time with their other children. Parents describe these breaks as 'life savers'.

Knowing there will be a break makes caring less stressful so we cope better. (Parent, responding to the Shared Care Network Questionnaire, 2000)

For disabled children and adults, short breaks offer time away from home, chances to enjoy new activities, and opportunities to form warm and loving relationships with short break carers, their families and friends. Most of the disabled children and adults who took part in the 1998 national survey of short break services (Prewett, 1999) indicated that they had short breaks because they enjoyed them and that they would like more.

I wanted to go and stay with some more people, to meet new people, better than staying at home all the time. (Young person in Prewett, 1999, p. 8)

I like Julie, Julie is nice to me ... Andrew is like a big brother to me and Amber is like a big sister. (Young person, in Prewett, 1999, p. 14)

Short break carers (as will be shown in this report) also enjoy providing short breaks and receive great satisfaction from their involvement with the children and their families. For many, providing short breaks enriches their lives.

I like being involved, working with the families. I like to feel I am helping to keep children at home, out of care, out of hospital. I'm giving respite to the families – they do 24 hours a day. It's

nice having the children come – I'll do it until I can't do it any more. (Short break carer)

Quality Protects and short break services

The Government's three-year programme for transforming children's services, Quality Protects, specifically promotes the increased provision of short break services to disabled children and their families.

To increase the number of families of children in need supported by a series of planned short term care arrangements involving for each child the same substitute (respite) carer. (Department of Health, 1998, Sub-objective 1.2)

To increase the number of disabled children in receipt of family support services – including short break services and domiciliary services – and the number of hours of service provided in order to enable disabled children and their families to lead as ordinary a life as possible. (Department of Health, 1998, Sub-objective 6.2)

Quality Protects policy objectives build on the established premise that all children have a right to access the services they need. Under the Children Act (1989) and the Children (Northern Ireland) Order (1995), local authorities have a responsibility to provide disabled children and their families with a range of services to give them the opportunity to lead as ordinary a life as possible. Failure to enable access by certain groups of children to such services could be seen as a denial of their rights following the United Nations Convention on the Rights of the Child (1989), or as discriminatory practice under the Disability Discrimination Act (1995).

Short breaks for children who are 'hard to place': key issues

Service providers are currently failing to provide short breaks for those children and their families most in need of a break. The findings from the 1998 national survey indicate that, even though short breaks were being provided for 7,521 children in the 152 schemes involved in the survey, almost half as many again (3,736 children) were on waiting lists. It also indicated that, while the overall number of short breaks provided in 1998 had grown since 1992, the number of children waiting for services had grown by 27 per cent (Prewett, 1999).

The 1998 national survey identified that nearly 90 per cent of the 152 schemes had a waiting list; that over half of the children registered with these schemes were waiting to receive services for more than nine months while a third were waiting for over a year (in fact, 60 per cent of schemes recorded having children who were waiting for more than a year). These figures do not include children waiting for services from schemes that did not participate in the national survey; nor do they include children who do not even get onto a scheme's waiting list (for example, children are not referred to a scheme or are not registered on a waiting list if it is known that a suitable short break carer will not be available). As such, the figure of 3,736 children waiting for short break services is likely to be a gross underestimate of current levels of unmet need.

The survey indicated that the main reason that children and young people were waiting for services was a lack of suitable carers, particularly for:

- older children and young people
- children and young people with behaviour regarded as challenging

- children and young people with severe physical impairments
- children and young people with complex health needs.

There is also a general shortage of short break carers for children and young people from minority ethnic communities. The 1998 survey revealed that there are more service users (12.5 per cent) than support carers (7 per cent) from minority ethnic communities. One-quarter of children's schemes pinpointed a need for short break carers from Asian communities, while around 10 per cent of schemes reported a need for more Afro-Caribbean or African short break carers. A small number identified the need for carers from specific religious backgrounds, such as Islam, Hinduism and Judaism (Prewett, 1999). Importantly, however, the precise extent of unmet need experienced by black and minority ethnic families is unknown and is unlikely to be reflected in scheme waiting lists (Chamba *et al.*, 1999; Prewett, 1999). The access of minority ethnic families to short break services is further complicated by lack of information about available services, concerns about services not being culturally sensitive and by the increased likelihood that these families will be referred elsewhere if it is known that there are no suitable carers to provide family based short breaks.

The number of children with complex health needs is growing, partly reflecting an increase in the number of children surviving premature birth and neonatal complications, and children with degenerative conditions who are living longer (Servian *et al.*, 1998). These children often require feeding by gastrostomy or nasogastric tubes, suction, catheterisation, nebulisers, injections, or the administration of rectal diazepam for the control of epilepsy. Over recent years, the false assumption that these children cannot use short break services has been challenged. Barnardos (Rhodes *et al.*, 1999) and Shared Care Network (Servian *et al.*, 1998) have produced care management protocols that enable scheme co-ordinators to ensure that children's needs are met, and that carers

carrying out invasive practices are trained and protected. Even so, there is a shortage of carers to provide short breaks for children with complex support needs.

Recruiting short break carers for children with complex health care needs and/or with severe physical impairments (who may require manual handling) is difficult. It requires carers with nursing experience or the confidence to undergo specific training. There may also be requirements for accessible accommodation and specialist equipment, aids or adaptations. Where older children have physical impairments and/or complex health care needs, they can be doubly disadvantaged by their need for two carers and/or equipment that schemes often cannot afford.

Children and young people who are not provided with short breaks are likely to receive no services at all, or to use residential centres, hospitals or even hospices for short breaks (see also Robinson and Jackson, 1999). Chamba *et al.* (1999) found that children from minority ethnic families were far more likely to have short breaks at a 'centre' rather than with a short break carer.

Different types of short breaks for children

Whilst this report primarily describes carers who provide overnight care in their own home, the concept of short breaks is broadening; schemes are increasingly providing day care, sitting and befriending services as well as in-home (domiciliary) support. These positive alternatives to overnight short breaks offer more choice for families and can enable schemes to meet more appropriately the individual needs of children and young people. Befriending services that enable people to take part in community events can work especially well for young people.

The organisation of short break services for children who are

'hard to place' and the payment schemes for short break carers providing these services are incredibly complex issues that scheme co-ordinators continue to engage with. There is often considerable variation between schemes. For example, in some schemes, short break carers providing services to children who are regarded as 'hard to place' receive a standard sessional rate whilst they might receive an enhanced payment, a salary or a retainer in other schemes.

Recruiting foster carers and short break carers

In 1999, the National Foster Care Association published its national standards and recruitment guidelines, and the Department of Health announced a recruitment campaign for carers (launched in 1999).

While short break carers are classified as foster carers according to the Children Act (1989), it must be recognised that they play a significantly different role to full-time foster carers. They provide vital support for families with disabled children and often enable these families to stay together. However, much less is known about the recruitment and support of short break carers than about mainstream foster carers.

Research has already identified the links between the shortage of short break carers and the fact that scheme workers often do not have the time to recruit, train and support carers because of a lack of staff and resources (Prewett, 1999). Many scheme workers have caseloads far greater than the recommended 20 cases (Audit Commission, 1994) in addition to working commitments in other teams. Even where scheme workers have a defined recruitment role, recruiting suitable short break carers can still be an uphill battle, made harder by apparent reductions in the pool of potential

short break volunteers, as more women return to work and as some areas are moving towards full employment.

If the worrying shortage of short break carers is to be addressed, particularly for children regarded as 'hard to place' and children from minority ethnic communities, then better knowledge about what motivates short break carers and how best to recruit, train and support them is needed.

The research

Research has shown that an increasing number of children are waiting for short break services because of a shortage of carers (Prewett, 1999). These children are often from minority ethnic communities or are regarded as 'hard to place' because of their complex health care needs or 'challenging behaviour'. This research sought to understand the characteristics and motivations of short break carers for children who are 'hard to place' and to identify appropriate ways of recruiting and supporting them.

The main research questions were as follows.

- Who becomes a short break carer for children regarded as 'hard to place' and why?
- How are short break carers recruited and assessed?
- What training and support are provided, or could be provided?
- How do short break carers view their role?

Forty-one interviews with 53 carers providing short breaks or shared care were carried out (in 12 interviews, both partners in a couple were present). The short break carers were from seven

schemes in England and Wales and were selected to represent the variety of short break carers for children regarded as 'hard to place' on those schemes. In ten interviews, the short break carers were from minority ethnic communities.

The carers included:

- six single women with no children
- three single men with no children
- seven single women with children still living at home
- two single women with children who had left home
- two single men with children who were with them part of the time
- one couple with no children
- eight couples with children still living at home
- 12 couples with children who had left home.

The carers were paid in a variety of ways:

- 31 received a sessional rate for their expenses and as some reward
- two received an enhanced rate of pay
- six were paid a fee in order to provide large amounts of short breaks
- two were paid a retainer by schemes.

These carers provided short breaks, sometimes on a weekly basis, for 93 children and young people who had severe or multiple impairments, and/or complex health care needs, and/or behaviour regarded as challenging. Specific impairments included Cerebral Palsy, Autism, Asperger's Syndrome and epilepsy. Many of the children and young people did not use speech or sign language to communicate, but used different ways to express themselves (such as eye contact). Some carers provided short breaks for up to six children. Some of the links had been established for over ten years.

In addition, short questionnaires were sent out to 50 former short break carers to seek their views; 13 questionnaires were returned. These confirmed the main themes emerging from interviews with current short break carers.

Scheme co-ordinators from the seven schemes working with the 53 carers were also interviewed to learn their perspectives on the issues explored in the research. The size (from less than 50 to over 200 service users) and staffing levels (from two part-time workers to six workers) varied between the schemes involved. Three were in metropolitan areas; two were in towns; and two were in rural areas. In terms of funding, three of the seven schemes were funded by a voluntary organisation, as opposed to a local authority.

The schemes were selected because they had experienced particular successes or difficulties in recruiting short break carers for children regarded as 'hard to place', and/or in recruiting short break carers from minority ethnic communities.

One scheme has been set up to provide short breaks specifically for children with complex health care needs. Of the other six schemes, three had comparatively low numbers of children with complex needs or 'challenging behaviour' waiting for services, while three had comparatively high numbers on their waiting lists. Of the metropolitan-based schemes, two were successfully recruiting

carers from minority ethnic communities, whereas one reported difficulties.

The research partners

The research was undertaken on behalf of Shared Care Network in conjunction with the Norah Fry Research Centre at the University of Bristol. The research was supported by the Joseph Rowntree Foundation.

Shared Care Network is the umbrella charity for family based breaks in England, Wales and Northern Ireland. Shared Care Network:

- promotes good practice
- campaigns to promote quality services
- provides an advice and information service
- conducts research to inform policy and practice
- organises conferences and training for professionals, parents and support carers
- produces publications.

Shared Care Network can be contacted via the Norah Fry Research Centre, 3 Priory Road, Bristol BS8 1TX.

2 Why be a short break carer?

This chapter describes why people are motivated to provide short breaks for children regarded as 'hard to place' and the satisfaction they receive from their involvement. It then looks at the short break carers' perspectives on the personal qualities that short break carers need to have. Finally, some of the difficult issues around the role of single men as short break carers are explored.

Reasons for starting to provide short breaks

- Knowing the child or their family (as friends or family; or as carers who already worked with the child).
- A general desire to help.
- Family experience of disability.
- Experience of working with disabled children or adults.
- Empathy for parents of disabled children.
- Responding to a scheme's invitation to apply.
- Believing you would do it well and have the skills.
- Love children.
- Awareness of the need for short breaks.
- Gaining work experience for a career.
- Gaining additional income.
- Working at home.
- Religious commitment.

Reasons for continuing to provide short breaks

- Loving and fun relationships with children (and their families).
- A desire to support families with disabled children, combined with the personal rewards gained from involvement.
- Opportunities to use existing knowledge, skills and experience, or to gain new knowledge, skills and experience.
- A way of working at home and/or gaining supplementary income.

Knowing the child and their family

One of the two main reasons short break carers started to provide short breaks for children who are 'hard to place' was because they already knew a family with a disabled child. Often becoming a short break carer formalised an ongoing relationship between family members or between a child and a worker already known to them. In some cases, these workers had been specifically asked to provide short breaks for a particular child they knew. One carer, who was a welfare assistant, was approached to provide short breaks for a colleague's son. In other cases, special school assistants provided short breaks for children at their school.

I knew the child, enjoyed being with him and I wanted to be more involved with people with special needs.

I was looking after my nephew to give my sister a break. I was informed by teachers to do a family link.

Relationship with the children

All of the short break carers discussed the importance of their relationships with the children. They spoke of 'love' and 'commitment'. Their relationships with the children were the main reason they continued providing short breaks, often over many years. The short break carers wanted the children they worked with to 'achieve their full potential' and were satisfied when they were able to help children develop. One short break carer who was going through a bereavement reflected that she valued the company of the children she cared for.

A number of short break carers had also developed 'quite a bond' with the parents of the disabled children. However, the development of the relationship with the children's parents was

definitely secondary to the joy of the relationship with the child. Some short break carers found it important to keep a professional distance with 'over-demanding' parents.

A desire to help

Another key reason for providing short breaks was a desire to help disabled children and their families. Some short break carers reflected that if they had a disabled child they would need support; they 'saw how much need there was for it' and empathised with parents. Supporting these families was a source of 'satisfaction' for short break carers.

I like being involved, working with the families. I like to feel I am helping the children at home, out of care, out of hospital. I'm giving respite to the families – they do 24 hours a day. It's nice having the children come – I'll do it until I can't do it any more.

Experience of disability – professional or personal – was often a factor behind short break carers' awareness of the support needs of families with disabled children. One had cousins who were disabled and had lived opposite a recently closed long-stay hospital for people with learning difficulties. Although she had no 'professional' experience of working with disabled children, she cared for an 11-year-old girl who had cerebral palsy, epilepsy, was tube fed and required massage. Another short break carer felt that his experience driving school taxis had allowed him to get to know disabled children and develop the patience and dedication necessary to provide short breaks. In one case, experience as a primary school teacher and of social work had informed a couple's decision to be short break carers. There was also an example of a child's foster carers providing short breaks when he returned home; and of a scheme approaching someone who had acted as a referee for another short break carer.

Having worked with families in the community, I was aware of a gap in service provision relating to children's medical needs. I knew it was possible to care for these children in the community if the families are given support.

Personal reward

It enriches my life experience – the day just fizzes – I'm a big kid. I do juggling – Tim claps – I can show off. The day doesn't drag. I look forward to it.

The more you do it, the more rewarding it gets.

All of the short break carers were motivated to continue providing short breaks because they enjoyed it. They received 'pleasure' and 'satisfaction' from providing short breaks. They felt that they received far more than they 'put in' and that they were 'doing good'. Providing support for parents was a source of satisfaction.

One couple (providing short breaks for a ten year old with cerebral palsy, visual impairment and who required tube feeding) felt that caring for their own children before they died had provided them with the skills to help other families. Providing short breaks allowed them to have the 'next best thing' to having more children of their own; while their own adopted teenager who had severe learning disabilities enjoyed caring for his friend and had established deep non-verbal communication with him.

For some, providing short breaks was also an expression of their religious commitment. This was raised specifically by three carers from Asian (Muslim) communities.

Community involvement

A quarter of the short break carers were motivated to provide short breaks through a desire to 'give something back' to their local community. Short break carers 'want to help' by 'doing their bit'. This enabled them to feel that they had 'achieved something'.

We wanted to give something back.

A work opportunity

For a small number, providing short breaks was a work opportunity. Some had given up careers in the disability field to be able to become short break carers.

One carer believed that many of the carers on her scheme (in a rural area) were in receipt of state benefits and needed the small amount of extra income that providing short breaks offered. The low levels of payment did not affect their benefits but were a vital contribution to their family income.

Had to find a way of generating income that wouldn't be touched. At the time we had three children at home.

A way of working and staying at home – the extra money helps.

Working at home was also an opportunity valued by mothers who wanted to combine providing short breaks with caring for their own children.

Finally, for a few carers, providing short breaks was a way of making good use of their free time.

Qualities of short break carers

The carers recognised that short break carers needed to be:

- caring
- patient
- understanding
- dedicated
- committed
- motivated
- experienced
- composed.

They would also need to:

- love children
- have a sense of humour
- be able to cope alone
- enjoy a challenge.

They felt being caring was a prerequisite for people who provide short breaks for children regarded as 'hard to place'. They also needed to love children, be patient and understanding, have a sense of humour, be dedicated and committed, and generally 'have their heart in the role'.

Caring for children with complex health care needs and/or 'challenging behaviour' is often very demanding. Carers need to be able to 'cope' and work on their own. As one carer explained, providing short breaks was:

... tiring, hard work, you feel you have to give 100 per cent of your time; it is physically and mentally draining.

You need a lot of composure and be able to handle difficult situations.

In six interviews, providing short breaks for the children regarded as most difficult to place was described as a very rewarding challenge.

The more you put in the more you get out – you're motivated to try and get a response from the child rather than accept that nothing is possible.

Experience

The short break carers involved in this study believed that one of the key characteristics of short break carers for children who were 'hard to place' was experience. Looking after a disabled child was not something that you would do 'cold'. Short break carers believed that experience would be necessary so that they 'knew what they were taking on'.

You wouldn't just think – oh today I'll look after a few disabled children if you had no experience. It would be hard to do it without any experience.

Short break carers and scheme co-ordinators identified that this experience might come from having disabled children, having disabled brothers and sisters, working with disabled children (in families, schools, etc.), or coming from a nursing background.

These carers knew enough about disability to recognise the need for short breaks. They also recognised that they had the skills to undertake the role.

We do know what it is like, it makes something good come out of the death of our children.

Importantly, four of the carers in this study had begun providing short breaks for children with little prior experience. These short break carers described how the provision of relevant experience could break down the 'fear of the unknown' regarding disability which they believed to be common amongst the general public. One short break carer described how experience at a special school helped her to learn about and feel comfortable with disabled children.

Only so many feel able to do it – a lot of people are afraid of disabled children.

I did one week on a Winged Fellowship Scheme. Great experience. Gave me the confidence to do Shared Care.

The desire to gain experience was the reason why one young person had become a short break carer. At 16, she became an evening sitter to gain experience prior to her nursing degree. Her role was soon extended to day care and then overnight care. By 21, she was providing short breaks for four children, three of whom use wheelchairs, require tube feeding, are doubly incontinent and use non-verbal communication. She provided short breaks while living at home with her parents and brother.

Two schemes provided potential short break carers with relevant experience (at a respite centre and at a Saturday club) prior to starting to provide short breaks. More schemes could provide potential short break carers with this kind of experience and highlight how providing short breaks can be a stepping-stone towards a career in the disability field. This would, though, require considerable input by scheme staff and appropriate funding to ensure that applicants without relevant experience were suitably prepared.

A woman's role?

The majority of carers felt that providing short breaks for children regarded as 'hard to place' was a 'woman's role' or a role suited to male/female couples and families. The importance of 'maternal instinct' was mentioned, and some short break carers felt that 'few men know about the needs of children'. Caring, as one scheme co-ordinator summarised, is traditionally a low-paid occupation for women.

It's not a male thing to do.

For some families, it may also be unacceptable on cultural or religious grounds for short break services to be provided by men.

The short break carers generally took two positions on the involvement of single men:

- a complete rejection of single men as providers of overnight short breaks in their home
- an understanding that suitable single men would be put off by the image of caring as a female role and by their vulnerability to child protection issues.

A number of short break carers also questioned why single men would want to provide overnight short breaks. Some felt that most men would not see themselves in a child-care role. A scheme worker believed that some scheme co-ordinators might subconsciously view single male carers as less able to provide short breaks, compared with men whose female partners are short break carers.

One scheme worker felt that the situation had deteriorated over the last ten years as a higher emphasis was placed on ensuring child

protection within social services. The message had been that everyone should be suspicious of men who want to work with children. The public perception that abuse is committed mainly by this group also meant that parents were more wary of links with a single male short break carer. The scheme worker felt that it should be highlighted that the majority of men were not a risk to children.

A lot of men may be frightened by the stigma that they may be thought to have an ulterior motive. The idea that you must be a pervert puts many people off.

Men are put off from caring because of the issue of abuse. It's rammed down their throats all the time. I have friends who would like to be carers but wouldn't touch it with a barge pole for that reason.

As long as society promotes 'caring' as a female activity and fears male involvement, men who are interested in becoming short break carers will feel inhibited by society's assumption that they have ulterior motives and by the fact that 'an incident misinterpreted could ruin a man's life for good'.

Some scheme workers recognised that they were more cautious about applications from single men. Workers on three of the seven schemes said that they undertook a deeper level of assessment for single men. These workers described this extra scrutiny as 'discriminatory'. In the light of current concerns to protect children, and also to protect male short break carers from unfounded accusations, closer scrutiny can perhaps be seen as appropriate, and possibly inevitable.

Single men who have the commitment, time and attitude required to provide short breaks can, along with single women or young people, contribute positively to the provision of short breaks without providing overnight care or care within a traditional 'family based'

set-up. These short break carers can be involved in providing befriending, day-care or sitting services. Befriending, a peer relationship with a carer, often enables young people to participate in community activities. The involvement of single men as befrienders, often with teenagers with challenging behaviour, was regarded as very positive by scheme co-ordinators.

In this study, four single men provided large amounts of day care while a fifth provided a large number of short breaks in his own home.

Summary

Two reasons dominated short break carers' discussions of why they had become a short break carer. The first was that they already knew the child or the family, either personally or professionally, and had offered or had been approached to help. The second was a more general desire to support families with disabled children. Short break carers also described the enjoyment and personal satisfaction they received from their relationships with the children.

Discussions with short break carers about what it takes to provide short breaks for children with complex needs or 'challenging behaviour' confirmed that 'carers care'. They cared about children, their lives and their development, and their families. They also felt that short break carers needed patience, dedication, commitment and the ability to work hard and enjoy a challenge. Providing short breaks was mainly seen as a 'female role' and the involvement of single men was either regarded as inappropriate, or as difficult because of vulnerability to allegations of abuse. Some short break carers and scheme workers identified a positive role for suitable single men, as well as single women and young people who do not have a traditional family set-up, in providing sitting and befriending services.

Short break carers felt that some prior experience of being with disabled children was necessary to enable short break carers to provide short breaks. In many cases, this experience enabled an understanding of the importance of short breaks. Where short break carers had not worked with disabled children, a number of factors combined to bring them to the realisation that they could provide care for children with complex needs or 'challenging behaviour'. A few carers did not have a background in disability but with experience and support through their schemes were enabled to provide short breaks.

Ideas for action

- Highlight the 'buzz' and satisfaction that people get from providing short breaks when doing recruitment posters and leaflets.
- Highlight the ways that being a short break carer can build skills and provide experiences that are directly relevant to many careers.
- Support people who are already providing short breaks to 'spread the word' within their communities, while also finding ways of reaching communities that are not represented in your scheme (for example, meeting with community leaders, setting up stalls at relevant local events, putting up posters and leaflets at different meeting points like religious centres, with general practitioners, in hairdressers, sports clubs, etc.).

Issues for discussion

- Does your scheme have a clear policy about single men as providers of short breaks or befriending services? Are there other ways that you could positively involve single male carers or befrienders?
- Are terms like 'family link' or 'family based short break' less relevant now, if more schemes are promoting different ways of providing short breaks (like befriending) and hoping to involve a wider range of carers (younger people, single people, couples without children)?
- Should Shared Care Network and schemes support accreditation to recognise the skills and expertise that carers gain, and encourage more people to become short break carers to gain valuable work experience?

3 Why do people stop providing short breaks?

This chapter explores the reasons why short break carers would stop providing short breaks from the perspective of 53 current carers involved in this study, and 13 ex-short break carers who returned a questionnaire about why they stopped providing short breaks.

Reasons for stopping providing short breaks

- Moving house.
- Changes in personal circumstances (e.g. ill health, bereavement, children leaving home).
- A link coming to a natural end.
- Finding that providing short breaks was not for them.
- Difficulties with the parents.
- Issues with the short break scheme.
- Lack of equipment to continue providing short breaks.
- 'The only reason I carry on is because the family is desperate.'

Changes in personal circumstances

The development of an often loving relationship between the short break carer and the child was one of the key reasons why short break carers provided short breaks, often over periods of many years. Some short break carers could not envisage why short break carers would want to stop providing short breaks. A change in personal circumstances was the key reason current short break carers believed short breaks would end.

Eleven of the 13 former short break carers who responded cited changes in their own lives as at least one of the reasons for stopping to provide short breaks. These changes included: moving house, the loss of a partner, children leaving home and personal ill

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health. One short break carer also felt that: 'People do different things at different stages in their lives'. Another key reason cited was a 'natural end of the link', because the child they cared for had died or grown too old to use the service. Some felt they 'didn't have the energy to start again' and also that their relationship had been 'special' and could not be 'easily replaced'.

Providing short breaks was not for them

Current short break carers believed that some new short break carers may begin providing short breaks and then find that the role is not for them. This ties in with short break carers' views of the qualities and commitment required when providing short breaks (discussed in the previous chapter).

People don't understand what caring is about and what it involves until you've been there.

They might not appreciate the enormity of commitment required at the outset which may have an impact on their own family.

It was recognised that, even where new short break carers had professional experience in the disability field, they might not realise how different it could be to undertake a 'tiring' and 'demanding' role in their own home. This highlights the dangers of assuming that new short break carers who have relevant skills and knowledge (e.g. from working with disabled children in schools) will 'automatically' be able to provide short breaks with minimal training and support. Preparatory training is vitally important as it provides new and potential carers with an opportunity to understand the role and evaluate its potential impact on their own lives and, where relevant, on their partners and families (see Chapter 6 on 'Training').

Lack of necessary equipment

They increase in size as they get older and it becomes impossible to manage in an ordinary house.

Some short breaks came to an end when the equipment necessary to enable the short break carer to continue providing short breaks could not be provided by the scheme. Scheme workers involved in this study recognised that they often could not provide the equipment required because of lack of resources.

Current short break carers also identified that an increase in the size and weight of a child or young person they cared for was a potential reason for stopping to provide short breaks. At least four short break carers recognised that they would have problems continuing to care for a child they currently carried upstairs to bed. In fact, one short break carer who was not provided with a hoist was continuing to care despite advice otherwise.

If the necessary equipment and/or additional support is not provided, then links will break down and children who are already regarded as the most difficult to place will either not be provided with overnight care, or will be provided with short breaks in residential units, hospices, hospitals, etc. This runs counter to the principles underpinning current policy and guidance (e.g. Quality Protects).

Difficulties with the children's parents

Whilst the majority of the relationships between short break carers and parents were good, this was not always the case. Sometimes the relationship between short break carers and parents 'didn't gel'. This could result in the failure of the link or in short break carers 'persevering' in developing a relationship, which, on occasion, was

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detrimental to themselves. In four interviews with short break carers (one-tenth), the carers explained that they were continuing to provide short breaks only because of their commitment to the children; they felt 'taken advantage' of by the parents and disillusioned with the role. One short break carer believed this was because parents thought that short break carers were getting paid more than they actually were. These short break carers continued providing short breaks because they would feel 'guilty' if they stopped, as there were no other services available to the families.

The only reason I carry on is because the family is desperate.

One ex-short break carer had stopped providing short breaks because a family did not co-operate.

We enjoyed looking after the child but felt the family were wasting our time in not co-operating and letting us down at the last minute.

This points to the importance of short break carers' contact with scheme workers; short break carers could easily be lost because of difficulties with parents of the child they are linked with. Supportive intervention from the scheme and good relationships with link workers could make all the difference in enabling a link to continue. One current short break carer described how the link worker had successfully resolved a 'problem with parents', which meant that the link continued.

Every link must be different so the social worker needs to find out what the parents and carers hope to get out of the link and then check everything is okay.

Issues with the scheme

A lack of emotional and/or financial support was identified as a potential cause for breakdowns in links. This related mostly to the provision of support through a link worker and also through the payments provided to short break carers.

With respect to relationships with link workers, one short break carer felt that she was 'left to get on with it' and there was a 'lack of support'. The 'as and when' method of providing support in response to requests from short break carers 'wasn't enough' (see Chapter 7 on 'Support').

Other short break carers noted that their schemes had 'limited resources' and 'financial constraints' which impacted on the payments received by carers and left some carers struggling financially. This financial issue was particularly pertinent for short break carers who had committed themselves to providing large quantities of short breaks and often relied on the payments as their main source of income (see Chapter 8 on 'Payments').

A bit of a strain on the financial side.

Summary

The majority of short break carers who had stopped providing short breaks had left because of changes in their own work or home circumstances. This was also the main reason identified by current short break carers as to why short break carers might stop providing short breaks, along with underestimating the level of commitment and the wider implications of providing short breaks.

Out of the 13 former short break carers who responded to this study, the majority stopped because of changes in personal

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circumstances (sometimes alongside other reasons). In some cases, links ended because short break carers had felt unsupported by their scheme – financially or emotionally – and/or because of poor relationships with the children’s family.

Some former short break carers had no choice but to stop providing short breaks because the child was becoming too large for them to manage in their own home and they had not been provided with the necessary equipment or adaptations to enable them to continue. Several current short break carers anticipated facing this barrier in the future.

Ideas for action

- Does your scheme identify future needs for equipment that will be vital if current links are to continue as children get older and heavier?
- Does your scheme have a system to ensure that scheme workers have frequent contact with carers, so they can respond to potential difficulties?
- Does your scheme ensure that parents as well as short break carers have clear and realistic expectations about short breaks, the scheme, etc.?

Issues for discussion

- Are ‘exit interviews’ a good idea, to learn what schemes can do or could have done to retain short break carers?
- Does your scheme require all new short break carers to undergo preparatory training, even if they have many of the relevant skills and expertise from their professional background?

4 Recruiting short break carers

This chapter describes how short break carers for children regarded as 'hard to place' were recruited, their views on the recruitment and on the different ways that the seven schemes they were linked with were reaching out to local communities. Examples of good practice in recruitment can be found in the Shared Care Network publication, *Stronger Links* (Jones *et al.*, 2000).

Recruiting carers

- Most of the short break carers involved in this study were recruited by 'word of mouth'. A smaller number were recruited through scheme posters, leaflets, television or radio adverts.
- It can be difficult for schemes to work out why a particular advert or campaign works, and what is likely to be most effective.
- Some scheme co-ordinators felt that it is getting harder to recruit new carers.
- Short break carers identified a need to raise more general community awareness about: what short breaks are; why they are so important; and the enjoyment and rewards that come from providing short breaks.
- Short break carers thought that schemes needed to ensure applicants from all backgrounds knew they were welcome. They could also provide opportunities for potential carers to gain experience with disabled children.
- Outreach by schemes operated at two levels: (a) general publicity and participation at local events; (b) targeted activities aimed at specific groups within the community, often to meet specific needs (e.g. for carers with wheelchair accessible homes, for befrienders, for minority ethnic short break carers, or for short break carers with some professional experience of disability).

Recruiting through 'word of mouth'

The majority of the short break carers in this study were told about short breaks by another short break carer or by the family of a disabled child. Some were invited to apply by a scheme worker.

Two carers had experience of providing foster care and heard about short breaks through their links with social services.

'Word-of-mouth' recruitment was seen as the method likely to result in the highest number of enquiries. Short break carers identified the important role they play in recruiting new short break carers, especially from their families and friends. Sometimes, this role was facilitated by the scheme publicity. One short break carer made her sister watch the scheme video.

'Word of mouth' is effective, but tends to recruit carers similar to those already providing short breaks. This might be problematic if it leads to a less diverse base of short break carers within a scheme.

For many schemes, constraints on staff time and resources make it difficult to recruit – in terms of the range of activities that can be undertaken, and concerns about not being able to respond to a large number of enquiries and process applications while supporting existing short break carers at the same time. Two scheme co-ordinators specifically discussed their inability to focus on recruiting short break carers because of time and money constraints.

I have a feeling that they are afraid to make it too successful – how are they going to assess people due to a lack of personnel, also how are they going to pay? There's a lack of funding.

If schemes are to recruit short break carers in a more proactive manner, they will need to be ready to react to enquiries and undertake assessments. This will be especially important as national campaigns for recruiting more foster carers and short break carers get under way.

Recruiting through publicity materials

Schemes need to go out there and increase public awareness.

People do not know there is a need.

One-sixth of the short break carers involved in this study were recruited through scheme publicity (four responded to leaflets; three responded to television or radio advertisements). Three scheme coordinators felt that the number of applicants responding to adverts, posters or leaflets was decreasing because potential applicants had less time. This was linked to increasing female employment and 'less of an emphasis in society on volunteering'.

Short break carers identified that good publicity needs to be: 'professional quality', 'exciting', 'eye-catching', with 'really good artwork, photos, good quality paper', and that the message should be informative but also encouraging. In some areas, it could be important to produce information in community languages, with appropriate images and messages.

The use of accounts of and by real short break carers, children and families could generate interest in short break schemes. One scheme had a picture of a short break carer who was invited to Buckingham Palace in their local paper. This 'worked a treat' and brought in a good response (compared to a standard advertisement in the same paper which generated no enquiries).

We got the son of someone to write an advert, and it was his own handwriting. We put a fancy border around it, and that got a good response.

It was felt important to ensure that materials depicting children showed that the children are respected and not 'paraded',

particularly when asking for short break carers for particular children.

Short break carers suggested that publicity should be placed 'where people congregate', such as doctors, surgeries, dentists, volunteer bureaux and supermarkets, and that schemes should attract people from all walks of life by running open evenings, visiting schools and colleges, and targeting workers with a background in disability.

Schemes would also ask to be included in publicity campaigns led by other departments and for other social work teams to tell people about short breaks, when appropriate.

Important issues in recruitment

People do not know how many disabled children there are. They have no awareness of the problems and the vast range of disabilities.

A large number of the short break carers believed that the general public is uneducated about and often 'afraid' of disability and is not aware of what short breaks are and why they are so important, and of the fact that they too could be short break carers.

Ordinary people can come forward – you don't have to be wonderfully special or a martyr.

Some carers felt that potential carers may be put off by the connection with social services given popular perceptions that social services departments deal with 'the rough end – children in danger'. This suggests a need to distinguish between mainstream fostering and supporting families with a disabled child through short breaks in future recruitment campaigns.

Those short break carers whose schemes were struggling to recruit new carers felt their scheme's recruitment campaigns were 'low key' and that their schemes had a 'low profile' in the local community. One scheme with a large number of carers from all of the minority ethnic communities in the area was described as having a 'very high profile'. This scheme had developed strong links with the different minority ethnic communities, employed workers who spoke relevant community languages and also organised forums for other social services and voluntary agency groups. As a result, 'people just come along'.

Often, it was difficult to work out what sort of publicity or activities would be effective. What worked on one occasion might not work on another.

Raising public awareness

Scheme co-ordinators described various strategies used to generate interest in schemes and to encourage people to apply to provide short breaks. For the most part, these involved posters and leaflets in relevant community areas such as shops, community centres, doctors, dentists, places of worship; and participation by scheme workers at local community events, such as agricultural or volunteer days (e.g. having a stall, handing out leaflets). This resulted, as one worker reflected, in 'a drip, drip, rather than a gush' of enquiries.

Do a variety of things in a variety of places.

One scheme co-ordinator described how they increased awareness of the scheme to recruit Asian short break carers, and then white carers. The scheme arranged to have a stall in a local shopping centre and encouraged Asian short break carers to bring their friends along. The scheme publicised the stall on Asian radio. Five

carers were recruited from the day. The scheme then repeated the process asking white short break carers to bring along their friends. The involvement of short break carers and users in planning and doing outreach activities was seen as important, since it enabled potential applicants to meet and identify with people currently involved with short breaks.

You get potential empathy with people, and I think people see that and respond to people differently with carers and users. So if we were sitting at a stand we would usually have a carer or a user there, or if we're doing a broadcast we'll have a carer or a user doing it as well.

Specific approaches to community groups

Schemes have also developed strategies to target specific groups. For example, when schemes need more short break carers with wheelchair accessible homes, then specific geographical areas might be targeted, through:

- postal drops
- locating a caravan in the area
- public meetings
- handing out leaflets in supermarkets
- putting adverts on the local radio.

Schemes were also developing relationships with local community groups. Through those relationships they could raise disability awareness and also promote a better understanding among parents and potential short break carers of what short breaks are.

It takes time and resources to build appropriate relationships with different local groups. One scheme had given talks at Gingerbread (the single parents' group); another scheme had targeted gay clubs while developing a service providing short breaks for adults with HIV/AIDS; another scheme used a directory from the Race Equality Unit to identify groups with possible interests in the scheme. These groups were invited to a consultation event to help guide the scheme 'along the right path' in working with community groups.

Recruiting carers from minority ethnic communities

We have got three black workers ... they all speak different languages ... We've got just one language – Bengali – that's not covered by one of our workers.

In recruiting short break carers from minority ethnic communities, it was felt important that potential applicants would know they were welcome and that recruitment materials conveyed appropriate images in community languages.

It was also felt important to employ black and minority ethnic workers who could speak community languages. One scheme co-ordinator kept a vacancy open for a year in order to find a suitable worker. Another scheme which was failing to recruit short break carers from minority ethnic groups was staffed by an all-white team.

Scheme co-ordinators were concerned that black and minority ethnic workers should not take full responsibility for the recruitment and support of workers from their own ethnic or religious background. Recruiting short break carers from diverse backgrounds was the responsibility of the whole team.

Targeting professionals

Scheme co-ordinators targeted groups who would have an understanding of the needs of children who were most difficult to place. This usually involved sending posters and leaflets to special schools, hospitals and care homes, etc. One scheme attended a parents' meeting held every term at a special school to encourage people experienced at caring to provide short breaks. In so doing, the scheme was giving a clear signal that potential applicants would be welcomed and had something to offer other families and their community.

Recruiting male carers

As explored in a previous chapter, there are some difficult issues around recruiting male carers. It may be (as some short break carers and workers identified) that some schemes do not want to recruit single male carers.

If men are to be recruited as befrienders, activity workers or short break carers, schemes will need to reach out to and encourage potential applicants, especially as many scheme offices are staffed only by women. Schemes would need to provide appropriate, relevant information to men to let them know they are needed.

I have a male friend who would be brilliant but his response is fear – he doesn't think he could hold the responsibility.

If we could get more men recruited it would obviously help.

Suggestions on how to recruit men focused on advertising in places such as day centres, nursing homes or schools where men already work, sports clubs and barbers. The posters used would need to be

eye-catching and convey what men might gain from providing short breaks or befriending.

Recruiting younger people

Youth clubs, sixth forms and colleges could be targeted to attract younger men and women. Three of the schemes had successfully recruited sitters and play workers in this way. Payment was identified as a major factor in recruiting young people, particularly students.

Students can't do it for nothing ... they have time, they want to, they thoroughly enjoy it but can't afford to do it, they need to pay off their overdraft and student loans so end up working in a café or Woolworth's.

Schemes need to be realistic with payments, while also highlighting the fun that providing short breaks can bring, and the relevance of skills and experience gained for career development and CVs.

Summary

Short break carers felt that their schemes needed to 'get out there' and tell society about the urgent need for short break carers and how others could become involved. This outreach could emphasise the need for carers with different experiences and backgrounds.

Scheme co-ordinators described various strategies to increase community awareness and involvement. These strategies worked on two levels. At a general level, strategies included posters and leaflets in community locations and participation at local events. Strategies also operated in a more targeted way, involving the development of direct relationships with local groups and minority

ethnic communities, providing information and reassurance about short breaks. In addition to this personal touch, schemes also developed materials and activities to target specific groups such as people already working with disabled children, men, younger people and those living in accessible homes.

Short break carers also identified that applying to provide short breaks can be daunting. Potential applicants need to know they are welcome – especially if they have little or no prior experience of being with disabled children, or are from communities or groups currently under-represented on schemes, such as people from minority ethnic communities, men, younger people.

Ideas for action (based on suggestions from carers and approaches used by the seven schemes involved in this study)

- Develop a twin-track strategy: (a) raising general awareness about what short breaks are, why they are important and who can provide them ('ordinary people'); and (b) targeting specific groups or communities in appropriate ways to meet the scheme's needs and encourage diversity.
- Highlight the pleasure and satisfaction people get from providing breaks; and how being a short break carer or befriender can build skills and provide valuable work experience (especially for younger people).
- Involve short break carers and service users in planning and doing publicity or recruitment campaigns – using their accounts of short breaks.
- Put posters or leaflets in community locations: doctors, dentists, places of worship, supermarkets and shops, volunteer bureaux, sports clubs and gyms, youth clubs, schools and colleges, barbers and hairdressers, special schools and care homes, etc. Posters and leaflets should be produced in the relevant community languages and should be 'eye-catching', 'good quality', 'encouraging' while using appropriate images (including 'positive' images of disability).
- Build a more diverse team of scheme workers reflecting the community.
- Develop strong links with local community groups, offering to give talks, attending community events.
- Use the media (television and radio adverts, newspaper adverts on the same page as TV listings, editorials with photos, etc.).

Issues for discussion

- 'Word of mouth' brings in the most enquiries for many schemes – but is it the most effective way of getting a range of carers from all walks of life?
- Are there ways that limited resources could be used differently to target specific groups (e.g. who work with disabled children or have accessible homes, who are from minority ethnic communities)?
- Does the scheme feel positive about recruiting from certain groups, e.g. younger people or men, to provide befriending and short breaks?
- Would it be helpful if Shared Care Network developed a higher national profile by producing standardised and high quality recruitment materials?

5 Assessment

This chapter discusses the short break carers' views of the assessment process. It establishes that the process is regarded as very thorough, appropriately so in order to protect children. Here, short break carers identified the importance of the interpersonal skills of the assessing social worker. An apparent hierarchy of assessment related to carers' sexuality and gender is described.

What did short break carers think of the assessment process?

- A thorough, intrusive and daunting process.
- Appropriately rigorous to protect children.
- The assessment process often took over six months.
- Potential carers might withdraw applications because of the length of the assessment process and lack of contact with a social worker or scheme during this time – especially if they felt lacking in self-confidence.
- Social workers doing assessments need good interpersonal skills.
- There is an apparent hierarchy of assessment.

A rigorous process

The short break carers in this study were assessed to become foster carers under the Children Act (1989). All of the schemes undertook the assessment for becoming a short break carer using the BAAF Form F through home visits. This process was described as 'rigorous', 'hard-going', 'intensive' and 'intrusive'.

If I had not already known Bobby, I doubt I would have continued. It was too much of a rigmarole, too complicated. I had to declare driving offences of 15 years before.

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

The short break carers approved of the thorough investigation of their motivations. They believed that applicants should be ‘checked out’. However, short break carers recognised that some applicants would find the process difficult if they were not self-confident. It would be easy for applicants ‘not to feel valued’.

In four interviews (out of 41), carers recalled how social workers’ negative attitudes to their past history had caused them discomfort. One short break carer felt there had been an over-emphasis on the reasons why they had been depressed, rather than focusing on the way they had recovered and their ability to provide short breaks.

I thought I’d blown it by not being perfect.

Generally, short break carers’ experiences of assessments had been good and the social workers involved were praised. Here, short break carers identified the need for social workers undertaking assessments to build a ‘rapprochment’ with the applicant and display a high degree of personal and cultural sensitivity. Scheme co-ordinators were aware that this was important but not always evident in all workers.

Scheme workers recognised that potential carers may not be able to see the ‘totality of the process’ and the need for such rigour, especially if they saw the role as purely ‘voluntary’ whereby ‘giving time is enough’. There is, as shown in Chapter 9, a need for better clarity regarding the way the role of short break carer is perceived by schemes and carers, and communicated to potential applicants.

A hierarchy of assessment

If it is a man or gay couple, then we do double the checks and need evidence of child-care ability to a much higher degree.

Whilst the majority of short break carers believed the assessment process 'fairly treated all applicants' a hierarchy of assessment seems to exist. It was succinctly described by one of the scheme co-ordinators as being organised by levels. The lightest assessment was for heterosexual couples. This co-ordinator explained that this reflected society's perception of risk – a view that the co-ordinator felt went against existing evidence that most assaults are made by men in a heterosexual couple. Yet these couples often receive a less rigorous assessment.

I think it's sorted by levels, heterosexual couple, then single women, then a lesbian couple, followed by gay couple, followed by single gay man, then a single straight man.

Assessment of male carers

Workers on three of the schemes reflected that their assessment processes 'discriminated' against male applicants, in that an even more rigorous level of investigation was undertaken for single men and gay carers. These extra checks were related to closer scrutiny from the panel, in relation to concerns about child protection. They can also be seen as building in protection for male short break carers from potential allegations.

Differences in the assessment process included paying more attention to potential male carers' motives and their previous relationships. One worker described visiting a short break carer's ex-wife when she would not usually visit ex-husbands of single women.

Panels scrutinise them just because they are men.

Assessment of gay carers

A lesbian carer involved in the study explained that the assessment process had been more difficult because of their sexuality.

The social worker doing the assessment felt uncomfortable about it, focused upon it rather than other things. Other couples may not want to go through that. They might think they will be turned down.

Another single female carer who shared a house with a female friend believed that her sexuality was an 'issue for her scheme'. Questions about their sexuality were not addressed directly by the worker, but were put to the referee. The carer said, 'I don't know what her response would have been if we had been'.

Approval by panel

None of the short break carers in this study had actually attended the panel meeting where their application was considered. Their files 'went' and the panel procedure was viewed by many carers as a formality ('I don't know anyone who's been turned down') unless there were issues relating to the short break carers' gender or sexuality. One scheme did not use a panel but approved its own short break carers, taking appropriate advice where necessary.

Panel caused a few of the short break carers to feel vulnerable if they had not seen the social worker's report on them. A small number of carers expressed that they ought to have the opportunity to attend the panel meeting.

How can they get to know me on paper?

It is accepted good practice that applicants see the non-confidential sections of their assessment report, and have the right to add written comments or relevant information, or attend the foster panel where their application is being considered (National Foster Care Association, 1999).

A few short break carers had attended the panel meeting when their registration was being reviewed. This experience was described as 'daunting' because of the number of people there. In one case, a scheme co-ordinator described how a skilled and experienced Asian female short break carer had a 'very traumatic experience' when the white male chair of the panel shook her hand (for cultural and religious reasons, she had not been touched by any man outside of her family). In addition to the need for race equality awareness on panels, it was also identified that some panel members lacked awareness of disability and short breaks. Scheme workers felt that panel members needed to be trained together on these issues.

Length of time involved in assessments

The process takes too long.

Assessments often took over six months. In fact, over a third of the 53 short break carers in this study noted that their assessment process took over six months. Three assessments took between nine and 12 months, two assessments took over a year and one assessment took 18 months.

In one case, a short break carer who was already working with a child in a hospital had to wait five months before she could start providing short breaks for him in her own home.

In at least two schemes, the length of the assessment period was due to a lack of staff to undertake assessments. One scheme described how having only two part-time workers meant that applicants who had preparatory training were only just starting to provide short breaks seven months later. Waiting for police and health checks can also lengthen the process.

A scheme co-ordinator recognised that short break carers coped with the 'time lag' more easily when they already knew of someone who had gone through the same experience, or wanted to support a particular family. Others might need more proactive support by the scheme. The length of time taken was thought to be a main reason for applicants dropping out of the process.

Summary

On the whole, the assessment process was seen as appropriately rigorous by short break carers. Some carers and scheme workers identified a hierarchy of assessment in relation to short break carers' gender and/or sexuality. This is a difficult area, reflecting concerns for child protection and wider social attitudes.

Time was a major issue, with assessments often taking longer than six months. Shortening the length of time could improve the whole process. It could lessen the possibility that applicants would find another use for their valuable time.

Given the often intrusive, daunting and very lengthy nature of the process, the role of the scheme worker could be all-important in keeping contact with applicants, providing reassurance and explaining the process, especially where applicants did not know other short break carers or a family they wanted to support.

Ideas for action

- Provide clear information to applicants about the process, what is involved, how long it takes; provide access to non-confidential parts of the report and opportunities to add information and/or attend panel.
- Find ways of keeping in touch with applicants (through newsletters, telephone calls, meetings), especially where applicants do not know families who need services or carers who provide short breaks.

Issues for discussion

- Is there a hierarchy of assessment based on gender and sexuality? Are there clear reasons for this? How can respect and fairness to applicants be balanced by ways of ensuring child protection?
- Who are the best people to be panel members? Should panels receive training, together, on race and disability equality and short breaks? Should panels reflect the local community?

6 Training

This chapter discusses the preparatory and ongoing training attended by the short break carers involved in this study. It describes their views on why they were trained and discusses variations in the quality of training between schemes.

The benefits which training provides

- Appropriate attitudes.
- An understanding of what is expected of short break carers.
- An understanding of what to expect from their scheme.
- An understanding of how to work with the families.
- An opportunity to network and meet other short break carers.
- An opportunity for social workers to get to know them – sometimes as part of the assessment process.
- A link to the provision of a professional service.

Purpose of preparatory training

What is expected of you as a carer, what you can expect from the service, what you can expect from and how to deal with families.

The short break carers who had attended preparatory training recognised that it provided insight into the scheme and the role they would play as short break carers for children regarded as 'hard to place'. The training helped prepare them for this role by building non-judgemental, appropriate and professional attitudes and, for some short break carers, by providing insights into the needs and lives of disabled children and their families.

Training also provided the opportunity to meet new people and enabled short break carers to establish supportive relationships with other carers.

For carers to get to know each other and establish contact for future support.

Training could provide applicants with the opportunity to decide if providing short breaks was for them, and scheme workers with a chance to identify applicants' capabilities and training needs (it is good practice to inform applicants if they are being 'assessed' during preparatory training).

A small number of short break carers identified a direct link between the provision of training and providing a good service. Five of the carers on the specialist scheme for children with complex health care needs noted that their training had been 'good' or 'excellent' and had 'instilled professional values' and built their 'confidence as carers'. This was particularly positive since the majority of these short break carers had already worked in the disability field in a previous career. There was also evidence that short break carers on schemes which provided less training were much more likely to regard themselves as volunteers (see Chapter 9 on 'Professional volunteers?'). As one short break carer explained, proper training supported a 'move away from a glorified baby sitter situation'.

Preparatory training: attendance and non-attendance

Preparatory training is a mandatory requirement for foster carers. However, this training had not been undertaken by a quarter of the short break carers interviewed in this study.

Why did some carers not attend preparatory training?

- Experience with disability in current or previous work (paid or voluntary).
- Living with a partner with relevant experience or training.
- Previous approval under another authority.
- A view that providing short breaks is 'voluntary', so attendance at training sessions must also be voluntary.
- A view that some short break carers could be exempt from training because they were not 'group people', and the training offered was group-based.
- Preparatory training was not available when the short break carer joined (this was the case in two of the 41 interviews).

In 12 of the interviews, at least one short break carer had been excused from preparatory training. Sometimes, short break carers with professional experience in the disability field were excused because of their skills and knowledge; sometimes their partners were excused on the basis that they were providing short breaks together with someone with such experience. For example, one short break carer did 'not need training because of my professional training', and her husband said he could get the information he needed from his wife (he explained that he would have had training if 'my wife had not been a nurse').

They felt they were reasonably proficient and comfortable with what we were doing.

One of the single male day carers did not have to attend training as he had already undertaken a course with another voluntary organisation. However, he felt he would have benefited from a 'What next?' session which focused on his involvement with the scheme.

The theory is that we are supposed to identify these people and make sure certain input is put in from the social workers who are doing it, but I couldn't put my hand on my heart and say that it happens in all cases. (Scheme co-ordinator)

We have a lot of pressure on us to make it voluntary. (Scheme co-ordinator)

One scheme worker confirmed that many short break carers already had training from their work. Another worker on the same scheme noted that their training was not mandatory, partly since short break carers were viewed as 'volunteers'. Another scheme co-ordinator explained that making some people attend training could lose potentially good carers if they were not comfortable with group work (this co-ordinator could not guarantee that training had been provided on an individual basis).

This lack of training, particularly relating to children's individual needs, could leave some short break carers vulnerable while caring for children who are regarded as 'hard to place' because of their complex or demanding needs, as the following examples show.

One couple with no prior experience of disability (aside from living next door to a disabled person years before) had been linked with a boy with epilepsy, which could require the administration of rectal valium. They were provided with no preparatory training or individual training on epilepsy.

In another case, a male day carer was linked with two teenage boys with behavioural problems, one of whom was described as having 'sexual problems with other children'. He 'was given a set of rules of the role'. He turned down another link because it involved lifting a child who had severe fits and he felt 'unsure' about doing this because of 'lack of knowledge'.

Quality of preparatory training

When short break carers had attended preparatory training, their description of the quality of the training provided ranged from 'excellent' to 'poor'. Some short break carers felt that the training was 'well organised and easily understood', or 'fine as it is'. However, another described it as 'very peripheral' and commented that he 'couldn't remember anything'. His training had taken place three years previously.

One scheme was severely criticised for the low quality and limited availability of training. A short break carer stated that training was offered 'in theory', but in reality was 'very poor'. Another short break carer from the same scheme said that group sessions were arranged on a very ad hoc basis.

Each of the seven schemes had a slightly different approach to the provision of preparatory training. The training was normally provided in groups or in a mixture of group sessions and individual training on each child's individual needs. Group training sessions either ran over two days, five days or a number of weekly evening sessions. One scheme often sent its carers to have practical experience in a school or nursery before they began providing links, and gave additional training on an individual basis.

The content of the training differed between schemes but commonly focused on attitudes to disability, child protection, expectations related to the role of short break carers, etc. (see Prewett, 1999 for more detail on the content of preparatory training). Suggestions for improvement tended to be specific to each scheme, but common requests were for training on first aid and manual handling. Training on both these important topics should be provided prior to a carer's first short break.

High quality training is required to ensure the safety of both the short break carers and the children or young people provided with short breaks; it is also crucial in ensuring that the short break carers are fully aware of the expectations related to their role. Established good practice guidelines on this have been produced (see Jones *et al.*, 2000).

Ongoing training

If they fancy it they put their name down. (Scheme co-ordinator)

Ongoing training was available to the majority of short break carers in this study. Sessions were provided, often at the request of short break carers, and they were informed of the event and were free to sign up if they wished.

Short break carers' perceptions of the quality of ongoing training varied dramatically. Descriptions included 'very good' and 'very poor'. The amount of provision also varied greatly, from training sessions every three or six months to 'very little' at all. One short break carer believed she had not been offered any ongoing training.

In addition to group events, individual training should be provided in relation to the changing needs of the children cared for or at the onset of a new link. In one scheme, training was provided in the appropriate language through support groups and accompanied by booklets which could be read at home.

The provision of and attendance at ongoing training were difficult for both scheme co-ordinators and short break carers. One scheme had reduced the amount of ongoing training provided because of a lack of staff time. Another was aware that they should have an

ongoing training programme but felt restricted in this by the scheme's small number of short break carers and a lack of staff time and funding. Significantly, short break carers on this scheme were more likely to class themselves as volunteers. A programme of ongoing training would show respect and commitment to the development of short break carers' skills.

It is finding the time. We have our support group, who want training and they work during the day, so what about in the evenings, so what about weekends, well they have commitments, either someone to stay or they have other plans.
(Scheme co-ordinator)

We are aware that they should have a programme of training but we are restricted by their numbers, time and budget.
(Scheme co-ordinator)

The short break carers were often very busy people as well. Some lived in rural areas away from the training venues so any wish to attend training was restricted by a lack of time and often a lack of transport. Moreover, attendance at ongoing training was usually unpaid, even though attending such training could mean that short break carers had to take time off from other employment.

Some short break carers did not see that a programme of ongoing training would be beneficial because: they had years of experience or a professional background in disability; and/or their experience of the training on offer was not very good; and/or they did not have the time, energy or financial capacity to attend training sessions.

Never done any because I've got the skills already from work.

Not good enough to inspire me to attend on experience so far.

However, it is important to recognise that ongoing training is a form of professional development and any failure to provide such opportunities could be regarded as 'taking carers for granted' and not allowing them to enhance their skills and knowledge.

Certification of training

When asked about the possible certification or accreditation of the skills involved in providing short breaks, the majority of short break carers believed this would be a positive development. Four short break carers said it would 'raise the status' of the care provided and 'help carers do their job'.

The need for certificates was partly related to short break carers' personal confidence and stage in life; providing qualifications was seen as particularly beneficial for young people developing their careers.

Of use to younger people; it shows appreciation and offers achievement.

It was clear that certificates were no substitute for experience or respect, and should not be made compulsory. Short break carers questioned whether a certificate could equate with years of practical experience. Several short break carers noted that they would not have been encouraged by certificates. Some who were broadly in support of providing qualifications were also concerned that a division could develop 'between those with certificates and those without'.

Does a young person with a certificate know more than us with 30 years of experience with children?

In one scheme, National Vocational Qualifications (NVQs) were available but the short break carers were unaware of this fact. In another scheme, a scheme worker noted that a few of the scheme's short break carers were already undertaking qualifications. In the specialist scheme for children with complex health care needs (a scheme where most of the short break carers had worked in the disability field), scheme workers felt they 'owed it to their carers' to investigate and, hopefully, provide NVQs. It was noted that carers who worked in similar ways in nursing homes were offered the opportunity to gain certificates.

Summary

Preparatory training was provided either individually, in groups, or through a mixture of both. The quality of this training varied between the schemes. Preparatory and appropriate individual training was important to ensure that short break carers acquired the skills, attitudes and knowledge required to meet the needs of the children or young people they were linked with. Training also offered opportunities to build supportive links with other short break carers, a clear understanding of what to expect and what is expected, and insights into the circumstances of families with disabled children. Yet one-quarter of the 53 short break carers in this study had not attended such training.

The provision of ongoing training appears to be linked to the ways in which short break carers saw their roles and felt respected by their schemes. Again, there were wide variations between schemes in terms of the content, frequency, quality and format of ongoing training. Some schemes had a programme of regular ongoing training; other schemes responded to specific requests on an 'as and when' basis. Short break carers identified lack of payment and transport to attend training sessions as additional problems.

The certification or accreditation of training in providing short breaks was seen as a positive development, particularly for people developing their careers, but it was also felt that this should not negate the value of experience.

Ideas for action

- Schemes could consider making attendance at preparatory training mandatory so that *all* short break carers attend, including people with (or whose partners have) relevant experience from a current or previous job.
- Schemes could consider developing a programme of ongoing training to: (a) update carers' skills and knowledge; (b) facilitate supportive links between short break carers; (c) show respect for and commitment to their short break carers.
- Schemes could raise the issue of funding short break carers to attend ongoing training sessions with their relevant managers and directors (in recognition of the cost of taking time away from other work, travel and their commitment to providing short breaks, etc.).

Issues for discussion

- Is there a need for a standardised national training programme with accreditation, e.g. linked to NVQs (National Vocational Qualifications)?
- If a system of accreditation was developed, what would need to happen to ensure it was not divisive and/or did not deter people from providing short breaks?
- Should training be a mandatory requirement for all providers of short breaks and shared care services (including befriending, day care, etc.)?

7 Support

This chapter discusses the short break carers' perceptions of the support available to them from their schemes; the families of the disabled children they were linked with; other short break carers; and their friends and families.

Sources and levels of support

- Some short break carers had good relationships with their link worker.
- Some short break carers had close ongoing support from their scheme; others initiated support from their scheme as and when needed.
- Only a quarter of the short break carers knew other short break carers providing short breaks.
- Only a third of the short break carers knew of a support group they could attend.
- Many short break carers had good relationships with the families of the children they were linked with; a few had poor relationships with the children's families.
- Most short break carers had some support from their own family and friends.
- There was very little support for the children of short break carers.

Short break carers' relationships with their schemes

As in the assessment process, the interpersonal skills of scheme workers and link workers were of paramount importance in developing relationships with short break carers. These relationships were made through visits at the start of a link and through telephone contact. One scheme co-ordinator recognised the skilled way in which scheme workers developed close relationships with short break carers, so that they were 'like a little family.'

She's always on the phone getting to know us.

Scheme workers' skills were especially important when they were the only person in the scheme who spoke the appropriate language and they were the short break carers' only scheme contact. In these schemes, all of the short break carers spoke very highly of their link worker, often stating that they 'liked her' or that she was a 'friend'. In fact, short break carers' relationships with scheme workers were described positively in three-quarters of the interviews.

When relationships had been established, there were two main approaches to ongoing support.

The first approach was most evident in the specialist scheme that provided short breaks for children with complex health care needs. This scheme maintained 'close support' which included time with occupational therapists and physiotherapists. One short break carer expressed concern that the high level of support would be threatened if social worker involvement did not keep pace with the growing number of carers.

The second approach was less structured: once link workers were satisfied that a link had been established appropriately, they would determine how often short break carers 'needed' to be contacted. Some short break carers were regularly telephoned every three or six months. In one scheme, however, workers only rang short break carers before their reviews. At reviews or during telephone contacts, link workers would discuss individual support and any training needs. Outside this contact, short break carers were left to 'get on with it'. Schemes explained that this approach was adopted because it allowed them to maximise the number of services provided within the budget available. There was, then, a trade-off between providing a high level of support to short break carers and seeking to increase the number of short breaks provided to children and their families.

We have a philosophy that we don't offer a Rolls Royce service. We are attempting to maximise the service to people and work on the basis that we expect them to raise problems.

The majority of short break carers knew that support was always available if required and link workers were praised for their efficiency in 'sorting out problems'.

One short break carer recalled how her link worker backed her up when she wanted to say no to having a child over Christmas. This kind of support would be more difficult to provide if the scheme worker was also the child's social worker. The situation could then be 'messy' and 'unsatisfactory'. It is worth noting that scheme workers value a clear differentiation between the role of a link worker and that of the child's social worker; whereas parents often prefer contact with one worker only (Newitt *et al.*, 1997).

If anything comes up then you can get the support.

The system of allowing short break carers to 'get on with it' and expecting carers to request support as and when needed was appreciated by the majority of short break carers. A few, however, felt that to admit there was a problem was to invite criticism from their scheme and to arouse concern over their skills and attitudes. One short break carer reflected that carers might not always be open with their link workers about how well a link was going. It was therefore for scheme workers to ensure that a link was working well and to be on alert to potential difficulties through ongoing contact.

Scheme workers ought to drop in every so often. I have only been visited once when I have a child. What I say and what I do could be completely different.

A few short break carers would have preferred more constant support but felt it was unavailable. One short break carer, for a 14-

year-old boy with severe impairments, felt 'left to my own devices' when he would have appreciated telephone contact two or three times a year. Also, he felt he would only be contacted if there were worries, rather than to acknowledge his contribution and encourage him with 'positive feedback that things are going right'.

While most short break carers said they liked their link workers, many were not receiving the support they deserved. The provision of more constant support and time for workers to encourage and motivate short break carers is inhibited by under-resourcing and the understandable emphasis on providing the maximum number of services possible to children and their families. More resources are required to enable schemes to support existing short break carers appropriately, to ensure their commitment is not taken for granted and to encourage them to continue providing short breaks.

Support for children of short break carers

A quarter of the short break carers noted that there was some support for their children who were still living at home and involved in the short break relationships. This support primarily involved the inclusion of their views during the assessment process and 'chats' with the worker if they visited the house. None of the schemes provided a support group which short break carers' children could attend. The short break carers took responsibility for their children's happiness. As one short break carer explained: 'If there was a problem for my children I would either sort it out or stop'.

Support from other professionals

Support from other professionals such as occupational therapists usually depended on the individual needs of the child or young person. These professionals were often involved in training short

break carers. Also, occupational therapists often visited the short break carer's house to advise on health and safety issues. After this, the involvement of other professionals tended to happen on an 'as and when' basis, for example, inclusion in case reviews.

Equipment

Schemes were usually able to provide the smaller, cheaper pieces of equipment such as bath aids and portable ramps, but were often unable to provide larger pieces of equipment. However, in one scheme, the situation was described as 'struggle and wait', as 'no one gets anything'.

We're not in the position to buy anything large. (Scheme co-ordinator)

Lack of equipment has already been identified as one of the reasons carers stop providing short breaks. For example, short break carers often require hoists to enable them to continue providing care as children grow larger. Equipment is therefore a key component of supporting carers to continue providing short breaks for children and families they are linked with.

Support from other short break carers

Levels of support from other short break carers varied widely, when available at all. One-quarter of the carers in this study were supported by other short break carers. This happened most successfully where they already knew each other prior to getting involved in the scheme. In a couple of cases, family members who were also short break carers provided emotional and practical support.

Nearly half of the short break carers said they had no support from other carers. Some did not require support from other short break carers. Others felt they would benefit from knowing other short break carers. Interestingly, one scheme co-ordinator assumed that his short break carers had local support but this was not the case.

It would be useful, but the system doesn't encourage it and there isn't a support network in place.

I don't know any other carers.

The provision of support groups to facilitate the development of relationships between short break carers varied between schemes. Only a third of the short break carers in this study knew of support groups provided by their schemes.

The specialist scheme actively tried to encourage support networks between short break carers but this, as in other rural schemes, was inhibited by the distance between short break carers. A couple of schemes in urban areas had tried to develop groups, but felt this was not an efficient use of social worker time.

If you only get the same three or four carers turning up and you're doing a lot of organisation, it's not the best use of time.

Examples of good support groups included an Asian support group set up by one scheme to build links between short break carers, while another scheme reported successful provision of ongoing training through support groups led by workers from the relevant minority ethnic communities.

Short break carers' relationships with the children's families

Always got on with mums, which helps. With a 'difficult' parent it wouldn't work.

The majority of short break carers described having a 'good' relationship with the parents of the child or children they cared for. Their conversations usually centred on caring for the child, sometimes combined with 'social chit chat' over a coffee. In some cases, the relationship between the short break carers and the family had developed into friendship. One short break carer described her link with one family as an 'extended family', and her relationship with another child's family as 'fine.' Some short break carers had also kept in contact with the families of children, once the link had officially finished.

We are all very close to Fran and Dave. We share the same sense of humour – it's a reciprocal relationship.

In contrast, some short break carers had continued to provide short breaks when their relationship with the child's parents was 'difficult'. Terms such as 'nightmare' and 'ghastly' were used to describe a minority of relationships.

Four short break carers (one-tenth of the carers in this study) had found it necessary to establish a 'professional distance' from the children's parents. One short break carer felt these parents treated them like 'employees' because they assumed they were getting paid more than they actually were.

Experiencing difficult relationships with children's families was one reason cited for stopping to provide short breaks (see Chapter 3). Short break carers recognised that it was very easy to get 'over involved' with families. However, scheme workers would not

necessarily be aware of this unless short break carers reported it (as mentioned above, most scheme workers left carers to get on with providing short breaks and dealing with families, expecting short break carers to contact them if there were problems).

I felt I was so involved and not getting anywhere.

These issues again highlight the need for more regular support from scheme workers. Funding must be made available to enable this to happen.

Support from family and friends

Nearly all of the short break carers said they were supported in some way by their friends and family. A few noted that their friends and family were not involved at all. The level of support varied greatly. Within one scheme, the quality of informal support varied from 'nobody takes an interest' to 'close family help if necessary' to 'it's a family thing'. A few short break carers also took their link children with them to visit friends and family and were proud to say that the children were accepted by all. Short break carers also spoke of informal support from people in the wider community such as shopkeepers and church communities.

It's excellent – they have all taken to them – all our close friends treat Katie and Sophie as part of our family.

Family and friends generally accepted the short break carers' role and allowed them to talk about issues when necessary, although this was restricted by the need to maintain confidentiality. Therefore, the support provided was usually on an emotional rather than practical level. This again pinpoints the need for high quality support from short break schemes.

Summary

The support available from schemes was usually on an 'as and when' basis, whereby short break carers could telephone their scheme for support when needed. Some short break carers said they would have preferred more constant support, including positive feedback. One scheme (a specialist scheme for children with complex health care needs) provided close ongoing support.

Less than half of the short break carers in this study knew other carers. Some of these carers felt they would benefit from knowing other short break carers.

Most of the short break carers received informal support from their own friends and family, and also described good relationships with the families of the children they cared for. Sometimes, these relationships developed into friendships. However, relationships with children's families were not always so positive. This could result in stress for short break carers and a need for more support from elsewhere.

The extent to which schemes were able to meet support needs was constrained by a lack of resources. Some identified that the need to provide better support to existing short break carers and established links had been outweighed by the need to increase the number of short breaks provided and bring down waiting lists.

Ideas for action

- Schemes could consider facilitating support relationships between short break carers through support groups, social events and ongoing training events.
- Where support systems work on an 'as and when carers request help' basis, do all of the short break carers feel comfortable to request support?
- Schemes could consider a system of telephone contact at regular times each year (e.g. every three months), using these calls to give positive feedback as well as to identify training or support needs.

Issue for discussion

- Given the often severe under-resourcing of short break schemes, how far should the importance of increasing the number of short breaks provided outweigh the need to support established links (through support and training for carers, through the purchase of necessary equipment to enable established links to continue, etc.)?

8 Payments

This chapter describes the short break carers' views of payments, particularly focusing on what payments were for and whether they were appropriate.

There was wide variation in the way that the 53 short break carers in this study were paid. Some received a sessional payment to cover their expenses; this might also include a 'reward' for their time and commitment. Others received an 'enhanced' payment for providing short breaks for a child or children regarded as 'hard to place'. Others received a retainer to secure their services so they could provide short breaks for more children. Six carers received a 'fee' for their full-time services and were regarded as self-employed. The levels of sessional payments varied between schemes.

Short break carers' views on payments

- Short break carers do not provide short breaks 'for the money'.
- Payments enable many short break carers to provide short breaks.
- There is a lack of clarity about 'what payments are for'.
- Payments are poor.
- Payments do not always cover costs incurred by carers.
- Poor payments stop some potential short break carers from providing short breaks.
- Poor payments show a lack of respect for the role of short break carers.
- Payments do not affect state benefits – higher payments could stop some short break carers providing short breaks.
- Higher payments show respect for skills and commitment.
- Some schemes have problems with their payment systems.

Two themes dominated the short break carers' discussions: that caring was not done 'for the money'; and that the payments received were inappropriate. These discussions were inhibited by

not wanting to appear 'interested in the money' or that they were providing short breaks for the 'wrong reasons'. Even so, it was clear that payments were an important issue and a potential source of dissatisfaction and disillusionment.

Caring is not an income

Short break carers reiterated the point that short breaks for children who are 'hard to place' are provided by 'caring' and 'committed' individuals who provided short breaks because they wanted to. Payment was not a first priority; the money was often seen as a 'bonus'.

In discussing the importance of payments, short break carers recognised that money was particularly important where short break carers were low paid, were in receipt of state benefits, or had given up paid work to provide large amounts of short breaks.

If somebody is caring for a difficult child, then I think the money actually helps them, but offering more money doesn't make them want to help. (Scheme co-ordinator)

When asked whether higher payments would 'influence the number of short break carers recruited', short break carers felt that more money would attract more short break carers, but they questioned whether these carers would be right for the role. Short break carers did not want the money to 'attract the wrong sort of people'. They thought, however, that the assessment process was stringent enough to ensure that any applicants motivated by money alone would be identified.

In a way it is good that it is not paid very well – that way you get people who want to do it.

The importance of payments

Whilst a third of the short break carers did not want to be seen to be overtly interested in the payment provided, the majority of short break carers felt they should be paid more and that current levels of pay were 'useless'. They could 'earn more in Asda'. They often worked 24 hours a day and were not being paid any more than a child minder.

Payments often did not cover the short break carers' costs, and did not allow for unexpected expenses such as soiling and breakages. These comments are supported by evidence that caring for a disabled child costs three times more than caring for a non-disabled child (Dobson and Middleton, 1998).

Ridiculous money basically. It's the same as Youth Training.

Someone needs to realise they cost a lot to look after.

Short break carers believed that there were potential short break carers who could not afford to provide short breaks because of the low level of payment. Nearly half of the short break carers expected some carers to be lost from schemes with the introduction of the minimum wage, since it is far more than they were paid.

There are caring people out there who cannot afford to do it.

While the payments were regarded as 'poor' and as an obstacle to some potential short break carers providing short breaks, it was also noted that the low level of payments did not affect state benefits.

In one rural scheme, a short break carer felt that this enabled the majority of carers on her scheme to provide short breaks and that higher payments would adversely affect these short break carers

and others in a similar situation who might want to provide short breaks in the future.

A lot of people like me who couldn't afford to do it as it affects my financial position ... It would require a substantial fee to encourage me to move out of the benefit system into a full-time wage and I would need to clear £150 a week.

Payment equals recognition

Many short break carers, including those for whom the actual level of payment was important, felt that the poor level of payment did not recognise the value of the service they were providing, their skills, dedication and depth of their experience. It was, as one short break carer stated, the 'principle' that was important: the skilled care they were providing was 'worthy of more appreciation'.

Also, a short break carer new to providing short breaks would generally be paid the same as an experienced carer; and a short break carer with professional qualifications would be paid the same as an unqualified carer. It was felt that improved payments would show more respect for short break carers' skills.

Doing voluntary work doesn't mean we've got a sign on us which says door mat.

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

One short break carer and scheme co-ordinator also recognised that the low level of payments reflected wider social attitudes about disabled people.

It sends out a message about how we value disabled children.

Enhanced payments

Over half of the short break carers believed that 'enhanced payments' for children regarded as 'hard to place' would reward them for their 'intensive work', the additional responsibility involved and their specialist skills; when a child was with a carer, they devoted 100 per cent of their time to them.

Because the responsibility is a lot more – you worry more – we deserve a little bit more.

It takes particular skills and experiences to look after children with medical needs or challenging behaviour. When she is there at the weekend, it's all her.

Some short break carers felt that enhanced payments could 'encourage' short break carers to continue caring for children who were 'very difficult'.

This theme was, however, balanced by the view that all children were individuals, and they should not be 'compared', 'measured' or 'labelled' so that enhanced payments could be provided. Some felt that the general payment should be improved, rather than setting up a hierarchy of payments based on the children's behaviour or impairments.

Children are difficult in different ways, we all work hard in different ways, they all require the same amount of commitment. Should just pay a decent rate all round.

Financial constraints on schemes

Three of the scheme co-ordinators specifically recognised the poor level of payments. One worker acknowledged that everyone who

works as a 'care professional is poorly paid' but that other care professionals such as social workers did not work 'for nothing'.

Highlighting the financial constraints within which schemes worked, these scheme co-ordinators said they would like to pay their short break carers more but their budgets would not allow them to do so.

We feel a bit embarrassed when we quote the sessional rate.

Lack of clarity

In six of the seven schemes, there was a lack of clarity regarding what payments were actually for and about claiming additional expenses. In the seventh scheme, short break carers were paid fees and encountered issues regarding their tax position. Three carers were seeking advice from their scheme regarding this.

We're self-employed and payment is a bit of a grey area. We get a boarding-out allowance and fee which is taxable. There's confusion about the tax allowance.

Some short break carers believed their payment was 'part costs, part rewards'. Others assumed their payment covered expenses only.

No explanation was given. I assume it covers everything including the expenses for the child during their stay.

Confusion could also occur regarding the different payment rates for different short break activities. Day care, sitting and overnight care could all be paid at different rates for the same child. On the schemes which paid an enhanced rate for providing short breaks for certain children, short break carers may provide short breaks on a higher rate for some children and at a lower rate for others. (See

Prewett, 1999 for more information about the variation in payments.)

There was also variation between schemes in the short break carers' understanding about additional expenses. In some schemes, short break carers knew they could claim travel or activity expenses in addition to their payment; in others, they were not clear.

No one ever discussed travelling expenses. We have never asked.

This lack of clarity was compounded by short break carers not wanting to ask about financial issues as they did not want to be seen to be 'doing it for the money'. It is important that schemes openly discuss payments in the recruitment and preparation process (National Foster Care Association, 1999). Only half of the short break carers recalled that payments had actually been discussed during their preparatory training.

Problems with the payment system

Nearly a quarter of carers reported problems with inefficient payment systems. This could result in short break carers having a poor relationship with their scheme. One short break carer reported not claiming for breakages as the payment system took too long.

Summary

Two themes dominated the short break carers' discussions regarding payments. The first was that people did not provide short breaks for the money. The second theme, however, recognised the importance of payments to a large number of short break carers,

particularly those in receipt of benefits and carers who had given up paid work to commit themselves to providing short breaks in their own homes.

The level of payments was described as poor and inappropriate given the skills, commitment and experience of short break carers. It was suggested that some people could not afford to provide short breaks because of the low payments. On the other hand, low payments benefited some short break carers who were able to provide short breaks and earn some extra income without affecting their benefits.

Ideas for action

Schemes need to ensure that:

- payments are discussed during recruitment and preparation
- short break carers are clear about what payments are for and what additional expenses can be claimed (e.g. for travel, entertainment, breakages, etc.)
- short break carers feel comfortable about discussing financial issues
- payment systems are efficient.

Issues for discussion

- Is it better for children using services that the standard level of payment is raised, rather than introducing a system of enhanced payments that involves labelling individual children as 'hard to place'?
- It seems that low payments may exclude people on low incomes from providing short breaks, but enable people who receive state benefits to be short break carers: is there any way round this?
- Is it acceptable that people providing a skilled and essential service are poorly recompensed for their contribution and commitment?
- If schemes had more resources, would higher payments be a priority?

9 Professional volunteers?

This chapter describes the different ways in which the role of being a short break carer is seen by carers and by scheme co-ordinators. Throughout the discussions, the skills and commitment of short break carers were highlighted, often irrespective of the actual words used to describe the role.

Words used to describe the role of a short break carer

- Volunteer
- Professional
- Semi-professional
- Just part of my life
- Substitute job
- Partnership with parents
- Service provider
- Trusted colleague
- Valuable resource
- Part of a team
- Support network
- Cheap labour
- A friend

Short break carers' views of their role

Recognition of their own skills and commitment permeated all the discussions with short break carers, irrespective of how they described their role. This relates to the reasons why short break carers started to provide short breaks: they recognised the need for short breaks for disabled children and their families, and they also recognised that they had the skills and dedication to provide this support.

There was wide variation in the way short break carers saw their role. A range of words and phrases were used to describe the role and status of short break carers. For example, in two interviews,

short break carers saw providing short breaks as their 'job' (indicative of the skills required to undertake the role) – it was 'a job with great satisfaction except a lack of pay'. Other short break carers reiterated the centrality of their relationship with the child, and saw their role as being a 'buddy or friend'. The most frequent words used were 'professional' (14 interviews), 'volunteer' (eight interviews) and 'semi-professional' (seven interviews).

Short break carers who described themselves as professional or semi-professional had all received training from their schemes. Short break carers with previous experience of work in the disability field and who had been targeted to provide short breaks on a more regular and formal basis were also likely to see their role as professional. They did not classify themselves as volunteers.

Short break carers who saw themselves as professionals

Short break carers in 14 interviews described their role as 'professional'. One short break carer who had cared for over 80 children stressed that the word 'professional' reflected the fact that she had more than 15 years of experience in providing short breaks. Another stated that providing short breaks was her 'occupation'. One couple providing large numbers of short breaks said they were professionals because they were trying to offer a good service, and providing this service was their main source of income. Others felt that the demanding nature of the role put it on a par with that of other professionals.

It's a very, very responsible job, looking after someone else's child in our own house.

He alters our lifestyle like a job.

One short break carer reflected on the way in which a professional role can move into a friendship role as close relationships develop between short break carers, the children and their families. There is a question here, though, about whether the development of a caring relationship means that the role of a short break carer ceases to be considered 'professional' (this links with wider social attitudes towards caring as a predominantly female role which affords little respect).

More of a professional role when started but then I got attached to the families, so it is more of a friend thing, they are more like relatives.

Short break carers who saw the role as semi-professional

Some short break carers felt that the role they held was partly professional and partly voluntary. They were 'in between' or 'semi-professional'. These short break carers were all confident in the skills they held, but identified factors that they felt made the role more voluntary, including the fact that they were offering love, and that they provided short breaks in their own home.

For some, the low level of payments prevented them from calling themselves full professionals: they were not paid as professionals but as volunteers.

Semi-professional – not anyone can do it, you need specialist qualities, but also a volunteer because we are only paid minimal expenses.

Short break carers who saw themselves as volunteers

In eight interviews, short break carers viewed themselves as volunteers, whilst recognising the skills and characteristics they brought to the role. They were 'wise and confident'.

Again, the low level of recompense was identified by one of the short break carers as a reason why short break carers are volunteers rather than professionals: although a trained nursery nurse, she saw herself as a volunteer because she was paid as such.

I use my NNEB skills in my work. I am a volunteer because it doesn't pay well.

These eight carers included short break carers from schemes that were less likely to provide ongoing training and/or short break carers who did not have an in-depth professional knowledge of disability (they had started to provide short breaks through knowing friends or family with a disabled child, or through driving school taxis).

Short break carers' views of how their scheme sees them

Short break carers noted that different workers on their scheme would have different views of the role of short break carers: one short break carer believed that some workers were aware of her skills and capabilities, whereas others were not. Even so, several short break carers felt that schemes did not share their own perceptions of the role. They used the following words to describe how they felt their schemes viewed their role:

- professional
- semi-professional
- carers
- volunteers
- trusted colleagues
- valuable resource
- part of a team
- cheap labour
- host parents.

In eight interviews, short break carers did not know how their role would be seen by their scheme. This lack of awareness seemed to result from infrequent contact with their scheme: 'don't know as only contacted once a year on the telephone before the review'.

In seven interviews, short break carers felt they would be regarded as professionals, mainly because they were providing a skilled service. One believed she would be seen as a professional because of her 'professional qualifications'. Another felt that the role acquired professional status through the scheme's reviews and formal procedures: 'formal procedures – they give it status'.

In four interviews, short break carers felt they would be seen as 'in between professional and volunteer'. Again, since the role of a short break carer was 'centred on family life', they felt that only certain elements of the role would be regarded as 'professional', such as involvement with the scheme and other agencies, and attending training.

Not professionals, because we provide care.

In four interviews, short break carers felt their schemes saw them as 'carers'. Interestingly, three of these short break carers had described themselves as professionals. One couple said they were seen as 'star carers' because of the length of time they had provided short breaks and their involvement in many other aspects of their scheme.

Three short break carers felt that they would be seen as 'volunteers' or 'host parents'; they did not seem to feel that their skills were especially valued by their schemes.

The way in which the remainder of the short break carers believed their role would be seen illustrated the value they felt their schemes placed on them: they were colleagues making a valued contribution. These short break carers felt 'part of a team' or 'support network', even if their role was regarded as being at 'a low level'.

Trusted colleagues who were a valuable resource.

They put us on a pedestal, they respect us and appreciate what we do and this helps and motivates us.

Unfortunately, one short break carer felt their scheme workers had a 'paternalistic attitude' and did not properly value them. Another felt they were seen as 'cheap labour'. Lack of respect was raised in two interviews.

What we do is easily undermined, it's not classed as anything. It needs to be brought up to a level and classed as something with a little more status. We deal with social workers a lot and we are very valuable. The parents do look to us for guidance.

Schemes' views of the short break carers' role

The way in which scheme co-ordinators viewed the role of the short break carer echoed the themes discussed by the short break carers. However, while the same concepts were evident, the views held by scheme co-ordinators did not always tally with terms used by the short break carers from their own schemes.

In three of the seven schemes, scheme co-ordinators described short break carers as 'volunteers'. In one scheme, the scheme co-ordinator actively promoted this view as a strategy to protect short break carers from excessive demands from parents.

Other scheme co-ordinators recognised that times are changing and that the role is becoming more of a job. These co-ordinators highlighted the training, skills and interaction with agencies and social services that are involved in providing short breaks for children regarded as 'hard to place'. These short break carers could no longer be classed as volunteers even though they are paid as volunteers. One scheme co-ordinator described them as 'service providers'.

We will pay you as a volunteer but treat you as a professional, as a colleague.

I think they always have been volunteers, but I have been looking at the sort of children that are now being referred, it is a job. It is not what it used to be.

Two schemes funded by the same voluntary organisation saw short break carers in the context of foster caring and the Children Act (1989). One co-ordinator viewed carers as 'host families' for short-term foster care; she was 'veering strongly away' from classing the scheme's carers as volunteers, but also felt that the term 'fostering' was not right either.

Definitely not volunteers. They are nearer to foster carers but we don't want to use the term fostering.

Summary

The terms used to describe the status of the short break carers' role varied dramatically. There was a continuum from 'volunteer' to 'professional'. Short break carers with more access to training and involvement in their scheme were more likely to regard themselves as professionals or semi-professionals, as did short break carers who (previously or currently) worked in the disability field.

As one scheme co-ordinator put it, the word 'professional' is a 'loaded term' that commonly relates to skills as well as payments. Overall, short break carers and scheme co-ordinators recognised that they undertook their role in a skilled and dedicated manner that could be described as 'professional'. However, the financial recompense associated with the term 'professional' was unavailable.

Ideas for action

- Short break schemes need to clarify the role and status of short break carers on their scheme.
- Schemes need to consider how to ensure that short break carers feel appreciated and valued (e.g. through regular contact and feedback, ongoing training, payments, clear procedures, supporting links with other agencies, etc.).

Issues for discussion

- Should the role of a short break carer be promoted as a 'professional' role, in similar ways to the professionalisation of fostering?
- Is it acceptable for short break carers to be paid as volunteers even though they provide a vital service that demands skills, knowledge and commitment?

10 Summary and discussion

- Who becomes a short break carer for children regarded as 'hard to place', and why?
- How are short break carers recruited and assessed?
- What training and support is provided, or could be provided?
- How do short break carers view their role and the service they provide?

This report has set out the findings from 41 interviews with 53 carers currently providing short breaks, and from interviews with co-ordinators and workers from seven schemes in England and Wales (in cities, towns and rural areas).

The urgent need for this research and the key issues relating to the importance of short break services for families with disabled children, the large numbers of children and young people who are waiting for these services, and the difficulties of recruiting short break carers to provide breaks for children regarded as 'hard to place' were set out earlier in this report. The relevance of this issue to current government policies like the Quality Protects Programme and the national recruitment campaign for foster carers was also highlighted.

In this chapter, three tasks remain: first, to summarise the main findings from the previous chapters; second, to pull out some of the overarching themes to emerge from the research; and, third, to highlight key issues for specific individuals and organisations who are well-placed to bring about change in local authorities, relevant voluntary organisations and local schemes.

Summary

The key research findings are summarised below. (Summaries, ideas for action and issues for discussion can be found at the end of each chapter.)

Why do people become short break carers?

Most of the short break carers in this study either knew (or were related to) a child or family who needed short breaks, or were aware of the urgent need for short breaks for families with disabled children. Most had some personal or professional experience of disability. Some had no experience of disability and had heard about short breaks through advertisements or leaflets.

Other reasons for wanting to provide short breaks included: using or developing one's knowledge and skills in ways that directly support families with disabled children; helping families and contributing to the wider community; and taking advantage of the opportunities to work from home and generate extra income.

The biggest reasons for continuing to provide short breaks related to the loving relationships that developed between short break carers and children, the pleasure and satisfaction from being with children, and the knowledge of how crucial their support was for the families involved.

What qualities make a good short break carer?

Short break carers identified a range of personal qualities and characteristics that they felt were important in taking on the responsibilities involved. These included being caring, loving, patient, understanding, hard-working, motivated, able to work alone

and totally committed. Some felt that previous professional or personal experience of disability was especially important when supporting children with complex health care needs, or 'challenging behaviour'. Some felt that previous experience was not necessary, and that anyone could take on the role with the right attitudes, training and support.

Providing overnight short breaks was generally seen as a role for women or for male/female couples. Many short break carers and scheme workers found it difficult to see why single men or same-sex couples (especially male/male couples) would want to provide such breaks, or they felt that suitable men would be put off from offering support by their vulnerability to child protection issues and the traditional image of caring as a female role.

Why do some short break links end 'prematurely'?

From the standpoint of those interviewed (including the views of 13 former carers who responded to the questionnaire), the main reason for stopping to provide short breaks is a change in personal circumstances on the part of the short break carer, the child or their family. Aside from this, and the fact that some new short break carers will find that the role is not right for them, there are other reasons why links end prematurely – reasons that could be addressed if schemes were better resourced to support short break carers. In particular a:

- lack of resources to provide aids or adaptations (like hoists or stair lifts) so that a short break carer is forced to stop providing short breaks to a child or young person for health and safety reasons
- lack of financial support from the scheme, especially if the costs of providing support to a child or young person are high

- lack of emotional support from the scheme, especially if there are difficult relationships with a child's parents or family.

How are short break carers recruited?

As in previous studies, most short break carers found their way into providing short breaks through 'word of mouth' (Beckford and Robinson, 1992; Prewett, 1999). The evidence from this research shows that recruitment campaigns can also be successful but it is often difficult to work out why campaigns succeed or fail.

What could help in recruiting more carers?

Previous research found that newspaper adverts prompt the most enquiries about providing short breaks (Beckford and Robinson, 1992; Prewett, 1999). However, as mentioned above, it can be hard to identify what works and why in advertisements or other recruitment methods. General points include:

- a need to raise awareness of short breaks (what they are and why they are so important) among the wider community and at a national level
- a need to tailor specific approaches to specific people, for example, people from minority ethnic communities; people working or interested in disability-related professions; men and young people who could get involved in befriending
- a need for diversity in scheme workers as an end in itself, as well as a means to promoting greater diversity among short break carers

- the importance of providing resources and training (e.g. race equality training) for scheme workers to undertake recruitment and have the time to follow up enquiries and make potential carers feel welcome.

What do short break carers think of the assessment process?

The assessment process was described as rigorous and intrusive, but most felt that this was necessarily so for child protection reasons. A hierarchy of assessment was noted in relation to gender and sexuality, with more stringent checks carried out with respect to single men (linked to concerns about child protection and suspicions about why men would want to take on what has traditionally been seen as a female role).

The process was widely regarded as 'too long'. Some had also felt 'in the dark' about what was going on. Here, the communication and interpersonal skills of the relevant social worker were crucial in reassuring applicants and keeping them involved.

The short break carers had not attended panel when their application was considered. Those who attended panel when their registration was reviewed described the process as daunting. In one case, the process was conducted in a manner that was culturally inappropriate, albeit unintentionally. Many of those interviewed were not invited to attend the panel meeting.

What do short break carers think of the preparatory training provided?

Even though preparatory training is a mandatory requirement, not all those interviewed had attended. Some were 'exempted' by their schemes or by themselves on the basis of their own, or their

partner's, professional background. Some schemes felt unable to make attendance a precondition of registration since short break carers are 'volunteers'.

Preparatory training was valued as a way of providing insights into the role of the short break carer, a chance to develop appropriate attitudes and an opportunity to meet other short break carers. The quality of preparatory training varied between schemes.

What do short break carers think of the ongoing training provided?

There was variation between the schemes in the frequency and quality of ongoing training. One scheme did not provide any ongoing training. All schemes identified lack of staff time and resources as barriers in providing high quality training programmes. Additional resources were needed to enable short break carers to attend training sessions (transport costs, payment for attendance).

Accreditation of training was felt to be a positive step, especially for those interested in gaining experience relevant to a future career. Certificates could not, however, act as a substitute for respect.

Do short break carers feel supported by their schemes?

One scheme was praised for providing 'good close support'. Other schemes elected to provide support as and when needed (again, reflecting dilemmas faced by under-resourced schemes between providing stronger support to fewer links, or providing less support to more links). Support from other professionals was also provided as and when required.

Short break carers also noted that little support was provided for their children; and that schemes were often unable to provide large pieces of equipment that would enable short break carers to continue providing short breaks as children grow.

Do short break carers access peer support?

Most of the short break carers interviewed did not know any other short break carers or have access to scheme-related support groups for short break carers. There are different views as to the importance of peer support over other support. Again, where support groups are offered, it is important that there are available resources to enable people to attend.

Do short break carers feel supported by the children's families?

Generally, the short break carers interviewed had a good relationship with the children's families. Sometimes, difficult relationships with parents could undermine the link relationship, leading to the breakdown of the short break link, or the continuation of the link but at personal cost to those involved.

Do short break carers feel supported by their own families and friends?

Most short break carers had some support from family or friends. Again, the levels of support varied. Issues of confidentiality also restricted levels of support.

What do short break carers think of the payments they receive?

Short break carers do not provide short breaks 'for the money'. However, payments can make a huge difference in enabling people to provide short break services. Payments were particularly important to short break carers who had chosen to provide short breaks as a means of generating extra income.

Short break carers described the payments as poor and felt that the low level of payments could stop some potential carers from providing short breaks, especially if they were on low incomes. Put simply, some people would not be able to afford to be short break carers. For others, the low level of payments provided a chance to generate income without affecting state benefits.

Generally, short break carers wanted increased payments: to demonstrate respect for their skills and commitment, and to ensure that all expenses incurred in providing short breaks were covered. There was some concern about the implications of 'enhanced' payment systems where these involved labelling children and young people.

Additional problems were lack of clarity about what payments were for and what additional expenses could be claimed; uncertainty about taxation where short break carers were self-employed; and the inefficiency of some schemes in processing claims and making payments.

What are the role and status of short break carers?

A lack of clarity about the role and status of short break carers was noted by both short break carers and scheme co-ordinators.

Short break carers variously described their role as: community-conscious volunteer, service provider, professional, semi-professional, valuable resource, a job, a friend.

Scheme co-ordinators seemed to respect the skills and commitment of short break carers, whilst appreciating that these were not demonstrated by the payments. It was noted that the nature of providing short breaks was changing so that more skills (e.g. providing total nursing care, managing difficult behaviour, learning to communicate differently) were now required. As one scheme co-ordinator explained: 'We will pay you as a volunteer, but treat you as a professional, as a colleague'.

Other issues arising from the research

The following points emerged through analysis of the research findings and discussions among the research partners and in the Project Advisory Group.

Clarifying the role and status of short break carers

There appears to be a lack of clarity and standardisation on a number of issues of fundamental importance to short breaks, particularly on the role and status of short break carers. How are short break carers and the services they provide perceived and recognised? Do they feel valued and respected within social services departments or voluntary organisations, by their own schemes and by the wider community? How are their skills, experience and commitment recognised?

As set out in Chapter 9 ('Professional volunteers?'), short break carers and scheme co-ordinators differed widely in their views of the role and status of short break carers. Descriptions of the role ranged from being a friend of the family to taking on a role requiring

the skill and commitment that would be expected of any professional in the field. Whereabouts short break carers and coordinators placed 'short break carers' along a continuum of 'professional–semi-professional–volunteer' reflected views about the following.

- **Payments:** the low levels of payment were felt to be at odds with the label 'professional', even though everyone involved recognised that short break carers were trained, skilled and committed people providing a critical service to families in the community, and working with children and young people with complex support needs.
- Caring as a traditionally female role carried out within the home was often afforded low respect and little remuneration (this view also fed into suspicions about single men as providers of home-based, overnight short breaks, alongside concerns about child protection).
- **Experience, training and support:** short break carers with previous professional experience in disability were more likely to view themselves as professionals. Significantly, those least likely to regard themselves as 'professionals' or as volunteers providing a skilled and 'professional' service were those who received less training and/or had limited involvement in formal scheme activities.
- **The word 'professional':** for some, the word does not convey the love, enjoyment and altruistic motivations linked to providing short breaks; for others, the word is primarily associated with levels of payment; for many, the word conveys the skills and expertise required to provide short breaks, and is a label that affords respect and recognition.

The lack of clarity about the role and status of short break carers reflects variations in the ways short breaks are valued within social services or voluntary organisations, and the way that short break carers are recruited, trained, supported and paid. There is a need for Shared Care Network and others to look closely at these issues and clarify their position regarding the status of short break carers, expectations and recompense, and consider the relevance to this group of short break carers of calls by the National Foster Care Association (Warren, 1997) for the 'professionalisation' of foster care.

Promoting diversity within schemes

Schemes may be missing out on untapped potential where they rely too heavily on 'word of mouth' in recruiting new short break carers. 'Word of mouth' is effective, but tends to result in recruitment of short break carers similar to those already involved (e.g. white couples with families are more likely to recruit other white couples with families).

Lack of staff time and resources means that outreach-based or 'tailored' recruitment drives (e.g. targeting specific groups) might be beyond the reach of many schemes. Even so, it might prove worthwhile for schemes to prioritise more targeted recruitment campaigns, especially where the target groups are likely to have (or are keen to acquire) relevant professional experience in working with disabled children or young people.

There may also be a need to rethink the image of short break schemes as 'family based' or 'family links' to ensure that potential providers of the range of short break services (home-based, overnight, befriending, sitting services, etc.) are not put off from expressing an interest.

Finally, working towards greater diversity among scheme workers

(particularly in relation to employing scheme workers from minority ethnic communities) may also help encourage diversity within schemes and raise awareness of the services among different local communities.

A severely under-resourced service

As is often the case with services to families with disabled children, the extent of under-resourcing is high, with significant implications for local schemes and local families. Short break carers and co-ordinators involved in this research highlighted several areas in which more resources would make a very real difference to the number and quality of services provided.

More staff, time and funding would enable:

- more effective and proactive recruitment campaigns, with adequate follow-up, to address the severe shortage of short break carers
- better quality programmes of preparatory and ongoing training, to maximise the skills and knowledge of short break carers
- more services to more families with children regarded as 'hard to place'
- more support to short break carers so that established links continue rather than end 'prematurely' owing to a lack of support from scheme link workers
- better recognition of the skills and commitment of short break carers, and the importance of the services they provide (e.g. through increased payments, accreditation, training and support)

- purchase of crucial aids and equipment that make all the difference between a 'link' being able to continue, or having to end prematurely; the premature ending of a link can mean that families receive no break at all, or that children are placed inappropriately in residential centres, hospices, or hospitals while their families have a break (this goes against current policy and legislation).

A vital and positive service

The Government's Quality Protects Programme and recent reports from the Social Services Inspectorate have confirmed that short break services are:

Almost universally regarded by parents as a critical service in supporting families within the community. (Department of Health Social Services Inspectorate, 1998a, Section 4.21)

Previous research has shown that short breaks can make a vital difference in enabling families to stay together, and in enabling access to new activities, environments and relationships for children who use these services (Prewett, 1999). This research has sought out the perspectives of those who provide short break services. The short break carers involved in this study highlighted the enjoyment, pleasure and satisfaction they gain from providing short breaks and from developing loving and positive relationships with children or young people regarded as 'hard to place'.

Areas for action and discussion

Ideas for action and ideas for discussion for short break schemes have been set out throughout the report at the end of each chapter. In addition, the research has highlighted several issues that local

schemes are not in a position to take forward alone. The commitment and action of elected members (given their key role in Quality Protects), of directors and managers in local authorities and voluntary organisations will be crucial. There are also issues that short break schemes and their national organisations will need to consider more closely.

Issues for elected members

- *Quality Protects* recognises that short break services are an essential support service for disabled children and their families, and can make a critical difference in enabling families to stay together. There is an urgent need to ensure these children and families do not fall off local agendas when allocating Quality Protects money and developing priorities for action.
- There are long *waiting lists* for these services, with many children waiting for over a year. Evidence from 152 schemes in 1998 suggests that 3,736 children and young people most in need of these services are still waiting for them. This figure is likely to be a gross underestimate of unmet need, especially in relation to disabled children from *minority ethnic families*. Many of these children and young people have complex support needs, severe and multiple disabilities, and behaviour regarded as challenging.
- More *resources* are required to cut the waiting lists by recruiting new short break carers to provide these services, and to support short break carers to continue providing services. This means resources for recruitment, training, support, payments, aids and equipment.

Issues for directors and managers in local authorities and voluntary organisations

- Continue to promote the vital support services provided by short break schemes and carers with elected members and colleagues in local authorities and voluntary organisations, so that short break services do not fall off the agenda when allocating funds or deciding priorities.
- Ensure that schemes are better resourced to enable recruitment of new short break carers and outreach into communities under-represented on local schemes.
- Ensure that schemes are better resourced to support short break carers, through staff support, ongoing training and appropriate payments.

- Enable the continuation of short break links where the provision of crucial aids and equipment can make or break an established link.

Ideas for short break schemes and their national organisations

- Clarify the role and status of short break carers, and the ways in which they are paid and rewarded for the services they provide.
- Discuss the appropriateness of the terms 'family link' or 'family based', given the interest in recruiting a wider range of short break carers (e.g. single people, young people) to provide a wider range of short break services.
- Produce standardised high quality recruitment materials and provide training to local schemes on effective recruitment and promotion activities.
- Explore opportunities to develop a standardised national training programme for ongoing training with accreditation (e.g. linked to GNVQs).
- Continue to work with managers and directors of social services so they are aware of the vital support service provided by short break carers, and its relevance to the objectives of Quality Protects.
- Continue to raise the national profile of short break services, making links with other recruitment drives to promote foster care and community volunteering.

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