

Supporting older families of people with learning disabilities

A briefing from the Foundation for People with Learning Disabilities

This is a briefing on the Foundation's Older Family Carers Initiative. The three-year Initiative has come up with a clear set of policy messages to help health and social care service providers to meet the needs of older family carers and their relative with a learning disability. We have found that there is still a long way to go to ensure that older people's services, carers' services, learning disability services and the voluntary sector work together to implement fully the aspects of the *Valuing People* White Paper that relate to older families and to provide them with ongoing support. The briefing makes recommendations for policy makers, commissioners, Learning Disability and Older People's Partnership Boards and the Foundation for People with Learning Disabilities.

Introduction

'It always hits me when I go to bed and then I lie awake just worrying about what will happen to him when I've gone.' (Margaret 73)

People with learning disabilities and their older family carers (referred to in this briefing as older families) are among the most marginalised groups in our society. Older family carers are usually parents or siblings who may have looked after their relative for 50 or 60 years, sometimes with little or no support. Relationships between family members are usually very close and often mutually dependent. People with learning disabilities living with older families are increasingly assuming a caring role for their ageing relative, but this is rarely recognised.

Older family carers live with the constant worry of what will happen in an emergency or when they can no longer care. Often in the past family carers expected to outlive their relative with a learning disability and so planning for the future was not a priority. Now fear about the future can be overwhelming. These anxieties are often shared by the person with a learning disability, who may have seen their friends losing their homes and the people closest to them simultaneously.

A bleak picture of the situation of these older families was painted in 1997¹. Older families were found to have had very poor experience of services throughout their lives and this lack of support continued into old age. A much needed focus on older families was triggered by the White Paper, *Valuing People*, in 2001. One of its policy objectives was for local Learning Disability Partnership Boards to establish a complete picture of older family carers aged 70 or over, in order to plan services in partnership with them². It also made older families a priority group for person-centred planning, helping them to make plans for the future.

Whilst the last four years have seen some real local improvements in the services and support for older families, such improvements remain patchy and initiatives are often reliant on short term funding.

Supporting Older Families

The Older Family Carers Initiative (OFCI)

The Foundation for People with Learning Disabilities was funded by a Department of Health Section 64 grant to lead a partnership including the British Institute of Learning Disabilities, HFT (Home Farm Trust), Housing Options, Carers UK and Mencap to support Learning Disability Partnership Boards to meet the needs of older families. This briefing paper is based on the findings of this Initiative.

Working closely with the Department of Health and the Valuing People Support Team, OFCI:

- produced a survey report, *Planning for Tomorrow*³, in 2003 indicating the level of support for older families from *Learning Disability Partnership Boards* and the way they planned to meet specific targets in the future
- contributed to the development of the toolkit, *Valuing Families*⁴, and its dissemination by the Valuing People Support Team
- held regional seminars, regional network meetings and action learning sets to promote, share and disseminate good practice
- published a pack, *Supporting Older Families: Making a real difference, Family Future* newsletters, good practice guidelines and booklets, utilising the shared learning from OFCI (see www.learningdisabilities.org.uk)
- carried out an evaluation in 2004 and 2005 of the impact of OFCI and to investigate how far the objectives of *Valuing People* are being implemented and proving effective on the ground.

The social policy context

Although some of the needs of older families can be met through learning disability policies, others will be met by older people's and carers' policies. These need to be tailored to their specific needs.

An ageing population

Older family carers are a subset of an ageing population. It is expected that in 2021 there will be more people over 80 than children under five⁵. People with learning disabilities are living longer. It has been estimated that over half will have a normal life span⁶.

Older families of people with learning disabilities need to benefit from the shift in policy towards older people to promote 'a wider expectation of well being, rights, choice and protection'⁷, and to partnership with older people in planning services. These are outlined in the National Service Framework for Older People (2001) and the NHS Plan (2000). These themes are also explored in *Support for Carers of Older People: Independence and well-being* (the Audit Commission 2004)⁸ and *All our Tomorrows: The triangle of care* (Association of Directors of Social Services/Local Government Association 2004)⁹.

Meeting carers' needs

It is not known how many families care for people with learning disabilities. It is estimated that there are six million carers in the UK, based on the 2001 census, and 1.25 million care for over 50 hours a week¹⁰. Most carers are of working age and approximately 70% care for older people. The experience of older family carers of people with learning disabilities will differ from that of other carers in its longevity and the expectation that the person they care for will outlive them¹¹.

The Carers National Strategy *Caring about Carers* (1999), the Carers and Disabled Children Act (2000) and the Carers (Equal Opportunities) Act (2004) are intended by Government to support the caring role. Taken together, they provide an entitlement to a carer's assessment and give access to short breaks. After April 2005, when the Carers (Equal Opportunity) Act is implemented, councils have a duty to inform carers of their rights to a Carer's Assessment (not just respond if they ask for one) and the assessment must consider their interest in work, study and leisure. Different departments in local councils are expected to work together to meet carers' needs.

Supporting Older Families

Key themes

Numbers and databases

In 2002 Mencap estimated that there were 29,000 people with learning disabilities living at home with family carers over the age of 70. They will need housing and support when their older family carer can no longer care for them¹². *Valuing People* also suggested that 25% of older families are ‘hidden’ and not known to services until there is a crisis.

A disturbing finding of OFCI was the lack of locally coordinated knowledge about numbers of older families and their needs. Of the 70 responses from Learning Disability Partnership Boards to the OFCI survey¹³, only 47% stated that they knew how many people with learning disabilities live at home with a family carer aged over 70. When asked if local information systems are updated to identify carers approaching 70, 43% replied in the negative. Only 13% of respondents stated that they had mechanisms for monitoring the establishment of a carers’ register by GPs, a key objective of the Carers National Strategy. Although not mandatory, it would be helpful if all GPs did record which of their patients were carers and with permission, contributed the information to a local database. GP practices are often the main point of contact for hidden older families.

The OFCI final evaluation has indicated some improvement in identifying older families over the last two years. Most respondents stated that databases of older families have been developed or are at a planning stage, but a majority reported ongoing difficulties. Those most frequently mentioned were: lack of time to keep it up to date; problems in identifying people not in receipt of statutory services; linking to other systems; lack of any baseline information; engagement with families from minority ethnic communities; the poor quality and lack of information previously kept, e.g. no date of birth for the person with learning disabilities or their family carer, and boundaries of data protection and confidentiality.

Where databases are maintained, as in Sheffield and Warwickshire, for example, they are an invaluable resource in helping to plan services, reducing isolation and ensuring that families are less likely to fall through the net¹⁴. It is preferable that such databases are maintained from school leaving age and not just introduced to record the needs of older families. Even if families are not currently using statutory services, they can be contacted by an annual or biennial phone call or visit.

Although support is becoming more individualised through person-centred approaches and self-directed services, there is a need for service commissioners to aggregate information about demand and use this strategically to feel confident that they can meet local needs now and in the future¹⁵. Otherwise there will be crisis management and the real risk that people with learning disabilities may be inappropriately placed, for example in a nursing home¹⁶ or away from their own community.

Building up confidence and maintaining continuity

“I haven’t seen a social worker for over ten years now. Don’t they care how I am doing?”

The OFCI evaluation confirmed that securing the confidence of older families is a long-term issue. It is hard to overcome the anger and mistrust of many families who feel let down by services and lack of communication and are weary with changes in policy and provision over a number of years or decades. *Caring About Carers* (1999) highlighted the fact that three-fifths of carers receive no regular visitor or support service at all – yet this form of proactive support is clearly valued by older families and can also ensure that services become alerted to problems before they become crises. Both *Valuing People* and the National Service Framework for Older People emphasise the importance of care coordination and person-centred approaches for individuals and their carers.

Older family carers often expressed a preference for talking with and being supported by someone from a voluntary sector organisation, believing that they will help them by advocating with statutory services.

Supporting Older Families

OFCI heard many positive examples of dedicated support posts for older families being funded within the voluntary sector in carers', older people's and learning disability organisations. Dedicated workers for older families within statutory teams have also proved effective, ensuring that older families have up-to-date assessments and regular contact. Feedback from older families about this kind of support is extremely positive, with family carers particularly valuing the opportunity to be known to and to build pro-active relationships with workers who can provide them with information and links to other sources of support. Sometimes different family members might welcome their own advocate to help them articulate their distinct needs.

In West Sussex families have access to an older families support worker through the Learning Disability Development Fund (LDDF), while funding from the Carers Grant (CG), is enabling families in Sheffield and Southwark for example to have a similarly dedicated worker. The LDDF provides short-term funding and the CG, although growing year on year, is no longer ring fenced. The desired aim of continuity is at risk if long term funding is not secured.

The Planning Ahead Project (at the Sharing Caring Project in Sheffield, part of the Foundation's Growing Older with Learning Disabilities [GOLD] Programme) emphasised that there are sensitive issues to address and that decisions about the future take time. It identified eight stages in planning ahead¹⁷. This project also underlined that there are often immediate issues that need to be addressed before longer term planning can begin, for example: what would happen in an emergency, benefits and short term breaks. This was particularly the case for those from minority ethnic communities, as demonstrated by the linked GOLD Pakistani Carers project.

The need for joined up approaches

As Malcolm Wicks, the Minister for Pensions, argued in 2004¹⁸ with respect to older people in general, 'If we are going to succeed in modernising services, we need to break down the organisational barriers which lead to poor fragmented services. We need to develop whole system approaches which look at the needs and aspirations of older people in the round.' This is of even greater importance for older family carers and their older relative with a learning disability, because of the complexity of their situation.

There is something badly wrong with the translation of policy into practice if one worker comes in to prepare half a pizza for an older family carer's tea and half an hour later another worker arrives to cook the other half for the person with learning disabilities, as reported by a learning disability nurse in one locality.

The work of OFCI has demonstrated the importance of learning disability, older people's and carers' services linking together, along with voluntary organisations, to meet the needs of these older families, with different organisations taking the lead in different areas. Pilot projects can provide learning about how services can best work together, recognising that each area will need to find its own solutions, but that good practice and models can be widely disseminated.

Coordination and collation of assessments linked to care management and future strategic planning remain a challenge. Several different assessments need to contribute to planning to meet the needs of different members of older families. These include the single assessment process for older people established through the NSF, person-centred planning linked to health action planning for people with learning disabilities as outlined in *Valuing People*, and carers' needs assessments (which may be relevant for some people with learning disabilities as well as their family carers).

Currently some people seem to have multiple assessments and others slip through the net. Advice from the Valuing People Support Team (2003) suggests that the role of a 'named person/service coordinator' should include helping to access services, service coordination and ensuring good communication between all involved people¹⁹. In many areas community learning disability teams are struggling to implement this advice.

Supporting Older Families

Training is crucial in delivering support across agencies. Training about good practice in working with older families should be required for staff from services for older people and for people with learning disabilities to ensure that they are aware of the complexity of overlapping issues and the impact of the lifetime experience of caring. Families need to be involved in designing and delivering such training.

The need for information

Families need information about eligibility criteria for their own needs as carers as well as for their family member. It is important for them to be aware that Fair Access to Care Services (2003) prioritises longer term risks to independence as well as addressing immediate needs. Local criteria do not always make this clear.

Staff and families need more information, particularly about the range of housing and support options that exist for people as they leave the family home. Many families may have very little knowledge of the changes that have occurred since the closure of the long stay hospitals and the opportunities for supported living (tenancy or home ownership with support, including the possibility of inheriting a family home)^{20 21}.

Misunderstandings about the options from conversations with professionals from many decades ago may need to be rectified to avoid false expectations and unnecessary fears and to allow for realistic planning.

One family carer in her late 80s dissolved into tears when discussing possible future housing options for her son. Fifty years earlier she had been told by a doctor that if her son moved anywhere she would no longer be allowed to have any contact with him.

There may also be misunderstandings about the implications of the term independent living, with many older family carers believing that this may result in a lack of appropriate support. Housing providers need to coordinate their systems with other services to ensure that older families can pass tenancies on where appropriate. Increasing capacity for outreach support and extra care housing may enable older families to stay together and remain independent within their communities for longer.

The development of Direct Payments and individualised budgets as envisaged in the Prime Minister's Strategy Unit report (2005)²² will have implications for local authorities and the development of the role of Centres for Independent Living to ensure that older families are fully informed and supported.

Currently the numbers of people with learning disabilities using Direct Payments, though growing remain small^{23 24}. Local authorities need to raise awareness amongst their staff about their duty to offer direct payments where people are eligible for them. They need to know that access to direct payments has been extended to older people and carers, and new provisions allow direct payments to be used to purchase care provided by a family member in exceptional circumstances. Direct payments is one way forward. It can offer real choice and flexibility. In widening access it is important that older families have the necessary support. It can appear onerous and may not appeal to all families, particularly older families.

Christine Bigby's research has recognised the importance of the continuing advocacy role of family and friends after the deaths of the primary carers through 'key line succession planning'²⁵. Involving other family and friends will provide much reassurance to older family carers and may also lead to more creative solutions to long term planning, such as using self-directed services.

Supporting Older Families

Addressing the poverty of many older family carers

Acheson²⁶ concluded in 1998 that older people are more likely to be living in poverty and the poorest pensioners who rely mostly on benefit have experienced a relative deterioration in their income. OFCI heard evidence about the vulnerability of older family carers. It is likely that their caring role has prevented at least one parent, usually the mother, from working and building up savings and a pension. Although the National Carers Strategy has led to carers over the age of 65 being able to claim Carer's Allowance, in reality this currently only makes their state retirement pension up to the full amount, although some may qualify for additional Pension Credit. This is a shock for many older family carers. People are often still providing regular and substantial care well into their 90s and are not able to 'retire'. It is also important to ensure that they are not unnecessarily penalised by the Fairer Charging Policies, particularly where there may be more than one person in the household receiving support.²⁷

If their relative moves away from the family home or dies, there is a real risk that the withdrawal of benefits which have contributed to the family budget over many decades will leave the older family carers in greater poverty. More supports need to be created so that future older family carers are able to work if they choose to and state benefits for long-term carers must be adequate.

Conclusion

It is so lovely to think that I can pick up the phone and talk to someone who understands, whom I have known for some time, and that I don't have to repeat my story over and over, We just didn't have any support before. I felt very alone. (Ann 81)

Giving older families confidence in the future by enabling them to plan for their immediate and future needs to be met is a pressing and ongoing task. The development of policy locally and nationally must involve older families and take account of the individual and collective needs of this vulnerable group.

Whilst some progress in local areas has clearly been made, the quality of support older families receive still seems based on a postcode lottery rather than being linked into monitored national standards. Time is running out for many older families, but meeting their needs must not be viewed as a quick fix for the generation of families who chose not to send their children to the long stay hospitals decades ago and now are caring in their eighties and even nineties. This is an issue that needs continuing attention and priority.

The expectations of younger families may differ from those of older families, but many will choose to continue to support their relative with a learning disability in the family home well into adulthood or to opt for self-directed services. These may still rely heavily on continued input from family carers. Improvements in medical and social care mean that future generations of older people with learning disabilities will, overall, have more complex disabilities and create greater challenges for services in the future. Eventually plans will need to be made for older age. Services need to be constantly planning ahead to meet the next generation's needs.

Some of today's younger families may well become 'hidden' after leaving the education system as more young people with learning disabilities live their lives in mainstream, rather than specialist provision. Unless it is possible to track them through their adult life (and they wish for this to happen) some may only become known to services when a crisis looms as families age.

It is important that age discrimination is rooted out. With the Public Sector Duty in the new Disability Bill, local authorities will have to address some of the current inequalities in support for older family carers and their families. Single Equality legislation would also be likely to benefit older families.

Supporting Older Families

It is consistent with the spirit of article 8 of the Human Rights Act 1998 (on the right to respect for private and family life) that older families should be supported and when it is time for a person with learning disabilities to move from their family home, the process should be conducted with sensitivity. They should be able to live in a place of their choosing with the right support, maintaining links with their community and their family if they so wish.

Recommendations

For the Foundation for People with Learning Disabilities

The Foundation for People with Learning Disabilities should carry out a study of the impact of the current benefits system on the lives of older families.

For government and local policy makers

A national learning disability information strategy should be developed encompassing a range of services with appropriate safeguards for confidentiality²⁸. Local authorities and Primary Care Trusts should ensure that databases are in place to record the numbers and needs of people with learning disabilities from the time that they leave full-time education. These should be updated regularly and used as a tool for strategic planning. Protocols should be drawn up to ensure that information is only shared on 'a need to know' basis.

For local policy makers

Older people's partnership boards, learning disability partnership boards and carers services should coordinate their work with the statutory and voluntary sectors to meet the needs of the older families of people with learning disabilities taking into account the number of people with high support needs living with older family carers. They should share responsibility, but identify one agency or partnership board to take the lead. They should ensure that older families have access to a named person/ service coordinator to support them in planning for their immediate and future needs.

Local authorities, older people's partnership boards, learning disability partnership boards and carers services should monitor quality outcomes from assessment and care management processes and person-centred plans to ensure that older families are enabled to plan for the future in a meaningful way.

Local authorities should ensure that Direct Payments and other forms of individualised funding, with the necessary information and supports, are available for the older families of people with learning disabilities who choose to use them.

For Government

The Government should monitor the implementation of the Carers (Equal Opportunities) Act to ensure that local authorities are progressively improving older family carers' access to practical support, leisure, employment, education and training.

The Government should increase funding for advocacy services so that all older family carers and/or people with learning disabilities who wish to use them can do so.

The Government should re-emphasise through national priorities and performance monitoring the importance of the Carers' Grant to provide on going support that can make a real difference to the lives of older families.

Supporting Older Families

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