



Supporting older families:

making a real difference

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Dalia Magrill

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Contents

Foreword	iv
Preface	v
Acknowledgements	vii
Introduction	1
Chapter 1: Older families are everybody's business	9
Chapter 2: Supporting older families in planning ahead	19
Chapter 3: Practical support for older families - the big things that make a difference	37
Chapter 4: Practical support for older families - the smaller things that make a difference	51
Chapter 5: Conclusion: Older families - meeting the challenge	83
Appendix 1: Checklist - how well is your local area supporting older families?	87
References	101
Resources	103
Websites	107

Foreword

Supporting families of people with learning disabilities is at the heart of *Valuing People*. Family carers have not always received the recognition and help they have needed in the past and this is an area of work the Valuing People Support Team is deeply committed to.

Older families in particular have often been very isolated. We know that many of the oldest families have remained hidden until times of crisis. When crises happen, often people with learning disabilities and their older families have fewer opportunities to make real choices over what happens next in their lives.

The Valuing People Support Team is pleased to endorse *Supporting older families: making a real difference* produced by the Older Family Carers Initiative at the Foundation for People with Learning Disabilities. The pack lays out the challenges that need to be met if older families are to receive the support they need, as well as highlighting the increasing amount of excellent work happening with older families around the country that is making a real difference locally. It is a practical tool, with a checklist I hope will be used by partnership boards and sub-groups to help shape local responses to the needs of older families.

Older families are a priority group for support, but it is important that their needs are linked in to the mainstream agendas of services for people with learning disabilities, older people and carers generally. It is important that we make sure that older families have their needs met now, and are supported to remain together for as long as they wish whilst planning for the future with confidence. However, it is equally important that we get things right for older families now so that others who are growing older do not face the same anxieties, uncertainty and fears that so many older family carers have lived with for decades.



Rob Greig
National Director for Valuing People

Preface

It is estimated that 29,000 people with learning disabilities will need somewhere to live when their older family carers are no longer able to support them at home (Mencap, 2002). Twenty five per cent of people with learning disabilities living at home with family carers over the age of 70 are unknown to services until there is a crisis (Department of Health, 2001b). Behind these figures are stories of families living with constant anxiety about what will happen in the future. Family carers have recurring fears about the time when they can no longer support their relative. People with learning disabilities often worry about their parents or other family carers dying or being unable to care. What will happen to their ageing carer without them? Where will they themselves go? Who will support them?

As people get older they also need more help in their caring roles, but often they struggle without support. People with learning disabilities become involved in caring without proper recognition.

These concerns are now being addressed. That local councils should pay particular attention to identifying and supporting carers aged over 70 was a key action in the White Paper, *Valuing People* (Department of Health, 2001b). The Older Family Carers Initiative (OFCI) has established that a key element in ensuring that older families have appropriate supports is the linking of learning disability, carers and older people's services and agencies. This requires detailed planning and improved communication and co-ordination at a local level. Through the lifetime of the Initiative we have seen that progress has been made for some older families, but for many there is still a long way to go, both in providing adequate supports in the present and ensuring that planning for the future is done with sensitivity and at the pace of the family.

This resource, *Supporting older families: making a real difference*, is a practical tool for learning disability partnership boards and others working to support older family carers and their relative with a learning disability –

referred to here as older families – to bring about positive changes in their lives. It should enable boards to measure what they are doing, how well they are doing it and to decide what they need to do next.

Families should be given the confidence to know that their relative will not suffer the trauma of losing their home and their family carer at the same time and that a crisis response will not be necessary. If *Supporting older families: making a real difference* helps ensure that older families have the support they need it will have fulfilled its purpose.

A handwritten signature in black ink that reads "Andrew McCulloch". The signature is written in a cursive style with a large initial 'A'.

Dr Andrew McCulloch

Chief Executive

The Foundation for People with Learning Disabilities

Acknowledgements

The Older Family Carers Initiative (OFCI) aims to support learning disability partnership boards to identify and meet the needs of older family carers of people with learning disabilities as prioritised in *Valuing People*.

We are extremely grateful to the many projects and people who have contributed to this pack by providing us with examples of good practice and case studies from across the country. Unfortunately there has simply not been the space to include everything in this pack and it is testament to the increasing amount of quality work happening around the country that we have been faced with the dilemma of what to leave out rather than struggling to find examples to include.

In particular we would like to thank the older families who have been willing to share their good and bad experiences with us and have helped to shape OFCI and this pack. Their contributions at Network meetings, awareness days and individually has been invaluable and largely come from their desire to help improve the situation for other older families around the country and for those families who follow them. In order to protect their privacy, all names have been changed.

The OFCI is led by the Foundation for People with Learning Disabilities in partnership with the British Institute of Learning Disabilities (BILD), HFT (Home Farm Trust), Housing Options, Carers UK, the Valuing People Support Team and Mencap, as well as a number of individuals with a particular concern for older families. The Foundation is grateful to the members of the OFCI advisory committee for their unfailing support and commitment throughout the Initiative:

Charlie Barker - Sefton Social Services, representing ADSS

Rosemary Frazer - Mencap

Maurice Harker - Housing Options

John Harris - BILD

Derek Hill - family carer

Emily Holzhausen - Carers UK

Phil Madden - HFT (Home Farm Trust)
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Giles Ridley - Chair and Family Carer
Carol Robinson - South West Learning Disability Network
Carol Walker - University of Lincoln
Cally Ward - Valuing People Support Team

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This report has been written by Dalia Magrill (OFCI co-ordinator) and was edited by Radhika Holmström. Special thanks to Richard Green, Paul Hewitt and Linda Fereday from the PTI course at Sheffield Mencap who worked with Dalia on the key points at the beginning of each chapter, and to the families who have allowed us to use their pictures on the cover.

Introduction

Key points

1

This pack will help everyone know what needs to happen to make it easier for older families to carry on being together and to plan for the future.

2

Older families are people with learning disabilities living at home and being looked after by someone over 65, like mum or dad or a brother or auntie. Sometimes the person with learning disabilities helps look after their older relative.

3

Many older families feel very alone; no one knows them and they don't know much about what help they could get and where to get it from. They worry a lot about what might happen if there is an emergency.

4

Things are getting easier for older families in some places but there is still a lot to do. Everyone needs to work together to make sure older families have the right help.

'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

'They say we are a priority age group. They say "we want to consult". You tell them your thoughts, make constructive comment - and then get completely ignored!'

John, 67

Time is running out for many older families. They need support if they are to go on living together and/or plan for their futures before there's a crisis. And despite some very good work in different areas – especially since *Valuing People* (Department of Health, 2001b) made older families a priority group – there is still a fair way to go. Many older families remain isolated. They aren't in touch with services they could benefit from. And above all, they do not know what would happen in an emergency, or about what the future holds for them.

Who is this resource for?

This resource aims to provide practical assistance for learning disability partnership boards and anyone else working with older families. Real life stories and examples from around the country illustrate key points and, we hope, will inspire statutory and voluntary groups and older families to move forward together. Learning disability services are certainly not the only key players; older people's services and generic carers' services also have responsibilities to this group.

We particularly highlight examples of joint working which have made a positive impact on the experiences of older families, almost always as a result of lobbying from family carers' and user groups.

The resource is divided into three key sections:

1. Fitting work with older families into the broader policy and practice contexts (**Chapter 1**).
2. Planning, at strategic and individual levels, to ensure that older families get what they need, and that the right services and support are in place now and for the future (**Chapter 2**).
3. Highlighting a range of opportunities, services and support that can make a real difference to the daily lives of people with learning disabilities and their older family carers (**Chapters 3 and 4**).

Who are older families?

Throughout this pack, we use the term older families to refer to the whole family: the older family carer(s) aged 65 or over, their relative with a learning disability and other members of their extended family and close friends. Although each member has their own rights and needs, those needs are usually very much intertwined and it is just not possible to look at people in isolation.

Many family members do not identify themselves as carers, because they are not paid. They see themselves simply as mum or dad, brother or sister or someone else who sees it as a natural part of their role to support their relative who has a learning disability. However, *Valuing People* (Department of Health, 2001b) defines older family carers as people who are aged 70 years or over (most authorities start at 65, in line with other provision for older people) and are still caring at home for one or more people who have a learning disability. These family carers usually made the choice, many decades ago, to care for their relative at home rather than place them in an institution – often after being told that people with learning disabilities were unlikely to survive past their late 20s. Now, some 40, 50 or even 60 years later, they are still caring at home and worry constantly about what might happen to their relative when they are no longer able to care. They may be very isolated. Many of them have been battling for decent services for many years, and they are tired now. Older family carers may no longer come to meetings but that doesn't mean they are not interested; they are often just struggling to get by from day to day and are exhausted by the talking. After dozens of consultations, they want results and to be able to feel confident that their relative will be supported properly in the future. Increasingly, older family carers have their own health and practical needs and additional caring responsibilities for other family members as well.

'When he was first born they told me he was a mongol. Then they said he was an imbecile. A few years later they said he was mentally subnormal, then mentally retarded, then mentally handicapped and then learning disabled. Now you're here telling me he has a learning difficulty. In another few years another nice young lady will come and tell me he's something else. But he's John.'

Peggy, 84

Older families have developed routines that may not be in line with current ways of thinking, but which have enabled them to survive. Often, the person with learning disabilities has taken on considerable caring responsibilities themselves, even though this is rarely acknowledged. Without working together as a team, many older families would not be able to remain living independently.

The main issues facing older families

Evidence from around the UK shows that almost all older families are affected by some common problems (Foundation for People with Learning Disabilities, 2002; Walker and Walker, 1998; Department of Health, 2001a; Magrill et al., 1997).

Some have virtually no contact with services at all. Many people with learning disabilities – *Valuing People* estimates around 25% of those living with older family carers – only make contact with formal services in a crisis, when their family support breaks down. This means that service planners and providers do not know what sort of services and support they should be developing, or who is likely to need this. Instead, they have to react to a crisis, in a way that isn't always the most appropriate (and often costs a lot), such as an out-of-area placement. It's often very difficult for the person with learning disabilities to adjust to their sudden new situation – especially if they are coping with loss and bereavement – and people who have been relatively independent until now may prove to need quite intensive support.

Even if the person with learning disabilities is regularly using services, their older family carers may no longer have any contact with services. Care management and assessment systems have moved away from the long-term relationship with one social worker which many families maintained for years. This means that services are often not drawing on families' expertise and knowledge of the person with learning disabilities, while family carers feel isolated and abandoned. Even if their problem is in fact quite easy to deal with, they don't know who to approach – or that services today are much more geared towards individual needs and independence than they used to be.

'I haven't seen a social worker for over 10 years now. Don't they care how I am doing?'

Betty, 74

Even if someone new does offer support, some older family carers have had so many different professionals coming in and out of their lives over the years that they are reluctant to tell their story again and have their expectations falsely raised. Many older families are afraid of what 'interference' might lead to – especially if the last time they were offered any services was several decades ago. Some older family carers think that the only alternative to home is an institution, while others still believe that their relative will be able to move permanently to the short break/respite service they use four times a year, because they were told this 25 years ago. Terms such as 'independent living' are interpreted as meaning 'left alone', with literally no help; this is particularly frightening to family carers who know that the person they care for needs more support than may initially be obvious. The only media coverage they see tends to be the horror stories. On a purely practical level, information may not be accessible to older people because the print is too small and/or contains unfamiliar terminology. People with hearing problems also have extra difficulty with phone calls.

As a result, older families are often missing out on a whole range of help which would make a big difference to their lives, including help from older

people's services, learning disability and generic carers' services, and which would cost their local authority relatively little.

One family carer in her late 80s dissolved into tears while discussing possible future housing options for her son. It turned out that the last time any professional had mentioned his future, she'd been told that if he moved anywhere then she would no longer be allowed to have any contact with him. That conversation took place over 50 years ago – with the doctor who diagnosed him shortly after his birth.

All these elements contribute to the biggest issue of all: worry about what will happen in the future, when family carers can no longer go on caring. Older family carers may tell workers that everything is all right, but often that is because they are worried that they will be judged and their loved one will be 'taken away'. In reality, almost everyone is desperate to know what will happen in an emergency, and what they should do now to start planning for the future. Some older family carers have become so worried and bewildered that they lose all confidence and ignore their own needs.

People with learning disabilities often share these anxieties, especially if they've known friends whose lives have altered very suddenly (or who've even disappeared from their local community completely) when something has happened to their family carers. They worry about how their ageing carer may cope without them or whether they might have to move before they are ready and willing to. The worries can affect their behaviour, and/or they may stop using services because they are so concerned about their relative.

Although services and support for people with learning disabilities are better than they have ever been, older families have been around for many years and have seen an incredible amount of change – not all of it good, particularly as resources dwindle. They need to be able to explore options and make realistic plans, but they also need to be convinced that planning will be worth it, and that there are the resources to cope.

'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

'I got my three wishes last year: my son Basil died at home, in my arms and before me...now I am content. I do not regret one bit these wishes – Basil was my life.' Mrs H, 91

Making a real difference

Whether as members of partnership boards or day centre workers, everyone has a role to play in making positive changes for older families. There is no magic solution. It takes time to build up the different elements of support, and some tasks require complex strategies; but as ever, the most important things are determination and creativity. Some older families need comprehensive support from a trained worker. Others simply need to have the correct phone number for the emergency duty social work team close at hand. At the end of the day, what matters is what makes a positive difference to the individual experiences of older families.

Edith is 87 and lives with her daughter, Carol, who is 56. When Carol was diagnosed with a learning disability at the age of eight, Edith was told by the doctor that Carol was an 'in-between' – not 'bad' enough to go to an institution but not 'good' enough to be educated – and to 'take her home and keep her happy'. When Carol was 40 Edith found out she was entitled to a cheap bus pass and got in contact with social services for the first time. Carol started attending different day services and her life opened out as she made friendships and developed her skills.

In 2000, Edith joined a project for older carers and got to meet other people in a similar situation. She started talking about her fears about the future. Over the next six months, Edith and Carol completed a life storybook with the project worker, allowing them both to talk about their hopes and dreams.

Carol said she would like to live in a flat near her family and friends, still have lots of holidays with her mum and have people come and visit her for tea and cakes. Edith and Carol decided to sell their house and moved to a bungalow closer to other family members. The bungalow has been bought in Carol's name and is held in trust for her, with Edith living there as her lodger.

Carol is building up her independent living skills. She is really happy and she is doing more and more for herself all the time. She is starting to get used to being on her own in the bungalow, and she knows that's the plan if anything happens to her mum. Edith still worries about the future but not as much as she did. She knows there are plenty of people that care a great deal about Carol and is confident that they will speak up for her when she is no longer able to.

Chapter 1

Older families are *everyone's* business

Key points

1

It's important that services that help older people, people with learning disabilities and carers talk to each other and work together to support older families.

2

Lots of the work that the government has asked different services to do is very similar. It will help services and older families if they work together to share the tasks.

3

Older families may ask for help in lots of different places, so it's important that workers in places like hospitals, day centres, housing departments and advice centres, know what to do and are understanding.

Valuing People (Department of Health, 2001b) makes support for older families a priority; people with learning disabilities living with older family carers are a priority for person-centred planning and supported living, and partnership boards are being encouraged to identify people living with older families and to support older families to plan ahead. However, the different members making up an older family very often require services from across the health, social care, and housing sectors. It's also important to remember

that an increasing number of people with learning disabilities are carers themselves for ageing relatives, although this care is very rarely formally recognised.

Older people's services and generic carers' services, as well as primary and acute health services, all need to consider, and respond to, the needs of older families. In fact, *Valuing People* (Department of Health, 2001b) actually carries less authority than a number of other policy and practice initiatives, since it is not backed up by the same stringent monitoring processes that accompany directives such as the National Service Framework for Older People (Department of Health, 2001d). **Diagram 1** highlights some of the key policy initiatives that impact on service responses to older families.

Older families will become visible to services for different reasons in different settings and at different times. Wherever they come forward, older families need clear pathways through services and support and they need to know that someone will be able to lead them down the right pathway for them. These clear pathways can only be created through communication, co-ordination and effective partnership working. If service providers do not achieve this, they may well duplicate the services they provide and/or be left without enough information to plan ahead properly. More importantly, the families who fall through the gap may very well find themselves isolated from the information and the support they need – and feel unable to do anything about this until matters reach a crisis point.

Diagram 2 highlights how priorities and services for older people, people with learning disabilities and carers often overlap.

One example of a cross-cutting priority across services is the need to identify older families.

Sharing the task of finding older families

One of the biggest problems for any work with older families crops up at the start – or in fact before the start. In many areas, it is extremely difficult

Diagram 1: Some key policy initiatives that impact on service responses to older families

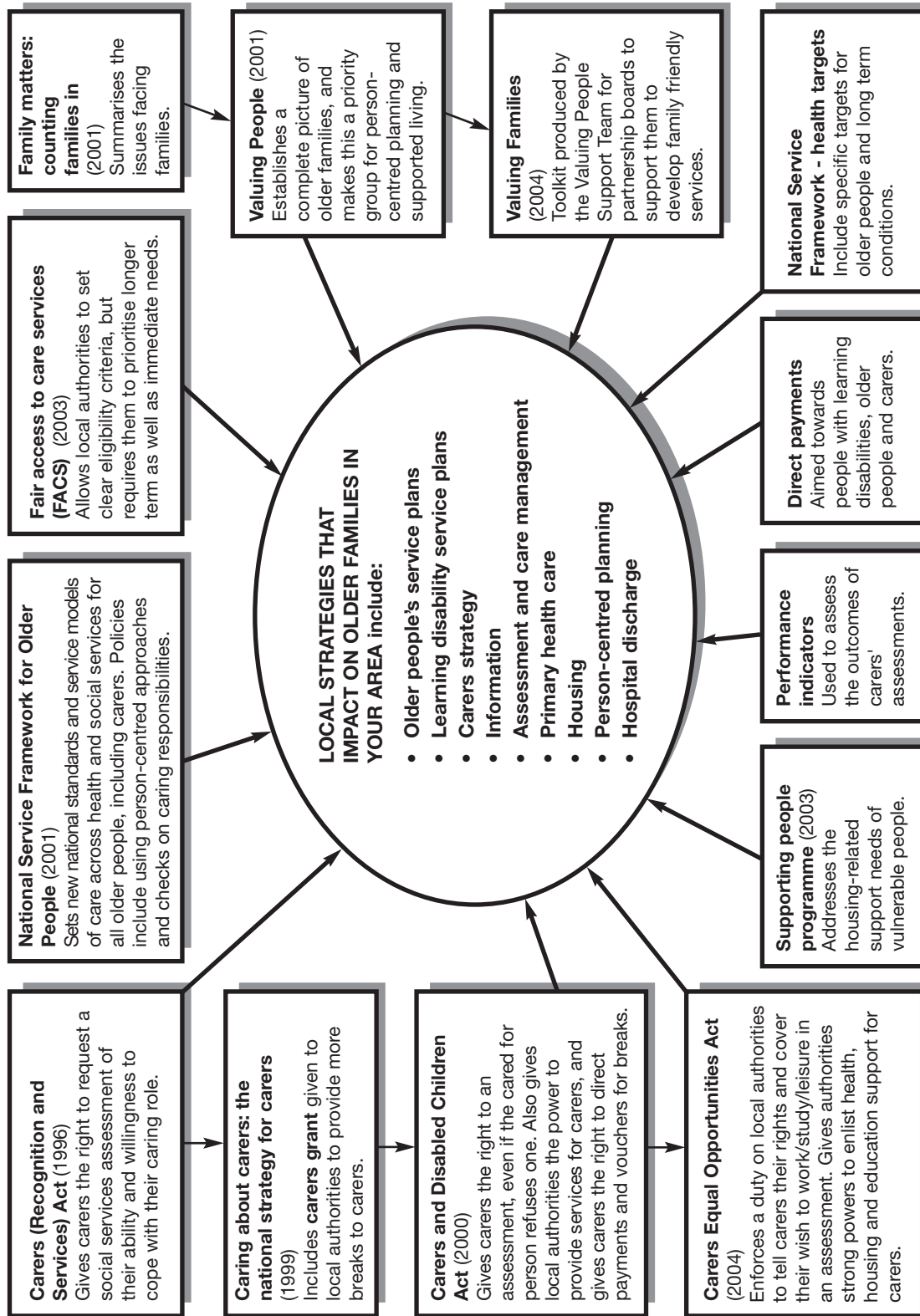
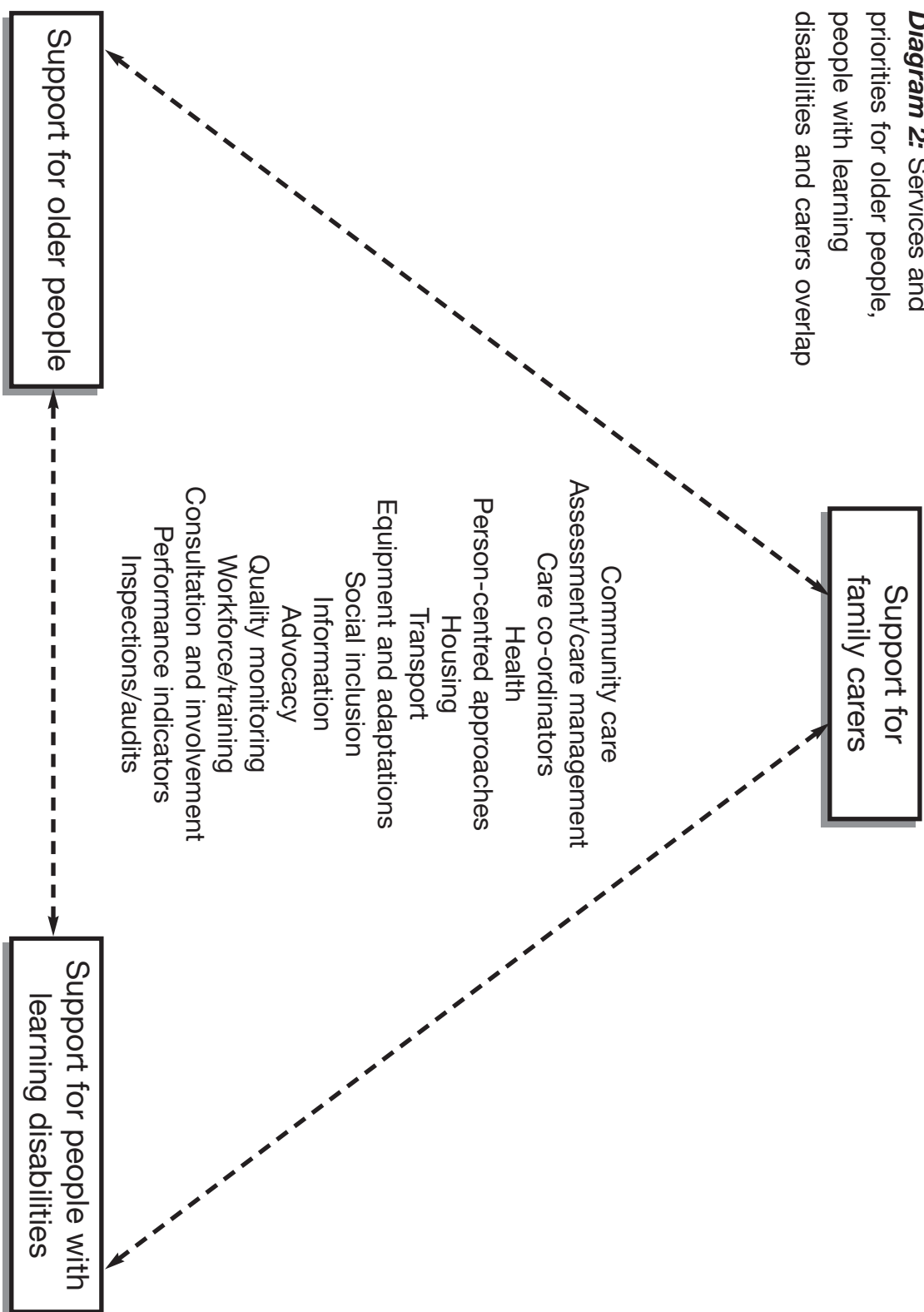


Diagram 2: Services and priorities for older people, people with learning disabilities and carers overlap



to find out who those older families actually are, let alone what they need and what they hope for.

The survey of 70 learning disability partnership boards' current and planned work with older families (Foundation for People with Learning Disabilities, 2003), highlighted the fact that many partnership boards only had information about the families which were actually using services and support. Since *Valuing People* estimates that at least 25% of people living with family carers over the age of 70 are not in contact with services until there is a crisis, this is clearly not good enough.

For further guidance, see *Guideline 2: Identifying Older Families and Guideline 3: Recording Information* produced by the Foundation for People with Learning Disabilities in 2003 and available to download from www.learningdisabilities.org.uk.

The Sheffield Case Register (part of Sheffield Care Trust) has information on 2,839 children and adults with learning disabilities in Sheffield. Figures produced in March 2004 show 413 people living at home with family carers over the age of 65 years. Of those 413 people, 182 are not known to be attending any recorded daytime activity and only 38 people are using statutory short breaks services. However, the city's Older Carers Support Service (which is linked to the Case Register) now employs two dedicated support visitors, who keep in regular contact with all family carers over the age of 70, and link them into all appropriate support.

For more information contact: The Sheffield Case Register, Ryegate Centre, Tapton Crescent Road, Sheffield S10 5DD. Tel: 0114 2666101.

Register Services, part of Sutton and Merton Primary Care Trust, designs and manages learning disability registers for a number of London boroughs. Amongst its other services, regular lists of names of individuals known to be living at home with family carers over the age of 80 are sent to the statutory services so that they, in turn, are able to work with and plan for those families. The details are mostly collected through postal questionnaires, and many families are very keen to supply the information.

For more information contact: Register Services, Orchard Hill, Fountain Drive, Carshalton, SM5 4NN. Tel: 0208 770 8237.

Email: register.services@swlondon.nhs.uk.

www.registerservices.nhs.uk.

A key point to remember is that learning disability partnership boards are not the only services charged with identifying older families. For example, *Caring about carers: the national strategy for carers* (Department of Health, 1999) placed a responsibility on GP practices to identify carers within their practices. Although the number and quality of GP carers' registers is patchy, areas that have dedicated carers' support workers attached to practices have been successful in finding hidden carers and linking them into better support.

In Lancaster, a local primary care trust is working with a local carers group, social services and the adult education college to promote carers' registers. As of 2003, 13 out of 15 GP practices are on board already and the other two practices were starting to establish registers.

Many generic carers' services have developed emergency cards that can also be used as a means of identifying carers in the local area. This could be taken up by learning disability services as well.

The Torbay Carers Register is a confidential and independent service open to all carers who live in Torbay. It is designed to 'engage' carers, whether or not they are in touch with services. Members receive an emergency response card which can be used to identify them if they are ill or in an accident, and staff at the carers register hold vital information about them and the person they care for. The service is linked to the local community alarm scheme and is available 24 hours a day, every day. Carers get the reassurance of round the clock assistance, and the register also gives services a clear picture of the number of people who need support.

For more information contact: The Torbay Carers Register on 01803 522228 or see the information provided at www.torbay.gov.uk.

A shared responsibility

Above all, all the people who should be involved in identifying older families – not just people working in learning disability services – need to be made aware that this is an important part of their job.

One learning disability community nurse witnessed two home care workers – one funded by older people's services, the other by learning disability services – arriving separately at a family home. The first one took a pizza from the fridge, cut it in half and cooked half for the mother, a frail woman in her 80s. The second arrived 10 minutes after the first worker left and cooked the other half of the pizza for the daughter, an adult with learning disabilities.

Older families may surface in all sorts of settings – from GP practices to accident and emergency departments. Social workers within older people's services need to identify clients who are also caring at home for a person with learning disabilities.

Molly is a single family carer in her early 70s who looks after her son David. He has learning and physical disabilities and needs a lot of hands-on support. One morning, while David was at his day service, Molly fell over and damaged her wrist. The doctor at the hospital casualty ward told her it was broken, and put it in plaster. Molly was in considerable distress and she told the nurse supporting her how worried she was that she would not be able to look after David's physical needs. The nurse listened sympathetically and made all the right noises before ending the conversation with, 'It's going to be really difficult for you – good luck!' and sending her home.

Who takes central responsibility?

Every area needs a co-ordinated approach with a clear focus for taking things forward for older families. The question is: who should co-ordinate the approach?

Learning disability partnership boards are charged with driving through the local changes which will achieve the objectives of *Valuing People* (Department of Health, 2001b). It is their responsibility to ensure that people with learning disabilities and their families receive the support, the services and the person-centred planning that they need. The Valuing People Support Team has produced a great deal of guidance towards this, and the toolkit *Valuing Families* (Department of Health, 2004) is particularly useful for anyone concerned with the needs of older family carers.

Because of this, learning disability partnership boards seem the obvious choice for overseeing a co-ordinated response to the needs of older families. In reality, however, the most effective structures for making changes in this complex network of older people's, learning disability and carers' services will vary from area to area. However, even if another body takes formal responsibility for older families, each board should definitely have representation from older people's services and generic carers' services. It hardly needs re-stating that the input of older families as service users – or potential service users – is equally crucial.

East Surrey and Mid Surrey valuing people groups, (which feed directly into the learning disability partnership board), championed the needs of older family carers so effectively that a dedicated project was set up with Mencap to identify and support older family carers in their local areas.

Wherever the ultimate responsibility lies in your area, these key questions need answers:

- how many older families (including those not currently using services) are there are in the local area?
- how many carers' needs assessments leading to real outcomes have been completed with family carers over the age of 65?
- how many person-centred plans have been completed with people with learning disabilities living with older family carers?
- how is the quality of the plans and outcomes being monitored?
- how does the local accommodation and support strategy incorporate the priority needs of people living at home with older family carers?
- which senior representatives from older people's services and carers' services are linked into the learning disability partnership board?
- are representatives from the learning disability partnership board linking into the equivalent boards driving through the National Service Framework for Older People and the carers' agenda?
- what systems are in place for measuring and monitoring how well services are working together to support older families?

Chapter 2

Supporting older families in planning ahead

Key points

1

Older families want to plan ahead, but it is not always easy and people need the right support and to not be rushed.

2

Good planning happens in lots of stages. Families need to have the right information and everyone should be listened to.

3

It's important that older families have help to work out what each person wants and needs and that this is written down properly. (Person-centred planning and carers' needs assessments).

4

It can take a long time to plan with older families but if it is done correctly then services will be able to plan what they do much better.

As the previous chapter demonstrated, supporting older families to plan for the future requires a co-ordinated approach and long-term commitment. Too often, nothing changes until there is a crisis, at which point the options can be very limited. There are no quick solutions for helping older families and services to plan ahead, but there are definitely frameworks for action that can support that planning. Above all, person-centred approaches and

carers' needs assessments are the key mechanisms that can bring about real change in people's lives.

Key stages to planning

Research in the report *Today and tomorrow* (Foundation for People with Learning Disabilities, 2002) identified eight key stages that older families travel through in order to plan successfully. This report revises those stages, particularly because the first stage has to be appropriate support to keep going in the current situation, if that is what everyone wants for now.

Stage 1

Supporting older families with their current needs

Most older families are only prepared to start the very emotional process of planning for the future if they have trust and confidence in the services available, and they are only going to feel that way if services are providing adequately for their needs at the moment (see **Chapter 4** for more ideas on providing older families with the support).

In reality, many older families are struggling to cope on a daily basis and, as the previous chapter noted, they are often hidden from the existing services. People whose first language is not English are even less likely to remain in contact with services after the person they care for leaves the education system (Foundation for Learning Disabilities, 2002; Department of Health, 2001c).

Older families need:

- to be known by people and services who may be able to help them
- proactive contact from services before a crisis
- the confidence to explain any practical, health, emotional and financial difficulties. It is important to remember that many people with learning disabilities are carers themselves

- positive experiences of support services
- the opportunity to discuss and record what might happen in a family emergency
- breaks from caring when they want and/or need them
- a non-judgemental approach and no pressure to take steps they are not ready for.

Services should:

- find older families and make sure information systems are kept up to date and used (see **Chapter 1**)
- work out ways of making sure that services remain in regular contact with older families (see **Chapter 3**)
- make sure that older families and their extended family members know how to make contact with services that may help them
- ensure that people already known to services have their needs regularly reviewed and get any additional support they need
- ensure that older family carers have regular carers' needs assessments
- ensure that carers with learning disabilities get their caring needs recognised, assessed and supported
- develop good links with relevant agencies, such as advice centres and GP practices, so that older families are able to access direct support more easily and effectively
- make sure that older families are supported to access appropriate short breaks services
- support older families to plan for the possibility of an unexpected family emergency
- make sure that workers have access to training on the particular issues that face older families.

The implications for service planning include:

- developing and linking up information systems in order to identify older families and meet their needs through existing processes

- re-examining the eligibility criteria guidance developed through *Fair access to care services* (Department of Health, 2003) to ensure that the needs of older families are recognised and prioritised
- ensuring that this information also informs other types of planning and commissioning
- proactive checks on families' well-being
- joined-up working between statutory and voluntary sector services for older people, people with learning disabilities and family carers
- proactive preventative work as well as work on identified needs.

What do I think about for Julie's future? Honestly? If I know when I'm going to die I'd like to sit us both down, make us each a hot chocolate and put all my pills in it and we'd go together. At least then I'd have seen her out of this life and know she'd always been happy, safe and loved.'

Mrs Foster, aged 72, in 1996

When Mrs Foster said this to a worker, she and her daughter were living together. Mr Foster had died 12 years earlier. They had some family close by but Mrs Foster was anxious not to 'over-burden' them. Julie had used day services for many years – and enjoyed them a lot – but that was the only support the family received. They had not asked for any short breaks/respice care. They were coping reasonably well for the moment, but Mrs Foster was starting to find that she was slowing down physically and wasn't able to get out and about as easily or take Julie to the places she used to enjoy. She was very scared about the future.

However, in 2002 Mrs Foster had a sudden illness and needed emergency hospital treatment. All the systems worked well together to bring the family the right support. Social services provided emergency support for Julie for three weeks at a short breaks hostel. The disability social work team also worked with the hospital social worker and later with the older people's team to provide a package of home support for both Mrs Foster and Julie when they returned home. Some of that package remained in place to give them help with some daily care tasks and they continued to use a home shopping service every week. Every month Mrs Foster has transport to take her to a carers' support group, and she has enjoyed meeting and talking to other people

who've shared similar experiences. Julie still has a five-day service but she is doing a variety of different activities, getting out and about more and enjoying life a great deal. She also enjoyed her time at the hostel and continues to go there for occasional breaks but loves going back home.

Julie is about to start work on her person-centred plan, and inevitably she will need to think about her future. Mrs Foster is still anxious about openly addressing her fears but she is happy it will be happening. Her illness forced her and other members of her family to start talking about the future and she now knows that they have always intended to remain a big part of Julie's life and to speak up on Julie's behalf. She is much more confident about the future now.

Stage 2

Thinking about the need to plan ahead and openly acknowledging that change is inevitable

Most older families worry constantly about what the future holds. Some hope that another family member will take over caring. Others are very concerned that their relatives should not have to take on such a heavy responsibility. Similarly, people with learning disabilities living with older family carers are often worrying about what will happen to them when something happens to their ageing carer.

However, many people are simply not ready to start the business of planning.

Many older parents were originally told they would outlive their children, and never expected to be at the stage of still caring 40, 50 or even 60 years later. By now, their natural support systems have usually shrunk as other close friends and family members have died, and/or it is harder to get out and about and keep in touch. Some older family carers have never had the opportunity to speak about their hopes and concerns for the future with anyone. They may find it too frightening to discuss, especially if they think nobody will understand or be able to offer a solution.

Older families need:

- to know that if they start thinking openly about the future, their plans will be supported
- to know that they will not be pushed into anything they are not ready for, or judged for their lifestyles or decisions.

Services should:

- ensure that workers are trained to be sensitive to the complex emotions older families often feel around planning for the future
- develop services that allow different members of older families to feel safe enough to talk openly (including support workers, carers groups and old-style 'tea and buns' visits – some of the most isolated older families find this the safest way to open up)
- check that facilitators and assessors are asking appropriate questions during the initial stages of person-centred planning and/or while they are reviewing a regular service
- create opportunities for different members of older families to talk openly but separately about their hopes and fears for the future away from other members of the family (while letting everyone know that these discussions are taking place).

The implications for service planning include:

- investing in training in the needs of older families, and supporting, bus escorts, day service workers and anyone else who has contact with this group
- developing close links with carers' support organisations, particularly in the voluntary sector (many older family carers find voluntary groups easier to approach)
- building into service specifications the capacity for workers to develop long term relationships with older families
- looking at the pathways that lead older families towards help and support and making these accessible

- working proactively with older people's and primary care services in this area.

Mr and Mrs Thomson are both in their mid-80s and care at home for their son, who is almost 60. They used services once very briefly when he was a teenager, but it was a very unpleasant experience and they have never used any others. The family now has regular contact with a support worker but still no other direct service.

Each time the support worker visits Mr Thomson starts to ask questions about planning for the future and different options for support, and Mrs Thomson almost always leaves the room. Mr Thomson is very concerned that she won't talk about the future. He says her attitude is that she is going to carry on for as long as possible and can't think beyond this; yet she often wakes up in the night scared about the future, especially if her own health has not been good. Mr Thomson is unwilling to go any further in the planning process without her co-operation, but he has found out about the different options. Mrs Thomson knows where the information is kept and he knows she has looked at it occasionally. He refuses to push the issue; it is not worth endangering the routines that enable the family to cope on a daily basis, and they know to approach the support worker when the time is right for both of them to move forward together.

Stage 3

Finding out what the options are

Many older families know very little about current housing and support options, although they have heard of things going wrong. Terms like 'supported living' and 'independent living' can be very frightening to people who think this means living alone with little or no support at all.

Older families need:

- information which is up-to-date and accessible to everyone in the family, and relevant to their particular situation. (Many people collect information which becomes out of date)

- the opportunity to ask questions (and get answers) and check that they have understood the different options
- information on practicalities such as finances
- information about the whole process involved in moving (especially assessment, care management and funding implications).

Services should:

- ensure that key individuals and services in housing departments, carers' groups and older people's organisations know how and where older families can find out what they need
- create checklists that workers can go through to help older families work out which options they might want to explore
- ensure that information is clear, accessible, up-to-date and in all the necessary formats and community languages
- offer training to older families (including extended families) on issues such as person-centred planning, direct payments and other creative housing options
- work at the family's own pace, but make sure the information they have is current
- accompany families on visits to potential care providers.

The implications for service planning include:

- building in capacity for the time this will take
- ensuring that any information strategy takes account of the needs of this group
- regular reviews and consultations to check that the information on offer is up-to-date and meets service users' needs
- producing information about how person-centred planning and assessment processes link into forward planning.

Mr Brown, aged 76, lived at home with his daughter Rachel who was in her early 40s. Following an illness that scared them both, Mr Brown and Rachel were anxious to find out more about what options were available to Rachel in the long term, although the family was not ready to do anything further at this stage. The topic came up at a day service review. Their key worker used person-centred planning techniques to put together a list of each person's hopes and fears for the future. They discussed where Rachel might want to live in the future and what was most important to her in terms of support, housing, activities, community and relationships. Mr Brown was involved throughout the process and added in the things that he felt were most important: the level of support he thought she needed, the need for the two of them to live near each other and see each other regularly, and his concerns about her potential vulnerability.

Their social worker put together information (leaflets and a video) about the local options which might suit them and both workers went through the different possibilities with the family. They also visited several places where Rachel might choose to live. Mr Brown was amazed and comforted to learn that there were a number of options very near to their home that he hadn't realised existed. He and his daughter are still living at home, but they have carried out a full person-centred plan and Rachel is using a local short breaks service which would also be available if Mr Brown is ill again.

Stage 4

Starting to plan

Again, person-centred planning tools and assessment and care management roles are crucial, as they are the processes that will lead to plans becoming a reality in the long term. It is also very important to recognise that different family members have different priorities, and that everyone should have the opportunity to express themselves and establish their needs. See also *Person-centred planning and older families*, a good practice guideline available from the Foundation for People with Learning Disabilities website on www.learningdisabilities.org.uk.

Older families need:

- to understand how identifying their needs will be used to help inform the planning process
- the opportunity to establish different members' needs
- to think about other friends and family members who may also want to be involved
- to express their feelings and needs without fear of being judged
- particular sensitivity if 'mutual caring' is taking place.

Services should:

- use person-centred planning approaches that usually feel less threatening than assessments, such as life story books and essential lifestyle planning, to identify needs
- ensure that they treat family carers' and other family members' contributions with respect
- ensure they are meeting any current needs that this process identifies.

The implications for service planning include:

- building in mechanisms for regularly reviewing everyone's needs
- overall systems for collating this information, in order to get a picture of what is needed throughout the area (for instance tracking the number of people who would like to live in a small group house).

Bournemouth social services with Dorset Healthcare Trust have set up a training flat attached to one of their residential homes using money from the Learning Disability Development Fund. The training flat provides 6-8 week training opportunities specifically for people with learning disabilities living with older family carers. It gives people a taste of living elsewhere and gives an occupational therapist the opportunity to assess their daily living skills and the support needed, and to put in place a training plan. During their stay, people are offered help to draw up a person-centred plan and a review is held near the end to decide what needs to happen next to help people with their plans.

Jill, who is 50 and has learning disabilities, decided that in the future she wanted to live in her own flat with support. Her parents were very unhappy with this, and wanted her to go into a residential home instead. The key worker facilitating their person-centred planning tried to resolve this deadlock by asking the parents what is was about residential care they found so attractive. They explained that they liked the idea of 24-hour support, the fact that other people would be around and the presence of qualified staff. When their worker explained that supported living could offer a very similar situation, they were able to think about this option instead. The final plan ended up reflecting the different elements that both Jill and her parents felt were essential and desirable for anywhere she might live in the future. This gave the family and workers a clear framework from which to move forward with plans.

Stage 5

The crossroads

Assuming that there has been no sudden crisis that has forced the planning process to happen differently, stage five is when older families make the decision about whether or not they are ready for real change to start happening in their life now.

For some older families, getting this far is enough for now. Their current situation is stable. They have been able to talk openly about their hopes and fears for the future. They have had their needs assessed and found out what they may be able to do in the future. They may have already taken some practical steps, such as setting up a discretionary trust, completing life storybooks, developing independent living skills or using short breaks services. Most importantly, they know what to do and who to approach when the time is right for them to move to the next stage.

Other older families may now feel the time is right to move to the next stage in the planning process and to actively plan for alternative living arrangements for the person with learning disabilities.

Older families need:

- support to be able to talk openly and realistically about whether to go ahead with plans or not
- to know that they will be able to take things further when the time is right
- to be able to have the right support available now if they have made the decision to press ahead with plans so that the process doesn't lose its momentum
- to have realistic information about what support they can expect from statutory services to move plans forward and what sort of timescale they are working towards
- support to continue to plan for a move now if that is their choice.

Services should:

- keep in touch with all these older families, regardless of whether or not they have opted to take plans further forward
- offer older families the opportunity to make any changes felt to be necessary or appropriate from plans so far
- be prepared to put some worker time towards supporting older families to continue to plan and to take their plans to completion

- have some process for recording what plans and ideas families have in mind so far. This may help to inform future service development and ensure that if suitable vacancies arise in the future, services can be proactive in approaching older families who might be interested.

The implications for service planning include:

- building in capacity for person-centred planning with older families
- building in the capacity for long term proactive contact
- ensuring that long term planning incorporates the needs of older families.

Stage 6

Practicalities

Once an older family decides to start making a planned transition, it is time for practicalities to begin. Practical support may include actively following up vacancies, liaising with housing providers, putting together packages of support, sorting out finances, physically moving and finding money to help provide essentials such as furniture and crockery.

Older families need:

- support from people who can help make things happen
- to know that once their plans are put into action, they will see some concrete results
- to be kept informed and involved, and to be able to keep questioning
- to be able to change their minds or slow things down.

Services should:

- be able to respond quickly. If there is a long delay, families often start becoming anxious and unsure that they are doing the right thing
- ensure good partnership working between the different agencies

- provide clear and accessible information about what the next stages are and what older families should expect
- keep older families informed, especially if there are long delays before a suitable vacancy comes up
- identify the necessary help with practical issues such as taking people to visits, helping them move their belongings, and transferring all the relevant paperwork around such things as benefits.

The implications for service planning include:

- maintaining the capacity for the necessary number of referrals into assessment and care management services
- ensuring sufficient numbers of person-centred planning facilitators to work intensively with older families who come forward at this stage
- reviewing policies and procedures to ensure that older families are not turned away just because they appear to be managing at the moment
- commissioning sufficient practical support.

Mr and Mrs Gupta and their son Sam had never had any formal contact with social services since Sam had always been cared for at home and had never used any statutory service. However, they had a good relationship with a carer support worker from a local voluntary organisation; they had known her for many years, and they turned to her when they started thinking about the future. The carer support worker helped them to explore their needs and the different options that might suit them.

The family all decided that since Mr and Mrs Gupta were becoming more frail, the time was right to move forward and to help Sam to move elsewhere while his parents were still alive and could help him make the transition. The carer support worker made a referral to social services for a social worker, who worked with her to complete all the necessary assessments and help them find a vacancy in a group home that seemed to meet most of Sam's requirements. She submitted his case for funding, which was approved, and after a series of planned

visits and overnight stays, Sam moved in. Even though it took nine months to find the right place, Mr and Mrs Gupta were surprised by how smooth the process had been. Most importantly, Sam blossomed in his new home. He has a very active social life and has amazed his parents with how happy he is and the number of new skills he seems to be picking up.

Stage 7

After the move

Even if someone is no longer living in the family home, their family carers are likely to still want to be involved. People don't stop caring just because someone has moved away from the family home. In fact, as more people with learning disabilities are supported to live more independently within the community, they often continue to rely on their older families quite heavily for some of their support and to maintain their quality of life. It is vital that services recognise and value the impact of the support older families continue to give their relatives and find ways of maintaining it should anything happen to the family. The final stage of supporting older families to remain in touch, involved and coping on their own is a critical part of the whole process.

Many older family carers experience feelings of enormous guilt and grief when a person moves on – even if they can see that they are happy and well supported. Caring has usually been the biggest part of their own identity and after decades of focusing their lives around the needs of the person they care for, it is often hard to adjust. It can also be hard to get used to seeing someone else supporting their relative, especially if the new people are doing things in a different way. If they have never had the opportunity to do much outside their caring role, they may be very isolated. By now, they may find it difficult to get around independently as well.

Many people with learning disabilities have been providing a great deal of practical and emotional support – including financial support, through the contribution of their benefits to the household income – to their ageing

relative. They need to know that their relatives are managing and getting the support they need, even if this is just knowing that they're being helped to carry their shopping back from the supermarket once a week.

Older families need:

- time to get used to how other people support their relative. (This applies to people with learning disabilities who've had caring responsibilities too)
- to feel that they are still valued partners in this support
- practical support with visiting their relatives, and possibly outreach support during visits as well
- practical support for carers who have been supported by the person with learning disabilities.

Services should:

- make sure housing and support services are trained to be sensitive to the practical and emotional needs of older family carers
- plan regular reviews (which involve family carers if the person with learning disabilities wishes for this)
- actively support people with learning disabilities to maintain contact with their older relatives
- keep in regular, proactive contact with older relatives
- link family carers into sources of statutory and voluntary support
- encourage family carers to remain involved in consultation exercises, carer support groups and possibly in bodies such as the partnership board.

The implications for service planning include:

- ensuring good links between different services
- providing the necessary training

- ensuring that all relevant workers have information about the support available to older people in this situation, and the possibilities of staying involved
- requesting input from former family carers into information and consultation systems.

Conclusion

Supporting older families to plan for the future and make changes usually takes a long time, and in reality many families do not manage it as crisis situations may overtake plans and they skip straight in at Stage 6.

No one doubts that services wish to support older families in planning for the future. Planning ahead makes life smoother for everyone, as service planners can design and budget for the services that everyone will need. However, it needs joined up structures and systems, a lot of information, and the resources and capacity for a lengthy, detailed and complicated process.

The joint processes of person-centred planning and carers' needs assessment offers a particularly supportive framework for supporting older families to plan ahead, with good partnership working between families and services and the individual firmly at the centre of the process.

Never lose sight of the fact that planning for the future is the single most important issue for most older families. Services may only have one opportunity to plan thoroughly with older families so it is important to make sure that it gets done right the first time. If older families lose confidence in the process then they are unlikely to risk trying again: the process can be too painful for everyone.

Try to take some time to consider how well your area is doing in supporting older families through the stages of planning for the future.

Chapter 3

Practical support for older families: the big things that make a difference

Key points

1

Older families get a lot of excellent support from projects and workers who are there just to help them.

2

It is very important to make sure that special work with older families is still part of everything else that is happening for people with learning disabilities, older people and carers.

3

Workers in lots of different places need to be trained to understand more about how they can help older families.

This chapter describes the kind of practical initiatives that support older families who want to go on living together for the time being. It covers the big schemes that offer dedicated support and require significant resources. **Chapter 4** looks at initiatives which often cost relatively little and may already be happening, but which do require a change of attitude and a shift in awareness. Even though much of the provision covered in this chapter may need substantial resources, it is cost-effective as there is growing

evidence that proactive dedicated support for older families is making a big impact on the lives of older families.

As this chapter will demonstrate, dedicated work is happening within both the voluntary and statutory sector. It is working most successfully when it is linked in with other mainstream practice.

There is growing evidence that older family carers need the opportunity to build up good relationships with workers they trust. An area may have any number of wonderful creative schemes available but if older families do not come forward – or aren't directed towards them – they have no effect. The schemes outlined below operate in very different ways and in different settings, but they have all been successful in giving older families the individual advocacy support they need to talk about their current and their future needs.

The following two examples illustrate dedicated support for older families happening within mainstream services for carers.

Planning for the Future project at Suffolk Carers

The Planning for the Future project was set up in July 2003 to identify and support older family carers (aged 65+) of people with learning disabilities across Suffolk. A worker from Suffolk Social Care Services was seconded to Suffolk Carers to work with older families for 22 hours a week. Some of the key achievements of the project so far include identifying and actively supporting more than 60 older families across Suffolk, carrying out carers' needs assessments, recording emergency contacts and plans for short- and long-term care for the person with learning disabilities. The worker has also supported many older families to apply for £200 - £400 from the Carers Grant to pay for flexible breaks, holidays, washing machines and driving lessons. The project's work also includes co-operating closely with a variety of support schemes for rural areas, including the Befriending Scheme and the Good

Neighbour Scheme, as well as with carers' link workers in GP practices.

For more information contact: Planning for the Future Project Coordinator, Suffolk Carers, Unit 8, Hill View Business Park, Old Ipswich Road, Claydon, Ipswich IP6 0AJ. Tel: 01473 835409. www.suffolk-carers.co.uk.

Older carer link worker, West Sussex

This post was set up in April 2004, funded through the Learning Disabilities Development Fund, and demonstrated its worth within a few months. Older families have appreciated the support a great deal, and there has been a steady (sometimes overwhelming) stream of referrals.

The link worker is actually based within the Carers Liaison Project in Worthing, in order to distance this post from statutory services (so that 'hidden families' are encouraged to come forward). Families also get the opportunity to find out about workshops on back care, benefits, aromatherapy, emotional counselling and more, while the postholder gets the support of a team that is supporting carers generally. She also works closely with the community teams, family members, GP surgeries and older people's mainstream services. She has been able to help bridge the gap between statutory services and older family carers; to advocate for family carers, and work alongside the social worker towards a positive outcome for the whole family.

Most of the link worker's time is spent talking and listening to family carers and building up a good, trusting relationship before any further planning or referrals to other services. Many of the families she meets need to talk about how they are feeling about their situation before they take things any further, and she has been an invaluable source of support at this stage. Once they have made

some decisions, she makes a report (with their permission) to the relevant departments and individuals, and everyone works together to find a solution.

As one older family carer puts it, 'I can ring Liz and have a chat and she will come to see me and I will be able to smile again as things can be put in perspective'.

*For more information contact: Older Family Carers Worker, Carers Liaison Service, Methold House, North Street, Worthing, West Sussex BN11 1DU. Tel: 01903 528600.
www.carerswsx.org.uk.*

The following example highlights a service for older families that links in directly to an information collection service.

Sheffield Older Carers' Support Service

The Older Carers' Support Service (OCSS) was set up in 2000, originally with funding from the Promoting Independence Grant and now with funding through the Carers' Grant. It is part of Sheffield Care Trust and works alongside the Sheffield Case Register, which collects information about more than 2,800 children and adults with learning disabilities throughout Sheffield.

The OCSS ensures that all family carers of people with learning disabilities in Sheffield aged 70 or over have the opportunity for regular contact and access to the information and support services they need. The Sheffield Case Register is used to identify potential service users, and the two OCSS support visitors then get in touch with them. The support visitor's role is to build up good relationships with the families; keep emergency contact records; collect up-to-date information about their needs; point them towards the different sorts of support they might use and encourage

people to come forward before their problems turn into crises. They keep in contact through regular phone calls, annual visits and more frequent visits if families want this (family carers often want someone to drop in every few weeks for a cup of tea, a chat and help with reading the post). They are currently in contact with around 280 families, and have linked people into support ranging from benefits advice, shopping services, sitting services and handyperson schemes right through to a parrot-sitting service during a hospital stay.

For further information contact: Older Carers Support Service, Ryegate Centre, Tapton Crescent Road, Sheffield S10 5DD. Tel: 0114 2663043. Email: ocss.ocss@sct.nhs.uk.

The next example highlights the difference that can be made by having a dedicated person working for older family carers within an assessment and care management setting.

Southwark Older Carers' Assessment Project

In 2003 an older family carers social worker post was set up, funded through the Carers Grant.

This dedicated social worker is based within Southwark's Community Learning Disabilities Team, and works closely with this team as well as the older people's team and other relevant local organisations. Her role is to ensure that older family carers of people with learning disabilities carers have up-to-date carers' needs assessments and know about the support options available to them.

Families are invited to contact the older family carers' social worker for an assessment. They receive a detailed letter explaining the sort of things an assessment covers, followed by a phone call to arrange a first visit. During this pre-assessment visit, carers are given an

information pack that includes a registration for the local carers' centre; information on direct payments, benefits entitlements and funds for taking a break; details for a home security visit; advice on registering for the local free taxi service and a blank carers' needs assessment form for information. They agree a date for their assessment discussion and once their needs assessment is complete they keep a copy for themselves while their social worker follows up the various referrals that they have decided on. They are also offered on-going practical and emotional support.

As a result of this project, older families have been much more able to access the services and support they need to continue to care and plan for the future. The assessments also showed that they need more information, so funding has been provided for seminars on future planning, wills, discretionary trusts and different housing options. A support group for older family carers has now been set up as well. And finally, because the worker has been able to build up a solid, trusting relationship with families, it's been possible to put some people with learning disabilities in touch for the first time with services, including short break services and/or social workers of their own.

For more information contact: Older Family Carers Social Worker, Learning Disability Team, Southwark Social Services, 151 Walworth Road, London SE17 1RY. Tel: 0207 525 2155.

As the following example demonstrates, basing a support service for older families within an organisation specifically supporting older people can be very effective.

Leeds Age Concern Older Carers' Support Service

The Older Carers' Support Service is designed to offer support to carers aged 65 and over of adults with learning disabilities in the

Leeds metropolitan area. The service is commissioned by Leeds City Council through the Learning Disability Partnership Board, but run by, and based at, Age Concern Leeds – so it is able to link into Age Concern’s range of other services for older people and network of other contacts in the area. Two workers support more than 150 older family carers throughout Leeds and offer them home visits, telephone support calls, social events and access to information and advice, alongside referrals to other services. They assess support needs, refer to appropriate services, advocate for carers, do benefits checks (15% of older family carers have already had benefits increases), provide information, and give pretty well any other sort of support that is needed. They have been received very positively by older family carers and have made links with carers’ groups throughout the city.

Older family carers are supported in looking at their current situation, planning for emergencies (including compiling lists of emergency contacts with details of what help each person can offer) and thinking about the future. Each family carer has an individual assessment and an action plan, which is agreed with them. They are also supported in thinking about the difficult emotional issues of what will happen when they cannot go on caring: where the person they care for will live, what support they will need, and what needs to be done now. Once they have thought through these issues, they are helped to tackle the practicalities including help with wills, trusts and solicitors. Older families have also been helped to complete life books, which have proved a great success.

*For further details contact: Older Carers’ Support Service, Age Concern Leeds, 188a Woodhouse Lane, Leeds LS2 9DX.
Tel: 0113 2031104. Email: ageconcern@leedssilversurfers.net.*

Basing support for older families within voluntary sector organisations already skilled in supporting people with learning

disabilities can be very useful in helping older families to feel confident in coming forward for support.

Leicestershire Mencap's Older Carers' Support Service

Leicestershire Mencap has been funded to provide a support service for older family carers (aged 60 or over) of people with learning disabilities since April 2003. The aim of the service is to identify older family carers aged 60 years or over and to work with those carers to ensure they are getting enough support and to help make plans for the future. The service has more than 100 older family carers registered on its database.

All older family carers receive a detailed information pack on the first visit that includes information on housing options, benefits, planning for the future, wills and trusts, local carer groups, social services, equipment and adaptations and emergency alarms. The scheme has been particularly effective in helping older family carers to collect extra benefits in their own right, such as Attendance Allowance, Pension Credit, housing and council tax benefits.

The case of Mrs G, aged 87, and her son, G, 61, helps illustrate how the service can help older families. Mrs G has now had equipment and adaptations fitted in her house to help her with getting around and showering. Her son has had a community care assessment and Mrs G has had a carers' needs assessment, which has resulted in them gaining a laundry service as well as plans being made for G to be able to remain in his home in the future.

*For more information contact: Older Carers Support Service,
Mencap Regional Office, Kimberley House, Vaughan Way, Leicester
LE1 4SG. Tel: 0116 2422740.*

Supporting older family carers with speaking up about their needs

Some older family carers find it very hard to speak up about their own needs. They may have had bad experiences in the past. They may be worried that if other people get involved, they'll take over. Many family older carers don't know very much about what is on offer these days, especially if it's a very long time since they last had any contact with services. However they do know that resources are scarce, and worry that they will be too much of a drain if they do come forward and help is actually offered.

The emphasis on 'negatives' – what you or your family cannot do – in order to meet the eligibility criteria for getting help doesn't help either, if the family is coping fairly well overall. Many families are very proud of the person with learning disabilities as well, and do not want to have them termed 'incapable' or 'a burden'.

Mrs Franks was supporting both her son with learning disabilities and her husband, whose health was failing and who was largely bed-ridden. She was not in good health herself, with her mobility seriously limited by arthritis. She contacted her local social services department to find out whether she could get any help in the home. At her interview, she was asked the usual questions about how she was managing at the moment, and she explained that she was cooking, cleaning and able to carry things up and down stairs. The interviewing officer said that she was managing fine, and advised her to look around for a private source of domestic help.

About three months later, Mr and Mrs Franks had their first visit from an older family carers support worker. After a couple of visits, Mrs Franks talked about how difficult she was finding it to keep on top of all the domestic tasks. When the support worker suggested approaching social services for help Mrs Franks said there was no point and told her what had happened before. The support worker made a re-referral with Mrs Franks next to her. During this interview she gave the same answers but her support worker encouraged her to explain that she could only cook very slowly and had to sit down for most of the process; she could not bend down to the oven easily; her wrists were

quite weakened from the arthritis; getting things up and down stairs took a complicated set of manoeuvres with the help of a trolley and tray, taking over half an hour each time. This time she qualified for some home care support for the family, particularly around mealtimes, and with other domestic tasks such as shopping and cleaning.

Supporting people with learning disabilities to speak up about their needs

People with learning disabilities living with older family carers may need dedicated time and support to enable them to identify their own needs, particularly if they are carers themselves. Even if they are not providing hands-on personal care, they may well be doing a lot of other household tasks. People often feel very proud of the support they are providing, and see it as a natural role to take on as their parents age.

Support schemes targeted primarily to older family carers do usually have a positive impact on the person with learning disabilities, but many people do also need some specific support in their own right. However, this is a very sensitive area of work. Many older families are reluctant to explain how much mutual caring is going on, in case somebody 'interferes'.

Sandra, aged 53, lived at home with her mother Edna, who was 81 and seemed in generally good health apart from her failing eyesight. They had no other family nearby. When Sandra started using some new day services, the change of routine exposed the fact that her mother was becoming increasingly confused and unable to cope independently. For example, Edna fell behind with paying her rent because she forgot which day to pay it on, while she would turn up at the optician's every week because she couldn't remember when her appointment was. She eventually accepted help from their older carer support worker, but refused to allow anyone else into her life.

Edna showed the support worker 15 carrier bags full of post that had been opened but not read from the last 12 years, since neither she or

Sandra could recognise anything except bills they could take to the Post Office. Although their worker talked to social services and health professionals, very little could be done without Edna's consent (particularly since she scraped through the assessment of her mental health needs). Throughout this time, Sandra maintained that everything was fine at home.

One day Sandra came to her day service with sandwiches made with very mouldy bread. When her key worker talked to her about this she became very distressed. She finally talked about how hard she was finding it at home, particularly over the weekends when her mum asked her the same questions over and over again, and about how worried she was about how her mum coped without her. She agreed to see a social worker, but said she wanted to stay living with her mother.

From that point onwards, Sandra and Edna each had separate social workers. Both received full needs assessments, including individual carers' needs assessments, and a support worker was introduced into the home to help with some domestic tasks and to take Edna out during the day. Sandra has now helped settle her mother into a nursing home, and has remained living in the family home with a support package to help her live independently.

Advocacy services can help people identify their own needs, while social workers and other key trusted workers can help people to work out what they need for their caring, but this may take some time. It is very important that all health and social care professionals are trained to recognise situations where people with learning disabilities are providing regular care and support for an elderly relative.

Shropshire Mutual Caring Assessment

Shropshire has developed a carers' assessment form that uses symbols instead of print, accessible to some people with learning disabilities who cannot read. The assessment is carried out with the person they trust most (usually a day service key worker, supported by the carers' link officer) and the form is recognised and valued by

social services. It has made it possible to realise, for example, that a person with learning disabilities who has requested a 'grab rail' to help them up and down the steps to their house actually needs this rail in order to do the family shopping for a housebound relative (which means that the older people's team will install the equipment the learning disability team has previously refused).

For more information about the mutual carers assessment form, contact: Shropshire Carers Link Officer. Tel: 01939 211006. Email: flick.pennal@shropshire-rcc.org.uk.

Bromley Mencap Mutual Carers Project

The Mutual Carers Project supports both the person with a learning disability who is now providing care and their older family carer. It employs a worker who currently has an active caseload of around 12 families but keeps in touch with many more. Part of her remit is also to find those families who haven't been in touch with agencies so far. In one family, a 62-year-old woman with learning disabilities had never had any contact at all with services – including school – and had spent her entire life with her mother, now aged 93. The father had died more than 30 years ago. They were only discovered when the project worker contacted a local church charity and found that a volunteer from the charity did the family's shopping.

Even families who have known about some services rarely know about everything that is on offer, so one important task is informing people about issues from bus passes to adult education. Once they have the information they need, their worker stays in touch and makes sure they receive the help they need, accompanying them to some appointments if necessary.

It has taken time for the project worker to build up a close relationship with families, but many families now see her as the first person to call for help, information and/or support with problems

like emergency care when an older carer goes into hospital. When the mother in the family above became seriously ill, the project worker had built up a sufficiently good relationship to be able to reassure the daughter that everything possible had been done for her mother, and help her come to terms with it all. In another family, a man with learning disabilities has been supported to become more financially independent (including opening a bank account) while his mother – who has dementia and has little short-term memory – has been put in touch with Age Concern for practical help in the house. Other family members have also said how reassuring it is to have someone else looking out for their relatives.

However, it is not always easy to make it clear that although the worker has a dedicated role, there is a limit to how much time they can give each individual family. It is also important to appreciate that this job cuts across two discrete services, set up and funded for either learning disability or older people; the 62-year-old woman with learning disabilities will become the responsibility of a completely different team in three years' time, which makes it harder to find a suitable place for her at the moment. It's also clear that anyone in a post like this does need to be supported, especially when they have to deal with issues that can be extremely draining, including bereavement.

*For more information contact: Mutual Carers Project, Bromley
Mencap, Rutland House, 44 Masons Hill, Bromley, BR2 9JG.
Tel: 0208 466 0790.*

Promoting 'older family awareness' in the workforce

Although dedicated projects are an extremely effective way of ensuring that this group receives better support, successful work involves a number of services and workers, from learning disability and older people's partnership

boards downwards. It is also unreasonable to expect that every issue related to older families should automatically be the responsibility of a dedicated worker. In order to ensure that this doesn't become an isolated, specialist area, a lot of people need to be aware of the issues, and able to recognise the signs that might indicate a problem. They also need to be able to work with older families effectively and sensitively and be able to direct people to other forms of support and information.

Valuing People (Department of Health, 2001b) discusses building training and awareness-raising into workforce development plans. This should apply to health professionals, day service workers and transport services as well as social workers and people involved in generic carers' and older people's services. It should cover:

- the impact of caring over a whole lifetime, especially the way services and clients' experiences of services have changed over the years
- the need to work at the family's own pace and avoid judging them
- mutual caring issues
- the effects of ageing on caring
- the fact that families constantly worry about the future
- the fact that many families have dealt with a succession of professionals who come into their lives and then disappear – and their story may well be already on record several times
- the importance of carers' needs assessments and of drawing on the full range of information and support available in the area.

Where possible, older families should be directly involved in delivering training. If this is not possible, they should be shown on video. Real stories are an incredibly effective way of highlighting the needs of older families. (Some examples of useful training resources can be found in the resources section on page 103).

Chapter 4

Practical support for older families: the smaller things that make a difference

Key points

1

There's probably already lots of good things that can help people with learning disabilities, older people and carers in your area.

2

It's important to make sure that organisations know they need to offer their help to older families that need it.

3

It's important that older families know about all the different things – small and big – that might help make things easier for them.

This chapter looks at ideas, schemes and projects that do not cost much but can make a huge difference to older families' lives. Most areas already have at least some of these, but often do not make them available as effectively as possible. It is important to remember that alongside the dedicated project work (described in **Chapter 3**), person-centred planning, along with assessment and care management systems, will usually be the process for uncovering unmet need amongst older families. So it is important that these processes are working well in your area.

A-Z of support

The topics covered here are listed alphabetically. They cover practical support, emotional support, access to information, and support with health and wellbeing. This is by no means an exhaustive list, but it gives a good indication of the kind of ‘small things’ that can make a big difference, and of the gaps that exist in some areas. The key point is that local authorities should work out a systematic response for ensuring that older families get all the support they need.

Advice and information

Older families of people with learning disabilities are often the people with the most out-of-date information about the kind of help on offer, or the sort of provision they might consider for the future.

Families often want information about services and support for people with learning disabilities, older people and/or carers; benefits and financial advice; housing advice; legal advice; and help with health questions. Many prefer one-to-one help. Others like to get information through groups they use. In either case, services need to be able to respond or feel confident to signpost them in the right direction.

Most local areas already have advice centres, Citizens Advice Bureaux (CAB), pension credit advisors and/or information services run by voluntary organisations such as Age Concern. Between these, home visits, telephone advice and help in a variety of community languages are often available. Other useful methods of getting information out to older families include libraries, (especially the library buses that operate in most rural areas), and local initiatives such as the Carers’ Bus that travels around West Sussex. Local radio is also a useful way to get information to isolated older families, particularly radio stations that transmit in different community languages.

However, many service providers do not know about the particular needs of older families of people with learning disabilities. For example, a local Age Concern may be able to advise someone about how to make a will but not about the importance of leaving money and property in a discretionary trust

so that the benefits of the person with learning disabilities aren't affected; or a project may not know which local solicitors are particularly skilled with disability issues, even though another scheme has compiled a list of them. It is important to make sure that information and advice services are aware of the needs of older families, and can help them get the right information in a format they can use.

Sheffield Carers' Centre sends out regular newsletters to thousands of carers throughout the city. In addition to a daily helpline staffed by trained volunteers, carers are offered regular free and confidential legal advice sessions in partnership with a local firm of solicitors, and benefits advice sessions delivered by a local CAB. Every other week the centre also runs a carers' information stall at the council's First Point reception (a one-stop shop for all council enquiries). Specific enquiries about learning disability issues are usually handled in conjunction with the Sharing Caring Project at Sheffield Mencap, which provides specialist information for these family carers.

For more information contact: Sheffield Carers' Centre, 7 Bells Court, Bells Square, Sheffield S1 2FY. Tel: 0114 2788942.

Email: office@sheffieldcarers.org.uk. www.sheffieldcarers.org.uk

Older people often have sight and/or hearing problems as well, which means it is very important to have information available in different formats, and people with learning disabilities also need information (both about the options for their own future care, and about support for any caring they may have taken on) which is accessible to them. These difficulties are compounded for older families whose first language is not English, and/or for families who have become increasingly isolated (especially families where the person with learning disabilities cannot help read letters or take telephone calls for a parent with sight and/or hearing problems).

Many areas already provide accessible newsletters and information packs, and a number of different organisations have produced good, clear guidelines on how to make information accessible. One simple but effective step is to produce all written information (including letters) in a minimum

size 14 font. In some areas, local tenancy support schemes or volunteer schemes can also help older families who need regular support to be able to read and respond to their mail.

Blackpool Learning Disability Partnership is one of many local areas to produce an excellent information pack for family carers of people with learning disabilities. Blackpool's pack *Signposts for Older Carers* is a series of fact sheets that can be easily updated. Developed in consultation with older family carers, the pack covers everything from carers' assessments, home repairs, and emergency cards to retirement benefits. The information is presented very clearly without too much overwhelming detail.

For more information contact: Older Carers Project Worker at Blackpool Learning Disability Partnership, Housing and Social Services, Progress House, Clifton Road, Blackpool FY4 4US. Tel: 01253 477249.

The following questions will help you assess how well the need for information and advice is being met in your area.

- How do older families in your area get information and advice?
- Do people know where to go for information?
- Has any work been done to find out what older family carers want and need to know?
- What provision is available for families whose first language isn't English?
- What sort of information is available for people with learning disabilities?
- Who is responsible for making sure that information for family carers, people with learning disabilities and older people is joined up, monitored and updated regularly?

Advocacy

Older family carers have usually spent a lifetime advocating for the needs of the person they care for. They need to be confident that someone who

knows and cares about their relative will continue to speak up for, and with, them in the future. Advocates could be other relatives, family friends, citizen advocates, workers or other people within a person's circle of support.

Just as it is now widely accepted that people with learning disabilities should be enabled to speak up and be listened to, it is also vital that older family carers have the support necessary to help them to speak up about their own needs. Workers often fail to understand how difficult it can be for family carers to identify that they have needs of their own, let alone speak up about what they might want or need in front of others, particularly professionals.

Different members of older families, (including members of the wider family), may want and need the opportunity for individual advocacy support to help them speak up at different times. Support with advocacy may be particularly important during any discussions around planning for the future: different people may have different viewpoints and wishes that can often be misinterpreted by others as 'conflicts of interest'. With the right advocacy support to ensure that everyone is able to express their points of view, concerns can usually be unpicked so that everyone can move forward with plans together.

Alongside the growing advocacy and self-advocacy support for people with learning disabilities in local areas, many older people can now seek advocacy support through local voluntary organisations for older people and carers as well as through advice services.

- Are older families in your area supported to be able to link into available advocacy services?
- Is advocacy support targeted towards people with learning disabilities living with older family carers who are making plans for the future?
- Are older people's, carers' and advice services aware of the need for advocacy support for older family carers and members of the extended family?

Benefits

Older families are often not getting all their benefit entitlement and are struggling to make ends meet. They may not know that they are entitled to some benefits (especially attendance allowance or pension credit), or they may find the paperwork too difficult to negotiate.

Many local areas offer free benefits checks to older people, family carers and people with learning disabilities, followed by support in applying for the funds they are entitled to.

Mrs Simm is an older family carer for her son, Donald, who still lives at home with her. She was visited at home by a carers' support worker who had recently been on a benefits training course and realised that she had been missing out on some of her benefit entitlement for some years. The worker helped Mrs Simm to make a claim for the back payment and then helped follow the claim through. Mrs Simm was eventually awarded £10,500 in benefits.

- How do you make sure that older families in your area are receiving the benefits they are entitled to?
- Are all local benefits advisers aware of the issues affecting older families?
- Can older families be targeted to ensure they are claiming everything they should?
- What support is available for older families who make extra claims?

Community alarm schemes

Most local areas already have some form of 24-hour community alarm scheme, mainly used by older people. Although they aren't usually free, these schemes can offer a real lifeline to older families. They are also particularly easy for people with learning disabilities, since users simply have to push a red button to get a voice on the other end of the phone. Community alarms are also very reassuring for friends and relatives,

especially schemes that contact key-holder relatives who might otherwise worry about not knowing about a family emergency. Most alarm schemes record who else has a key to the home and who should be contacted.

- Does your area offer a community alarm service?
- How are older families told about the service?
- Does your local scheme record caring responsibilities, so that it's clear that there is more than one vulnerable person at the same address?
- Is the service equipped to deal with the particular needs of older families of people with learning disabilities?

Death, dying and bereavement

Coping with death, dying and bereavement is very difficult for most people, and it is often particularly difficult for older families of people with learning disabilities. Although most learning disability services are becoming increasingly able to offer support, the support needs of older family carers can be overlooked. Frequently they have to cope with their own grief while supporting the person they care for and, if it's a fellow-carer who has died, making the adjustment to being a single carer as well. And even the families who have had a good support network in the past usually find that this support drops off as everyone gets older or dies.

Many older families very much appreciate having someone to talk to, and older family carers in particular usually need help ensuring that the person they care for is able to understand and deal with their loss. Most areas have local bereavement services that can offer a range of support. However, they do need to be aware of the specific issues that older families of people with learning disabilities face in connection with bereavement, so they may need training in this area.

Cruse Bereavement Care is the leading charity in the UK specialising in bereavement. It is a non-religious organisation that welcomes people of all beliefs and none. Local branches may vary, but generally Cruse can usually offer a range of counselling and support to people who have been bereaved.

For more information contact: Cruse Bereavement Care, Cruse House, 126 Sheen Road, Richmond, Surrey TW9 1UR. Tel: 020 8939 9530. Email: Helpline@crusebereavementcare.org.uk. www.crusebereavementcare.org.uk

Families also need very practical support with tasks such as sorting out clothes, informing banks and benefits agencies, sorting out funeral arrangements and so on, including additional breaks or help caring in the home so that they actually have time for these activities. It is also often very important to inform all the agencies and services with which they are in contact. The government's website at www.direct.gov.uk offers a lot of clear and useful information on topics including registering a death, organising funerals and financial help.

North Staffordshire has produced a number of leaflets for people with learning disabilities and workers to help support and empower people with learning disabilities who have experienced bereavement. The leaflets offer a framework for talking with people and finding out the best ways of supporting them.

For more information about Bereavement Support for People with Learning Disabilities (BSLD) contact: Broom Street Specialist Resources, Broom Street, Hanley, Stoke on Trent, Staffs ST1 2EW, tel: 01782 425080 or Royal Mencap Society, Winton House, Stoke Road, Stoke on Trent, Staffs ST4 2RW, tel: 01782 848800.

- What sort of information and support services are available in your area for older families coping with death, dying and bereavement?

- Are local bereavement services aware of the issues facing older family carers and people with learning disabilities?

Direct payments

All local authorities are being encouraged to offer direct payments to people eligible for services, including people with learning disabilities. Older family members may qualify for support on the basis of their age, learning disabilities and/or caring responsibilities.

Direct payments do not suit everyone – some older families find the responsibility quite daunting – but many service users feel that this is an unequalled way to increase their choice and control over the support they get. Direct payments to older family carers or people with learning disabilities who are also carers may be particularly useful for paying for support around the home with tasks such as ironing and cleaning, or for help with getting out of the house. Most local areas now offer good support to people using direct payments, and other family members are also sometimes able to help with the administration and paperwork, either directly or through a trust.

Bill, who is 72, and Mary, 67, live at home with their son Graham. Graham receives direct payments as well as monies from the Independent Living Fund (ILF), and his parents receive direct payments in their own right as family carers. Graham gets regular support from workers with daytime activities, and regular flexible support at mealtimes and in the evenings. The support workers also stay at home with him when his parents are away. He is out and about more; he's had more support for his health needs (which has improved his quality of life) and he regularly spends time at his support workers' homes as well. Bill and Mary have also used their payments to fund more external support for Graham. This has enabled them not just to get more time to themselves, but to attend carers' groups and other meetings. Everyone receives separate advocacy to make sure that their individual support needs are being met, and direct payments have worked so well for them that they have been able to recruit an excellent team who

they are confident will be able to support Graham in the long-term. They have now made arrangements to leave their house in trust to their son with the peace of mind that he will be safe, happy and well supported when they are no longer around.

Bill is now a passionate advocate for direct payments and spends a great deal of time telling others about the huge difference it has made to their lives, and trying to encourage other families to make the most of the opportunities it can offer. As he says: 'The younger care workers are able to give Graham more of what he needs because they are closer to his age. He's not living the life of a pensioner any more.'

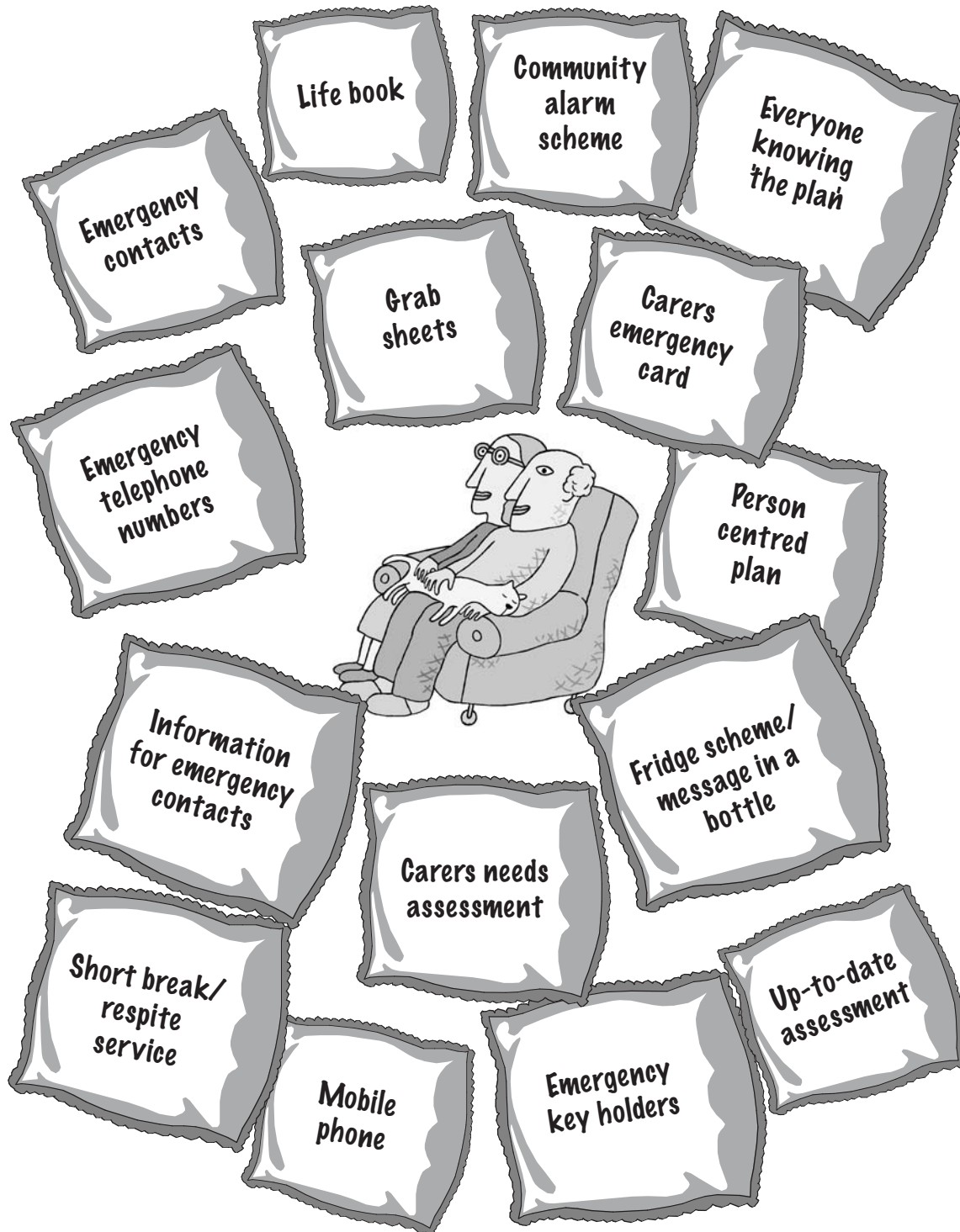
- Do older families in your area get help with finding out about, accessing and using direct payments?
- Are any older families willing to speak to others about the difference direct payments have made to their lives?

Emergency planning

The top worry for pretty well every older family carer is 'what is going to happen to the person I care for if something unexpected happens to me?' Depending on the family, this can range from a traffic jam which prevents them getting home in time, to sudden illness. Whichever it is, older families want and need support to make plans for a crisis.

The Older Family Carers Initiative has produced detailed guidelines outlining ways of planning for a family emergency. These guidelines are available to download free from the older family carers page at the Foundation for People with Learning Disabilities website at www.learningdisabilities.org.uk. The key message is that local areas need to look at ways of 'cushioning' older families in readiness for emergencies. As **Diagram 3** illustrates, 'cushions' can be provided in a variety of ways, and the cushions are often readily available. They just need to be built into existing systems for supporting older families.

Diagram 3: Cushioning the impact of a family emergency



The inner London borough of Tower Hamlets provides a pro forma for an emergency plan, which is offered to all carers over 60. It is written in a person-centred way, and should involve the person being cared for as much as possible.

The form is intended to provide a plan that covers all the different emergencies a family may encounter. The actual process of making the plan is often quite a difficult one for many older families. They have to face up to the prospect of bereavement and loss, and they may find that different people have different expectations of what will happen once the main carer dies. These are useful discussions, but they need to be handled very sensitively.

The finished plan identifies the different options for each emergency; lists these in order of the family's preference; gives a full list of contacts who can be drawn on (and the kind of support they can offer); and sets out the practical information like where the spare keys and medication are kept. It should be reviewed and kept up-to-date every year, as part of the family's general review, and it should be made available to all the professionals who might need to use it (especially emergency duty teams). It's also important to remember that if an emergency happens out of hours, the people responding to it probably will not be able to go into a central office to get hold of a copy.

For further information contact: Tower Hamlets Learning Disability Care Management Team Manager. Tel: 020 7364 5540.

- What 'cushions' are already available to older families in your area?
- How are older families supported to plan for a family emergency?
- How do you ensure that families' emergency plans are kept up-to-date and reviewed regularly?

Emergency cards

Emergency cards are a very straightforward way to give people peace of mind. They can be carried by family carers and/or people with learning

disabilities, with contact details of who to contact in an emergency and an explanation that the holder is a carer.

Blackpool's carers' emergency card scheme collects information about the carer and the person they care for. The actual card only gives a telephone number and reference number for callers to quote, so the card-holder's personal details are kept confidential. Anyone who rings the number is put through to a 24-hour community alarm response centre which holds the relevant information. The card is free to all carers in Blackpool.

*For more information contact: Carers Team, Housing and Social Services, Progress House, Clifton Road, Blackpool FY4 4US.
Tel: 01253 477788.*

See also **Chapter 1** for details of the emergency response card offered in Torbay.

- Are emergency cards available to older families in your area?

Equipment and adaptations

Equipment and adaptations – from jar openers to bath chairs – can make an enormous difference to older families. Most of these are available through the local health and/or social services departments, usually on the recommendations of an occupational therapist who can help advise on options that might suit individual situations best.

- Do older families in your local area have information about adaptations and equipment, and about how they can get hold of these?

Fridge schemes (message in a bottle)

Many local areas have developed emergency fridge schemes (sometimes known as message in a bottle), although often they are more heavily publicised within older people's services. The scheme works on the assumption that every home has a fridge in a fairly obvious place, so emergency information is stored in a container in the fridge, with a green sticker displayed on the front of the fridge door and inside the front door. Emergency services are told about the scheme, and know to search for the containers in any fridge with these stickers. Some people also keep containers in their car glove compartment, with a sticker on the front.

- Are schemes of this type available in your area?
- If they are available, is the information inside customised to accommodate older families where someone has a learning disability?
- Is there support to help people with learning disabilities, and older family carers, supply all the necessary information?
- Is everyone (emergency services, GPs and social workers), trained to recognise the stickers?

Gardening schemes

An overgrown garden is a security risk. It's often a sign that the person living in the house is physically vulnerable. However, this is not the only reason to offer older families gardening support. Many older families get enormous pride and pleasure out of their gardens, and feel very unhappy when they're not able to continue maintaining them.

Many local voluntary organisations can provide a gardening service to older and/or disabled people, and organisations like Help the Aged or Age Concern can usually direct older families towards sources of local help. In many areas, there are also tenancy support schemes that include support with gardening, and/or community service schemes that can provide gardening help.

Derbyshire has a service which combines employment for people with learning disabilities and support for older families. Teams of people with learning disabilities provide gardening and basic home maintenance for older people in Chesterfield and north east Derbyshire.

- How can older families in your area get support with looking after their gardens?

Grab sheets

This is another way to keep all the basic information about emergency contacts, medical details and so on easily to hand in case of an emergency.

Grab sheets are simple forms that capture basic essential information that might be needed by anyone responding to an emergency concerning a person with learning disabilities or their older family carer. The sheets contain information including emergency contacts, medical information that might be vital in an emergency, and key details about how an individual communicates and the support they may need with their personal care. The family keeps a copy and copies are distributed to other key individuals involved, such as a key worker at a day service and a GP.

Shropshire's carers' link worker has developed a system of making sure that all vital and relevant information about people with learning disabilities is recorded on one 'grab' sheet and this is kept up-to-date and distributed to the key people and services that have contact with the individual.

*For more information contact: Shropshire Carers' Link Officer.
Tel: 01939 211006. Email: flick.pennal@shropshire-rcc.org.uk.*

- Do you have any type of grab sheet system in your area?

- How are older families (including the member with a learning disability) supported to complete grab sheets and keep them up to date?
- What systems ensure that everyone relevant either has a form or can get hold of one easily – at any hour of day – in an emergency?

Health support

Many older family carers neglect their own health needs, often putting off appointments and medical treatment because they're worried about how the person with learning disabilities would manage without them. As a result, many projects and workers find that health needs become a priority concern.

GP practices can offer a lot of support to older families, and should already be offering proactive support through the annual health checks offered to everyone over 75. An increasing number of practices now record patients' caring responsibilities and either support carers directly or point them towards other sources of support. A good GP practice can be invaluable: small things like home visits, or appointments at convenient times, can make a huge difference to the quality of older families' lives.

Help with transport to appointments can also make a huge difference, as can information about chemists who offer home prescription delivery services, and/or help with administering medication.

Health Action Plans offer a great opportunity for people to make sure that the person with a learning disability living with an older family is getting their health needs met. They're also a good way to identify less obvious areas where older families may be struggling, such as with getting people to appointments.

Health link workers in Slough work with vulnerable isolated families from black and minority ethnic communities who are caring for children and adults with learning disabilities. The workers form a link between the community teams for people with learning disabilities and other

statutory agencies providing information and advocacy for families who often don't have English as their first language.

For more information contact: Carers Support Service - Slough, Upton Hospital, Albert Street, Slough SL1 2BJ. Tel: 01753 635520.

Wolverhampton social services, health workers and Mencap run a free service for adults with learning disabilities called Home Support +, helping people stay in the family home if they have a health-linked emergency (including family carers going into hospital). Support is planned initially for six weeks, but it can be extended beyond this.

For more information visit the website at www.wolverhampton.gov.uk or contact the learning disabilities team. Tel: 01902 572572.

- Are GP practices, hospitals and health workers in your area equipped to deal with the issues affecting older families?
- Are Health Action Plans paying specific attention to the difficulties older families may be experiencing?

Help around the home

Many older families who can cope very well with their personal and everyday care needs still struggle with bigger tasks around the home. Although most social services can offer some support through home care services and laundry services, this does not cover things such as cleaning, redecorating or minor DIY.

Local organisations such as Age Concern or Help the Aged can usually direct older families towards other sources of help, often including specific people who are known to be reliable and trustworthy. Some schemes even run their own volunteer 'handyman' services.

Slough social services and the primary care trust have developed a voucher scheme for older carers and carers looking after older people. If assessed as eligible, carers receive a book of 12 vouchers which they can use as they want, with a list of approved providers offering window cleaning and shopping. The main provider is Age Concern Slough and the scheme links in closely with Slough Carers' Support Service.

*For more information contact: Slough Social Services Department,
Slough Town Hall, Bath Road, Slough SL1 3UQ. Tel: 01753 552288.
www.slough.gov.uk.*

- Do older families in your area know how to get help with tasks around the home?
- Are the organisations providing support aware of the needs of older families?
- Are learning disability services aware of the support other voluntary and statutory sector services can provide in this area?

Home safety checks

Many tenancy support services and housing schemes offer home safety checks to older people and disabled people – whether tenants or homeowners – and either put in adaptations like handrails themselves, or help families claim for bigger refurbishments (such as central heating to replace open fires). Local crime prevention teams can also offer useful help with getting window locks and other security measures.

- Do older families and workers in your area know about home safety checks?
- Are the organisations offering home safety checks equipped to respond to older families?

Housing information

Older families are usually very keen to find out about different types of housing and support available for their relative, both now and in the future. Their housing needs should have been covered by the housing strategies produced by learning disability partnership boards, but they may not have all the information and advice they would like. Local housing departments need to be aware of the issues affecting older families, and people with learning disabilities need to be encouraged to register on their local housing lists in good time (which also helps inform future planning).

Hammersmith and Fulham Housing Department has a housing officer for people with learning disabilities, who promotes the interests of people with learning disabilities, promotes partnership working between the housing department, social services and voluntary agencies, and works directly with service users. They have also produced an accessible booklet outlining the housing and support options for people with learning disabilities and older family carers, which helps older families start planning this aspect of their futures.

For example, the worker has been able to ensure that a woman with learning disabilities will inherit her mother's tenancy and will also get the support she will need to live on her own. This plan – which took a lot of discussion and negotiation – has enabled the mother to feel very much happier about the future (especially as her other daughter lives in a flat only two floors above).

Many older families simply do not know how many different creative forms of housing and support for people with learning disabilities are on offer. They need comprehensive information – complete with contact details – and often appreciate the opportunity to see videos and meet representatives as well.

Housing Options provides an independent housing advisory service for people with learning disabilities, their family carers and workers. It offers information on a huge range of housing options, including such things as shared ownership and leaving property in a discretionary trust. The organisation has also developed individual assessment Housing Options Plans for use with families, advocates and support workers.

*For more information contact: Housing Options, 78a High Street,
Witney, Oxfordshire, OX28 6HL. Tel: 0845 4561497.
Email enquiries@housingoptions.org.uk. www.housingoptions.org.uk.*

- How do older families in your area find out about housing and support options?
- Is housing information available in different formats and languages?
- Are local housing services aware of the needs of older families?
- Are people with learning disabilities living with older family carers encouraged to join the housing register?

Internet

A lot of information and access to many services is now available through the internet, but many older people are not computer literate or familiar with this. Older family carers may find it particularly difficult to spare the time for a computer course, or the money to buy their own computer. As a result they are losing out on a lot of opportunities including shopping from home, email contact with friends and family, and online support groups. However, there is a national drive to equip older people with computer skills and a lot of voluntary and statutory organisations offer help to older people who want to find out more about using computers.

Shropshire has supported seven older family carers of adults with learning disabilities onto an IT training course. The course is run under the umbrella of Learning for Life and the education authority tailored this course specifically to meet family carers' needs, and ran it at times to fit in with their caring responsibilities. Family carers who did not have their own computers got reconditioned computers from the local recycling furniture scheme. The family carers have loved the course and learnt the skills to be able to email their grandchildren, keep in touch with each other and also do things like research their family history. For family carers not wanting to complete an IT course, the Shropshire carers link officer offers an internet search facility. Requests for searches have included finding a firm that can provide bags for an obsolete vacuum cleaner to looking for cheap travel insurance for an older family.

Age Concern Leeds runs four Silver Surfers computer access and training courses at different levels, including digital photography and scanning. More than 600 older people have been trained and are continuing to use computers. The service also offers free access services each week so that people can keep up their skills, and encourages older people to use the 450 computers in the 57 local libraries across the cities.

*For more information contact: Silver Surfers, Age Concern Leeds, 188a Woodhouse Lane, Leeds LS2 9DX. Tel: 0113 2458579.
Email ageconcern@leedssilversurfers.net.*

- Are older families in your area able to access the internet?
- Are there organisations that can provide training and support to older families on using the internet?
- Do services provide accessible information on their websites?
- Can computer recycling schemes offer older family carers the opportunity to get connected at home?

Life story books

There are many variations on life story books evolving around the country. Life story books record some of the most important information that people with learning disabilities, their families and services will need when they are making emergency and long-term plans. Older families usually find that completing life story books is a positive experience, but they also need support with doing this; partly because the process brings up some difficult issues (like death and the future), and also because many older family carers just don't realise quite how much they do every day unless someone is going through every stage of the day with them.

The Sharing Caring Project developed My Life Book to provide a framework for capturing essential information about people with learning disabilities living with older family carers. More than 600 copies have been given out to people in Sheffield living with family carers over the age of 55. One sheet from the books is returned to a central 24-hour accessible location so that it is known in an emergency who has a life book and where it is kept.

For more information contact: Sharing Caring Project, Norfolk Lodge, Park Grange Road, Sheffield S2 3QF. Tel: 0114 2758879. Email: office.sharingcaringproject@btconnect.com. www.sheffieldmencap.org.

HFT has been developing ways of supporting people with learning disabilities to complete their own life stories using computers, with the help of workers and/or family carers. They can combine favourite pictures of special events, and video clips and sounds can be combined with text or symbols to make an updateable, animated record of their life and interests which they save onto a disk.

People with a wide range of learning disabilities are using these life stories as a way of introducing themselves to new friends and workers; older family carers appreciate the fact that their relatives have 'captured' special aspects of their lives, and also that the workers who have gone through this with them have built up a really valuable knowledge of the person and the things that matter to them.

*For more information contact: HFT Karten CTEC Centre, Milton Heights, Milton, Abingdon, Oxon OX14 4DR. Tel: 01235 835507.
Email: c-tec@hft.org.uk. www.hftcteccentre.org.uk.*

Life story books should be updated regularly and kept easily to hand. There is no point compiling a lot of information into a life story book if nobody can find it (or knows about it) in an emergency.

- Are older families in your area supported to complete some sort of life story work?
- What systems ensure that life story books are easy to find and that the information they contain feeds into person-centred planning strategies?

Pamper sessions

Many carers' centres offer carers the opportunity for a bit of pampering and relaxation as a break from the stresses and strains of caring.

Stoke Sharing Caring Project works in conjunction with North Staffs Carers Association so that older family carers of people with learning disabilities can attend their pampering sessions. At these sessions they can have Indian head massages, reflexology and aromatherapy sessions as well as a lovely lunch.

For more information contact: Stoke Sharing Caring Project, Mencap, Winton House, Stoke Road, Staffs ST4 4RW. Tel: 01782 848800.

The Shropshire Carers Link Officer has arranged pampering day sessions for older family carers, in conjunction with local colleges, beauty therapists and the local Red Cross. Everything is arranged, including payment and transport, and the services provided range from full body aromatherapy treatments to eyebrow waxing. Older family

carers also enjoy the chance to chat to the people who are pampering them. The sessions have been running successfully for four years now, and an increasing number of carers are appreciating the opportunity to have somebody else look after them for a change.

*For more information contact: Shropshire Carers' Link Officer.
Tel: 01939 211006. Email: flick.pennal@shropshire-rcc.org.uk*

- Can local beauty schools, training colleges and therapists in your area provide pampering sessions to older family carers?

Shopping schemes

Almost all the big supermarket chains now deliver, and most local authorities offer deliveries or other shopping support to people who need this. These schemes are a lifeline to many older people, including many isolated older family carers.

- Do older families and workers in your area know about home shopping schemes and how to register for them?

Support groups

The opportunity to meet other older families is probably the one most important source of support available. Support groups offer a safe environment for people to share their stories, swap ideas and experiences and gather information. They can also enable people to make new friends and keep in touch with old ones.

Most older family carers do prefer it if someone else is responsible for organising support groups (which also means that workers who are running the groups get the opportunity to catch up with members and pick up on any problems that may be developing). Some people are happy to join with generic carers' groups; others want to talk to other people caring for

someone with a learning disability as they say that no-one understands them like other family carers who have shared a lifetime experience of caring. In a few areas there are specialised support groups for siblings or fathers.

Anyone organising a group should consider transport, refreshments, timing (how does it fit in with other commitments, or day service hours), the venue (is it accessible, and easy to get to), and whether members need any support to cover their caring responsibilities. Above all, meetings should be enjoyable.

Torbay's Older Family Carers Initiative project includes providing information and advice for older families to help family carers in their current role and to start planning for the future. Part of the remit of the project is to organise social events and support family carers to build their own networks of support. The project worker has held 'tea and cake' mornings in a friendly local hotel and invited speakers along to give information and advice. Around 20 older family carers attend each session and people with learning disabilities living with older family carers are welcomed along too. Speakers have included benefits advisors and solicitors, and individual follow-up visits are often made.

For more information contact the project worker at Torbay Older Family Carers Initiative, c/o Community Alarm Service, Brookfield Close, Paignton TQ3 2JE. Tel: 01803 665834.

The Sefton Saturday Club is a registered charity set up as a self-help group for family carers and people with learning disabilities. The Saturday Club has been running for 14 years, and all the volunteers are full-time carers of sons and daughters with learning disabilities. The club serves the whole of Sefton in Merseyside and it aims to support family carers and the people they care for, to offer an improved quality of life to members, to support one another on all caring issues, and to campaign on all issues concerning family carers and their relatives. Members also get the opportunity for a lot of different leisure activities. They've successfully applied for grants for short breaks and they have

raised money for a minibus. A lot of solid friendships have been formed, and members have even gone away on holiday together.

For more information contact: Sefton Saturday Club, c/o 33 Broad Hey, Ford, Liverpool L30 2NF. Tel: 0151 474 7725.

Email: admin@carersonsaturday.com. www.carersonsaturday.com.

Southampton Mencap has started a Family Carers Network Lunch Club, mainly attended by older family carers. Family carers attending enjoy talking together over a delicious free lunch about the many issues they have faced or are still dealing with in their years of caring. Different speakers of the families' choice come along to the sessions to share information and lead lively debates.

For more information contact: Southampton Mencap, 187a Portswood Road, Southampton SO17 2NF. Tel: 02380 584088.

*Email: co-ordinator@mencapsoton.freeseerve.co.uk.
www.southamptonmencap.org.*

- Are support groups for older family carers available in your area? If so, is there a choice of different groups?
- Are there arrangements for making sure that older families can get to meetings?
- Do social workers and health workers regularly attend meetings to pick up on key issues (if members want that)?
- Are groups open to all family members?

Telephone lists

In several areas, family carers receive lists of all the phone numbers that might be useful in an emergency, usually including 24-hour contact numbers for social services, health services and so on. Families are encouraged to keep the lists by their phone, along with details of their

personal emergency contacts, and show them to neighbours, family and friends. Obviously these – like all other lists – have to be kept up-to-date.

*For good examples of telephone lists for older families contact:
Redbridge Older Family Carers Project, Redbridge Forum, 98-100 Ilford
Lane, Essex IG1 2LD. Tel: 020 8478 1451 or*

*Sharing Caring Project, Norfolk Lodge, Park Grange Road, Sheffield
S2 3QF. Tel: 0114 2758879.*

Email: office.sharingcaringproject@btconnect.com.

- Do families in your area receive telephone lists?
- Who is responsible for updating these lists when any of the information changes?

Training and awareness

Many older families appreciate the opportunity to take a brief training or awareness course on a relatively new topic like person-centred planning or direct payments. Even older carers who do not want to attend a course themselves may want another family member to go.

Halton's specialist learning disability team has run a number of training sessions for family carers on different topics. Older family carers are targeted directly through the team's database, and the sessions are publicised to younger family carers in a number of other ways too. Sessions have covered person-centred planning, wills and trusts, and back care. The team also runs training and awareness sessions for people with learning disabilities which have included health promotion, first aid, relaxation and healthy eating.

*For more information contact: Community Learning Disability Nurses,
Halton PCT, Bridges Learning Centre, Crow Wood Health Centre, Crow
Wood Lane, Widnes WA8 3LZ. Tel: 0151 420 7619.*

- What training/awareness courses are available to older family carers and older people with learning disabilities in your area?
- Has anyone asked older families what sort of training/awareness sessions they would be interested in?
- Can older families who would like to take a course draw on any support, such as transport or sitting services?

Transport

However inviting a service or social opportunity may be, families have to be able to get to it. Transport is always an issue for people with learning disabilities and family carers, and as everyone gets older it can become one of the biggest problems in their lives. One older family carer told her key worker that she and her son hardly left the house after his day service bus dropped him off on a Friday afternoon until it picked him up the following Monday morning – and she’s certainly not a unique case. Transport is also a very obvious consideration in any emergency planning. If – as quite often happens – only one person in the family can drive, what happens if they aren’t available or become too frail to continue driving? This issue should be picked up in all person-centred plans and carers’ needs assessments.

Taxi voucher schemes are a particularly useful way of providing older families with control over getting around, particularly in rural areas. The Countryside Agency’s website (www.countryside.gov.uk) has lots of links to successful schemes and a toolkit that outlines the benefits to voucher users, taxi drivers, organisers and funders, and recommends ways that groups can set up similar schemes.

Most areas offer a variety of transport schemes, including mobility buses, subsidised taxis, volunteer driver schemes and electric scooters that can be hired in city centres and big shopping centres to help people get around.

- Are older families routinely offered transport to meetings, groups, reviews etc?

- Is there a record of the transport needs of older families in your area?
- Are older families and their supporters aware of the range of community transport options available locally?

Well-being

Older families need practical help, but they also need support for their physical and emotional needs, otherwise everyone in the family is affected. If older family carers are not feeling up to going out, quite often the person with a learning disability will not go out either, and everyone becomes even more isolated and depressed. Local organisations are already supporting older families in lots of different ways – often very creatively – although it's important to ensure that people with caring commitments can still take full advantage of this.

Centre 404 (formerly Islington Mencap) runs a Caring for Carers programme, on the basis that no one looks after family carers better than other family carers. The centre offers weekly shared courses in Tai Chi for older family carers and people with learning disabilities, along with complementary therapies such as massage, reiki, homeopathy and reflexology. All services are free to families.

For more information contact: Centre 404, 404 Camden Road, London N7 0SJ. Tel: 020 7607 8762. Email: general@centre404.org.uk.

Sheffield's Sharing Caring Project runs a lunch group for women family carers from the Pakistani community twice a month, which is attended by many older family carers. There is a bilingual advice worker, Halal food, different speakers, health information, and chairbics sessions.

*For more information contact: Sharing Caring Project, Norfolk Lodge, Park Grange Road, Sheffield S2 3QF. Tel: 0114 2758879.
Email: office.sharingcaringproject@btconnect.com.
www.sheffieldmencap.org.*

- Does anyone find out what older families in your area would find helpful for their general well-being?
- What opportunities do older families get to take part in exercise or complementary therapies?
- Are any transport or short break services available to older families who'd like to attend sessions?

Wills and trusts

Many older family carers are particularly concerned about being able to leave some of their money or property to their relative with learning disabilities without affecting their benefits and care arrangements. The best way to do this is through a solicitor who knows about disability law and how to set up a discretionary trust.

Many local organisations organise meetings for family carers on topics like this. Voluntary organisations, such as Mencap, can usually advise older families about local solicitors who understand the issues and can help them. Solicitors are often happy to make home visits or help check the details in a will.

In partnership with Housing Options (www.housingoptions.org.uk) the Older Family Carers Initiative has produced a booklet for older family carers about leaving money and property in trust. The booklet, *Discretionary Trusts: a guide for families*, can be downloaded free on www.learningdisabilities.org.uk, and can be customised for your area with information about local solicitors who are experienced in disability issues.

- Do any organisations locally provide information about wills and trusts?
- How do older family carers get the information they need to set their financial affairs in order?
- Is there a list of recommended local solicitors?

Conclusion

This is a long list, but it certainly is not exhaustive as there is simply not room to include all the good practice examples already happening around the country. Older families have many different needs, and there are a lot of different ways to meet those needs. Even where work like this is going on, it is still important to ensure that older families can take full advantage of it and that all the different services on offer are in touch with each other. Older families need to know that whichever route they take, they can get all the support they need.

Chapter 5

Conclusion: Older families - meeting the challenge

Key points

1

Support for older families is getting better, but there is still a lot to do to get things right.

2

Services need to join up and communicate better to make things easier for older families to carry on and to plan for the future.

3

Work with older families needs to be joined into other work that services are already doing.

4

It's important to get on with helping older families now.

'At the end of the day, I just want some peace of mind that he'll be alright when I've gone.'

Jess, 84

Older families need to be confident about the future and to be able to trust that their relative with learning disabilities will be safe, happy, well supported and able to enjoy a variety of opportunities. The support needs

of older families may change over time but older families will never go away. The current generation of younger adults with learning disabilities who live with their families will in their turn grow older and they and their families will need support to meet their additional needs and to plan for the future.

Services and support for people with learning disabilities and family carers have improved, especially since the publication of *Valuing People* (Department of Health, 2001b). However, the good practice, which undoubtedly exists, is still very patchy; and there's a real danger that it isn't being integrated into other strategies and mainstream services.

The checklist in **Appendix 1** of this pack provides a detailed breakdown of the practical issues that need to be addressed. The key points are:

- local areas must develop and invest in systems for finding, and keeping in contact with, families – including those who will be considered 'older families' in the future
- services for people with learning disabilities, older people and carers must communicate and co-ordinate their strategies and practice, and ensure that older families' needs are always considered
- older families need to be a specific responsibility, but should not be isolated from more general service planning
- local areas need to look for long-term solutions for addressing the needs of older families, particularly in terms of resources and capacity
- services working with older families should be able to measure their outcomes and results – including the responses from the older families themselves.

The effectiveness of dedicated support for older families is indisputable. Older family carers in areas where there are local projects or workers cannot speak highly enough of the proactive contact and support they now receive. However, there needs to be continuity in staffing to enable families to build trusting and lasting relationships.

Work with older families is often seen as specialised, and it is happening in isolation from other services and support. There is a real danger that older families will remain marginalised if their needs and new work is not linked into mainstream services and strategies across service areas and across organisations. Workers across a whole range of settings need to be made aware of the needs of older families and able to point them in the appropriate direction.

Whilst there is an urgency to meeting the needs of older families, it is arguably even more damaging to older families if hopes and expectations are raised unfairly. Older families have often been disappointed in the past and it may be difficult for them to trust workers and services again. It takes a great deal of courage for many older families to come forward seeking information, support and help with their current and future needs. Be realistic in what you offer and move at the family's pace. Doing nothing is not an option.

Older families should be prioritised as time is running out to get things right for them. Things need to happen now, but solutions need to be well thought through if they are to be effective and bring lasting benefits to older families. Services need to join up now to ensure a co-ordinated response. Within every local area there is already a wealth of services and support that can make a real and lasting difference to the lives of older families.

Hopefully this report has inspired you to go through the following checklist and look carefully at how you can work together to make a real difference to older families.

Checklist: How well is your local area supporting older families?

This checklist offers a framework for you to find out and measure how well your local area is meeting the needs of older families. Ideally it should be completed in partnership by the various services and representatives who can make a real difference to the lives of older families. This includes representatives from voluntary and statutory services for older people, people with learning disabilities and carers. The checklist can also be used by individual projects and services to measure how well they are meeting

older families' needs. It is very important to sign and date the checklist and agree a date to come back and regularly review the progress that has been made.

A template of this checklist is available to download on the Foundation's website www.learningdisabilities.org.uk.

Chapter 1: Working together for older families

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
1.1 Ensure that learning disability, older people's, carers', and health and housing services are working together for older families.				
1.2 Using the expertise of older families, train workers from all service areas to recognise older families and steer them to information and support.				

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
1.3 Ensure that strategies for older people, carers, learning disability, housing and health cover older families.				
1.4 Ensure that local areas have a complete picture of the numbers and needs of older families.				
1.5 Link up information systems across services and departments to identify older families wherever they appear.				
1.6 Offer older family carers and people with learning disabilities who are carers the opportunity to complete a carers' needs assessment that leads to real outcomes.				

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
<p>1.7 Establish registers in GP practices showing who is a carer, and ensure that practices can direct older families to appropriate support.</p>				
<p>1.8 Identify named contacts, as recommended by the National Service Framework for Older People and Valuing People.</p>				
<p>1.9 Ensure that local eligibility criteria for services address the needs of older families.</p>				

Chapter 2: Supporting older families in planning ahead

Stage 1: Supporting older families with their current needs

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
<p>2.1a Make sure that older families have the support they need with their current needs. (Single assessment process, including carers needs assessments, and person-centred plans will help move this forward)</p>				
<p>2.1b Involve members of the extended family and special family friends.</p>				
<p>2.1c Make sure older families have their needs reviewed regularly.</p>				
<p>2.1d Make sure older families have the opportunity to access a variety of short break/respite services.</p>				

Stage 2: Thinking about the need to plan ahead and openly acknowledging that change is inevitable

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
<p>2.2a Develop a range of services and support to allow members of older families to talk openly (but separately if necessary).</p>				
<p>2.2b Make sure members of the extended older families have the opportunity to open up about their concerns.</p>				
<p>2.2c Train workers from a range of settings to understand and be sensitive to the issues of planning ahead for older families, and to feel confident to direct them to other forms of support.</p>				

Stage 3: Finding out what the options are

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
2.3a Circulate and publicise up-to-date information in a range of formats on planning ahead, housing and support options.				
2.3b Train housing services to deal sensitively with enquiries from older families.				
2.3c Offer older families training sessions on direct payments, leaving property in trust, person-centred planning and similar topics.				
2.3d Support older families in exploring different options for the future.				

Stage 4: Starting to plan

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
2.4a Use person-centred planning approaches with people with learning disabilities living with older families to find out what they want and need.				
2.4b Identify the needs of older family carers, and make sure that any plans meet these needs as well.				
2.4c Cover the views and needs of other family members and special friends.				

Stage 5: The crossroads

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
2.5a Provide the advocacy support older families need.				
2.5b Provide regular reviews, so that families can decide when to take things further.				
2.5c Support families with a named worker when they do decide to make changes and to help see them through the process.				
2.5d Record long-term plans of older families and incorporate these into long term commissioning or strategic planning.				

Stage 6: Practicalities

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
2.6a Provide practical support to older families throughout any moving process or major change.				

Stage 7: After the move

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
2.7a Ensure that older family carers get the help they need to remain living independently.				
2.7b Ensure that housing and support services keep in contact with older families.				

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
<p>2.7c Continue to monitor the support older families give to relatives who have moved out, and respond if they can no longer provide this support.</p>				
<p>2.7d Hold regular reviews and keep other family members informed and involved in the services and support their relative receives.</p>				

Chapter 3: Practical support for older families: the big things that make a difference

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
<p>3.1 Offer older families the opportunity to build long-term relationships with workers, and link them into voluntary and statutory services.</p>				
<p>3.2 Explore the opportunity to develop partnerships with voluntary sector organisations.</p>				
<p>3.3 Promote older family awareness amongst workers and services.</p>				

Chapter 4: Practical support for older families: the smaller things that make a difference

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
4.1 Support older families in planning for an emergency.				
4.2b Link families' emergency plans into other services.				
4.3 Make sure families' emergency plans are kept up-to-date.				
4.4 Ensure that statutory and voluntary sector organisations can support older families with the whole range of physical, emotional and				
Note: It will be useful to check what you are providing locally against the examples listed alphabetically in Chapter 4.				

Chapter 5: Older families - meeting the challenge

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
5.1 Develop and invest in long-term joined up systems for finding and keeping in contact with families.				
5.2 Make sure that work with older families is not happening in isolation from mainstream services and objectives.				
5.3 Agree who is responsible for work with older families – but make sure all relevant services/departments are involved in any plans.				
5.4 Look for long-term solutions for securing the resources and capacity to keep work with older families going.				

Actions	What have we achieved with this so far?	How do we know this is working well?	What do we still need to do?	Who needs to help and when?
5.5 Ensure that older families are involved in any assessment of services' performance.				
5.6 Develop a strategy for ensuring that workers from across services are trained to be 'older family aware'.				

Completed by: _____

Date: _____

Agreed review date: _____

References

Department of Health (1999) *Caring about carers: the national strategy for carers*. London: Department of Health. Available to download from www.dh.gov.uk.

Department of Health (2001a) *Family matters: counting families in*. London: Department of Health. Available to download from www.valuingpeople.gov.uk.

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

Department of Health (2001c) *Learning difficulties and ethnicity*. London: Department of Health. Available to download from www.valuingpeople.gov.uk.

Department of Health (2001d) *National Service Framework for Older People*. London: Department of Health. Available to download from www.dh.gov.uk/nsf/olderpeople.trm.

Department of Health (2003) *Fair access to care services*. London: Department of Health.

Department of Health (2004) *Valuing families*. Available to download from www.valuingpeople.gov.uk.

Foundation for People with Learning Disabilities (2002) *Today and tomorrow: the report of the Growing Older with Learning Disabilities programme*. London: Mental Health Foundation.

Foundation for People with Learning Disabilities (2003) *Planning for tomorrow: report on the findings of a survey of Learning Disability Partnership Boards about meeting the needs of older family carers*. London: Foundation for People with Learning Disabilities. Available to download from www.learningdisabilities.org.uk.

Magrill, D et al. (1997) *Crisis approaching!* Sharing Caring Project. Contact: Sharing Caring Project, Norfolk Lodge, Park Grange Road, Sheffield S2 3QF. Email: office.sharingcaringproject@btconnect.com.

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.

Walker, C and Walker, A. (1998) *Uncertain futures: people with learning difficulties and their ageing family carers*. Brighton: Pavilion Publishing.

Resources

You will find links to a variety of useful resources and examples of good practice within the chapters of this resource. In addition see:

A practitioner's guide to carers' assessments under the Carers and Disabled Children Act 2000. London: Department of Health. Available to download from www.dh.gov.uk.

Adult family placement schemes for older carers: perceptions of users, family carers, placement providers and social workers. R. McConkey, J. McConaghie, P. Roberts and D. King, 2002. London: Foundation for People with Learning Disabilities. Available to download from www.learningdisabilities.org.uk.

Carers and Disabled Children Act 2000. London: The Stationery Office. Available to download from www.dh.gov.uk.

Caring for Kathleen: a sister's story about Down's Syndrome and dementia. M. Fray, 2000. Kidderminster: BILD Publications.

Discretionary trusts: a guide for families. N. King, 2004. Available to download from www.learningdisabilities.org.uk.

Elsie's story. A video of one older family carer's story that is an effective tool for raising awareness about the needs of older families. Available to buy from the Sharing Caring Project, Sheffield. Tel: 0114 2758879.
Email: office.sharingcaringproject@btconnect.com. www.sheffieldmencap.org.

Family homes: using parental property to provide future housing for people with learning disabilities. N. King, 2001. London: Foundation for People with Learning Disabilities. Available to download from www.learningdisabilities.org.uk.

Get moving. A booklet for people with learning disabilities who are thinking about leaving home and moving to new accommodation. It provides information about the many choices faced, giving examples of each situation and explaining what is

involved. It also gives contact details and publications to refer to, for both people with learning disabilities and their families and supporters. Available to download from www.learningdisabilities.org.uk.

Good practice guidelines produced by the Older Family Carers Initiative at the Foundation for People with Learning Disabilities include:

Guideline 1: Introduction

Guideline 2: Identifying older families

Guideline 3: Recording information

Guideline 4: Carers' needs assessments

Guideline 5: Involving older family carers

Guideline 6: Planning for family emergencies

Guideline 7: Supporting older families to access short breaks

Guideline 8: Supporting older families of people with autistic spectrum disorders

All available to download from the Foundation's website on www.learningdisabilities.org.uk.

How good is your service to carers? A guide to checking quality standards for local carer support services. R. Blunden, 2002. London: King's Fund.

In their own right: the Carers Act and carers of people with learning disabilities. V. Williams and C. Robinson, 2000. Bristol: The Policy Press.

It's good to be part of things: working with older people with learning disabilities. A. Wertheimer, 2004. London: Age Concern England (Practice Briefing).

Learning with families: a training resource. London: Foundation for People with Learning Disability, 2004.

Leaving home, moving on: housing options for people with learning disabilities. Nigel King and Maurice Harker, 2000. This booklet helps family carers understand the different ways in which housing and support can be provided for the future. Available to download from www.learningdisabilities.org.uk.

Resources

Lifetime of caring – a website on raising awareness of the needs of older family carers, provides open learning materials for workers and offers practical help for services. www.lifetimecaring.org.uk.

Living alone or with others: housing and support for people with learning disabilities. N. King and M. Harker, 2000. London: Foundation for People with Learning Disabilities. Available to download from www.learningdisabilities.org.uk.

Loss and learning disability. N. Blackman, 2003. London: Worth Publishing.

Moving on without parents: planning, transitions and sources of support for middle-aged and older adults with intellectual disability. C. Bigby, 2000. London: Maclennan & Petty.

Person-centred planning and older families. D. Magrill and H. Sanderson, 2005. This booklet has been written to support people to use person-centred planning effectively with older families. Available to download from www.learningdisabilities.org.uk.

Shaping the future together. A. Cole and A. Lloyd, 2005. London: Foundation for People with Learning Disabilities.

Support for carers of older people - Independence and well being 5. London: Audit Commission, 2004. Publication available to download from www.audit-commission.gov.uk/olderpeople.

Valuing people: a new strategy for learning disability for the 21st century: planning with people towards person centred approaches: guidance for partnership boards. London: Department of Health, 2001. Available to download from www.valuingpeople.gov.uk.

Working with older carers: guidance for service providers in learning disability. Kidderminster: BILD Publications, 1998.

Your place to live, making it happen: a housing and support plan for people with learning disabilities. Video and manual that explore the housing and support options available to people with learning disabilities. Available from Housing Options. Tel: 0845 4561497. Email: enquiries@housingoptions.org.uk. www.housingoptions.org.uk.

Websites

Age Concern England www.ace.org.uk

BILD (British Institute of Learning Disability) www.bild.org.uk

Carers UK www.carersuk.org.uk

Department of Health www.dh.gov.uk

Foundation for People with Learning Disabilities website, including the Older Family Carers Initiative www.learningdisabilities.org.uk

Help The Aged www.helptheaged.org.uk

HFT (Home Farm Trust) www.hft.org.uk

Housing Options www.housingoptions.org.uk

Lifetime of Caring www.lifetimecaring.org.uk

Mencap www.mencap.org.uk

Princess Royal Trust for Carers www.carers.org.uk

Valuing People Support Team www.valuingpeople.gov.uk

The Foundation for People with Learning Disabilities

We use research and projects to promote the rights of people with learning disabilities and their families.

We do this by:

- Identifying work that is needed to overcome barriers to social inclusion and full citizenship.
- Communicating our knowledge to a wide range of people.
- Turning research into practical solutions that make a real difference to people's lives now and in the future.

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