Claire Goodchild

Claire Goodchild is Director of The Halcyon Project and works across care and health specialising on issues concerning older people and people living with dementia. For six years until April 2011 she worked at the Department of Health, England latterly as National Programme Manager (Implementation) for the National Dementia Strategy. She undertook research for this report whilst leading the programme to implement improved community personal support for people with dementia. She has a background in social work, public health and joint health and care commissioning.

clairegoodchild@thehalcyonproject.co.uk
www.thehalcyonproject.co.uk
## Contents

### Section one - Personal budgets for people with dementia
- Summary: 3
- Methodology: 4
- What is a personal budget?: 4
- What's special about dementia?: 5
- Challenges of working with people with dementia: 6
- Data on uptake of people with dementia accessing personal budgets: 7
- Overcoming discrimination and raising expectations: 7

### Section two - Culture of local authorities and the whole system
- "Nothing different" for people with dementia: 8
- Carers as proxy for working with the person with dementia: 8
- Systems geared to physical needs: 9
- Professional mindsets: 9
- The recovery model in mental health: 10

### Section three - Strategic leadership
- Local authority social services budgets and brokerage: 11
- Local political leadership: 12
- Strategic team leadership: 12
- Commissioning and market development: 13
- Managing team budgets: 13

### Section four - Organisational readiness
- Training NHS staff: 14
- Personal budget champions: 14
- Data recording systems: 15
- Inclusion of persons with dementia and their carers in developing systems for personal budgets: 15
- Supporting people through the self directed support process: 15

### Section five - Operational practice
- Workforce training: 16
- A robust assessment system: 16
- Accessible information: 18
- Advocacy: 18
- Managing the money: 18

### Summary of challenges and potential solutions: 19

### Annex one - Personal testimonies on personal budgets for people with dementia: 20

### Annex two - Acknowledgements: 21

### References: 22
Section one
Personal budgets for people with dementia

It is now nearly two years since the introduction of direct payments for people who lack mental capacity. A number of organisations have published reports commenting on progress of implementing personal budgets and this report adds to the growing body of literature by focusing on personal budgets for people with dementia.

This report was initially conceived as a compendium of good practice on personal budgets for people with dementia. In seeking examples from across England it became evident that there was a limited pool of good practice for people with dementia. The legal issues concerning direct payments to people who lack mental capacity was proving an obstacle to delivering personal budgets to people with dementia, whether or not they required a direct payment or lacked mental capacity. The focus of the report therefore shifted to explore the challenges and solutions within the system to delivering personal budgets to people with dementia.

The report focuses on personal budgets rather than wider aspects of self-directed support although inevitably the paper touches on key related issues of Resource Allocation Systems and support brokerage. Personal budgets are a means to an end; a vehicle through which people can gain more control over the support and services they require.

The report outlines four levels at which the success of delivering personal budgets to people with dementia is determined:

- The culture of local authorities and local whole systems
- Strategic leadership
- Organisational capability
- Operational practice.

Summary of key issues

- Data collection in local authorities is such that it is difficult to assess the number of people with dementia in receipt of a personal budget
- Systems to support personal budgets for people with dementia are not well developed
- Anecdotally local authorities report that where they have supported the delivery of personal budgets to people with dementia they have concentrated on younger onset rather than the majority of older people with dementia
- Local authorities report a reticence on the part of older people in general and families to seek a personal budget
- Local authorities are aware more work is needed to engage mental health trusts in the personal budgets agenda
- The reasons for slow implementation are complex and multi-layered across the local authority culture, strategic planning, organisational infrastructure and operational systems.
Methodology

The paper is based upon a review of the current literature and on interviews with personalisation leads and dementia service leads in local authorities. The findings might not be exhaustive but rich information and evidence is emerging about the implementation of personal budgets for people with dementia and their carers.

We contacted 16 local authorities and carried out nine in-depth telephone interviews from staff at eight of them. The first cohort of nine local authorities was selected on the basis of their reputation for making good progress on personal budgets across all adult care. Those initial contacts signposted us to other local authorities that they thought had developed their work on personal budgets.

This report is based on interviews and research originally carried out in Autumn 2010. Prior to publication in 2011 the status of personal budgets for people with dementia was reviewed. Whilst specific data might have changed, for example, local authorities might have slightly increased the number of personal budgets available, no significant and substantive changes were found.

We also reviewed literature about personal budgets for dementia and older people in general. We made one locality visit to a service that has been developed to provide flexible services to people with dementia.

In the process of writing the paper we did not seek the views of persons living with dementia. Their experiences of personal budgets are documented in numerous case studies (see annex 1 for references) in online videos and in related publications.

What is a personal budget?

A personal budget is the term used to describe the amount of money that will fund a person's care and support costs. It is calculated by assessing a person's needs. It is spent in line with a support plan that has been agreed by both the person and the council. It can be either a full or a partial contribution to such costs. The person may also choose to pay for additional support on top of the budget. So the term personal budget refers to social care money. A personal budget may be taken by an eligible person:

- in the form of a direct (cash) payment, held directly by the person or where they lack capacity, by a “suitable person” (from 9 November 2009)
- by way of an ‘account’ held and managed by the council in line with the person's wishes i.e. to pay for community care services which are commissioned by the council, or as an account placed with a third party (provider) and ‘called-off’ by the user in direct negotiation with the provider
- as a mixture of the above.

ADASS Making progress with putting people first 2009

The Guidance on Direct Payments to people who lack capacity was published in September 2008 and enacted from November 2009. It states: ‘Where the person with eligible needs does not have the capacity to consent to the making of direct payments, the payments can be made to an appointed suitable person who will manage the payments on their behalf.’
What’s special about dementia?

Every ‘care group’ has particular needs relating to personal budgets. People with dementia have complex needs as outlined below. This is not to single out dementia as any more special or complex or higher priority than other care groups but a necessary exploration of why many people with dementia are likely to require specific support to access a personal budget through a direct payment.

People with dementia are a heterogeneous group yet united by their condition and by some of the experiences of symptoms of their condition.

The National Dementia Strategy defines the condition as:

‘The term ‘dementia’ is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function, including decline in memory, reasoning, communications skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness’.

In addition, the majority of people with dementia are in later life and therefore more likely to have co-morbid physical conditions and illnesses that interact with their dementia and further complicate health and care needs. Just 2% of people with dementia are aged 65 or under.

Some of the complexities in working with people with dementia can include:

- Denial about their condition and their needs because of the stigma and personal fear about ‘having’ dementia
- An inherent part of dementia – combined with the interplay with their psychological needs – is that some people lack insight into their condition and their needs
- Fluctuating levels of need on a day to day basis; like all of us, people with dementia have ‘good days and bad days’. Symptoms of dementia can vary so that some tasks can be managed one day but not the next. A person’s abilities are closely related to the their sense of emotional, psychological and physical well-being
- Dementia is a degenerative condition and so abilities and needs change over time.

However not everything is negative. The purpose of the National Dementia Strategy is to create a health and care system where people feel they are ‘living well with dementia’.

Whilst every person’s needs are individual, there are some common themes about good quality support and care for people with dementia:

- Familiar surroundings, especially if the person is disorientation in place in a way that causes them distress
- Continuity of staff/care workers who are skilled in working with people with dementia. This has dual benefits - the person with dementia is likely to remember the person (either with direct recall or will have a ‘sense’ of familiarity with the person) and the care worker will have a good understanding of the person with dementia and will know what works well for them
- Routine can be vital for many people with dementia so reliability of care workers can be essential for a good support system
- Stimulating and meaningful engagement and activity that is manageable for the person with dementia.

For these very reasons, individualised, tailored support and care that a personal budget can facilitate can have enormous benefits to a person with dementia.

There are numerous personal stories in the current literature and websites that are testimony to the improved outcomes that personal budgets can bring (see list in annex 1). The testimonies show that tailoring a package of care through personal budgets can be more effective in delivering the above themes of good quality care than centralised, block-contracted services.

**Challenges in working with people with dementia**

As identified above, particular communication skills are required to assess and plan care with a person who has dementia. Whilst we aim to work on an asset/skills model it is pertinent here to list the difficulties that some people with dementia experience:

- Difficulties in understanding new or complex concepts: the ways in which social care and support is assessed and provided can be difficult for anyone to understand and especially so for a person whose cognitive functions are compromised through dementia
- Having insight into – and conveying – one’s own needs. A person might have difficulties with recall, remembering and articulating their needs
- Problem solving to work out the solutions to meet those needs
- Even though the person might not be able to retain information, they might, in a period of insight, be able to come up with a solution that feels good for them
- If a person is unable to express themselves in straightforward language then they are likely to express themselves in verbal and non-verbal behaviour so an assessor should have the skills to observe and understand behaviours.
Overcoming discrimination and raising expectations

The majority of people with dementia are older people and in our society older people still experience discrimination and have relatively low expectations about quality of life and rights to access support and services. The local authorities we spoke to reported that older people are more likely to want traditional 'provided' services rather than taking on the management of a direct payment.

We did not speak directly to people with dementia as part of this project but there is evidence that older people have lower expectations of autonomy than younger adults with physical or mental impairments. This is likely to change over time as the 'young old' emerge as a more dominant group in terms of their numbers and self/group advocacy. In the meantime, older individuals who do seek to set up their own packages through personal budgets are likely to need a very strong support network of family to assist them in accessing and managing a budget.

A number of interviewees reported that during consultation they found that many older people, their carers and families have limited expectations of what is possible in terms of social care support. It was particularly noted in some areas where there are high levels of deprivation.

Data on uptake of people with dementia accessing personal budgets

There are 570,000 people in England who have dementia. However, only 40% of these people have a formal diagnosis.

There is no reliable data on the number of people with dementia who are in receipt of, or who have been assessed for, a personal budget. Local authority National Indicator NI130 records the number of social care clients in receipt of Self Directed Support defined as ‘Numbers of adults, older people and carers receiving self-directed support in the year to 31st March as a percentage of the clients receiving community based services and carers receiving carers specific services aged 18 or over’. Social services have a target to deliver self-directed support to 30% of all adult clients.

To achieve this target many local authorities admit to targeting more straightforward care groups. One interviewee admitted “we have gone for the low hanging fruit but that doesn’t stop us aspiring to higher branches”.

We know anecdotally that people with dementia are not accessing personal budgets to the same degree as other care groups but the formal quantitative data is not there to support this argument. There is a lack of data to track the uptake of personal budgets for people with dementia for two reasons:
- local authorities usually do not record a person’s diagnosis for good ‘social model of disability’ reasons because the intention is to focus on the person and their needs rather than labelling them as a diagnosis
- People with dementia might not have a diagnosis (only 40% of people with dementia have a formal diagnosis) and so there might be people in mainstream services who have dementia.
This section looks at issues relating to organisational culture that arose in the interviews. Whilst people we spoke to were generally very positive and supportive of the principle of personal budgets for people with dementia most admitted that sensitivity to the nuances of dementia is yet to develop within their local systems.

‘Nothing different’ for people with dementia

Some of the personalisation leads in local authorities that we spoke to said they were doing ‘nothing different’ for people with dementia than is available to other adult care groups. One local authority reported “everyone is included and we look at how to overcome obstacles” on a case by case basis. This approach is limited and is unlikely to be proactive enough to counteract the multiple discriminations that people with dementia experience such as low expectations of and for people with dementia, risk averse practices and limitations to choice and control.

In the context of the challenges to communication listed above, it is unlikely that a ‘nothing different’ approach meets standards of equity and fairness. One size does not fit all. One interviewee was adamant that personal budgets have been developed to suit younger disabled adults and people with learning disabilities. The interviewee felt there had been a failure locally and nationally to address the needs of older people with dementia so that, yet again, dementia has been left behind.

Good practice example
East of England appointed a lead for personal budgets for people with dementia who worked across the whole system to promote the implementation of personal budgets for people with dementia. Working with frontline services this project developed a number of resources to support delivery of personal budgets for people with dementia.
For more information and resources see http://jipeast.org/index.php?option=com_content&view=category&id=174&Itemid=154

Carers as proxy for working with the person with dementia

Working through carers was seen by a couple of local authorities as being a good enough proxy for working directly with the person with dementia. In many cases working in this way will deliver positive outcomes for the person with dementia. However, a person with dementia and their carers should not necessarily be regarded as a ‘family unit’ – as was described by one local authority. People with dementia and their carers might be inter-dependent and working well together but some might have conflicting needs. Therefore it is necessary for local authorities to have systems to work directly with the person with dementia.

Our interviews showed that where a direct payment is made to a person with dementia there is almost always a carer who manages the money. This indicates that most local authorities have yet to develop money management services for people with dementia.
Systems geared to physical needs

Most local authorities we spoke to now have systems in place where all new referrals access the system for self-directed support (SDS).

A number of local authorities provide a re-ablement programme – usually for up to six weeks – to older people at the point of referral and before long term care plans are put in place. The re-ablement services we were told about focus on physical needs rather than mental health needs and few had an understanding of the needs of people with dementia or had put in place liaison or integration with specialist dementia services. Nevertheless, people with dementia were being referred to the re-ablement service because that is the process specified by the local pathway.

The risks of such a system to people with dementia include:
- their needs are assessed at a higher level than necessary because they did not improve with re-ablement services that focused on physical abilities
- the unsuitability of the re-ablement service can exacerbate their confusion and reduce their self-confidence.

Professional mindsets

A number of local authorities reported that health services – both general and specialist mental health – are not yet on board with the personalisation agenda and prematurely raise with people with dementia and their carers the notion of moving to a care home before a full assessment is complete and options for remaining in their own homes have been explored.

A couple of our interviews reported that some professionals – across health and social care and at all levels of seniority – retain a 'professional knows best' mindset. The interviews with people who lead on personalisation found this particularly notable with professionals working with older people compared with other care groups such as learning disabilities and working age adult physical disability.

Letting go of power, adopting a new mindset and reluctance to learn new skills were thought to be holding back the implementation of personal budgets for people with dementia.
The recovery model in mental health

One local authority reported that the recovery model of specialist mental health services has established an organisational culture that is not conducive to the needs of people with dementia. There appears to have been a mistaken interpretation that recovery equates to cure. However, Allen et al. clarify the relationship between mental health and personalisation.

In common with personalisation, recovery promotes the expectation that people using services can and want to take as much control as possible over their own journey towards improved well-being. The recovery journey is of and for the person using services – it is not a service-defined ‘care pathway’. It also represents a shift towards an approach to self-determination that is not predicated on the presence or absence of ‘symptoms’.

It is not about ‘cure’ but about people finding a better way to live. It has been characterised as being founded on optimism, hope and opportunity, building on individual strengths. It provides powerful, galvanising concepts to guide how mental health services can do their work in the detail of day-to-day practice, in all parts of the mental health support system.

This interpretation of the recovery model is very much in harmony with personalisation in general and personal budgets are an ideal vehicle through which individuals can achieve positive outcomes.
This section examines the impact of strategic leadership on the implementation of personal budgets for people with dementia.

**Local authority social services budgets and brokerage**

A number of our interviewees reported that keeping a cap on the social care budget presented a major concern in introducing personal budgets for people with dementia.

In one authority, where reassessments are taking place across all care groups, it was coming to light that whilst older people are the biggest care group in terms of numbers and the collective budget, at an individual level people with dementia are generally receiving a lower weekly payments compared to other care groups.

The reasons are two-fold: firstly, many social services allocate a lower maximum rate per week for people aged over 65 than those under 65 years of age. Secondly, other ‘care groups’ tend to benefit more from other sources of funding such as Supporting People. One authority stated their aim to achieve a level playing field across all care groups but admit they cannot afford to ‘scale up’ payments to older people and people with dementia.

Another authority that had yet to introduce personal budgets for people with dementia went as far as to admit that with the tightening budgets that local authorities are facing that people with dementia might have ‘missed the boat’ with regard to personal budgets.

The costs of delivering personal budgets to people with dementia are also higher than some other care groups. It is more likely that people with dementia are unable to manage the recruitment and pay process for personal assistants and so the cost of providing these elements of personal budgets need to be considered by the local authority.

A number of interviewees said they are facing great uncertainty regarding the social care budget in the context of cuts across the whole of the public sector. A number of interviewees said they felt that personal budgets for people with dementia will need to be introduced with great care and within the realistic context that resources are limited. The additional costs of brokerage and managing the money was of great concern to a number of local authorities.

**Case example**

Enfield made a strategic decision not to purchase a bespoke brokerage service. Instead, they signalled the need for brokerage to the market place and invited accredited providers to manage the money. The aim is to encourage market forces to find the right price for brokerage.

**Case example**

The Barnsley evaluation showed that support brokerage works well from the perspective of the person needing support, rather than from the perspective of the care manager who might be more organisationally focused.
Local political leadership
Political leadership was reported as being a significant enabler to implementing personal budgets across all care groups and including dementia. Interviewees reported that a strong political drive locally can make a significant difference and if an elected member is championing personal budgets for people with dementia then implementation is likely to develop at a faster pace.

Strategic team leadership
One interviewee said that if the senior team in the social services and across the local authority has a good understanding of the needs of people with dementia then it is likely there will be a ‘seep’ into the whole system, resulting in cross-organisational engagement. This will result in very tangible gains such as inclusion in commissioning strategies so that the market is developed resulting in more choice when it comes to spending personal budgets.

Case example
Barnsley has established a new joint programme board called People in Control. This is a joint approach to personalisation with NHS Barnsley with joint sponsorship. The Board reports into the Local Strategic partnership. Whilst social services is the programme sponsor tasked with driving the systems forward personal budgets have become embedded as everybody’s business. Barnsley also has ‘partnership in action’, a pooled budget that facilitates the implementation of personal budgets and is a pilot site for personal health budgets.

Case example
Doncaster has left people with dementia as the last care group for strategic focus because they know it is the most complex and they wanted to learn from other programmes before addressing the specific needs of people with dementia. The mental health trust provides services to people with dementia and they already have a single assessment process in place which, they feel, is a good building block. There is already an Integrated Programme Board in place with the PCT and the mental health foundation trust. The local authority social services will lead the engagement with the mental health foundation trust to unpick the single assessment process and to build a process that is suitable for people with dementia. They know that some of the key issues they want to address is putting mechanisms in place to manage budgets for people who cannot manage the money for themselves.
Commissioning and market development

A number of our interviewees reported that local markets are not yet developed to deliver personalised and flexible services for people with dementia. This is not unique to dementia. One described this as a ‘chicken and egg’ challenge: locally people with dementia were not accessing personal budgets and therefore local providers were sticking to traditional models of care. This links to the issue above of developing strategic team leadership where cross organisational sign-up can influence commissioning strategies and local market development.

Managing team budgets

One local authority reported that some team managers are concerned about overspending their team budgets if personal budgets for people with dementia are implemented.

Most of the local authorities we spoke to were unable to provide evidence that resource allocation systems have narrowed the gap in the maximum weekly allocation that people can receive aged under 65 or over 65. Indeed, one local authority suggested that the resource allocation system penalises people with dementia because tasks often take longer for people with dementia and so, to achieve the same outcomes as people with other disabilities, they would need a higher weekly budget. Whilst there is an uplift for specialist dementia day, residential and nursing care this is often not reflected in the personal budget allocation.

Case example

Lincolnshire has developed a resource directory that they plan to develop into an e-market place for all providers across all sectors catering for all care groups to showcase the types of services they offer. The information is publicly available to anyone seeking individualised support and services. See www.ibnl.org.uk
Section four Organisational readiness

This section explores the readiness of organisations to implement personal budgets. Availability of information, confidence of people living with dementia in the local system and data collection are crucial platforms upon which to build organisational systems.

Training NHS staff

A number of local authorities pointed to the differences in approach between mental health services and local authorities as a significant block to implementing personal budgets for people with dementia. It was felt by a couple of interviewees that clinicians in particular can block progress in implementing personal budgets by advising the person with dementia and carers that a move to a care home should be the next step in meeting the person’s need. One contributor suggested the lack of targeted information and training for clinicians understandably results in them not embracing the concept of personalisation and personal budgets.

Personal budgets champions

A number of local authorities have developed personal budgets champions across all care groups where learning can be transferred and champions can act as catalysts within their care group and assessment teams.

Case example

Lincolnshire set up a personal budgets champions network. A member of the champions network had a positive experience of working with a person with dementia where a personal budget solved some seemingly intractable problem. As a result the practitioner was able to positively influence other champions and members of their team.

Lincolnshire also links with a neighbouring authority so that staff can shadow and learn from each other.

Case example

Barnsley has an NHS project on care navigation for people with dementia so that NHS staff understand personal budgets and become embedded in the mindset of all frontline staff. Barnsley now have a People Development Strategy, and are working on a range of joint initiatives with NHS Barnsley such as motivational interviewing and e-learning for dementia.
Data recording systems

A number of authorities reported their data recording systems were not conducive to personal budgets. One authority in particular reported its system was unable to reflect the fluctuating need of people with dementia and as a result the costs of back-office manual systems had increased.

In the South West the lead for Personalisation for Mental Health reported the incompatibility of IT systems across local authorities and many mental health trusts. There is a willingness to make things work and many mental health trusts have put in place manual systems and ad hoc ‘sticking plaster’ system until a more sustainable solution can be achieved.

Inclusion of people with dementia and their carers in the development of systems for personal budgets

A number of local authorities indicated that local personal budgets systems were not set up with people with dementia in mind. They are therefore playing catch up and trying to shoehorn people with dementia into a system that is not entirely compatible with their needs. One interviewee stated that a crucial success factor in overcoming this challenge is to engage local people with dementia right at the beginning of the planning process for personal budgets.

Supporting people through the self directed support process

It was felt that people with dementia and their carers need to know that the local authority is there to support them when times get tough. Those times might include changing needs of the person with dementia, changing needs of the carer and problems with the provision of care.

Case study

Voluntary Action Barnsley have recently administered a small grants scheme on behalf of Age Concern to support the development of Peer Support within Self Directed Support. A Local voluntary sector organisation, Barnsley Independent Alzheimers and Dementia Support (BIADS) have been given a grant to help them develop champions for SDS and enable them to support and advise individuals and carers thinking about SDS.
This section examines the operational issues that enable frontline practitioners to deliver personal budgets. Training and systematic assessment processes for assessment are key.

**Workforce training**

It was clear from the interviews that good staff training is essential for successful implementation of personal budgets for people with dementia. The training must address the specific needs of people with dementia and all members of multidisciplinary teams should be involved to ensure personal budgets are embedded into the local culture. We have seen above how real success stories are an essential element to illustrating the efficacy of personal budgets for people with dementia.

Training in techniques of communication with people with dementia was thought to be essential in ensuring equity of access to self-directed support. The use of observational methods such as Dementia Care Mapping and talking mats were highlighted as particularly useful.

Interviewees also reported that staff in general older people’s teams need to have good back-up from specialist staff in older adult mental health and the local authority personalisation leads to assist them in finding solutions to complex assessment processes and managing money.

**A robust assessment process**

In addition to the assessor’s professional skills and judgement, key steps in the assessment process include:

- Continuing good practice with regard to care management, risk management and safeguarding regime
- Carrying out checks to establish whether there is a person who is prescribed as a Representative in relation to a service user, a Deputy appointed by the Court of Protection, donee or registered Lasting Power of Attorney relating to welfare decisions and/or property and affairs
- Checking whether there is any Advance Decision in place or a written account of decisions made when the person had capacity which need to be taken into consideration
- Where a service user does not have the capacity to consent to direct payments, the payments can be made to an appointed suitable person who will manage the payments on their behalf. All steps must be taken to ensure service users eligible to receive direct payments have as much help and support as they need to manage their direct payments and remain in control of the arrangements at all times
- Where a service user may have capacity to consent but may need help with managing the money, payments may be made to a third party (nominee) for delegated management of the money
- Criminal Record Bureaux (CRB) checks should be obtained in respect of persons identified in Statutory Instrument 2009 No 1887. Where a CRB check is not a requirement, it is usually the case that family do not object but discretion should be used and a strong recommendation given that a CRB check should be carried out
- All decisions and support plans should be put in place in the best interests of the service users. Careful consideration needs to be given to the needs of carers and situations where it might be in the best interests of the service user that the carers’ needs are met so that they are able to continue with their caring role.

(Thanks to Merralyn Sandison, Herts Partnership NHS Foundation Trust for the above checklist).
Case example

Hertfordshire Partnership NHS Foundation Trust has a specialist Self Directed Support Team who work jointly with the Local Authority implementing personal budgets in specialist mental health teams.

In 2010 initial data analysis shows that 601 people with dementia have been assessed for a personal budget and 68 receive direct payments. A growing number of carers are requesting direct payments to provide more flexible support than traditional services can offer. Personal budgets using direct payments are increasingly being put in place when there is a family member managing the money but this is not always the case. Changes introduced by 9th November 2009, DOH Direct Payment Guidance extended the system of direct payments to include that a “suitable person” can receive direct payments on behalf of a person who lacks the capacity to consent to the making of direct payments.

Merralyn Sandison has worked in adult mental health since 1991. She is a Social Worker, Best Interest Assessor and qualified Systemic Therapist. From her experience, she finds that starting an assessment from a position where assumptions are not made relating to capacity promotes practice which is consistent with the Mental Capacity Act five key principles, the test to assess capacity and best interest decision making process. The first support plan she was involved with putting in place was following a request from a carer for a direct payment to pay for a personal assistant as an alternative to a traditional home care package and a way of providing additional and more flexible support for a service user whose dementia was at an advanced stage. Even in the advanced stages of dementia, it is Merralyn's experience that it is unusual for a person to completely lack autonomy.

Evidence of choices being made can be observed from how the person interacts with people they know well and everyday decisions made, such as food and drink choices and preferences. The views of close family members and people who have known the person over time need to be taken into account as they are the people who will be best placed to know what the service user's decisions relating to how their social care needs are best met might have been when they had capacity. Family were able to contribute background knowledge relating to the decision the service user had made when she had capacity for a family member to manage her financial affairs.

In the assessment process, the service user engaged positively with family members and the person the family were planning to employ as a personal assistant. The consensus was that the service user's social care needs would be better met by someone who was familiar to her and where there could be a continuity of care. A support plan was agreed and a referral made to Leonard Cheshire, who work in partnership with the Local Authority offering a Direct Payment Support Scheme which provides assistance to service users and carers with all aspects of employing a personal assistant, including recruitment, setting up a payroll service, contracts of employment, budgeting, CRB checks and employers' liability insurance.

Merralyn's experience is that the mental capacity assessment should be completed following on from the needs assessment. At this point, the assessment avoids the pitfalls associated with presumption of lack of capacity and benefits from being able to include any evidence of fluctuating capacity, evidence of any decisions which the service user might have been able to make or not make, the views of close family, friends and professionals and cultural considerations which need to be taken into consideration when making the best interest decision.
Accessible information

Interviewees attested to the benefits of good quality local information about personal budgets that is accessible to people with dementia. The information should include:
- The process of self directed support and resource allocation systems and the support that people with dementia who have communication, insight and recall needs can access to support them in this process.
- The different ways in which money can be managed by, or on behalf of, the person with dementia.
- The types of support and services that can be purchased with a personal budget.

Interviewees felt that the process for self-directed support should be transparent and smooth as no amount of information can overcome complex processes.

Advocacy

Good advocacy tailored to the needs of people with dementia was regarded by a number of authorities as being essential for securing personal budgets for people with dementia. A number of localities report that advocacy across all care groups – including dementia – is still in development and is not yet achieving full potential.

Managing the money

One interviewee acknowledged that some people with dementia and their carers find the prospect of managing a large budget as needs increase in the future off-putting. This was thought to be particularly pertinent where people are managing the budget independently.

The interviewee felt it was necessary to have robust systems in place to manage budgets on behalf of the person with dementia and that people receiving a personal budget should be made clearly aware of alternative and supportive systems right from the beginning. It was thought that this would overcome the reticence that some people have in embarking on the personal budget option.

Case example

Enfield has introduced the E-card (Enfield-card) where money from a Direct Payment is loaded onto the card. Each time a contracted agency is used money is deducted from the E-card by the agency, rather like an Oyster travel card. Transactions are monitored by the provider agency, social services and the person’s nominated carer. The E-card is an interim arrangement for use with domiciliary care agencies only and is part of the transition arrangements from block contracted services. Safeguards have been put in place including:
- Setting a strict financial envelope for each client and if more care is needed a re-assessment must take place.
- A member of the Transformation team works with each provider to ensure the smooth running of the system.
Regulations made in November 2009 paved the way for all people with dementia to receive a personal budget. Whilst the legislative framework is now fully in place, the cultural, organisational and operational practice is still playing catch up. There are examples of good practice but they remain in pockets rather than being evenly spread throughout the whole system. Most local authorities have put in place the foundations for personal budgets and having achieved the first stages of transforming adult services. There is now scope for them to embed good practice for people living with dementia.

Summary of the challenges in delivering personal budgets to people living with dementia:

- Data collection in local authorities is such that it is difficult to accurately assess the number of people with dementia in receipt of a personal budget
- Systems to support personal budgets for people with dementia are not well developed
- Anecdotally local authorities report that where they have supported the delivery of personal budgets to people with dementia they have concentrated on younger onset rather than the majority of older people with dementia
- Local authorities report a reticence on the part of older people in general and families to seek a personal budget
- Local authorities are aware more work is needed to engage mental health trusts in the personal budgets agenda
- The reasons for slow implementation are complex and multi-layered across the local authority culture, strategic planning, organisational infrastructure and operational systems.

Potential solutions:

- Data collection to identify the number of people with dementia in receipt of personal budgets should be mainstreamed. Failing that, local authorities and the NHS could undertake annual audits to assess the numbers
- Local authorities and the NHS should involve people living with dementia in (a) devising appropriate processes for self directed support assessments, and (b) developing appropriate systems for managing direct payments
- Mental health trusts and local authorities should explore the opportunities that personal budgets and personal health budgets present to people with dementia and develop systems that maximise effective implementation of both budgets
- Local authorities should ensure that they support people living with dementia throughout the assessment process and through the duration of receiving care and support
- Personal budgets for people with dementia should also work positively for family carers and where there is a conflict of interest local authorities should ensure advocacy is available to both the person with dementia and their family carer
- Staff working with people with dementia should receive training in both assessing, enabling and managing risk as well as safeguarding so that they feel confident in working with personal budgets and personal health budgets for people with dementia
- Champions for personal budgets for people with dementia, including local authority elected members, should be appointed at all levels of the organisation and partnership.
Personal testimonies on personal budgets for people with dementia

Please note that sometimes links to web pages become broken. The links below were functioning at the time of publication in October 2011.

Dementia Choices, Mental Health Foundation

See Edith and Jackie’s story
http://www.barnsley.gov.uk/online/self_directed_support

Hazel’s story:
http://www.dhcarenetworks.org.uk/Personalisation/Stories/index.cfm?parent=2738&child=4544&type=wmv

Geoffrey’s story:
http://www.dhcarenetworks.org.uk/Personalisation/Stories/?parent=2738&child=4543

Frank’s story
http://www.dhcarenetworks.org.uk/Personalisation/Stories/?parent=2738&child=4908

Florence’s story
http://www.dhcarenetworks.org.uk/_library/Resources/Personalisation/Personalisation_Advice/Florence's_Story.pdf

Barbara’s story
http://www.in-control.org.uk/support/support-for-individuals-family-members-carers/personal-stories/barbara's-story.aspx

Personal testimonies in personal budgets for older people – making it happen
http://www.puttingpeoplefirst.org.uk/_library/Resources/Personalisation/Personalisation_Advice/PSSOP.pdf
Acknowledgements

Thanks to the following interviewees for their time and thoughtful consideration to personal budgets for people with dementia. Particular thanks to the invaluable and insightful contributions from Bernadette Simpson.

**Local authority interviewees**

Wendy Lowder, Barnsley, Assistant Executive Director - Personalisation

Brenda Lindsay, Cumbria, Service Development Manager

Suzanna Joyner, Doncaster, Assistant Director Modernisation and Commissioning

Matt White, Enfield, Commissioning Manager, Physical Disability

Marralyn Sanderson, Hertfordshire, Practice Development Practitioner

Alan Dean, Lincolnshire, Workstream Manager, Putting People First Team

Diane Eaton, Manchester, Head of Business Development

Pip Coterille, Joint Commissioning Manager, Older People

Christine Jupp, North Somerset, Planning and Development Manager

**Other interviewees**

Pam Richardson, South West Joint Improvement Partnership, Personalisation Lead

Mike Murkin, South West Joint Improvement Partnership, Development Consultant for Personalisation and Mental Health

**Other contributors**

Bernadette Simpson
Independent consultant previously DH Personalisation Programme

Toby Williamson, Mental Health Foundation, Head of Development and Later Life

Tina Lightfoot, East of England Joint Improvement Partnership, Project Manager, Dementia

Nye Harries, Department of Health, contributed during his tenure as National Programme Manager, Older People and Dementia
References

1 Eg The National Personal Budget Survey, Think Local Act Personal, June 2011; Oversight of user choice and provider competition in care markets, National Audit Office, Sept 2011

2 Living well with dementia: A National Dementia Strategy, DH 2009, page 15

3 Dementia UK, Alzheimer’s Society, 2007


5 Inquiry into home care for older people, Equalities and Human Rights Commission, interim report June 2011

6 Ruth Allen, Peter Gilbert and Steve Onyett, Leadership for personalisation and social inclusion in mental health, SCIE 2009


8 For information on Dementia Care Mapping see www.brad.ac.uk/health/dementia/DementiaCareMapping/

9 Talking mats use a set of symbols to help people arrive at decisions by using a structured system of presenting information in small, manageable chunks. See http://www.talkingmats.com/
The Mental Health Foundation is a UK-wide charity that carries out research, campaigns for better mental health services, and works to raise awareness of all mental health issues to help us all lead mentally healthier lives.