

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

Guideline 4: Carers' needs assessments

'She came and filled in a form and I signed it. Was that a carer's assessment? I've not seen her since.' Older family carer, Sharing Caring Project, Sheffield.

Carers' needs assessments¹ (Williams and Robinson, 2000). involve more than simply recording information. They allow carers the opportunity to have services provided to meet their assessed needs.

According to guidance issued by the Department of Health (2000), 'a carer's assessment under the Carers and Disabled Children Act 2000 is carried out at the request of the carer in order:

- to determine whether the carer is eligible for support
- to determine the support needs of the carer (i.e. what will help the carer in their caring role and help them to maintain their own health and well-being)
- to see if those needs can be met by social or other services.'

Every effort must be taken to ensure that carers' needs assessments are a positive experience for older family carers of people with learning disabilities. They should enable older family carers to address all aspects of the impact of caring on their current needs, as well as allowing them to explore the future in a sensitive manner. Carers' needs assessments need to ensure that they deliver outcomes and contain mechanisms to ensure they are regularly reviewed and updated.

¹ The term 'carer's needs assessment' will be used throughout this paper instead of the standard carer's assessment term. This is to reflect the fact that many family carers find the phrase carer's assessment threatening, judgmental and generally negative.

BACKGROUND INFORMATION

The rights of family carers to have an assessment of their own needs was first laid out in the Carers (Recognition and Services) Act 1995 and strengthened in the Carers and Disabled Children Act 2001.

The latter act gives family carers the right to an assessment of their own needs, regardless of whether the person they care for allows an assessment of their own needs. The act also gives local authorities the power to provide services to meet the assessed needs of a carer, although carers may be charged for the services they receive.

There is much evidence from direct practice and research studies to show that while there is some good practice across the country, the experience of family carers of the assessment process is very patchy and often depends on where they live and who is carrying out the process (Williams and Robinson, 2000).

DEVELOPING EMPATHY WITH OLDER FAMILY CARERS

Older family carers need to be equipped with information about the process of having a carer's needs assessment and their rights, as well as having an assessor who is able to guide them through the process in a sensitive and skilled manner.

However, it must be acknowledged, understood and valued that older family carers may have additional needs during this process. First, assessors must recognise that in the older family carer's lifetime experience of caring, they may have been through similar processes before with many other professionals, and not every experience will have been a positive one. Workers must be familiar with any information about a family before they visit for the first time and ask appropriate questions to find out how accurate the older family carer feels that information is.

People carrying out assessments must also bear in mind that going through an assessment process may feel both threatening and negative to older family carers. It may feel to some older family carers that they are being assessed to see whether or not they are doing a good enough

job of caring for the person with learning disabilities. They may well be very anxious and not willing to open up about their real needs, particularly if the person carrying out the assessment is not someone with whom the family has been able to develop a relationship. Many older family carers genuinely fear that involvement from social services may lead to changes that they are not prepared for. Many older family carers will have been caring for over 40 years if not longer. Most aspects of their lives and identity is likely to be caught up in their role as a carer and this needs to be valued and respected by the person coming into their home to carry out the assessment.

WHO SHOULD CARRY OUT CARERS' NEEDS ASSESSMENTS?

The actual work of completing carers' needs assessments does not necessarily need to be carried out by qualified assessors such as social workers, but there do need to be systems in place for validating the plans and intended outcomes. Appropriate workers to carry out the actual carer's needs assessment process should be those who have had the opportunity to build up positive relationships with older family carers, such as carers' link workers from statutory or voluntary organisations, or key workers from day services. The key issue is the need to have a co-ordinator in place who is able to ensure that the carers' needs assessments are getting done, being reviewed on time and that appropriate follow-up action is being taken to ensure that the intended outcomes are happening.

KEY CHARACTERISTICS OF GOOD QUALITY CARERS' NEEDS ASSESSMENTS

Older family carers should have the opportunity to have someone carry out the assessment with them who they are comfortable with or at least to have someone else they trust present if that is their choice. It may be necessary to carry out separate assessments for each carer, where there is more than one, to reflect accurately individual needs. Similarly, it may be important to have other relatives present to make it easier to discuss sensitive issues, such as planning for future transition or an emergency.

Assessors need to be well trained and have an empathy with carers. They also need to be familiar with the issues affecting carers, people with learning disabilities and older people. Assessors need to take a person-centred approach and see the carer as a person with needs of their own as well as in their caring role.

As with other needs assessment, the worker carrying out the carers' needs assessment should take a holistic approach. Good carers' needs assessments must go beyond looking at the daily tasks of caring and the physical impact of them. The assessor should focus on more than the immediate situation. The focus of the assessment should include a range of issues and how they combine to affect the life of the older family carer. The assessor should also approach anyone else who is significantly involved in the life of the carer or who might be able to provide a specialist assessment, such as an occupational therapist. This will help to inform the outcome of the assessment. Carers' needs assessments must also take full account of the emotional impact of caring, particularly where older family carers of people with learning disabilities have often been caring for many decades.

The assessment should provide older family carers with the opportunity to air their hopes and fears for the future and whether they feel able and willing to continue to care. They should be able to discuss what will help them continue to care and plan for the future so that a transition can be made at the appropriate time, a time appropriate to them.

THE RELATIONSHIP BETWEEN THE CARER AND THE PERSON WITH LEARNING DISABILITIES

Assessors must be trained to recognise situations where the older carer and the person with learning disabilities are co-dependent. In these situations, it may be appropriate to also complete a carer's needs assessment with the person with learning disabilities to make sure that the situation is recognised and any additional support needs are identified and met. However, this needs to be handled with great sensitivity as older family carers may find the idea of a formal carer's need assessment for the person they care for threatening.

It is easy to overestimate a 'conflict of interest' between family carers and people with learning disabilities. Research has shown that very often the source of perceived conflicts of interest is unsatisfactory services designed to give family carers a break, but which do little to provide a positive experience for the person being cared for (Williams and Robinson, 2000). The assessor needs to be aware of the need to strike a balance between the needs of older family carers and the needs of the person with learning disabilities. This can be a very delicate situation requiring a great deal of skill and sensitivity on the part of the assessor.

THE CARER'S NEEDS ASSESSMENT PROCESS

Government guidance (Department of Health, 2000) states that 'practitioners must always tell carers who are identified during a cared for person's assessment, or at a later stage, that they have the right to request a carer's needs assessment.' They should also provide the carer with a copy of the Government leaflet: *How to get help in looking after someone: a carer's guide to a carer's assessment*.

There should be clear, accessible information for older family carers about the needs assessment process. The Government leaflet mentioned above can be adapted to ensure it is accessible to older family carers, (for example, printed in a minimum size 14 font). This leaflet could also be incorporated into an information sheet where the assessor can record their name and contact details and the date when the assessment was completed. It should be made clear to family carers that they are entitled to a copy of the carer's needs assessment and to make sure that their views and feelings are reflected accurately.

It is never acceptable to leave a carer's needs assessment form for the carer simply to fill in alone unless that is their choice. Even if it is their choice, the assessor should go through the completed sheet with the carer and clarify that it clearly reflects the carer's situation and needs.

Older family carers should be provided with clear and accessible information about different and creative options and choices for services and support. It is very difficult for anyone to express opinions about their situation if they are not aware of the different choices they may be able to make.

Carers' needs assessments should actually lead to practical outcomes that are positive for the carer and the family. There must be proactive systems processes in place for regularly reviewing, updating and monitoring carers' needs assessments. This process should include methods of recording, collating and reviewing unmet needs. It is particularly helpful if review dates are recorded on a computerised calendar of activity so they are flagged up and review meetings can be arranged.

Older people's services and learning disability services need to develop good cross-discipline and joint working protocols. This is especially important with health and home support services as these have traditionally not served older family carers to any significant level.

CHECKLIST OF KEY AREAS TO COVER IN CARERS' NEEDS ASSESSMENTS WITH OLDER FAMILY CARERS

It is important to see the individual as an older person and not just as a family carer.

1. Check that the primary carer knows the focus is on them in the process, that the term 'carer' means them.
2. Establish how long have they been caring.
3. Establish their daily routine.
4. Identify particular points of stress during the course of a year.
5. Establish if they have any other caring responsibilities.
6. Health.
7. Physical and emotional impact of caring.
8. Suitability of housing.
9. Finances/benefit check.
10. Mobility and transport.
11. Informal networks of support.
12. Help from statutory/voluntary agencies.
13. Regular breaks from caring, including daytime, evening and overnight arrangements.
14. Does the family carer have information about what services and supports are available to him/her.
15. What help is needed?

16. What immediate changes are desired for the person being cared for?
17. What immediate changes are desired for the older family carer?
18. Hopes for the future, including any unfulfilled ambitions and dreams.
19. What steps are being taken to support the person with learning disabilities to plan for their future?
20. What steps are being taken to support the older carer to prepare for the future? (including dealing with financial matters such as writing a will).
21. An agreed action plan based on the carer's needs assessment.
22. Clear process for reviewing the action plan.

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.

Department of Health (2000) *A Practitioner's Guide to Carers' Assessments under the Carers and Disabled Children Act 2000* London: Department of Health.

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

www.lifetimecaring.org.uk

A website that focuses on raising awareness of the needs of older family carers and their adult 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.

Older Carers Support Service

The Older Carers Support Service (OCSS) ensures that all 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. The two OCSS Support Visitors build positive relationships with older family carers to encourage people to come forward for support with problems before they turn into crises. The workers also record information about the carer and cared for person to be used in emergencies.

For further information contact: Older Carers Support Service, Sheffield Care Trust, c/o Sheffield Case Register, 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.

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* (Initiative 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

Other guidelines available in this series include 1,2,3 and 5. Please visit www.learningdisabilities.org.uk