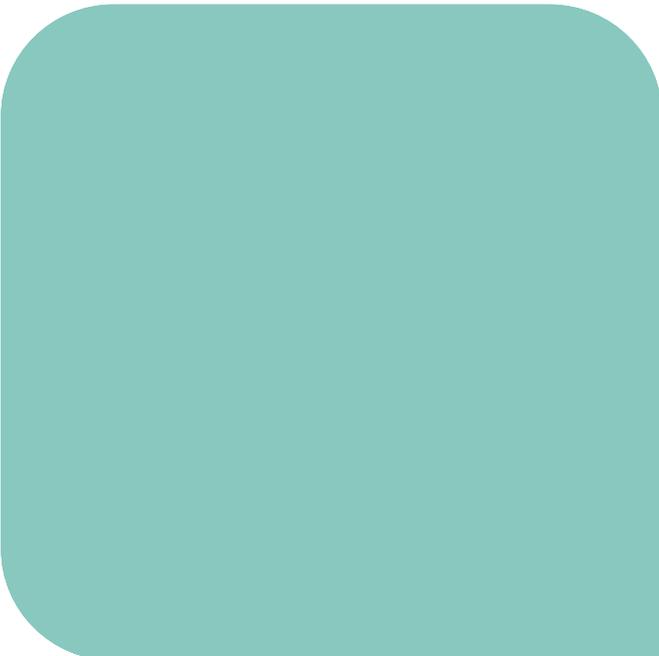
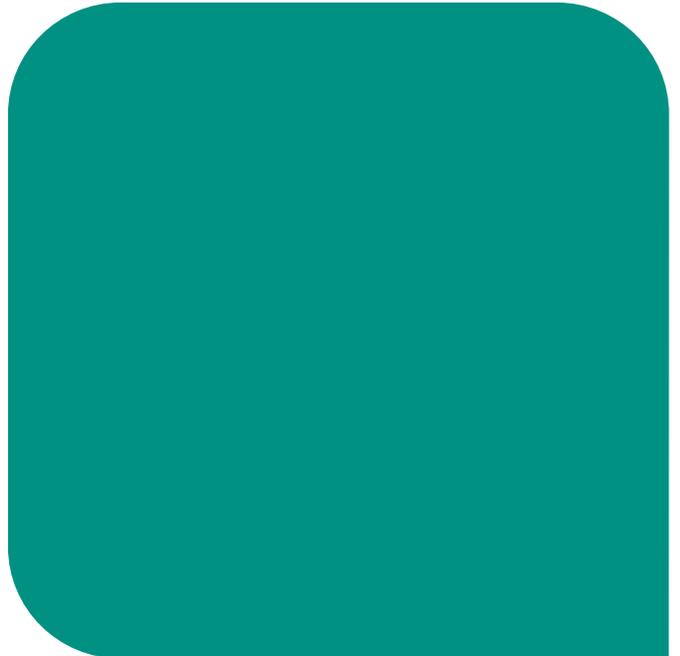




Improving personal budgets for older people: A research overview



The Social Care Institute for Excellence (SCIE) was established by Government in 2001 to improve social care services for adults and children in the United Kingdom.

We achieve this by identifying good practice and helping to embed it in everyday social care provision.

SCIE works to:

- disseminate knowledge-based good practice guidance
- involve people who use services, carers, practitioners, providers and policy makers in advancing and promoting good practice in social care
- enhance the skills and professionalism of social care workers through our tailored, targeted and user-friendly resources.

First published in Great Britain in January 2013
by the Social Care Institute for Excellence

© SCIE

All rights reserved

Written by Sarah Carr

This report is available online
www.scie.org.uk

Social Care Institute for Excellence
Fifth Floor
2–4 Cockspur Street
London SW1Y 5BH
tel 020 7024 7650
fax 020 7024 7651
www.scie.org.uk

Contents

Introduction.....	1
Executive summary	1
Methodology.....	4
Review findings	4
Direct payments for older people: findings pre-dating personal budgets	4
Independent living and older people: culture and system change	6
Making choices and decisions	7
Information and advice	9
Direct payment support services.....	12
Understanding allowance and spend.....	14
Budget management, monitoring and review.....	15
Risk management and contingency planning	17
Time.....	18
Continuity and consistency	19
Older people living with dementia: data and systems	20
Conclusion.....	21
References	22
Appendix	25
Project Steering Group	25

Introduction

This short report is an evidence overview of key pieces of UK research between 2007 and 2012, which focused on the implementation and uptake of personal budgets and direct payments for older people (including those with dementia) in England. It is not a systematic research review or an exhaustive examination of published research on the topic. Rather, it aims to give an overview of the main themes of research findings which help to identify the challenges and solutions to improving choice and control for older people (including those living with dementia) through the use of personal budgets and direct payments.

The research is analysed thematically and themes are either conceptual (such as independent living) or operational (such as support provision). This report presents a structured discussion of the evidence relating to these themes and looks at both established and emerging challenges and solutions.

Executive summary

Early findings on the barriers and facilitators for older people using and benefiting from direct payments predicted many of the challenges for implementing personal budgets for older people. These findings have been further established in later evidence on personal budgets. More detail is now known about what helps and hinders, and how direct payments can work for older people with dementia. The following are some of the key themes from the UK literature overview:

- **Independent living and older people: system and culture change**
Direct payments are underpinned by the principle of independent living. This means having choice and control over where and how to live, and over support and assistance. It applies to older people, including those living with dementia. Independent living for older people may include managing a fluctuating or degenerative condition or sudden disability, which can be very different from younger adults with more stable conditions. The amount of funding and the choice of services on offer to older people can restrict their ability to use personal budgets in a preventative way or for social and community activity. The cultural attitude that older people are expected to lead more restricted lives than younger adults can also limit the opportunity or ability to use their personal budgets.
- **Making choices and decisions**
For older people (including those living with dementia), their families and carers, making choices about care and support is a complex area. This is especially true in the context of personal budgets and direct payments, where informed or supported decisions need to be made at several stages. For these reasons the principles of the Mental Capacity Act (2005) may help to support engagement in decision-making.

- **Information and advice**

These are critical to making personal budgets and direct payments work for older people (including those living with dementia), their carers and families. Clear and accurate information and advice is needed at different stages in the personal budget or direct payment process so people can make the choice that is right for them. Information and advice is not just limited to knowing what services and support are available at the time of planning. Awareness raising information and advice about the availability and use of personal budgets and direct payments is also needed to support people making choices about which personal budget option to take. The type of support offered by user-led organisations (ULOs) has been highlighted as being particularly effective if they have the capacity to meet the needs of older people (particularly those with dementia), their carers and families. Links with local health dementia advisors and independent advocacy services help to keep staff informed.

- **Understanding allowance and spend**

Evidence suggests that older people's personal budget allowance and spend is different to that of younger personal budget users, even if they opt for a direct payment. It appears that older people are less likely to use a personal budget or direct payment for more creative or innovative support and activity and their budget is often lower than for other service users. It has been difficult to achieve market diversification, innovation and choice for older people because care and support services are often still tied up in long term block contracts that have not been decommissioned.

- **Budget management, monitoring and review**

Managing a budget directly can seem or feel like an administrative burden or too much of an additional responsibility. Older people with carers and/or family may more often be offered a direct payment. If an older person is frail or is living with dementia, their carers and families are more likely to be managing the budget. It is important to have access to ongoing advice and support, as well as clear guidance about monitoring arrangements, clarity and degrees of flexibility about budget spend and carry over. The role of the 'suitable person' in managing a budget for a person living with dementia should be explored. Monitoring and review of support should be regular and responsive to service user and carer prompts, particularly for people living with dementia, to take account of rapidly changing circumstances.

- **Risk management and contingency planning**

Staff concerns about risk can lead to older people – particularly those living with dementia – not being offered the direct payment option, or being given a restricted range of support choices. Positive risk taking and concerns about safety should be discussed during the personal budget assessment and

support planning process. This requires support and leadership from management and the organisation. Contingency planning is important for older people, carers and families using personal budgets and direct payments. This can range from having back up care and support cover if arrangements with a directly employed support worker or PA broke down or the worker needed to take time off sick, to maintaining an emergency contingency fund from possible under-spend.

- **Time**

There are two distinct areas where time was seen to have an impact on how well a personal budget or direct payment could work:

- a) sufficient time to explore and discuss all options at the beginning and to assemble a support plan, and
- b) a reduction in the length of time and delays in local authority decision-making over assessments, support plans or reviews. Lengthy processes and delays can impact badly on people living with dementia, as it is a degenerative condition where circumstances and needs can change over time and sometimes rapidly.

- **Continuity and consistency**

A significant emerging theme of the research is the importance of continuity and consistency in relation to the people or organisation providing support and advice to older people with a personal budget or direct payment. Being able to employ a consistent person or people and have a relationship of trust and familiarity was very important. This is particularly the case for older people living with dementia. Effective risk assessment also benefited from a consistent and knowledgeable relationship between staff and individuals. In certain circumstances, employing known people like family and friends is potentially the better solution.

- **Dementia: data and systems**

Most significantly, research on direct payments and personal budgets for people living with dementia in England strikingly revealed an absence of collected data. There is a crucial need to address this lack of data. Both the NHS and the local authority are involved in care and support for older people living with dementia, and they have an opportunity to bring together personal budgets and personal health budgets and improve choice, control and integration for older people living with dementia. Research highlights the fact that personal budgets cannot be approached as a 'one size fits all' solution for older people living with dementia, particularly as dementia is distinct from a stable physical, sensory or learning disability.

Methodology

The research in this review was identified by conducting a sub-search of a larger SCIE database of international studies on personal budget schemes dating between 2009 and 2012. This search yielded the most relevant UK studies on older people (including those living with dementia) and personal budgets or direct payments. The search was supplemented by some reference harvesting, targeted internet searching and expert advice. The draft report was peer reviewed by the project steering group members (see Appendix).

Review findings

Direct payments for older people: findings pre-dating personal budgets

Some of the challenges and solutions for older people accessing and using direct payments had been established in evidence pre-dating the implementation of personal budgets in 2007.

The 2007 direct payments national survey (undertaken 2004/05) reported that uptake by and spend on older people was lower than for people with physical or learning disabilities, with some regional and local variation (Davey *et al* 2007). The authors note that:

'The main barriers to greater uptake suggested by other commentators have been:

- poorly informed care managers
- lack of direct payments support services
- lack of enthusiasm among local authorities (Clark *et al* 2003)
- poor public information
- overly complicated monitoring systems
- difficulties with associated responsibilities.

Older people in particular feel less able to use direct payments without sufficient support services, including access to a payroll service [CSCI 2004].' (Davey *et al* 2007 p 36)

An earlier 2003 Joseph Rowntree Foundation research project on making direct payments work for older people revealed similar challenges and solutions. It also showed positive indications of the improvements in older people's lives, including Somali elders (Clark, Gough and Macfarlane 2004). The research indicates the following as important for making direct payments work for older people:

- direct payment support services – including audit and administration – to enable people to use direct payments
- allocate hours in packages to allow for employing PA assistance
- a register of PAs to help with choice and recruitment

- challenging the assumption that older people should have a restricted lifestyle
- address difficulties when younger adult service users cross the administrative boundary into older people's services
- care managers need sufficient knowledge of direct payments and direct payment support services, support from line managers and time to think and work creatively.

(Adapted from Clark, Gough and Macfarlane 2004 p 1)

Direct payments for older people were considered as part of the Wanless Social Care Review (King's Fund 2006). The review identified these barriers to take up:

- the lack of clear information for older people
- poor awareness of direct payments among social services staff and their reluctance to promote this option
- lack of support to help the older person with the administration of employing a care worker
- concerns about obtaining criminal record checks and reliable references for personal assistants.

(Adapted from King's Fund 2006 p 4)

The Wanless Review further identifies systemic and operational factors that hinder how well direct payments work for older people. Firstly, the older person often only comes into contact with – or is eligible for – social care services at crisis point, when direct payments may not be suitable. Once direct services have been arranged in response to the crisis, there is a question of whether these are reviewed and a direct payment offered once the older person improves. The Review also notes that some older people may not want to take on the role and responsibility of being an employer without significant support, at least in the first instance.

Finally, the Wanless Review was optimistic that direct payments and the anticipated 'individual budgets' [*sic*] would mean that 'older people will in the future benefit not only from choosing components of a care package, but also from gaining choice about the degree of support that is preferred', but warning that 'the challenge will be to calculate transparent charges for the complete range of services and support which are currently provided by local authorities' (King's Fund 2006 p 9).

These early findings on the barriers and facilitators for older people using and benefiting from direct payments predicted many of the challenges for implementing personal budgets for older people. The findings have been further established in later evidence on personal budgets. More detail is now known about what helps and hinders, and how direct payments can work for older people with dementia.

Independent living and older people: culture and system change

Understanding the concept of independent living in general, and for older people in particular, appears to be one of the broader cultural barriers to older people being able to access and benefit from personal budgets and direct payments.

A 2001 paper exploring the principles of independent living in the context of direct payments for older people concluded that:

'Direct payments are a means to an end. That end is independent living... Independent living means different things to different people. However, two defining concepts mark independent living from other approaches... choice over where to live, how to live, who provides assistance and control over who assists and what they do.' (Hasler and Zarb 2001 p 1)

However, research into direct payments and improving choice and control for older people suggests that the way services for older people have been configured and delivered presents a barrier to independent living through direct payments:

'It was otherwise difficult to creatively use direct payments, given the focus on "personal care" and the lack of hours for social activities when it came to assessed needs.' (Clark, Gough and Macfarlane 2004 p 3)

Systems designed to address the physical support needs of older people often cannot adapt to the needs of people living with dementia (Alzheimer Scotland 2010 and Goodchild 2011). Cultural assumptions about the types of life older people live can restrict the thinking of the older person, carer or staff on care and support for independent living rather than just for personal care. These assumptions can extend to blocking the progress of personal budgets for people living with dementia when practitioners advise 'that a move to a care home should be the next step in meeting a person's need' (Goodchild 2011 p 14). In these circumstances, the individual and the relative nature of independent living need to be understood:

'Independence means different things to different people including being able to do things alone, make decisions, and be in control of one's life. However, the relationship between choice and independence is not simple; choices that sustain independence in one aspect of life can create dependency in other domains, or restrict the independence of other people.' (Baxter, Rabiee and Glendinning 2011 p 1)

The need to transform social care services with a legacy culture and system that is not set up for older people's independent living is emphasised in research on personal budgets and direct payments for older people living with dementia. A key issue for promoting independent living remains the application of eligibility criteria. This can mean that older people – including those living with dementia – 'are not eligible for social care services until crisis point. At this time a personal budget may no longer be an option – for example if entry to a care home or hospital is necessary' (Alzheimer's Society 2011 p vi). This delay also affects the opportunity a person with dementia may have to make

their wishes known, as dementia is a degenerative condition where loss of capacity over time is a factor (Alzheimer Scotland 2010). Other key operational issues hindering older people with dementia from living independently include:

'...proportionately fewer resources in social care funding for older people compared to other groups... a propensity towards personal care, and an expectation that older people lead more restricted lives than younger adults' (Alzheimer Scotland 2010 p 10).

The finding on differences between services and support for younger and older adults is underpinned by research, which suggests that some local authorities have focused on younger people with dementia when developing personal budgets (Goodchild 2011 and Lightfoot 2010).

The Mental Health Foundation concluded that understanding dementia in terms of the mental health recovery approach, which is 'not about "cure" but about people finding a better way to live' (Goodchild 2011 p 10) with a condition, offers a way to understand supporting people living with dementia.

Overall, the principle of independent living means having choices, and research suggests that older people should be given a range of options for personalised care and support, including personal budgets and direct payments (Wood 2010, Alzheimer's Society 2011 and Orellana 2010). Independent living for older people may mean having to manage a fluctuating condition or sudden disability, which is very different from younger adults with more stable conditions or disabilities. Reflecting this, Age UK (Orellana 2010) has argued that older people might not want to take on a direct payment in the current system because:

- 'they often start using services following a crisis, at which point they may not be interested in taking responsibility for organising services or managing finances
- they are often coping with new or unstable levels of need, so are less likely than younger disabled people to know what support they will require either now or in a few months' time
- managing services to meet constantly changing needs is harder work than directing a stable care package' (Newbronner *et al* 2011 p 13)

Making choices and decisions

Research into how older people make choices about social care and support reveals this is a complex area. This is especially true in the context of personal budgets and direct payments, where informed or supported decisions need to be made at several stages. These stages were outlined in SCIE's commissioned research into the experiences of older people who had gone through the personal budgets process:

- initial decision to take up a personal budget or a direct payment
- assessment and resource allocation
- support planning

- setting up services
- managing the personal budget
- reviewing the personal budget and support plan.

(Newbronner *et al* 2011)

The Choice and Change research project at the Social Policy Research Unit (SPRU) looked at older people's and disabled people's experience of choice. It concluded that 'without appropriate recognition of, and support for, the challenges and difficulties involved in making choices, choice-based policies [such as personal budgets and direct payments] risk not just inequity but less than optimal outcomes' (SPRU 2011 p 19). The research specifically showed that:

- 'Having choice is important in improving health, maintaining independence and retaining chosen identities. However, exercising choice can be hampered by lack of information or acceptable options.
- Information is a precondition for choice; people are not always aware they have choices about services. People with gradually increasing support needs and no prior knowledge about services can be disadvantaged by their lack of access to relevant information at the pre-choice stage.
- The process of making choices creates some positive but mainly negative emotions. Negative emotions can lead to delays in making choices, thus also delaying any resulting benefits.
- People move in and out of using direct payments; sometimes an initial lack of support can result in people ceasing to use direct payments in favour of local council-commissioned services after relatively short periods. Direct payments users wanted more frequent contact with advisers; contact tended to reduce after initial reviews were completed.
- People revisit choices particularly after: changes in health or social circumstances; realising the outcomes of previous choices are not satisfactory; or interventions by professionals.
- People instigating revisions to choices of their own accord, and who have little contact with professionals, can lack support.
- People learn from both the processes and the outcomes of making choices. They share their learning with other people and learn from the experiences of others. However, opportunities for learning can be restricted for some people by the complexity of their conditions, or by limited life opportunities.'

(Baxter, Rabiee and Glendinning 2011 p 1)

There is a clear need for older people, carers and families to be able to make informed, supported choices at different stages of the process. This includes the initial decision to take a personal budget or direct payment, as well as reviewing support packages if circumstances change (which is particularly important for people with dementia, their

carers and families) (Newbronner *et al* 2011, OPM 2012a and Alzheimer's Society 2011): 'Increasing personal choice and control improves decisions, avoids the need for expensive resources, improves health and wellbeing, is rewarding for everyone involved, and ensures that older people get the right support at the right time for them' (NDTi 2011 p 1).

For some older people with dementia, assessment of capacity under the Mental Capacity Act 2005 may be necessary to support choice. However, this is a complex area and dementia is a condition where capacity can fluctuate (Alzheimer's Society 2011, McDonald 2010 and Alzheimer Scotland 2010). The Mental Health Foundation has noted that 'the legal issues concerning direct payments to people who lack mental capacity were proving to be an obstacle to delivering personal budgets to people with dementia, whether or not they required a direct payment or lacked capacity' (Goodchild 2011 p 3). The Alzheimer's Society also highlighted a lack of understanding of how to apply the Mental Capacity Act (2005) and its underlying principles. They recommend that for older people living with dementia who may lack capacity, decisions about care and support should 'fully engage the person with dementia where possible, based on the principles of the Mental Capacity Act, rather than as tokenistic discussion' (Alzheimer's Society 2011 p 43).

Information and advice

Evidence shows that having access to information, advice and support is the most important factor in making personal budgets and direct payments work for older people, their carers and families. It is highlighted as the chief facilitating factor in making personal budgets and direct payments work for people with dementia (Alzheimer's Society 2011, Goodchild 2011 and Alzheimer Scotland 2010). Information and advice is vital to achieving choice and control for older people: 'information and advice is not an add-on to the day job. It *is* the day job' (Horton 2009).

Research is beginning to reveal more about the different types of information and advice needed at different stages in the personal budget or direct payment process so that people can make the choice that is right for them. It shows that information and advice is not just limited to knowing what services and support are available at the time of planning. Awareness raising information and advice about the availability of personal budgets and direct payments is also needed to support people making choices about which personal budget option to take.

- To make fully informed choices – including whether to take up a direct payment or personal budget in the first place – older people need access to information and advice at each stage of the process (as highlighted above). Research into older people's use of information to make choices generally shows the importance of:
- Trusted sources of information including trusted people – 'Once trusting relationships had been built, professionals remained valued sources of information'.

- Ease of access to information – including social care teams at time of crisis, informal networks – ‘for older people it was particularly important to have easy access through family who often sought information on their behalf. Regular contact with professionals was also important’.
- Timeliness of information – ‘Accessing information at the right time was important, especially for people with fluctuating support needs for whom situations might change frequently’.

(Baxter and Glendinning 2011 p 276-277)

‘Peer advice and experience’ has been highlighted as a valued source of information (SPRU 2011 p 18), together with the role of user led organisations as providers of information and advice. These findings on information and advice sources have been echoed in the findings of the three-year longitudinal study of personal budgets in Essex which showed that ‘the support provided by family and friends... as a source of advice, information and advocacy has to date played a significant role in ensuring personal budgets have a positive impact on service users’ (OPM 2012a p 2). An investigation into how personal budgets might work for older people living in rural areas suggested that ‘a central task will be to inform rural networks that are in touch with older people because these may be trusted and accessible sources of information and advice’ (Manthorpe and Stevens 2010 p 1463).

Explorations of the uptake of personal budgets and direct payments suggest that older people are slowest to take up the direct payment option (Davey *et al* 2007 and Wood 2010) and that they are most likely to be on a ‘managed’ personal budget option (TLAP 2011). However, this may relate to the amount of knowledge older people have about the options available to them: ‘For older people, the figures are more worrying: 92 per cent reported knowing nothing or very little’ (Bartlett 2009 p 20). This indicates an urgent need to raise awareness of the options for older people. Elsewhere it has been shown that for direct payments ‘lack of information and support for the financial and administrative side of managing direct payments can lead to people reverting to conventionally provided services after relatively short periods of time’ (Arksey and Baxter 2012 p 161). So information and advice needs to be available to older people, their carers and families at the point of deciding whether to take up the personal budget option at all. SCIE’s commissioned research showed that when deciding on a personal budget:

‘Personal budget holders and carers emphasised the importance of clear and understandable information on what a personal budget is, how it can be used and what is involved in holding one’ (Newbronner et al 2011 p 4)

People use written, verbal and experiential information (Baxter, Rabiee and Glendinning 2011) and older people who had been through the personal budget process said that the following range of information would help them decide on a personal budget (PB), including a direct payment:

- ‘leaflets/booklets being written in plain English with minimum use of jargon
- providing information about different aspects of PBs in ‘bite-sized chunks’

- information being presented in a format that is accessible and manageable
- offering alternatives to written information (e.g. DVDs, podcasts)
- information tailored to the needs and interests of different groups of people who use services, with concrete examples of what the money might be spent on (following approval)
- information specifically designed for carers
- better information about the financial aspects of PBs.

While PB holders and carers valued having written information, it was usually the time spent discussing PBs with their social worker, community psychiatric nurse or support provider organisation that helped them the most. A number of factors enhanced the experiences of PB holders and carers:

- practitioners had a sound understanding of PBs and could talk about the process of taking up and managing a PB clearly and knowledgeably
- people felt they were being listened to and PBs were being discussed with them in relation to their lifestyles and circumstances
- there was adequate time for issues to be explained/explored and questions covered
- there was scope for more than one discussion, allowing time to digest written information in between discussions, with information being repeated if necessary’.

(Newbronner *et al* 2011 p 4–5)

Research into direct payments, including use by older people, showed the vital nature of practitioner knowledge in helping older people decide on the option: ‘social workers need to give up-to-date information to potential recipients about the use of direct payments, associated management activities and any administrative support available’ (Arksey and Baxter 2012 p 161).

Once the older person has made a fully informed decision on whether to opt for a personal budget approach, they should then be given access to sufficient information and advice about the options available to them, including a direct payment. The principle of independent living underpins the direct payment process: ‘Expressions of initial uncertainty about a direct payment should not automatically be taken as indicating the unsuitability for this option. Rather, this should highlight the need to find out [what is causing concern] and [to identify practical support]... when the option is explained fully and people have been able to consider it in their own time, many older people respond very positively to the benefits which direct payments can offer’ (Hasler and Zarb 2001 p 4).

The evidence shows the importance of frontline staff to be up-to-date with knowledge about options: ‘If people considering their options for social care support are to be helped to feel confident, professionals, particularly those advising on direct payments and personal budgets, need to maintain their knowledge levels’ (Baxter, Raibee and Glendinning 2011 p 4). However, the IBSSEN study of the individual budgets (IB) pilot

indicated that this might be culturally challenging for some: ‘care managers working with older people tended to be relatively paternalistic, protective and risk-averse, and did not feel that older people could cope with managing an IB and did not want to “burden” them with extra responsibilities’ (Moran *et al* 2012 p 17). The attitude of workers presenting options was also highlighted in research on personal budgets for people living with dementia (Alzheimer Scotland 2010). The need for staff training, particularly in dementia, is vital (Goodchild 2011).

SCIE’s commissioned research shows what helps older people decide on which personal budget option to take:

‘Decisions about how to manage the PB can have a powerful knock-on effect in terms of the ways in which people can exercise choice and control. PB holders emphasised the importance of ensuring people were able to make informed decisions about which option would be best for them and the support they would need to make it work. There was concern among support providers and some LA/trust staff that many PB holders, especially older ones, were being steered away from direct payments and towards managed accounts or services commissioned by the LA. PB holders, staff and providers suggested this could be addressed by:

- ensuring staff have time to discuss different deployment options (fully, at an early stage and more than once) with potential PB holders
- using staff training to break down assumptions about which deployment option may ‘suit’ any particular group of service users
- providing information about deployment options throughout the PB process
- a much more flexible interface between reablement and people taking up a PB
- a much more flexible approach to reviews so that people could initially opt for commissioned services but move to other options at a later date without having to be reassessed
- making it much easier for PB holders to move between management options as their needs change or their condition fluctuates
- providing clear information about the support available to people for managed accounts and direct payments, and allowing time for staff to discuss this with PB holders
- providing opportunities for PB holders, particularly those who have opted to have their PB as a direct payment, to share experiences with potential PB holders’.

(Newbrunner *et al* 2011 p 9–10)

Direct payment support services

Personal budgets and direct payments can work well for older people (including those living with dementia), their carers and families if the right information and support to use and manage the budget is available (Carr 2010). This includes knowing about and being able to access direct payment support services to help with support planning, budget

management, brokerage and aspects of recruitment and employment of staff such as PAs (Clark, Gough and Macfarlane 2004, Orellana 2010, Alzheimer's Society 2011, Goodchild 2011 and Arksey and Baxter 2012). Anxiety and concern about organising and managing budgets and staff is highlighted in the research as being a particular factor for older people, their carers and families (Carers UK 2008 and Moran *et al* 2012) so 'support in managing the financial and administrative demands [is] identified as crucial in making direct payments work for older people' (Clark, Gough and Macfarlane 2004 p 2).

Bearing in mind that the underlying principle of direct payment is to promote independent living, it has been emphasised that: 'some older people may need considerable help with managing either the money or workers. It is important not to view the need for assistance as a problem. Keep in mind what payments are for – focus on how to make them work. A person can have as much (or as little) assistance with managing a payment as she wants' (Hasler and Zarb 2001 p 2-3). The importance of having ongoing as well as initial access to such support has been emphasised (Arksey and Baxter 2012 and Goodchild 2011).

The type of support offered by user-led organisations (ULOs) has been highlighted as being particularly effective if they have the capacity to meet the needs of older people (particularly those with dementia), their carers and families. Research shows that given the right investment and capacity building, 'support planning was experienced by service users as more "human" when delivered by a ULO than by a local authority, with less bureaucracy involved' (NDTi 2011a p 1). Age UK research findings show that 'staff [must] be proactive, making themselves aware of support planning and brokerage services in their area and passing information on to older people to enable them to make choices' (Orellana 2010 p 6), which would include ULOs and specialist services for carers and older people living with dementia. For people living with dementia, their carers and families it has been suggested that independent advocacy services have a role to play (Goodchild 2011) and that making links with local dementia advisors in health is an important way to provide an integrated approach to support for those using personal budgets including direct payments (Lightfoot 2010).

Experiences of older people and direct payment and personal budget support provider organisations suggest that the experience for the budget holders could be enhanced if there were:

- 'clear referral mechanisms and protocols to and from the LA (local authority) with scope to expand the involvement of support providers
- multiple referral routes to providers from all types of community organisation
- outreach activity/'warm-up' meetings facilitated by providers to enhance peer support
- stronger emphasis on the direct accountability of providers when they tender for LA contracts
- more joint training between support providers and LA staff
- more opportunities for LAs and local support providers to exchange ideas and information, and so increase mutual understanding and trust

- a closer working relationship between providers and care managers to promote their role and encourage referrals
- an integrated support network from which PB holders could choose to obtain support at all stages of the PB process’.

(Newbronner *et al* 2011 p 7–8)

Understanding allowance and spend

Evidence suggests that older people’s personal budget allowance and spend is different to that of younger personal budget users, even if they opt for a direct payment (Davey *et al* 2007, Glendinning *et al* 2008, Bartlett 2009, Wood 2010 and Moran *et al* 2012). An analysis of findings on older people from the IBSEN individual budget (IB) pilot study (Glendinning *et al* 2008) summarises the situation:

*‘Per capita social care funding for older people is lower than for equivalent levels of impairment in younger age groups [Forder 2008]. This raises the question of whether, when funding is comparatively low for the level of need, it is simply not possible to take advantage of the potential flexibilities of IBs. It is certainly observed that older people tended to make less use of innovative approaches to support and deployment options [Glendinning *et al* 2008]. This might help explain the lack of a positive impact of IBs on older people and, if so, challenge the potential for achieving better outcomes at a time of financial austerity’ (Netten *et al* 2011 p15).*

Research on both personal budget and direct payment spending choices for older people show that these are often restricted to traditional or basic forms of support like personal care, home care and sometimes equipment or adaptations (Glendinning *et al* 2008, Bartlett 2009, Moran *et al* 2012 and OPM 2012b). Studies show that older people are less likely to use a personal budget or direct payment for more creative or innovative support and activity, and this could be down to a range of factors including:

- the limited expectations or confidence of the older person, their carers and family or practitioners
- the continued use of the traditional care management model in older people’s services, with the practitioner deciding need, entitlement and support
- the over-focus on personal care for older people
- assessments based on service hours rather than outcomes
- the size of the personal budget or direct payment allowance
- the impact of eligibility criteria
- the degree and quality of support an older person, their carers and family get to think more creatively at the planning stage
- broader cultural issues of expectations that older people have restricted lifestyles

- choice limited by availability of services and diverse support and/or activity options (including rural location and people living with dementia)
- concerns about the quality and safety of different support options
- operation of the Resource Allocation System (particularly whether ‘carer neutral’ or not).

Early investigations into how direct payments can work for older people identified the challenge of limited budgets and the possibilities to use them in creative or preventative ways.

‘It was otherwise difficult to creatively use direct payments, given the focus of “personal care” and the lack of hours for social activities when it came to assessed needs.’ (Clark, Gough and Macfarlane 2004 p 3)

However, research has shown the positive and cost-effective impact on wellbeing and prevention that low-level services and support can have for older people (Centre for Policy on Aging 2011). It also reveals that ‘having access to social activities is centrally important for older people’ (Orellana 2010 p 5). The National Market Development Forum has identified the difficulty of achieving market diversification, innovation and choice for older people because care and support services are often tied up in long term block contracts that have not been decommissioned (IPC 2011). The Alzheimer’s Society have recommended that for personal budgets and direct payments to work for older people living with dementia, their carers and families, ‘it is vital to improve the type and quality of services and forms of support available... particularly with early intervention and prevention services and specialist support for people in their own homes’ (Alzheimer’s Society 2011 p 41).

Budget management, monitoring and review

There is evidence that managing a personal budget – particularly the direct payment option – is a crucial area for success for older people, including those living with dementia, their carers and families: ‘older people reported anxieties about the responsibility of organising their own support and managing their budget’ (Moran *et al* 2012 p 1). Managing a budget directly can be perceived or experienced as an administrative burden or too much of an additional responsibility (Arksey and Baxter 2012, OPM 2012a, Alzheimer Scotland 2010 and Carers UK 2008). As noted, information must be available on the options for taking a personal budget and an informed discussion should take place with a knowledgeable, trained practitioner before a decision is made. Research suggests that those opting for a direct payment can find budget management one of the most challenging aspects, particularly if they do not have good information and ongoing access to support and advice.

A frequent deciding factor is whether or not the older person had support from a family member, friend or carer to manage their budget: ‘a number of service users noted that older people who did not have a family member who was able to take responsibility for the management of the personal budget would find the additional administrative burden quite difficult and that this in fact would make them less willing to opt for self-managed personal budgets [or direct payments]’ (OPM 2012b p 3). This was particularly true for

older people who were very frail or were living with dementia, where a 'suitable person' can hold a direct payment on someone's behalf if they lack capacity to manage their own money (Newbronner *et al* 2011 and Alzheimer Scotland 2010).

The use of the Mental Capacity Act (2005) may be needed to ensure older people who may lack capacity are properly engaged (Alzheimer's Society 2011). The Mental Health Foundation recommends that in accordance with official guidance on direct payments for people who lack capacity, practitioners should carry out 'checks to establish whether there is a person who is prescribed as a Representative in relation to a service user, a Deputy appointed by the Court of Protection, done or registered Lasting Power of Attorney relating to welfare decisions and/or property affairs' (Goodchild 2011 p 16).

Research shows that older people and their carers can benefit from the ongoing support of a social worker or a direct payments support provider such as a user-led organisation (Newbronner *et al* 2011 and Moran *et al* 2012). Clear guidance about monitoring arrangements, clarity, degrees of flexibility about budget spend and carry over, and access to ongoing advice is important (Arksey and Baxter 2012). Older recipients and their carers could be concerned about 'getting it wrong', particularly with over- or under-spending (Moran *et al* 2012). The experience of older people who have been through the personal budget process suggests the following could make budget management easier for personal budget (PB) and direct payment holders:

- 'clear guidance about what is expected in terms of records and paperwork
- optional training for PB holders and carers in "managing your PB"
- having a nominated person in the local authority direct payments team with knowledge of individual cases that PB holders and their carers could contact in the event of problems
- not having to keep receipts for small items of expenditure
- clear information about how under-spends will be dealt with
- alternative ways of carrying out audits (e.g. a home visit) for those receiving high PBs.'

(Newbronner *et al* 2011 p 11)

Research from Age UK shows that 'outcomes for older people on personal budgets should be monitored to ensure effectiveness and satisfaction. Monitoring and review of support should be regular and frequent to take account of rapidly changing circumstances' (Orellana 2010 p 6). However, emerging evidence suggests there can be some confusion and apprehension among people living with dementia and their carers about the support review, which includes a review of the personal budget. They are concerned about two main aspects: triggering a review when needs and/or circumstances change and anxiety that a review will result in a reduction in funding and therefore support. Again the solution focuses on the need for continuing access to clear, consistent information and advice:

'People need easy access to on-going advice and support as their situations and capabilities change. Situations can arise in which direct payments recipients need advice about their continued entitlement to direct payments, or whether or not the award can be "topped up" from other existing sources of funding. In relation to fluctuating health needs, recipients can sometimes be too frightened to

ask for advice as they do not want to risk a reduction in their present level of award.’ (Arksey and Baxter 2012 p 160–161)

Experience from the Essex longitudinal study of personal budgets highlighted a challenge faced by budget holders, their carers and families – when the review process is not responsive to changing needs and is fixed, e.g. annually. These arrangements mean that service users and/or carers cannot organise a review when they need it (OPM 2012b). This barrier seems to be particularly acute for people living with dementia, their carers and families because dementia is a fluctuating condition where deterioration and an increase in support needs can occur quite quickly (Alzheimer Scotland 2010, Alzheimer’s Society 2011 and Goodchild 2011). SCIE’s commissioned research suggested that: ‘generally older PB holders and carers seemed unclear about when reviews should take place, and the division of responsibility between the local authority and the [personal budget and direct payment] support provider (if they used one) was not always clear to them. There was also anxiety about the practice of “closing” cases because PB holders and carers wanted to be able to re-contact the social worker that knew their circumstances (Newbrunner *et al* 2011 p 62). The Essex study recommended that ‘local authorities should be clear with service users about when a review should be instigated and by whom’ (OPM 2012b p 5).

Risk management and contingency planning

Staff concerns about risk can lead to older people not being offered the direct payment option, or a restricted range of support choices. One regional research and development project showed that a ‘risk averse culture is a major block to staff supporting people with dementia in the community via [direct payments and personal budgets]. This is by far the largest obstacle’ (Lightfoot 2010 p 9). It has been suggested that, to overcome this, local authorities should develop ‘a risk assessment tool that can be used to help practitioners identify “actual risk” as opposed to “perceived risk”’ (Lightfoot 2010 p 11). The evidence shows ‘the importance of knowing the person, their relationships and circumstances... on self-directed support for older people, as has the role of the voluntary sector, community resources and peer support in safeguarding’ (Carr 2010 p 30) for older people. Positive risk taking and concerns about safety should be part of the conversation during the personal budget assessment and support planning process. This requires support and leadership from management and the organisation (Carr 2010, Lightfoot 2010 and Newbrunner *et al* 2011). Continuity and consistency are also relevant to effective risk assessment, as highlighted below.

Several studies and reports mentioned the importance of contingency planning for older people using personal budgets and direct payments. This ranged from having back up cover for care and support if arrangements with a directly employed support worker or PA broke down or the worker needed to take time off sick (Arksey and Baxter 2012 and Alzheimer’s Society 2011) to maintaining a contingency fund from possible under-spend (Newbrunner *et al* 2011). The need to make contingency plans has been highlighted for people living with dementia and their families (Alzheimer’s Society 2011). Carers UK recommend that ‘local authorities should have appropriate back up and contingency plans in place before a carer is required to manage the direct payment independently’ (Carers UK 2008 p 10). Similarly for older people living in close-knit rural communities or in relative isolation in rural settings, there is a ‘need for contingency planning for

emergencies and breakdowns in caring arrangements' (Manthorpe and Stevens 2010 p 1460). Research has found that older people and their carers are more likely to want and benefit from contingency planning and would like it to be strengthened in the process, suggesting that:

- 'contingency arrangements should be discussed and recorded during assessment and, if appropriate, documented in the support plan
 - PB holders should be allowed to keep unspent contingency funds at the end of the year
 - when contingency arrangements have to be put in place, staff and carers should be enabled to do this without a reassessment being required
 - an authority-wide contingency budget should be established for those with high-care needs, so that staff can draw from it to set up additional support in a crisis.'
- (Newbronner *et al* 2011 p 6–7)

Time

Time was seen to have a significant impact on the successful implementation of personal budgets and direct payments for older people (particularly those living with dementia), their carers and families. Age UK have noted that in implementing personal budgets and direct payments for older people 'time spent learning from the experiences thus far is time well invested' (Orellana 2010 p 5). There were also two distinct areas where time was seen to have an impact on how well a personal budget or direct payment could work: sufficient time to explore and discuss all options at the beginning to create a support plan, and a reduction in the length of time and delays in local authority decision-making over assessments, support plans or reviews (Newbronner *et al* 2011).

A longitudinal study of personal budgets in Essex showed that service users, including older people, can experience stress and anxiety 'when there are delays in receiving the personal budget, either initially when the budget is set up or following a change of circumstances or a review' (OPM 2012b p 4). There were similar findings from a Carers UK study, which found that the application process for a direct payment was often too long (six months to one year) when 'need is great', and sometimes increasing (Carers UK 2008). Emerging findings about the effect of administrative and local authority decision-making delays on people living with dementia are of particular concern: 'processing of direct payment applications is too slow in some authorities for people nearing long term care, taking up to 6 months to get the packages up and running. Long timescales have a bigger impact upon people with dementia than others who have more stable impairments' (Alzheimer Scotland 2010 p 47). Another time factor for people living with dementia relates to eligibility thresholds for personal budgets including direct payments, which are often only met when the person's 'condition has deteriorated, thus limiting the opportunity to arrange support in a planned way and have the person's view taken into account' (Alzheimer Scotland 2010 p 37). Carers UK recommend local authorities 'speed up the application process [by cutting] waiting times and [simplifying] the application process' (Carers UK 2008 p 9).

Continuity and consistency

A significant emerging theme to come from the research is the importance of continuity and consistency in relation to providing support and advice to older personal budget or direct payment users and to people providing the personal care and assistance to the older person. This is particularly emphasised for older people living with dementia.

Evidence suggests that when older people have moved onto direct payments, they receive support at the set-up and planning stage, which then reduces dramatically. This lack of access to continuing support and advice is noted as one of the major frustrations with direct payments. Budget holders would benefit from more continuing input from advisers (Arksey and Baxter 2012). Carers UK say that 'families should not be abandoned but should be reassured through regular contact' (Carers UK 2008 p 10). However, to make personal budget and direct payments work well for them, older people, their carers and families constantly report that: 'having one consistent social worker as a point of contact has lots of positive impacts associated with personal budgets. In particular, they felt that having one contact meant they were able to start receiving payments quickly, have a review of their needs when necessary, receive an adequate level of personal budget and also were able to access advice and guidance when necessary' (OPM 2012c p 5). This finding is consistent with other research, which highlights the need for 'continuity of staff in the self-assessment and support planning processes [and] a named member of staff (or team) familiar with the PB holder's circumstances' (Newbrunner *et al* 2011 p 7-8) and for 'one point of contact to advise recipients throughout the process' (Alzheimer Scotland 2010 p 36). This is also emphasised in evidence on risk enablement and safeguarding in self-directed support and personal budgets (Carr 2010).

For older people in need of support for personal care and activities, being able to employ a consistent person or people that they can develop a relationship of trust with was shown to be a valued aspect of having a direct payment (OPM 2012b): 'building up a relationship with one care worker was expected to promote dignity and privacy, enhance senses of safety and security and improve the quality of support' (Moran *et al* 2012 p 13). This is shown to be particularly helpful for older people living with dementia: 'using direct payments provided familiarity: it allows the opportunity to employ someone who is known to the person with dementia, and it can also keep the person in familiar surroundings with recognisable things around them' (Alzheimer Scotland 2010 p 29).

Although there are concerns about employing known people like friends or family members, which should be explored at the beginning of the planning stage and built into possible future contingency plans (Arksey and Baxter 2012), older people living with dementia, some older people from black and minority ethnic communities and older people living in rural communities report that this can result in more positive outcomes for both them and their carers and families (Moran *et al* 2012, Manthorpe and Stevens 2010, Carers UK 2010, Alzheimer Scotland 2010 and Carers UK 2008).

Older people living with dementia: data and systems

Many of the main messages for improving personal budget and direct payment uptake and use by people with dementia are common to the issues for older people in general. However, there are some additional specific issues that need to be addressed, some of which have already been highlighted. The Mental Health Foundation research recommendations included recognising that the situation and some of the challenges for older people with dementia, their carers and families is different from older people without the condition (Goodchild 2011). One issue is the involvement of both the NHS and the local authority in care and support for older people living with dementia. The recommendation states that 'mental health trusts and local authorities should explore the opportunities that personal budgets and personal health budgets present to people with dementia and develop systems that maximise effective implementation of both budgets' (Goodchild 2011 pc19). Research highlights the fact that personal budgets cannot be approached as a 'one size fits all' for older people with dementia (Goodchild 2011 and Alzheimer's Society 2011), particularly as dementia is distinct from a stable physical, sensory or learning disability and 'delays in providing a direct payment are therefore especially problematic... dementia is a progressive illness with needs increasing over time. There is a need for timely intervention in response to changing and increasing care needs' (Alzheimer Scotland 2010 p 49). The effective use of the Mental Capacity Act (2005) for supporting decision-making and the options to appoint a 'suitable person' as a proxy budget holder have already been highlighted.

Most significantly, research on direct payments and personal budgets for people living with dementia in England strikingly revealed that there appears to be no data being collected about people living with dementia who are receiving personal budgets or direct payments (Alzheimer's Society 2011, Goodchild 2011 and Lightfoot 2010). This is reflected in the wider issue about patchy local authority data collection on personal budgets and direct payments (Audit Commission 2010). The Alzheimer's Society have emphasised the crucial need to address this lack of data and knowledge about older people living with dementia:

'There is a lack of robust data at a national and local level on access to direct payments or personal budgets for people with dementia. This presents a real challenge to opening up the system for this group. Accurate data is vital and must include overall numbers, as well as drilling down into exactly who is accessing the system and which personal budget options are being used' (Alzheimer's Society 2011 p v)

Conclusion

Older people, their carers and families can benefit from personal budgets and particularly direct payments if they have the information, advice and support they require to empower them to use their budgets to exercise greater degrees of choice and control over their care and support: 'for older people to benefit fully from cash for care schemes they need sufficient resources to purchase more than basic personal care; and access to help and advice in planning and managing their budget' (Moran *et al* 2012 p 1). However, the evidence shows that the two main challenges for implementing personal budgets and direct payments for older people, including those with dementia, are 'a lack of information about personal budgets and direct payments and a concern about taking on the burdens that direct payments can bring' (Alzheimer's Society 2011 p 37). Research is therefore suggesting that 'more people with dementia and carers could benefit from direct payments than currently do, although this is only appropriate if the right support is in place which eliminates the reported burdens' (Alzheimer's Society 2011 p iii). The majority of older people who receive personal budgets and direct payments are using them for personal care rather than to support social and community activities. Issues concerning eligibility criteria, level of budget funds, understanding older people's independent living, service configuration and provision for older people and expectations about care and support need to be recognised and addressed.

The present generation of older people may be different from the coming generations in terms of expectations, but for now it appears that 'people in later life are less likely to want to take on responsibility for managing their budget and organising their care and support themselves, but they do welcome the opportunity to exercise choice and control over the care and support they receive' (Orellana 2010 p 5). This offers a challenge for increasing the use of direct payments by older people. But the evidence shows that older people, their carers and families (and indeed all people) using direct payments will need access to clear, consistent information and advice in many formats, most particularly in the 'human' form (i.e. a peer or a practitioner), time and support services to help them plan support, manage the budget and to confidently instigate rapidly responsive reviews when needs and circumstances suddenly change, as they do for older people living with dementia. Current systems and cultures in local authorities and health do not appear to be supporting people living with dementia, their carers or families to use personal budgets to their best effect: 'the reasons for slow implementation are complex and multi-layered across the local authority culture, strategic planning, organisational infrastructure and operational systems' (Goodchild 2011 p 19).

References

Age Concern London (2010) *Rhetoric or reality? Care personalisation choices for older Londoners*, London: Age Concern London.

Alzheimer Scotland (2010) *Let's get personal – personalisation and dementia*, Edinburgh: Alzheimer Scotland.

Alzheimer's Society (2011) *Getting personal? Making personal budgets work for people with dementia*, London: Alzheimer's Society.

Arksey H and Baxter K (2012) 'Exploring the temporal aspects of direct payments', *British Journal of Social Work* 42, pp 147–164.

Audit Commission (2010) *Financial management of personal budgets: challenges and opportunities for councils*, London: Audit Commission.

Bartlett J (2009) *At your service: navigating the future market in health and social care*, London: Demos.

Baxter K and Glendinning C (2011) 'Making choices about support services: disabled adults' and older peoples' use of information', *Health and Social Care in the Community* 19(3), pp 272–279.

Baxter K, Rabiee P and Glendinning C (2011) *Choice and change: disabled adults' and older people's experiences of making choice about services and support*, York: SPRU.

Carers UK (2008) *Choice or Chore? Carers' experiences of direct payments*, London: Carers UK.

Carers UK (2010) *Half a million voices: Improving support for BAME carers*, London: Carers UK.

Carr S (2011) 'Personal budgets and international contexts: Lessons from home and abroad', *Journal of Care Services Management* 5 (1), pp 300–322.

Carr S (2011) 'Enabling risk and ensuring safety: personal budgets and self directed support', *Journal of Adult Protection* 13 (3), pp 122–136.

Clark H, Gough H and Macfarlane A (2004) *Rowntree Foundation Findings 234: Making direct payments work for older people*, Joseph York: Joseph Rowntree Foundation.

Centre for Policy on Ageing (2011) *How can local authorities with less money support better outcomes for older people?* York: Joseph Rowntree Foundation.

Davey V, Fernández J L, Knapp M et al (2007) *Direct payments: a national survey of direct payments policy and practice*, London: PSSRU/London School of Economics.

Glendinning C, Challis D, Fernandez J, Jacobs S, Jones K, Knapp M, Manthorpe J, Moran N, Netten A, Stevens M and Wilberforce M (2008) *Evaluation of the individual budgets pilot programme: final report*, York: SPRU University of York.

Goodchild C (2011) *Personal budgets for people with dementia*, London: Mental Health Foundation.

- Hasler F and Zarb G (2001) 'Direct payments and older people: the principles of independent living', *Research, Policy and Planning* 18(2), pp 1–7.
- Horton C (2009) *Creating a stronger information, advice and advocacy system for older people*, York: Joseph Rowntree Foundation.
- IPC (2011) *National Market Development Forum Papers*, Oxford: IPC.
- King's Fund (2006) *Wanless Social Care Review: Direct Payments and Older People*, London: King's Fund.
- Lightfoot T (2010) *Project Manager for Dementia: to increase awareness and uptake of Direct Payments and Personal Budgets – Final evaluation and lessons learned*, London: Department of Health/ADASS/Joint Improvement Partnership for the East of England.
- Manthorpe J & Stevens M (2010) 'Increasing care options in the countryside: Developing an understanding of the potential impact of personalisation for social work with rural older people', *British Journal of Social Work* 40, pp 1452–1469
- McDonald A (2010) 'The impact of the 2005 Mental Capacity Act on social workers' decision making and approaches to assessment of risk', *British Journal of Social Work* 40, pp 1229–1246.
- Moran N, Glendinning C, Wilberforce M *et al* (2012) 'Older people's experiences of cash-for-care schemes: evidence from English Individual Budget pilot projects', *Ageing and Society* doi:10.1017/S0144686X12000244.
- NDTi (2011) *NDTi Insights 9: Increasing the voice, choice and control of older people with high support needs: Lessons from SERI*, Bath: NDTi.
- Netten A, Jones K, Knapp M *et al* (2011) 'Personalisation through Individual Budgets: Does it work and for whom?', *British Journal of Social Work Advance Access published November 21 2011* doi: 10.1093/bjsw/bcr159.
- Newbrunner L, Chamberlain R, Bosanquet K *et al* (2011) *SCIE Report 40: Keeping personal budgets personal: Learning from the experiences of older people, people with mental health problems and their carers*, London: SCIE.
- OPM (2012a) *Briefing paper 4: Family, friends and personal budgets – Findings from the third round of a three-year longitudinal study in Essex*, London: OPM.
- OPM (2012b) *Briefing paper 3: Ways to improve the impact of personal budgets – Findings from the third round of a three-year longitudinal study in Essex*, London: OPM.
- OPM (2012c) *Briefing paper 2: Factors that facilitate personal budgets to have a positive impact – Findings from the third round of a three-year longitudinal study in Essex*, London: OPM.
- Orellana K (2010) *Personalisation in practice: lessons from experience, Making personal budgets, support planning and brokerage work for older people in later life*, London: Age UK.
- SPRU (2011) *Choice and independence over the lifecourse: Final report to the Department of Health*, York: SPRU University of York.

TLAP (2011) *Personal budgets: taking stock, moving forward*, London: TLAP.

Wood C (2010) *Personal Best*, London: Demos.

Appendix

Project Steering Group

Dwayne Johnson, Strategic Director, Health and Community - Halton Borough Council

Iain McBeath, Assistant Director, Health and Community Services - Hertfordshire County Council

Ian McCreath, Personal Choice Programme Implementation Manager – Alzheimer's Society

Guy Patterson, Project Officer – Age UK

Martin Routledge, Programme Manager – Think Local Act Personal (TLAP)

Dame Philippa Russell, Chair - Standing Commission on Carers

William Vineall, Deputy Director of Social Care Policy and Innovation – Department of Health

Bridget Warr, Chief Executive – United Kingdom Home Care Association (UKHCA)

Dawn Warwick, Director of Adult Social Services – Wandsworth Council

Making personal budgets work for older people and older people living with dementia: A UK evidence overview

This short report is an evidence overview of key pieces of UK research between 2007 and 2012, which focused on the implementation and uptake of personal budgets and direct payments for older people (including those with dementia) in England. It is not a systematic research review or an exhaustive examination of published research on the topic. Rather, it aims to give an overview of the main themes of research findings which help to identify the challenges and solutions to improving choice and control for older people (including those living with dementia) through the use of personal budgets and direct payments.

Social Care Institute for Excellence

Fifth Floor
2–4 Cockspur Street
London SW1Y 5BH
tel 020 7024 7650
fax 020 7024 7651
www.scie.org.uk