

Supporting Mutual Caring

A booklet for workers in services who
are supporting older families that include
a person with learning disabilities



Part of the Mutual Caring Project

Foundation for People
with Learning Disabilities

Acknowledgements

The Mutual Caring project helped to promote the recognition of good practice and provide the guidance in supporting older families where a person with learning disabilities is providing regular and substantial care to their elderly relative who is also their carer.

We are extremely grateful and would like to thank all the families who have been willing to share their good and bad experiences with us and have helped to shape the films and the supporting booklets. Their contributions have been invaluable as their personal stories can help all of us to learn better ways to support families as they grow older and where mutual caring is happening.

We would particularly like to thank Bromley Mencap's Mutual Caring Project, families and workers from Shropshire, Norfolk, Leeds, and Sheffield for helping us to take our work forward, along with members of the National Network for Carers with Learning Disabilities organised and facilitated through the Valuing People Family Carers programme.

The Foundation is also grateful to the members of the Mutual Caring advisory committee for their support and commitment throughout the project:

Cally Ward – Valuing People Family Carer Lead, Office of the National Director (Learning Disabilities)

Professor Carol Walker – University of Lincoln – author of project evaluation and Need2Know guidance

Flick Pennal – Community Council of Shropshire

Andrew Roffy – Bromley Mencap

Annette Elliment – Bromley Mencap

Noelle Blackman – Respond

Christine Towers – Foundation for People with Learning Disabilities – author of Circles of Support booklet

Molly Mattingly – Foundation for People with Learning Disabilities

Recognition:

Dalia Magrill (Project Co-ordinator – Mutual Caring Project) – author of booklets for Mutual Caring Project as edited by Radhika Holmstrom

Justin Pearce-Neudorf - Foundation for People with Learning Disabilities - publication design



Supporting Mutual Caring

A booklet for workers in services who are supporting older families that include a person with learning disabilities

Contents

Who should read this booklet?_____	1
Introduction_____	2
Understanding older families and mutual caring_____	4
Responding to the challenge of mutual caring_____	9
Getting local support right for mutual carers_____	14
References_____	23
The Mutual Caring project_____	24

Who should read this booklet?

This booklet should be read by anyone who is working in a service or role where they may come into contact with an older family in which a person learning with disabilities is taking on a caring role for their older relative.

It focuses on three main topics:

- understanding mutual caring
- responding to the challenge of mutual caring
- getting support right for families who are caring for each other.

A DVD called 'Mutual Caring' has been produced to support this booklet. It contains four different films:

- 1. Being a carer.** An overview of the key issues around mutual caring.
- 2. Person centred planning.** This film shows the story of George and his Aunt Margaret and how person centred planning approaches have helped them get the help they need now, as well as plan for the future.
- 3. Carers' assessments.** Michael's story highlights how his life as a carer for his mum was improved following recognition of his role and a carer's assessment.
- 4. Group and peer support.** This film focuses on the benefit of group and peer support for both carers with a learning disability and older family carers as demonstrated by Bromley Mencap's Mutual Caring Project.

In addition to this booklet and DVD, a further three booklets have been produced by the Foundation for People with Learning Disabilities for older family members where mutual caring may be happening. The booklets help family members and friends think about help that may be useful now, planning for emergencies and long term planning.

For more information about supporting older families of people with learning disabilities generally, please visit the website of the Foundation for People with Learning Disabilities at www.learningdisabilities.org.uk where there are a number of free downloadable resources. These include the publications *Supporting Older Families: Making a Real Difference*; *Person Centred Planning Approaches and Older Families*, and a number of other good practice guidelines and policy briefings you may find useful.

Introduction

What is mutual caring?

More people are living longer than ever before, including people with learning disabilities. As a result, an increasing number of people with learning disabilities are still living at home with family carers who are now 70 or older. Those carers may be parents, siblings, grandparents, other close relatives or friends. They have often spent a lifetime caring.

Over the years, as family carers start needing more support themselves, the families have often developed routines and ways of coping that mean that both the older person and the person with a learning disability are looking after each other. This is known as mutual caring.

An increasing number of people with learning disabilities are providing regular and substantial care for their ageing relatives. This care ranges from help with personal care, medication, cooking and cleaning, to help with shopping and keeping them company as they go out and about less. In many cases, neither person would be able to remain living independently within their local community without this support.

However, mutual caring amongst older families often remains hidden. Mencap's report, *The Housing Timebomb* (2002), estimated that 29,000 people with learning disabilities are living at home with family carers aged 70 or over; *Valuing People* (Department of Health, 2001) estimated that one in four of these families is not known to statutory services until there is a crisis.

What can you do?

This booklet will highlight some of the main issues facing mutually caring older families and some of the ways that people in different services and roles can make a positive difference. The suggestions in each chapter are not a definitive list, but they should help you get started.

Identifying and supporting mutually caring older families and the needs of carers with learning disabilities are priorities for Learning Disability Partnership Boards and are also highlighted within the National Carers Strategy, *Carers at the Heart of 21st*

Century Families and Communities (Department of Health, 2008). There may already be initiatives supporting mutually caring older families in your area, and/or services that are not aimed specifically at this group but which they can use effectively. However, it may be that, because these families are not known to services, there is nothing for them – which means that when they do come to attention, nobody quite knows what to do.

All too often mutually caring older families slip through the net between services for older people, people with learning disabilities and generic carers' services. Families have said they often feel they are juggled between services and no one will take any responsibility for meeting their needs.

You can play a very important part in making sure that someone does take that responsibility.

Understanding older families and mutual caring

This section will outline some of the main points in more detail.

Who do we mean by older families?

The term 'older families' is quite loose, and that is deliberate: it covers all the members of the family. Those members have separate needs, but at the same time those needs are interlinked and are sometimes difficult to differentiate.

Older families can usually be defined as including:

- The older family carer(s): the person or people aged over 65 (usually but not always a parent) caring for someone with a learning disability, usually at home. Many people in this situation do not recognise themselves as a 'carer', but think of themselves as just carrying on the way they always have. They may well also have health, mobility and/or financial needs of their own by now.
- The person with a learning disability: this person may be in their 40s or older, but may be considerably younger – especially as increasing numbers of grandparents are taking up caring roles. Many of the people living at home with older family carers are among the more able of the learning disabled population.
- Members of the extended family and close friends: whether these people live nearby or far away, they are often still very involved in their family's life and provide a mixture of practical and emotional support. They also often have other family, caring and work responsibilities – and possibly also needs of their own as older people – that frequently get overlooked. It can be very difficult for these family members to cope with the mixed emotions of knowing that mutual caring is keeping their relatives together whilst also knowing that often the person with a learning disability is not able to make as many choices over their caring as they have been able to themselves.



“You just do it and get on with it and don’t think anything about it.”

Annie, 93, has cared for her son, Ian, for over 50 years. Annie still supports and guides Ian throughout daily life, and Ian now does lots to help his mum manage everyday tasks. Both Annie and Ian are supported daily by Ian’s sister, Sandra, who lives nearby.

Older families are often caring for other people too, such as grandchildren, partners and/or other relatives.

In addition, many older families continue caring (on both sides) even if and when the person with a learning disability stops living full-time in the family home. Family members frequently continue to provide regular practical and emotional support, as well as advocacy, and a lot of people with learning disabilities who are living independently still spend a significant amount of time with their families.

Why are many older families ‘hidden’ from formal services and support?

Many families have never dealt with services at all since the point when their child was diagnosed with a learning disability. They were given the choice between institutional care and looking after their relative at home – and often literally picked up their children, walked from the room and never saw anyone to do with statutory services after that point. This is particularly the case for people born before the mid 1960s, since children with learning disabilities have only had the legal right to an education since 1971.

Other families have had some contact with services, but still do not trust them – especially as they have seen so much change, and so many different people, over the years. A lot of people have read or seen very negative coverage of the things that can



go wrong, and/or do not know much about what is on offer to support with people with learning disabilities today.

Many older family carers feel very strongly that they are the best ones to care for their relative with learning disabilities. Because those families have worked out their own ways of dealing with any problems, people outside the family usually assume that they are coping well, until it is quite apparent that things have gone badly wrong.

In addition, many older family carers simply do not make their own needs a priority. They do not want to take valuable resources away from people who may need them. Eligibility criteria that require people to admit to having critical or substantial needs do not help. When asked, many older people will say 'I manage', and do not mention any difficulties they have with managing.

When does 'helping out' turn into 'mutual caring' in older families?

There is no fixed point where the balance of caring tips so that both the older person and the person with a learning disability are caring for each other, especially as it is usually a slow process during which everyone involved adapts as they go along. (The exception is if the older family carer has an accident or suddenly becomes ill.)

Some aspects of caring and support are easy to recognise, like preparing meals, pushing a wheelchair or helping a person with their personal care. Others are less obvious, such as providing emotional support, companionship, making sure someone is safe in their own home and ensuring that they take their medication. These forms of caring are often overlooked, yet they play an equally important part in enabling someone to live in their own home and community.

Eddie, 63, had lived at home with his father his whole life. His father was becoming frailer, the two of them rarely went out and Eddie seemed to want a change of scenery. His brother and daytime support workers arranged for Eddie to start using a local short breaks service, and the introductory tea visits went well. However, on his first overnight stay Eddie became uncharacteristically distressed, throwing furniture and shouting loudly. When he returned home the next day, it became quite clear that he'd been worried about how his father would cope without him. Until that point, no one had realised how much the two of them relied on each other.



What are the biggest issues facing mutually caring older families?

Some of the hardest issues facing families in this situation include:

- Not fitting neatly into services and support. Often, nobody is sure which service should take responsibility for these families; so they are passed around, they fail to get adequate support from anyone, and difficult situations deteriorate. The only way to deal with this is through a 'whole family' approach, and by developing protocols for recognising and responding to the needs of mutually caring older families. Personal budgets offer great opportunities for 'joined up' support, and for enabling families to get the specific support they need – but families do also need the right practical support in order to use personal budgets most effectively.
- Not recognising that they are carers. Older family carers in particular can find it very hard to accept how much they now have to rely on another person, especially when they have spent a lifetime caring for that same person. Similarly, many people with learning disabilities do not recognise their role as caring.
- Fear of 'interference'. Families who have had little, if any, contact with formal services can be extremely frightened of how services may respond if they realise how much family members depend on each other. Older family members are particularly worried about 'strangers' coming into the home. Above all, they worry that these strangers will break up the family.
- Feeling 'judged'. Many older family carers already struggle with comments and attitudes that make them feel they have been selfish and overprotective and that they are denying their relative opportunities for independence – even though the reality is often very different, and they have actually made it possible for that person to live a full, happy and healthy life. Now that the person with a learning disability is caring for them too, they worry that they will be seen as restricting their relative's life even further.
- Lack of information about alternatives. Many older family carers and many people with learning disabilities who now find themselves caring are simply not aware that there are alternatives to caring in the way they are doing now. Even if up to date, relevant and accessible information about topics such as health conditions or useful services is available, nobody may have realised that they need it.
- Lack of practical support. Even families who are managing relatively well could benefit from help with things like shopping, changing light bulbs, gardening,



getting to and from appointments and filling in paperwork and forms. These are often tasks that neither person can manage, and community services and schemes that can provide this kind of support are enormously useful.

- **Social isolation.** It is widely recognised that most carers do not have the same social, work, learning and leisure opportunities as other people. Many older family carers of people with learning disabilities have been isolated for decades already, and as they get older their social networks shrink further. Similarly, the people with learning disabilities whom they support can become isolated by their caring responsibilities too – especially if their social lives relied on someone who cannot take them out and about any more; often, they feel that they cannot go out to use day or evening services, because their older relative needs them.
- **Emergency and long term planning.** This is usually the biggest concern of all. Most older family carers have always been extremely worried about emergencies and/or the future, but these worries get even worse as they become less independent themselves. It is absolutely crucial that these families get the opportunity to start talking about their concerns, and get the help they need to start working out ways of dealing with them.

Most of the issues and challenges that have been raised in this section are common to all carers. However, the struggle is usually even more difficult when one of the carers is a person with a learning disability.

There is a lot you can do to support older families who are providing mutual caring. The next sections will suggest ways in which you, your service and other organisations and workers can do this effectively.

Responding to the challenge of mutual caring

“Ever since you talked to me about mutual caring, I’m starting to see it everywhere.” Worker from Shropshire

Supporting older families that are providing mutual caring can be quite low-key: it can be anything from just ‘keeping an eye’ on the situation to making an actual referral. The key thing is that you are able to recognise mutual caring, appreciate the complexity of it and have some ideas about how you can offer different levels of support.

Joining up support and funding for mutual caring families

A range of services ought to be aware of the issue, including:

GP practices. Often GP practices are the first to have the opportunity to realise the extent to which family members are caring for each other. Many GP practices now have carers’ link workers, and keep records of which patients are carers too. It is particularly important that they also record carers with learning disabilities.



A GP practice raised concerns about an older family after being visited by a man with a learning disability who was very worried about his mother and her medication. A home visit by a practice nurse revealed that the two people were struggling to cope with daily tasks, and that the son was very anxious about helping his mother with her medication as he was unable to read labels. The practice arranged for pills to be delivered regularly using a Nomad system, helped the son understand more about his mother’s condition and made a referral to the local social services that resulted in practical support for both people.

Hospitals. Hospital admission and discharge are the most crucial time for identifying the needs of older families who are providing mutual caring.



Following a fall at home, an elderly woman was admitted to hospital. Despite considerable discomfort, she was very anxious to be back at home as soon as possible. When her details were taken, she said she lived at home with her son. Ward staff got used to seeing her son, as he visited her regularly, and it was evident he had a learning disability.

When she was discharged, she said her son would help and they would 'muddle along together', but three days later she was readmitted to the same ward following another fall and deterioration in her general health. Her son was extremely distressed. He had not been able to help her at home, felt it was his fault that his mum was back in hospital and was struggling on his own in the house. With hindsight, ward staff realised they should have alerted their social work department to the possibility of mutual caring so that the right support could have been put in place at that stage.

Learning disability services. Often these services are the first to pick up on subtle signs of mutual caring, as they have a long-standing association with the family. They are also in a very good position to start following this up sensitively with the different family members.



Workers at a day service became concerned when one of the people who regularly attended started missing more and more days. When she did come in she seemed in low spirits and was always anxious to get home. Her key worker spent time talking with her and gradually discovered that she was worried about leaving her mother, who had been ill and might not manage well on her own at home.

The key worker arranged a home visit to talk to both of them and then helped make a referral to the older people's social work team, who visited the family jointly with the day centre worker. As a result, a community alarm was installed, the mother started attending a lunch club while her daughter was at the day service, and they started using a home shopping service to cope with the heavy items that had been causing them problems. Both



family members were much happier, and felt less vulnerable and isolated. Most importantly, the daughter felt able to go back to her regular friends and activities, and was supported to ring her mum once a day to check all was well. Her key worker continued to talk to her regularly about home and has since been able to alert services when they needed further help.

Home support workers. Workers who regularly go into people's homes to support them with different tasks can also be some of the earliest people to pick up on mutual caring and/or anything families are struggling with. This can often involve a sensitive balance between recognising the different family members' rights and capabilities (including the rights of the person with a learning disability to provide care if they want to) and recognising if they need extra support.



Following a hospital discharge, a home care service began working with an elderly man who lived with his daughter who had a learning disability. During his recuperation, home support workers went in three times a day to help him with personal care and medication, and to give him lunch while his daughter was out.

As the different workers got to know the family, they raised concerns with their manager about how well they were coping at home. They had noticed that both people were often wearing dirty clothes, the general cleanliness of the house had deteriorated and there wasn't much food in the home. Their manager informed the older people's social worker. Following a home visit and discussion with both the father and daughter, it emerged that the daughter was taking on as much as she was able, but missed the practical guidance and support her father had given her. She was particularly nervous about using the cooker and washing machine. They were worried about being split up if people thought they couldn't manage together.

A referral to the learning disability service resulted in an increased package of support from the same agency. The workers supported the daughter with completing household tasks and learning to cook simple meals. When the father was fully recovered, part of the package stayed in place so that the daughter could develop her daily living skills and ultimately live independently in her home.

Voluntary sector services. Families providing mutual caring may use a variety of services, including lunch clubs, advice centres, carer support groups, advocacy services and exercise classes. They are often happier to talk frankly about any problems to people employed by the voluntary sector, as there is a general worry that if statutory services know the family is not coping well they will be split up.



A local Alzheimer's Society referred a mother and son to an older family support project within a local learning disability charity after realising that the son had a learning disability and was struggling to understand the information he was given. He had used no learning disability services up to this point.

The specialist project for older families was able to help the son speak up about his fears and concerns, to prepare for a carer's assessment and to make a person centred plan about his life now and in the future. Following a multi-agency, multi-disciplinary meeting, a joint package of support was set up to support the family, with clear communication lines to prevent the family from slipping further into crisis. Three years later, the son acknowledged that he was no longer able to look after his mother despite all the additional help, and was supported in finding her a home nearby while he remained in the family home. He continues to visit his mother at least four days a week, uses carer support services through the local Alzheimer's Society and the carers' centre, and has also been helped to find other ways to broaden his social networks and fill his time in a meaningful way.

There are plenty of other examples of workers and services well placed to support mutually caring older families. What is clear is that services and support for older people, people with learning disabilities and carers must find effective ways of working together to support these families. There must be clear pathways and protocols and regular awareness raising to ensure workers and services feel confident to recognise and respond to their needs.

Obviously, joined up approaches work better for families. But they also make support more cost-effective too – and avoid the traps of 'double funding' overlapping services by both older people's and learning disability services.



Pizza story

A community nurse visiting an older family arrived early when just the mother was home. They sat and chatted while waiting for the daughter to arrive home from her day service. In the meantime, a home care worker arrived and chatted to both as she cooked tea for the mother – half a big pizza. After her 20 minutes were up, the home care worker left and shortly after this the daughter arrived home. While they all chatted and had a cup of tea, another worker arrived at the home. This worker was from an agency and had come to support the daughter to cook her tea – the other half of the pizza!



The community nurse was shocked, but the family was bemused – they assumed that the workers who organised the support for each person knew about the other person’s support. The community nurse was able to report the matter to her manager, who alerted both older people’s and learning disability services. As a result, the agency worker continued to visit the family and supported the daughter in preparing a meal for both herself and her mother.

Getting local support right for mutual carers

The *Carers Compass* (Banks et al., 1998) offers a clear and excellent framework for responding to carers' needs, and it is a very useful model for looking at the needs of older families who are providing mutual caring.

It covers eight key areas:

1. Recognition
2. Information
3. Quality services
4. Breaks from caring
5. Emotional support (including health and well-being)
6. Training to care
7. Financial security
8. Having a voice.

It is undoubtedly a challenge to meet all these needs, but it is essential.

Carers at the Heart of 21st Century Families and Communities (Department of Health, 2008), the new National Carers Strategy, highlights the priorities for supporting carers over the next 10 years. Many of the key areas in the Carers Compass remain priorities within the new national strategy, which highlights the needs for joined up working, assessment, workforce development, choice and control over support, health and well-being, assistive technology and the importance of making good links for carers with housing, leisure and transport services.

The following sections outline support that may or may not be available in your local area that link to both the Carers Compass and the National Carers Strategy. It is not a definitive list, but it is a good starting point, and anything that is not already provided should be a priority.

1. Recognition

Many family carers do not apply the term 'carer' to themselves. They consider that they are just mum, dad, sister, brother, or grandma, taking on a natural role and responsibility – even though they may struggle regularly with aspects of this role. Similarly, many people with learning disabilities don't realise when helping out has progressed to caring. It is often easier for people outside this situation to recognise that this is, in fact, mutual caring.

- Make sure that mutual caring is an element of all carers' strategies, and people working in this area are kept up to date about hidden groups of family carers, including mutual carers and carers with learning disabilities.



Top tip: Use the Mutual Caring DVD or develop a similar local resource to bring the issue alive and ensure workers and services are 'mutual carer aware'.

- Bear in mind that older families providing mutual care may require four separate assessments in order to identify everything they are doing, everything they need and the necessary financial support: a needs assessment and a carer's assessment for each person. The importance of thorough carers' assessments that are reviewed regularly cannot be over-emphasised.



Top tip: Two resources have been produced to help carers of people with learning disabilities and carers with learning disabilities understand carers' assessments and prepare for them: see the back of this booklet for more information.

- Ensure that health services' admission and discharge plans cover mutual caring and that people do not leave hospital without the support they need.



Top tip: Information on discharge planning in hospitals could be reviewed to make sure mutual caring is mentioned sensitively and that it is presented in a format that people with learning disabilities can use.

2. Information

Information for people with learning disabilities, older people and carers needs to be clear, accessible, up to date and available in different formats. It should also be easy to get hold of – since many older families struggle to find the information they need.

- Review the information provided for generic carers, carers of people with learning disabilities and carers of older people. (This applies to everyone providing information: including acute and primary health care services, statutory services, advice services and the voluntary and community sector.) You may need to commission some specialist information for mutual caring, if there is nothing suitable.



Top tip: Mencap has guidelines on making information accessible, and your local learning disability services may also be able to help.

- Find out how people are helped to find and understand this information; this may be through advocacy and advice services, patient liaison services and/or carers' support workers. These workers and services may need to be made more aware of mutual caring.






Top tip: Many areas have older family support projects linked to their learning disability services. Supporting older families to understand options and make use of information is often a key role that has guided people through systems and particularly towards services that have prevented crises.

3. Quality Services


Are your local services joining up to meet the needs of carers, including carers with learning disabilities? How are you measuring what makes a quality service for a carer with a learning disability in a mutual caring situation? It is particularly important that older people's services take people with learning disabilities into account when they are considering the needs of family carers.

- Check that services and workers are aware of the needs of mutual carers and of carers with learning disabilities. They should be included in the measures such as accessibility, information and outcomes from carers' assessments.

-  **Top tip:** Check how many carers with learning disabilities or mutual caring families are known to services, and how their experiences and needs are recorded, for instance through performance indicators around carers' assessments.
- Check that systems for monitoring the quality of services for older people are accessible for carers with learning disabilities.
- Check that other services, including housing, leisure and transport are also joining up to ensure that the needs of the whole family are being met.
-  **Top tip:** The Care and Repair report *Living on the Edge* (Easterbrook, 2008) helps highlight how housing providers and support organisations can help older people with learning disabilities living in their own homes and many of the recommendations relate very well to mutually caring older families.
- Is there a way of ensuring that carers with learning disabilities know how to handle medication? It is very important that anyone administering medicine understands the instructions, any side effects to look out for, and what they should do if they are worried.
-  **Top tip:** easyhealth.org.uk is a website that hosts lots of easy to use information for people with learning disabilities and their supporters.

4. Time off/breaks from caring

Carers need breaks from caring and time to themselves – but it is rarely a real break unless they know that the person they care for is happy, safe and well looked after. Carers' assessments should always cover time off from caring, and help people find regular breaks that suit them. This is particularly complicated with mutually caring older families – it requires a range of choices, and a lot of flexibility. In practice, individual budgets are often the best way to make this possible.

- Check that local breaks strategies recognise the needs of mutually caring older families, and can provide some suitable options. For example, can local breaks services for older people and those for people with learning disabilities work together and offer them breaks at the same time?
-  **Top tip:** Ensure that breaks services know if someone is a mutual carer, so that they can respond appropriately. Develop protocols that address the needs of both parties and give a clear pathway for workers supporting these families.

- Make sure families get all the different information about opportunities for breaks, and support to think through what might work best for all of them.



Top tip: Carers' centres and similar services are well placed to hold information about a range of breaks opportunities and may be able to help families explore options that work for everyone.

- Make sure that families are supported to take breaks together where appropriate. Many families hugely enjoy the opportunity to do something new together.



Top tip: Lunch clubs, day trips and holidays that provide support can be great options for mutually caring older families.

- Check that mutually caring older families have all the assistive technology they need. This equipment can offer real peace of mind to carers who are having some time off.



Top tip: Make sure instructions to use equipment are very clear, using pictures and symbols where necessary.

5. Emotional support, including health and well-being


Caring can be extremely lonely. Mutual carers are often especially isolated because, although there may be many local organisations offering emotional support to carers, people with learning disabilities or older people, very few of these link together to meet mutual carers' particularly complex needs. Carers can often overlook their own health and well-being because of the impact of caring. It is critical that all carers are supported to have the time to care for themselves as well as their relatives.

- Check if – and how – any local support and/or advocacy services work with mutually caring older families.




Top tip: Some local areas are starting to offer support groups for carers with learning disabilities. Other areas have telephone schemes where people get regular phone calls just to chat and overcome the isolation they may be feeling.

- Check how local groups dealing with particular health issues, such as dementia or stroke survivors, support both patients and their family carers. Ensure they are aware of mutual caring and geared up to respond appropriately.

 **Top tip:** Courses run to help carers understand and cope with conditions such as dementia could run sessions for carers with learning disabilities, if it's found that these are necessary.


- Check that GP surgeries are maintaining their carers' registers and that GP practices and carers' link workers are included in workforce training around recognising mutual carers, particularly carers with learning disabilities.

 **Top tip:** GPs should be offering annual health checks to people with learning disabilities and some areas are now piloting annual health checks for carers too. Make sure that mutual caring is known about widely to ensure any issues are picked up through these checks.

6. Training for caring

Many carers of people with learning disabilities have been caring for many decades with few opportunities for training and being kept up to date with new techniques and equipment. By contrast, carers with learning disabilities are often new to this and appreciate training and guidance on things like first aid, moving and handling and using equipment.

- Are Caring with Confidence courses in your area open and accessible to carers with learning disabilities?

 **Top tip:** Many local carers' support services and similar organisations already offer training, which could be extended to people with learning disabilities.

- Does your carers' strategy ensure that you regularly check the training needs of carers with learning disabilities, and provide ways of meeting those needs?

7. Financial security

Many older families that include a person with a learning disability are already financially disadvantaged as the result of a lifetime spent caring. Older family carers are no longer able to claim carer's allowance after retirement age – even though they are still caring – and many do not know about Pension Credit or the carer premium. The majority of adults with learning disabilities are not in paid work, and even those who are do not get paid very much; if they have caring responsibilities, it is even less likely that they will be in paid work.

Many older family carers and people with learning disabilities struggle to understand benefits and grants that they may be entitled to, and the forms they have to fill in. Self-directed support and charges for services are additional stresses. Few people with learning disabilities realise that they may be entitled to carer's allowance, particularly if they are already claiming a disability benefit – and often people worry, too, that if the Department for Work and Pension finds out about their caring they will actually lose some of the benefits they do get.

- Check that advice services are aware of the needs of mutually caring older families, and are able to respond appropriately.



Top tip: Home visiting services are particularly valuable for older people whose mobility is restricted and people with learning disabilities who cannot easily travel without support. Make sure they are a priority group for home visiting.

- Make sure that information about charges for any of the services that may be offered is extremely clear and backed up by easy read information or even illustrated through a short film. Many older people are very worried about charges, and the financial assessment can feel very threatening.



Top tip: Make sure that, when charges are worked out, it is made very clear from the beginning what is being charged for. For instance, some areas do not charge for carers' services but may charge for services for people with learning disabilities or older people.

- Check that older mutual caring families can get assistance with managing their finances and correspondence, but make sure there are robust safeguards against financial abuse.



Top tip: Age Concern England has produced a LifeBook that helps older people, and those who may take over running their affairs when they are no

longer capable, to set their personal and financial affairs in order. This is a very useful tool, which should be used more widely.

8. Having a voice

It is very important to involve carers in decisions that affect them, as well as in the wider decisions about policy, practice and planning locally. Older family carers and carers with learning disabilities have lots of skills and experiences, and these should be valued.

- Make sure older family carers and carers with learning disabilities know their rights as carers and their right to be listened to. Make sure they know how to get assistance with speaking up and being heard. They should be able to give their views through a variety of different channels, including complaints, concerns and compliments procedures.



Top tip: Work with local advocacy services for older people, people with learning disabilities and carers to ensure they are aware of the needs of mutually caring older families.

- Make sure that older family carers and carers with learning disabilities are involved in planning for emergencies, and long term planning as part of a person centred planning process.



Top tip: Request the person centred planning strategy and process for people with learning disabilities in your local area through the Learning Disability Partnership Board. Look at various resources available on emergency planning, planning for older people and people with learning disabilities at the Foundation website www.learningdisabilities.org.uk

- Ensure your local carers' strategy has a way of getting the views of mutually caring older families, and particularly the views of carers with learning disabilities, and use this to inform service development and delivery.



Top tip: If your area has a Carers' Partnership Board or something similar, make sure that carers with learning disabilities are able to become members of the Board or at least feed into it in a meaningful way.

Don't forget the positives!

Despite all these concerns – and more – it is very important to acknowledge and indeed celebrate the positive aspects of mutual caring. Families are working together to keep everything running smoothly, and carers – on both sides – are extremely proud to know that the person they love and care for is able to stay safe and happy in their own home and remain independent for as long as possible.

At the same time, many of these families do need more support than they are getting at the moment. Mutual caring does not fit neatly into one service or another and it never will; so providing for mutually caring families is never going to be simple. Listen to families. Build relationships with them wherever possible. Involve them and respond to their needs in a way that recognises the complexity of their situation. At the moment, far too many mutually caring families are going unrecognised, and they are losing out as a result.

The last word goes to Maureen from Shropshire, whose story about how she and her mum got the support they needed to carry on living together and caring for each other helped mutual caring become recognised on a national level.



"Not enough people listen. I felt I was struggling until people started listening to me. Now our lives together are better."

References

Banks, P., Cheeseman, C., and Maggs, S. (1998) *The Carers Compass: Directions for improving support to carers*. London: Kings Fund

Department of Health (2001) *Valuing People: a new strategy for learning disability for the 21st century*. London: Department of Health. Available to download from www.dh.gov.uk

Department of Health (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities*. London: Department of Health. Available to download from www.dh.gov.uk

Department of Health (2008) *Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*. London: Department of Health. Available to download from www.dh.gov.uk

Easterbrook, L. (2008) *Living on the Edge*. London: Care & Repair England

Magrill, D. (2005) *Supporting Older Families: Making a Real Difference*. London: Foundation for People with Learning Disabilities. Available to download at www.learningdisabilities.org.uk

Mencap (2002) *The Housing Timebomb: the housing crisis facing people with a learning disability and their older parents*. London: Mencap. Available to download from www.mencap.org.uk

The Mutual Caring project

The Mutual Caring project was set up to help promote recognition of good practice and develop improved service provision for older families where the balance of the caring relationship between the long-term family carer (often a parent) and the person with learning disabilities (normally an adult son or daughter) has changed. This project aimed to highlight this neglected area and provide evidence of practical approaches that can be used in different settings.

Publications in this series include:



Mutual Caring – a DVD containing 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



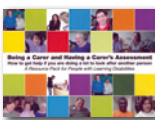
Supporting Mutual Caring: A booklet for workers in services who are supporting older families that include a person with learning disabilities



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



Need 2 Know Mutual Caring: A briefing note for policy makers, commissioners and services from the Foundation for People with Learning Disabilities



Being a Carer and Having a Carer's Assessment: A pack to help people with learning disabilities work out if they are a carer and some of the ways to get help. This pack was produced by the Valuing People Support Team and written as part of the Mutual Caring Project.

For more information on all these or to receive any of them please visit the Mutual Caring website: www.learningdisabilities.org.uk/mutual-caring

This project has been supported by Lloyds TSB Foundation for England and Wales. We would also like to thank Valuing People and the Calouste Gulbenkian Foundation for the funding for various phases of the Mutual Caring Project.

About the Foundation for People with Learning Disabilities

We promote the rights, quality of life and opportunities of people with learning disabilities and their families. We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship
- support local communities and services to include people with learning disabilities
- make practical improvements in services for people with learning disabilities
- spread knowledge and information.

If you would like to find out more about our work, please contact us:

Foundation for People with Learning Disabilities
Sea Containers House
20 Upper Ground
London SE1 9QB

Tel 020 7803 1100
Email fpld@fpld.org.uk
Web www.learningdisabilities.org.uk

The Foundation for People with Learning Disabilities is a part of the Mental Health Foundation, registered charity number 801130 (England) & SC 039714 (Scotland).