

Getting personal? Making personal budgets work for people with dementia



Document purpose	This report has a focus on personal budgets (including direct payments). It presents new evidence on the benefits and challenges of using personal budgets and direct payments, as described by people with dementia and carers. This evidence is intended to support the commitment to ensure personal budgets for all by 2013 in England and the work already beginning to take place within local authorities to make this happen. It is also intended to support the discussions around personalised care and the use of personal budgets happening in Wales and Northern Ireland.
Title	Getting personal? Making personal budgets work for people with dementia
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Target audience	This report is intended for everyone working towards meeting the 2013 commitment for personal budgets for all in England, including commissioners, providers and professionals. It is also for those thinking about personal budgets in Wales and Northern Ireland. It will also be relevant for people working towards wider social care reform.
Acknowledgements	<p>Alzheimer's Society would like to thank the people with dementia and carers who generously offered their time and views by taking part in our focus groups and telephone interviews. We would also like to thank everyone who took part in the survey that informed the Support. Stay. Save. report published in January 2011. All of the information and evidence provided by them has made this report possible.</p> <p>We would also like to thank everyone who reviewed the report and provided feedback – your input was invaluable.</p>
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Executive summary

Personalisation is intended to transform social care by putting people at the centre of their own care so that they have independence, choice and control over the services they use. Personal budgets continue to be a key way of delivering the personalisation agenda in England. Discussions around the use of personal budgets (particularly direct payments) are also happening in Wales and Northern Ireland.

A personal budget describes the amount of money that a council decides to spend in order to meet the needs of an individual eligible for publicly funded social care. It can be taken by the eligible person as a managed option by the council or third party, as a direct (cash) payment or as a combination of these options. At their simplest level, personal budgets involve a discussion with the service user/carer about how much money has been allocated to meet their assessed care needs, how they would like to spend this allocation and recording these views in the care plan.

The coalition government has made a commitment that everyone receiving social care services will be in receipt of a personal budget by April 2013. However, in the first three years, the focus has been on older people, and people with learning disabilities, mental health issues and physical disabilities. The specific issues faced by people living with dementia have therefore not always been addressed.

It must be acknowledged that councils are working towards the 2013 ambition and considering how to meet the needs of all individuals eligible for publicly funded social care to make this happen. As part of this work there must be a specific focus on people with dementia and carers. If this focus is not applied there is a risk that people with dementia and carers will not receive the intended benefits of personal budgets. This report is intended to support the work taking place to meet this commitment in England and inform developments in Wales and Northern Ireland. It presents new evidence on personal budgets from the perspective of people with dementia and carers and includes case studies highlighting people's experiences. Evidence is from a survey sent in late 2010 to people with dementia and carers as part of Alzheimer's Society's report *Support. Stay. Save.* (2011) and focus groups and telephone interviews conducted in 2011 with people with dementia and carers.

The evidence shows that there are clear benefits to people with dementia and carers using direct payments, but that accessing and using them can also be a big burden. Alzheimer's Society believes 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.

However, the evidence also shows that direct payments will not be suitable for all people with dementia and carers. In these cases, every person with dementia and their carer still wants choice and control over the services they use in the way that is most appropriate for them. In England, this means that options other than a direct payment must be available. These 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. In Wales and Northern Ireland a similar system that allows people to be involved in their own care planning is needed to ensure personalised services.

There are currently barriers that prevent people with dementia and carers accessing the range of personal budget options. These include a system that has not yet adapted to the needs of people with dementia and carers, and a lack of understanding and information on personal budgets for people with dementia, carers and professionals. In addition, there are wider barriers such as a lack of funding in the social care system and strict eligibility criteria. There is a risk that personal budgets are seen as a cure-all for the social care system but social care reform is necessary to address these wider barriers.

The government White Paper due in spring 2012, which is intended to reform social care, is a key way that a change in dementia care can be delivered in England. In addition, the Sustainable Social Services for Wales framework (Welsh Assembly Government, 2011a) and the current Review of the Provision of Health and Social Care services in Northern Ireland (see www.dhsspsni.gov.uk/hsc-provision.htm) must ensure that the needs of people with dementia are addressed.

Key findings

Access to direct payments or personal budgets

A survey for Support. Stay. Save. (2011) was conducted in late 2010 and surveyed people with dementia and carers across England, Wales and Northern Ireland. In total there were 1,432 respondents. The survey asked whether the person with dementia is using a direct payment or personal budget to buy social care services.

- 204 respondents said that they were using a personal budget or direct payment to purchase services and care. In total 878 respondents had been assessed and were receiving social services support, meaning that 23% of eligible respondents were using a personal budget or direct payment arrangement.
 - A further 15% (130 out of 878) said they had been offered a direct payment or personal budget but had declined.
 - 60% (855) of the total number of respondents to the survey reported they had not been offered a personal budget. This includes people who would not have been eligible for publicly funded social care.
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- People who lived alone appeared to be less likely to be offered, or use, direct payments or personal budgets than those who lived with a carer.
- Younger people with dementia and their carers appeared more likely to have been offered, and be using, direct payments or personal budgets than older people 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 to 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.

Evidence on the use of direct payments

The views and experiences shared by people with dementia and carers, collected via the Support. Stay. Save. survey were clearly in reference to the use of, and perceptions about, direct payments. In addition, the focus groups conducted in 2011 to further inform the evidence base sought the views of people with dementia and carers on direct payments in particular. The following key findings are therefore about direct payments in particular.

How people with dementia and carers are using direct payments

- Direct payments are used particularly to purchase care staff in the home (27%), personal care (22%) and respite services (sitting service 14%; respite care 21%), but also for support such as cleaning and gardening, and for holidays.

Perceptions of the support received through a direct payment

Survey respondents using direct payments were more satisfied with particular aspects of their care and services than those not using direct payments. In particular they were:

- more likely to say they have received enough information; that the person with dementia is getting all the support they need; and that services made life easier
- more satisfied with support received at an early stage and that services were focused on meeting the person's specific needs
- more satisfied with particular services: help with household tasks (such as cleaning, gardening, shopping); care workers who visit (to help with personal care or provide support in the home during the day or night) and visits from care managers, social workers and occupational therapists.

However, problems were experienced in terms of acquiring and using a direct payment. For example, the process was seen as stressful and there was a lack of information. In addition, there was no indication that survey respondents had found services more flexible.

The views of people with dementia and carers who had been offered but were not using direct payments

The survey asked respondents why they did not take up the offer of a direct payment.

The top four reasons people gave were:

- 31% (28): hard enough to cope as it is
- 14% (13): not confident managing direct payments
- 13% (12): happy/satisfied with present arrangement
- 11% (10): too complicated/difficult.

The views of people with dementia and carers who had not been offered direct payments

Those who had not been offered a direct payment were asked what they felt might be the potential risks and benefits. The top five views were:

- 17% (78): able to choose own services
- 14% (64): open to abuse
- 14% (64): do not understand money matters
- 13% (62): don't know what it is
- 11% (50): adds to responsibilities of carers/more stress/workload.

The key barriers to people with dementia and carers accessing personal budgets

The key barriers that have emerged from the evidence gathered for this report and from previous research are:

- a personal budgets system that has not yet adapted to the needs of people with dementia and their carers, and is overly complex and burdensome
 - a lack of appropriate support to enable people with dementia and carers to use direct payments
 - a lack of information for people with dementia and their carers, leading to a lack of understanding about personal budgets and direct payments and concerns about their use
 - the attitudes and understanding of health and social care professionals – for example there is low understanding of dementia and low awareness of the change in law regarding direct payments for people who lack capacity
 - local markets that are not yet fully developed to deliver a range of different types of dementia services
 - insufficient funding – for example, in some areas low levels of payment can mean that people with dementia cannot meet their assessed or changing needs as their condition progresses
 - substantial and critical eligibility criteria, which mean that many people 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 into a care home or hospital is necessary.
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Recommendations: making personal budgets work for people with dementia

The full recommendations can be found in section four. In brief:

- 1 Ensure that people with dementia and their carers are fully involved in the personal budgets agenda, at a level appropriate for the individual. This may be through access to direct payments, or another form of support that engages with the person with dementia as fully as possible. It should include a discussion about the amount of money available and possible care and support options, and be recorded in a care plan.
 - 2 Personal budgets must not be seen as a cure-all for the social care system. Social care reform must address wider barriers – in particular a lack of funding and strict eligibility criteria – working against the personal budgets system.
 - 3 Ensure that the market is fully developed to deliver a range of different types of dementia services.
 - 4 Make sure the personal budgets system is adapted to meet the particular needs of people with dementia and their carers.
 - 5 Provide timely and appropriate information for people with dementia and their carers.
 - 6 Implement awareness raising and training for health and social care professionals.
 - 7 Ensure an improved evidence base on dementia, including pilot sites to evaluate effective models of provision and accurate data on current use of personal budgets.
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1 Introduction

This report has a focus on personal budgets (including direct payments). A personal budget is the amount of money that a council decides to spend in order to meet the needs of an individual eligible for publicly funded social care. Personal budgets are a key way of delivering the personalisation agenda in England. The personalisation agenda is intended to transform social care for all by putting people at the centre of their own care so that they have independence, choice and control over the services they use.

The coalition government in England has made a commitment that everyone receiving social care services will be in receipt of a personal budget by April 2013 (preferably in the form of a direct payment). The Think Local, Act Personal partnership (www.thinklocalactpersonal.org.uk) has also stated all should benefit from personal budgets. However, to date the focus has been on older people, and people with learning disabilities, mental health issues and physical disabilities. Discussions around the use of personal budgets (particularly direct payments) are also happening in Wales and Northern Ireland.

This report presents new evidence on the benefits and challenges of using personal budgets, and direct payments in particular, as described by people with dementia and carers. This evidence is intended to support the commitment to ensure personal budgets for all and the work already beginning to take place within local authorities to make this happen. To ensure that the commitment is met there must be a specific focus on people with dementia and carers. If this focus is not applied there is a risk that people with dementia and their carers will not receive the intended benefits of personal budgets such as those demonstrated in the National personal budgets survey commissioned by the Think Local, Act Personal partnership (Think Local Act Personal, 2011a). The evidence is also intended to support developments in Wales and Northern Ireland.

However, while the focus of this report is on personal budgets, it must be acknowledged that this agenda sits within the wider context of the social care system. Currently, personal budgets are being delivered in a context of concerns about the impact of cuts, the need to make financial savings, strict eligibility criteria and a lack of funding within the social care system. There is a risk that personal budgets are seen as a cure-all for social care, but wider reform is necessary to address the current context.

While it is not within the scope of this report to discuss the issue of social care reform in any depth, there are many emerging opportunities to deliver more effective, person-centred care for people with dementia via the opportunities that social care reform presents. In particular, the White Paper due in spring 2012 in England, the Sustainable Social Services for Wales framework (Welsh Assembly Government, 2011a) and the current Review of the Provision of Health and Social Care services in Northern Ireland (www.dhsspsni.gov.uk/hsc-provision.htm) must ensure that the needs of people with dementia are addressed. It must be acknowledged that to have a social care system that offers a range of quality services – which include early intervention and prevention services that are made available to a greater number of people – serious consideration must be given to the level of funding required and where this money can be found.

Note: This personal budgets-focused report does not cover the wider issue of personalisation in all care settings and the need to improve the quality of dementia care overall. This report focuses on personal budgets in the delivery of social care for people living in their own homes and does not cover personal health budgets.

1.1 Methodology

A literature search of the Medline and Health Management Information Consortium (HMIC) databases was conducted by the British Medical Association on behalf of Alzheimer's Society in March 2011. This research revealed that while there is some evidence on personal budgets for older people and those with mental health conditions, little evidence exists on personal budgets and dementia. In particular, little evidence exists in the form of data and case studies on the views and experiences of people with dementia and carers themselves.

In late 2010 a survey was sent to people with dementia and carers. Many of the questions asked were analysed and used to inform Alzheimer's Society's report *Support. Stay. Save.* (2011). However, some questions relating to personal budgets were not used in the *Support. Stay. Save.* report. These questions have been analysed for this report.

- There were 1,432 responses to the survey in total, 91% from England, 6% from Wales and 2% from Northern Ireland, broadly in line with the proportion of the population across the nations. In total, 3% of responses were from people with dementia, and 96% were from their carers (1% did not respond to this question).
- Alzheimer's Society also held three focus groups in Wales and England in May and June 2011. These focus groups consisted in total of six people with dementia and 19 carers. Seven telephone interviews were also conducted with carers who had experience of managing a direct payment on behalf of a person with dementia.

Work produced by key stakeholders and organisations has also been collated to inform this report.

1.2 Introduction to dementia

People with dementia and carers are one of the largest and fastest growing groups of people needing care and support. There are 750,000 people living with dementia in the UK and by 2021, 1 million people will be living with dementia (Alzheimer's Society, 2010a). One in three people over the age of 65 will die with dementia (Brayne et al, 2006). The financial cost of dementia in the UK is currently £20 billion each year and this will rise to £27 billion each year by 2018 (Alzheimer's Society, 2010a).

Two thirds of people with dementia live in the community (Alzheimer's Society, 2007). Alzheimer's Society's report *Support. Stay. Save.* (2011) provides insight into people with dementia living in the community and their carers. It found that a third of respondents reported that the person with dementia has lived at home with dementia for more than seven years. Around 79% of respondents said the person with dementia lived with a carer and 11% reported that the person with dementia lived in their own home, but with the support of a carer who lived elsewhere. There are estimated to be 600,000 people in the UK acting as the primary carers for people with dementia (Alzheimer's Society, 2007). This saves the UK £6 billion per annum, an average of approximately £10,000 per annum per carer (Alzheimer's Society, 2007).

As the symptoms of dementia progress people need increasing amounts of care. Once the symptoms of dementia become severe it is often appropriate for an individual to live in a care home. One third of people with dementia live in a care home and at least two thirds of care home residents in the UK have dementia (Alzheimer's Society, 2007).

1.2.1 What aspirations and quality of life outcomes are important to people with dementia?

Recent work has begun to provide an understanding of the quality of life outcomes and aspirations that are important to people with dementia. This includes My name is not dementia (Alzheimer's Society, 2010b), Quality outcomes for people with dementia (Department of Health, 2010a), the Dementia Action Alliance National Dementia Declaration for England (2010) and Support. Stay. Save. (Alzheimer's Society, 2011).

In the Dementia Action Alliance National Dementia Declaration for England, people with dementia and carers described seven outcomes as most important to their quality of life. These are:

- I have personal choice and control or influence over decisions about me
- I know that services are designed around me and my needs
- I have support that helps me live my life
- I have the knowledge and know-how to get what I need
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community and civic life
- I know there is research going on which delivers a better life for me now and hope for the future.

The report Support. Stay. Save. surveyed carers about the aspirations and needs of people living with dementia in the community. It found that people with dementia want to remain independent and engaged in their communities. Respondents highlighted independence, being active and engaged, and socialising as key. 83% of respondents said being able to live at home was very important to people with dementia and 59% said that being active in the community was very important to people with dementia. The report also demonstrates the importance of services in enabling people with dementia to remain independent: 82% of respondents said services were vital to supporting people with dementia to live in their own home. Respondents said that they wanted services to enable and empower people with dementia, rather than simply address specific care needs.

1.2.2 What does the current system of care and support look like for people with dementia?

A series of reports has identified that people with dementia, their carers and families are not getting the care and support they need, indicating that the issue of care has been a crisis in the making for many years. Some of the key reports relating to care for people with dementia are listed below, along with their main findings.

- The National Audit Office report (2007) concluded that although there is significant spending on dementia it is often spent badly. Spending often occurs at a late stage when services are more expensive and do not deliver consistently or cost-effectively. It concluded that service redesign to allow for cost effective intervention was needed.
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- The review of antipsychotic use for people with dementia by Professor Sube Banerjee on behalf of the Department of Health (2009a) found widespread over-use of the drugs. Of 180,000 prescriptions for antipsychotic drugs for people with dementia overall, 140,000 were found to be inappropriate.
- The All-Party Parliamentary Group on Dementia (2009) found that the social care workforce as a whole has very limited knowledge of dementia and is not able to provide high quality dementia care.
- The All-Party Parliamentary Group on Dementia (2011) found that services and resources in dementia care have long been focused on people with complex needs and those who are facing crises in their situations, to the detriment of early intervention and prevention services.
- Alzheimer's Society's Support. Stay. Save. (2011) report on people with dementia at home found that half of the people surveyed said the person with dementia was being provided with insufficient support and over half of carers perceived that they were getting insufficient support to carry out their caring role.

In recognition of the size of the challenge, dementia has been identified as a government priority in England, Wales and Northern Ireland. In February 2009, the Department of Health in England published *Living well with dementia: a national dementia strategy for England* (Department of Health, 2009b). In Wales dementia action plans were published by the Welsh government in May 2010 (Welsh Assembly Government, 2010), followed by a national dementia vision in February 2011 (Welsh Assembly Government, 2011b) and in Northern Ireland a dementia strategy is expected to be published soon, following consultation on a draft strategy during 2010.

1.3 Introduction to personal budgets

Personal budgets are a key way of delivering the personalisation agenda. Personalisation is about putting people at the centre of their own care so that they have independence, choice and control over the services they use, with a focus on supporting people to live independently through early intervention.

A personal budget is the amount of money that a council decides to spend in order to meet the needs of an individual eligible for publicly funded social care. A personal budget can be taken by the eligible person as a managed option by the council or third party, which means not having to take on direct budget management responsibilities. Alternatively it can be taken as a direct (cash) payment or as a combination of these options.

At their simplest level, personal budgets involve a clear and upfront allocation of resources and a discussion between social services and a service user/carer about how much money has been allocated to meet their assessed care needs, how the service user/carer would like to spend this allocation and recording these views in the care plan. Personal budgets for social care are at a different stage of development than those for health care and this report focuses only on personal budgets for social care.

While government ministers throughout the UK have broadly endorsed personal budgets, expressions of support have been much stronger in England than elsewhere (Riddell et al, 2006). There is also a different emphasis on the method of providing support in different parts of the UK. For example the Welsh Government has strongly promoted the use of direct payments as a means of empowering users of social care services, while taking a clear policy stance not to follow the English model of personal budgets (Social Services Improvement Agency, 2011).

1.3.1 England

Personalisation is a central element of the government's agenda to transform the health and social care system in England. Building upon policy and practice developments over the previous decade, the personalisation agenda was first described in full in *Putting People First* (Department of Health, 2007). The coalition government confirmed the continued commitment to personalisation in the coalition agreement and then in the *Vision for adult social care* (Department of Health, 2010b). A continuing sector-wide commitment to moving forward with personalisation and community-based support in adult social care was finalised in April 2011 (*Think Local, Act Personal*, 2011b). Key events regarding personal budgets are outlined below:

- Prior to 2009, there was very low uptake of direct payments for people with dementia. For example, a survey showed that only 0.1% of older people in receipt of direct payments in England had mild to moderate dementia (Davey et al, 2007).
 - In 2009 direct payments were extended to people who lack capacity to consent to receiving them. If the person with assessed needs is an adult who lacks the capacity to consent to the receipt of direct payments, then subject to certain conditions, direct payments may be made to another person on behalf of the person needing support (Department of Health, 2009c).
 - The coalition government said they are committed to rolling out personal budgets, with a previous target of 30% of eligible people to be offered their own budget by April 2011 (Department of Health, 2007), and an existing target for all eligible people to have a personal budget by April 2013. As of April 2011, all new users of ongoing adult social care should have an offer of a personal budget and be able to exercise more choice and control, even if they are content with any services they have been receiving.
 - Progress on personal budgets was surveyed by the Association of Directors of Adult Social Services (ADASS) in September 2010, who found that one in four eligible people are receiving them, and 22% of all eligible older people have a personal budget. This was a 55% increase on March 2010, where only one in six people had a personal budget, suggesting councils were well on their way to meeting the 30% target (ADASS, 2010).
 - Progress was again reassessed by ADASS in March 2011. A survey of 153 councils in England found that the number of personal budgets delivered by councils in England had doubled in the year to March 2011. They found that one third of all people eligible for social care support are now receiving a personal budget, with half of these being received by people over the age of 65. However, it also found that progress was variable: a significant minority of councils are delivering personal budgets to less than a fifth of potential eligible users (ADASS, 2011a).
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- The most recent ADASS personalisation survey (October 2011) has found that councils have taken significant and sufficient steps to achieve the target of providing universal personal budgets by 2013. For example, 98% of respondents said they have a clear strategic approach for meeting the ambition (ADASS, 2011b).
- The National Personal Budgets Survey undertaken for Think Local, Act Personal by In Control and Lancaster University and published in June 2011 found that significant majorities of personal budget holders reported positive experiences of the impact of personal budgets, but many experiences of the personal budget process were deemed unsatisfactory. Though all groups reported positive outcomes, those for younger adults (up to 65 years old) were more positive than older adults' and their carers. The survey also revealed markedly different outcomes across councils (Think Local, Act Personal, 2011a).

1.3.2 Wales

The Welsh Government is undertaking to deliver improvements under two categories which imply personalisation: providing users and carers with a stronger voice and greater control over the services they receive, and ensuring people receive the help they need to live fulfilled lives (Welsh Government, 2011c). In addition, the Welsh government has recognised that there may be a place for personal budgets in Wales in the context of social care, and in particular, that for some people direct payments are an important tool for greater control. However, the English model of personal budgets, whereby all users of adult social care will be required to have a personal budget by 2013, will not be adopted (Welsh Assembly Government, 2011a).

There is currently variable local implementation of direct payments. Two separate independent reviews have shown that expressions of commitment to the principles of personalisation and claims to be applying them were not always being accompanied by real changes in practice (Independent Commission on Social Services in Wales, 2010), and only a minority of people who were eligible for them were being offered direct payments (Social Interface report to the Welsh Assembly Government, 2007). Although there have been steady increases in the number of people using direct payments, it seems to remain a significant minority of older people who are taking this option in Wales (Social Services Improvement Agency, 2011).

- Figures from the All Wales direct payments forum show that 2,855 people in Wales were receiving direct payments at 31 March 2010. While a recent estimate of the level of use is not available at the time of this report, previous estimates show that in 2006–7 only 1,360 adults were using direct payments (Welsh Assembly Government, 2008).
 - Only 432 older persons (aged 65+) and only 31 older people (aged 65+) with mental ill health were receiving direct payments in 2009/10.
 - However, the scope of direct payments was extended to people who lack capacity in April 2011.
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1.3.3 Northern Ireland

Direct payments were first introduced in Northern Ireland in 1997, with regulations introduced in 2004 in the form of the Personal Social Services and Children's Services (Direct Payments) Regulations (Northern Ireland). These placed a new requirement on health and social care trusts to make direct payments to people who satisfy the eligibility criteria, if requested. Where a person is in receipt of a direct payment but is not capable of managing the payment themselves, it can be made to another person to manage on their behalf. In addition, direct payments can be used to support the carer in her/his caring role or help maintain the carer's own health and well-being. The Department of Health, Social Services and Public Safety (DHSSPS) has expressed commitment to promoting self-directed care and stated that it should become part of the mainstream of social care (2009–11), yet there is an absence of direction on how this is to be progressed (Gray and Horgan, 2010).

- In Northern Ireland, there were 2,098 people using direct payments at 31 March 2011 (Department of Health Social Services and Public Safety, 2011).
 - Of these, 720 were classed as elderly, constituting 34% of people using direct payments. This represents a gradual but continuing increase on previous quarters. Estimates from earlier years found that uptake of direct payments in Northern Ireland among older people was 3.3% (Department of Health Social Services and Public Safety, 2005).
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2 Personal budgets in the context of dementia

2.1 Do people with dementia and carers have access to direct payments or personal budgets?

Summary

204 survey respondents said that they were using a personal budget or direct payment to purchase services and care. In total 878 respondents had been assessed and were receiving social services support, meaning that 23% of eligible respondents were using a personal budget or direct payment arrangement.

A further 15% (130 out of 878) said they had been offered a direct payment or personal budget but had declined.

60% (855) of the total number of respondents to the survey reported they had not been offered a personal budget. This includes people who would not have been eligible for publicly funded social care.

People who lived alone appeared to be less likely to be offered, or use, direct payments or personal budgets than those who lived with a carer.

Younger people with dementia and their carers appeared more likely to have been offered, and be using, direct payments or personal budgets than older people 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 to 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.

In the survey completed in 2010 for Support. Stay. Save. (2011), respondents from England, Wales and Northern Ireland were asked, 'Is the person with dementia using a direct payment/personal budget to buy social care services?'

- 204 respondents said that they were using a personal budget or direct payment to purchase services and care. In total 878 respondents had been assessed and were receiving social services support, meaning that 23% of eligible respondents were using a personal budget or direct payment arrangement.
- A further 15% (130 out of 878) said they had been offered a direct payment or personal budget but had declined.
- 60% (855) of the total respondents (1,432) reported they had not been offered a personal budget. This includes people who would not have been eligible for publicly funded social care.

The Support. Stay. Save. survey also explored whether some people with dementia were more likely to be offered, or were using, direct payments/personal budgets than others.

- People who lived alone appeared to be less likely to be using direct payments or personal budgets than those who lived with a carer. 85% of respondents who used direct payments or personal budgets lived with a carer; 5% lived on their own, but with support from carers elsewhere, and only 3% lived alone.
- Younger people with dementia and their carers appeared more likely to be using them than others. 24% of respondents where the person with dementia was 41–64 years old were using a personal budget or direct payment, compared to 17% of those aged 65–69; 13% of those aged 70–79 and 13% of those aged 80 and over.
- In addition, 62% of people with dementia in the 80+ age group had not been offered them, compared to 49% of 41–64 year olds. Only 11% of people who lived in sheltered housing were offered a personal budget or direct payment – this compares to 24% of people who lived in their own home. This includes people who would not have been eligible for publicly funded social care.

While the Support. Stay. Save. data and other lines of evidence currently available give an indication of the number of people with dementia and carers using direct payments or personal budgets, accurate data is needed. National data on the numbers of people with dementia and carers accessing direct payments or personal budgets is small-scale, limited to particular research projects and very often anecdotal. The lack of robust data available at a national level is well documented, for example by the Mental Health Foundation dementia choices project, which ran from 2009 to 2011 (Mental Health Foundation, 2011) and the East of England Joint improvement partnership dementia work stream (2010). This presents a real challenge to opening up the system to people with dementia. The data must drill down to ensure that we understand the numbers of people with dementia and carers using personal budgets, including the types of people accessing them (for example younger people with dementia) and how each individual is accessing that support (for example via a direct payment or a managed budget).

2.2 What are the experiences and views of people with dementia and carers using a direct payment?

Summary

How people with dementia and carers are using direct payments

Direct payments are used particularly to purchase care staff in the home (27%), personal care (22%) and respite services (sitting service 14%; respite care 21%), but also for support such as cleaning and gardening, and for holidays.

Perceptions of the support received through a direct payment

Survey respondents using direct payments were more satisfied with particular aspects of their care and services than those not using them.

In particular they were:

- more likely to say they have received enough information; that the person with dementia is getting all the support they need; and that services made life easier
- more satisfied with support received at an early stage and that services were focused on meeting the person's specific needs
- more satisfied with particular services: help with household tasks (such as cleaning, gardening, shopping); care workers who visit (to help with personal care or provide support in the home during the day or night) and visits from care managers, social workers and occupational therapists.

However, problems were experienced in terms of acquiring and using a direct payment. For example, the process was seen as stressful and there was a lack of information. In addition, there was no indication that survey respondents had found services more flexible.

The statistics in the following sections are from data collected in a survey conducted in late 2010 for the Support. Stay. Save. report (2011), with qualitative data from focus groups and telephone interviews conducted in May and June 2011. The views and experiences shared by people with dementia and carers via the Support. Stay. Save. survey mainly focused on direct payments and were clearly in reference to the use of direct payments. In addition, the focus groups and interviews asked for the views of people with dementia and carers on direct payments in particular. This section therefore refers to direct payments throughout.

2.2.1 How are people with dementia and carers using direct payments?

The Support. Stay. Save. survey found that direct payments are particularly used for care staff in the home, personal care and respite care. This was also the case with those who participated in focus groups, where the main services accessed using a direct payment were home care and respite or sitting services.

Table 1: What are people with dementia and carers using direct payments for?

27% (41)	carers/care staff/care in the home
22% (34)	personal care/hygiene
21% (32)	respite care
14% (21)	sitting service
14% (22)	day care/day centres
11% (17)	domestic/house cleaning
6% (9)	gardener/help in the garden
6% (9)	meals/help with feeding
6% (9)	transport
5% (8)	holidays/short breaks
5% (8)	day trips/socialising/going out and about

(Based on 153 responses; respondents could select more than one answer.)

In addition, more detailed responses to the survey highlight the variety of different services that a direct payment may be used for:

‘Employing a cleaner for three hours per week. Having a hair wash and set every four weeks. Paying for glasses for vision. Having a larger screen TV to help her see the picture to get some entertainment. Buying shoes that suit her feet now.’

Support. Stay. Save. respondent

2.2.2 Perceptions of the support received through a direct payment

The data suggests the respondents to the survey who used direct payments were more satisfied with particular aspects of their care, and with some of the services received via direct payments, than those respondents not using direct payments (see Tables 2 and 3).

Table 2 highlights the particular aspects of support that respondents to the Support. Stay. Save. survey who are using a direct payment say they are more satisfied with than those not using direct payments.

Table 2: The perceptions of people with dementia and carers on the support received via a direct payment compared to those not using a direct payment

Respondents to the Support. Stay. Save. survey who are receiving direct payments are more likely to:

- say they have received enough information (50%, compared with 44% who had been offered a direct payment but not taken up the offer and 39% who had not been offered a direct payment)

- be more satisfied with support received at an early stage (20%, compared with 14% and 15% respectively)

- be more satisfied that services were focused on meeting the person's needs (17%, compared with 9% and 12% respectively)

- be more likely to say that the person with dementia is getting all the support they need (54%, compared with 38% and 43% respectively)

- be more likely to say services made life easier (35%, compared with 26% and 29% respectively).

However, there was no indication that they had found services more flexible. 9% of people using a direct payment reported that they were very satisfied with the flexibility of services, compared with 8% of people who had turned down a direct payment and 7% of those who had not been offered a direct payment.

(This data was drawn from a number of different questions. The number of responses for each question varied.)

Table 3 highlights particular services that respondents using direct payments are more likely to be satisfied with in comparison to those not using direct payments.

Table 3: The services that people with dementia and carers using direct payments are more likely to be satisfied with than those not using direct payments

People who were receiving direct payments were more likely to be satisfied or very satisfied with the particular services that they received. This was true for the following services:

- care assistants who visit to help with personal care (82%, compared with 77% of those who had been offered a direct payment but not taken up the offer and 70% who had not been offered a direct payment)

- care workers providing support in the home during day/night/overnight (82%, compared with 69% and 69% respectively);

- help with household tasks, such as cleaning, gardening, shopping (81%, compared with 57% and 70% respectively);

- visits from care manager/social worker (74%, compared with 70% and 69% respectively)

- visits from occupational therapist (78%, compared with 60% and 71% respectively).

(This data was drawn from a number of different questions. The number of responses for each question varied.)

The evidence shows that respondents feel that the care they are provided with via a direct payment is more able to meet the person's needs and they are more likely to say that they are getting the help they need. This may be linked to the fact that 27% of people were using direct payments for a care worker to come into the home (Table 1). The experiences of people with dementia and carers who participated in interviews and focus groups support this, as they stressed being able to use a direct payment for a care worker as an area of vital importance. Typically, focus group participants described having a number of different homecare workers over short periods of time, many of whom are insufficiently trained, do not involve the carer and do not have enough time allocated to provide good care. A direct payment was seen as providing a possible solution to this problem:

'Being able to employ your own carer might allow you to choose someone who is trained and who understands and is experienced in caring for people with dementia. And who would provide sufficient stimulation and socialisation, rather than a narrow definition of care.'

Carer, Wales

The opportunity to have greater involvement with and control of homecare workers was identified repeatedly in focus groups as one of the most attractive incentives to having a direct payment arrangement. It was felt that this would allow greater consistency and better quality of care, in turn improving the person's quality of life. Greater consistency would also allow any homecare worker to develop a better understanding of the person's needs and how best to meet them. One carer talked about how they welcomed having more control of how their homecare worker spends their time. For example they can ensure that the care they provided was more person-oriented than task-oriented and that it provided sufficient stimulation for her husband. Another carer talked about how one of the homecare workers she employed directly had a sports car that her husband loved to talk about and go for drives in. She believes that this was far beyond the standard offering of care provided directly by the local authority and contributed to his quality of life.

There was great emphasis placed on the importance of choice about support:

'There was a time when I was putting my husband to bed up to 15 times a night, and I was totally exhausted. I was visited by a professional (can't remember who) who asked about the current situation and said she'd ensure an extra session of day care for my husband. But if she'd asked me what I wanted most, it would have been extra night cover, so that I could just have some sleep.'

Carer, England

Case study 1

G has a direct payment arrangement for his mother who has vascular dementia. As her condition progressed, it became harder for her to cope without support and she moved to Wales to be nearer to G. Her husband subsequently followed. They live independently, with a live-in care worker employed using the direct payment. G has power of attorney and manages the direct payment arrangement for his mother.

G says that he didn't consider anything other than a direct payment, because he believed that the only other alternatives (residential care or domiciliary care provided through the local authority) would not be good options for his mother and he had no confidence in the quality of care that would be provided. G also knew that his mother would need a flexible service that could change over time to meet her needs and that using direct payments would allow this. He says, 'I was sure that direct payments were the best way forward. My only concern was about finding the right assistant.'

They recruited a live-in care worker, who has remained with his mother since the beginning of the direct payment arrangement. While the person lives with his mother, they do not provide 24-hour care, but variable rates of support day-to-day, as required by his mother. He believes this works better for his mother than any standard arrangement that the local authority could have provided.

Case study 2

M lives in Northern Ireland. She manages a direct payment for her partner, who has Alzheimer's disease. This was set up around two years ago, as a preferred arrangement to the standard day care service available. The payment is used to directly employ someone for eight hours a week to support her partner to do whatever she wants to do – for example, visit art exhibitions, or go to concerts or for walks.

M directly employs two people for this purpose, but stresses that she couldn't have done this without guidance from the Centre for Independent Living (CIL). She says that directly employing staff has been one of the benefits of the arrangement, because you have direct contact with staff and can develop a much more personal arrangement with them. She feels that it 'is more personal than the other way' and that you are much more in control of things. Her partner was involved in choosing the staff, so also gets on well with them.

However, there are challenges. M says that even with good organisational skills, you can get yourself into 'awful corners'. It also took time to get used to the arrangement, particularly for her partner who had to adjust to having new people coming into her home. Additionally, it would be good if the money could be spent on a broader range of things. For example, the direct payment only covers the salary of the people she employs and nothing additional to this, such as travel expenses, so they have to meet these extra costs themselves.

Case study 3

L lives in England. She received a direct payment for her husband, T, which she managed on his behalf. She requested this arrangement, following a period of time in which her husband lived in residential care, when they were told he probably only had six months left to live. L decided to bring him home again and arranged home care for him through a direct payment arrangement. In fact, T lived at home for another seven years and L believes that direct payments played a large part in keeping him independent.

L feels that key to the success of their arrangement was that she chose to directly employ live-in staff herself. This was crucial as it allowed her to choose people who she really believed could provide the best quality care for her husband. For example, her husband loved classical music, so she tried to find care workers who shared this interest. She describes it as a very different experience to having agency staff provided through social services, which she said was like having 'a stranger come into your home'. L chose to screen applicants via the telephone, discussing with them how her husband was affected by the dementia and making clear the expectations of the role. L narrowed down the list of candidates and held interviews, including observing how they interacted with her husband. She also took into account how she and her husband reacted to them and considered their personality and experience as well as their qualifications.

Being able to choose their own care workers meant that the staff L employed stayed longer, providing greater continuity of care and they came to be trusted by T, who was calmer and more content because he was being provided with the sort of stimulation he needed. L says, 'I don't know what I would have done without them.' However, one of the disadvantages to employing staff directly was that unless L arranged it, there was no back-up for planned absences or emergency cover if staff were ill. This was an extra worry for L to plan for.

Other reports have found similar benefits when using personal budgets. For example, the National Personal Budgets Survey (Think Local, Act Personal, 2011a) found that most personal budget holders reported personal budgets having a positive impact on certain aspects of their lives, including being supported with dignity and respect; staying as independent as they want to be; being in control of their support people; having control over the important things in life; and their mental well-being and physical health. For people with dementia and carers, Alzheimer Scotland (2010) found that direct payments provided a number of benefits including:

- flexibility, choice, control and consistency over when support is provided and by whom
- providing appropriate responses to the particular needs of people with dementia, such as enabling care aimed at maintaining skills and allowing people who are known to the person with dementia to be employed as personal assistants
- helping to keep the person with dementia at home in the advanced stages of the illness.

2.2.3 Lower levels of satisfaction when using a direct payment

Despite the positive benefits described by people with dementia and carers when using direct payments, the evidence also describes problems that people experienced when accessing and using them.

2.2.3.1 The process of acquiring and using a direct payment

These concerns were discussed at a focus group by a carer using a direct payment in England who talked about ‘the worry time’ and ‘the stress of all the “peripheral” things that you now need to think about’.

Another carer in Northern Ireland stressed that:

‘You need a clear head. I wouldn’t recommend it for someone who didn’t feel that they could be on top of it all.’

Carer using direct payment, Northern Ireland

One of the carers interviewed expressed their frustration about the level of ‘misinformation’, suggesting that this causes many of the anxieties about direct payments. Those using a direct payment who were interviewed had all experienced barriers caused by a lack of information in either accessing a direct payment or setting up their arrangement.

Case study 4

B is in the process of trying to arrange a direct payment for his mother. He has found that accessing direct payments is not easy, despite the government targets, 'There was a real lack of information. It's been like pulling teeth!'

B's mother has been receiving care from the local authority for some time, but experienced problems with the care agency who provided home care. For example, care agency staff visiting at 5pm, to assist his mother in going to bed, and being unable to visit any later. When these issues couldn't be resolved, a direct payment was offered. It was the first time it had been mentioned.

The direct payment was explained by the social worker in 'an unduly complicated way' and B was told that he would have to pay for someone to come and do a care plan. B had many years of experience writing care plans himself, so said this was not necessary as he would do it himself. He wrote the care plan and submitted it to the social worker. When they heard nothing back, B contacted the social worker to find out what was happening. The social worker said that the decision was made by the council, not by the social worker, and she hadn't yet sent the care plan to the council for a decision.

When the care plan was sent, the council rejected it as the care plan was not in the right format. The council then sent someone to do a new care plan. When they arrived they said that the care plan B had done was sufficient, took the information away and put it into a computerised system and came out with a figure. However, B and the professional working with him at the time were in agreement that this amount did not seem to correspond to the care plan and was not enough to cover the amount of care that B's mother had been assessed as needing. The professional agreed to appeal this amount, but before he was able to do so, he left his job.

The council sent someone else to work through the care plan and assessment in its entirety. Based on the new practitioner's assessment the amount allocated has been higher. However, currently there has been no further information about how this amount is translated into a running direct payment arrangement. B describes the experience as feeling 'like a secret thing where we'll only tell you what you need to know' and is very frustrated that six months on, the direct payment is still not established.

Case study 5

J cares for his wife. Social services had organised a domiciliary care agency to provide care for J's wife. When the agency lost the contract with the local authority, J chose to have a direct payment so that they could continue to use the agency and keep the staff they knew. However he encountered problems with payment procedures.

The care agency would send J monthly bills, which he was required to pay by cheque. However, the agency bills varied month-by-month, because of the different rates charged for different types of care and also because the date they billed on was not consistent. This made it difficult to budget for and was very disconcerting, as previously he had just paid a flat monthly rate to the council and knew what he would be getting for that amount. The agency did not give receipts when they received J's cheques, so he assumed that they were receiving his payments. It was a big shock when J was contacted by the agency to say that they had not received payment for several months of care, up to eight months previously, and that he owed them around £2,000. While J acknowledges that he could have done more to check whether payments had gone out of his account, he feels that the agency could have done more to prevent this situation: 'I'm just me looking after my wife, they're a business!'

J has come to an arrangement to pay the agency bill. However, as a result of the difficulty, he has returned to having care provided for his wife by the local authority, to avoid any further 'financial headaches'. He says this was a very difficult decision because the care staff who had been provided previously had offered quality care and they had built up a relationship with him and his wife.

Other reports have found similar issues. In particular the National Personal Budgets Survey (Think Local, Act Personal, 2011a) found that respondents found many negative aspects to the personal budgets process, including the experience of assessment, the speed of the process, the burden of paperwork and clarity around the nature and availability of service choices.

The process of acquiring and using direct payments is discussed further in section 2.3, based on the perceptions of those people with dementia and carers who were offered a direct payment but decided not to take up the offer, and those who had never been offered a direct payment or even heard of them.

2.2.3.2 Flexibility

Concerns about the flexibility of direct payments found in the Support. Stay. Save. survey (Table 2) were echoed in the comments made at the focus groups. One carer said they were concerned that flexibility is simply not a reality, based on their experience. For example, the care agency that was used to receive care in the home objected when they tried to cancel a visit because it was not needed. She felt that, 'this doesn't fit in with personalisation at all, as it doesn't reflect changes or fluctuations in someone's condition.'

A related issue raised in both focus groups and interviews was the lack of flexibility when employing staff and the need to make contingency plans. For example, how to find replacement care when the homecare worker employed has to take time off for sickness or leave:

‘You’ve always got to have a plan B, as you’ve no backup otherwise.’

Carer, England

In interviews, carers highlighted how they had overcome this problem, usually by employing more than one person. This meant that there was some flexibility for extra cover if one of their employees needed time off for sickness or holidays, however it was highlighted as one of the issues that must be considered.

2.3 What are the views of people with dementia and carers not using direct payments?

Summary

The views of those who have been offered but are not using direct payments

The survey asked respondents why they did not take up the offer of a direct payment. People said they did not take up the offer because:

- 31% (28) hard enough to cope as it is
- 14% (13) not confident managing direct payments
- 13% (12) happy/satisfied with present arrangement
- 11% (10) too complicated/difficult
- 10% (9) considered self-funded/not eligible
- 9% (8) hassle of becoming an employer.

Summary

The views of those who have not been offered direct payments

Those who had not been offered a direct payment were asked what they felt might be the potential risks and benefits. Perceptions included:

- 17% (78) able to choose own services

- 14% (64) open to abuse

- 14% (64) do not understand money matters

- 13% (62) don't know what it is

- 11% (50) adds to responsibilities of carers/more stress/workload

- 8% (36) risk of employing people who are not suitably qualified/provide inferior standard of care

- 7% (32): if not managed properly it could result in inferior services/care

- 6% (27) budget would need to be managed by someone else

- 5% (25) enables flexible use/responsive to changing needs

- 5% (24) independence/control over choice of where and how the money is spent.

People with dementia and carers were asked their views on direct payments in particular. The Support. Stay. Save. survey explored the perceptions in more depth of those people who were offered a direct payment but decided not to take up the offer (Table 4). It also explored the opinion of those who had never been offered, or had never heard of direct payments (Table 5). The respondents who had never been offered or heard of direct payments were asked what they felt are the potential risks and benefits. In focus groups, people were also asked their opinion of direct payments in general.

This helps to reveal some barriers that exist to people with dementia accessing a direct payment. The barriers will be discussed further in section 3.

Table 4: Views on direct payments by people with dementia and carers who were offered a direct payment but did not take it up

31% (28)	hard enough to cope as it is
14% (13)	not confident managing them
13% (12)	happy/satisfied with our present arrangement
11% (10)	too complicated/difficult
10% (9)	considered self-funded/not eligible
9% (8)	hassle of becoming an employer
7% (6)	happy to be supported by social services
7% (6)	concerned about the responsibility of employing someone
7% (6)	amount was too low/insufficient funding to cover costs
7% (6)	didn't want the responsibility of paying/arranging services/care
4% (4):	unable to see any advantages at the time/no practical benefit
1% (1)	don't know
16% (14)	other

(Based on 90 responses.)

Table 5: Views on the potential risks and benefits of direct payments by people with dementia and carers who were not offered them

17% (78)	able to choose own services
14% (64)	open to abuse
14% (64)	do not understand money matters
13% (62)	don't know what it is
11% (50)	adds to responsibilities of carers/more stress/workload
8% (36)	risk of employing people who are not suitable qualified/provide inferior standard of care
7% (32)	if not managed properly it could result in inferior services/care
6% (27)	budget would need to be managed by someone else
5% (25)	enables flexible use/responsive to changing needs
5% (24)	independence/control over choice of where and how the money is spent
4% (17)	possibly underfunded/insufficient to cover costs/risk of running out of money
3% (16)	depends on how the dementia affects the person
3% (12)	increased social opportunities/better quality of life
2% (10)	being over-charged/not getting a fair deal from supplier of services
2% (8)	too complex
1% (7)	not eligible as had savings
1% (5)	in principle idea works well/good idea
1% (5)	self funded
1% (3)	nothing
13% (59)	don't know
8% (38)	other

(Based on 467 responses.)

The evidence highlights that both groups of respondents feel that a direct payment will be an added burden. People with dementia and their carers will very often be going through a difficult time emotionally and physically and any change in circumstance and system can therefore be very daunting. In addition, the system of direct payments is seen as challenging and complicated.

These concerns about direct payments were echoed at a focus group in Wales, where people felt that they were ‘overwhelming’ and ‘daunting’. There was also scepticism about whether there was really enough information and support available on direct payments, combined with an understanding of dementia, to assist a person with dementia to benefit from a direct payment arrangement.

A common response to the idea of direct payments were that they would ‘make life even harder for carers and people with dementia’ and that it ‘sounds like one more thing to worry about,’ (Support. Stay. Save. respondents).

‘It’s much easier when the council deals with all the bills, rather than the carer having to deal with the paperwork and bills.’

Carer, England

Several times, direct payments were perceived negatively:

‘Pushing responsibility onto you.’

Person with dementia, Wales

‘Just a way of passing the struggle to obtain help from the local authority to the sufferer, by taking on the legal responsibilities of an employer, keeping accounts and generally being enmeshed in bureaucracy. This is going to produce more stress, not less. Who on earth needs this? The money granted is not likely to suffice and will be eroded by inflation, tax changes, agency fiddling etc...’

Support. Stay. Save. respondent

‘A way that social services “can wash their hands of the whole thing.”’

Carer, England

Other reports have found that older people may not want to take on a direct payment because they often start using services following a crisis, at which point they may not be interested or able to take on the responsibility. In addition, people are often coping with changing levels of need and managing services to support these changes can be very hard work (Age UK, 2010).

It must be remembered that there are positive aspects to using direct payments, as discussed in section 2.2. Alzheimer's Society believes that more people with dementia and carers could benefit from direct payments than currently do. However, this is only possible if the right support is in place for people with dementia and carers, to ensure that the burdens described when using direct payments are removed. In addition, information for people with dementia and carers is vital, to both highlight the benefits of using direct payments and to address concerns.

Alzheimer's Society also believes that direct payments will not be suitable for all people with dementia and carers. In these cases, people should still be given choice and control over the services they use in a way that is appropriate for them. In England, a personal budget must be offered. This would ensure that people with dementia and carers at the very least understand the amount of money available to spend on their services and are involved in care planning discussions. In Wales and Northern Ireland, the principles underlying personal budgets should be followed, meaning that discussions about care planning should take place. These discussions must fully engage the person with dementia where possible, and the carer, based on the principles of the Mental Capacity Act, rather than being a 'tokenistic' discussion. As the National personal budgets survey (Think Local, Act Personal, 2011a) found, it is important that personal budget holders and carers are kept informed of essential aspects of the personal budget. People who did not know how their personal budget was managed or did not know the amount of their personal budget reported less positive outcomes.

It must also be acknowledged that some people with dementia and their carers will be self-funders. While self-funders do not officially have a direct payment, they have the right to an assessment of their needs, to have a care plan and require the same level of information and support as those eligible for financial help with their services.

The barriers to people with dementia and carers being offered and using personal budgets and direct payments and how these might be overcome, are discussed in more detail in section 3.

3 What are the key barriers to personal budgets working for people with dementia?

The views and experiences of people with dementia and carers outlined in sections 2.2 and 2.3 from survey data and focus groups, along with existing evidence, highlight the key barriers that exist to them accessing and using personal budgets. These are discussed in the following sections and summarised below.

Summary

Currently, there are barriers to people with dementia and carers accessing the personal budgets system. These include:

- a personal budgets system that has not yet adapted to the needs of people with dementia and their carers, and is overly complex and burdensome
 - a lack of appropriate support to enable people with dementia and carers to use direct payments
 - a lack of information for people with dementia and their carers, leading to a lack of understanding about personal budgets and direct payments and concerns about their use
 - the attitudes and understanding of health and social care professionals, for example there is low understanding of dementia and low awareness of the change in law regarding direct payments for people who lack capacity
 - local markets that are not yet fully developed to deliver a range of different types of dementia services
 - insufficient funding – in some areas low levels of payment can mean people with dementia cannot meet their assessed or changing needs as their condition progresses
 - substantial and critical eligibility criteria, which mean that many people 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 into a care home or hospital is necessary.
-

3.1 People with dementia having to fit into a system that is not geared towards their needs

As discussed in section 2.2.3, people with dementia and carers can find the process of acquiring and using personal budgets difficult. In particular, the current system appears to have been geared towards particular service users. This was identified by the East of England Joint improvement partnership dementia workstream (2010), which found that some organisations felt they were still struggling to develop their process and systems, along with mainly concentrating on service users categorised as having learning or physical disabilities, or older people. There was a strong message that these authorities were ‘not ready’ to look at personal budgets for people with dementia, as it was seen to be too complex and too risky. People with dementia will have different needs to many other older people or those with mental health problems. For example, dementia is a progressive condition with changing levels of need, and the system needs to be adapted to reflect this.

In addition, managing the financial issues associated with direct payments has been noted as a difficulty. This was made clear at the focus groups held by Alzheimer’s Society. Carers said that they found it very stressful to manage financial arrangements, and that this is not helped by their council’s finance department. For example, one carer had been mistakenly undercharged for day care provided by the local authority over a period of several months and was asked for a large back payment. Another carer described the invoices issued by the finance department at their local authority as ‘an absolute shambles’. They described a system where the invoices were not itemised, so you did not know what you were paying for or even for which time period. Other comments made by carers also highlighted issues with the financial arrangements:

‘The finance department can’t cope with personal budgets.’

Carer, England

‘Our arrangement had been running for six years before the local authority (LA) decided to do any sort of financial check. I’d kept all the relevant paperwork, so apart from a few errors and a stern letter from the LA, this was fine, but how many other people would have coped with this? I was surprised they’d left the check for so long really.’

Carer, Wales

Some of the difficulties of the system pre-date the personal budgets system, yet can still hinder and complicate the process for service users, and some affect people with a range of conditions. For example, respondents to the National personal budgets survey (Think Local, Act Personal, 2011a) found many negative aspects to the personal budgets process, including the experience of assessment; the speed of the process; the burden of paperwork and clarity around the nature and availability of service choices. This makes it vital to simplify the system and processes for all, along with providing appropriate support to help people navigate the system. Forthcoming advice from the Think Local, Act Personal partnership confirms this and makes recommendations for improving local practice.

3.1.1 Providing appropriate support – brokerage

The right type of support (for example brokerage, which involves assistance to help people make choices and support to put those decisions into action) to enable people with dementia and carers to use direct payments is necessary.

This is evident by the responses of people with dementia and carers in section 2.3 (those who were offered but did not take up direct payments and those who were not offered them). Concerns centred around not being confident with managing direct payments, not having the knowledge to deal with ‘money matters’, direct payments being too complicated and carers not wanting to take on extra burden. In addition, during focus groups, the need for brokerage services was highlighted:

‘I couldn’t have done it without the support of the Rowan Organisation. People need to know that there is support there to help you.’

Carer, England

‘There’s no way you could do it without a helping hand.’

Carer, Northern Ireland

‘Apparently there are organisations that can help you set up arrangements, but I don’t understand why you have to pay for them.’

Carer, England

‘I would need a lot of information and help, especially with accounting and employment.’

Person with dementia, Wales

‘There’s lots of information on the internet, but so much so that it’s hard to know what is most relevant and of good quality. So you’d need support with this.’

Carer, Wales

‘It is an extra responsibility... When it did go pear-shaped... it was very upsetting... I did feel very abandoned.’

Carer, England

Personalisation in practice: lessons from experience (Age UK, 2010) suggests that support planning and brokerage are still a work in progress and there are still many questions to address. However, the report also acknowledges that support planning and brokerage services are crucial to enable people to access the system.

While it is not within the scope of this report to detail the types of support brokerage that could be provided, the Age UK report does provide learning for local authorities on ensuring effective support services and the Think Local, Act Personal website links to a wide range of resources. See www.thinklocalactpersonal.org.uk for more information.

3.2 The understanding and attitudes of people with dementia and their carers

Tables 4 and 5 in section 2.3 highlight the views of people with dementia and carers who chose not to use direct payments or have not been offered them. These show that there are several perceptions held that mean that people will not want to access direct payments, including:

- not feeling that they can cope with a direct payment given the incredibly difficult situation they are already facing and feeling it will just add to the stress
- not being confident in using them, for example because they don't understand them or don't feel confident managing money
- not knowing what direct payments or personal budgets are, which suggests that they are not being offered by local authorities or individual professionals, or not being explained
- being happy with the current arrangement.

These tend to fall under two key areas – a lack of information about personal budgets and direct payments and a concern about taking on the burdens that direct payments can bring.

Many people perceived that they did not have an understanding of personal budgets. In the focus groups held for this report awareness of personal budgets appeared to be very low. At one focus group only two out of 14 people had heard of personal budgets and they had limited knowledge about the practical implications:

‘We need to hear from people who have done it, and what their experience has been. It’s very confusing.’

Carer, Wales

‘Would the direct payment cover all the overheads that are currently covered by the local authority? Would the rate given be enough?’

Carer, Wales

These findings are similar to those documented by the Mental Health Foundation from their dementia choices project. They found that many people with dementia and their carers did not know personal budgets existed or did not understand the details (Mental Health Foundation dementia choices project, 2011).

The Mental Health Foundation also found that people, in particular carers, were apprehensive about taking on what they considered to be yet another responsibility. Again, this message was echoed at focus groups and also by those interviewed who had used or were using direct payments:

‘Carers do not have the spare mental energy or time to do this.’

Carer, Wales

‘They may be better for a younger generation, to an older person it is, well, very daunting. Without the internet to access information, I should think it would be impossible.’

Daughter of person with dementia, Wales

Underpinning the understanding and attitudes of people with dementia and carers is the need for the right information at the right time. Many of the concerns centre on direct payments and people may not realise that other options exist and should be offered. People must understand the range of options available to them, what these options would entail and what support is available.

The Social Care Institute for Excellence (SCIE) (2011) found that many older people would have liked earlier access to information about personal budgets and highlighted the importance of key groups of health and social care staff and providers knowing about them. SCIE also emphasised the importance of clear and understandable information, tailored to the needs and interests of different groups of people, with concrete examples of what the money could be spent on.

‘It doesn’t matter which route people take, but they should at least be given the choice about what will work best for them.’

Carer, England

3.3 The understanding and attitudes of health and social care professionals

Research has shown that issues relating to the awareness and attitudes of health and social care professionals can act as a barrier to people with dementia and their carers having an understanding of, and using, personal budgets and direct payments.

‘Any challenges come solely from the local authority...Social services just don’t understand direct payments. I knew about direct payments so I could fight for them, but I would definitely have needed support to push social services if I had been someone else.’

Carer, Wales

‘Why are social services so suspicious of this? Is it because they are not in control any more?’

Carer, England

It has been suggested that pockets of good practice are based around individual practitioners rather than any organisational drive (East of England Joint improvement partnership dementia workstream, 2010). At the current time, it seems that a culture shift is needed for many professionals. An Audit Commission report (2010) found that people with mental health care needs are less likely to have personal budgets than other service users and that one of the biggest challenges is the culture change required for social care workers, finance staff, and service providers, as well as service users. The message from people who participated in focus groups was that local authorities need to:

‘Make sure people are informed, including staff providing frontline services – about the spirit of direct payments as well as the law!’

Carer, Wales

‘Accept that personalisation is appropriate for dementia and that direct payments are a way of doing this.’

Carer, Wales

Many of the concerns of professionals appear to focus on the suitability of direct payments for people with dementia, particularly when people are already struggling with their condition. Some feel concerned that direct payments will be pushed onto people for whom they are not suitable. The fact that direct payments are not suitable for all individuals has been acknowledged and a professional’s judgement about the appropriateness of direct payments for individuals can be extremely valuable.

However, evidence also shows that professionals can be over-cautious about the use of direct payments for several reasons. The East of England Joint improvement partnership dementia workstream (2010) highlighted practitioners' lack of knowledge and confidence and/or negative attitudes as barriers. The Mental Health Foundation dementia choices project (2011) found that people with dementia and carers may be being put off by staff with a prefixed notion of what people with dementia can and cannot take on. Morrison (2010) discussed the unease felt by frontline staff in relation to personal budgets for mental health clients.

Underpinning these issues is a lack of understanding and knowledge. For example, health and social care professionals may not understand dementia and the ability of people with the condition to engage with the personal budgets agenda. In addition, professionals may not have a full understanding of the agenda, including the difference between personal budgets and direct payments, and the change in law concerning direct payments and those who lack capacity. This may also be linked to a lack of understanding about the Mental Capacity Act (2005) and the principles underlying this.

3.4 A market that is not yet fully developed to deliver a range of different types of dementia services

There was some scepticism in discussions at the focus groups about whether there was a sufficient range of services available for people with dementia using a direct payment and whether they would have enough support to access these services:

'They may have the money to pay for services, but will the appropriate services be there to buy? What help will we receive in deciding what services will be suited to her needs?'

Support. Stay. Save. respondent

'Are there enough support services available to choose from? I'm not sure that there would be.'

Carer, Wales

'There is a danger that direct payments are only offered when local authorities are struggling to provide services themselves, for example, in isolated rural areas where they can't find care workers for people, they just hand over this difficulty to the person. I'm worried about this.'

Carer, Wales

It is vital to improve the type and supply of services and forms of support available relevant to people with dementia, particularly early intervention and prevention services and specialist support for people in their own homes. The lack of a range and supply of services is a barrier to being able to use personal budgets effectively:

‘There is definitely a market for a specialist agency providing care for people with dementia.’

Carer, Wales

3.5 The level of funding

Research has found that the amounts paid as a direct payment can vary. In Wales, the hourly direct payment rate paid varied between £6.58 and £11.35 in 2009–10 (Social Services Improvement Agency, 2011). Enquiries made to a selection of local authorities in England in 2011 revealed that hourly rates for those surveyed varied between £7.50 and £11.81 and hourly rates paid by health and social care trusts in Northern Ireland also varied. In some cases a low rate may mean that an individual does not have enough money to buy the care and support that meets their assessed needs. One carer interviewed described the amount of funding people receive as ‘a drop in the ocean’ in meeting the 24-hour needs of the person they care for. There were also concerns that the situation was going to get worse:

‘Let’s face it, there are huge cuts this year... and I don’t think we’ve seen the full effects yet.’

Carer, England

Several carers at focus groups and in the interviews described their frustration that personal budgets were not adaptable enough as the person’s dementia progresses. They gave examples of either no changes in payment amounts, or, in one case, a reduced amount, paid to them as a direct payment after a reassessment, despite increases in the care and support needs of the person with dementia. However, this was not a universal picture – another carer said that she had received increased payment amounts as her husband’s dementia had progressed.

The personal budgets agenda is taking place in a context where there is a need to make financial savings. It must be acknowledged that to have a personal budget system that allows people to access a range of quality services that meets their needs, a serious debate is needed about the level of funding required and where this money can be found.

3.6 Strict eligibility criteria

Substantial and critical criteria mean that many people with dementia will not receive publicly funded social services until crisis point. A 2010 survey based on Freedom of Information requests found that three-quarters of councils were meeting critical or substantial care needs only. This was predicted to rise to 80% by 2011 (Community Care, 2010).

At this point, some people with dementia may have to enter hospital or residential care, which may mean that a personal budget is no longer an option. (Alzheimer's Society notes the Law Commission review of adult social care recommendation that direct payments should be extended to cover residential accommodation.) Or, some people may perceive that it is too late for them to manage a personal budget once the dementia has progressed. However, in these instances, a discussion about the types of services available can still be held, to ensure that people have as much choice and control as possible post-crisis.

4 Recommendations: making personal budgets work for people with dementia

1 Ensure that people with dementia and their carers are fully involved in the personal budgets agenda.

- Alzheimer's Society supports all people with dementia having a form of personal budget by 2013 in England at a level appropriate for them, ranging from a discussion about the amount of money available and possible care and support options, to access to direct payments.
- In England, Wales and Northern Ireland more people with dementia can benefit from direct payments than currently do. However, if direct payments are to be increased for people with dementia, the burden that people experience when using them must be removed, more people must be offered the option and good information must be available. The information should highlight the benefits that people experience when using direct payments.
- It must be recognised that direct payments are not suitable for all. In these cases, people with dementia and their carers should be given choice and control over the services they use in the way that is appropriate for them. This must fully engage the person with dementia where possible, based on the principles of the Mental Capacity Act, rather than being a tokenistic discussion.
- There is much that can be achieved through the Think Local, Act Personal programme. Alzheimer's Society supports the principles of the programme and acknowledges its intention to address the needs of people with dementia. The Society emphasises that this must happen as a matter of priority.

2 Personal budgets must not be seen as a cure-all for the social care system. Social care reform must address wider barriers – in particular a lack of funding and strict eligibility criteria – working against the personal budgets system.

- The White Paper due in spring 2012 in England is a key way that a change in dementia care can be delivered. This is the biggest opportunity in a generation to address the current inadequate social care system. In addition, the Sustainable Social Services for Wales agenda and the current Review of the Provision of Health and Social Care services in Northern Ireland must ensure that the needs of people with dementia are addressed.
 - It must be acknowledged that to create a social care system that offers a range of good quality services for people, which include early intervention and prevention services, a serious debate is needed about the level of funding required and where this money can be found.
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- Restrictive eligibility criteria must be addressed. In England, there is much that can be done via implementation of the proposals from the Commission on Funding of Care and Support (2011) and it is recommended that eligibility for services is set lower than a 'substantial' threshold.
- In addition, quality care for people with dementia based on outcomes that are important to them must be ensured. For example, the outcomes frameworks and the future NICE social care quality standards provide opportunities at a local level to ensure good outcomes.

3 Ensure that the market is fully developed to deliver a range of different types of dementia services

- It is vital to improve the type and supply of services and forms of support available relevant to people with dementia, particularly early intervention and prevention services and specialist support for people in their own homes.
- There is much that can be done to stimulate market development and Alzheimer's Society recognises the ongoing work of programmes such as Think Local, Act Personal in this area. Addressing the needs of people with dementia is vital through this work.
- Commissioners should recognise the considerable resources already being spent across health and social care on dementia and must be encouraged and given the opportunity to spend resources more effectively to provide quality care of the appropriate type.

4 Make sure the personal budgets system is adapted to meet the particular needs of people with dementia and their carers.

- Adequate funding within the system is essential to ensure that the level of a personal budget allows an individual with dementia to have the care and support that meets their assessed needs and progressive nature of the condition.
- Systems and processes must be streamlined so that accessing personal budgets, and direct payments in particular, is straightforward. This must include the financial systems that people navigate when using direct payments.
- Commissioners must commission support brokerage services to facilitate and empower access to personal budgets among people with dementia. A wide variety of support services must be available to meet the individual needs of people with dementia.

5 Provide timely and appropriate information for people with dementia and their carers

- Information must be available for people with dementia and carers. This must include the various personal budget options available. In addition, balanced information that addresses the concerns that people hold around direct payments and that highlights the positive experiences people can have when using them is essential. This information should be provided at an early stage.
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6 Implement awareness raising and training for health and social care professionals

- It is vital that the understanding and knowledge of professionals regarding the inclusion of people with dementia and carers in the personal budgets system is improved.
- Particular areas of focus include the principles of the Mental Capacity Act; the extension of direct payments to people who lack capacity; the need to balance safeguarding with allowing people to take risks; and an understanding of dementia.
- Training must be wider than local authority staff, and in particular, must incorporate GPs and memory clinic staff, to ensure that people with dementia and carers have access to information at an early stage.

7 Ensure an improved evidence base on dementia, including pilot sites to evaluate effective models of provision and accurate data on current use of personal budgets.

- Pilot sites to evaluate effective models of provision for people with dementia and their carers must be conducted.
 - Accurate data on the current use of personal budgets, including direct payments, by people with dementia and their carers is also vital. Local authorities should be asked to collect specific data on the numbers of people with complex conditions including dementia using personal budget options.
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Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

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