

## Respite services for adults with learning difficulties

The White Paper *Caring for People* cited as a key objective the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible. New research by the National Development Team has built up a picture of what respite services are provided for adults with learning difficulties by social services departments in England. As part of the study, the researchers explored 'innovative' respite services which are developing new approaches in nine local authorities. The researchers found that:

**f** The most common form of respite care provided is in residential units.

**f** Social services departments and adults with learning difficulties have different views about what constitutes a valued respite service.

**f** The noteworthy elements of the innovative respite services visited are that they:

- involve people with learning difficulties in planning
- develop befriending services and friendships
- create new opportunities for people
- seek to promote safety through partnerships
- offer training which seeks to improve the quality of their services
- promote choice, by learning from people with learning difficulties

**f** Most of the nine services visited were uncertain about their future, not least because of their fragile financial position.

**f** There is a dearth of information about the comparative cost-effectiveness of different forms of respite services.

**f** The numbers of respite places available in England or of adults using these in a single year are unknown, because of inadequacies in social services departments' information technology.

## Introduction

The provision of respite services for people with learning difficulties is widely believed to be crucial to enabling them to remain at home. This study explored the form and nature of these services. The research team sent questionnaires to all social services departments in England. Of 108 departments, 76 surveys were completed and returned. Information technology deficiencies in social services departments caused individual respondents to express concerns about the accuracy of the numerical information they could supply, and accordingly many provided estimated figures.

A smaller survey of nine departments was then undertaken to learn about 'innovative' services. These departments were visited by the team.

## What kinds of respite services are available?

The survey revealed that the most commonly available form of respite service for adults with learning difficulties is in residential units. Most of the 76 social services departments reported the availability of residential respite, either in a dedicated unit or a unit which was combined with other services. (It is noteworthy that the services available are not necessarily those used by the social services or provided by them.) After these types of unit-based respite, the most commonly available types, both within and outside local authority boundaries, are:

- day services
- family-based respite
- volunteer or befriending schemes
- hospital
- holiday respite
- domiciliary services

## Where people lived close to boundaries, or in large dispersed authorities, neighbouring services which were more accessible were sometimes preferred.

Twenty-four social services departments reported using dedicated respite units outside their boundaries, and in another 32 authorities they are combined with other services. Twenty-three social services departments make use of family-based respite outside their own boundaries.

Social services departments are typically involved in the provision of family-based, residential and domiciliary services. They provide less holiday respite and volunteer or befriending schemes. Voluntary sector services provide more volunteer or befriending schemes, holiday and domiciliary services. Respite accessed via district health authorities, NHS trusts and the private sector is typically hospital- and unit-based provision.

## Waiting times

A particular casualty of information technology deficiencies was information about waiting times to access services. Of those who provided average waiting times, it appears that immediate access to either home-based services or residential units is a remote possibility.

## 'Innovative' respite services

Although the questionnaire did not define 'innovative respite services', 32 social services departments identified some.

The eight services visited which had innovative respite schemes:

- clearly stated that their aims and service philosophies were developed from the ideas, preferences and experiences of people with learning difficulties and their families;
- emphasised the importance of person-to-person support and of building new relationships for people which extended beyond their immediate families;
- recognised that sharing leisure activities as part of the respite service can realise additional advantages and opportunities for adults with learning difficulties and, in turn, their families.

The study demonstrated that there are problems in identifying innovative services via a process which relies heavily on self-reporting and reputation. Although the services were screened via telephone, service publicity and documentation prior to the visit, it was subsequently necessary to re-cast one unit-based service as 'once innovative'. Its aspiration to be a service 'on demand' in 1985 had been progressively compromised by fewer qualified staff and an increase in the numbers of service users, but no increase in either the staffing complement or the budget for the day-to-day running of the unit, for example. Although still held up as a 'model' service by senior managers, it had become inflexible and very narrow in terms of its capacity.

## The views of self-advocates

A parallel investigation of respite services in Liverpool (funded by the Department of Health initiative, *Caring for People who Live at Home*) had a strong influence on the methodology of this study. In particular, the service principles identified by the user committee of a large day centre in that project influenced this research's definition of what respite services should be like. Respite services should:

- enable people to have control
- offer good experiences and personal advantages
- sustain feelings of personal worth and esteem
- be small-scale and separate from accommodation offered to people on a long-term basis
- promote individual support as a result of individual planning
- sustain people's significant relationships and make links with their lives - particularly their diverse roles in their families
- be local, even in emergencies
- be responsive to the ideas and concerns of service users
- part company with the dispiriting features (such as lost clothes, inattention to essential medication, unfamiliarity with people's routines and preferences) associated with unit-based respite

These ideas were not reflected in the working definitions of respite services nominated by social services departments, many of which referred to the benefits of respite for people's parents and carers.

#### Characteristics of innovative respite services

The eight services visited which were classed as innovative were characterised by diversity. Broadly, they focus on people's otherwise unstructured evenings and weekends. Some offer day-time support to people who would otherwise have no daytime occupation.

To different degrees the services demonstrated a readiness to learn from the experiences of people with learning difficulties. One was unequivocal about the service being primarily for people with learning difficulties. The others more readily acknowledged that parents, as service providers as well, also benefit. As the co-ordinator of one service explained:

*"My work when I first started was very much talking to people with difficulties about what they wanted from a scheme. We didn't want to say, 'Well here it is!' People with difficulties were saying that what they lacked was a one-to-one friendship."*

Most of the services visited take pride in the extent to which they have created new opportunities for people whose lives would otherwise be very circumscribed. It was usual for people's parents to rate these opportunities as more important than the breaks they enjoyed themselves:

*"They've opened a new world to her and I see her differently...her understanding has deepened, she's more grown-up and she reacts quicker. They try things with her that I wouldn't do and they work. I feel very vulnerable if I take her out somewhere and she causes a scene. She used to lie down and thank God that's gone...Now she gets all excited and it's obvious she looks forward to it. They understand that she's a one-person person."*

While person-to-person support characterised most of the services visited, it is striking that one service offers group activities as a result of the prosecution of a man for the sexual abuse of children with learning difficulties in a local school. The parents of people who use this service endorse the belief that there is safety in numbers. The mother of a woman with extensive support needs told us of her long-standing concerns for her daughter's safety and her sense of how this should be addressed:

*"I made it clear I didn't want her to be cared for by men. She has no speech so I'm her safeguard. They respect that."*

The services recognise the dangers of imposing the choices of others on people with learning difficulties. As a corrective measure they offer 'tasters', either in the form of organised days where people sampled from a range of activities, or planned introductory visits to locations permitting people to try an activity at their own pace.

While in some services training in preparation for the service is designed to complement the leisure, sporting interests and skills of volunteers and sessional workers, others seek to enhance the team member's understanding of what constitutes good support to individuals. Some services have been more successful than others in attracting a diverse workforce, including people with learning difficulties who they once thought might like to use the service.

Self-scrutiny, networking and learning from current and past experiences are familiar activities in most of the eight services.

#### Costing innovative respite services

Although little is known about costing respite services, four of the services visited had hourly costs which lie within the range of £11 to £18 per hour. Of the remaining, three had lower costs per hour and one was notably more expensive. The service with the lowest hourly costs did not extend to people with challenging behaviours or very extensive support needs. The most expensive service worked with people with very extensive support needs, and as a

result had high staffing levels (including nurses). These services are all prepared to be flexible in their budgeting in response to identified needs.

### The fragility of innovative respite services

In contrast to established residential respite services, innovative respite services have a gauntlet to run. They have not imitated the familiar architectural 'model' of two respite beds in a 24-bed hostel (to which there remains a great deal of loyalty). Resistance to considering options beyond such known and established services is one factor in keeping the hostels going.

Social services, voluntary organisations, and to a lesser degree health authorities, have all been influential in the development of innovative respite service provision. They have had varying influences in terms of policy sharing, management, accountability and funding, for example. However, although they have directed new schemes towards funds and supported funding bids, most schemes have been established with short-term funds and *ad hoc* grants. The uncertainty this creates has in turn led to some staff seeking more secure positions elsewhere and the expansion of a scheme in terms of the numbers of people served without an equivalent expansion of resources. Most services were aware of the conflict of interest between service provision and the distraction of fund raising, cost cutting and drafting grant applications.

### About the study

The research was carried out by Lesley Cotterill, now of the University of Liverpool, Lesley Hayes, now of the University of Keel, Tricia Sloper, now of the University of York, and Margaret Flynn of the National Development Team.

There were several strands of initial activity: writing to research and practitioner journals seeking information about innovative respite services; meeting with self-advocates; and distributing questionnaires about the types of respite service most likely to be offered to adults with learning difficulties

to social services departments, NHS trusts, district health authorities and voluntary organisations in England.

Nine services were visited and meetings were arranged with people with learning difficulties, their parents, support personnel, service co-ordinators and managers. Individual reports summarising findings and lessons were sent to each service. These formed the basis of the full report.

### Further information

A full report, *A Break with Tradition: The Findings of a Survey of Respite Services for Adult Citizens with Learning Disabilities in England* by Margaret Flynn, Lesley Cotterill, Lesley Hayes and Tricia Sloper, is published by the National Development Team. Priced £12.50 plus £1.25 postage and packing, it is available from National Development Team, St Peter's Court, 8 Trumpet Street, Manchester M1 5LW (Tel: 0161 228 7055).

For further information about the research please contact Margaret Flynn at the above address.

The Liverpool project referred to on page 2 is by Margaret Flynn with Liverpool Self Advocates (1994), *Taking a Break: Liverpool's respite services for adult citizens with learning disabilities*, Manchester, National Development Team.

#### Related Findings

The following *Social Care Findings* look at related issues:

- 52 Evaluating a citizen advocacy scheme (Jun 94)
- 66 Housing and support for people with learning difficulties (Apr 95)
- 70 Crime against people with learning difficulties (Aug 95)
- 72 Day care in rural areas (Aug 95)
- 75 Disparities in service provision for people with learning difficulties living in the community (Dec 95)

For further information on these and other *Findings*, contact Sally Corrie on 01904 629241



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