

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

### ***Guideline 1: Introduction***

*'Everyone should have help, not just older carers. But as you get older it gets harder.'* Older family carer, Sharing Caring Project, Sheffield.

The Older Family Carers Initiative (OFCI) aims to support Learning Disability Partnership Boards across England 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.

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 older family carers. They are intended as a tool to help Learning Disability Partnership Boards, commissioners and frontline workers 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.

Learning Disability Partnership Boards are key to the implementation of the Government's *Valuing People* strategy, published in 2001. They bring together senior representatives from social services, health bodies, education, housing, community development, leisure, independent providers, and the employment service as well as representatives of family carers and people with learning disabilities.

As OFCI develops, further guidelines will be added to reflect the lessons being learned and the good practice being developed across the country.

## WHO IS AN OLDER FAMILY CARER?

The term older family carer is used to describe those older people, usually parents, who are looking after a person with learning disabilities at home. Older family carers may also be brothers, sisters or other family or friends of the person with learning disabilities. *Valuing People* defines older family carers as those aged 70 or over. However there is no fixed age that defines an older family carer: some authorities may choose 65 years as this is when people are traditionally eligible for services for older people. Even if someone is not over 70, it is important that services know which people will soon be in that age bracket so that they can plan services to meet future needs.

*Valuing People* recognises the neglect of many older family carers of people with learning disabilities and prioritises providing support to these carers. Many will have witnessed significant changes in services and support since they started caring. They may also have found themselves increasingly isolated from effective support and services. Older carers often have increasing health and practical needs of their own as older people.

A key objective of *Valuing People* is to identify and plan with older family carers to enable them and their relatives with learning disabilities to be better supported and able to plan for the future with greater confidence. Identifying older family carers and their needs will also enable local authorities to plan their services and support more effectively.

## OLDER FAMILY CARERS AND VALUING PEOPLE

*Valuing People* set out a number of targets and performance indicators for local authorities and their Partnership Boards to ensure older family carers and their relatives are better supported. These targets include identifying family carers over the age of 70, prioritising people living with older family carers for person-centred planning and supported living options and introducing a performance indicator to measure the percentage of carers aged 70 or over for whom a plan has been agreed.

Taking account of the needs of older family carers should be incorporated into most aspects of service planning and development for people with a learning disability. For example, any strategies for developing housing, modernising daytime opportunities, employment and short-break/respite services will undoubtedly impact on family carers where people with learning disabilities are still living at home. Local authorities must be aware that the impact of change is often particularly difficult for older family carers as they have lived through decades of change and although there have been big improvements in services and support overall, they may have also seen the erosion of some services they valued highly.

## **KEY MESSAGES FROM OLDER FAMILY CARERS AND PEOPLE LIVING WITH OLDER CARERS**

In recent years there has been a growth of research and dedicated support work to determine the key issues for older family carers and the people with learning disabilities that they support. The key messages from this work is outlined below (Foundation for People with Learning Disabilities, 2002).

Older family carers want:

- To know what will happen to their relative in an emergency, especially if that emergency occurs out of office hours.
- To feel confident that the organisations which are likely to be involved in their relative's care in the future know of both their existence and their needs.
- To feel confident that other family members and/or advocacy services will ensure that their relative is supported to speak up and that his/her happiness, safety, best interests and well-being will be prioritised.
- Time to plan for the future with their relative and others who can provide informed and consistent support.
- Information about the support available to enable them to continue their caring role and to plan for the future when the time is right for them and their relative.

- Flexible breaks from caring, including overnight breaks in a setting which might possibly become a realistic long-term placement for the person they care for, such as a shared care arrangement.
- Opportunities to build up positive relationships with individuals and services likely to have a role in supporting their relative in the future.
- Workers to understand their lifetime experience of caring and not to feel judged about the way they have cared for and supported their relative.
- To have peace of mind that their relative will be well looked after when they are no longer able to care.
- To be able to share the expertise and knowledge they have built up over decades of caring so that it will be available when they are no longer able to care.
- Services to recognise and value mutually dependent relationships between older family carers and their relatives with learning disabilities.
- To remain involved and valued in their relative's life, even if that person is no longer living with them in the family home.

People with learning disabilities living with older family carers have said they want:

- Choice and control over what happens to them in the future and when it happens.
- Their family carers to be involved and to support them in the process of planning.
- To feel recognised and valued as carers where they provide essential help to their older family carers.
- To have clear, easy to understand information about what might happen in the future and what would happen to them in an emergency.
- To be able to try out different housing and support options so that they can make informed decisions about their future.
- The opportunity to get to know those people who might help and support them in the future.

- To know that they will not be moved from the people and places they know and feel happy with.
- To feel confident that there will always be someone they trust available to support them to speak up and be listened to.

## 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.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

Foundation for People with Learning Disabilities website includes information about the Growing Older with Learning Disabilities programme and Older Family Carers Initiative.

[www.lifetimecaring.org.uk](http://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, Dalia 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 3QE.

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

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 (OFICI newsletter) contact:  
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Other guidelines available in this series include 2, 3, 4 and 5. Please visit [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)