

## **Good practice guidelines in supporting older family carers of people with learning disabilities**

### ***Guideline 2: Identifying older families***

*'I just want to know that someone knows we're here.'* Older family carer, Sharing Caring Project, Sheffield.

A fundamental starting point to any work with older family carers is being able to identify them. It is not possible to support older family carers and plan for the future if local authorities do not know who and where these older families are. Identifying older family carers must be a priority, especially as their needs as an older person are likely to have an impact on their ability to continue to care in the near future.

It is estimated that 25% of people with learning disabilities and their family carers live in the community as 'hidden families', that is, not known to statutory services until there is a crisis (Department of Health, 2001). It is likely that a high proportion of this 25% will be made up of people with learning disabilities living with older family carers (Walker C and Walker A, 1998).

Substantial numbers of people living with the oldest carers may have slipped through the system, as they have not been in contact with services or contact has broken down. Some older family carers have developed their own support networks and systems for coping and managing without using services. However, research has shown that older family carers want to know that someone knows of them and will be able to support the person they care for when they are ready to plan for the future or in the event of an emergency (Foundation for People with Learning Disabilities, 2002).

Before embarking on any project to identify older family carers, commissioners and planners should determine what they want to gain. What is planned once the details of older family carers have been

identified? What information needs to be gathered? How will the information that is gathered be used to support family carers and to plan and develop services and support? How will information be kept up to date? Failing to think through these issues is likely to lead to the production of work that is useful only in the short term. This failure may also contribute to disillusion among older family carers who feel that the system is regularly 'losing them'.

There are several additional questions that need to be asked when identifying older family carers:

- Who should we be identifying?
- How should we identify them?
- How do we ensure they are willing to be identified?
- Who should take ownership of identifying older family carers?

## WHO SHOULD BE IDENTIFIED?

A key objective of *Valuing People* is establishing a complete picture of the number of older family carers (i.e. those aged 70 and over) in the local area in order to plan services (Department of Health, 2001). The initial priority for each Learning Disability Partnership Board is to find family carers over the age of 70 years in their area, as this is the time when they are eligible for services as older people. However, it is shortsighted to focus only on finding family carers over the age of 70. Commissioners and service planners need to put long-term mechanisms in place so that family carers who are currently 65, for example, are identified in five years time.

Local authorities also need to decide whether their primary aim is to develop a carers database with information about the people they support or a database of people with learning disabilities that includes information about their family carers. The decision that is taken locally will reflect the relative development of either of these registers.

## HOW SHOULD OLDER FAMILY CARERS BE IDENTIFIED?

The obvious starting point for identifying older family carers is by locating the people with learning disabilities they care for who are using services. Most services will have a record of who lives at home with a family carer, but not everyone will have a record of the age of the family carer.

There is a need to be creative when trying to identify 'hidden' older family carers and workers will need to look beyond the existing statutory systems. Some local authorities have used the local press to generate awareness and encourage older family carers to come forward. Other routes include GP practices, lunch clubs, voluntary organisations such as Gateway clubs, chemists, places of worship and Citizens' Advice Bureaux. Also, do not underestimate the carers' grapevine. Family carers find out a lot from each other and networks are often very strong having been built up over decades.

## HOW DO YOU ENSURE THAT OLDER FAMILY CARERS ARE WILLING TO BE IDENTIFIED?

Accept that not all older family carers want to be identified. Some older family carers have had extremely negative experiences with services in the past, been let down by the system or seen too many people with good ideas come and go with those ideas not being followed up. Furthermore, some older family carers may be concerned about the consequences of becoming known to organisations such as social services and any 'interference' that may follow. They may feel that they are managing fine and would prefer to get in touch when they feel they can no longer cope. Although some older family carers may be suspicious of statutory services, many have indicated that they would prefer that statutory services knew them as they were likely to become more heavily involved in the care of their relative in the future. There is a recognition by many older family carers that there are risks involved in sharing their details with voluntary organisations whose long-term funding is not secure. (Magrill et al., 1997).

Many older family carers might need an incentive to come forward, particularly if the person they care for is not currently using services.

Incentives could include ensuring that people have regular contact with carer support workers, regular carers' needs assessments, links to services such as alarm schemes, initiatives such as carers' emergency cards or simply the assurance that they will be kept up to date with information about their local services.

There are strong arguments in favour of employing dedicated workers to identify older family carers, particularly where on-going contact is envisaged. Enabling older family carers to form a relationship with workers who may be able to offer information, advice and support can be a crucial part of ensuring families remain visible and their needs taken into account for planning purposes even if they are not currently using services.

## WHO SHOULD TAKE OWNERSHIP OF IDENTIFYING OLDER FAMILY CARERS?

*Valuing People* gives the ultimate responsibility for identifying older family carers to Learning Disability Partnership Boards. However, within this structure consideration needs to be given to the following factors:

- Which agency/organisation should take the lead?
- What information will be collected, how and for what purpose?
- Will information be shared? If so, how will it be shared and for what reason?
- Confidentiality.
- Data protection.
- Long-term financial and resource commitment.

The push further outlined in *Valuing People* toward developing more inclusive services for people with learning disabilities is a compelling reason for investing in long-term systems for identifying older family carers. When more people with learning disabilities are accessing mainstream services such as employment and leisure opportunities it may be harder for learning disability services to keep track of them. However, people with learning disabilities may still be vulnerable and require regular contact with learning disability services on at least a monitoring basis. Moreover, Partnership Boards will need to have

some mechanism to enable them to measure the outcomes of the work that is being done to be able to judge how effective they are in implementing the objectives of *Valuing People*.

It is crucial to make a long-term commitment and allocate resources to any project aimed at identifying older family carers. It must be anticipated and accepted that it will take time to build up useful systems for finding older family carers. Taking a long-term approach and identifying younger family carers at the same time as older family carers will ensure that, over time, the task becomes easier, planning systems become more comprehensive and effective, and building relationships and communicating with family carers becomes far simpler and more positive.

Transition from child to adult services is the last time when statutory services have to collect data about young people with learning disabilities and their family carers. Information should be gathered systematically at this stage so that in the long term, older family carers can be more easily identified. Information systems should gather data about family carers of all ages and it should be possible to track family carers approaching late middle and old age. It is therefore helpful to have an agreed point for transfer of information to any adult register or database at this time. This may be particularly important in identifying people with learning disabilities from Black and minority ethnic communities for whom services are often inappropriate or inaccessible.

## REFERENCES, RESOURCES AND USEFUL CONTACTS:

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century planning with people towards person centred approaches – guidance for partnership boards* London: Department of Health.

Department of Health (2001) *Family Matters: counting families in* London: Department of Health.

Foundation for People with Learning Disabilities (2002) *Today and Tomorrow: The report of the Growing Older with Learning Disabilities Programme* London: Mental Health Foundation.

**www.lifetimecaring.org.uk**

A website that focuses on raising awareness of the needs of older family carers and their relatives with learning disabilities, provides open learning materials for frontline workers and offers practical suggestions for how services might become more responsive to older families.

Magrill, D. et al. (1997) *Crisis Approaching* Sharing Caring Project. For a copy, contact Sharing Caring Project, c/o Sheffield Mencap, Norfolk Lodge, Park Grange Road, Sheffield S2 3QF.

Walker, C and Walker, A (1998) *Uncertain futures: People with Learning Difficulties and their Ageing Family Carers* Brighton: Pavilion Press.

**Sheffield Case Register**

The case register is part of Sheffield Care Trust and run to serve the needs of providers of learning disability services in Sheffield. It was set up in 1974 as part of the Sheffield Development Project. The case register covers all ages and collects information about Health, Social Services, Education and independent services. Information about people with learning disabilities themselves is gathered by means of questionnaires which are completed by two home visitors. The case register records demographic details, service use information, family carer details, living situations, diagnosis, abilities and self help skills. The Register has around 2,800 active clients out of a Sheffield population of 533,000. For further information contact: Sheffield Case Register, Sheffield Care Trust, Ryegate Centre, Tupton Crescent Road, Sheffield S10 5DD Tel: 0114 2666101  
Email: caseregister@sct.nhs.uk

**Torbay Carers Register & Emergency Response Card**

Membership of the Torbay Carers Register is free of charge, voluntary and open to all carers who live in Torbay. It is a confidential and independent service designed to 'engage' carers, whether or not they are receiving services from agencies. It aims to give carers peace of mind with access to round the clock assistance. The data held on the Register gives a clear picture of the number of carers in Torbay and ensures that future services for carers and the people they care for are developed on the basis of accurate information. The Register acts as a mailing service enabling carers to be sent information about support

and to be consulted on service development. Being a member of the Torbay Carers Register also enables carers to receive the Emergency Response Card which is used as an instant source of identification in case of accident or sudden illness. Staff at the Carers Register hold information about the person cared for, what needs to be done to support that person and how to get access to other people who can help. The service is available 24 hours a day, 7 days a week. For further information, contact James Drummond at Torbay Social Services. Tel: 01803 208438 Email: james.drummond@torbay.gov.uk

### **The Older Family Carers Initiative (OFCI)**

OFCI aims to support Learning Disability Partnership Boards to identify and meet the needs of older family carers of people with learning disabilities as prioritised in *Valuing People*, the Government's white paper on learning disability. The OFCI, a three year project led by the Foundation for People with Learning Disabilities, has produced these guidelines to provide useful, good-practice information and ideas for supporting these older family carers. They are intended as a tool to help Learning Disability Partnership Boards, commissioners and frontline workers across England reflect on the way that older family carers are supported in their area. They are also designed for older family carers, to inform them of their rights, what support they could receive and of the processes outlined in *Valuing People* that will affect them. Guidelines 2 and 3 are designed to be read and used in conjunction with each other.

The Older Family Carers Initiative is led by the Foundation for People with Learning Disabilities in partnership with a range of organisations and individuals including BILD (British Institute of Learning Disabilities), HFT (Home Farm Trust), Valuing People Support Team, Housing Options, Carers UK and Mencap. It is funded by a Department of Health section 64 grant.

For more information about the Older Family Carers Initiative and to join the mailing list for *Family Futures* (OFCI newsletter) contact: Older Family Carers Initiative, Foundation for People with Learning Disabilities, 83 Victoria Street, London SW1H 0HW Tel: 020 7802 0329 Email: [fpld@fpld.org.uk](mailto:fpld@fpld.org.uk)

Other guidelines available in this series include 1, 3, 4 and 5. Please visit [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)