Committed to caring Family-based short-break carers’ views of their role

Short-break carers are short-term foster carers who provide regular care, often one weekend a month, for disabled children. Beth Tarleton reports on a study of 53 short-break carers offering short breaks for children with high support needs. The research found that short-break carers provided short breaks because they enjoyed it and developed real relationships with the children, but that the way in which they were recruited, assessed, trained, paid and supported was often influenced by a lack of staff time and resources, and a lack of clarity regarding their role.

Introduction

Family-based short-break carers were one of the groups of foster carers included in the national recruitment campaign undertaken in England, Wales and Northern Ireland in 2000. They are foster carers under the Children Act (1989), subject to family placement regulations when providing overnight care, and the National Code of Practice and National Standards for Foster Care. However, they play a significantly different role compared with that of full-time foster carers in that they provide a series of short episodes of care, previously known as respite. Family-based short-break schemes link disabled children with individuals, couples or families who can care for them for short periods on a regular basis. (The arrangement is often called a link.) The amount of care provided can vary from a few hours a week to several days each month. The traditional model is one weekend’s care a month. A small number of schemes offer more regular shared care, perhaps a few days a week for children with complex or more demanding needs. These schemes sometimes use retained or salaried carers. Many schemes also offer sitting and befriending services.

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 a 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 home all the time. (Young person with learning difficulties 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 with learning difficulties in Prewett, 1999, p 14)

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)

Family-based short-break services are provided for approximately 10,000 children and young people in the UK (Department of Health 1998a). There are also services providing short breaks for disabled adults. Short-break services provide a break for all the members of the family and can make it easier for them to stay together as a family. The importance of short breaks as a source of support to parents is well documented (Baldwin and Carlisle, 1994; Beresford, 1994). The essential family support provided by short-break services was recognised in two Social Services Inspectorate reports: Removing Barriers for Disabled Children...
(Department of Health, 1998b) and Disabled Children: Directions for their future (Department of Health, 1998a). The Department of Health’s Quality Protects programme also specifically promotes the increased provision of short-break services to disabled children and their families.

There are approximately 400 family-based short-break schemes in the UK. The majority of these are part of a nationwide network of services co-ordinated by Shared Care Network. However, they are often not recognised as part of the national network because they use a variety of titles including Family Link, Families Together, Home from Home Schemes and Shared Care.

Virtually all short-break schemes provide services for children with learning difficulties, while 85 per cent of children’s schemes cater for users with physical impairments and half also provide services for children whose behaviour is perceived as challenging. Increasingly services are providing short breaks for children with HIV and AIDS (NFCA, 1997); a quarter of the children’s schemes included this group in 1998 (Prewett, 1999). Short breaks are also being used to support children in need, who do not have disabilities, to maintain them in their own families (Bradley and Aldgate, 1994; Berridge, 1997).

The 1998 survey of family-based short-break schemes (Prewett, 1999) showed that the number of short breaks provided for disabled children had increased by eight per cent over the preceding six years, but even so nearly 90 per cent of children’s services had a waiting list. In the 152 schemes involved in the 1998 survey, 7,521 children were receiving services while 3,736 children were waiting for them. Thus the numbers on these waiting lists were equal to half the number of children actually receiving services. These figures do not include children waiting for services from schemes that did not participate in the national survey; nor did they include children who do not even get onto a scheme’s waiting list. Children and young people are frequently 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 significant underestimate of current levels of unmet need.

The 1998 survey confirmed previous research (Stalker and Robinson, 1991; Beckford and Robinson, 1993) indicating that some of the key reasons that children and young people were waiting for services was a lack of suitable carers, particularly for children and young people with:

- behaviour that was regarded as challenging;
- severe physical impairments;
- complex health needs.

The number of children with complex healthcare needs who require short breaks 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.

Until recently, it was believed that these children could not be cared for by short-break carers in their own homes. However, care management protocols have been developed to ensure children’s needs are met and that carers are trained and protected (Servian et al, 1998; Rhodes et al, 1999). This means that carers confident enough to undertake invasive procedures are in very great demand.

Children with complex healthcare needs, as well as children and young people with severe physical impairments, often cannot be provided with services. This is because of their need for specialist equipment, adaptations to houses to accommodate their equipment, two carers to lift/move them or carers with the confidence to administer invasive procedures.

The research reported in this paper...
responded to the urgent need for short-break carers for children for whom it is difficult to find placements. It aimed to find out why short-break carers provided short breaks for children with high support needs in order that more such carers can be recruited and appropriately supported.

The research investigated the recruitment, motivation and support of 53 short-break carers who were providing short breaks for 93 children and young people with severe or multiple impairments, and/or complex healthcare needs, and/or behaviour that is regarded as challenging (for further details see Prewett, 2000). The children’s and young people’s specific impairments included cerebral palsy, autistic spectrum disorders and epilepsy. Many of the children and young people used ways other than speech to communicate such as sign language, the use of pictures and symbols or eye contact.

**Research design**

Seven schemes in England and Wales which had experienced particular success or difficulty in recruiting short-break carers for children for whom it was hard to find placements were selected as case studies. Three were in metropolitan areas, two were in towns and two were in rural areas. Semi-structured interviews were carried out with the scheme co-ordinators and 53 short-break carers took part in 41 interviews (in 12 interviews, both partners in a couple were present). The short-break carers included:

- 12 couples with children who had left home;
- eight couples with children still living at home;
- seven single women with children still living at home;
- six single women with no children;
- three single men with no children;
- 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.

In ten interviews, the short-break carers were from minority ethnic communities. The short-break carers were ‘paid’ in various ways including expenses with a reward element, enhanced sessional rates, retainer or fees.

The interviews with the short-break carers and scheme co-ordinators investigated:

- Why do short-break carers provide breaks for children with high support needs?
- Why do short-break carers continue to provide short breaks?
- What qualities should good short-break carers have?
- How are short-break carers recruited?
- What did short-break carers think of the assessment process?
- What do short-break carers think of their training?
- What do short-break carers think of the ‘payments’ they receive?
- How do short-break carers see their role?
- Do short-break carers feel supported by their schemes?
- Why do some short-break links end?

Thirteen confidential questionnaires were also returned by former short-break carers. These questionnaires also covered why they had actually stopped providing short breaks. Their responses confirmed the main themes emerging from the interviews with current short-break carers.

**Why do people become short-break carers?**

In common with the foster carers in Gorin’s (1997) study and the Performance Review and Research Unit (1995), all but four of the short-break carers in this study had some personal or professional experience of disability and felt they could help others. They either knew or were related to a family who needed short breaks:

*I know the child, enjoyed being with him and I wanted to be more involved with people with special needs.* (Female carer)
I was looking after my nephew to give my sister a break. I was informed by teachers to do family link. (Female carer)

In some cases, the carers were workers (such as special school assistants or teachers) who had been specifically asked to provide short breaks for a child they knew.

Other short-break carers’ professional experience had allowed them to recognise that families were in need of short breaks:

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 it 24 hours a day. It’s nice having the children come. I’ll do it until I can’t do it anymore. (Female carer)

Importantly, however, four of the short-break carers had no experience of disability and had heard about short breaks through advertisements or leaflets. This finding highlighted the need for effective recruitment campaigns.

Providing short breaks was also a chance to ‘give something back’, to help others and a way to express religious commitment. This was raised specifically by three short-break carers from Asian (Muslim) communities.

Why continue to provide short breaks?
Again in accordance with Gorin’s (1997) findings, all of the short-break carers were motivated to continue providing short breaks because they enjoyed spending time with the children. They developed real, positive relationships with the children and often said they ‘loved’ them:

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. (Male carer)

The more you do, the more rewarding it gets. (Female carer)

They received ‘pleasure’ and ‘satisfaction’ from being with children and often felt they were doing good by providing much needed support for families with a disabled child:

[It] gives great pleasure and satisfaction helping the parents. (Female carer)

The short-break carers also developed a positive relationship with the disabled child’s family, a relationship that occasionally turned into real friendship. However, the relationship with the child was always of paramount importance.

Four of the short-break carers continued to provide short breaks even though there were difficulties with their relationship with the child’s family. They continued because they would have felt guilty if they stopped:

The only reason I carry on is because the family is desperate. (Female carer)

This finding points to the lack of alternative support for families with a disabled child and to the importance of the link workers’ role in ensuring that short-break carers are happy with their link relationship. Link workers are the social workers responsible for supporting short-break carers. The short-break carers’ views of their relationship with their link worker is discussed below.

What qualities should good short-break carers have?
The 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.

They felt that 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. (Female carer)

Six of the short-break carers also emphasised that providing short breaks for children and young people with high support needs was a very rewarding challenge which most people would not generally think of undertaking. The 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 have had no experience’. It would be hard to do it without any experience. (Female carer)

This experience could, however, be provided for applicants with the right attitudes by the short-break scheme. Four of the carers in this study had begun providing short breaks for children with little prior experience. As noted above, they had found out about short breaks through leaflets or advertising. These carers had been provided with initial experience by their schemes. One scheme enabled applicants to help at a residential short-break (respite) centre and another at a Saturday club before they began providing short breaks.

Providing overnight short breaks was generally seen as a role for women or for male/female couples. Most of the carers and four scheme workers found it difficult to see why single men or male same-sex couples would want to provide such breaks. Men were usually regarded as supporters to their female partners. In the words of one female short-break carer, ‘It’s not a male thing to do.’

Confirming the conjectures of Smith (1988) and Newstone (2000), one scheme co-ordinator summarised that caring is still traditionally a low-paid occupation for women which is equated with mothering and not undertaken for the money. When the short-break carers acknowledged men’s ability to provide short breaks they also recognised that male carers are subject to suspicion because of the need to protect children from abuse:

_{Men are put off from caring because of the issue of abuse. It’s rammed down their throats all the time._ (Female carer)"

As a male short-break carer confirmed:

_{A lot of men might be frightened of the stigma that they may be thought to have an ulterior motive. The idea that you must be a pervert puts people off._ (Male carer)

Male and female short-break carers supported findings by Gilligan (2000) and Newstone (2000) that men are likely to be seen as a potential risk, while one scheme worker recognised that the situation had deteriorated in recent years as child protection had risen up the agenda in society and social services departments. As will be discussed below, single men, as well as gay carers of both sexes, were subject to deeper assessments because of this ‘potential risk’.

**How are short-break carers recruited?**

In accordance with previous research about the recruitment of foster carers, the majority of the short-break carers were recruited through ‘word of mouth’ when short-break carers or scheme professionals told others about the role (Berridge, 1997). Short-break carers identified the important role they themselves play in recruiting others, especially from their families and friends. Female carers often recruited other women to the role. Sometimes this role was facilitated by the scheme publicity. For example, one short-break carer ‘made’ her sister watch the scheme video.

While one-sixth of the short-break carers were recruited through scheme publicity, focusing on recruitment was difficult for schemes. Confirming the findings of the national survey (Prewett, 1999), four of the schemes had very small budgets, particularly for recruitment, and scheme workers were often struggling with case loads far in excess of the Audit Commission’s (1994) recommendation of 20. Therefore they did not have the time or money to recruit carers pro-actively.

This was recognised by scheme workers and two short-break carers. For example:

_{I have a feeling that they are afraid to make it too successful. How are they going to assess people due to the lack of personnel? Also, how are they going to pay? There’s a lack of funding._ (Female carer)

The carers believed that scheme materials should be ‘professional looking’, ‘exciting’, ‘with really good artwork’, ‘photos and good-quality paper’, but on four short-break schemes the materials were at
that time not of such a high standard. Carers believed this publicity should be placed in community venues available in community languages and tailored to the appropriate target groups.

There were some important issues relating to the recruitment of short-break carers which they believed needed to be addressed. Virtually all of the short-break carers believed that the general public is uneducated about and ‘afraid’ of disability:

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

They also recognised that people did not know about short breaks, their recruitment campaigns were ‘low profile’ or ‘non-existent’ and that:

*Ordinary people can come forward. You don’t have to be wonderfully special or a martyr.* (Female carer)

More schemes could provide potential short-break carers with relevant experience. The carers also believed that schemes could highlight the fact that providing short breaks can be a stepping-stone towards a career in the disability field. However, this would require considerable input by scheme staff and appropriate funding to ensure that applicants without relevant experience were suitably prepared.

**What did short-break carers think of the assessment process?**

Short-break carers usually undergo the full foster carer assessment process which they described as necessarily ‘rigorous’ and ‘intrusive’ so that children are protected. They said:

*It can be a bit daunting if you have never had any dealings with social services, wondering am I good enough?* (Female carer)

*I thought I’d blown it by not being perfect.* (Female carer)

While the majority of short-break carers believed the assessment process ‘fairly treated all applicants’, a hierarchy of assessment seemed to exist which was linked to short-break carers’ sexuality:

*As lesbians it wasn’t good. 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.* (Female carer)

This hierarchy was described by one of the scheme co-ordinators as being organised by levels:

*I think it’s sorted by levels: heterosexual couples, then single women, then a lesbian couple, followed by a gay couple, followed by a single gay man, then a single straight man.* (Scheme co-ordinator)

These levels of assessment appear to reflect society’s perceptions of risk while workers on three schemes recognised that their assessment process discriminated against single male and gay carers. The scheme workers linked the extra scrutiny directly to concerns from the panel regarding child protection and protecting carers from potential allegations. These findings confirm Blunden (1988), a single woman who was applying to foster, who highlighted that carers need to be resilient to withstand the assessment process, and Skeates and Jabri (1988) and Hicks and McDermott (1999) who described some social workers’ unsympathetic attitudes to gay and lesbian carers.

The short-break carers felt the assessment process took too long. Over a third of the carers’ assessment had taken more than six months and three over a year. This was due to the short-break scheme workers’ lack of time and the length of time taken for police checks.

**What do short-break carers think of their training?**

The preparation of short-break carers is a legal requirement. However, preparatory training had not been undertaken by a quarter of them. They were excused
because of their own or their partner’s relevant experience:

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

(Male carer)

The short-break carers saw their preparatory training as providing an insight into their scheme and the role they will play. It also brings them into contact with other short-break carers:

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

(Female carer)

Worryingly, two short-break carers with no relevant experience had not been provided with preparatory training. This had left them feeling ‘unsure’ and ‘vulnerable’, thus highlighting the importance of preparatory training to ensure the quality of the short breaks provided and carers’ full awareness of their role as well as their own and their scheme’s responsibilities.

Ongoing training was available to all of the short-break carers involved in this study. They were usually notified of future events and, as one scheme co-ordinator put it, ‘If they fancy it they put their name down.’

All of the schemes recognised that their ability to provide ongoing training was reduced by lack of staff time and resources, as well as the carers’ inability to attend sessions owing to lack of time and other commitments.

In two schemes, National Vocational Qualifications were available to short-break carers, but the carers spoken to on the schemes were unaware of this fact. The short-break carers responded to the issue of certification of training by taking one of three stances. Firstly, it would be a positive development and ‘raise the status of the care provided’. Secondly, qualifications were beneficial for young people developing their careers; they are ‘of use to younger people; it shows appreciation and offers achievement’. Thirdly, the certificates were no substitute for experience or respect and they should not be made compulsory. The short-break carers questioned whether a certificate could equate with years of practical experience and whether a division could develop ‘between those with certificates and those without’.

**What do the short-break carers think of the ‘payments’ they receive?**

The carers in this study were paid in several different ways, this diversity representing the variety of arrangements found across short-break schemes. The majority received a sessional payment to cover their expenses, which included a reward element. Two received an enhanced rate of pay, six were fee paid to provide short breaks on a full-time basis and two were paid a retainer by their schemes. As noted in previous research regarding the motivation of foster carers, the short-break carers clearly stated that they did not provide short breaks ‘for the money’ (Ramsay, 1996). They were ‘caring’ and ‘committed’ and were concerned that increased payments could attract the ‘wrong type of people’. Payment was not a priority and often seen as a bonus. However, the money provided did help carers provide short breaks, particularly when they were low paid, were in receipt of state benefits or had given up paid work to provide large amounts of short breaks.

Most short-break carers felt that the current rates of pay did not cover their costs and that:

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

It was felt that the poor level of payment did not recognise the value of the service the short-break carers were providing. Their skills were ‘worthy of more appreciation’ and they felt that:

*The money is no good at all. It needs a complete review. We’re either a valuable resource or we’re not.*

In keeping with this view, half of the short-break carers believed that enhanced payments would reward them for their intensive work with children with high support needs:
Because the responsibility is a lot more – you worry more – we deserve a little bit more.

They felt that enhanced payments could encourage short-break carers to continue caring for children with higher support needs. However, this view was countered by the stance held by the other half of the short-break carers that all children were individuals and should not be compared or labeled so that enhanced payments could be provided:

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.

The payments issue relates very directly to the short-break carers’ view of their role which varied from ‘volunteer’ to ‘professional’.

How do short-break carers see their role?
Just under a third of the short-break carers saw their role as ‘professional’. They believed they were skilled, often experienced and that the service they provided altered their lifestyle ‘like a job’, ‘a very, very responsible job’.

The short-break carers who were paid a fee, provided with large amounts of training and support, and who had often given up professional roles to provide short breaks on a full-time basis, definitively saw themselves as professionals.

The ‘poor payment’ was an important factor in the short-break carers’ view of themselves as semi-professional. These short-break carers were confident of their skills but pointed out that they provided ‘love’, were supplying breaks in their own home and the low level of payment indicated to them that they were semi-professional or ‘in-between’ volunteer and professional:

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

Returning to the issue of lack of payment for nurturing skills, the eight short-break carers who saw themselves as volunteers were also confident in their role, but again the low level of recompense indicated to them that they were volunteers. As one female carer put it, ‘You are not paid to care.’

Other short-break carers saw themselves as colleagues with the professionals, part of a support network, cheap labour and friends of the children’s family.

The scheme co-ordinators also described the short-break carers’ role in a number of ways ranging from ‘volunteer’ to ‘professional’, while recognising the skills held by these short-break carers for children with high support needs. They also felt that the payments provided did not recognise their skills. One scheme co-ordinator succinctly summarised the issue:

We pay you [short-break carer] as a volunteer, but treat you as a professional, as a colleague.

While the foster carers in this study provide short breaks for disabled children for whom it is difficult to find a placement, it can be clearly seen that the issues permeating their comments reflect those relating to foster care as a whole. Fostering Network’s call for the professionalisation of foster care should therefore be considered for this group of short-term foster carers, too (NFCA, 1997).

Do short-break carers feel supported by their schemes?
All of the short-break carers liked their link worker and felt that they had a positive relationship with them. However, in accordance with the ‘respite carers’ in the Performance, Review and Research Unit study (1995), the majority of the short-break carers from five schemes felt that support was difficult to obtain and only available on an ‘as and when’ basis: ‘If anything comes up, then you get the support.’

Once a positive relationship had been established between the short-break carer and link worker (the social worker who
supports them), they were left to ‘get on with it’. As one scheme co-ordinator put it:  

*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.*

Although this position was valued by the majority of short-break carers, a few 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.

Six of these short-break carers would have preferred more constant support, but this was unavailable. They felt that they would only be contacted if there were worries, rather than to acknowledge their contribution and encourage them ‘with positive feedback that things are going right’.

In contrast, on one scheme carers reported high levels of contact with and support from their link workers. These short-break carers, as shown above, saw themselves as professional as they were fee paid and had had previous experience in the disability field. They saw themselves as working in partnership with services, a similar aim to short-term foster carers investigated by Sellick (1992). Sellick recognised that short-term foster carers want to work in partnership with services and that they need a relationship with and easy access to social workers.

Most of the short-break carers did not know any similar carers, nor did they or their children have access to support groups provided by their scheme, although they had varying levels of support from family and friends. The latter was inhibited by confidentiality issues.

Considering the lack of informal support from other short-break carers, link workers have a vital role to play in ensuring that links are working well by providing ongoing support and being alert to any potential difficulties. This type of support is considered vital to the retention of foster carers and the provision of quality services (Ramsay, 1996; Sellick, 1996).

**Why do some short-break links end?**

From the standpoint of all of those interviewed (including the views of 13 former short-break carers who responded to the questionnaire), the main reason for no longer providing short breaks is a change in personal circumstances on the part of the carer, the child or their family. As one short-break carer stated: ‘People do different things at different stages of their lives.’

In addition to these ‘natural’ endings, the short-break carers felt that some new carers would find that the role is not for them. As was discussed above, such carers need to be very committed to this role, which is undertaken in their family home and will affect all the members of the family.

Other links end prematurely when the equipment necessary to enable the carer to continue providing short breaks cannot be supplied by their scheme. In the words of one carer:

*As children increase in size and they get older . . . it becomes impossible to manage in an ordinary house.*

Scheme workers recognised that they often could not provide the equipment because of a lack of resources. The severe under-funding of short-break schemes was a finding highlighted in each of the three national surveys of short-break schemes undertaken in 1989, 1992 and 1998 (Orlik et al., 1990; Beckford and Robinson, 1993; Prewett, 1999).

Link workers also lacked the time to support short-break carers proactively and the carers felt that they were not always aware when there were ‘issues’ developing in their relationships with parents. Sometimes the relationship did not ‘gel’ or short-break carers had a specific difficulty with parents which could result in the end of the link. However, one current short-break carer described how the link worker had successfully resolved a ‘problem with parents’ so that the link continued.
Summary and conclusions

Short-break carers for disabled children for whom it is difficult to find a placement are a vital resource. They enjoy and are committed to providing positive relationships with often severely disabled children and to providing the parents of these children with some time out.

However, their vital role exists within the context of lack of understanding, lack of clarity and the paucity of financial resources that exists within foster care more generally, and which inhibits recognition of their value and the provision of the support they need.

Their motivations for providing short breaks were very similar to those exhibited in mainstream foster care, namely that they love the children and do not provide care ‘for the money’ (Ramsay, 1996). Short-break carers undertake their role in a professional manner while feeling that society does not understand disability or the concept of a ‘short break’. Their views regarding their role also display a lack of clarity while parents regard short breaks as a critical service. Short-break carers and the professionals with whom they work view the role as varying from volunteer to semi-professional to professional colleague. The perceived status of the role is related to the lack of financial reward for their recognised skill and commitment, and the associated societal perception of the role of a carer as a low-paid female occupation carried out in the home. This perception also impacts on the way male short-break carers are viewed both by scheme co-ordinators and carers: either they are seen as a valued resource or it is considered that short-break care is not an appropriate role for men. This negative response has been greatly reinforced in recent years by the increasing strength of child protection procedures and the perception that abuse is usually perpetrated by males. Word-of-mouth recruitment of new carers by short-break carers also bolsters up the view that the role is woman’s work.

The lack of funding available to short-break schemes compounds these difficulties. Scheme co-ordinators struggle to recruit, train and support carers, and find it hard to recruit a wider variety of carers, particularly male, and challenge ‘traditional’ perspectives regarding care work.

It is clear that steps need to be taken at both national and local levels not only to promote and support the role of short-break carers, but to recognise, clarify and respect the vital part they play in supporting families with a disabled child, as well as providing these children with a wider circle of friends, new experiences and social environments.

A fundamental review of the role of the short-break carer is needed to clarify, alongside mainstream foster carers’ call for professional respect, that the provision of short breaks is and should be undertaken in a professional manner by a diverse range of people. Furthermore, it is worthy of payments which not only reflect short-break carers’ highly developed skills, but respect the individuality and inherent value of disabled children. This is again a concept that is generally lacking in society and which various organisations, including Shared Care Network and short-break services, are trying to redress through both local and national advertising.

When the ‘worth’ of short-break carers is recognised at a national policy level, high and sustained levels of funding will need to be committed by social services departments and voluntary organisations. This is not only to ensure that recent initiatives established through Quality Protects funding are not lost, but to make certain that suitable potential carers from a wider range of backgrounds can be provided with the necessary experience and training, that link workers can support short-break carers appropriately and that their skills can be recognised through proper financial reward.

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