

findings



People with learning difficulties and their ageing family carers

Despite the growth in independent living, most people with learning difficulties still live in the family home. As their life expectancy increases, a growing proportion will continue to live with very elderly family members, usually parents, and will survive them. Carol Walker of Sheffield Hallam University and Alan Walker of the University of Sheffield reviewed research, policy and practice on service provision for adults with learning difficulties living at home with older family carers and spoke with carers, users and staff. Their study found:

- f* Older family carers differ from other groups of carers in that they are more likely to be sole carers, have smaller support networks, have usually negative experience of the paid service sector and are especially reluctant to seek help.
- f* There is a high degree of consensus in research and between carers, users and fieldworkers on how the paid service sector should help maintain the caring relationship and provide greater certainty for the future.
- f* Older family carers interviewed wanted to be able to support their relative as long as possible but felt under-valued and unsupported by the paid care system.
- f* Older family carers lived in fear of the future. They wanted to plan for the future care of their relative but faced practical and emotional barriers in doing so.
- f* Older family carers and their relatives wanted effective external systems of support which would serve as a safety net in the event of an emergency and which would put in place an appropriate package of care as a permanent alternative once family care begins to break down.
- f* Professionals felt that improvements were needed in planning, providing preventive rather than crisis services, greater awareness of the needs of carers, more flexible service provision and better provision of information.
- f* The researchers conclude that some of what is required relates to very basic, practical help and information. In addition, however, the paid service sector needs to look at the way it works with older family carers and, in particular, at the extent to which they are accepted as equal partners in the provision of support to their relatives.

Background

Most contributions to the literature and to research on older family carers have concentrated either on spouses or adult children, who assume responsibility for the care of a spouse or parent who has become frail or ill in older age. Service provision has also tended to focus on these groups of carers. Policy-makers and service providers have paid little attention to the needs of lifelong older family carers. Most of this group have had minimal statutory support during their lifetime.

This study examined the situation and service needs of older family carers supporting relatives with learning difficulties at home. This focus is important for two reasons. First, for many people with learning difficulties, family carers are their only source of support; their quality of life is crucially dependent on the health and well-being of their family carer. Secondly, and notwithstanding the rights of people with learning difficulties as individuals, *in practice*, family carers act as a conduit between the paid service sector and their relatives. They are central to any major decisions. Effective work with the service user with learning difficulties is dependent on securing the co-operation of the family carer.

A growing concern

Much of the policy discussion and research of the last decade has concentrated on people with learning difficulties moving out of the large, long-stay institutions into community settings. Less attention has been focused on the majority of people with learning difficulties who continue to live with their families and who tend to get less support from the paid service sector (see 'Disparities in service provision for people with learning difficulties living in the community', *Findings* Ref: SC 75, December 1995).

The lack of adequate and appropriate support for people with learning difficulties living in the family home is emphasised as their family carers age. New types of support, e.g. for transport or for domiciliary help, may not be introduced even though the older carer is becoming less able. This failure of services to adjust to the changing, more fragile, situation in the family home means that the life of the person with learning difficulties becomes more restricted while the burden on the family carer becomes more onerous precisely at the time when the ability to cope is diminishing.

As people with learning difficulties share in the improved life expectancy of the rest of the population, a significant proportion will live with family members, most frequently parents, whose

caring role is being extended into their own advanced old age, often until they die or are too frail to provide care any longer. The number of people with learning difficulties who will outlive their family carers will continue to rise with further improvements in life expectancy and because of the population bulge of the 1960s.

Key issues for older family carers

Older family carers share many characteristics with their younger counterparts, but there are also important differences which have an impact on their need for services and their dealings with the paid service sector.

Older family carers are under greater physical and mental pressures because of their age and the frailty this often brings; and they become increasingly anxious about the future.

Because of the duration of their caring relationship, which is often lifelong, they are likely to have a particularly intense, inter-dependent relationship with the person they are supporting.

They are more likely to be caring alone.

They have smaller support networks as parents, partners and friends age and die.

They have a very different experience of the service sector from new generations of carers. They were often advised to forget or reject their child, encouraged to have very limited expectations of his or her life expectancy or abilities and usually had to fight very hard for any support from the statutory sector.

Older family carers are often very reluctant to seek help. Reasons for this include past negative experiences of the paid service sector, and a fear that by seeking help they are admitting their own diminishing capacity and that they will lose control.

Fear of the future is a common experience shared by all family carers, but this anxiety becomes more intense as they get older. 'Resettlement' from the family home generally occurs only after a crisis. People with learning difficulties have been excluded from the more independent types of community placements which have increasingly replaced institutional care, though many express a desire to move on. The caricature of the family carer as a barrier to the greater independence of their relative with learning difficulties over-simplifies complex

family relationships. However, many family carers do have serious misgivings about their relative leaving home. These stem from a number of factors, such as dissatisfaction with the range and quality of care available, their belief that their relative does not want to leave, and their own inter-dependent relationship with their relative for companionship or practical or financial support.

Supporting older carers and their relatives

What the families want

There is considerable agreement between older family carers on the role the paid service sector should play in order to alleviate some of the everyday stress they experience. This would involve both practical services to assist them and their relatives, and changes in service culture. Families wanted service providers to play a more pro-active, preventive role; to acknowledge and respect the role played by family carers; and in particular to recognise the inter-dependent relationship which they have with their relative.

Changes in service practice families would like to see include:

- greater continuity in staffing, structure and service provision and planning;
- safety net provision to cope with crises;
- good quality, flexible service provision;
- more information on services and how to access them.

Changes in culture include:

- service professionals working in partnership with family carers and people with learning difficulties;
- valuing the role of family carers and respecting their views; and
- more preventive work to aid planning for the future.

Ideas from the service professionals

Service responses to the needs of this group have been limited and patchy. Respondents in the paid service sector highlighted a number of ways this might be improved, several of which reflected the views expressed by older family carers. These included:

- greater concentration on preventive services as opposed to crisis intervention;
- improved inter-agency working;
- procedures to enable longer-term planning;

addressing and balancing the needs of the family carer and the needs of the person with learning difficulties;

working with family carers to establish "carer-aware", "carer friendly" policies;

better collation and dissemination of local information on services and how to access them;

better and more flexible service provision to support older family carers;

better training for workers to help them to work with family carers as partners and to work with carers and people with learning difficulties on the sensitive issues of bereavement and the major changes such an occurrence would bring.

Conclusion

The needs of adults with learning difficulties living in the family home and of their older family carers are now well-established. There is a high level of consensus in research and between family carers and service professionals about what the problems are and, even, what needs to be done. The next critical step is for the paid service sector to act to provide people with learning difficulties with a more secure and certain future, and their family carers with the peace of mind they are seeking and fully deserve. Some of what is required relates to the provision of very basic, practical help and information, and effective ways of accessing it. But, in addition, the paid service sector needs to look at the way it regards and interacts with older family carers and, in particular, at the extent to which they are accepted as equal partners in the provision of support to their relatives.

The future needs of people with learning difficulties living with older family carers are wholly predictable: the future involvement of the paid service sector is inevitable, only the timing is uncertain. If health and social service agencies establish an effective database which records the extent of need and provides a predictor of future service involvement with a much neglected group of service users, this would enable them to move from current inefficient and costly crisis intervention to effective strategic planning.

The report makes a number of practical recommendations which are intended to assist policy-makers and practitioners, which would enhance the lives both of older family carers and the relatives with learning difficulties whom they are supporting. As a follow-up to the research, the authors will be organising good practice workshops

with a view to producing best practice guides. If you wish to contribute to this ongoing debate please contact Professor Carol Walker, School of Health and Community Studies, Sheffield Hallam University, Collegiate Crescent Site, Sheffield S10 2BP; email C.A.Walker@shu.ac.uk.

About the study

As well as undertaking a comprehensive literature review, two focus groups with people with learning difficulties and three with older family carers were organised. In addition, the authors are grateful to the Sharing Caring Project in Sheffield for allowing them to take part in some of the focus groups they organised. Information on current policies and provision was collected, in the first instance by telephone, from 19 NHS Trusts responsible for delivering community services to people with learning difficulties and 39 social services departments. These and other contacts led to information being collected from some other statutory sector and voluntary sector organisations.

How to get further information

A full report of the research findings, *Uncertain Futures: People with learning difficulties and their ageing family carers* by Carol Walker and Alan Walker, is published by Pavilion Publishing in association with the Joseph Rowntree Foundation (ISBN 1 900600 90 0, price £12.95 plus £1.50 p&p).