

Shared care services in England, Wales and Northern Ireland

Shared care services link disabled children and adults with families, couples or individuals who are willing to offer them short breaks. These support carers (also known as shared, respite, link or short-term foster carers) can provide the children and adults with high quality personal care, enriching experiences and new friendships while their families/long-term carers have more time to 'get on with their own lives'. This study investigated users' views of the services they receive and current provision and practice. It found:

- f** There are at least 400 schemes in England, Wales and Northern Ireland.
- f** The 204 shared care services involved in the study provided services for 7,521 children on the 152 children's schemes and 2,021 adults on 52 adults' schemes. A typical user is provided with one twelve-hour session per week at a per capita cost of £1,767 for children and £1,407 for adults.
- f** Virtually all schemes provide services for people with learning difficulties; they are also catering for more people with physical and sensory impairments, HIV and AIDS, complex health care needs or behaviour that is perceived as challenging.
- f** The services improve disabled children's and adults' quality of life by providing real caring relationships with their support carers.
- f** Short breaks enabled service users to enjoy new experiences and to develop wider social networks.
- f** The majority of the users involved in the study said they enjoyed short breaks and would like to see more of their support carers. Most of the adults recognised that their short breaks also gave their carers a rest.
- f** The ability of schemes to provide good quality services which meet demand is seriously threatened by a number of key issues including:
 - low status of services within social service departments
 - under-investment in services
 - variable compliance with statutory regulations and good practice guidelines
 - lengthening waiting-lists.

Introduction

The important role played by shared care schemes was emphasised in 1998 by two Social Services Inspectorate Reports and in 'Quality Protects', the local authority social work objectives for children. Shared care schemes, however, have been undergoing significant change. Schemes have been amalgamated or re-structured in the light of local authority re-organisation and scheme co-ordinators report increased stress, financial constraints and an inability to meet ever increasing demands for services.

These findings report on:

- the views of 38 users regarding the services they receive;
- the survey returns from 152 children's shared care schemes and 52 adult schemes out of a total of 400 schemes in England, Wales and Northern Ireland. These findings are compared with a similar survey carried out in 1992 (see 'About the study').

Users' views of services

Two main themes dominated the users' discussions about why they had shared care. The first was that they liked spending time with their support carers. The users developed real relationships with their support carers - often carers and users became friends. These relationships were often fundamental to the users' social life and network or enabled them to enjoy everyday family life. They also provided new interests and activities. Some of the adult users also recognised that their short break provided a break for their long-term carers too. However, the main reason for users having short breaks was because they enjoyed them.

Users were rarely unhappy with their support carer. They were usually only dissatisfied when their contact with their carers was restricted because of changes in their carer(s)' circumstances or over issues such as food or who controlled the television. While seemingly insignificant, these household issues could have a large impact on the individual's ability to 'feel at home' while at their support carer(s)' home.

All but one of the users interviewed would tell someone if they disliked an aspect of their short break. One individual stated he felt "nervous" and "worried" while at his weekly tea visit with his carers. Individuals shied away from discussing things they did not like with their carers. They preferred instead to talk to their parents or long-term carers and, when confident of the relationship, their link workers (the social worker who organises short breaks). A couple of individuals had made their dislike of previous carers known to their carers/parents and as a result their support carers had been changed.

The majority of individuals could not think of any way to improve their short breaks other than seeing their carers more. Other suggested improvements related to household arrangements, which could prevent users from feeling completely at home.

Services provided

Shared care schemes are providing short breaks for a wider range of users:

- The majority of services make provision for children and adults with learning difficulties.
- Eight-five per cent of children's and nearly half of adults' services are catering for users with physical impairments who may or may not have learning difficulties.
- Over half of children's and a third of adults' schemes accept users with behaviour that is perceived as challenging.
- Two-thirds of children's and half of adults' services provide for people with sensory impairments.
- A quarter of children's and 20 per cent of adults' services cater for users with HIV/AIDS.
- The number of people from minority ethnic backgrounds provided with services has risen; the number of children by 3 per cent and the number of adults by 4.5 per cent since 1992.

As well as providing short breaks with support carers:

- Forty-five per cent of children's and 31 per cent of adults' schemes provide a 'sitting' service (short breaks provided in or from the users' home),
- Thirty-two per cent of children's and 31 per cent of adults' schemes provide a befriending service (a one-to-one peer relationship often enabling access to leisure facilities), and
- Twenty-five per cent of children's schemes and 17 per cent of adults' provide other services, such as youth or Saturday clubs or escorts to holiday placements.

The 204 schemes included in the survey were used by 7,521 children and 2,021 adults. Since 1992, there has been a marked increase in the number of children (8 per cent) and adults (15 per cent) using shared care services.

Over 85 per cent of schemes have eligibility criteria to protect services for the users who are in most need. Nearly 90 per cent of children's schemes and 65 per cent of adults' schemes have a waiting-list. The numbers on these waiting-lists are equal to half the number of children and a quarter of the adults actually receiving services. A third of users wait over a

year for services. This high level of unmet need is, however, likely to be an under-estimate since users whose needs are unlikely to be met are frequently not referred to services.

The reasons users are waiting for services remain unchanged from the previous survey. They are:

- a shortage of support carers
- a shortage of scheme staff to recruit support carers
- a shortage of funding.

Support carers

There were 7,844 support carers for children and 1,386 for adults in the schemes which responded to the survey. This represents an increase of 26 per cent on children's schemes and 4 per cent on adults' schemes since 1992.

- Eighty-six per cent of children's support carers and 73 per cent of adults' support carers provide short breaks in their own home.
- Four per cent of all support carers provide domiciliary care (short breaks in the user's home, often involving personal care).
- Six per cent of children's support carers and 16 per cent of adults' carers provide a 'sitting' service.
- Four per cent of children's support carers and 7 per cent of adults' support carers are befrienders.
- Over 75 per cent of services now accept gay men and women as support carers, in contrast with 55 per cent in 1992.
- The number of children's support carers from minority ethnic backgrounds has risen by 0.4 per cent, however the percentage of adults' support carers from minority ethnic backgrounds has decreased by 3 per cent. In some areas there are shortages of white carers. The vast majority of matches are made with support carers of the same race.

Payments to support carers

Since 1992, payments to children's support carers have risen by up to 10 per cent and adults' services by varying amounts above inflation. Table 1 shows the average payment made to support carers.

Table 1: Average payment to support carers

Length of session	Children's support carer	Adult's support carer
12 hours	£16.22	£22.64
24 hours/overnight	£24.28	£29.54
one week	£155.80	£202.36

Befrienders are paid an average of £3.17 per hour for children and £2.78 for adults. 'Sitters' are paid an average of £4.11 per hour for children and £4.39 for adults.

Organisation, control and cost of services

Most services are controlled by local authorities. Only 25 per cent of children's and 10 per cent of adults' schemes are controlled by voluntary organisations. All schemes are funded at least in part by local authorities. Local authority run services are located in various departments within social services and it is unusual for them to be managed by senior managers.

The typical amount of care provided for both adults and children is one twelve-hour session per week although this may be used in blocks of time, eg. a whole weekend. The mean per capita cost for children's short breaks is £1,767.28 per annum. The mean per capita cost on adults' schemes is £1,407.29.

Fifty-five per cent of adults' schemes charge users for services. Charges have increased substantially since 1992. Users on these schemes generally use their benefits to pay for services.

Variations in policy and practice

The number of dedicated social work hours available, the size of budgets and salary costs vary immensely between schemes. Scheme workers often carry caseloads which far exceed the Audit Commission's (1994) recommendation of 20 while also working for other teams. Little support is provided by other professionals, such as occupational therapists. Large numbers of users do not have a social worker other than from the scheme, so the responsibility for reviewing placements falls to the scheme worker. This is in addition to the link worker's role with support carers which usually includes recruitment, training, assessment and on-going support. It is not surprising, therefore, that workers frequently report being overloaded and stressed.

Variations from established good practice and legislative guidance include:

- Only two-thirds of children's schemes and a third of adults' schemes expect all their support carers to attend preparatory training. Moreover, the amount of training provided to support carers varies.
- Only 86 per cent of children's and 70 per cent of adults' schemes have a panel which approves support carers.
- Fifteen per cent of adults' schemes do not carry out police checks on support carers.
- Only three-quarters of support carers are provided

with foster care agreements (children) or contracts (adults) and copies of the schemes' complaints procedure.

- The planning of children's placements is not standardised. The way in which the Looked After Children form (LAC) is used varies immensely.
- Care plans are only reviewed by 56 per cent of children's schemes and 44 per cent of adults' schemes.
- Far more adults' schemes invite users to reviews (70 per cent) than children's ones do. Only five children's schemes invited 75 per cent or more of their children to their reviews.
- The way in which placements/links are supported varies immensely; some workers do not visit clients when they are with their support carers because the links (placement) take place at weekends.

On the positive side, most schemes carry out reviews of support carers. Over 90 per cent of children's but only 65 per cent of adults' schemes review and re-approve their support carers annually. The reviews provide an opportunity to discuss the maintenance and development of support carers' skills while also providing an opportunity for support carers to voice any concerns.

The Registered Homes (Amendment) Act (1991) states that adults' carers should be registered if they are providing more than 28 nights care per year. This formalisation of support carers' roles has had a detrimental impact on the number of support carers available. Some schemes employ 'protective strategies' which include ensuring that carers do not care for more than 28 nights per year.

Schemes often cannot provide the equipment and adaptations necessary for support carers to be able to provide care for users with the most severe needs. Inevitably, this leads to longer waiting-lists and the families likely to be under most stress are the most unlikely to receive short breaks.

Conclusion

Users enjoy and benefit from the services they receive. More services are being provided while the number of users waiting for services has also increased. The quality of the services are, however, threatened by inconsistencies in practice. Issues which need to be addressed include:

- Under-investment in services.
- Low status of services within local authorities.

- Training, assessment, support and payment of support carers.
- Workers being overloaded, which affects their relationships with users and their ability to comply with statutory and good practice requirements.

About this study

The study was undertaken in 1998. Thirty-eight individuals with learning and other disabilities were supported in order that they could provide their views on their short breaks. The questionnaire survey covered England, Wales and Northern Ireland and had a response rate of 55 per cent (63 per cent from children's schemes and 40 per cent from adult schemes). The second national survey of shared care services, to which these findings are compared, was undertaken in 1992 (Beckford and Robinson, 1993).

How to get further information

The full report, **Short-term break, long-term benefit: Using family-based short breaks for disabled children and adults** by Beth Prewett, is published for the Foundation by JUSSR and *Community Care* magazine (ISBN 0 907484 37 9, price £11.95).