

### Aims

The aims of the project were:

- To directly support the development and promotion of good practice in supporting older families to plan for the future where a person with learning disabilities is providing regular and substantial care to their elderly relative.
- To provide expertise and support directly to a sample of Local Authorities to enable them to develop a coordinated response that can be proven to make a positive difference to the lives of people with learning disabilities and their ageing relatives who are caring for each other.
- To champion innovation and support for the needs of all members of older families, particularly in relation to mutual caring, which has not been highlighted nationally by other organisations or policies.
- To disseminate good practice and lessons learned from the development work.

### Making use of the findings

The conclusion of the project is that the incidence of mutual caring is growing, but that its true extent is not known. Mutual caring is often not recognised because older family carers and their

relatives with learning disabilities do not recognise the implications of their changing roles and levels of dependency; where they do recognise the situation, there may be a reluctance to inform services for fear of generating an unwelcome or over-intrusive intervention. Mutual caring may be a short-term issue, for example if the older family carer becomes ill, but for many it reflects the increasing frailty of the older family member and is therefore longer term and likely to become more onerous for the person with learning disabilities. Older people's services, learning disability services and carers' services are generally unaware of the emerging issue of mutual caring. Because of professional boundaries and conventions, lines of responsibility are confused and families can fall between all three services.

The findings from this study, and the accompanying materials that have been produced, provide guidance and strategies for how to develop an effective service response to these families. They can also help commissioners in the development and review of their strategies on older family carers and people with learning disabilities.

Recent and proposed changes in social care, including the personalisation agenda and individual budgets, together with increased pressures on social care budgets, provide both opportunities for and threats to the provision of an adequate service response to older family carers that include

people with learning disabilities. It is imperative that the needs of such families are acknowledged and addressed sensitively and urgently.

On the following pages we set out some of the main findings of the project. Based on what was learned during the project, a number of recommendations are made as a basis for future good practice with this family situation. There is also reference to a number of resources that can be used by older families and workers, as well as a DVD, based on family stories, which can be used to raise awareness amongst families, service professionals and commissioners about this emerging but urgent social issue.

## Key findings

- People with learning disabilities may get immense satisfaction from the responsibility of providing care for their older family members and carers. However, like all family carers, they may not recognise the tipping point at which the strain of providing care becomes too much and when some external support would be appropriate.
- Families whose members are providing mutual care often fail to recognise when the situation has arisen or has reached a point where it may not be sustainable because of the pressure it puts on one or both parties.
- Where such families do recognise the changing nature of their caring relationship, there is often a reluctance to inform care professionals in case this results in excessive or intrusive intervention over which they have no control and, at its most extreme, prevents them from living together.
- The increasing frailty of a family carer living with a relative with a learning disability can lead to additional pressure being placed on other family members (not living in the home) who may assume responsibility for both members.
- Learning disability services, older people's services and carers' services often do not work well together. This is evidenced both in the response to the needs of mutual caring families and in attempts to develop appropriate services and service responses in some areas. Yet they all have a responsibility to support these groups.
- Most health and social care professionals are not aware of the growing incidence of mutual care and therefore are not on the alert to identify warning signals. Older people's support workers should consider the impact of the growing frailty of a family carer on their learning disabled relative; day service workers should follow up on people with learning disabilities who have frequent, unexplained absences. This may often be associated with a need for the learning disabled person to provide increasing support to the older family carer.
- Health and social care professionals still do not sufficiently address the interdependency of the ageing families of people with learning disabilities living at home. This leads to interventions that can jeopardise the caring relationship or that put additional pressure on the other family member. For example, in one family the learning disability team began arrangements for their client to move out of the family home without any consultation with

his mother with whom he was living, who was dependent on him for her own care needs and on whom he too depended for support in day to day living. Similarly, changes in the support given to the older family carer will have an impact on the quality of life of the person with a learning disability.

- Given the pressures on both learning disability and older people's services, attempts are often made to offload responsibility from one service sector to the other (even though support may not be forthcoming). This leads to a care gap for families and presents greater problems in the longer term.
- Early identification of families when mutual caring is becoming established will enable early interventions to be made that can support and sustain the family in staying together in the family home. Failure to provide early, often low level, support can lead to the caring relationship breaking down and more radical and expensive service options being needed for both the older family carer and the person with a learning disability.

## What can commissioners and care managers do?

### *In relation to health and social care staff*

- Raise awareness among workers about mutual caring.
- Provide on-going training and awareness raising across a wide range of services, with a particular focus on frontline staff such as GP receptionists and learning disability day centre workers.

- Include appropriate questions in assessments for carers and for people with learning disabilities to identify situations of mutual caring and repeat at regular intervals, especially where family carers are over 65, or where there is only one family carer.
- Introduce a means of measuring the incidence of mutual caring.
- Develop close working relationships between learning disability and older people's services to ensure appropriate sharing of information and to enable the delivery of support services, that address the interdependent needs of the family carer and the person with a learning disability.
- Integrate the needs of this group of people into local carer services, which are generally unfamiliar with people with learning disabilities acting as carers.
- Ensure person-centred planning includes crucial family members, specifically the older family carer and the learning disabled carer as well as appropriate extended family members.
- Develop service protocols that set out clear lines of responsibility between learning disability and older people's services for providing appropriate interventions to families providing mutual care. These will respect the needs both of the family carer and of the person with a learning disability who is assuming caring responsibilities.
- Learning Disability Partnership Boards should link with mainstream older people's and carers' programmes and seek to work in greater

partnership with these services. In particular, they need to ensure that their respective strategies join up and that funds linked to the Carers Grant and elements of the new National Carers Strategy include initiatives to benefit mutual carers.

### *In relation to families*

- Develop relationships with families to provide them with the confidence to say when a situation of mutual care exists.
- Provide accessible information for families about mutual caring. This might include information on services, e.g. short breaks and respite, available through learning disability, older people's and carers' services.
- Work with the older family carer and the person with a learning disability who is assuming caring responsibilities and help them to recognise and acknowledge the extent of mutual support being given and so consider whether it is appropriate and sustainable. Ensure carers' assessments are conducted with both the family carer and with the carer with a learning disability, and that these lead to practical, joined up outcomes, including robust emergency plans.
- Make sure that care packages and personal budgets reflect the changing nature of the caring relationship and take into account the needs and preferences of both family members.
- Promote Circles of Support as a way of involving more people in a family's network.
- Develop effective person centred planning: this

is the key to working well with families and is most likely to reveal mutual caring.

- Improve advocacy for older people and people with learning disabilities and carers. This will enable needs to be identified more quickly and the views of the person and the family to be heard.
- Provide support groups for people who are mutual caring to make sure they get the practical and emotional support they need.

### **Lessons from the project**

The project was originally designed to conduct in-depth work with five families in each of four areas. Although all areas had volunteered to participate because of their interest in the topic, three were unable to deliver even this small number of families for inclusion. In two areas this was because of the loss of the local champion who had been keen to develop this work. In the third area, very important and influential work had been conducted on this topic and there was originally very considerable enthusiasm to take it forward. However, after protracted inter-service negotiations on issues such as structure, staff contracts and lines of responsibility, the project failed to get established.

Three of the original pilot sites involved work that took place in voluntary sector organisations. While work in the voluntary sector often offers greater opportunity for innovation and may be seen as less threatening to older families, there are greater challenges in getting statutory bodies to take ownership of the issues revealed. Most projects that have been most active in revealing mutual caring have been short term and on soft funding, which threatens the long term security of their work.

These kinds of issues, which fundamentally affected the progress and eventual shape of this project, are endemic in developing new service initiatives and reveal considerable vulnerability in bringing them to a successful conclusion. These negative lessons contributed to a consensus among those involved that service provision for families providing mutual care must be embedded within mainstream services to ensure that it will be effective and can be sustained over time. Older people's services offer the most practical avenue for mainstreaming support for mutual carers, though the pressure on resources for older people's services in general remains problematic.

Case studies from the project highlighted the use of person centred planning approaches as underpinning successful work with older families where mutual caring was happening. The approach enabled all family members to explore and speak up about their wishes, needs and concerns and feel a valued part of a process. It also offers a transparent framework for gathering the views and concerns of others, whilst looking for solutions that could be agreed by those involved. Discussing the caring role of both the older person and the person with a learning disability fitted naturally within this framework, in many cases leading to carers assessments for one or both of the carers' resulting in improved practical support and recognition of the mutual caring situation within the household.

Carers' assessments remain the most important mechanism for identifying and supporting carers. As part of this pilot, Shropshire was able to embed an easy-read version of their carer's assessment within mainstream processes and highlighted issues through training and awareness-raising sessions. The project was able to build on this success by working alongside the Valuing People

Team and their Network for Carers with Learning Disabilities to develop and write *Being a Carer and Having a Carer's Assessment: How to get help if you are doing a lot to look after another person*. This resource pack for carers with learning disabilities has proven an effective tool for people with learning disabilities to use with someone they trust to identify whether they are a carer and what support and help may be useful. It has been freely and widely distributed through the Valuing People Team and feedback has been extremely positive, with workers reporting the pack as a 'safe' tool to enable them to broach the issue mutual caring with older families.

## Influencing policy

Mutual caring in older families that include people with learning disabilities has gained wider recognition nationally and the Mutual Caring Project has been heavily involved in working in partnership with others to influence the policy agenda.

The 2008 national carers' strategy, *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*, singles out carers with learning disabilities as one of the hidden groups of carers whose needs must be identified and met as part of the new strategy. The document includes a case study supplied through the Mutual Caring Project that directly illustrates the interdependency within older families that include people with learning disabilities. Strong links between the National Network for Carers with Learning Disabilities and the Standing Commission on Carers are ensuring that mutual caring remains visible within the wider carers' agenda.

Valuing People Now (2009) identifies carers with learning disabilities, older families and the need to mainstream their issues within mainstream carers' services as a key priority within its delivery plan. As a direct result, three streams of work are being led through the Families Programme at the Office of the National Director of Learning Disabilities, all of which ensure that the needs of older families where mutual caring is happening are being prioritised and supported at local and regional levels. This work is being steered through the National Valuing Families Forum and the Network for Carers with Learning Disabilities and includes a partnership with the Princess Royal Trust for Carers and Crossroads Care.

Policy initiatives that affect the lives of older people, such as the Prevention Package for Older People and the Partnerships for Older People Projects, emphasise the need to provide on-going and preventative support to maximise older people's choice, independence and well-being. Strategic leads for health and social care for people with learning disabilities need to link with the strategic leads for older people to ensure that older families where there is mutual caring are offered the support that is available through these initiatives.

## Conclusion

The Mutual Caring Project has shown that growing numbers of people with learning disabilities living with ageing family carers are themselves assuming caring responsibilities. The support given ranges from help with shopping, to relatively heavy domestic tasks such as changing beds and the provision of intimate personal care. As previous work has shown, families are often reluctant to involve service professionals because of bad past experiences or because of their fear that outside intervention may jeopardise their caring relationships.

The kinds of problems identified in this project are similar to those identified in previous studies of the circumstances of older families of people with learning disabilities: for example, the need to recognise their interdependence, the need for timely and appropriate interventions that respect the wishes and experience of both family members and the need for the different service sectors to work more effectively together.

Mutual caring is a natural extension of more people with learning disabilities surviving into older age, living in the family home. The needs of these families are immediate and urgent. Neglecting them will lead to greater costs to services in the longer term and seriously threaten the quality of life of family members in the short and long term.

## More information

The Foundation for People with Learning Disabilities has produced a number of resources from the Mutual Caring Project that can all be downloaded from the Foundation's website at [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk):



*Mutual Caring* – 4 films: Being a Carer, Carer's Assessment, Person Centred Planning, and Peer and Group Support. All of these films feature older families where mutual caring is happening.



*Supporting You as an Older Family Carer*: A booklet to support older family carers of people with learning disabilities to get the right support now and to plan for emergencies and the long term.



*Supporting You and Your Family as You Grow Older Together:* A booklet for people with learning disabilities who live at home with an older family carer.



*Supporting You to Support Your Family:* A booklet for family and close friends of older families that include a person with learning disabilities.



*Supporting Mutual Caring:* A booklet for workers in services who are supporting older families that include a person with learning disabilities.



*Circles of Support and Mutual Caring:* A booklet outlining the use of circles of support with older families that include a person with learning disabilities.

If you require bulk copies of the above resources for your service or agency please contact us.

The Foundation can provide training and consultancy to organisations who want to enhance and improve their services to older people with learning disabilities and their families.

To discuss your training and consultancy needs please contact Molly Mattingly:

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