

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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