

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

Guideline 3: Recording information

‘They come from social services and they tick the boxes. They say, “We’ve done this one and we’ve done that one”, and that’s it. I’m just a number on their books aren’t I?’ Older family carer, Sharing Caring Project, Sheffield.

Building a system to record information about older family carers and the people with learning disabilities they care for will take time and little will be achieved without making a long-term commitment and investment in the process. However, once effective systems are in place the benefits to both older family carers and services can be enormous.

There are several key questions that need to be asked when considering recording information about older family carers of people with learning disabilities:

- Who should take ownership of this on-going process?
- What will be done with the information that is recorded?
- What information should be recorded?
- How should information be collected and recorded?

WHO SHOULD TAKE OWNERSHIP OF THIS ON-GOING PROCESS?

As with *Guideline 2: Identifying older families*, ownership and responsibility for ensuring that there is a co-ordinated and centralised mechanism for recording information and keeping it up to date needs to be closely linked to the Learning Disability Partnership Board. Safeguards need to be in place to ensure confidentiality and data protection systems policies are complied with and that, with the agreement of family carers, information can be shared with appropriate agencies, particularly in emergency situations, and to inform the planning and development of future services and support.

Existing good practice from around the country points to the need for there to be dedicated workers responsible for maintaining contact with older family carers and keeping information as up to date as possible.

WHAT WILL BE DONE WITH THE INFORMATION THAT IS RECORDED?

Before determining what information should be collected, each Partnership Board needs to work with the different services in its area to determine what will be done with the information that is collected. There is little worth in discovering anything more than the most basic personal details of the person with learning disabilities and their family carer(s) if there are no plans to do anything more than record how many older family carers there are in each area.

Consider the following questions.

- Do you want to collect information about the person with a learning disability or the family carer or both?
- Do you want to link the information collected into a system for anticipating future needs?
- Do you want to ask older family carers about their plans for the future?
- Do you want to have a system for recording vital information that can be used in an emergency to ensure appropriate support can be given to an individual? If so, how can that information be accessed in an out-of-hours emergency?
- Do you want to establish a two-way mechanism for passing information between services and family carers?

It is important to acknowledge the different motivations behind recording information. The Partnership Board is usually recording information to use in the development of its services and support. Family carers are likely to be passing on information in the hope that it will be used to ensure that the person they care for is known by services and to ensure that sufficient and appropriate services will be available to him or her in the future.

WHAT INFORMATION SHOULD BE RECORDED?

Determining what information should be recorded depends entirely on what the information is going to be used for and whether the focus is weighted more towards the person with learning disabilities, the family carer or both equally.

Information being recorded about older family carers needs to include personal care needs, mobility, social and health needs as well as information relating to their role as a carer. Information being recorded should also address issues of co-dependency and important details about the person being cared for that might be needed in an emergency situation.

The information that is recorded about an older family carer may also vary according to whether or not the person with learning disabilities they care for is already using or known to services. If the individual is known to services then there may be no need to duplicate information, except to ensure that basic details are recorded along with a clear signpost to the best source of alternative information. However, if the person with learning disabilities is not using any services and is effectively hidden then it is important to ensure that far more detailed information is recorded.

Besides basic personal details, including date of birth, information that could be recorded about both the older family carer(s) and the person with learning disabilities includes:

- personal care needs
- mobility needs
- suitability and type of current accommodation
- communication needs
- ethnicity
- language(s) spoken
- language(s) understood
- faith and cultural needs
- method of transport used by the family
- emergency contacts and what those contacts are prepared to do in an emergency

- support the older family carer(s) and the person with learning disabilities need with daily living tasks
- level of support/supervision needed by the person with learning disabilities
- any other regular caring responsibilities of the older family carer(s) and the person with learning disabilities
- whether the family carer(s) is involved in any local carers' services
- how much help the person with learning disabilities regularly provides to their older family carer(s)
- details of the health of the older family carer(s) and person with learning disabilities
- GP contact details
- details of any daytime services used by the person with learning disabilities
- details of any short-break/respite services used by the older family carer(s) and people with learning disabilities.

Although this list seems very comprehensive, this process is not to be confused with a carer's needs assessment. Carers' needs assessments are not usually carried out comprehensively and effectively and most older family carers are not requesting assessments unless there is a crisis (Williams and Robinson, 2000)¹. Therefore, collecting this information and ensuring that it is kept up to date is a step forward and could also form an excellent starting point for informing and carrying out more effective assessments of older family carers' needs in the future.

HOW SHOULD INFORMATION BE COLLECTED AND RECORDED?

As a rule, it is not appropriate to collect information from older family carers through postal or telephone surveys. Most family carers do not like to simply fill in a form and return it; they prefer a personal visit and for the reason they are supplying this personal information to be thoroughly explained (Magrill D. et al, 1997). Older family carers often

¹ See also Good Practice Guidelines 4: *Carers needs assessments for older family carers of people with learning disabilities* also available from the Older Family Carers Initiative

have additional barriers caused through their age, such as poor eyesight, which can make filling in forms more problematic.

Older family carers want to feel reassured that agencies know them and are aware of their situation and needs, but they need to know that this will be part of an on-going process. They need to see the same person wherever possible and have the chance to build up relationships to ensure that they can open up about their needs and circumstances.

The process of information collection should be about local services getting to know a family so that appropriate support can be offered and planned for. It should also be part of an on-going process with built in mechanisms for monitoring and reviewing information and recording unmet needs. Also, information should flow both ways. Services should provide clear information to older family carers to assist them to get appropriate help and support where a clear need is identified in the process of routine information recording.

Thought needs to be given to how and where the information collected is stored. Besides the technical issues such as data protection, if the information recorded would be essential in an emergency then it needs to be stored somewhere that is secure and accessible 24-hours-a-day, 365-days-a-year. Some local authorities use residential accommodation where there are always staff on duty, while other areas link their information systems to personal alarm schemes most often used by older people.

REFERENCES, RESOURCES AND USEFUL CONTACTS

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

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.

Williams V and Robinson C (2000) *In Their Own Right: The Carers Act and Carers of People with Learning Disabilities* Bristol: The Policy Press.

Carers Link Officer – Shropshire

The Carers Link Officer supports family carers in rural Shropshire and is part of the Care Development Team hosted by the Community Council of Shropshire. Carers needs, dreams and plans for the future are recorded when family carers are regularly visited by the Carers Link Officer or the Older Family Carers Support Worker. The information gathered covers everything including basic details, health needs, appointeeship, housing, carers' own needs and transport. By building trusting relationships with families, the two workers are able to support families in thinking about their own needs and futures as well as the person they care for. The service has also developed a 'grab sheet' that is used by service providers in emergencies and it records vital information about the needs of the person with learning disabilities. The details are held in a database also used to provide additional overall information about the needs of family carers as evidence to support the work of the local Partnership Board. For more information contact: Flick Pennal on 01939 211006 or email flickpennal@tiscali.co.uk

Older Carers Support Service

The Older Carers Support Service (OCSS) ensures that all older family carers (aged 70 or more) of people with learning disabilities in Sheffield receive regular contact and are linked into relevant information and support services. OCSS is part of Sheffield Care Trust and works alongside the Sheffield Case Register (see *Guidelines 2: Identifying older families*) who identify the older family carers for the OCSS to arrange to visit. A key task of the two OCSS Support Visitors includes recording information about the situation and needs of the older family carer, as well as information about the person being cared for that could be used in an emergency situation. The questions that form the basis of the interview are then used to formulate an agreed action plan with the family carers. For further information about the scheme and for a copy of the information questionnaire used, contact: Older Carers Support Service, c/o Sheffield Case Register, Sheffield Care Trust, Ryegate Centre, Tapton Crescent Road, Sheffield S10 5DD Email: ocss.ocss@sct.nhs.uk

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
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Other guidelines available in this series include 1, 2, 4 and 5. Please visit www.learningdisabilities.org.uk