

Valuing Older Families Now



DH INFORMATION READER BOX

Policy HR/Workforce Management Planning/ Clinical	Estates Commissioning IM & T Finance Social Care/Partnership Working
Document purpose	Best Practice Guidance
Gateway reference	13819
Title	Valuing Older Families Now
Author	Department of Health
Publication date	25 March 2010
Target audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Local Authority CEs, Directors of Adult SSs, Directors of HR
Circulation list	Medical Directors, Directors of PH, Directors of Nursing, NHS Trust Board Chairs, Directors of Finance, Allied Health Professionals, GPs, Directors of Children's SSs, Voluntary Organisations/NDPBs
Description	This document will assist Learning Disability Partnership Boards review how well local systems are meeting the needs of older families, at least one of whom will have a learning disability.
Cross reference	Valuing People Now: a new three-year strategy for people with learning disabilities (HMG 2009)
Superseded documents	N/A
Action required	N/A
Timing	N/A
Contact details	Social Care Policy and Innovation Department of Health Area 110 Wellington House 133-155 Waterloo Road London SE1 8UG scpi-enquiries@dh.gsi.gov.uk
For recipient use	

© Crown copyright 2010

First published March 2010

Produced by COI for the Department of Health

The text of this document may be reproduced without formal permission or charge for personal or in-house use.

www.dh.gov.uk/publications

Valuing Older Families Now



Contents

Introduction

Making the most of this booklet	3
Why prioritise older families?	4
Policy supporting older families	6
How can your Partnership Board make a difference?	8
How well are older families in your area being supported?	9

Key questions

1. Do members of your Partnership Board understand the issues facing older families?	11
2. Does your Partnership Board know how many people with learning disabilities live at home with a family carer aged 65 or more, and who these families are?	13
3. Is your Partnership Board checking that all older families are being encouraged to make themselves known?	16
4. Is your Partnership Board checking that older families are able to build up relationships with workers and services that they may need later on?	19
5. Is your Partnership Board making sure that detailed information about older families is collected, collated and used to inform local planning?	22
6. Is your Partnership Board linked in with other services and groups who have a responsibility for meeting the needs of older families?	24
7. Is your Partnership Board measuring and monitoring the degree to which older families are being supported?	27

Conclusion

Moving forward	30
Appendix 1: Supporting older families – the Sheffield model	32
Appendix 2: Supporting older families – useful resources	36

Introduction



Making the most of this booklet

This booklet is designed to offer Learning Disability Partnership Boards an opportunity to review how effectively they are supporting older families in their area. It outlines **seven key questions**, most of which will link directly to information your board will need to provide in any case, as part of its annual self-assessment report for the Regional Programme Board.

Asking these questions is not a one-off exercise. It's important to set a date for reviewing progress, asking the questions again and measuring your successes.

Ideally, we will reach a time when there is no need to focus specially on older families, because **all families** are getting the right support they need at every stage. However, we are not at that point yet, and in the meantime there is still much that can be done.

Key messages

- This booklet is to help Partnership Boards check how well they are helping older families.

Why prioritise older families?

The term 'older families' is quite loose, and this is deliberate. It does not simply mean older family carers, or older people with learning disabilities. It refers to whole families, including:

- the person with a learning disability – of whatever age – who may also be providing an older relative with regular care and support;
- the older person (aged 65 or over) who is also a carer. This is often a parent, but could be a sibling, grandparent, aunt or uncle or another relative. They are often receiving care as well as providing it; or
- other close family members and friends who are involved with these two people.

It is a crucial time for many older families, especially if they are in a situation of 'mutual caring' between the family carer and the person with a learning disability. They need help and support with planning the next stage of their lives, because it is unlikely that they can continue living together in exactly the same way for much longer.

Mencap's *Housing Timebomb* report in 2002¹ estimated that 27,000 people with learning disabilities living with family carers over the age of 70 would need alternative housing and support in the future. The ageing population, and the fact that people with learning disabilities live far longer than they used to, means this figure is likely to have risen. Services – health, housing and social services – will ideally want to know what needs they should plan to meet in the future.

Older families have said consistently that they want:

- to be known to services **before** a crisis;
- understanding and support in planning for emergencies and the long term;
- support that will make it possible to stay together for as long as they want;
- positive partnership between families, care workers and services;

¹ Mencap (2002) *The Housing Timebomb: The housing crisis facing people with a learning disability and their older parents.*

- clear, up-to-date information and the support that will enable them to make good use of it;
- the ability to make their own decisions without feeling rushed into making changes or judged for the way they have cared; and
- confidence in knowing that the person with a learning disability will be happy, safe and able to speak up when older family carers are no longer able to support them.

Key messages

- The term 'older families' applies to people with a learning disability, the older people who look after them and other family and friends.
- Older families want to know they can get good help and support when they need it.
- Lots of older families worry about what will happen when they can't stay together. They want help now to prepare for this.

Policy supporting older families

*Valuing People*² highlighted older families as a priority group for action. It estimated that one in four older families with a family carer aged 70 or over was unknown to services, until there was a crisis, such as the family carer becoming ill or dying. In circumstances like these, it can be very difficult to do the 'best thing' for the family. Nothing has been established in advance, which means that there will be only a limited range of options that can be put in place at short notice – this can be compounded by the fact that the family members are often worried, distressed and less able to think as quickly as they would be usually. The result is often a solution that nobody would ideally have chosen.

*Valuing People Now*³ and the Delivery Plan⁴ that supports it stress that the needs of families, including older families, must be considered throughout. *Good Learning Disability Partnership Boards: 'Making it happen for everyone'*⁵ also sets targets in the annual self-assessment report, many of which relate directly to older families.

This emphasis on older families has already produced some very effective local and national work over the course of the last decade. Some of this is specifically targeted, through specialist workers and projects. Other improvements are the result of general advances in support for carers, such as carer support workers being linked to GP practices.

However, this support – especially support in planning for the future – is patchy. In addition, some specialist work with older families has not lasted beyond the pilot stage: either there has been no further funding, or mainstream systems have failed to take it up.

2 DH (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*.

3 DH (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities*.

4 DH (2009) *Valuing People Now: The delivery plan*.

5 DH (2009) *Good Learning Disability Partnership Boards: 'Making it happen for everyone'*.

Key messages

- Lots of people with learning disabilities living with elderly carers don't have any outside help until something bad happens.
- *Valuing People* and *Valuing People Now* say Learning Disability Partnership Boards should be making sure older families are supported.

How can your Partnership Board make a difference?

Learning Disability Partnership Boards are in an excellent position to be able to **oversee, influence and monitor** local strategy and support systems to help ensure that the needs of older families are being recognised and met.

One reason for this is that Partnership Boards bring together everyone concerned with learning disability issues, including self-advocates and family carer representatives. The Partnership Boards that are supporting older families most effectively are those where everyone is working together and involving the older families themselves. Importantly, boards need to engage with generic services and support for older families and carers, areas that are probably not represented on the main board.

Key messages

- Learning Disability Partnership Boards can check that older families are getting the right support.
- They can work with services for older people and carers to make sure they don't forget to help older families, too.
- Everything works out better for older families when everyone works together to support them.

How well are older families in your area being supported?

The following questions, suggestions and points to consider are designed to help you and your Partnership Board think about and discuss how well older families in your area are being supported and what could be improved. Tick the colour that best represents what is happening locally:

- Red** means 'we've still got lots to do'
- Yellow** means 'we're making progress'
- Green** means 'we're doing this well'.

You may not all agree on every answer, but the most important part is actually having the discussions and trying to reach an agreement as to how well things are going in your area. This will give a clear indication of where there are significant gaps to fill.

Key questions



1. Do members of your Partnership Board understand the issues facing older families?

Not everyone on a Partnership Board may understand why it is important to make older families' needs a priority. It's important that board members whose main concern is, for example, people from black and minority ethnic communities or people with high individual support needs also understand how older families' issues may impact on the group they are championing.

Using real-life examples

Some Partnership Boards regularly review case studies, either in the form of short films or as direct presentations by the people involved. This is a very good way of demonstrating key issues and concerns. Why not have a case study featuring an older family at least once a year?

Points to consider:

- Are all board members encouraged to read this booklet (with support if they need it)?
- Is the topic of older families regularly covered in board meetings, either as a specific item on the agenda or as a routine element of all plans and discussions?
- Are projects working with older families regularly asked to come to board meetings or the relevant task group's meetings?
- Does the board have named 'champions' whose role is to make sure that discussions and work plans take account of the needs and wishes of older families?

Rate how well your Partnership Board is doing to make sure members understand the issues facing older families:

Circle the box

**We have lots
to do**

**We're making
progress**

**We're doing
well**

What can we do better over the next 12 months?

2. Does your Partnership Board know how many people with learning disabilities live at home with a family carer aged 65 or over, and who these families are?

If you are going to identify the needs of older families in your area, you first need to be sure you have identified these families.

This is not just about knowing the numbers. It is essential that you know who these families are – not individually, but that you have a good overall picture, including what they want and what they are likely to need in the future.

Link to the Partnership Board Annual Self-Assessment Report⁶

The Annual Report requires a local description of those people with a learning disability aged 18 or over, including their age, ethnicity and whether they are living with family carers over 65. Other information, for example about people's housing situations, will also help complete other sections of the Annual Report.

⁶ An electronic version of the report template is available on a CD-Rom and via the *Valuing People Now* website: www.valuingpeople.gov.uk/dynamic/valuingpeople365.jsp

Register Services

Register Services is part of the Public Health Directorate of NHS Sutton and Merton. It provides a unique service for setting up, managing and developing registers of adults with learning disabilities for the London boroughs of Lambeth, Merton and Sutton.

The registers collect and collate data on carers including elderly carers. For example, in Sutton, there are currently 900 registered adults with learning disabilities; 261 live with family carers; 80 primary carers are known to be aged over 65, of whom 29 say they have “no backup” carer and nine say they have a disability themselves; 14 per cent of older carers care for a family member from an ethnic minority group; and 11 per cent receive short breaks (respite).

These learning disability registers have proved enormously helpful in providing data for planning services, for identifying individuals at risk and for targeting groups who should receive information.

For more information on the Service and data on the registers, please see ‘Reports’ on www.registerservices.nhs.uk

Points to consider:

- Are robust systems in place for identifying the full population of adults with a learning disability in your area, including their ethnicity, their age, the age of their carer, their housing situation and the services – if any – that they use?
- Is information about the local population of people with learning disabilities regularly presented to Partnership Board meetings?
- Is information about the local population routinely used to inform strategies and work plans?

Rate how well your Partnership Board is doing to make sure members understand the issues facing older families:

Circle the box

**We have lots
to do**

**We're making
progress**

**We're doing
very well**

What can we do better over the next 12 months?

3. Is your Partnership Board checking that all older families are being encouraged to make themselves known?

Identifying 'hidden older families' before they reach crisis point remains a big issue. Some families, especially the oldest ones, may not even realise they are entitled to support: they may have had bad experiences in the past; and/or they may be very worried about asking for help because they fear that the person they support will be removed from the family home and left without any support at all.

Are you sure most of the older families in your area are known?

Figures from the **Sheffield Case Register** in November 2009 show that there are:

- 3,128 children and adults with a learning disability known to the case register to be living in Sheffield; and
- 1,065 people with learning disabilities who are over 18 years old and living at home with a family carer.

Of these 1,065 over-18-year-olds with a learning disability, 401 are known to be living with at least one family carer aged 65+. Of these 401 people:

- 136 live with a single carer over 65;
- 265 live with two family carers (usually parents or siblings);
- 65 had a recorded overnight short-term break in 2009, and 336 don't use any recorded service; and
- 215 have a regular daytime service recorded, and 186 don't (this includes further education but not employment).

The Sheffield Case Register is part of the Sheffield Joint Learning Disability Service. For more information, please ring the Case Register on 0114 2716940 or email case.register@shsc.nhs.uk

The most successful way to encourage hidden older families to come forward is to offer incentives that acknowledge, and enhance, their caring role. For example, most older family carers worry a great deal about what may happen to the person they care for in an emergency, so they are very likely to be attracted to emergency card schemes.

The 'I Count' Card



Register Services (see the box on page 14)

introduced the 'I Count' card for those registered on their database, and it has proved very successful in encouraging new people to come forward. The card offers easy access to concessions, including sports and leisure facilities and tourist attractions. It is widely recognised and has been very well received.

Please see www.i-count.org for further information.

General carer policy and practice also highlights the need to identify all carers, including older carers and carers with a learning disability, so there may well be relevant initiatives already up and running.

Linking in with GP practices

The vast majority of people are registered with a GP practice, and many practices already have registers of who is a carer. Annual health checks for people with a learning disability now mean that practices are in an even better position to identify carers, and particularly those in older hidden families.

As part of their Carers Strategy, many local areas now have support for carers linked into their healthcare systems. For example, all GP practices in **Torbay** are linked to a Carers Support Worker, who can offer advice and information and put carers in touch with local groups.

Link to the Partnership Board Annual Self-Assessment Report

The Annual Report asks Partnership Boards to report on what is being done to improve the information that underpins service planning and commissioning. Finding hidden older families will clearly help with this.

The report also includes targets for supporting family carers, including a clear plan for working with and supporting **all** families.

Points to consider:

- Are systems in place which automatically record new people with learning disabilities living at home with family carers?
- Does your local Carers Strategy cover the issues of hidden family carers, and are learning disability services aware of initiatives identifying hidden carers? Does your local Carers Strategy include finding hidden carers, especially in older families and families where mutual caring may be happening?
- Are GP practices identifying previously unknown families, and putting them in touch with support services?
- Is information about support for people with a learning disability and carers widely available in formats and places where it will be useful?
- Are there specialist workers and/or projects for identifying and keeping in contact with older families, even if the families are not currently eligible for a funded service?

Rate how well your Partnership Board is doing to make sure good work is happening to find hidden older families:

Circle the box



What can we do better over the next 12 months?

4. Is your Partnership Board checking that older families are able to build up relationships with workers and services that they may need later on?

The most successful examples of work with older families from around the country have one thing in common: families have had time to **build solid, trusting relationships** with workers and services. Sometimes these are specialist services to support older families, but they may also be short-break or day services.

This is not always easy. Older families may fear being seen as unwilling to accept change, or overprotective of the person with a learning disability. However, many have had extremely poor – and disrupted – experience of services. This is the generation of families who may have been told that their relatives would not live past the age of 20, and were often advised to put them into an institution. They may well have spent 50 years or more providing full-time care: children with learning disabilities have only had the legal right to full-time education since 1971, which means that carers have often had literally no breaks at all. If, over the years, they have had contact with services, they have probably seen a succession of different people.

Since *Valuing People*, many local areas have developed specialist projects and workers who have the remit of developing relationships with older families and offering them support. These relationships have made it possible for families to start talking about the help they need before they reach crisis point, and to start making longer-term plans.

Older Carer Support Workers

There are many excellent schemes supporting older families, often based in the voluntary sector. They are usually linked to learning disability services or mainstream carers services, but they are sometimes linked into older people's services, such as Age Concern. Many of these schemes are funded through the Carers Grant or the Learning Disabilities Development Fund.

The Carers Support Team at the **Community Council of Shropshire** has three specialist support workers for older family carers of people with a learning disability. Their role is to keep in touch with family carers over the age of 60 and to provide emotional and practical support. They visit families at least every six months, and also complete and review carers' assessments. The work was originally funded by the Learning Disabilities Development Fund, but is now core-funded by the local authority.

The purpose of this work is to put families in touch with the provision that already exists – it should not be seen as something separate. Partnership Boards need to ensure that any special initiatives for older families are linked in with existing systems.

Link to the Partnership Board Annual Self-Assessment Report

The Annual Report asks Partnership Boards to address a number of targets that enable older families to develop relationships with workers and services.

Points to consider:

- Is support targeted directly at older families through named contacts and/or specialist roles and projects?
- Do older families feel they are able to establish relationships with workers and services?
- Are families regularly sent information, even if they are not using services directly at the moment?

Rate how well your Partnership Board is doing to make sure that older families have the opportunity to build up trust and good relationships with services:

Circle the box

**We have lots
to do**

**We're making
progress**

**We're doing
very well**

What can we do better over the next 12 months?

5. Is your Partnership Board making sure that detailed information about older families is collected, collated and used to inform local planning?

It is absolutely essential to have a clear idea of what is wanted and needed, both now and in the future, by people with a learning disability and their families – especially since they are likely to need to put their longer-term plans into action sooner, which has direct implications for support and service provision.

Some areas already have very effective methods for getting and recording this information. However, even these can often be enhanced – for instance, by recording family carers' dates of birth. Carers' assessments and person-centred plans are two obvious routes to getting the data, but they should not be the only routes to collate or record this information. All the usual work on issues such as housing, person-centred planning and personalisation ought to take older families into consideration.

Leeds Older Carers Support Service was set up to find and support family carers aged 60 or over who are still caring at home for people with a learning disability. The project is part of Leeds Age Concern, and they are currently in touch with 230 families. With the permission of the families, information collected is fed back every month to social services and used to inform planning and service delivery. For more information, email ocss@btconnect.com

Link to the Partnership Board Annual Self-Assessment Report

The Annual Report asks Partnership Boards to report on progress in improving information used to plan and commission services. Under its personalisation targets, the report also asks boards to report on how groups, including older families, are being included in person-centred planning strategies; and specifically on plans that include accommodation, which is a priority topic for older families.

Points to consider:

- Do champions for older families routinely check that older families' views have been collated, recorded and used in planning?
- Do involvement and consultation plans routinely discuss how the views of older families will be gathered?
- Do person-centred planning systems collect information about the wishes and needs of people living at home with older family carers?
- Are older families' emergency plans recorded, and used to inform planning?
- Do housing-needs databases or similar systems record information about family circumstances?

Rate how well your Partnership Board is doing to ensure that information about the wishes and needs of older families is routinely collected, collated and used to inform future planning:

Circle the box

**We have lots
to do**

**We're making
progress**

**We're doing
very well**

What can we do better over the next 12 months?

6. Is your Partnership Board linked in with other services and groups who have a responsibility for meeting the needs of older families?

Older families are not the sole responsibility of Learning Disability Partnership Boards. Other strategic groups and services, such as housing, health and older people's services, also have a duty of care towards older people, people with learning disabilities and carers.

The national policy framework for older people is very similar to policy for people with learning disabilities, in that it focuses on independence and on person-centred support. Current policy for carers is set out in the National Carers Strategy,⁷ and the emphasis is on improving the situation for carers and enabling them to have a life outside their caring responsibilities.

At local authority level, older people's health and social care services are responsible for the needs of people aged over 65, including older people who are carers. These services also cover older people with learning disabilities, although learning disability services usually have more targeted skills and experience in supporting this group. Most statutory services have worked out their own protocols for working with older people with learning disabilities; but the other family members are usually supported by a different department. As a result, many families are in a confusing situation which doesn't take into account the family as a whole, and they are passed from one service to another when they ask for help.

This is made even more complicated for families who are providing 'mutual caring' – where the person with a learning disability is looking after their ageing carer (physically or emotionally), and neither can manage entirely without the other. These families particularly need to know where and how they can get support easily.

⁷ HM Government (2008) *Carers at the heart of 21st-century families and communities*.

One option at board level may be an 'older families task group' across different agencies and services; a priority for this group could be identifying the 'pathways' through which older families can get support from different services.

Mutual Carers' Support – Bromley Mencap

The **Mutual Caring Project** supports older families that are providing mutual caring. Project workers have helped individuals and families with a range of practical issues, including welfare rights, equipment and adaptations, housing issues and health advocacy. They have also helped educate the local hospital and the local carers' centre about mutual caring and its implications.

For more information email enquiries@bromleymencap.org

Link to the Partnership Board Annual Self-Assessment Report

One of the key areas of the Annual Report focuses on workforce development. People who are not working exclusively with people with learning disabilities often need to be more skilled and confident in supporting this client group.

Similarly, data that has to be collected for the *Adult Social Care Combined Activity Return* on targets such as settled accommodation provide the opportunity for departments to work together to see where the links and opportunities for joint working are.

Points to consider:

- Are older people's services, carers' services and learning disability services all in touch with each other, and are they linking up where relevant (this includes the voluntary and community sectors)?
- Does your Partnership Board have formal links with the Older People's and Carers' Partnership Board (or the local equivalent)?
- Is there information for older families and the people supporting them about how to get help from other sources?
- Can people working in older people's, carers' and learning disability services get some training on older families and their issues?
- Do GP practices and hospitals know about older families and about mutual caring?
- Does the Carers' Grant and Emergency Respite Grant spending cover the needs of older families?

- Are non-statutory services, such as LINKs (local involvement networks), aware of older families and the complex issues involved in supporting them?

Rate how well your Partnership Board is doing to make links with other services and groups with a responsibility for supporting older families:

Circle the box

**We have lots
to do**

**We're making
progress**

**We're doing
very well**

What can we do better over the next 12 months?

7. Is your Partnership Board measuring and monitoring the degree to which older families are being supported?

Older families are complex, and meeting their needs comprehensively can take a long time. The important thing is to make sure that work is under way, that it is genuinely improving these families' lives and that this improvement will continue.

Some of the things that make improvement possible include:

- funding for specialist work for older families, including funding to continue good work that has been piloted;
- projects that combine expertise from different sectors, such as older people's services, advice services and/or voluntary organisations supporting older people or people with a learning disability;
- advocacy for older family members – both for the person with a learning disability and for the older family carer;
- information (in different formats) that explains the older families' options for support at the moment, in emergencies and in the longer term; and
- training and improved awareness for people working in different sectors in older family issues, and fuller explanation of the options for supporting them (this is often most effectively delivered by older families themselves, either in person or through a DVD presentation).

'Moving Forward Training'

Central Bedfordshire Council's Learning Disability Service offers a course to family carers to support them with the processes involved when the person they care for moves out of the family home. The course has proved to be effective and of value.

For more information contact the Adult Learning Disability Team on 0300 300 8100

Link to the Partnership Board Annual Self-Assessment Report

Most sections of the Annual Report guidance can, and should, cover the needs of older families – including the achievements that have been made in meeting their needs.

Points to consider:

- Are there specific mechanisms for monitoring the support that older families get?
- Are the types of initiatives for improvements outlined above in place?
- Are there benchmarks for monitoring improvements in the area?
- Are there routine systems in place to review progress within services: for instance, the number of people who have come forward in the area; the number of carers' assessments being completed and reviewed, as well as their outcomes; the number of emergency plans which are registered; the uptake of direct payments and individual budgets; and the use of short-term services.

Rate how well your Partnership Board is doing to make sure that systems are in place for measuring and monitoring how well older families are being supported locally, and for planning what still needs to be done:

Circle the box

**We have lots
to do**

**We're making
progress**

**We're doing
very well**

What can we do better over the next 12 months?

Conclusion



Moving forward

Time is running out for many older families of people with a learning disability. Many have already spent a lifetime worrying about what will happen in an emergency or in the long term, and as the population continues to age, this issue will only get bigger. Older families need to be confident that information and support is out there to help them make choices about the future and to begin preparations.

The time has never been better to make sure your area is supporting older families. For example:

- Personalisation and Putting People First provide the opportunity for joined-up budgets for older families and more creative, flexible ways of supporting them now and in future.
- The National Carers' Strategy highlights the need for joined-up, flexible approaches to supporting carers.
- *Valuing People Now* and the Annual Self-Assessment Report provide a framework for measuring and monitoring how well your area is identifying and supporting older families, and other related targets, like housing and personalisation.
- There is lots of excellent work to support older families in a range of settings all over the country, and more opportunities than ever to network through regional events, the internet and organisations.
- There are also more resources than ever to support older families and service planners and providers.

Getting things right for older families will take a long time and needs a joined-up, committed approach. There are small and big steps to take in the process – but what matters is that you start, that you keep checking how you are doing and what difference it is making to the lives of older families where you live.

Key messages

- Now is the best time to support older families.
- It might take a long time, but it is important to get started and to keep checking how well you are doing.

Appendix 1: Supporting older families – the Sheffield model

Since 1996, Sheffield has been working hard to develop robust systems for supporting older families, as a result of sustained lobbying from family carers concerned about what would happen to their relatives when they died or could no longer care for them.

Currently, the situation in Sheffield is as follows:

- The majority of family carers over the age of 65 (around 400 families) are known by the Sheffield Case Register.
- All families where the family carer is aged 70 or over are offered regular contact through the Older Carers Support Service. Information about their needs and the needs of the people they support is recorded at least once a year.
- The oldest and most isolated older families who have no funded support from statutory services are being prioritised and helped to plan ahead by a specialist team, the Older Families Planning Project (OFPP). The aim is to make sure plans are in place for people before a crisis develops. As a result, many people have been supported to make planned moves or to make a choice to stay on in their family home with the right support in the future.
- Older families remain a priority group within accommodation and support strategies and on other agendas.

The voluntary and statutory services have become far better able to meet the needs of older families. The emphasis is on:

- a demonstrable commitment to this group;
- partnership working between health and social care services, the voluntary sector and families;
- identifying older families;
- involving older families in developing the framework for supporting them;
- regular, low-level contact with older families to prevent crisis;

- person-centred planning, with an emphasis on a family-centred approach;
- advocacy and support, provided by the voluntary sector; and
- identifying 'invest to save' outcomes through prevention and planning work.

This has not tackled the issue fully, but it has proved to be a good and effective start. The main challenge for the future is developing more robust links with services for older people, and ensuring that this specialist work is not considered a luxury or at a tangent to the mainstream.

Diagram 1 overleaf shows the main structures and services that have been developed to support older families across the city.

Sandra's story

Sandra lives with her parents, who are both in their late 80s. The family have been working with the OFPP to start preparing for the future. Through person-centred planning, Sandra was able to clarify that she wants to be able to stay on in the flat she shares with her parents when anything happens to them. She is well known locally, has good neighbours and is close to other family members who are very supportive of her choice. Sandra had never stayed by herself before and planning helped her work out what she felt confident to do and what she needed support with.

The project's occupational therapist and development worker helped Sandra to build her skills in some areas of daily life, and worked with her so that she is clear about what help will be needed with other things. Sandra has been slowly building up her time alone in the flat and has now spent some weekends alone with regular calls arranged. The tenancy for the flat will now pass to Sandra in future, and she is currently working with the project to find some regular support for a few hours a week to help her practise and maintain her skills, and enable her and her parents to help others understand the practical and emotional support she will need in the future. Funding for an emergency plan have been agreed in principle to allow Sandra extra support in a crisis. The plans will be regularly reviewed and altered as needed.

Diagram 1: The structure for support for older families in Sheffield

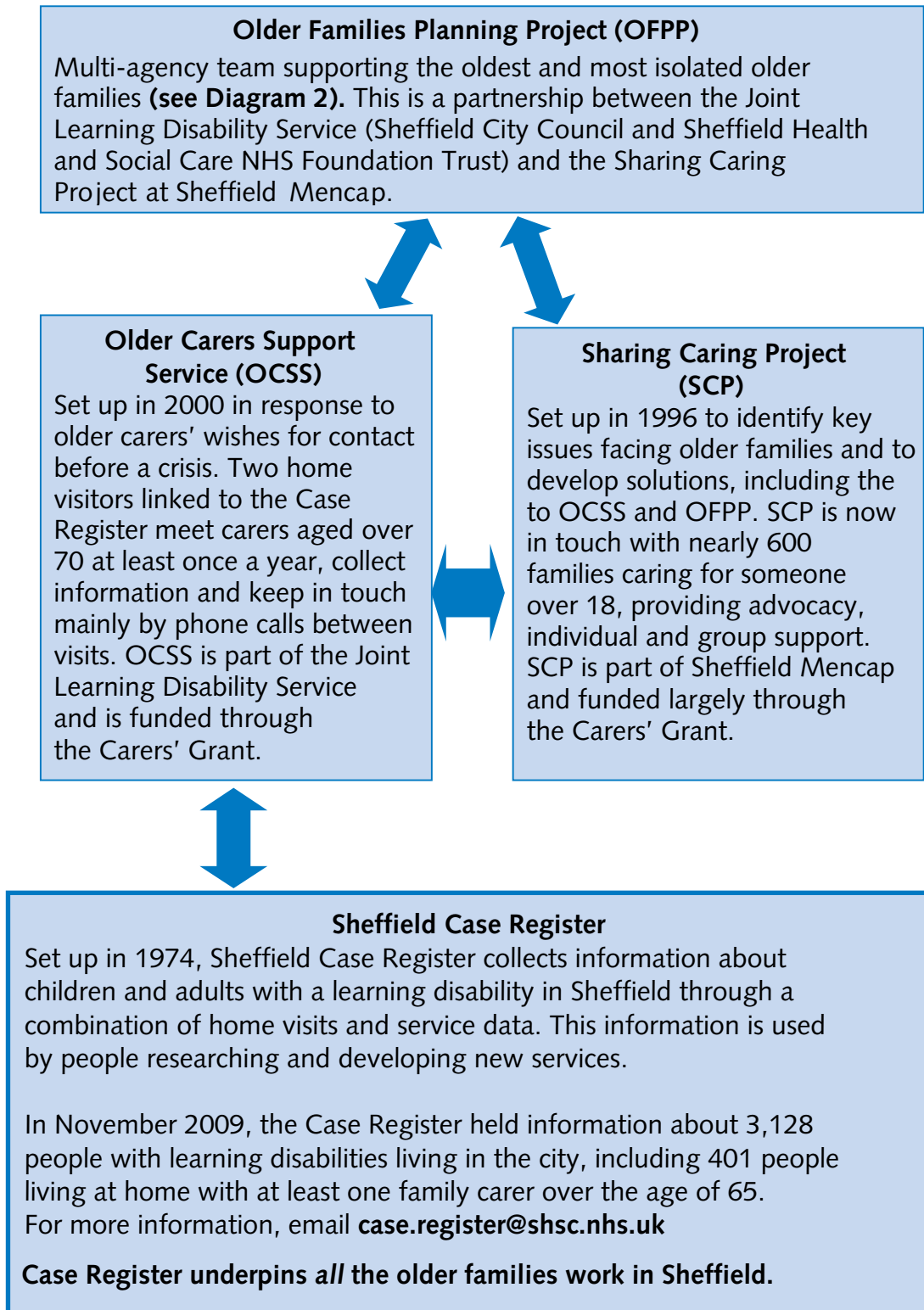
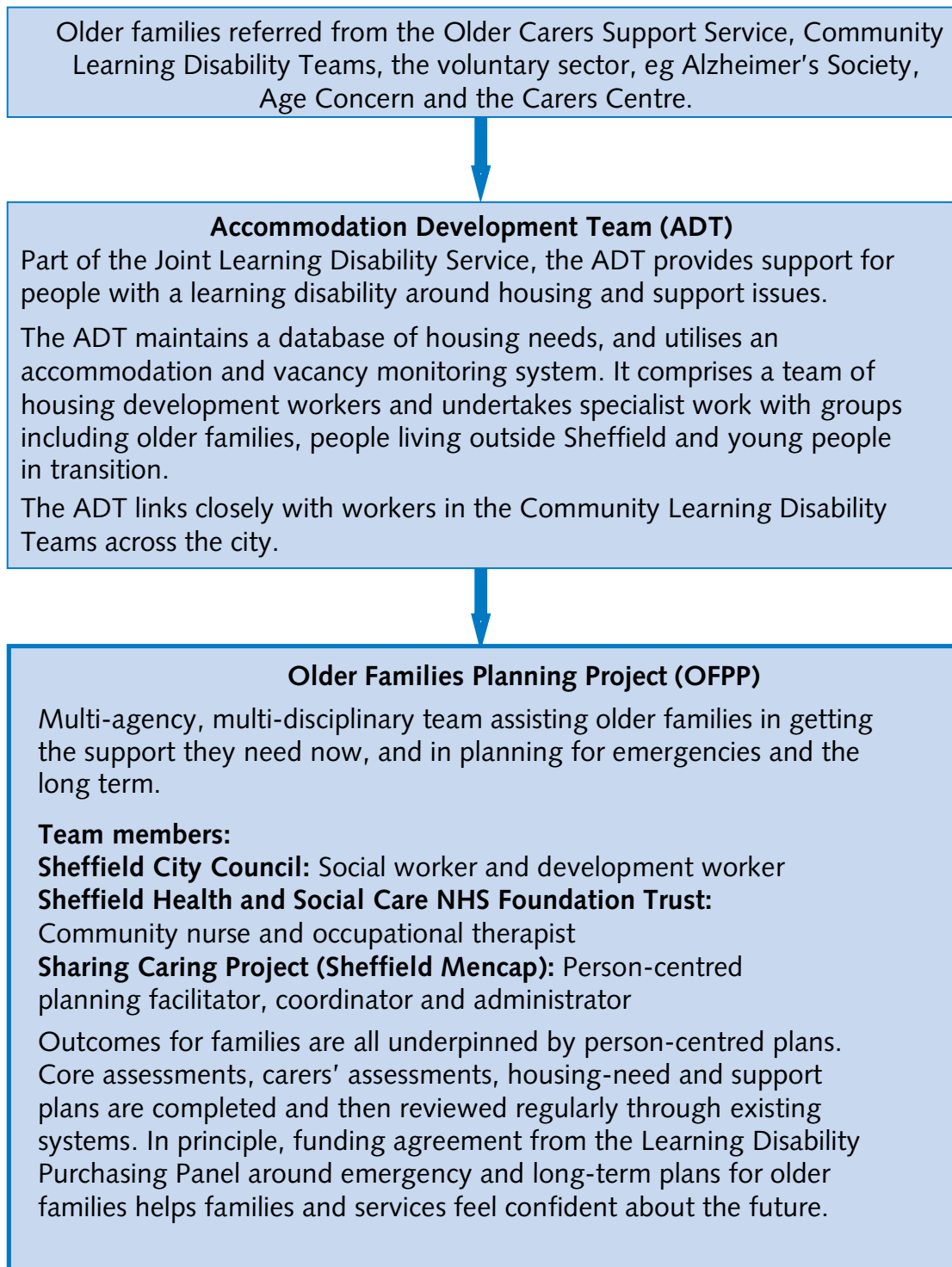


Diagram 2: The Older Families Planning Project



Appendix 2: Supporting older families – useful resources

Foundation for People
with Learning Disabilities

The Foundation for People with Learning Disabilities has produced many resources through their Older Families Initiative and the Mutual Caring Project.

The resources below can be downloaded from their website at www.learningdisabilities.org.uk or you can email fpld@fpld.org.uk for more information. Resources include:

Supporting older families: making a real difference. D. Magrill, 2005. More detailed information about ways local areas can best support older families.

Person-centred approaches and older families. D. Magrill, H. Sanderson and A. Short, 2005. A booklet to help people to use person-centred planning effectively with older families.

Mutual Caring. 2010. A DVD containing four films: *Being a Carer*, *Carer's Assessment*, *Person Centred Planning*, and *Peer and Group Support*.

Supporting you as an older family carer. 2010. A booklet to support older family carers of people with learning disabilities to get the right support now and to plan for emergencies and the long term.

Supporting you and your family as you grow older together. 2010. A booklet for people with learning disabilities who live at home with an older family carer.

Supporting you to support your family. 2010. A booklet for family and close friends of older families that include a person with learning disabilities.

Supporting older families and people with learning disabilities who are caring for each other. 2010. A booklet for staff who support older families that include a person with learning disabilities.

Circles of Support and Mutual Caring. C. Towers, 2010. A short guide to support people to set up and run their circles of support.

Need2Know: Mutual Caring. 2010. A briefing note for policy makers, commissioners and services from the Foundation for People with Learning Disabilities.

Being a Carer and Having a Carer's Assessment. A pack to help carers with learning disabilities work out if they are a carer and some of the ways to get help. This pack was produced by the Valuing People Support Team and written as part of the Mutual Caring Project. It's available to download from the Foundation's website (as above) or the Valuing People website at www.valuingpeople.gov.uk

Good practice guidelines in supporting older families of people with a learning disability. 2003. Produced as part of the Older Families Initiative, these guidelines include identifying older families, planning for family emergencies, accessing short breaks and supporting older families of people on the autistic spectrum.

Discretionary Trusts: A Guide for Families. N. King, 2004. This resource explains more about leaving property and money in Trust for people with a learning disability.

Today and Tomorrow. 2002. The report of the Growing Older with Learning Disabilities (GOLD) project shares the findings from the UK-wide initiative that aimed to increase understanding of the concerns of older people with learning disabilities and their families. The report includes a series of recommendations for policy makers and planners, commissioners and providers. This report is out of print and only available to download from the Foundation's website.

Other useful resources and websites

Supporting Learning Disability Partnership Boards to Implement the National Carers Strategy. D. Magrill, C. Towers and H. Morgan, 2009. Produced by the Princess Royal Trust for Carers and Crossroads Care and available to download from the Valuing People website at www.valuingpeople.gov.uk

Living on the Edge. L. Easterbrook, 2008. London: Care & Repair England. Report about enabling older people with moderate learning disabilities to live independently.

The Housing Timebomb: The housing crisis facing people with learning disability and their older parents. Mencap, 2002. Available to download from www.mencap.org.uk

Housing Options – www.housingoptions.org.uk

Housing Options is a housing advisory service for people with learning disabilities, their families and supporters. The website is a comprehensive source of information about housing and related issues for people with learning disabilities.

Care & Repair – www.careandrepair-england.org.uk

Care & Repair's mission is to innovate, develop, promote and support housing-related policies and practical initiatives which enable older and disabled people to live independently in their own homes for as long as they wish.

Age Concern and Help the Aged (Age UK) – www.ageconcern.org.uk and www.helptheaged.org.uk

Both organisations have joined together to form a single charity aimed at improving the lives of older people. They have a comprehensive range of information guides, fact sheets and services that are very useful for older people and older families.

This booklet was written by Dalia Magrill, Sharing Caring Project at Sheffield Mencap. It was commissioned by the Family Carers Programme of Valuing People Now.

Further copies are available from the Valuing People website – www.valuingpeople.gov.uk



© Crown copyright 2010

302370 Xap X.Xk Mar 10 (ESP)

If you require further copies of this title visit

www.orderline.dh.gov.uk and quote:

302370/*Valuing Older Families Now*

Tel: 0300 123 1002

Minicom: 0300 123 1003

(8am to 6pm, Monday to Friday)

www.dh.gov.uk/publications



50% recycled

This is printed on
50% recycled paper