Making managed personal budgets work for older people

What older people want, what works and how to achieve the best outcomes
To assist local authorities and others to improve their support for older people on personal budgets by:

• highlighting what older people want from their care and support
• identifying what works
• demonstrating how the voluntary sector can support the local authority to achieve outcomes.

Personalisation leads and local authority commissioners, social workers, care managers, occupational therapists, local Age UKs and other service providers.

Making managed personal budgets work for older people. What older people want, what works and how to achieve the best outcomes

April 2013

A guide for local authorities, relevant professionals, Age UKs and other providers to help them ensure that managed personal budgets offer the same level of choice and control for older people as direct payments. It highlights research and best practice on what older people want and need from a personal budget and what support local authorities should provide and/or commission to help older people achieve the best possible outcomes from their personal budgets. It also focuses on local authority support for self funders making similar decisions to those on a personal budget. It includes a variety of individual and service case studies.


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## Contents

Case studies 3  
Key messages 4  
Introduction 6  

### 1 The importance of personal budgets and direct payments 8  
1.1 The benefits of personal budgets for older people 9  
1.2 The incentives for local authorities and providers 11  
1.3 Measurement of progress 12  
1.4 Work to improve take up by older people 13  

### 2 What do older people want? 14  
2.1 Current social care users 17  
2.2 Future users of social care 22  

### 3 What systems and practice methods are needed for personal budgets to work well for older people? 23  
3.1 Supporting social care users to make choices and to have real choice 26  
3.2 Keeping service users informed about essential aspects of their personal budget 35  
3.3 Resourcing choice for service users 37  
3.4 Restricting choice for service users 38  
3.5 Care management and case reviews 39  
3.6 Commissioning practices and market management 44  

### 4 Supporting older people to have full choice and control in practice 47  
4.1 Person-centred practices 48  
4.2 Individual Service Funds 65  
4.3 Peer support networks 69  

### 5 The contribution of the voluntary sector 81  

Endnotes 88
Case studies

1. The difference that a personal budget can make
2. Direct payments support person with dementia to continue living at home
3. Support from a broker can help ensure a care and support package is tailored to individual needs
4. The importance of information and advice at the right time
5. The benefits of tailored information and advice
6. Experiences of a project that helps older people onto personal budgets
7. Self-funder using Age UK Cheshire’s Independent Care Brokerage Service to access services
8. The need for a case review
9. Person-centred support planning
10. Access for Black, Asian and Minority Ethnic (BAME) Elders
11. Age UK Newcastle service design
12. Age UK Isle of Wight’s personal assistants
13. Age UK Oxfordshire’s home support and companionship service
14. Developing and delivering person-centred services
15. Person-centred planning
16. Supporting someone with complex needs in a person-centred way
17. People involved in Oxfordshire’s Roots and Circles project
18. Age UK Gloucestershire’s modular day service
19. Age UK activity centre
20. Individual Service Fund user (Barking and Dagenham)
21. Individual Service Fund in residential care
22. Peer support for people with dementia and their carers
23. Using older volunteers to reach older people
24. Peer support for Asian elders
25. Peer support brokerage service
26. The benefit of advice and support services
27. Age UK Wirral’s Personalisation Project offers support through the application and support planning process
28. Age UK Sheffield’s Self-Directed Support (SDS) Support Planning Service for people with a personal budget
29. Age UK Cheshire’s Independent Care Brokerage for self-funders
Key messages

What older people want (see Chapter 2)

Some older people welcome the option of a direct payment. Many do not, but they still want choice and control over the help they receive: who, what, where, when and how. This often has less to do with a choice between providers and more to do with a choice about how support is delivered by the chosen provider. What older people value is:

• Support from a named person, from assessment through to support plan implementation – and beyond to ensure that it remains appropriate
• As little bureaucracy as possible
• Flexibility, continuity and on-going relationships with care providers
• To get out and about, with support if necessary, and to be involved in social and community activities
• Help to put creative support arrangements in place, but also traditional services: day services and activities, help with housework and gardening
• The same types of help, especially to plan care and support and to put it in place, regardless of how it is being funded.

Supporting people to make choices

Access to a budget does not, in itself, ensure choice or personalisation. Many self funders exercise little real choice and often achieve poor outcomes. Often people have little understanding of what is available and what is possible. People with care and support needs require:

• Good, accessible information and advice, as early as possible in their care journey, with the option of face-to-face contact (see section 3.1)
• Access to advocacy, especially for people with dementia and others who may have difficulty in representing their needs (see section 3.1)
• Person-centred support that starts with the needs, capabilities and preferences of the individual, not with service-based solutions or categorisation of need (see sections 3.2 and 4.1)
• Help to understand what is possible within the care system and what support is available within their local community
• Assistance to plan care and support, put it in place; and review its continued effectiveness and appropriateness as needs and circumstances change.
Making a reality of choice

Choice is meaningless without diversity. People need to know what is available and the options have to be realistic for them. Resource allocation systems should generate indicative budgets that are adequate to meet assessed need – where they fall short, budgets must be increased. But there is also a responsibility on local authorities and providers to increase the range of choice:

• Local authorities must take an active role in stimulating and managing the market to deliver the quality, diversity and volume of services needed (see section 3.6)

• It must be recognised that individual purchasing power alone cannot ensure a high quality and diverse social care market (see section 3.6)

• Information derived from individuals’ goals, priorities and preferences should inform decisions when planning and commissioning for populations (see section 4.1)

• People on local authority managed personal budgets should have the same choices as others, not be restricted to ‘preferred’ providers (see section 3.4)

• Providers share responsibility for ensuring diversity: choice within services is as important as choice between services (see section 3.6)

• Providers should use person-centred methods to tailor their services to the needs and preferences of individuals (see section 4.1)

• Person-centred practices can be used to deliver both one-to-one and group-based services (see section 4.1)

• Individual Service Funds, managed by providers or others, offer a creative alternative to both direct payments and local authority managed budgets (see section 4.2)

• Individual Service Funds can support outcomes-based commissioning (see section 4.2).

The contribution of the voluntary sector (see Chapter 5)

Many voluntary organisations are care and support service providers. They also have a crucial role in providing information, advice and advocacy; and in providing support planning and brokerage services. Many older people, including self funders, would prefer to receive these services from a known and trusted, independent organisation, rather than from the statutory body responsible for determining eligibility and rationing resources. But voluntary organisations are not only service providers: they can also work to bring people together in community networks. This can include volunteer or good neighbour support schemes, bringing personal budget holders together to jointly purchase services, and facilitating the development of peer support. The latter has been shown to be invaluable in helping people to make effective use of their budgets and in managing the practicalities of direct payments. All these sorts of activities also help local authorities to meet their targets in extending choice and control.
Introduction

Personalisation of care and support provision is one of the most fundamental policy and practice changes of recent years. Supported and strongly advocated by successive Governments, professional representative bodies and user and stakeholder groups, it has taken hold and been pursued as a way to ensure that care and support is tailored to individuals and their particular needs and preferences.

Delivering change has been a complex task, requiring an altered approach to many elements of provision, administration and organisational culture. Guidance and policy has been published to support the process of change. Whilst much of this is clear about the general principles of personalisation, the how of implementation has been generally left to the discretion of individual local authorities, providers and professionals.

The guidance highlights the characteristics of personalisation, which include: tackling how assessment is organised; giving individuals a clear allocation of resources as a personal budget; the support planning and other sources of assistance available; ensuring there is a choice of support; the process of review arrangements; etc.

Of these characteristics perhaps the greatest attention has focused on delivery of personal budgets, partly because this has required one of the largest changes to local authority budgeting and allocation procedures, and partly because it was the subject of a take up target set by Government.¹

However, implementation of personalisation and of personal budgets specifically has not been consistent and can vary considerably both within and across local authorities and providers.² This appears to be the result of many factors, including, but not exclusively related to, the approach of the individual local authorities, the attitudes of social workers and other care professionals, the availability of support and guidance services, and the preferences of the older service users themselves. Additionally, older service users are the group most likely not to know about personal budgets or understand how they work making it very difficult to assess quality and outcomes nationally.³

The barriers to implementation as well as what assists implementation are outlined in Chapter 3.

Where personal budgets are working, there is evidence that they can help service users to achieve better outcomes, because people feel in greater control of their everyday support, are empowered to make decisions about their care, can challenge when arrangements aren’t working, etc.⁴

Despite the positive findings, there are concerns that older people are not accessing the full benefits of personal budgets and direct payments. A review into their use by older people is ongoing, led by the cross-sector collaboration Think Local, Act Personal.

The proportion of older people on personal budgets rose to 45.2 per cent by the end of March 2012, but this was still significantly lower than the level for people with a learning disability (58.8 per cent).
While 45.2% of older people are in receipt of self-directed support, only 6.9 per cent of service users are on direct payments, it is, therefore, reasonable to assume that approximately 85 per cent of those on self-directed support are on managed personal budgets.  

A particular area of concern for Age UK is the apparent lack of choice and control that council managed personal budgets offer to service users. The evidence outlined in Chapter 3 shows that council managed personal budgets offer a more limited range of choice and control and that care and support arrangements are less flexible. Because older people are more likely to have a council managed personal budget than a direct payment, they may be missing out on influencing their care and support arrangements and are therefore not accessing fully personalised services.

Alongside supporting and encouraging older people to choose a direct payment, we think that choice and control can be further extended so that managed personal budgets offer the same flexibility and range of benefits. This can be achieved by supporting service users to understand and evaluate the available choices, making explicit the budget available to them, and offering support to alter their care when they want to.

This Age UK expert series report is designed to support local authorities and service providers to do this.

A note on the terminology

- **Managed personal budget:** following assessment and allocation of a budget to an individual, a local authority retains the physical cash, but supports the service user to make decisions about their care and support package.

- **A third-party provider managed personal budget:** this is where the funds are transferred from the local authority to a care and support provider or broker who supports the person to set up a care package using services from the provider themselves or, where preferred, by buying from other providers. This could be organised as an Individual Service Fund.

- **Direct payment:** a transfer of the cash from the local authority to the individual’s bank account that they can use to spend directly with care and support providers, or any other suitable source of support. Service users should have free choice over how they use their budget, provided that the support they purchase results in their assessed needs and agreed on the outcomes being met. Third parties, such as family members, can manage this budget on behalf of a service user, including where they don’t have mental capacity to manage a budget themselves. There are many options for managing the cash itself, using pre-paid cards, vouchers, or by setting up a User-Controlled Trust.  

- **A mixture of the above:** so that people can ensure that their care and support package is as flexible as possible. Local authorities should support people to review arrangements and make changes, perhaps switching between models as needs alter, or as they become more confident in managing their own affairs.

This publication mainly focuses on how older people should be enabled to use council-managed personal budgets to achieve the best outcomes.
This chapter looks at the benefits of personal budgets for older people and outlines the incentives and challenges for local authorities and service providers in ensuring that personal budgets work well for older people. It considers progress made in the take-up of personal budgets by older people and what have been the main barriers.
1.1 The benefits of personal budgets for older people

Personal budgets have been shown to give service users greater choice and control, supporting them to stay independent, and ensuring that the support that they receive promotes dignity and respect.

However, older people are more likely to report personal budgets as making no difference to the outcomes they achieve; and less likely to report improvements in outcomes concerned with a greater sense of control, improved social contacts and community engagement. To this extent personal budgets are failing to deliver the benefits to older people which younger disabled people are able to achieve.

Delivery of personal budgets for people with dementia is underdeveloped. Alzheimer’s Society research found that the system ‘has not yet adapted to the needs of people with dementia and their carers, and is overly complex and burdensome’, although this could also be applicable to older people more broadly. It advocates that options for people with dementia ‘must include a managed budget or open discussion to ensure that people with dementia and carers understand the amount of money there is to spend on their services and are involved in care planning discussions’.

However, there are individual examples of older people using personal budgets in an extremely effective way. This good practice needs to become more widespread so that more older people can gain the benefits of a more flexible approach to their care and support.

The difference that a personal budget can make

Mr A came to England from Poland after the war and now lives with his wife. He has dementia. Although he has lived here for over 40 years and spoke English, his progressing dementia means that Mr A is no longer able to understand English, and has reverted back to his original language, Polish. He received reablement support from social services but was unable to communicate with any of the carers.

Mr A was referred to Age UK Cheshire’s Independent Care Brokerage service and was assisted to get a personal budget from the council so that he could choose his own care agency. The brokerage team was able to find a care agency that employed Polish speaking carers.

Although Mr A cannot always remember the carers, he now has a general chat with them in Polish and is able to find out what is happening in his local community.
Mrs G lived alone for 10 years after her husband died and wanted to continue living in her own home. Two of her six adult children live over 150 miles away and all have full time jobs and families. In 2008, her children alerted the GP to their concern about her memory. The GP referred her to memory services, but she refused to attend appointments and her dementia has remained undiagnosed. She continued to live at home with support from her children.

Over the next few years, Mrs G deteriorated and her family became more and more stressed as they supported her. They approached her local social services and she was given a direct payment which was used to pay one of Mrs G’s daughters-in-law to visit her twice a day to prepare and supervise meals and things settled down.

About 18 months later, Mrs G had a series of mini-strokes. After she fell and cut her head, it became clear that she needed 24 hour care. Her family stayed with her on a rota basis. When this became too much, they approached social services who agreed to increase the direct payment to allow her family to employ a live in carer to take over the day-to-day care. This process took time and one of her daughters managed to take time off work to live with her mother for a month, and finally managed to employ a carer in February 2011. This arrangement has worked well for the last two years as it has allowed Mrs G to remain at home which is where she wants to be, while receiving the support she needs.
1.2 The incentives for local authorities and providers

Personalisation delivered through the allocation of personal budgets is absolutely central to the government’s agenda for transforming social care. This was reflected in the inclusion of direct payment (and later personal budget) take-up in the National Indicator Set.9 More recently it has been reflected in the emphasis on service users’ experience of choice and control in the Adult Social Care Outcomes Framework,10 to be measured by surveying the views of service users.

Clearly, a switch to personal budgets needs to be much more than an administrative or book-keeping exercise: it needs to fundamentally change the experience of service users. No local authority could be considered to be performing well unless this transformation in the experience of receiving care and support is achieved. And, as older people are the largest group of social care users, personalisation cannot be working well unless it’s working for older people.

Particularly in the present economic climate, high performance against policy objectives inevitably needs to be tempered by the imperative to improve cost efficiency. It now seems unlikely that the switch to personal budgets can deliver immediate cost savings across the board. The prospect of 20 per cent average savings suggested by In Control in the early stages of the transition to personal budgets was based on a very small sample of individuals on very high cost care packages switching to direct payments.11 For older people on much more modest budgets, such short-term savings are improbable. But it is clear that, properly implemented, personal budgets can lead to improved levels of effectiveness of support at similar cost and of user satisfaction. In turn this should result in much more sustainable solutions which will deliver savings in the medium term.

For providers, the improved levels of user satisfaction and service effectiveness achievable through personalisation also provide a powerful incentive: service users are much more likely to want to stick with a provider who can tailor support to their individual needs and preferences. Local authority commissioners will also need to be convinced that providers have taken on board the fundamental changes in practice that personalisation entails.

It is important not to understate the challenges for providers in adapting to the individual, rather than block, purchase of services that the switch to personal budgets usually entails.12 Nor should the challenge of changing attitudes and practice to deliver genuinely personalised services be underestimated.13 14 But those providers who have risen to these challenges report greatly enhanced levels of both staff and user satisfaction. And it is those providers which can succeed in this transformation of the way they operate that will thrive in future.
1.3 Measurement of progress

Implementation of personalisation in its broadest sense has proven difficult to measure and record in practice. There are some activities and targets which have been used to indicate that a local authority or provider is taking a personalised approach to provision, but we know that it is as much about culture change and attitude of staff as about process and procedure. Policy documents related to personalisation in social care are, therefore, a mixture of description of the vision of personalisation combined with gentle persuasion aimed at local authorities and providers to implement change.

Where targets have been used, local authorities have come under criticism for concentrating too heavily on ‘ticking the box’ for targets, while losing sight of the broader vision for personalisation and service transformation. This has particularly been the case in relation to targets for take up of personal budgets and implementation of resource allocation systems, at the expense of the other equally important elements of personalised delivery.

One specific target relates to the take up of personal budgets, with an original aim of 30 per cent of eligible adults using a personal budget by April 2011. The Government’s Vision for Social Care in 2010 extended the deadline to April 2013 but increased the target to 100 per cent of eligible users. However, in October 2012 the Care Services Minister reduced this to 70 per cent, in recognition that the target was having a distorting effect on the way in which personalisation was being implemented.

Surveys of local authorities also help to give a picture of progress in implementation of personalisation. Although the proportion of people aged 65 and over receiving self-directed support almost quadrupled between 2009–10 and 2011–12 (from 9.6 per cent to 45.2 per cent), this increase was almost entirely due to an increase in the number of older people having a personal budget managed by the council, rather than direct payments.15

In 2011 Think Local Act Personal published the results of a national survey of service users on personal budgets.16 The survey found that there was a large national variation in the way that local authorities set up personal budgets, managed funds, arranged brokerage and support, and authorised spend of a personal budget. It also found that older people were less likely to be using a direct payment as a means of managing their personal budget and were more likely than other groups to not know how their personal budget was managed.

As part of the localism agenda, the coalition Government removed the necessity for local authorities’ performance to be measured against the National Indicator Set, but instead introduced the Adult Social Care Outcomes Framework17 designed to guide local authorities towards identifying and measuring their local priorities. The outcomes in the framework have been measured since 2011–12 and will be the sole tool in use from April 2013. Measures include the experiences of service users, taking into account whether they felt in control of their care and were able to exercise choice and control.
1.4 Work to improve take up by older people

Older people have, to date, not taken up the offer of personal budgets and particularly direct payments to the same extent as other service user groups, and those who do use them tend to report fewer positive outcomes than other groups. There have been a number of studies which have explored the possible reasons for this and, in 2012, the Association of Directors of Adult Social Services, having recognised that personalisation is not working well for older people, proposed a review into the current approach to personal budgets for older people in order to explore how they can be made more effective. The care sector consortium Think Local Act Personal (TLAP) took on this review. Outputs so far include a research review which covers some of the barriers to personal budgets for older people as well as further analysis of the 2011 National Personal Budgets Survey results.

There are a number of common barriers identified in the studies and reviews completed to date. The areas relating to managed personal budgets concern how service users exercise choice and control over their budget, including the ability to access support to make the best use of the budget.

There have been several publications by Think Local Act Personal, Department of Health and others, which have stressed that local authorities should not pursue take up of personal budgets at the expense of the broader spirit of personalisation intended to support service users to have more choice and control.

The rest of this report highlights key areas for improvement and offers practical suggestions for ensuring that older people with managed personal budgets are offered the same flexibility and range of benefits as direct payments.
What do older people want?

This chapter summarises research findings around what older people expect from their care and support and their purchasing habits. It presents case studies that illustrate the sorts of care and support older people have chosen and what they say they may use in the future.
In order to ensure there is a successful system in place providers and local authorities need to have a clear understanding of what their service users want and need. This helps them ensure that service provision is meeting the needs of the local community.

Everyone, regardless of support needs, wants to live a meaningful life that comprises of rewarding activity and relationships and giving as well as receiving. Budgets allocated to older people with care and support needs are often insufficient for the entirety of what people may want to put in place, sometimes only covering immediate personal care needs. However, it is also important to note that what may appear to be small changes can have a huge impact (e.g. company at lunch time). Creativity and careful support planning can go a long way to supporting people in a way that positively impacts on their sense of wellbeing. Throughout this report there are case studies of older people in various situations that illustrate the sort of care and support that is typically preferred by this group and how best to support them.

Think Local Act Personal’s ‘I’ statements are a good reminder of the priorities of service users and their families.

Progress markers for personalised, community-based support

- Information and advice: having the information I need, when I need it.
  - ‘I have the information and support I need in order to remain as independent as possible.’
  - ‘I have access to easy-to-understand information about care and support which is consistent, accurate, accessible and up to date.’
  - ‘I can speak to people who know something about care and support and can make things happen.’
  - ‘I have help to make informed choices if I need and want it.’
  - ‘I know where to get information about what is going on in my community.’

- Active and supportive communities: keeping friends, family and place.
  - ‘I have access to a range of support that helps me to live the life I want and remain a contributing member of my community.’
  - ‘I have a network of people who support me – carers, family, friends, community and if needed paid support staff.’
  - ‘I have opportunities to train, study, work or engage in activities that match my interests, skills, abilities.’
  - ‘I feel welcomed and included in my local community.’
  - ‘I feel valued for the contribution that I can make to my community.’
• Flexible, integrated care and support: my support, my own way.
  ‘I am in control of planning my care and support.’
  ‘I have care and support that is directed by me and responsive to my needs.’
  ‘My support is coordinated, co-operative and works well together and I know who to contact to get things changed.’
  ‘I have a clear line of communication, action and follow up.’

• Workforce: my support staff.
  ‘I have good information and advice on the range of options for choosing my support staff.’
  ‘I have considerate support delivered by competent people.’
  ‘I have access to a pool of people, advice on how to employ them and the opportunity to get advice from my peers.’
  ‘I am supported by people who help me to make links in my local community.’

• Risk enablement: feeling in control and safe.
  ‘I can plan ahead and keep control in a crisis.’
  ‘I feel safe, I can live the life I want and I am supported to manage any risks.’
  ‘I feel that my community is a safe place to live and local people look out for me and each other.’
  ‘I have systems in place so that I can get help at an early stage to avoid a crisis.’

• Personal budgets and self-funding: my money.
  ‘I can decide the kind of support I need and when, where and how to receive it.’
  ‘I know the amount of money available to me for care and support needs, and I can determine how this is used (whether it’s my own money, direct payment, or a council managed personal budget).’
  ‘I can get access to the money quickly without having to go through over-complicated procedures.’
  ‘I am able to get skilled advice to plan my care and support, and also be given help to understand costs and make best use of the money involved where I want and need this.’
2.1 Current social care users

The bulk of research around direct payments and personal budgets has related to younger people with physical and learning disabilities who were able to use direct payments long before they were opened up to older people, and take-up among these groups has always been much higher. Some of the more recent research includes larger samples of older people, and shows that preferences and usage of services are very different between people with learning disabilities and older people. Caution should, therefore, be exercised when generalising from other research based predominantly on choices made by different user groups. Local authorities will need to be aware of this and not simply reinforce these preferences by commissioning or providing a narrow range of services. They need to ensure that there is sufficient variety of provision for people to choose from.

It is also important not to start with the assumption that all older social care users will want to change their support if they were in receipt of personal budgets. Demos found that a large number of older people would want to keep things largely the same, using the same types of services, but perhaps changing provider. Therefore, an increase in use of personal budgets will not necessarily reduce demand for established, mainstream services, such as day centres, if they continue to meet needs for care and social contact in appropriate ways.24

Much of the recent research confirms that older social care users – whether in receipt of statutory funding or not – want to maintain their independence, health and wellbeing. These are key aspects of the current provision of care and support and confirm that the personalisation agenda, including the emphasis on preventative interventions, is the correct one.

Participants in a study exploring the preferences of older people with high levels of need25 recounted their experience of organising and managing their care. They highlighted their strong desire for choice and control exercised through being supported to have personalised care and support. But they stressed that having control of money did not necessarily equate to having control over decisions about care. This tended to be a result of other people managing money on someone’s behalf, for example, a care home manager or relative. Participants also highlighted the deficiencies in the care market which they felt did not offer adequate options to meet their needs, and in which they felt as though they were treated as a ‘commodity’.

Some preferences are for the way that services are arranged and provided. So older people and carers want to have flexibility over their care package, to be able to change services and support, but they also place a great value on continuity of care and having a rapport and relationship with the care staff themselves. Relationships and continuity have been noted as of particular importance for people with dementia.26 27 28 29

Service users want as little bureaucracy as possible in the personal budgets process, particularly when they are undertaking a self-assessment, and stress the need for supported self-assessment (to supplement the required statutory one) due to concerns about understating needs leading to both the cared-for and carer losing out.30
Older people are the service user group least likely to know about personal budgets and most likely to need support to plan the support package. Being supported to have a basic understanding of the options available, and what they will entail, through clear information and guidance is critical to the success of any care arrangements made both for personal budget holders and carers. Face-to-face information and advice is particularly important for council funded service users and those on personal budgets or direct payments.

Service users also like to feel they can access support from a professional (either from the local authority or a third party organisation) to ask questions about setting up their care package, or with queries after it has been set up. They particularly value having a named individual they can call on who they know is aware of their circumstances and can give tailored advice. It is important that this professional has the time to provide proper ongoing, but occasional, support to the service user.

Similarly, support planning and brokerage is seen to have a key role for older people when they set up a care package. The evidence as to who it is best provided by is conflicting. SCIE’s research found that service users made no distinction about who provides it – although getting support planning from an organisation that the service user chose as a provider of services was seen to be helpful. The Cabinet Office found that direct payments recipients preferred to receive support planning and brokerage from trusted, independent, organisations rather than from the statutory bodies that are inevitably involved in rationing decisions.

Creative support arrangements are welcomed by older people. SCIE’s research identified some examples of this. Several personal budget holders had a short break with their family rather than using residential respite. A woman whose husband has Alzheimer’s is now able to spend enjoyable quality time with her daughter and son-in-law while her husband is at a day centre, as she pays for someone to do the household tasks they used to do for her. Her social worker had also suggested installing broadband and buying a laptop which has been ‘a huge, life-enhancing change for her’, providing her with ‘a window to the world’. One carer purchased Sky Sport as her husband, who had dementia, had always been a keen sports fan. She was able to get on with housework or have some time to herself while he was watching television.
Support from a broker can help ensure a care and support package is tailored to individual needs

Mrs W is 75, lives in an urban area and has vascular dementia. She was referred to Age UK Cheshire’s Independent Care Brokerage Service following an assessment by an Older People’s Team social worker. Her care needs had been increasing, which put strain on her daughter and two sons who supported her by providing meals, and domestic and social support. Mrs W was adamant that she would only accept care from her family and had no interest in any outside support services, for either domiciliary or day care services.

A personal budget of £99.67 a week, received as a direct payment, was set up. Mrs W employed her daughter to provide the required support and the account was managed on her behalf by one of her sons and her daughter. The broker worked with the family to set up a payroll service and provided advice regarding employment issues, insurance, etc.

Eighteen months after initial contact, the direct payments package remains the same, and support to family members is provided when required. All involved agree that the arrangement has worked well for Mrs W and her family. As in many cases where family members are employed, much more care and support is provided than is allowed for in the financial package. There is a lot of satisfaction with the way in which direct payments have created a more formal arrangement, recognising the support that the family provides. Mrs W has trusted, committed support from people she chose to provide her care and remains living as independently as possible.

Mrs W was also referred to Age UK Cheshire’s Supporting You service for an Attendance Allowance claim and information on other services provided within Age UK Cheshire and by outside bodies.
People of all ages say that they would have valued, or did value, the input of their peers when they were deciding whether to take up a personal budget and what they wanted to use it for.\(^{38}\)\(^{39}\)

When comparing what older council funded service users do currently with what they said they would do if they had a personal budget, the Demos study\(^{40}\) found that older service users express a strong preference for traditional services like day centres, which can provide both personal care and weekday opportunities for socialising, and home helps. Practical help at home is important to older people, including for occasional activities such as mattress turning, bottom cupboard cleaning and window cleaning.\(^{41}\) The Essex longitudinal study\(^{42}\) found that older people are more likely to spend most of their personal budgets on traditional social care services – including help with personal care and meals, visits to day centres a few times a week as well as respite services to give family members a break or the opportunity go on holiday. These findings correspond with more recent studies which found that most older people used their direct payments for domiciliary care, day opportunities, equipment or cleaning,\(^{43}\) and that older personal budget holders often used their budget to pay for regular personal care, cleaning, gardening, or help with getting out and about and, where the level of budget allowed, residential respite, day services and warden call systems.

Having access to social activities is centrally important for older people. Socialising was the most common activity that older council-funded social care users said they would like to fund with a personal budget if they had one in the Demos study, closely followed by meeting new people and help going out. Older people are keen to be active members of the community.\(^{44}\) There is an appetite for accompanied trips whether these are attending health appointments or social groups, doing the shopping, or simply getting out of the house for a change of scene.\(^{45}\)\(^{46}\)\(^{47}\)

Transport is also of central importance.\(^{48}\)\(^{49}\) Problems in accessing free or cheap transport result in older people being unable to access the things they want to do, from visiting family or friends to joining in with community activities. This is particularly the case in rural areas where bus services are infrequent, people may no longer be able to drive, and taxis are the only option but are seen as an unaffordable luxury. Just over a quarter of older direct payment or personal budget holders surveyed by Demos were using their funding on leisure services and activities.

There are other types of need and preference expressed which relate to ethnicity. For example, the Demos study found that Black Caribbean older service users are more likely to express a preference for support with their financial affairs than all other groups. Other ethnic elders cited that their main preference was for support with physical health, holidays and weekday activities.\(^{50}\) It therefore remains imperative that local authorities are able to tailor the choice of services to the expressed preferences of particular groups of people. Where this support to make choices is provided well, there is the opportunity to improve outcomes for marginalised groups, like black and minority ethnic communities.
Older people also want **flexibility to be able to move between payment options**.\(^{52}\)

The Essex longitudinal study\(^{51}\) found that older personal budget holders are much **more likely to change providers** than service users with physical or sensory impairments, particularly if they are unhappy with the quality of care provided.

Demos’ *Personal Best* also shows that over half (55 per cent) of the local authority funded care users would change their care and support if they could. These were service users who were not using a personal budget to manage the care and support they received, implying that what they were getting from the local authority wasn’t entirely what they wanted. It is another reminder that personalisation, choice and control should be a key element in any care and support package, regardless of the mechanism for delivery.

Reliable data about **self-funders** is difficult to collect, not least because people in receipt of direct payments also organise and pay for their care and support themselves. Providers will not always be able to distinguish self-funded from direct payment funded purchasing. Additionally, people in receipt of state-funded services often top up their funded package, paying for additional support themselves.

Research findings\(^{54}\) confirm the importance of domestic support to maintaining independent living, showing that purchasers of home care pay for similar services regardless of the funding source: cleaning, personal care, shopping, support to get out and about and for carer respite sitting services. Self-funders frequently mention personal care, cleaning and shopping, gardening, transport and handyperson services.

Participants in a small-scale, qualitative study into what support self-funders buy\(^{55}\) said:

‘It’s even nice when my cleaner comes because I have somebody to chat to.’

‘... the things that makes me cross, not that I particularly want Social Services, but they talk about your personal care being important. They don’t sort of go into much with housework and all that, but no matter how well you keep yourself clean, if your house isn’t clean then you can’t be comfortable.’ (talking about cleaning the bath)

The less intensive forms of self-funded home care and support are difficult to monitor because of their tendency to be informally arranged.

Demos research found that carers, who are often older themselves, welcomed the flexibility offered by a personal budget or direct payment as it could relieve some of the stresses and demands of caring. Outcomes for carers were linked with service-user outcomes.\(^{56}\)
2.2 Future users of social care

One often hears middle-aged people say ‘that’s not what I would want at that age’ when talking about services older people use. Baby boomers are often considered to be individualistic, in contrast to earlier generations which put more emphasis on collective solidarity. They are also a vanguard generation having lived through, and been actively involved in, social transformations. They grew up in a consumer society, have been subject to advertising all their lives, expect their individual wants and needs to be satisfied, and have been encouraged to define themselves by the personal consumer choices they make.57

Despite the above and despite baby boomers being known for their reluctance to engage with the idea of growing older, research – which required them to imagine becoming old and frail – found that the preferences of baby boomers are remarkably similar to those of the current generation of older people.

In 2004, the King’s Fund undertook research with middle-aged people to find out what the next generation might expect from care services in the future.58 In the same year, Demos carried out research with baby boomers to explore their hopes, fears, perceptions and priorities.59 There was consensus that they would want to maximise and retain their independence and to stay in their own homes, supported by a range of services that are often currently not available within the care system, including practical help with housework, shopping and home maintenance.

Social interaction and activity would be very important, including access to learning and leisure opportunities, underpinned by the availability of appropriate transport. Choice and adaptability – having individual needs and preferences accommodated and catered for – were also rated highly, even more so amongst minority ethnic groups. A key theme was the interconnectedness of security, home care, health, personal care and social life. Having a clean, well-maintained home and good social networks would be essential to their sense of security and to their physical and mental health.

Demos (2004) found that those with experience of looking after parents or parents-in-law did not want to be a burden on unwilling children, and seemed willing to pay for whatever they decide they need.
What systems and practice methods are needed for personal budgets to work well for older people?

This chapter looks at some of the process and system issues that affect the delivery of personal budgets for older people, including managed personal budgets. It identifies some of the solutions that could support older people to have real choice and introduces the idea that having a personal budget is not the same as having control.
This chapter covers the systemic issues (i.e. those processes that a local authority or provider uses to arrange the budget process from assessment to use of services) and considers the elements of provision which local authorities should aspire to have in place in order to make successful operation of personal budgets more likely. It covers issues related to resources and managing the market, and recognises that changing practice will be disruptive. It covers the importance of information and advice, of support to make decisions and of keeping people informed during the whole process from assessment onwards, including options around changing the way that their support is provided and the options for managing the money.

It also looks in closer detail at the practical day to day issues that older people and other service users highlight as causing difficulties and, conversely, factors that really assist their use of personal budgets. These difficulties represent some of the main barriers to uptake of personal budgets and effectiveness of their use. Through understanding the experiences of older people and considering them alongside some of the findings from local providers, organisations will be better equipped to improve their services and increase the effectiveness of personal budgets for older people.

None of the issues or solutions identified will create success in isolation.

Some overarching issues continue to influence the way that personal budgets are implemented. It has often been said that older people ‘don’t understand’ or ‘don’t want’ to take up a personal budget. This mainly refers to using a direct payment as a means of delivery. Many older people are capable of managing and do choose to use direct payments, but shouldn’t be under any pressure to accept this delivery mechanism (or a traditionally commissioned service) as the only alternative. The same principle applies to personal budgets – if people do not know about them and are not supported to use them confidently, they will continue to be an administrative exercise only. Giving consideration to what could change within the managed personal budget system so that they support better outcomes for service users is of real importance.

There is very little research evidence which specifically relates to how managed personal budgets work for older people. Many of the larger pieces of research (e.g. the POET survey and IBSEN evaluation) have emphasised exploration of cash payments. Given the historic policy focus on uptake of direct payments (see Chapter 1), this is not surprising. However, it is possible to use the results of these pieces of work to inform how managed personal budgets should be operated as they may provide a reasonable indication of some of the difficulties or success factors which might affect the delivery of managed personal budgets. Understanding what older people want from managed budgets and how they can be made to work well will be helpful to local authorities, and should help older people who do not want to manage their own personal budget to receive high quality care and support that they have influenced themselves.

There is emerging research that looks specifically at the use of managed personal budgets, so evidence will soon be more widely available.
Many service users responding to the National Personal Budget Survey\textsuperscript{63} were negative about most aspects of the process they encountered to get their personal budget: assessment, review, timeliness, paperwork, employment, restrictions and clarity, with clarity – often regarding how money could or couldn’t be used – faring the worst. Brokerage received the most positive and least negative feedback.

Think Local Act Personal’s recent review of personal budgets for older people\textsuperscript{64} draws on a reanalysis of the National Personal Budgets Survey and identifies a number of issues relating to how older service users experience the system and how it supports them to meet their outcomes. It also identifies some of the system and process issues that can cause difficulties for local authorities and prevent adequate implementation:

\begin{itemize}
  \item Capacity and funding pressures relating to local authority financial positions;
  \item Workforce issues which mean that uptake of personal budgets is not supported fully by staff;
  \item Inadequate information, advice and guidance;
  \item Lack of market development.
\end{itemize}

Many of these issues are addressed in more detail below.

Organisational barriers to person-centred support operate at all levels. These include increased bureaucratisation, tightening administrative controls, inflexible organisations, crude target setting and a negative emphasis on risk, often framed in terms of health and safety requirements.\textsuperscript{65}
3.1 Supporting social care users to make choices and to have real choice

All service users should be able to choose who supports them and how, and should be supported to exercise this choice. It is widely recognised that having choice benefits people’s wellbeing and improves outcomes. People who choose a service or package of support are more likely to get something that meets their requirements than if they are restricted to standardised provision. However, choice only benefits a service user if the options available are all realistic ones, and if they know about them and are supported to make an informed decision. Much of the evidence highlights the benefits of supporting people to access information, advice, brokerage and advocacy in order to properly exercise their ability to choose.

Research shows clearly that most providers and local authorities are supportive of service users having more choice over the way that they receive their care, at least in principle. However, in practice, many local authorities unnecessarily restrict the use of personal budgets. And those funding their own care often face a restricted choice of services, receive little or no support from their local authority to navigate the options available and are often unclear how their own funds can best be spent. Access to cash alone does not increase choice.

The measures from the 2011-12 Adult Social Care Outcomes Framework revealed that 26 per cent of older service users did not feel sufficiently in control of their daily life. Local authorities need to explore how they can better support older service users to exercise real choice and control over their care and support.

There has been increasing emphasis on the value of proper signposting and advice for everyone who has care and support needs in a local area, irrespective of the means of funding. As a result of the Caring for Our Future White Paper, local authorities will be expected to ensure that information and advice about local services are available to everyone, linked to a national directory of care providers and a care provider quality profile.

However, for older people, the choices that appear to be most important are not so much about choice of service provider but about how services are delivered. In The Case for Tomorrow, ADASS said, ‘For many older people the choices they want are not so much about who provides, but what is available, when and whether they feel they have a rapport and relationship with that particular care worker.’ Chapter 2 covers in more detail the choices older people are making about use of personal budgets.
Information and advice must be effectively delivered

All surveys of service users highlight the importance of information and advice when accessing care and support services. This applies across the range of needs (from low to critical) as well as across funding mechanisms (from self funder to fully funded by the council).

Much of the research shows that older people struggle with the process of setting up, managing and reviewing a budget, and people would generally like information earlier in their social care journey so they can consider whether a personal budget is suitable for their needs. This is a common experience across all service user groups but is particularly notable among older people who may have less informal support from family and friends.

For example, some self funders are unlawfully screened out of assessment services by local authorities because it is known that their level of need would not make them eligible for services or that their income or assets would be too high for them to qualify for local authority funded provision. The role of ‘signposting’ – providing information about other potential sources of help but usually without any follow up – has been highlighted as positive but limited: it is useful for giving people more of an indication about their subsequent options, but is not specific or detailed enough.

It can be counter-productive not to support self funders with adequate information and advice. Making poor care choices might mean someone’s needs escalate more quickly than they would otherwise or that their personal funding runs out – both meaning they could become the responsibility of the local authority.

Self funders report that the information they acquire in advance of setting up support is gathered from informal, and not necessarily well-informed, sources: family, friends and peers. Or they might bypass information gathering altogether and simply contact a home care agency directly without researching alternatives.

Policy and guidance have reinforced the need for local authorities to provide universal information and advice services – most recently in the Care and Support White Paper – and the Government has committed to the introduction of a national and universal source of information about the health, care and support system. Local authorities will also have increased duties to offer information and advice about local care services to all who ask for it, including self funders. Reviewing information and advice provision will help local authorities to be certain that no-one in their area is excluded from access.

The following case study highlights the impact that not being given appropriate information and advice can have on a frail older person.
The importance of information and advice at the right time

Jean, 89, is a widow, a double amputee and uses a wheelchair. She is already a client of the local Age UK having been originally referred to the befriending scheme.

Jean recently had a long stay in hospital after falling out of her wheelchair and fracturing her leg. She was discharged with a care package involving four daily visits from a care agency. The package cost £512 per week, which concerned Jean, and she requested Age UK’s project worker to visit her at home to discuss this.

Jean had been advised by a social worker in the community based rapid response team that she would be required to have a financial assessment if a referral was made to Adult Social Care, which is not the case. Clients declining a financial assessment are expected to pay the full cost of their care, but only up to the weekly limit. The social worker had not given her any information about personal budgets. Because she felt the package was too expensive, Jean had cancelled some of the visits to reduce the cost.

During the discussion about what support Jean would like to help her maintain her independence, the project worker gave her information about personal budgets. The worker contacted Adult Social Care’s financial department and was advised that the maximum cost of care an individual would be expected to pay per week was £297, and that a direct payment could be set up if a client’s care costs exceed this.

Jean was grateful for this information but, subsequently, as a result of cancelling some of her care visits, fell out of her wheelchair trying to transfer into a chair and was admitted to hospital again. After discharge, she chose long term respite care to help with her recovery.

What Jean had needed at the beginning was accurate information about the processes, costs, service and support options, for any risks to be highlighted and to be talked through how to manage these so that she could make an informed decision about what to do. A client also benefits from having the support of a worker, or volunteer, until their support plan is in place and they are happy with it. Being more involved with planning her care package and costs early on would probably have resulted in a more suitable care package that Jean had control over. She would not have felt the need to downsize her package and may avoided the second fall.

A volunteer from the project now supports Jean to continue being active in her community by escorting her on outings.
Information and advice best supports service users to make decisions **when focused on particular topics or issues** and when is provided in a **face-to-face environment**. Older people want information available from various sources and highlight that NHS organisations should provide information about personal budgets and social care, for example, before hospital discharge. Self-funders particularly value being able to access emergency advice and information. Service users in SCIE’s study highlighted that advice and information from the provider organisations was useful, as it helped build up trusting relationships and was considered useful alongside that from local authorities.

In a study of personal budgets users in Essex, it was highlighted that advice from the local authority staff at the start of the process was essential. This worked particularly well when the service user had a single named contact that they could direct all of their queries or concerns to. Interestingly, this included receipt of advice on benefits and other non-social care issues but which people considered to be relevant to their overall wellbeing and good use of the personal budget.
Mr and Mrs H are 85 and 79. They were referred to Age UK Bromley and Greenwich by a home repair tradesperson who had visited to repair their roof, and expressed concern about them. A support planner spoke to Mr H who said they were able to take care of themselves, but confessed to feeling very down at times, particularly since they lost their beloved dog. He also said that his wife had been losing weight and didn’t have much appetite. He said they still went out driving occasionally. He was very reluctant for anyone to visit, but agreed that the support planner could ring again.

The support planner rang a few days later to see how they were, and Mr H agreed that she could visit for a cup of tea. The support planner visited Mr and Mrs H several times over the following weeks and found that the couple were struggling to look after their home and Mrs H was quite thin and had a very poor appetite.

After a rapport had been established between them, Mr and Mrs H agreed that they would like some external assistance and, together, they agreed on the following support plan:

- Referral for Mrs H to a health visitor for advice on diet and nutrition
- A trained Community Volunteers Time Bank member to carry out a home and fire safety check and fit a free smoke alarm
- Contacting a pet bereavement service
- Submitting an Attendance Allowance claim for them both
- Encouraging Mr and Mrs H to take up dancing which they had given up
- Brokering a regular gardening service for the couple through Age UK Bromley and Greenwich’s First Check Point Repair service.

Outcomes:

At each visit, the support planner offers information, support and guidance. Most importantly, she has been able to develop a relationship of trust with the couple, and they have become more open to the idea of receiving more practical help in the future to support them to remain independent. Being able to talk to someone who understood the impact of the loss of their dog helped both of them to feel more positive. Mrs H’s eating has improved and she has started to gain weight which is regularly monitored. The couple now receives Attendance Allowance. They are also dancing once a week again and say that it gives them a lot of pleasure. The support planner continues to visit at regular intervals, and has also made a referral to an NHS Community Matron based at a local GP practice.
Work with people currently using personal budgets also highlights that information and advice provision must continue beyond setting up a care package. A Demos study found that over half of council-funded care users would change their care package if they could. This indicates that, had the information been available to support these people to change their support package, they would probably have done so. The message for local authorities here is that it shouldn’t be assumed that service users will or will not want to alter their support, but that during reviews, or when needs change or stabilise, existing arrangements should be reviewed and people should have access to information and advice about their alternatives. This includes switching between methods of payment for a personal budget, supporting people to move from a council-managed budget to a direct payment or Individual Service Fund, or vice versa, or local authority managed budgets.

### Offering a wider choice of personal budget options

Choice of delivery mechanism for a personal budget does not appear to be widely offered to older social care users. A significant proportion of older people involved in the POET research did not even know whether they had a personal budget which suggests they had not been involved in their support planning process. This may be due to initial levels of need being very high or unstable or because professionals are concerned that an older person may not be able to manage a cash payment or personal budget. As needs change over time or stabilise different management options may become more suitable.

Groundswell has noted that there are commonly only two options offered by local authorities: council managed budgets or direct payments. Most older people on a personal budget still have service commissioned on their behalf by their local authority, but the extent to which this offers any extension of their choice and control, or supports them to create more imaginative care packages, is not clear. What is known is that the method of delivery of a personal budget appears to have an effect on the outcomes achieved by service users, and service users emphasise how important information about the different deployment options is.

A range of options for deployment would allow people more flexibility to manage in a way that suits their particular circumstances, and this could usefully be a wider range than only a direct payment or managed personal budget. Conducting regular reviews of care needs and budget deployment arrangements may also be valuable. It is good practice for regular local authority reviews of social care users to cover the alternative payment arrangements available, including the option of taking part of their budget as a direct payment and part in another form.
Alternative models of managing budgets are becoming more widely available, for example, Individual Service Funds (ISFs). ISFs are one way that service users can exert greater control over the way their care and support is provided, without the burden of managing cash flows and accounting for spend. However, ISFs do not have a long history of being used with older service users although they are being developed by some providers and local authorities. Recent work has highlighted encouraging take up and developing an offer relies on many of the same features of a well-run personal budget system within a local authority. Pricing of support, description of services available as well as good market management are key features of a system which would encourage take up of ISFs. Groundswell also highlights that support can be rolled over from one month to the next, helping people save funds for contingency or emergency support or to better meet changing levels of need. There is more information about ISFs in section 4.2.

Some local authorities are developing more light touch systems for managing small pots of cash given to service users. In Barking and Dagenham service users complete a short self-assessment form for housing adaptations and if eligible are able to spend their allocation in the way they feel will meet their needs. The council argues that this supports people to use small amounts of preventative spending in a way which is not over burdensome to the council or service user.

There is a need for more research that compares the benefits of alternative options for deploying a personal budget, particularly in newly developing areas like Individual Service Funds (ISFs).

Councils should consider developing alternative models for management of personal budgets so that it is standard practice to make Individual Service Funds, for example, available.

Support to make decisions

In implementing self-directed support and personalisation, ADASS amongst others have highlighted the importance of support planning and brokerage to assist social care users to navigate the system and negotiate their way through making arrangements. This support is in addition to information and advice, being a more proactive approach that specifically explores opportunities for peer support or examples of what has worked well for other people. It might be provided by a local authority but could also be a third sector organisation or user-led organisation to which people are referred. Putting People First’s Personalisation Toolkit acknowledges that ‘effective support planning and brokerage are crucial in enabling disabled people to exercise more choice and control in their lives. Support planning and brokerage, including easy access to information, advice and advocacy, should offer disabled and older people the opportunity to make decisions for themselves that might otherwise be made for them by other people’. People should be able to obtain whatever assistance they require, and support – whether termed advocacy, brokerage or support planning – should be flexible enough to respond to individual needs.
The availability of advocacy is regarded as being essential for securing personal budgets, particularly for people with dementia who often need a representative to help convey their needs and preferences, but a number of local authorities report that advocacy across all care groups – including people with dementia – is still in development and is not yet achieving full potential.88

Personal budget holders highlight the value they put on being able to talk to other people who have been through the same process of setting up a package of care and support. This is especially useful in the early stages of having a personal budget, before care is set up and whilst people are making decisions about their options. In some of the sites used for the Social Care Institute for Excellence study of older people and personal budgets, provider organisations facilitated groups so that existing users could meet new or prospective users. New service users also highlighted the value of more informal peer support through information sessions and drop-ins, existing networks and community events.89

However, some experience within local Age UKs has shown that this peer support can be difficult to arrange, particularly where the care and support needs of the prospective or existing service user are quite high and where attending meetings, etc, might be more challenging as a result. Another problem highlighted by local Age UKs is the delay involved in a council assessing need, waiting for a panel decision on the budget to be allocated before the budget can be awarded. This can be difficult for both the new service user and the existing service user because needs may have changed or deteriorated in this time, making it less easy to give or receive support.

Age UK Hereford and Localities’ Rural Choice project aims to help older people onto personal budgets using volunteers. There is increasing awareness of the difficulties involved in supporting older people with high and complex needs who are eligible for council-funded social care. The summary below demonstrates the limitations of peer or voluntary support and the need for professional expertise in the process.
Experiences of a project that helps older people onto personal budgets

People visited seem receptive to the project and keen to know about how the social care system works in general. Many struggle to grasp details of personal budgets and frequently ‘switch off’ when explanation gets to the direct payment/directly commissioned care stage.

There is plenty of opportunity to refer people for low level help. Visits are also a good opportunity to encourage people to think about what help they feel they need (or what might be possible) in preparation for assessment and a personal budget if they are eligible.

The project is helpful to family carers who are encouraged to be present at visits, as this helps them feel supported and listened to and they may hear information about help they might receive. It is helpful in informing self-funding individuals who would not be eligible for a personal budget but may find themselves struggling to organise care at home.

However, project staff remain cautious about accepting referrals for urgent or complex cases which the volunteer team is neither resourced nor trained to manage, especially as the project involves the volunteers usually visiting before social workers.

Most cases have been in a non-urgent, non-complex, category and have progressed without issue, but some referrals would have tested the social care knowledge, skills and confidence of individual volunteers had they visited alone.

Volunteer, Age UK Hereford & Localities Rural Choice Project

Section 4.3 goes into more detail about the practicalities involved in providing peer support for older people on personal budgets.
3.2 Keeping service users informed about essential aspects of their personal budget

Many older service users express frustration with the bureaucracy associated with using their personal budget. This relates to almost every element of the process. Studies have shown that this is largely down to the way that local authorities organise their internal procedures.

Resource allocation

The Resource Allocation System (RAS) used by councils to allocate an indicative budget to an individual has been found wanting in many aspects. This report will not be looking at this in detail, but it is known that many people find that their indicative budget is not set accurately, that their budget is inadequate and does not allow them to purchase sufficient support to meet their assessed needs. This may be less problematic if this budget is only used as intended – for planning purposes – but is a more serious issue if the local authority is, in reality, using the RAS to determine the amount the person actually gets. Where individuals can challenge the amount allocated by the RAS budget reviews can be arbitrary; and in many places there is no allowance for emergencies or contingency planning.90

Service users also highlight that a single budget that they can spend without needing to subdivide according to their areas of need is preferable.91

Recent analysis of RAS data from a small number of local authorities shows problems with the mechanism for setting an indicative budget for care and subsequently agreeing a final actual budget. The variation between the two figures was often significant, with the final amount tending to be lower. This results in service users having a poor understanding of the amount of support they will be able to afford using their budget, making effective planning very difficult. These discrepancies could, in turn, result in increased numbers of challenges by service users to the indicative budget which will further increase delays. Local authorities need to develop RASs that they have confidence will accurately generate a reasonably accurate indicative budget for an individual service user.

There is a need for advocacy and support where a person’s indicative budget turns out to be insufficient to properly meet their needs and decisions or assessment processes need to be challenged.

A further conclusion was that the implementation of personal budgets and establishing indicative budgets via the resource allocation system had made the assessment process more time-consuming and repetitive. As more time was being spent on each assessment and the number of assessments had remained constant, staff were unable to carry out as many reviews or deliver as many professional support packages.
Arranging support and authorising care and support plans

Many studies show that people are delayed or frustrated in their efforts to set up their care and support package, because their local authority is unclear about what they may spend their budget on and because of the authorisation process used.

Whilst restrictions on spend are frustrating for service users and should be avoided, some of the difficulties can be solved by local authorities being clear about what these are at the start of the process. It is good practice for local authorities to have a clear policy setting out what purchases will be allowed and this should be made available to service users, support organisations like brokers and advocates, as well as providers.92

Many older service users also report long delays in agreeing what they can spend their budget on, which can be as a result of the protracted authorisation process within local authorities.93 94 For some people, the assessment and support planning process can take over a year95 which bears no relation to the typical semi-urgent/high risk service provision needs of older people. Part of the problem is that managers in local authorities rarely delegate authority to social workers to sign off care packages.96 This authorisation process is frustrating for staff who accept that large or complex support plans need senior approval, but who report feeling that their professional discretion was routinely undermined.97 Delays can act as an additional barrier to take up of a personal budget where people need services or support immediately, or may experience significant deterioration while waiting for support to be put in place. It also puts additional pressure on family and informal carers, where present, who may be forced to meet the unmet need themselves.

To ensure that the process is as efficient as possible, local authorities could monitor the time between assessment and final setting up of care packages.

Ongoing monitoring

Service users have identified where local authorities might be able to cut down on unnecessary paperwork and bureaucracy that can accompany a personal budget. This includes not requiring receipts for small amounts of expenditure and allowing service users to keep records which may not account for every penny. Service users reported that spending money on small items, such as bus tickets, sometimes doesn’t generate a receipt and such expenditure is harder to keep track of, making their own administrative burden much more cumbersome to manage.98
3.3 Resourcing choice for service users

Local authorities are facing unprecedented challenges in the demand on their available budget for social care services. This has led to restricted numbers of people who can access state support, reduced packages of care or increased charges for state provision of care. Professionals involved in allocating resources to individual older people have reported that assessment processes and Resource Allocation Systems (RASs) disadvantage older people by funding less comprehensive packages of care than for younger people, limited to meeting basic personal care needs while ignoring needs for social contact and rewarding activity. There is a great deal of anecdotal evidence that older people’s budgets have been reduced yet further as a result of more widespread pressure on the local care and support systems. Funding cuts also place additional pressure on the workforce which then makes it difficult to allow adequate time for assessments and planning with clients, limited time for reviews and supporting people to make creative use of their personal budget or look at non-traditional options; and staff attention focussed on managing resources rather than supporting service users. A survey of social workers in December 2012 confirmed this: 70 per cent of respondents reported that funding pressures were compromising the quality and quantity of care available to their older clients.

Many of the surveys show that, for older people, this generally means their budget only covers their personal care needs, restricting the ability to buy support for their leisure, personal development or social contact needs.

There is evidence that shows people using direct payments (as opposed to a personal budget or any other means of delivery) are generally allocated substantially more funding. And there is evidence that those who are allocated a larger personal budget are more likely to achieve better outcomes.

To counter the effect of these factors, to comply with statutory duties and to support older people to have full choice over their care and support package (not just their care services), local authorities must ensure that the level of budget is sufficient to meet someone’s assessed needs, and that the service user is not being forced to make a choice between assessed needs. The resource allocation system should clearly demonstrate how someone would be able to purchase the necessary care and support using the budget made available by the local authority (including the contribution made by the individual, if applicable). If the indicative budget generated by the RAS is insufficient to meet assessed needs, it must be increased.
3.4 Restricting choice for service users

Access to a budget (whether nominal or cash) does not equate to having control over care and support. There is increasing evidence that service user choice in how they meet their needs and manage their personal budget is being restricted by local authorities. Evidence shows that some local authorities have become over-prescriptive about how individuals decide to spend their personal budget or direct payment. The recent Cabinet Office review of choice in social care highlighted that some local authorities constrain service user choice through approved provider lists and very close monitoring of spend to ensure users buy only approved support. This concern was raised in 2008 following the evaluation of the Individual Budget pilots – where councils operated preferred provider lists to reduce transaction costs, while acknowledging that this had the effect of standardising services and reducing or eliminating real choice.

The review also highlighted that those people who remain users of council-commissioned services (with or without a personal budget allocation) are either not offered any choice of provider or are offered only a limited choice from those providers the council has block contract arrangements with. It concluded that choice is also restricted by complexity of local authority systems, lack of signposting and support to make decisions (not just information and advice), too great an emphasis on needs rather than individual’s capabilities, and restrictions in the market which mean the full range of support is not available. For example, some older service users were not allowed to buy pets to help with walking or companionship and money was clawed back because older people had used it for classes rather than day care. Unnecessary constraints to service user spend of allocated personal budgets can be eliminated if local authorities review restrictions applied and focus on achievement of outcomes rather than narrow service-based solutions.

This restricted choice can be seen reflected in the experiences of self funders but is also reported in studies with social care users. A group of older people with high support needs reflected that, although some were self-funding in reality, it was their care home manager or family who were in charge of major decisions and personal finances. The participants felt that because of this they were not regarded as consumers with rights, entitlements and purchasing power. This serves as a reminder that more is needed alongside allocation of a budget to support someone to experience full choice and control.
3.5 Care management and case reviews

Effective operation of care management and case reviews is crucial if older people are to be well-supported.

Introduced by the NHS and Community Care Act 1990, care management was intended to support social workers to put service users’ needs at the forefront and to enable them to source a range of services from different providers to meet users’ needs. It was characterised as a ‘needs-led’, rather than ‘service-led’, approach and is a cyclical process which has many potential benefits:

- Tailored packages of care and support that are more effective in addressing the needs of individuals
- An individual’s desired outcomes are identified and responded to
- Care and support planning is more effective as a result of integrating assessment with the purchasing/commissioning of services
- A wider range of (integrated) services is available
- Greater continuity of care.

In practice, care management has tended to have more of an administrative and bureaucratic focus than was originally envisaged. A combination of factors has stood in the way of its development and implementation, including: service-driven decisions, an under-developed market, a pressured and under-resourced environment and over-emphasis on assessment. Recent research\(^{112}\) has found that council social care staff productivity has reduced between 2007–08 and 2010–11. Numbers of assessments were stable, but numbers of service users receiving professional support each year from council social workers and other practitioners fell by 27 per cent; and numbers of annual reviews decreased by 14 per cent. These reductions occurred in spite of the fact that the numbers of adult social care staff carrying out these roles had risen by 8.6 per cent.

Many older people eligible for local authority provision of support have high levels of need as 85 per cent of local authorities set their eligibility criteria at substantial or critical. **Regular and frequent monitoring and review is essential if support is to continue to be tailored to changing needs** whether sudden (e.g. as a result of a fall) or fluctuating (e.g. due to a health condition which is not constant). This is something research highlights is not consistently available for personal budget holders. **It should also be possible for a change in needs or other circumstances to trigger an urgent review.**
The example below is an example of good practice in supporting someone to change their support after an initial period.

Self-funder using Age UK Cheshire’s Independent Care Brokerage Service to access services

Ms A, 92, was referred by the Rapid Response team, having been in hospital and then respite care for about three months before returning home with support. Rapid Response’s six-week period of care was coming to an end and Ms A wished to continue care on a private, self-funded basis.

Through the Independent Care Brokerage Service, Ms A was able to tailor a care and support package that she felt met her care needs and assisted her to retain her level of independence. Initially, Ms A wanted her care package to remain the same as she could not cope with too many changes. It was arranged for a care agency to take over four domiciliary care calls a day at the same times, and for hot meals to be delivered every day.

Ms A was much more settled by the six-week review and wanted to regain some independence. Her lunch and tea calls were cancelled. The Meals on Wheels were reduced to three days, with frozen meals provided on the other days to increase the choice and variety of meals. This gives Ms A more independence to get her meals herself when she is ready for them, but without having to stand and prepare a full meal.

Ms A mentioned that, every Saturday, she sees her neighbours come back from the fish and chip shop and expressed how long it had been since she had eaten fish and chips. The support broker spoke to the neighbour who agreed that they would get some fish and chips for Ms A on Saturdays.

It was also agreed that a care agency worker would escort Ms A once a week to the local garden centre or other place of interest as Ms A is unable to go out without someone taking her in the wheelchair. Ms A has no family who are able to do this for her.
Flexibility in planning is critical given that needs increase over time and many initial assessments of older people take place following a crisis when their long-term needs are uncertain. Setting up a care and support plan expected to last 12 months may not be appropriate in the first few weeks. It is almost inevitable that needs will change rapidly, and certainly during the first few weeks of an initial period of recovery, for example. It is good practice to carry out a case review to check that the support plan is meeting all eligible needs soon after a service commences, that there are no safeguarding or risk issues and that the funding is adequate. Any necessary adjustments can then be made.

Following this, regular reviews will take into account changing needs and the possible consequences of these for support planning and funding. People value the opportunity to revisit their choices not only after changes in circumstances, but also when they find previous choices to be unsatisfactory.113

Some local authorities are using the period of six weeks of reablement support to stabilise levels of need; and then setting up a support plan intended to last only 2–3 months before being reviewed.

Service users report that they would value the opportunity to have a temporary or short term support plan alongside access to a fast track brokerage system which did not require the detailed level of authorisation or sign off required for more permanent plans.114 Local authorities may like to consider whether provision of this type of short-term planning can be made available to service users.

A significant minority of older people may become vulnerable to financial abuse and exploitation, but there is no current evidence that holders of direct payments are experiencing greater abuse.115 Empowering people can reduce their vulnerability to abuse, but continued support and monitoring also has a role to play in helping to prevent this.

Department of Health guidance emphasises that councils should be flexible and consult people about what works for them in terms of the way a review is carried out and who should be involved.116

Effective reviews will be person-centred, looking at a person’s life and supports, what is and what is not working and what’s important to the person at the time and in the future. The views of family, friends and any staff who are supporting the person can be valuable in identifying what is and is not working well. It should result in outcomes for change being agreed.
The importance of reviewing support should not be underestimated as the case study below demonstrates.

The need for a case review

Mrs C, 76, was referred to a local Age UK Personalisation Project service by the organisation’s Carer Support service. She had been granted ‘personalisation’ but did not understand what her entitlements were and was visited by the project coordinator and a volunteer.

Mr C has Alzheimer’s and colon cancer, and Mrs C is his carer. Mrs C was worried that her husband’s cancer had worsened, had just been visited by the district nurse and the GP was due to visit later that day. She looked very tired and was upset. Her husband had been in respite at a local care home for the weekend, but had been very distressed at being separated from her.

Looking at her support plan, it became clear that, although it covered Mr C’s care, it did not take into account how Mrs C was to accomplish this care on a 24/7 basis. As she did not drive and felt that she could not afford to use taxis, she needed to walk more than 3 miles to the nearest shop to buy groceries. She found this very difficult, and was paying privately for a carer to look after Mr C while she did the shopping. She wanted to care for her husband, but it was becoming a big strain for her which needed to be reflected in her support plan to give her peace of mind that she would not be away from him for too long. When asked what would make her feel better, she felt that a weekend break with someone looking after her husband would be ideal.

The service contacted social services to recommend that someone visit to speak to her as the situation had changed dramatically since the support plan was put in place five months beforehand using a local authority managed personal budget, and Mrs C now needed more help. She had not used any of the money granted to her husband until he’d gone into respite the previous weekend. Mrs C needed the money to be given to her directly so that she could control spending and feel secure in the knowledge that it was available to improve the situation.

Mrs C felt a lot happier knowing that something was being done and was able to smile. Simply knowing that there was someone to speak to who had some knowledge of personal budgets and could sympathise with her situation helped her as, sometimes, technical terms are involved in the application process. The volunteer also felt she benefited from helping someone through the process.
Information gathered from reviews can contribute towards broader future strategic commissioning and service changes. Guidance has been produced by the Department of Health on how to use the ‘Working Together for Change’ approach to ensure that active partnerships with local people and families are the driving force behind social care transformation programmes; to create effective community engagement in the joint strategic needs assessment (JSNA); and as a tool for strategic commissioning and service development.\(^{117}\)

**Changing the way support is provided**

Evidence from research studies suggests that some service users find it difficult to change or amend a care package once it has been set up.\(^{118}\) This applies both to those using a personal budget who, having reached final authorisation of a care package after a long delay, might not want to repeat the process for a change of support, but also affects those using traditionally commissioned services.

Practice in local authorities to review care plans and packages of support is inconsistent. Some undertake reasonably frequent reviews, especially towards the beginning of someone needing social care services, so that alterations can be made to make sure the support meets the individual’s changing needs. But other local authorities undertake only annual reviews, after which time someone’s needs could be very different and possibly result in a major upheaval of the care and support.

Service users find the sudden withdrawal of services very distressing – something that can be avoided by having regular reviews of the care package alongside incremental changes in provision. This issue has been highlighted in the recent Care Quality Commission report into home care services, which found that some services fell short of good practice and failed to adequately assess needs and undertake regular review and updates of care packages.\(^{119}\) Where a review takes place after a lengthy period, like a year, changes in services to meet new levels of need can feel sudden and be distressing to service users. More regular reviews will mean that changes to support are less disruptive.\(^{120}\)

Choice and control also means being able to change support once needs have stabilised.

**Service users report a desire to be able to move between delivery mechanisms for their care and support**, and a study of older users in Essex showed that older people were more likely than other service user groups to have changed services as a result of being unhappy with support.\(^{121}\) In addition, Putting People First reminds local authorities that they should ensure that service users are able to move between methods of delivery by ensuring information and support is available. There is no reason why local authorities shouldn’t be able to offer service users this flexibility. However, it does require a workforce that has the capacity to undertake reviews and administration of the changes and would rely particularly on having systems and processes in place which are responsive and involve the minimum of paperwork.

In some cases, it may be possible that service users accept a particular delivery option because they were not aware of the alternatives. Older people sometimes report being steered away from choosing a direct payment or personal budget because commissioned services are thought to be more suitable. If a support package is set up in the optimum way at the start, it might reduce the need to move between delivery mechanisms.
3.6 Commissioning practices and market management

Current commissioning practice in local authorities may be a barrier to the choice available to service users on managed personal budgets.

Consultation with people approaching the care system invariably shows that they want to remain as independent as possible, for as long as possible: they do not want to be reliant on care when they do not need to be.

However, providers currently have an incentive to maximise the number of hours with a service user. This may be counter-productive for an individual because they become more reliant on care and it is also financially inefficient. Some councils are seeking to address this by ensuring that there are multiple assessments and short review periods so that care provision can be tailored to needs as they change during a short period of time.\(^\text{122}\)

Many councils are introducing a period of reablement (up to six weeks) as the default response to new referrals, to explore the extent to which needs can be minimised and stabilised. Some councils are exploring the potential of outcome-based commission to eliminate perverse incentives to maximise care.

Emerging evidence from a current study underway looking specifically at council-managed personal budgets for older people\(^\text{123}\) is also highlighting that commissioning practice is an important factor in the extent to which local authorities can offer service users choice and control. Where local authorities are making good progress supporting people on managed personal budgets (the study looks closely at three) they have changed contractual arrangements with providers, moving away from block contracting to Framework Agreements which offer some expectation of business although without a guaranteed minimum. However, the researchers have found that where the local authorities offer choice to a service user, this is often limited to them expressing a preference. So a service user might prefer a male or female care worker, or opt for a time of day, but there is no guarantee that preferences will be met. And, where services do not meet assessed needs or preferences, negotiating a change is a lengthy process.

It appears that there is recognition within local authorities that commissioning practice needs to change, but that good practice is patchy and that some local authorities have yet to make progress towards commissioning for outcomes (36 per cent of local authorities in a recent survey used outcomes-based commissioning but only on a limited basis).\(^\text{124}\)

The responsibility to change how services are delivered lies with both local authorities and providers. Negotiations about what support is provided and how it can be tailored to individuals should become more common so that standardised provision of services is no longer the norm.
Managing a successful market

The power of the consumer in shaping supply of support should not be overestimated. It is crucial that local authorities continue to take an active role in market management.

Single individual purchasers (e.g. self funders and people using direct payments) do not generally have the collective power to demand a particular type of service or support. There is a continued need, therefore, for more active market management by local authorities to ensure sufficient quality, quantity and diversity of provision is available, as well as a responsive provider sector ready to alter its offer to consumers. This point is reinforced by the RSA which says, ‘... introducing personal budgets influences demand, but does not by itself shape supply’.

The limitations of consumer influence have been demonstrated in a number of research and evaluation studies. In work conducted by Demos exploring how people use personal budgets it was clear that providers need to change their offer of services and support in order to meet changing customer demands. In addition, the professionals interviewed in a SCIE study reported that they had not seen a change in the provider profile or care market since the introduction of personal budgets, again reinforcing that consumer influence alone did not change the provider offer.

Local authorities will, therefore, need to have continued awareness of their own market shaping powers when purchasing or commissioning services and support (and this will be equally true of Clinical Commissioning Groups, hospital trusts commissioning community and reablement services and Health and Wellbeing Boards where they directly commission).

Local authorities are well placed to help develop more innovative approaches like encouraging personal budget holders to pool budgets and promoting the development of user-led commissioning, mutuals, cooperatives and micro-enterprises. Pooling budgets is of particular interest to older people as it will help to maximise the impact of their personal budgets which tend to be quite low. There are opportunities for adult social care to identify people who could benefit from coordination, perhaps by a voluntary sector organisation, to arrange pooled transport or an extended outing, for example, and people living in the same village could be supported to employ a shared personal assistant.

Staff of provider organisations interviewed for the SCIE study of older people and personal budgets also highlighted their desire for more collaboration between themselves and local authority staff. This might help generate more ideas for the development of service provision, highlighting customer trends and demand for new services as well as changes in the form of existing provision. Care management and the relationship between providers and the local authority care management staff also has a key role to play in developing the market.
The market shaping role of local authorities has been further supported by recent Department of Health initiatives and in the Care and Support White Paper.

Evaluating what a good market looks like has been shown to be linked strongly to quality of provision as well as quantity. Older people report a range of difficulties in finding the right support, for example a lack of available personal assistants, particularly in rural areas, or inappropriate existing services. This is reflected in the results of a local study which took place in Essex. Some service users reported a lack of high quality providers, forcing some to employ people who provided substandard care.

There is support available for local authorities in the form of a range of useful publications highlighting good practice as well as policy and Government guidance.
Chapter 4: Supporting older people to have full choice and control in practice

This chapter introduces the concept of person-centred practices, and that one way of offering person-centred support is by implementing Individual Service Funds. It also covers the value and benefits of peer support and the challenges in providing it.
Much of what has been covered earlier in this report relates to the need for support which enables older people to make deliberate and informed decisions about their care and support. This chapter covers some of the practical ways in which local authorities and service providers can make this happen.

The first section provides a background to person-centred practices, which are at the heart of making personalised services available within a personalised system. It outlines what person-centred planning involves and how to carry it out.

The following sections consider the benefits of peer support, and of Individual Service Funds, in terms of how they can contribute to choice and control for older people, together with an overview of some of the practicalities involved.

These principles and tools should be used for everyone getting local authority support and care regardless of means of payment. Person-centred practice is not dependent on means of payment. Ensuring that everyone can access this type of support will make it much easier to deliver the policy intentions of Government, including for people on managed budgets.

### 4.1 Person-centred practices

The current vision for adult social care expects individuals, not institutions to take control of their support. Using person-centred practice empowers older people to have maximum flexibility in achieving the outcomes they want, and should become a mainstream activity in the process of self-directed support and in services themselves.

**Person-centred practice is an approach that puts the person at the centre** of the process of planning support and, ultimately, of the support itself, and helps to ensure that a person’s ‘care/support life’ does not take precedence over, or dominate, their ‘ordinary life’. It starts by exploring life from the person’s own perspective as far as possible, focusing on a person’s life history, relationships, their needs and preferences; and what they are able to contribute. It is a way of acknowledging a person’s strengths and resources, not just their needs and deficits; and of planning support in such a way that the person feels valued.139

Since it was introduced, person-centred thinking has moved from being viewed as an alternative approach to one that is widely accepted as central within health and social care. Person-centred care underpins the clinical guidelines for working with people with dementia and their carers;140 and Department of Health guidance141 states that: ‘the assessment process should be person-centred throughout and also consider the wider family context. Councils should recognise that individuals are the experts on their own situation and encourage a partnership approach, based on a person’s aspirations and the outcomes they wish to achieve, rather than what they are unable to do. Professionals should fully involve the person seeking support by listening to their views about how they want to live their lives and the type of care and support that best suits them and by helping them to make informed choices. This includes identifying the support the person needs to make a valued contribution to their community.’
Using person-centred thinking is central to good practice in support planning and brokerage as it facilitates the building of a truly personalised package of support that is not necessarily just made up of health and social care or services. Thinking about different ways to meet a person’s needs and outcomes in ways that are both preferable to them and are practicable can improve their quality of life and sense of control. For those lacking, or with limited, capacity to consent, the process will involve exploring and clarifying the best interests of the service user, which decisions will be made by them personally, which will be taken by others and how best to support them. Forward planning can also be undertaken to record how a person would like to be supported if they become very unwell or lose capacity.

Many older people will be in contact with local authorities or support services after having experienced a crisis (e.g. sudden onset of disability or ill-health, bereavement). Others will have experienced cumulative loss over a number of years, and this is likely to have eaten away at their confidence and reduced their informal support networks and the control they have over their lives. They are more likely to accentuate the negative than to develop unrealistic expectations. It is very important to encourage positive thinking about real possibilities, without losing sight of what is practical and achievable.

Simple, effective and evidence-based person-centred practice can change people’s lives and help them achieve the outcomes they want. In time, using this approach may help the expectations of, and assumptions generally made about, older people to move away from an emphasis on illness, frailty and dependence towards independence, contribution, aspirations, fulfilment and control. For some time, it has been assumed that younger people with learning and physical disabilities would like to achieve these outcomes, but it is yet to become the norm for this assumption to be applied to older people with care and support needs.

In terms of outcomes measurement, local authorities will be interested in implementing tried and tested ways of offering choice and control since one of the domains in the Adult Social Care Outcomes Framework covers ‘enhancing quality of life for people with care and support needs’. As well as numbers of people receiving self-directed support and direct payments, this includes social care-related quality of life, the proportion of people who use services who have control over their daily life and carer-reported quality of life.

Services and professionals will need to work in ways that put the individual at the centre of decision-making about their life and the services and support they want and need. Wider decisions relating to commissioning and providing services for whole populations need to be informed by information derived from individuals’ priorities, goals and preferences. Person-centred practices are, therefore, crucial for transforming public services and the personalisation of adult social care and for ensuring that people using managed budgets are fully supported.
Using person-centred practices

Person-centred practices can be used with people who are funding their own care and support as well as with those who qualify for financial support and are, therefore, useful for shaping how local authorities offer support to all groups of service users.

Many practical tools are available to support the process and the following section draws heavily on tools developed specifically for working with older people with high support needs as part of the Practicalities and Possibilities project. This project was a joint initiative between the Older People’s Programme and Helen Sanderson Associates, working with the Centre for Policy on Ageing, that shared what was working well in person-centred approaches. The practical development programme supported 11 localities to make person-centred thinking and planning happen for more older people so that real improvements could be seen and felt by older people in all aspects of their lives.

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<thead>
<tr>
<th>Person centred thinking tools that provide the foundation for support planning</th>
<th>Questions to ask</th>
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<tbody>
<tr>
<td>Appreciations</td>
<td>A key aspect of person-centred practice is appreciation, and having a focus on what we like and admire about people.</td>
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<td></td>
<td>Ask family, friends and carers what they like and admire about the individual.</td>
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<td>Relationships</td>
<td>A relationship map or circle is a good way of identifying and capturing who is important to an older person, to ensure that there is ‘at least one person’ and to actively seek to widen the connections and relationships that someone has.</td>
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<td></td>
<td>Who’s in your life now? What about where you live?</td>
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<td></td>
<td>• What time do you spend with others</td>
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<td></td>
<td>• What time do you spend on your own?</td>
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<td></td>
<td>• Who would you like to see (more of)?</td>
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<td>Communication</td>
<td>The communication chart is a powerful and simple way to record how an older person communicates. This is critical if someone doesn’t talk, and is also important where people only use a few words, communicate most powerfully with their behaviours. It can also help if the person has memory or orientation problems, as in the case of people with dementias.</td>
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<tr>
<td></td>
<td>Ask family, friends and carers how the individual communicates their likes, dislikes and preferences, including non-verbally.</td>
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<tr>
<td>Histories</td>
<td>Older people’s histories can easily become lost or be left untold. A conscious effort to listen to and record individual histories can help staff to understand and appreciate people in a different way, and in doing so develop different relationships with them.</td>
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<td></td>
<td>How did you get where you are today?</td>
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<td></td>
<td>• Tell me about yourself</td>
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<td></td>
<td>• Tell me what you are proud of, like family, work</td>
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<td>• Who was in your life in the past?</td>
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### Person centred thinking tools that provide the foundation for support planning

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<tr>
<th><strong>What’s important to and for people?</strong></th>
<th><strong>Questions to ask</strong></th>
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<tr>
<td>The fundamental person-centred thinking skill is to be able to separate what is important to someone, from what is important for them. Important to is about what really matters to the person, from their perspective. Important for is about the help or support that they need to stay healthy, safe and well.</td>
<td>What are your ‘must haves’ and what are your ‘like to haves’? What really matters to you in terms of how you live your life?</td>
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<tr>
<th><strong>Good days and bad days</strong></th>
<th><strong>Questions to ask</strong></th>
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<tr>
<td>One of the ways to discover how best to support someone is to ask about their good days and their bad days.</td>
<td>How are you today? How do you spend your time? • What makes a good day for you? • What makes a bad day for you?</td>
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<th><strong>Working / not working</strong></th>
<th><strong>Questions to ask</strong></th>
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<tr>
<td>Simply asking an older person what is working and not working in their life tells us so much. This information may be used to change what can be changed and to help us understand what really matters to people.</td>
<td>What does, or could get in the way of how you would like things to be done? • How is your health? • Is there anything that you need to leave or grieve for? • What are you worried about? • What or who could help?</td>
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<th><strong>Wishing</strong></th>
<th><strong>Questions to ask</strong></th>
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<tr>
<td>Older people may be keen to share and explore their own personal goals and dreams – their wishes.</td>
<td>What ideas do you have about how you would like your life to be? • Would you like to see and hear what other people have done or other examples of support plans? • What matters to you? • What do you miss that you do not do anymore? What would it take to get that back on track? • How would you like your week to be? • What do you want to change about your life? What do you want to keep the same? What would life be like if all this went well? Where do you want to be in 12 months time?</td>
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This information gathering exercise will be followed by:

- discussion about how any money will be spent: on care and services, but also on support, activities, transport, equipment, etc
- information about options (e.g. direct payment, indirect payment, managed personal budget, individual service fund) and where to go for advice or support – if the person qualifies for financial support
- discussion about managing the money and support. Does the person need help on a day-to-day basis or if there is a crisis? Is a contingency plan in place?

Final question: What are you going to do to make this happen?

Adapted from Person Centred Thinking with Older People. Practicalities and Possibilities, Bowers, H, Bailey, G, Sanderson, H, Easterbrook, I, and Macadam, A (2007) Helen Sanderson Associates Press. This publication provides more detail on the tools referred to and how to use them.

A support plan resulting from gathering such information should tell a care manager, social worker or support broker what is important to the older person; what they want to change and what steps they are going to take to make these changes; and how they plan to use their money to achieve this.

Presenting at least some of the information collected graphically can be invaluable on a day-to-day basis. For example, making a person’s one page profile available, or putting it on display, in their home, day care centre or care home means that everyone supporting that person has access to key information that will enhance the older person’s wellbeing. Examples of completed, one page profiles can be found on Helen Sanderson Associates’ website: www.hsapress.co.uk/media/5077/personcentredthinkingwitholderpeople.pdf and in Person Centred Thinking with Older People. Practicalities and Possibilities (2007) www.helensandersonassociates.co.uk/media/12222/full%20book.%20practicalities%20and%20possibilities.pdf

A major skill that underpins successful person-centred planning is the ability to develop a relationship with someone who needs support in order to work well with them to ensure they have choice and control over that support.

The following summarised case study is one of many that appear in Department of Health guidance on how councils can make personal budgets work for older people and their families.
Mrs N, 69, lives with her husband in an adapted bungalow. She has various health problems and uses an electric wheelchair. Her husband has had two strokes, has become forgetful and has difficulty walking. After a hospital stay some years ago, Mrs N has been receiving agency care morning and evening to help her with getting washed and dressed. When personal budgets were introduced, her social worker helped her through the self-directed assessment process and she was allocated a personal budget.

Mrs N was encouraged to think about things that could make her life better. She identified that her priorities would be to continue her personal care, to get help with the garden, household jobs and shopping trips and keep her Motability car in good condition. Her support plan helped her to:

- Change the domiciliary care agency to a smaller local one that charged less and only charged for hours actually used. This saved money to spend on other support.
- Shop around to get the best deal for car cleaning and engage a gardener at the most economical rate.
- Employ her grandson as her personal assistant for shopping trips (having checked that she only needed to pay him student rates).
- Employ a personal assistant to help with household jobs.
- Afford chiropody once a month.
- Hold a small float for such things as bank holiday agency rates.

Mrs N has enjoyed the process of planning her support: ‘I didn’t find it tedious. I knew that support was available from the Independent Living Association (ILA) and my social worker, but it gave me a real sense of purpose doing it myself. I don’t use the ILA’s Payroll Service either – I have found it is quite easy to do it myself with helpful assistance from the Inland Revenue.’

Mrs N found the whole process helped her to be more in control: ‘Everyone has been wonderful – I haven’t been made to feel dependent and the personal budget has given me my freedom. It’s not an easy thing to admit to being disabled, and before the personal budget it felt as if people were doing me a favour – now the relationship has changed and we work together.’

She has found that her personal budget has made her more independent and it has altered her relationship with her family, including her three sons: ‘I don’t feel so dependent on my family – I like to be part of their lives, but I don’t want to be their lives.’
Access for Black, Asian and Minority Ethnic (BAME) Elders

Age UK Lewisham and Southwark’s support planning services aim to improve access to mainstream and culturally specific services within the boroughs of Lewisham and Southwark. The Access Project provides a service for BAME (Black, Asian and Minority Ethnic) older people to help with person-centred planning which gives BAME elders and their supporters the opportunity to explore what really matters to them. The plans help to create a common language to express these wishes to those around them, including health and social care professionals.

‘I enjoyed it, it helped me to tell my story and have a report ready to hand for any social worker or doctor.’ (BAME elder)

BAME elders supported through this project work with a trained volunteer to co-produce a person-centred plan. The volunteers, who are matched with older people with the same cultural background and language, work with the older person for 12 weeks. The issues addressed through the person-centred planning process might include developing a healthier lifestyle, improving social contact, relationships with friends and family members, building confidence to try new activities, or resume former interests, addressing money issues and more.

‘She told me it is the first time someone is interested in her life and that this makes her happy. Although she is feeling very depressed, she now tells me that everything in her life can be changed with time. We were talking about things in her life that are working and those that are not working and we will carry on with the steps.’
(Volunteer, working in Spanish with female Latin American elder).
Person-centred approaches in services

Taking a person-centred approach to care and support provision is important for all service users, but particularly so when considering how personal budgets can be made to work most effectively for the individual.

Within a service, taking a person-centred approach means delivering the service in a personalised way that puts the service user at the centre, not just fitting them into an existing service because no alternative is available. Recent research found that ‘most service users valued choice over how mainstream services were delivered more than the ability to purchase services from the market. This meant that councils needed to work closely with providers – both traditional providers and user-led and community organisations – to develop flexible and responsive services.’

There are various approaches to ensuring that services are person-centred. These include implementing service design so that services are developed, or adapted, to reflect what is wanted and needed by older people; using person-centred planning tools to ensure that both one-to-one and group services provide the support required; and using Individual Service Funds and other budget deployment options to give personal budget holders the opportunity to define the support they receive.

Service design

One way to develop services to ensure that they meet needs and preferences is to take a ‘service design’ approach which is design-led and involves user engagement.

Age UK Newcastle and service design

Age UK Newcastle embedded service design thinking and approaches into the culture and strategy of the organisation through a Knowledge Transfer Partnership.

By engaging and listening to the needs and wants of the customer, opportunities to increase engagement, enhance the customer’s experience and strengthen the organisation’s impact were identified. Using this approach enabled front-line staff, volunteers and customers to contribute creatively to the development of new services and taught staff how to work effectively with stakeholders to achieve this. The project is described in detail in Designing better services together, and the roll out of a ‘phone neighbours’ peer-based friendship network has resulted.

A new three year strategy focuses on reshaping the organisation into one that is more person-centred and sustainable through innovation. A leadership programme has equipped managers with the skills and tools they need to transform services. Using person-centred planning tools and techniques with existing and prospective customers, Age UK Newcastle followed the service design work up by focusing on transforming its day services and lunch club offers, and a new model for daytime activities is being developed and shared with commissioners.
One-to-one support

One-to-one support services for people eligible for support from their local authority have, in practice, usually meant personal care or home help, although the latter has been heavily cut. The actual activities involved in providing care and support are, too often, specified in advance by the commissioning body without the agreement or involvement of service users. With the advent of personal budgets, services are being developed for this group that allow the person paying for it the flexibility previously only afforded to private purchasers. This type of individual and personalised support has been the norm for younger people with learning and physical disabilities for some years.

The benefits of personalised one-to-one support is that a person’s true needs and preferences are met, leading to improved quality of life and being able to remain independent at home for longer, which is what older people have said they want.

A recent paper, *Person-centred home care*, \(^{148}\) explains in detail what a person-centred package of home care looks like and the processes involved in putting it in place and reviewing it.

Below are examples of flexible, person-centred services.

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**Age UK Isle of Wight’s personal assistants**

**Just About You offers Personal Assistants who help older people to retain their independence and remain living in their own homes for as long as they wish to do so.**

A home support assessment is carried out to discuss and agree support needs, and a vetted, trained and insured PA is then identified who will visit at the agreed times, including weekends. They can provide: domestic cleaning; laundry and ironing; shopping – escorted or by list; prescription collection; help with paperwork; day and night sitting; pet feeding; dog walking; and local outings. The individual older person chooses what they want to do, or to be done, during the hours of the PA’s time that they have purchased. Client satisfaction is monitored on a regular basis. Currently, an average of 347 hours of service are provided each week.
Age UK Oxfordshire’s home support and companionship service

My Life, My Way offers support to older people who would benefit from a little extra help to enable them to live life the way they want to. It aims to meet individual needs and support people in their home so that they can continue to be independent.

Vetted, trained, experienced and supervised staff visit during the day assisting in the following areas: domestic tasks (light housework); spring cleaning; shopping; accessing social activities; transport to health check-ups/appointments; light gardening; going for lunch or coffee; dog walking; going out for short walks; attending a special event; and writing letters and paying bills. The service is bookable by the hour and the individual older person decides how that time is to be spent.

Age UK Tunbridge Wells runs an Independent Living Support Service similar to those profiled above. Following recent cooperation during a crisis, the organisation has developed its relationship with the local authority learning disability team, and has received more referrals than previously. The case study below shows how the Independent Living Support Service, which is fully person-centred, and the Bathing Service, which is being further developed as a result of this experience, can work together to positively impact on an older service user with learning disabilities’ life and that of her family.

Developing and delivering person-centred services

Rosie, 52, lives with her mother in an annex attached to her sister’s house. She has Down’s Syndrome and is very dependent on her mum. Her mum is becoming increasingly frail and is no longer able to help her bathe.

Rosie refused to have a bath at home and got angry if her sister, Margaret, tried to help her. She has a weekly shower at a day care service for people with learning disabilities. As her mother may need to move into residential care at some stage, leaving her alone in the annex, and due to uncertainty about the future of the day care service, Rosie needed to become more independent. Although physically capable, Rosie does not like change.
Developing and delivering person-centred services

As a result of a safeguarding investigation that led to recognition of tensions between the sisters and the difficulties these cause, the care manager agreed that Rosie could and needed to be more independent. She wanted to provide a service that could support Rosie to develop some independence and support her to recognise that she has learning difficulties and is getting older.

Five additional hours of support per fortnight were agreed and Age UK Tunbridge Wells was asked to develop a service that would help Rosie become less dependent. She was offered the home Bathing Service once a week so that she could start to address her own personal care needs while continuing to shower at the day centre. The bathing assistant takes an enablement role, encouraging Rosie to show her how she likes to have a bath and to develop her own routine. After four baths, a care plan was drawn up to reflect Rosie’s preferences. This has been a learning curve for the staff involved as some of Rosie’s needs are quite different from others who use this service.

Rosie is now able to bathe at home, seems to enjoy it and is very much in charge of how the service is delivered. She is less dependent on her mum and the tensions with her sister have diffused. She is in much a better position to cope if the shower at the centre were to stop.

An Independent Living Support Service support worker also accompanies Rosie on an afternoon outing of her choice every other Saturday. She enjoys having her nails painted, going the cinema or bowling, and likes to eat lunch at McDonalds. Rosie is beginning to understand that there will be less time to go bowling if she chooses McDonalds. The outings also give her a few hours away from her mum and the day care service.

Rosie pays for her services via a direct payment managed by her sister. Both services can be adapted as her situation changes.

Age UK Tunbridge Wells’ Chief Officer said about the learning from this experience: ‘Despite believing we offer a person-centred service, delivering a bathing service to Rosie has been challenging and has made us think that we sometimes make assumptions about people’s preferences. Rosie can be quite stubborn about how things are done, and any deviation can cause a lot of anxiety. Her bathing service has to be delivered in the way she expects; she is less forgiving than some of our other clients who perhaps tend to put up with a service rather than make a fuss or simply say what their preferences are. We are looking to see how we can transfer skills being developed to assist Rosie to all our clients and encourage them to feel more in control.’
The example below shows how services using person-centred approaches in planning support with people can have a positive impact.

**Person-centred planning**

Mr B was referred to the Age UK West Cumbria’s Promoting Choice Project following an Adult Social Care needs assessment. The social worker had identified that Mr B’s main priority was to be involved in activities and that he would have to contribute the full cost of any services.

Mr B lives in a very remote area and spends long periods on his own as his wife works. He suffers from a condition which has stopped him driving, and feels very isolated and bored.

Mr B was visited at home to talk through his interests and priorities in relation to becoming more socially active. A holistic discussion identified his likes and dislikes, what was working in his life at the time and what was not working. This enabled the support worker to identify the support he may need and consider any risks involved with the choices he made. They sourced activities and events available in his local area to suit his interests and support him to meet his goals. A support plan was written and shared with Adult Social Care so they were aware of how Mr B would be meeting the needs identified in the initial assessment.

As a result of this intervention, Mr B now has contact with the local voluntary car scheme which has greatly improved his inclusion in the community. He shares his skills and life experiences by volunteering at an Age UK West Cumbria computer class. He is also helping to develop another computer drop-in session at his local library support with from a Promoting Choice volunteer. He has also volunteered to support a new digital photography class.

Mr B had been unaware of the services that were available and that he could use his skills to encourage and help others whilst enjoying his interests. The information regarding transport was extremely valuable to him as is no longer able to drive.
Supporting someone with complex needs in a person-centred way

David, 60, has Asperger’s. The hotel he worked at and boarded with has been sold and he is unemployed. The local authority supported him to move into social housing and claim benefits as he cannot read or write. He has a number of serious health conditions, including liver and kidney failure.

David ate only bacon and eggs as he had limited cooking skills. He was unable to care for his pet cat properly. He had been offered personal care and housework support but had refused to let agency staff into his flat. He was being financially abused by the local alcoholics and drug users he allowed in. He received a gas bill of over £600 and had no heating. Any money he did have went on CDs, of which he had over 2,000. David had signed up for cable TV and mobile phones which he could not pay for. Bailiffs visited regularly and he was afraid to go out in case they ‘took him to prison’. He was very unhappy.

David was referred to Age UK Tunbridge Wells by the local police following a number of emergency calls to his home. They had tried other agencies with no success. A holistic approach helped him to organise his life and address his health needs. The local authority agreed to purchase seven hours per week from the Independent Living Support Service. David later transferred to a direct payment to enable him to continue to purchase the service, and he receives support to manage this himself. This tailored intervention has helped David get back in control of his life.

To begin with, David saw his support worker daily. His support needs have changed and he now likes to have blocks of time so that he can accomplish an activity or be accompanied to a hospital appointment. Age UK helped David with benefit maximisation, information, advice and advocacy to help with his debts. He started to attend the day care centre for personal care and laundry. With help, he keeps his home tidy and clean. He is very proud of it and likes to invite visitors in. He has learnt to be cautious, uses a door chain and has developed the confidence to send unwanted callers away. David has a ‘Lifeline’ device so he can summon help in an emergency.

David’s support workers assist him by showing how to complete new tasks such as cooking simple dishes. Pictures of healthy food items in his kitchen remind him what is good for his diet. His health issues have been addressed, helped by regular check-ups and sticking to his medication regime. His local chemist delivers his medication in a dosset box so that he can manage it himself with very little intervention.
Group services

A person-centred approach can also be implemented in group settings, such as day care or clubs, by using creative thinking for individual solutions to meet a person’s goals and interests, thus adding value to the service. People are able to purchase a group service with confidence that it will meet their personal requirements. The process can help service users to feel more in control and can enrich their lives, leading to improved wellbeing. It is possible to do this in both preventive services and in services for people with higher levels of dependency.

This is important given that Demos’ research confirmed that a high proportion of both older people who self-fund and those with a personal budget are keen on attending day services (40 per cent and 46 per cent respectively). Chapter 2 looks in more detail at what older people want.

An approach to personalising older people’s experiences in day centres, clubs and other group settings called ‘Roots and Circles’ was successfully tested by Age UK Oxfordshire (formerly Age Concern Oxfordshire) in two social services’ day centres in 2007. The aim was to support people to identify, and then achieve, their dreams, hopes and wishes through establishing and/or expanding and strengthening their networks.

The Roots and Circles approach involves asking older people to take and share photographs of what is important to them in their lives now, talking about these and about their broader life history (roots) and current social networks (circles). The emphasis is placed on finding out about people’s lives, their interests and skills, and on helping them regain their confidence by prompting them to remember their

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Supporting someone with complex needs in a person-centred way

David needs continued support to manage his money but his financial situation is structured so as to avoid impulse buys. He manages to save some money which has enabled him to buy things he needs – a new washing machine, a new bed and a battery operated bath seat. He is now bathing at home unaided. He also buys clothes and the occasional music CD. He enjoys going on shopping trips with his support worker. New storage cases display his music collection, and he is sorting out his CDs and donating duplicate copies to good causes.

David now volunteers at the day centre which he very much enjoys as he likes helping other people, and the walk to and from the centre helps keep him fit. The cat was rehomed and he does not miss it. David said:

‘My life is much better now and I don’t feel so ill and frightened.’

‘I am really happy now, I like going shopping and I have lots of money now, I help people at Age UK and I like helping them.’
achievements. Everything is recorded in scrapbooks. Information is then combined to give a picture of what people are interested in now; whether there were things they used to do that they might like to try again; and how they might pursue those interests, both at the day centre, and elsewhere in their day to day lives. Those supporting the process then work with the older person to identify ways to expand the range of activities and people in their lives, and then support them to put these in place.

Older people involved in the project experienced a variety of outcomes. Some found alternatives and additions to day care. They:

• joined other interest clubs, receiving day care staff support for their first few times of attending
• became local volunteers, including for Age UK Oxfordshire
• started to socialise with others they got to know at this group (‘Scrapbook Group’, ‘Circles Group’, ‘Photographs Group’) outside the sessions at the centre
• helped to run similar sessions with new groups of older people.

Others chose to continue attending day care so that they would be part of a larger group. They said:

‘I stopped writing after my stroke, but I wanted to do the scrapbooks so I made myself practice at home and now I am writing again. Last weekend I decided if I could learn to write again I could learn to knit again. So I knitted all last weekend, listening to Classic FM in the background. It was the best weekend in ages.’

‘I like it when they come here; they have different ideas for what we could do.’

‘Your encouragement has worked wonders in our understanding of each other.’

‘Last winter I felt so low I thought about moving into a nursing home. Now I feel there are people at the day centre I could talk to if that happened again.’
Another approach to personalising group services is to offer a menu of activities and support that are individually priced. People then select individual activities or a package of activities. This relies on people having a clear understanding of the budget they have been allocated.

Age Gloucestershire’s UK modular day service

Age UK Gloucestershire has split its whole day provision into different activities which can be purchased individually. This ‘Pick and mix’ approach is very attractive to those with personal budgets.

The service aims to be responsive to delivering the service people want, for example cooking classes and crafts specifically for men, such as making a bird table instead of the traditional knitting and suchlike.

The service is charged for on a sessional, or half-day basis (with or without lunch) or a whole-day basis.

People involved in the Oxfordshire Roots and Circles project

One woman enjoyed making tapestry and wanted to join a needlework group. The Information and Advice Service found a weekly evening embroidery group that was happy for her to join. She planned to ask her daughter-in-law for a lift, as she kept offering – but the woman hadn’t been able to think before of where she could be taken.

A second woman, aged 87, was a newcomer to the town and wanted to meet people. Another woman at the centre belonged to a group that met for day time talks, getting a lift there from a neighbour. When she told her neighbour about this lady, the neighbour offered to take both of them each week. The member was pleased to introduce the woman to other local people. For this to happen, the initial discussion – that the woman wanted to meet people – had to take place; this had to be shared with others at the centre, for possible solutions to be aired; another person had to offer practical help; and the woman had to be willing to try it out.

A man talked to people on the other day he attended, about the photographs, the scrapbooks and the ideas of trying things out in the town. He and two of these ‘Thursday ladies’ told the manager they would like to go swimming together. One of these ladies revealed she had been a champion swimmer in her youth, and brought in her swimming medals, certificates and photographs to share.
Age UK activity centre

The Haven Centre is an activity day centre for the over 50s where older people can enjoy a social day, participate in a selection of activities which promote healthy living and independence. Currently 70 per cent of clients are self-funders. Other places are spot-purchased by those with statutory funding. The day includes:

- Door-to-door transport to the centre by volunteer drivers (8.45–9.30am)
- Refreshments on arrival (10.00am)
- Activities (10.30am) – the following are a selection of some of the activities provided:
  - Creative: crafts, flower-arranging, painting, photography, books
  - Entertainment: music and singing, demonstrations and talks by invited guests, day trips, jewellery and clothes sales
  - Active and healthy options: seated exercise, garden activities, snooker table, healthy living and awareness
  - Stimulating activities: quizzes, crosswords, word searches, Scrabble, computers, family history
  - Pampering sessions: foot care, hairdressing, massage, manicure.
- Hot two-course meal – freshly cooked, locally sourced food (12.15pm)
- Refreshments followed by further activities and games (1.00pm)
- Transport home (2.30-3.00pm).
4.2 Individual Service Funds

Individual Service Funds (ISFs) are one of the money management options available for people in receipt of a personal budget. When a personal budget – or part of one – is held by a service provider on behalf of the personal budget holder in order to provide them with the service they choose, it is called an ISF.

Holding an ISF is a good halfway house arrangement for someone who does not want a direct payment, but who does want to have as much choice and control over the support they receive as is possible. This option gives providers a new level of flexibility to provide services in a person-centred and outcomes-focused way that was not usually possible under block contracts. With an ISF, a person is able to purchase any service from the provider of their choice and to specify exactly what they want, how and when they want it, and by whom they would like it to be delivered, without the need to manage paperwork. ISFs can support people to roll over money from one month to the next – something that service users express a wish to do in order to set money aside for emergencies or fluctuating needs.

Putting People First guidance for councils states that, with this sort of managed personal budget, ‘the contract is between the council and the third party/provider, whilst the day-to-day arrangements are between the individual and the third party/provider as provided for in the contract.’ Thus, without being directly responsible for managing a budget, a person decides how they would like their money to be spent to meet their individual, agreed outcomes. The provider is then accountable to that person for providing the specified service.

As ISFs are individual agreements between an individual and a provider, they sit beneath any framework contract that may be in place between the local authority and the provider. A person may hold multiple ISFs with different providers.

The service provider holds the ISF as a distinct, named budget or cost centre, and can only use the money to provide a service to the named person (and to cover any associated management charges agreed at the outset). It cannot pool the funding into a general budget.

Individual Service Funds require providers to take a person-centred approach to service provision that is led by the person purchasing the service. Many service providers have, traditionally, tended to work in a service-centred way that works around the needs of the providing organisation and its employees.

For councils, ISFs are a way of individualising arrangements within existing block contracts or alongside spot purchasing from framework contracts. They do not require new or different contractual models to be put in place and can be used regardless of the prevailing contractual situation, but can support a move towards outcome-based commissioning. All that is needed is willingness to collaborate and be flexible.

To date, use of ISFs has predominantly been amongst people with learning or physical disabilities and there are very few written-up examples of them being used by older people.
Through its survey of the impact of local authority commissioning of home care services, UKHCA found that ‘despite some encouraging growth in the numbers of people accessing direct payments, there is little evidence of the use ISFs, and our member organisations question whether a move to managed personal budgets, where they are available, is effecting any genuine change in the way that services are commissioned and arranged.’ The survey found little evidence of outcome-based commissioning and that local authorities tended to be more interested in cost than quality.

**Person-centred home care** explains in detail how a person-centred package of home care can reflect the principles of ISFs.

The London Borough of Barking and Dagenham was one of the areas that piloted individual budgets with older people. They subsequently introduced ISFs as part of their work to change their approach to contracting and provider relationships to be more compatible with the aims of personalisation and personal budgets. They invited home care providers to develop their services to support people who wished to manage their personal budgets through the use of ISFs. Four home care organisations took up the offer and started to provide a diverse range of personalised services and to develop collaborative links with one another and with other organisations to do so. The learning from this experience was written up by the Department of Health’s Putting People First programme.

The case studies below show, through two very different examples, how ISFs can make a difference to people’s lives.

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**Individual Service Fund user**

**Margaret, 64, lives with her husband. She suffers from angina and arthritis, and numerous strokes have left her with reduced mobility. Her husband’s own health problems mean that he is unable to care for her or maintain the house.**

Setting up an Individual Service Fund allowed Margaret to keep the same carers and agency involved in her care, but she has changed how they support her in the things she particularly needs and wants help with.

She developed her support plan with help from the care agency managing her Individual Service Fund, her care manager and her husband. She said:

‘I wanted to get my independence back and to get my house sorted out. I don’t feel safe going out alone, so having someone to come with me when I go shopping really helps, rather than them doing the shopping for me. I’ve got my social life back as well, as I’ve started going back to the social club I went to at the British Legion before all of this happened.’

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**Case study 20**

**Making managed personal budgets work for older people.**

April 2013
Sam’s care home manager found out about person-centred thinking and decided to take an Individual Service Fund approach to personalising residents’ options. A way of working out shared ‘background hours’ and ‘individual hours’ was devised. Sam’s monthly entitlement was four individual hours. A support plan for these hours was developed to ensure that he would spend them in a way that was important to him, and the revised contract would be reviewed with him every six months.

Sam was missing his bowling club, having lost all contact with old friends after a three month hospital stay and then going to live in the care home four years earlier. He was matched with a new staff member, Greg, who was also keen on bowling and they started going to the bowling club together once a fortnight. Sam’s hip injury stopped him bowling, but he enjoyed catching up with friends.

The care home manager and Greg used the person centred thinking tool ‘presence to contribution’ with Sam to help them think about how Sam could make a contribution. Sam now writes the bowling club’s monthly newsletter. Prior to retiring, he was a keen writer and produced the weekly church newsletter, so he feels that he is giving something back.

Sam’s life feels very different now and as he said recently, ‘I’ve got something to get up for, meeting the lads and I’m working on a newsletter.’

Full details can be found in Sam’s Story.
As with other aspects of personalisation, implementing ISFs comes with many potential benefits as well as challenges. The table below summarises some of these.

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<th>Group</th>
<th>Benefits</th>
<th>Challenges</th>
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| **Individuals with ISFs** | Person-centred: people’s needs and preferences are met leading to improved wellbeing. More responsive to rapidly changing needs.  
No need to manage paperwork.  
Rolled-over money allows for emergencies/changing levels of need. |                                                                                                                                                  |
| **Informal carers**    | Peace of mind and confidence that their loved one is being treated as an individual.                                                        |                                                                                                                                                  |
| **Service providers**  | Greater autonomy to negotiate care provision directly with service users.  
Demonstrate quality, responsiveness and service user planning.  
Demonstrate compliance with regulations.  
Improved customer retention due to improved satisfaction. | More complex staff rostering.  
Big change in culture and working practices:  
- significant training implications for care workers.  
- changes necessary to group service planning, e.g. day services. |
| **Care workers**       | Better relationship with service users.  
Greater personal responsibility.  
Increased job satisfaction.                                                                 | Training needs – change in working practices and culture.                                      |
| **Local authority**    | Improves local authority’s Adult Social Care Outcomes Framework (ASCOF) annual results by offering a more person centred focus, with  
less prescriptive care and support planning. It enables people to manage their own support as much as they wish and to be in control of what they receive which is likely to contribute towards having a positive experience of care and support.  
Simplifies care manager’s role and overall process to some extent. | Increase in contract administration (if services used are not block purchased).  
Training needs – change in working practices and culture. |
4.3 Peer support networks

As with a lot of things related to personalisation, there are a certain number of difficulties to overcome when putting peer support into practice. This section looks at the challenges involved and examples of how and where these have been experienced. Despite the obstacles, it is worth pursuing development of peer support for older people on personal budgets and for those who may need them in the future.

What is peer support and how is it helpful?

Peer support involves people with a particular experience or background advising and supporting others in a similar situation. Shared experience or background may be based on one, or many, factors. These might include age, disability, ethnicity, sexuality, gender, religion or being a carer, a refugee, widowed or in receipt of social care services.

Peer support networks provide an effective system for transferring knowledge, benefits from the experiences of others and solving problems. Accessing such support can be quicker and easier than searching for official ‘how to’ resources. It can also provide practical tips and the sort of support that cannot be found elsewhere. People who are reluctant to approach official bodies for help may be more comfortable asking for support from their peers. This may apply especially to hard-to-reach or minority groups. Peer support also has potential to support the increase in take-up of Individual Service Funds or direct payments, as it may encourage more older people to have the confidence needed to do so. The Equality and Human Rights Commission recognised that peer support would be a vital element in the successful rollout of self-directed support160 and went on to recommend that it should be widely implemented so that personalisation could work for all communities, particularly those who are marginalised.161

Social Policy Research Unit research on choice and independence over the life course found that peer advice and experience was a valued source of information.162

Research by SCIE163 found that a number of older personal budget holders and carers would have welcomed peer support, particularly when they first got their personal budget. This would have helped them to decide whether to take up a personal budget and given an opportunity to exchange ideas about what to use it for. Some would have liked the opportunity to speak to an existing personal budget holder or carer, a ‘personal budget buddy’, on an individual basis, but peer support was mainly available through support groups.

The National Centre for Independent Living’s (NCIL) (now Disability Rights UK) review of peer support activity in the context of the personalisation of adult social care concluded that there was considerable value in peer support across the personalisation agenda, particularly in supporting people to make choices about the best sources of social care provision and in improving outcomes for individuals.164
Peer support in policy

There is strong policy support for peer support, and an assumption that it will mainly be delivered by user-led organisations (ULOs). In 2005, Improving the life chances of disabled people recommended that, by 2010, ‘each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing Centres for Independent Living.’ These ULOs would provide a range of services, including information and advice, advocacy and peer support, support in using direct payments and individual budgets, and disability equality training.

In 2008, Department of Health information, in support of Putting People First and the transformation of adult social care programme, required councils to have in place, by 2011, ‘an enabling framework to ensure that people can exercise choice and control and with accessible advocacy, peer support and brokerage systems with strong links to ULOs. Where ULOs do not exist, a strategy to foster, stimulate and develop ULOs locally.’

ULOs were defined, by the Department of Health, as organisations where the people whom it represents or provides a service to, have 75 per cent of voting membership on the Management Committee or Board, and where there is clear accountability to members and/or service users.

The following understanding of ULOs has also emerged: ‘organisations that bring together people with a common purpose and can include any people with impairments, such as people with learning disabilities, mental health survivors, people from ethnic backgrounds and older people.’ One of the benefits of ULOs is that they may help local authorities deliver greater personalisation and improve engagement with hard-to-reach groups. This can also be achieved through tapping into existing community or social networks which are not related to someone’s status as a ‘care user’ or ‘service user’.

Think Local, Act Personal’s Making it Real framework is built around ‘I’ statements which express what people want to see and experience; and what they would expect to find if personalisation is really working well. It includes the availability of peer support:

- Examples of how the marker ‘Information and advice: having the information I need when I need it’ would look in practice include the availability of local advice and support including ULOs, disabled people’s and carer’s organisations, self-advocacy and peer support.

- One of the ‘I’ statements under the ‘Workforce: my support staff’ marker is ‘I have access to a pool of people, advice on how to employ them and the opportunity to get advice from my peers.’

The 2012 care and support White Paper, Caring for our future: reforming care and support, encourages the development and commissioning of a range of independent advice and support options. It goes further, in suggesting that ‘new models of advice and support such as peer networks and user-led organisations could also help to bring different people together to purchase care and support collectively and make better use of their funding.’
We can see that peer support is considered to be an essential part of a personalised social care system, that it can help local delivery of policy and that there is no doubt as to its value. These are strong reasons for making peer support accessible not just for people on personal budgets or direct payments but for all older people.

Peer support for older people on personal budgets

Peer support is an established part of the self-directed support system for younger people with physical and learning disabilities, particularly for those using direct payments, yet there is little evidence of peer support for older people with personal budgets. This is likely to be due to practical complications. Given that it may increase some older people’s confidence in using managed personal budgets, it is certainly worth local authorities and service providers making the effort needed to set up peer support networks for older people.

There are many differences between the circumstances of older people and younger physically and learning disabled people who use personal budgets, with the latter groups tending to have more stable conditions as well as families, often parents, who support them. Younger disabled people’s personal budgets can be relatively large and there is a real focus on ‘living life’ when planning support, whereas personal budgets for older people are often considered to be purely about personal care and maintenance and, as a result, tend to be much smaller. Most older people will have lived a full life, without having experienced the barriers that younger people with learning and physical disabilities encounter. The onset of disability can be very sudden for some, for example after falling and breaking a hip or having a stroke, and others may have gradually become increasingly frail leaving them more and more isolated. Many older people will also be living with dementia. In addition to their current circumstances, older people face the invisibility that can accompany ageing and negative assumptions that are often made about their capabilities and aspirations which can lead to poor decisions being taken, often without their active involvement, with regard to social care and support options.

As eligibility criteria for older people to access social care have tightened and, in most areas, are restricted to people judged to have critical or substantial needs, when older people access the social care system, they are usually in crisis or on a downward spiral in terms of health and ability to live independently without support. A person qualifying for social care is likely to have difficulty in participating in mainstream community life without support to do so. In addition to general lack of wellness or mobility difficulties, a person may have dementia which, being a degenerative condition, will progressively limit their ability to engage with more complicated processes.

Given these obstacles to active participation, some considerable challenges would need to be overcome for peer support to become commonplace amongst older people holding personal budgets. It may be necessary to recognise that models that work successfully for some groups are not always fully transferable to others in the same form. Service providers themselves could organise for peer support to be offered by some of their clients, and people with lower levels of need, or those who self-fund, might be able to organise it themselves.
Approaches to providing peer support for older people

In some areas, peer support for people with dementia and their carers is being provided successfully. The initiative below was cited as an example of good practice in the Mental Health Foundation’s 2011 review of how personal budgets were working for people living with dementia.\(^{172}\)

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### Peer support for people with dementia and their carers

**Barnsley Independent Alzheimer’s and Dementia Support**\(^{173}\) (BIADS) secured funding from Age UK Barnsley, through Voluntary Action Barnsley, to promote peer support for people with dementia and their carers, with the aim of supporting them to plan, choose and control what services they need to live a better life. The project launched in November 2010.

The Peer Support group was set up to try to encourage BIADS members to have the confidence to explore the opportunities available. BIADS recruited Personalisation Champions from within its membership of carers who have been using personal budgets successfully for some time allowing them to better care for someone with dementia. Champions are available at BIADS meetings and events to share their experiences and knowledge. They have also supported the development of an information pack on self-directed support specifically aimed at people with dementia and their carers which includes case studies involving BIADS members.

Bi-monthly Self-Directed Support Forums are led by service users and BIADS development workers, and people with dementia and their carers are invited to attend. Forum meetings allow people to gain information on peer support and personal budgets; to learn more about obtaining services and help in Barnsley for those families affected by dementia; to share experiences, problems and successes with other people with similar needs and wants who use peer support and personal budgets. Barnsley Council’s Self-directed Support Team attends to provide advice. Attendees can also meet the BIADS Personalisation Champions to talk, compare and learn from their knowledge and experiences of using personal budgets to manage their lives better.
Although a very positive practice example, BIADS has struggled. Numbers of carers attending forum meetings have varied from none to seven. There have been some successful experiences of people moving onto personal budgets, but members generally accept what is offered by social services – or are too worried they will lose what little support they have – and most are not aware whether or not they have a personal budget. Many of their member carers of older people with dementia are older themselves, with health issues of their own. At a time when life is already overwhelming for them the last thing they want to do is arrange their own support.

Champions met with the council personalisation lead to share the problems they were having in advising people, but the difficulties they had in obtaining consistent information from social services continued, and what was meant to happen in practice invariably didn’t.

This example sets the scene suitably for some discussion around the practicalities involved in setting up and running peer support networks for older people on personal budgets and their carers.

Although there are no formal standards or recognised quality assurance for peer support, NCIL’s review of peer support found that, in order for peer support to benefit service users, peer supporters would need to:

- have adequate training (listening skills, how to deal with queries, confidentiality, safeguarding)
- receive supervision (as service users are more likely to share difficulties with a peer)
- have an agreed value base to avoid inadvertently harming the person they are supporting
- consider boundaries (crossovers into information and advice, befriending, counselling)
- not impose views, be independent
- be consistent
- have impairment specific training
- possibly have a CRB check.

Ideally, people should be able to choose from a range of peer supporters because everyone has different experiences and perspectives, and what people consider to be important will vary. NCIL gave the following example: ‘A second or third generation young Somali origin woman may share little beyond language with a recent immigrant who is an older Somali woman who might feel she has more in common with an elderly Jewish lady who has experienced being a refugee.’
Ideally, if a peer support network of and for older people on personal budgets were to be fully representative, the following would be recruited:

- older people meeting eligibility criteria in receipt of a direct payment
- older people meeting eligibility criteria in receipt of a council-managed personal budget
- older people meeting eligibility criteria taking their personal budget as an Individual Service Fund
- carers who manage a direct payment on behalf of a service user.

Assuming it is possible to identify a group of potential peer supporters, a number of practical matters would need to be resolved and resources required for the above to be put in place.

Given the life experience older people have, how would they feel about being required to undergo training to provide peer support? They may consider it to be unnecessary simply to have what they see as conversations. Who would provide the training? Likewise, would they object to being supervised? Who would supervise them?

In terms of monitoring the quality of the peer support offered, consideration would have to be given to where the support would take place given potential mobility limitations of older peer supporters and the people they would be supporting (home, office, telephone) and the practicalities involved in doing so (e.g. office space, room hire, transport, telephone reimbursements, hearing impairments, monitoring of calls).

Maintaining an adequate pool of trained peer supporters could be both problematic and costly due to health deterioration and a higher attrition rate than with other groups due to death. To meet the definition of ‘peer’ they should be eligible for social care and will, therefore, have substantial or critical needs and probably face rapid deterioration.

Also, as we saw in earlier chapters, although the number of older people on personal budgets has increased substantially over recent years, many are on managed personal budgets yet are unaware of this. In order for the pool of potential peer supporters to be large enough to be able to draw upon, this will need to change. Local authorities will need to get better at making people aware of what a personal budget is, of the flexibility it can bring, and that support is available to plan care and support. Local authorities would also need to get better at referring people to the support available, both external and internal. Referrals to voluntary organisations providing support services have tended to be low.

In addition to the above, delays within the social care system – particularly with regard to lengthy waits for assessments and panel decisions – will mean that peer supporters may have to provide support for some time. This is a big commitment at a time when they may have unstable health conditions themselves.
Informal carers may be recruited as peer supporters of other carers. They may be older themselves, or younger and trying to hold down employment whilst caring. Whatever their age, they may be feeling the burden of their caring role and, as a result, may not be willing to commit to the additional responsibility involved in providing peer support.

Anecdotal evidence received by Age UK confirms the reality of some of these potential obstacles in building peer support networks of and for older people on personal budgets, as the examples in the following paragraphs illustrate. If older people are to reap the benefits of peer support, certain compromises will have to be made in terms of the way it is offered.

- One Age UK service reported that just over one quarter of the 100 people referred over a six month period died before receiving a personal budget. All of them were awaiting allocation to a social worker, waiting for an assessment or moving from intermediate care which illustrates just how frail and ill people referred for an assessment are.

- The same organisation also attempted to identify potential peer supporters via its local Independent Living Service as some of its clients with learning or physical disabilities have grown older with direct payments, and are now over 50. The Service used to run coffee mornings for clients so they could act as peer supporters to each other as well as doing something social, but these were unsuccessful as most people just want to get on with their lives once the direct payment has been set up and they are receiving regular support to manage it.

- A ULO involved in a Department of Health action learning programme served older people as well as disabled people, collaborating with two local Age UKs (previously Age Concerns) to do so. Although there was a peer support element to the project, it was mostly about younger disabled people providing information about personal budgets and direct payments to older people. Peer support provided by older people did not develop as expected due to the low number of personal budgets being taken up as direct payments.

- Five local initiatives make up Age UK’s Maximising Older People’s Personal Budget Use (MOPPU) project that is funded by the Department of Health under its Health and Social Care Volunteering Fund. One of the project’s four aims is to develop volunteer peer support community-based networks of existing recipients to support those not yet using a personal budget. This is proving challenging, not only for some of the reasons given above, but also because there can be a statutory sector view that such networks may evolve into formidable lobbying groups, capable of taking the council to task on a number of issues to do with local practice around personal budgets. This can lead to reluctance to encourage their development.
• One local MOPPU project approached one of its clients about the possibility of offering peer support to others with a personal budget. The 66 year old had suffered a stroke some years before and took a direct payment, to pay for carers, which his brother helped him to manage. He had initially said he would be happy to talk about his experiences of managing a direct payment, and had attended two volunteer training sessions, nodding when the trainers talked about personal budgets. However, when following up with him about the possibility of offering peer support, it emerged that he was much more vulnerable than had originally appeared. He was not ready to support others as he was lonely and tearful and needed support himself.

• Another local MOPPU project has found that volunteer peer supporters – mostly carers of people in receipt of a personal budget – do not have enough time to commit to regular network meetings to assist with one-to-one support, or to attend awareness-raising presentations. Therefore, any peer support has been on an informal basis.

The above demonstrates some of the difficulties involved in providing peer support using the fullest and tightest definition of ‘peer’. However, if a looser understanding is used, many of these complications could be overcome. For example, it may suffice for a ‘peer’ to be in the same age group, but not in receipt of any form of social care. In this case, the ‘peer’ would not be able to draw on their own experiences of social care services although they will gain sufficient knowledge through their experience of supporting other people receiving them. Being in a similar age group may assist relationship-building and will mean that some of the experiences of ageing, from health conditions to repeated bereavement, are shared. Using older researchers has proven effective in forming the relationships necessary for eliciting rich information that may not have come to light had the researcher been much younger.\textsuperscript{176,177}

Or ‘peers’ could have experience of social care services, but not of ageing.
Below are examples of peer support that fall under this looser understanding of peers.

Age UK’s Maximising Older People’s Personal Budget Use (MOPPU) project has tried broadening the criteria for peers and, as a result, is successfully reaching its target audience, older people.

Using older volunteers to reach older people

Part of Age UK’s Maximising Older People’s Personal Budget Use (MOPPU) project involves raising awareness and understanding of personal budgets and what they can offer in order to increase take up. Much of this work involves volunteers who, being older people themselves, understand and empathise with their situation. They are trained to be able to provide information about personal budgets using clear and appropriate language. For those who are being supported to get the most out of their personal budget, volunteers are adding value to support plans by identifying a range of services and activities for the older person.

In one area, GPs have shown interest in the project which they see as potentially educational for the patients they think need social care but who are reluctant to engage with social services due to suspicion and a perception that social care is the first point on a slippery slope to residential care.

In another area, discussion with local Independent Living Forum has led to hopes of a jointly developed peer network that may build on the existing direct payment servicer user group which meets regularly.
Peer support for Asian elders

Asian People’s Disability Alliance (APDA) is run by Asian people with direct personal experience of disability and caring, and works across a number of London boroughs. Amongst other activities they provide peer support to Asian people with physical impairments or learning disabilities and to Asian older people. The organisation also provides or assists people to access culturally appropriate services which are not available from mainstream providers.

Peer support runs throughout the organisation and is there to assist people with independent living skills, guiding and supporting people through local authority services and procedures, and supporting Asian people to access and use direct payments. People are encouraged to have direct payments because they are seen as a way to enable and empower Asian disabled people and a way to access support that is culturally sensitive and supports people’s religious needs.

Peer supporters are volunteers and they receive training in specific issues such as safeguarding, dementia, moving and handling, and health and safety.

Peer support has led to people gaining in confidence and given them a desire to take a wider role in their local community. The organisation believes that people have gained an ‘I want to do’ attitude. A number of Asian disabled people have also gained employment.

Given that people tend to approach the specialist organisation they identify with the most for support, making peer support to older people available from an organisation that predominantly supports disabled people – reflected through its name – may be problematic in that it may deter older people from approaching it. However, the above example could work well for Asian older people who may identify more with the ethnic aspect of the service, thus overlooking the disability aspect.
Peer support brokerage service (chargeable)

MySupportBroker empowers disabled people – people with physical or mental health conditions – and older people to devise and complete their own support plans and manage their own direct payments.

People complete their own support plans using a DIY model, with light touch assistance through MySupportBroker’s Check & Send model, or ask an accredited Peer Support Broker to help them from start to finish.

All MySupportBroker Peers are accredited by MSB College, recognised by Open College Network London Region (OCNLR), to NVQ/QCF level 3 training in Peer Support Brokerage.

MySupportBroker has found that the average delay between completion of plan and approval is two months. Its model and business plan saves local authorities significant administrative costs and frees up valuable Adult Social Care staff time. The delay between completion and approval has now reduced to one week where MySupportBroker is involved.

Case studies of people supported

Larry has recently been diagnosed with dementia. His family live far away and were finding it hard to be around to help Larry make the changes he needed to accommodate to his new situation. Larry’s daughter contacted MySupportBroker for help. She and her sisters paid £150 for a peer broker to work with Larry to put a support plan together. Larry chose his own broker, Mike, and together they found local services for Larry including a housekeeper, going to a local social club and a community alarm.

Pam recently had a stroke. After a period of rehabilitation she is delighted to be going home with the support of a council funded personal budget. As part of her rehabilitation Pam’s local council offered her a choice of support brokers to help plan, source and manage the support services she wants to buy from her new personal budget. The council paid My Support Broker £250 for a peer broker to help Pam put her support plan and services in place in time for her to go home.
The organisation has actively decided to use a broader definition of peer than is conventionally used as it has found, as was mentioned earlier, that people seeking peer brokers do not necessarily choose people ‘like themselves’ in terms of disability, but use a much wider set of decision criteria that include cultural background, language, interests and family composition. For MySupportBroker, peers are people whose lives have been shaped by disability, long-term health conditions, learning disabilities, mental ill-health – their own or that of someone they care for or support – and peers, therefore, have a wide diversity of experience. Although it is one of the few that explicitly includes older people amongst those supported, few of the peer brokers profiled on the organisation’s website fall into the category of older. All have, however, been trained to support others to produce person-centred support plans. It is perhaps of note that the organisation is a Community Interest Company and peer brokers are paid. The service offered is charged-for which reflects both a desire to serve self-funders as well as those on personal budgets and the responsibility and volume of work involved in support planning. It also reflects their view that ‘peer’ is not synonymous with ‘volunteer’ and recognises the training that is needed to learn the skills and competencies to support others in this way.

The reality is that public and professional awareness of peer support is low, funding is insecure and bureaucratic and the efforts of the people running such groups is often unrecognised and unsupported despite the demand for mutual support.

‘Organised right, [peer support] would also provide a whole new dimension to choice – an option to give and receive mutual support – as well as providing a cadre of volunteer navigators. It would also potentially unleash energy from public service users capable of underpinning the long term survival of services with a human face, and of broadening the scope of services that are provided. The new mutual support network would not take work from existing professionals or managers, but it would also be able provide the kind of options that services ought to provide – befriending, advising, DIY, changing light bulbs for older people – which they are currently unable to.’

There is no doubt about the value of peer support for older people. Making true peer support networks available for them will not be straightforward for a variety of reasons. However, given their perceived value, it is worth investing energy in working towards potential solutions rather than dwelling on, or ignoring, the challenges involved.
The voluntary sector can make an important contribution to the implementation of personalisation and can assist local authorities in supporting older people to make the best use of their personal budget and, in doing so, support local authorities to meet some of their target outcomes. This section brings together some of the points made earlier in this report and which are illustrated by the case studies that feature throughout.
People naturally approach the organisation which they identify with the most, and this will depend on how they perceive themselves and what they believe they are looking for. In approaching an organisation, older people may, primarily, be looking for support networks that will enable them to avoid using services regardless of their level of need and how they will fund any care or support. Those who do need care and support may not see themselves as disabled or as service users. Members of minority ethnic groups may prefer to obtain support through their own organisations, and some groups, such as people living with HIV\(^{184}\) and older lesbian, gay and bisexual people,\(^{185}\) are very reluctant to access support through mainstream routes.

User-led organisations (see 4.3) are often hailed as the route through which social care users can be reached and as the non-statutory solution to support planning and brokerage provision, for example. Many voluntary organisations meeting the Department of Health's definition of user-led are of and for younger disabled people.\(^ {186}\) Those that do not meet the Department of Health definition may be equally skilled in applying their detailed knowledge and experience of working with a particular client group for the benefit of that group. In doing so, they may be supporting local authorities to reach their targets, such as those in the Adult Social Care Outcomes Framework, at the same time as supporting personal budget holders to make the best use of their budget in a range of ways.

Information and advice services are often the first point of contact, particularly when face-to-face interaction is available as this is the preferred option for older people.\(^ {187} {188}\) Such services can be most effective when designed to meet the needs of particular target audiences, such as older people.\(^ {189}\) In terms of information, advice and awareness-raising work, the voluntary sector is known for its ability to engage with groups that tend to be harder to reach such as people from minority ethnic groups, lesbians, gay men and bisexuals, those who are socially isolated and those who are averse to approaching statutory bodies for help. This can be achieved by employing individuals from target groups or providing specialised services for them.
Mr H, 90, is a widower. He had a minor stroke some years ago and suffers from myasthenia gravis which causes muscle weakness. He contacted Age UK Bath and North East Somerset as he was no longer able to get out of bed and dress by himself, and was finding his twice weekly shower exhausting. His former cleaner helped him with shopping once a week. The co-ordinator and a volunteer visited Mr H at home to carry out a support planning session.

The service researched options and advised Mr H that agency care was available locally and what to expect to pay. He was helped to develop a template timetable for his care which took into account his wishes and current routine. Although the service is able to broker care arrangements, Mr H is very organised and was happy to be provided with information so that he could make his own arrangements.

The service put together a ‘What’s important to me’ document, a written record of Mr H’s wishes on how best to support him should he have difficulty communicating in the future. It shows, for example, that he likes things to be neat and tidy and that he wants to do as much as possible for as long as he can. Lastly, the service suggested that he look into adaptations to help him to get out of bed and gave him details of a local mobility shop.

Mr H has found that the agency’s help with his twice weekly shower and in making his tea at about 5pm has greatly increased his confidence and reduced his fear of having a fall.

Voluntary organisations have access to built-in awareness-raising opportunities via, for example, their day services. Many people attending day services are in receipt of social care but may be unaware that they have a managed personal budget and are entitled to have choice and control over the care and support they receive. Or they may not qualify for support yet but will be keen to know about what the options are for the future. In-house experts can often provide relevant key information and support, from leaflets to full support planning and brokerage. They may also effectively ‘piggy-back’ on other community-focused initiatives such as clinics, café drop-ins, road-shows and library services taking information to a much wider audience. Access to existing service users, targeted awareness-raising activities, widely distributed newsletters and leaflets, word of mouth and chance encounters all contribute to this extended reach which is often much broader than that of statutory services. 190
Local voluntary organisations tend to be knowledgeable about and engaged with community networks and can facilitate access to local activities and resources effectively, as well as offer their own range of services. People accessing one part of an organisation often go on to benefit from another of its offers and remain with them for some time. For example, GP’s often refer older patients to their local Age UK for benefit checks. During a benefit check, other needs may be identified or activities that may be of interest highlighted.

Their unique trusted position in local communities means that voluntary sector organisations are ideally placed to improve outcomes for older social care users, including those on managed personal budgets, whether through their own service provision or their knowledge of their client group.

They can also provide important support to local authorities by, for example, helping adult social care caseload management by doing preparatory work with older people in readiness for the support planning process. This could involve informing people about how personal budgets work and what sort of support could be available to them in their local area. It could also mean ensuring that older people do not fall through gaps in the net by providing informal monitoring of people’s changing needs through their regular contact with them, and alerting adult social care to any need for reviews. To an extent, they can also bridge the gap between referral and assessment, helping to prevent an older person reaching crisis point.

The following case study shows people benefit from voluntary sector support through the application and support planning process. It is followed by outlines of two very different voluntary sector support planning and brokerage services.
Age UK Wirral’s Personalisation Project offers support through the application and support planning process

Mr B has dementia and his wife is his sole carer. He was offered a personal budget and the social worker helped him to write a support plan. Mrs B had an issue with part of the support plan and became confused and distressed on hearing that the person she needed to speak to was on holiday. A member of Age UK Wirral’s Carers Support service arranged a meeting with someone from its Personalisation Project for the same day.

Mrs B had trouble understanding the intricacies of the personal budget application process. This, and being her husband’s carer, had taken a very heavy emotional and physical toll on her. She felt that she was ‘losing hope’ and ‘was getting the run-around’. She was ‘really struggling’ to understand the process and worry was stopping her having a good night’s sleep.

Personalisation Project staff clarified the uncertainties Mrs B had whilst being sympathetic to her feelings and ultimate wishes. Afterwards, she seemed to be a lot more at ease about where she was in the application process and how much longer she would have to wait until the money from the local authority was forthcoming. This was important as she had highlighted some financial concerns.

Mrs B said that the support offered by the project was ‘a lifeline’. She had felt that the support plan was ‘just words on a piece of paper’ and sufficient time was taken to clearly explain the parts she did not understand. She slept for seven hours that night – much longer than usual – which had put the ‘oomph’ back in.

Mrs B thought this type of service is needed in the future: ‘it’s definitely needed because... you had time to listen, you understood and I felt confident that at last somebody was there who could make some headway into all the complications.’

Mrs B thought it would be helpful if someone spoke to people when they are filling in a support planning template. ‘Mine was so confusing and the format was confusing, especially when some parts of the support plan had been rejected.’

Having benefited from it, Mrs B would consider volunteering as part of the project to help people in the future who are applying for a personal budget: ‘there is a need to manage people’s expectations of what they are going to get as I thought I would have everything I stated in the support plan accepted but that wasn’t the case.’
Age UK Sheffield’s Self-Directed Support (SDS) Planning Service for people with a personal budget

The service is for people who have been assessed by Sheffield City Council as having critical or substantial needs. Referrals are received from the local authority’s Support Planning Department, individual social workers, other health and social care professionals and customers themselves or their friends/family etc. All that is needed is a copy of their assessment questionnaire and indicative budget.

Workers from the service visit people at home. They explore people’s lives with them, aiming to match their identified needs with free and chargeable services and equipment that best suit them. People are encouraged to think more broadly than they may be used to so that they can have a good quality of life and can continue to live independently.

The service is chargeable to customers who allocate part of their budget to it. However, the council funds this element entirely and it isn’t an additional cost to the customer despite being taken from their budget. After the first visit, workers estimate how long it will take to support the person through to the implementation stage, and decide which service level the customer will need to pay for. This is agreed with the customer who signs an agreement to pay.

Customers approve their support plan before it is submitted to the council for approval. Paid staff carry out support planning and volunteers assist by researching service options and drafting paperwork. Workers have received training from the council, and the service meets their quality standards for support planners and brokers. In order to give customers as much choice as possible, the council has developed information, including a factsheet on choosing how to plan support which includes a provider list.

Sheffield City Council decided to encourage external support planning after recognising that a bottleneck of people waiting for assistance with support planning following a needs assessment was developing.
Age UK Cheshire Independent Care Brokerage for self-funders

The service is for people aged 65 and over who have been assessed by a social worker as needing non-residential services, and as being self-funders who are deemed able to pay for their own care, or for those who do not want a social worker involved. Referral to the service is via social services, following an assessment of care needs which is forwarded to the service. Anyone coming to the service before an assessment of need has been carried out is referred to social services for a care assessment, with their consent.

Support brokers, who are paid staff, make home visits to discuss what clients want, and to clarify needs and expectations. They then offer assistance with preparing and costing a personal support plan, arrange and implement support plans, and monitor and review the support package as instructed by the client. Support may include helping to find carers, budgeting, advice and assistance on keeping records, employment law, health and safety, tax and National Insurance, payroll, and providing a safe environment for meeting and interviewing prospective carers. Brokers also help to build networks, promote choice and control, and tap into local networks and funding opportunities. Each broker covers a limited geographical area, enabling them to become very familiar with what is available in their own local patch. Monitoring and review of the package of care and support is carried out on an individually agreed basis. An initial review takes place after six weeks with follow-up reviews as necessary, but at least annually.

The service receives an average of 45 referrals per month across both local authority areas.
Endnotes

1 Originally set at 100 per cent of eligible service users, changed to 70 per cent by the Care Services Minister in October 2012. See Comments made in speech by Norman Lamb at October 2012 Association of Directors of Adult Social Services conference reported at www.guardian.co.uk/society/2012/oct/26/councils-social-services-personal-budget

2 The main user surveys completed to date are the IBSEN evaluation of Individual Budgets, the National Personal Budget Survey and a piece of SCIE research looking at the experiences of older people. There are other smaller scale user surveys referred to throughout this report.


4 The National Personal Budget Survey (2011) Think Local Act Personal www.thinklocalactpersonal.org.uk/Blog/Transforming_social_carer_learning/from_the_outcomes_people_experience/?parent=9362&child=8993


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15 NHS Information Centre (2012) SD1: Number of clients receiving self-directed support and/or direct payments provided or commissioned by the CASSR during the period, by primary client type and extended age group. Cited in The Case for Tomorrow: Facing the Beyond. A joint discussion document on the future of services for older people (2012) Association of Directors of Adult Social Services www.adass.org.uk/images/stories/Policy%20Networks/Older%20People/Key%20Documents/TheCaseforTomorrow080312.pdf


21 Personal Budgets: council commissioned services. Advice note (2010) Putting People First www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Personalisation_advice/Personal_Budgets_Council_Commissioned_Services_-_Advice_Note.pdf


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Individual Budgets: A report on consultation with older people (2008) Age Concern West Sussex. As part of the county’s involvement in the pilot, in 2007, it commissioned Age UK West Sussex to carry out a consultation with a wide range of older people and carers in West Sussex on the introduction of individual budgets. www.ageuk.org.uk/brand/partners/global/westsussexvpp/docs/age_concern_ibsconsultation_mar08.doc


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Making managed personal budgets work for older people.

April 2013


105 On average, people receiving direct payments receive 80% more funding than they would have if available spend on social care was evenly distributed. Can personal budgets really deliver better outcomes for all at no cost? Reviewing the evidence, costs and quality (2012) Slasberg, C., Beresford, P. and Schofield, P., Disability and Society Vol 27 No 7 www.tandfonline.com/doi/pdf/10.1080/09687599.2012.736671


110 Half of the self-funders involved in the Demonstrs Study Personal Best wanted to change their support, which indicates that only having control over money does not necessarily lead to people experiencing good outcomes or having a positive experience of their care.


123 From a presentation Managed Personal Budgets: myth or reality, from the study underway by Social Policy Research Unit entitled Personalisation of Home Care for older people using managed personal budgets. Presentation accessed 31.01.13 at www2.lse.ac.uk/SEHealthAndSocialCare/pdf/SSCNNannualConferencePresentations/Pavran-v-Rabbee.pdf


128 Ibid.


131 In September 2012 the Department established a programme of work ‘Developing Care Markets for Quality and Choice’ which is designed to help local authorities build their capacity to shape a diverse, vibrant and high quality market for social care services.


In 2010, the National Market Development Forum published five briefing papers to help purchasers and providers address the market development agenda in their local area.

1. The Future Social Care Market
2. Developing Market Intelligence
3. How will ‘personalisation’ change the way services are procured?
4. The implications of personalisation for social care tendering
5. Building constructive market relations

www.thinklocalactpersonal.org.uk/Browse/commissioning/developing/?parent=856&child=7959


142 Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care (2010) paragraph 83 www.thinklocalactpersonal.org.uk/library/Prioritising_Need_in_the_context_of_Putting_People_First_A_whole_system_approach_to.pdf


145 Personal budgets for older people: making it happen (2010) Department of Health (Putting People First) www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Personalisation_advice/Personal_Budgets_Council_Commissioned_Services_Advice.pdf


147 The project is described in detail in Designing better services together (2011) Laura Warwick www.qualityoflife.org.uk/images/publications/DesigningBetterServicesTogether.pdf


151 Contracting for personalised outcomes: Learning from emerging practice (2009) Department of Health (Putting People First) www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Personalisation_advice/CFPO.pdf

152 Care is not a commodity: UKHCA Commissioning Survey 2012 (2012) UK Home Care Association www.ukhca.co.uk/pdfs/UKHCACommissioningSurvey2012.pdf 739 responses were received from homecare providers supplying to 189 (90 per cent) of the 211 local authorities in England, Wales and Scotland and the Health and Social Care Trusts in Northern Ireland. 95 per cent of responses came from independent providers, and 5 per cent from voluntary providers. Providers completed a detailed, confidential, on-line survey form asking about their supply of homecare services to a single LA (or Health and Social Care Trust in Northern Ireland) with which they currently trade.

153 www.helensandersonassociates.co.uk/media/80201/person-centred%20home%20care.pdf Dec 2012


156 www.helensandersonassociates.co.uk/media/60768/sam%20story.pdf Also cited in Choice and Control for All. The role of Individual Service Funds in delivering fully personalised care and support (2012) Groundwell Partnership www.groundwellpartnership.co.uk/choice-and-control-for-all

157 Outcomes-based commissioning pilot in West Sussex (2007), West Sussex County Council: Aimed to evaluate whether outcomes-based commissioning would improve individuals’ and their carers’ quality of life. Contracts with an independent domiciliary care provider contracted by West Sussex County Council were altered from ‘time and task’ to being a number of hours over a four week period. Clients negotiated directly with the provider, using the hours flexibly to achieve the outcomes agreed at assessment. Existing customers didn’t make significant changes to their packages of support, but new people entering the system preferred a different type of support. Paid carers experienced increased job satisfaction. Outcomes were found to be an unfamiliar concept for social workers and providers, and significant training was necessary.

158 Outcomes-based commissioning pilot in West Sussex (2007) West Sussex County Council


168 Putting people first: working together with user-led organisations (2009) www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation/working_together_with_user-led_organisations.pdf


172 Personal budgets for people living with dementia (2011) Mental Health Foundation www.mentalhealth.org.uk/content/assets/PDF/publications/Personal_budgets_for_people_living_with_dementia.pdf

173 www.biads.org.uk/projects/budgets/budgets.htm

174 Bott, S., Peer support and personalisation. A review prepared for the Department of Health (2008) NCIL (now Disability Rights UK) www.thinklocalactpersonal.org.uk/_library/Peer_support_Final_1.doc

175 Sharing the learning: user-led organisations action and learning sites 2008-2010 (2010) Dept of Health

176 Get the picture: older people’s day to day lives in rural West Oxfordshire 2004-2007 (2007) Godel, M., Age Concern Oxfordshire - aimed to capture in words and pictures the everyday lives of a typical rural English community in order to pass on to the rest of the community their stories, wisdom and experience.

177 Well-being in old age: findings from participatory research (2012) University of Brighton and Age UK Brighton & Hove – aimed to gain an in-depth understanding of what growing older means to people, and how they seek to sustain and develop their wellbeing as they go through the changes that accompanying this. www.brighton.ac.uk/sass/older-people-wellbeing-and-participation/

178 Bott, S., Peer support and personalisation. A review prepared for the Department of Health (2008) NCIL (now Disability Rights UK) www.thinklocalactpersonal.org.uk/_library/Peer_support_Final_1.doc


180 MSB College supports MySupportBroker. A separate department in the company, it provides accredited training to both MySupportBroker and on a consultancy basis to other companies. All trainers and associates are Peers, being either disabled or people with long term health conditions.

181 www.ocnlondon.org.uk


186 Organisations where the people whom it represents or provides a service to, have 75 per cent of voting membership on the Management Committee or Board, and where there is clear accountability to members and/or service users. Good practice in support planning and brokerage (2009) Putting People First http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/Good_Practice_in_Support_Planning_and_Brokerage.pdf


189 Ibid.


93
The Age UK expert series is for people influencing, designing, commissioning and delivering services for later life. The reports present evidence, lessons from experience and practical solutions.