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Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers

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Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers

Liz Newbronner, Ruth Chamberlain, Kate Bosanquet, Chris Bartlett, Bernd Sass, Caroline Glendinning

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Abbreviation List

BME	Black and minority ethnic
CASSR	Councils with adult social service responsibilities
CPN	Community psychiatric nurse
IB	Individual budget
LA	Local authority
LGBT	Lesbian, gay, bisexual and transgender
PA	Personal assistant (employed by the PB holder)
PB	Personal budget
PB holder	Personal budget holder
RAS	Resource Allocation System
SAQ	Self-assessment questionnaire
SPO	Support provider organisation
ULO	User-led organisation

Executive summary

Introduction

This report is a summary of people's experiences of using self-directed support and personal budgets. The national evaluation of the Department of Health (DH) individual budgets pilots concluded that while individual budgets could enhance people's sense of control and satisfaction with services, there was substantial variation in the benefits and experiences of older people and people with mental health problems. These findings were consistent with the large body of earlier research evidence on the barriers to the take up of direct payments, and have been supported by a number of more recent reports. In the light of this evidence, the Social Care Institute for Excellence (SCIE) commissioned this practice investigation to explore further the experiences of these groups and their carers.

The overall aim of the research was to provide evidence to inform good practice in personal budget (PB) processes for people with mental health problems and older people. It draws primarily on the experiences of PB holders and carers, supported by the views of practitioners and managers from local authorities (LAs), trusts and support provider organisations. The findings are structured around the main stages of the PB process.

Methods

The research was conducted by a joint team from Acton Shapiro, the National Centre for Independent Living (NCIL) and the Social Policy Research Unit (SPRU). An advisory group was also established to help steer and inform the research. The research team began by bringing together the key policy and research literature to ensure that the project could build upon what is already known about PBs. This information was also used to inform the development of the research instruments and to establish the criteria which would guide the selection of case study sites. The research was then conducted in three main stages.

Recruitment of the case study local authorities

Interviews with 10 national organisations and the knowledge and contacts of the research team were used to identify possible case study LAs. Five LAs (two with partner mental health trusts) agreed to take part. They provided a broad mix of councils, and different geographical, demographic and socioeconomic characteristics.

Fieldwork in the case study sites

For each LA/trust, the research team began by drawing together basic contact and PB information. A combination of approaches to data collection was then used:

- individual telephone or face-to-face interviews with PB holders and carers
- focus groups with PB holders and carers, drawing on existing groups or networks
- interviews and small group discussions with officers with responsibility for implementing *Putting people first* (DH 2009, 2010), and practitioners and staff from social services and local support provider organisations.

A number of approaches (tailored to each site) were then used to find people who use services and carers willing to take part in the study. The exact mix of interviews and groups varied, but 69 PB holders and carers, 40 practitioners and managers and 12 support provider organisations (including five user-led organisations) eventually contributed to the research.

Analysis and development of findings

All the interviews and discussions were recorded and transcribed using detailed notes and quotes. The data was then analysed thematically and illustrated using 'personal stories' from PB holders and carers, and 'positive practice examples'. Some of these are provided throughout this report.

Moving to a personal budget

The majority of PB holders and carers in the study had heard about PBs from their social worker or community psychiatric nurse. Many would have liked earlier access to information about PBs and highlighted the importance of key groups of healthcare staff and providers knowing about PBs.

Deciding on a PB

PB holders and carers emphasised the importance of clear and understandable information about what a PB is, how it can be used and what is involved in holding one. In particular they highlighted:

- leaflets/booklets being written in plain English with minimum use of jargon
- providing information about different aspects of PBs in 'bite-sized chunks'
- information being presented in a format that is accessible and manageable
- offering alternatives to written information (e.g. DVDs, podcasts etc.)

- information tailored to the needs and interests of different groups of people who use services, with concrete examples of what the money might be spent on (following approval)
- information specifically designed for carers
- better information about the financial aspects of PBs.

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

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

The information-giving role of the support provider organisations in the study varied widely. While a few actively marketed their services, some provided information about PBs only to people referred to them by the LA. Generally, user-led organisations saw themselves as having a wider and more experience-based information-giving role.

Assessment and resource allocation

Being assessed for a PB

The majority of PB holders with mental health problems completed a self-assessment questionnaire and had variable help or support in doing so. While some said self-completion had boosted their confidence, most would have liked more help. Many older people found it difficult to recall the detail of the assessment process and only a few mentioned self-assessment. Even though people with mental health problems and older people appeared to have had different experiences of the PB assessment process, their ideas for how it could be improved were similar. In particular they wanted:

- the level of support and the forms provided to be much more tailored to their individual needs, without assumptions being made about what certain 'groups' of people who use services could or could not do in terms of self-assessment

- a consistent contact person throughout the assessment process who knew their circumstances and whom they could get to know
- fewer people involved in the assessment process overall – but also having the opportunity to access and involve other people if required
- assessments to be focused on outcomes and to address aspirations as well as needs.

Very few PB holders could recall risk and safety issues being explicitly discussed as part of the assessment process. The discussions with staff also revealed a mixed picture in terms of the consistency with which risk and safety issues were assessed. The feedback highlighted the need for:

- clear guidance on how issues of risk and safety should be included in the assessment, including how to balance (and record) choice and safety concerns if PB holders' and practitioners' views differ
- explicit separation in the PB process of the mechanisms used to judge the risks to the LA (e.g. financial risk) and those used to assess the safety of the PB holder and their carer
- robust systems for linking risk assessment or safety issues raised at the assessment stage to risk management in the support planning stage, especially when undertaken by different agencies/staff.

Resource allocation and the level of personal budgets

Different resource allocation systems were used across the sites. Where a generic system was used it highlighted inequalities in resource allocation between client groups. Older people, especially those with high care needs, appeared to be most disadvantaged. Only one site had a 'carer neutral' resource allocation system. Levels of devolved responsibility and arrangements for 'signing off' PB assessments and support plans varied across the study sites and between client groups, but there were examples of flexible systems.

The majority of mental health PB holders and carers were very happy with the amount they had received in their PB, but satisfaction among older PB holders and their carers was much more variable. Some resource allocation systems gave PB holders more flexibility than others. Older PB holders and their carers were more likely to have been advised to set aside a budget for contingencies. PB holders, carers and staff felt that contingency planning should be strengthened and suggested that:

- contingency arrangements should be discussed and recorded during assessment and, if appropriate, documented in the support plan
- PB holders should be allowed to keep unspent contingency funds at the end of the year

- when contingency arrangements have to be put in place, staff and carers should be enabled to do this without a reassessment being required
- for those with high-care needs, an authority-wide contingency budget should be established on which staff could draw to set up additional support in a crisis.

Support planning and setting up services

Support planning

PB holders' experiences suggest that there are a number of ways to ensure the support planning process is positive and flexible:

- a 'fast track' option from assessment to support plan, where the PB holders' wishes are clear and there are no major concerns about safety or financial risks
- the opportunity to agree a short-term or temporary support plan, which gives people time to think about what they want before their full support plan is developed
- support planning 'templates' which are flexible and where PB holders are encouraged to use different ways to express their views (e.g. video recordings)
- continuity of staff involved in the self-assessment and support planning processes
- offering the opportunity to involve a support provider or user-led organisation in the support planning process, especially if that organisation is likely to support the holder in managing their PB
- active involvement of staff/support provider organisations in encouraging people to think beyond traditional service models and develop innovative ideas about how to meet their needs
- where service users are 'transferred' to a PB, and/or their care needs are relatively prescribed, the development of the support plan should still be used to give them maximum choice and control over how they are supported.

The role of external organisations in support planning

All the case study LAs had a service level agreement with one or more support provider organisations to undertake discrete tasks (particularly concerning brokerage and payroll services), but they often became involved informally in support planning. Discussions with the support providers suggested that the experience for the PB holders could be enhanced if there were:

- clear referral mechanisms and protocols to and from the LA with scope to expand the involvement of support providers
- multiple referral routes to providers from all types of community organisation
- outreach activity/'warm-up' meetings facilitated by providers to enhance peer support
- stronger emphasis on the direct accountability of providers when they tender for LA contracts
- more joint training between support providers and LA staff
- more opportunities for LAs and local support providers to exchange ideas and information, and so increase mutual understanding and trust
- a closer working relationship between providers and care managers to promote their role and encourage referrals
- an integrated support network from which PB holders could choose to obtain support at all stages of the PB process.

Setting up services and support (brokerage)

For most PB holders, once their support plan had been approved, the services and support they wanted were put in place relatively quickly, and people used their PBs in a wide variety of ways. A number of factors helped or hindered PB holders' abilities to make the most of their PB, and holders and practitioners suggested four things which they had found helpful:

- clear basic guidance on 'using your PB' which explains the link between expenditure and the support plan
- a named member of staff (or team) familiar with the PB holder's circumstances
- guidance and training for LA, trust and provider staff on the use of PBs and scope for team managers to approve special requests
- the opportunity to exchange ideas with others about how they were using their PBs.

Availability of the service and support which people wanted was also an important issue. Managers and practitioners suggested a number of things which LAs could do to encourage diversification and development of provider services:

- training and development work with existing providers to help them understand the principles and practice of PBs, and encourage them to adapt their services
- creating an infrastructure which makes it easier for PB holders to pool their 'purchasing power' to jointly commission the new services or support

- giving staff time to work with PB holders with unconventional/innovative ideas to help them source new types of support, and share the learning from the experience.

Managing the personal budget

Deciding how to hold the personal budget (deployment options)

Across the case study sites PB holders were offered four ways of holding their PB:

- services directly commissioned and/or managed by the LA
- third-party managed accounts (usually a support provider organisation)
- a direct payment held and managed by the PB holder
- a mixture of these options.

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

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

- providing opportunities for PB holders, particularly those who have opted to have their PB as a direct payment, to share their experiences with potential PB holders.

PB holders using direct payments clearly felt this had given them much greater choice and control. For PB holders with mental health problems the sense of responsibility increased their confidence. Older PB holders who had opted for a direct payment were equally positive. A number of older PB holders had taken their PB as directly commissioned services or a managed account. Although this could work well for some (with the right input from their social worker and a flexible, creative support planning process), the evidence suggests that currently these deployment options often result in less choice and control than a direct payment.

Ongoing management of the personal budget

Most PB holders with mental health problems were able to manage their PB themselves with little or no support. Where help was needed, the main source was their community psychiatric nurse or social worker. Some people also had support from family or friends. Older PB holders were more likely to receive active support in managing their budget. A significant proportion had support from a support provider or social worker. Older PB holders and carers were generally positive about the service provided by support organisations; where people were less happy, the main reason concerned charging. Where older PB holders were very frail or had dementia, carers had often taken full or substantial responsibility for the budget.

All sites had provider organisations offering PB holders support, although the number and nature of these varied. Most had some grant funding but all made a charge for some of their services, a practice most PB holders and carers were happy to accept. Generally providers offered a 'menu' of support. No provider appeared to charge for more general support and advice. PB holders and carers reported that access to this 'free' informal support was important, both in terms of the sense of security it gave them and in building a positive relationship with the support provider.

In all sites, the main form of peer support offered was groups. A number of PB holders and carers said that they would have welcomed peer support, especially when they first got their PB. They felt this could be offered in a number of ways including the opportunity to talk to an existing PB holder or carer about the experience of having a PB or to be linked up with a 'PB buddy'.

Monitoring arrangements

Systems for monitoring and audit varied considerably from 'light-touch' time-based reviews to systems linked to the size of payment. PB holders and carers suggested a number of things which had or could make monitoring easier:

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

Key themes and issues

The themes and issues set out here are primarily aimed to assist those 'in the field' who are implementing PBs, but some have wider policy implications. They are:

- 'promoting' PBs
- strengthening risk assessment
- encouraging creativity in support planning
- improving the supply of services
- maximising control regardless of deployment option
- offering choice in support to manage the PB
- establishing manageable monitoring systems
- recognising the central role of carers.

More generally, as LAs gear up to make PBs available to more and more service users, they need to find ways to keep the PB process 'personal'. With high workloads and resource constraints this is easy to say and very difficult to do. There may, however, be a number of steps which they can take to avoid PBs becoming 'bureaucratised'.

1 Introduction

In November 2005 the DH set up 13 individual budget pilots, which were designed to test new ways of providing support for older people, disabled adults and adults with mental health problems who were eligible for publicly-funded social care services. Individual budgets were intended to give people more choice and control over how their needs were met, and greater clarity about the resources available. The DH also commissioned a national evaluation – the Individual Budgets Evaluation Network (IBSEN). The final report from the IBSEN evaluation (Glendenning et al. 2008) concluded that individual budgets could enhance people's sense of control and satisfaction with services. However, it also showed substantial variation in the benefits experienced by different groups of people who use services, and specific challenges in integrating health and social care services and developing staff skills and practice, in relation to older people and people with mental health problems. In particular it noted that:

- Older people reported lower psychological wellbeing with individual budgets in comparison with previous LA-managed care, and were generally more cautious about such budgets compared to younger disabled people. This raises questions about the way PBs are presented and negotiated with both the older person and their carer(s), and what support is required to make them work well for this group of people.
- People with mental health problems reported a significantly higher quality of life and improved psychological wellbeing as a result of using individual budgets. However, the report stressed that the success of PBs for people with mental health problems needs to be set against certain barriers to take up and difficulties in integrating funding streams from health so that support remains unified and effective.
- Questions about perceived risk and professional decision-making, purchasing non-traditional services and negotiating innovative support choices may also need to be considered for both older people and people with mental health problems (Spandler and Vick 2005).

These findings were entirely consistent with the large body of earlier research evidence on the barriers to the take up of direct payments for these groups of people (Davey et al. 2007). More recently, a number of studies and policy documents have expanded on the issues set out by the IBSEN evaluation. Age UK's recent report, *Personalisation in practice* (Orellana 2010), raised the concern that people in later life are 'being squeezed in to a "one-size-fits-all" model of personalisation designed for younger people with physical and/or learning disabilities'. The report emphasised that PBs represent a major transformation that should not be seen as being entirely about direct cash payments to buy care. It contends that many older people will 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 in taking on responsibility for organising services or managing finances
- they are often coping with new or unstable levels of need, so are less likely than younger disabled people to know what support they will require either now or in a few months' time
- managing services to meet constantly changing needs is harder work than directing a stable care package.

In its guidance, *Personal budgets for older people – making it happen*, the DH (2009) notes that, in many councils, direct payments are emerging as the option of choice for older people. However, the guidance emphasises the importance of older people being offered a flexible range of options to manage their money and goes on to stress that this has to be accompanied by a range of support options and close working with the older person, their family and friends to decide the nature of support and its provision.

The Age UK report also draws on earlier research by DEMOS (Bartlett 2009), which showed that older people are the group least likely to know about PBs and most likely to need help to plan support and manage the budget. A report by the Joseph Rowntree Foundation (Horton 2009) also highlighted the importance of providing guidance and support, not just information, to older people if they are to fully benefit from PBs. DH guidance on support planning and brokerage with older people and people with mental health problems also emphasises the need for clear, written, local information and the importance of access to a range of support, including peer support (DH 2010). In Control have also highlighted the importance of free information, advice and advocacy. In the second report from the evaluation of the In Control Pilots, Hatton (2008) notes, 'The continuing free availability of such services may be critical to fostering confidence on the part of the people considering taking up Personal Budgets. It will also help provide reassurance that independent assistance is available should difficulties need to be tackled at a later stage'.

The Audit Commission's recent report (2010) on the financial management of PBs found that people with mental health problems were less likely to have a PB than other service users and that PBs were less developed for this group. The report takes the view that this partly reflects the difficulty of disentangling pooled NHS and social care funds, but some of the research participants also considered there to be a financial risk in offering PBs to people with mental health problems. This issue was also picked up by the National Mental Health Development Unit in their report on PBs which draws attention to the part that 'stigma' and 'ignorance' have played in the low take up of PBs among people using mental health services. An earlier study by MIND (2009), which involved a number of PB holders with mental health problems, highlighted the 'confusion and misunderstanding' surrounding PBs in mental health services and

commented that this was resulting in people who use services feeling less confident about expressing their right to choice and control.

The IBSEN evaluation recommended that, going forward, PB policy and practice in relation to these two groups needs to be further developed. Recognising this, the SCIE decided to commission a practice investigation which would build on existing evidence to specifically explore the experiences of older people, people with mental health problems and their carers.

1.1 Aims of the research

In its specification, the SCIE defined the overall aim of the research as being to: 'examine personal budget processes and practices for people with mental health problems and older people by investigating the front-line experience of service users from these groups and to … produce evidence to inform good practice in this area and [in a second stage of work] to develop learning resources for workforce skills development'. To address these aims, the research focused on a number of key areas, including:

- information and advice
- arrangements for assessment, self-assessment and supported self-assessment
- alignment of carer assessments and carers' needs
- support planning and brokerage arrangements
- support with ongoing management of PBs
- organisational barriers and facilitators for developing good frontline practice for the groups under investigation.

The research was essentially a practice investigation, not an evaluation of PBs, and as such was very practical in its nature. In particular it sought to draw on the experiences of PB holders and carers, and the views of practitioners and managers from LAs, mental health trusts and support provider organisations, to identify positive practice. While there were many examples of positive practice, all the case study sites emphasised that it was still 'early days' for them in terms of the implementation of PBs, and both their PB systems and front-line practice were still evolving. Recognising this, the research notes where PB holders' experiences had been less good, and then brings together PB holders' and practitioners' ideas about ways in which PB processes and practices could be improved or strengthened.

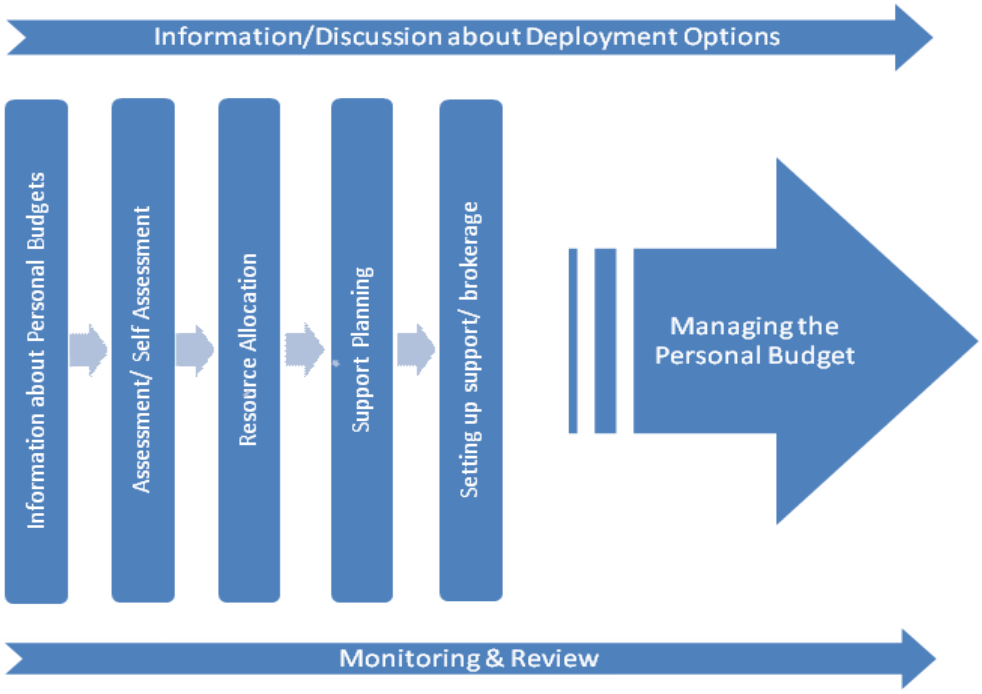
1.2 Structure and focus of the report

The interviews with PB holders and carers suggested that the PB process they had experienced had a number of key stages. These are set out in Figure 1. In practice, these stages were not always distinct, with some 'merging' (e.g. assessment and support planning) or occurring more than once (e.g. the provision of information about PBs or discussions about deployment options). Despite this, the research team and the advisory group (see Chapter 2) felt that the report should be structured around the main stages of the PB process. It also became clear as the work progressed that while the experiences of older PB holders, PB holders with mental health problems and carers did differ in some respects, there were far more areas of common ground. For this reason, we have not separated our findings in relation to these groups into distinct sections. However, for clarity, in most sections we begin by considering the experiences of PB holders with mental health problems and their carers, then look at older PB holders and their carers, and finally set out common themes and issues.

The report begins by describing in Chapter 2 how the research was conducted. A much fuller description of the methods used, the difficulties encountered and the strategies adopted to overcome them is set out in an accompanying technical report. Chapter 3 focuses on how people came to 'choose' a PB, in particular the information and support they were given, and their initial expectations and concerns. Chapter 4 looks at assessment and resource allocation and Chapter 5 sets out the findings in relation to support planning and setting up services. PB holders' and carers' experiences of managing their PBs, including monitoring and review arrangements, are explored in Chapter 6. Finally, Chapter 7 draws together a number key themes and issues.

Throughout the report we have used PB holders' and carers' personal stories to illustrate how positive practice has made a difference to them. We have also presented several 'positive practice' examples which provide illustrations of how organisations in the case study sites have developed new and effective PB procedures and practices.

Figure 1: Stages in the PB Process



2 Methods

This chapter describes how the research was conducted, including the role of the service user researchers and the overall structure and approach to the study. A number of practical and methodological challenges emerged in the course of the research, which are touched on here. However, a much fuller description of the methods used, the difficulties encountered and the strategies adopted to overcome them is given in the accompanying technical report (Newbronner et al. 2010).

2.1 The research team

The research was conducted by a joint team from Acton Shapiro, the NCIL and the SPRU at the University of York. The fieldwork was conducted by researchers from Acton Shapiro and NCIL, including a small group of experienced researchers who also use services who were supported by NCIL. Their role is described in more detail below. SPRU acted as research sponsor, provided advice and guidance on the conduct of the research and supported the analysis of findings and development of the report. In addition to the core research team, an advisory group was established to help steer and inform the research. The role and membership of the group is set out below.

2.1.1 Researchers who use services

A group of five researchers who use services was recruited to undertake the bulk of the interviews with PB holders. These researchers had direct experience of PBs or direct payments and so were able to apply an in-depth understanding of the central issues. They were already trained and experienced in undertaking interviews, either from their professional lives and/or through the Experts by Experience project associated with the Shaping Our Lives User Network.

One member of the research team (from NCIL) took primary responsibility for supervising the these researchers. The 'user researchers' were brought together with core members of the research team in the preparatory stages to ensure there was a shared understanding of the research aims and methods and to discuss practical aspects of undertaking the interviews. They met again while the fieldwork was in progress for the purpose of sharing experiences and checking quality.

Once the fieldwork was concluded, the core research team prepared summaries of the findings and the user researchers were asked to provide feedback on these, in particular whether the emerging findings reflected what had emerged from the interviews with PB holders.

2.1.2 Advisory group

An advisory group was established to help support and guide the research, including commenting on research tools and topic guides, advising on recruiting and communicating with people who use services and carers, and commenting on emerging findings. The group included:

- three PB holders and two carer representatives (these were recruited via networks known to the research team)
- representatives of two national organisations with expertise in mental health (the National Mental Health Development Unit) and older people (the Older People's Advocacy Alliance)
- representatives from two LAs (not directly involved in the study) who had substantial experience of implementing PBs (although in practice the LAs' representatives rarely had time to attend meetings but provided feedback by email instead
- members of the core research team.

Representatives of people who use services and their carers were provided with a small financial contribution as an appreciation of their time, and all expenses were met including 'back-fill' carer support.

2.2 Overall structure of the research

Given the pace of development in both thinking and practice in relation to PBs, the research team began by bringing together the key policy and research literature in an effort to ensure that the project could build upon what is already known. This information was also used to inform the development of the research instruments and to establish the criteria used to guide the selection of case study sites. Given the central involvement of service users as both researchers and influential advisers to this project, some time was spent in this preparatory stage planning and setting up all aspects of user and carer involvement. This included arrangements for the advisory group and remuneration and support for the 'user researchers'. The research was then conducted in three main stages:

- recruitment of the case study sites
- fieldwork in the case study sites
- analysis and development of findings.

Each of these stages is described in detail below.

2.3 Recruitment of the case study local authorities

PBs are now being implemented across the country and so it was important to try and gain an up-to-date insight into which LA areas and/or organisations were considered to demonstrate good practice in relation to PBs for older people, people with mental health problems and their carers. To do this, the research team conducted telephone interviews or had email correspondence with 10 representatives from key national organisations (including the DH, the National Mental Health Development Unit, Carers UK, MIND, Age UK, In Control, the Afiya Trust and Regard).

Drawing on the policy and research literature, the national interviews and the knowledge and contacts of the research team, a list of 13 possible case study LAs was drawn up. Six were then shortlisted, which provided a broad mix of types of councils, and different geographical, demographic and socioeconomic characteristics. The LAs were then contacted to see if they would be willing to participate in the research. Unfortunately. one LA, which initially seemed positive, declined to be involved several weeks into the research and so a decision was taken to reduce the number of sites to five.

The final five case study sites included two large rural county councils (and their local mental health partnership trusts), two unitary councils and a London borough. A short profile of each council/trust is provided in the Appendix. Although the research covers older people, people with mental health problems and carers, not all councils wished to include all of these groups in the fieldwork in their area. The main reason for this was limited capacity to support the research, and so each one became involved to the extent that they thought was manageable for them. The focus within each council/trust was as follows:

- Council A older people
- Council B mental health
- Council C older people, mental health and carers
- Council D older people, mental health and carers
- Council E older people, mental health and carers.

2.4 Fieldwork in the case study local authorities

In each site the research team began by drawing together, from existing sources, basic information about the council/trust, such as their PB history, details of their current approach and practical information, such as names/contact details for organisations, networks and individuals who might contribute to the fieldwork. A combination of approaches to the data collection was then used:

- individual telephone or face-to-face interviews with PB holders and carers

- focus groups with PB holders and carers which drew on existing groups or networks (e.g. those being supported by provider organisations)
- interviews (either face-to-face or by telephone) and small group discussions about assessment, brokerage and support planning arrangements with officers having lead responsibility for implementing *Putting people first*, and with practitioners and staff from social services and local support organisations.

2.4.1 Personal budget holders and carers

To maintain confidentiality and conform to data protection requirements, PB holders and carers were initially contacted via the participating LA or mental health trust, although they were asked to screen out anyone they knew who lacked capacity to consent or had recently experienced a life event which might make it inappropriate to contact them. In the five LAs, a letter and information sheet was sent to all PB holders and carers inviting them to take part in the research. Those people who wanted to be involved were asked to return a consent form to the research team in a pre-paid envelope, or ring a freephone number to complete the form by telephone. Both mental health trusts had relatively low numbers of people using PBs and some were only using PBs in certain localities or with specific groups of people who use services. Furthermore, difficulties in obtaining local research governance approval in the trusts delayed the fieldwork and so instead of a mailshot to all PB holders, the research team decided to work through the relevant mental health teams to target PB holders and carers who they felt might be willing and able to participate.

PB holders and carers were given the choice of whether they wished to be interviewed individually (by telephone or face to face) or take part in a focus group. Interpreters or other means to enable access were offered. The majority of PB holders chose an individual interview, but in two localities a group of older people using PBs was contacted and brought together via the local support provider organisation, and in another area three older PB holders living in extra care housing were brought together for a group discussion.

A total of 69 users and carers contributed to the research. Of these, 11 took part in focus groups and 58 were interviewed individually, either face to face or by telephone. Table 1.1 shows the breakdown between older PB holders, PB holders with mental health problems and carers.

Table 2.1 Breakdown of participants

Participant	Number
Mental health PB holder	17
Mental health carer	9
Older person PB holder	29
Older person carer	10
Older person & mental health carer	4

Of those interviewed, 48 were female and 21 were male, and there was a broad spread across the age groups used (i.e. 25–39, 40–64, 65–74 and 75 and over). Seventy-three per cent (n = 53) considered themselves 'white British' or 'white Irish' and 7 per cent (n = 5) were from other ethnic backgrounds; 16 per cent (n = 11) did not provide information on ethnicity. There was a poor response to the question asking about sexual orientation with 30 per cent (n = 21) not providing an answer. All those who did respond indicated that they were 'heterosexual/straight'.

All PB holders and carers who contributed to the research were sent a £15 shopping voucher as a thank-you for their involvement. Following each interview, they were also sent a list of local and national information and advice service contact numbers, in case the process raised any questions or concerns for them in relation to either the research or PBs themselves.

The individual interviews and focus groups were undertaken using a semi-structured topic guide covering:

- expectations
- information
- the assessment process
- involvement of carers (where relevant)
- support planning
- managing and monitoring of the PB
- impact of the PB
- advice for staff and/managers from LAs and trusts.

2.4.2 Local authority/trust managers and practitioners

PB leads in each of the five participating LAs were the key point of liaison in terms of setting up and implementing the research with staff, PB holders and carers. Early informal interviews with the PB leads were used as an opportunity to capture information about how PBs had been implemented and what systems and processes were in place. Systems and processes were not analysed in any detail but it was important to have some understanding of this in order to set PB holder and carer experiences in context.

Subsequent to this, focus groups were held in each LA (including staff from mental health/partnership trusts where mental health services had been transferred), with practitioners who were involved in delivering PBs. This largely included social workers/care managers, but in some places also involved community psychiatric nurses and staff involved in finance assessment or wider work connected with PB implementation/transformation. In total, seven discussion groups and 10 individual interviews were conducted, involving 40 staff

from across the sites. Facilitated discussions within the focus groups used a semi-structured topic guide to explore staff perceptions of culture change, systems and processes, support for people to manage their PB and staff training and support.

2.4.3 Provider organisations

The PB leads also provided information about what support was available externally from provider organisations to assist people with support planning, brokerage and/or ongoing management of PBs. The research team then contacted local provider organisations to invite their staff and/or managers to contribute to the research. A total of 12 agencies were involved across the sites, five of which were user-led organisations. Their input was mainly through individual interviews over the telephone but in one area where a relatively large number of providers had been established, a group discussion was held. The interviews/group discussions, using a semi-structured topic guide, explored provider perceptions of their role/function, partnerships, referral and information systems, choice and control for PB holders and carers, and anticipated developments.

2.5 Analysis and development of findings

Where possible, and with the consent of those involved, the interviews and focus group discussions were digitally recorded and then written up using selective quotations. An initial analysis of these notes was undertaken, split by older PB holders, carers of older PB holders, PB holders with mental health problems, carers of PB holders with mental health problems, staff and managers and provider organisations across all the case study sites. This initial analysis was shared with the user researchers to ensure that the early findings reflected the impressions they had gained from their interviews.

The team then used the stages in a 'PB journey' undertaken by a person using services as a framework for analysing the data across all sites and groups (Bryman et al. 1993). However, within each stage in the PB journey an 'inductive' process (Pope et al. 2000) was used to identify themes and issues contained in the records of the interviews and focus groups.

The fieldwork yielded a huge amount of information about PB holders' and carers' experiences, and how they and staff felt systems and processes were working. From this it was possible to draw out a number of examples of positive practice, or suggest ways in which the experience of PB holders and carers could be improved. However, the analysis also highlighted a number of broader themes and issues relating to PB implementation and national policy. These are considered in the final chapter of this report.

2.6 Ethical approval and research governance

An application for ethical approval was submitted to the Social Care Research Ethics Committee and, following some amendment to the application and supporting papers, the research was approved in January 2010. Approval from the Association of Directors of Adult Social Services (ADASS) Research Committee was also applied for and obtained. Local research governance approval was obtained for each of the LAs and mental health trusts.

3 Moving to a personal budget

Three out of the five of the study sites were moving to a system where all new clients were automatically given a PB, and most were trying to move existing people who use services onto PBs, indicating that the PB will increasingly become the 'norm' in social care. Nevertheless, PB holders and carers emphasised the value of PBs being more widely marketed, and the importance of good information, which enabled people to understand what a PB could offer them and what might be involved in managing one.

3.1 How people heard about personal budgets

The majority of PB holders and carers in the study had heard about PBs from their social worker or community psychiatric nurse. A few people had been told about PBs by hospital staff, before being discharged, and one person had been pointed to a PB by her employment officer. Others, mainly older people, had learned about them through friends who already had a PB or knew someone who had. Several PB holders had heard about them for the first time at a point of crisis or when they were discharged from hospital to a homecare reablement service. However, they would have liked to access that information earlier.

Both PB holders and carers felt very strongly that PBs and the support for them should be more actively and consistently 'marketed' by LAs and mental health trusts, so that more people could benefit from them at an early stage in their involvement with social services. Although they recognised that PBs were still quite new in many areas, PB holders emphasised the need for more general awareness of PBs and the processes involved. They highlighted the importance of:

- key groups of social care and health staff (notably GPs, community nurses and hospital staff) knowing about PBs and being able actively to point users and carers to where they could get more information

- care agencies and third-sector organisations being informed about PBs so that this information could be passed on and people guided to sources of help and information
- facilitating meetings with peers where people can informally pick up insights about accessing and managing PBs
- using the local media (e.g. local papers, radio, LA newsletters) to publicise PBs as one way to ensure that people are aware of them directly or via family and friends, before they come into contact with social care services.

Unfortunately, relatively few of the PB holders and carers who contributed to the research were from the black and minority ethnic (BME) community and/or lesbian, gay, bisexual and transgender (LGBT) communities. From this study it is therefore difficult to know whether people from these communities are less likely to hear about PBs but there is certainly existing evidence that they can experience discrimination in social care services and as a result may be more reluctant to engage with them (Commission for Social Care Inspection 2008; National Black Carers and Carers Workers Network 2008). However, a few examples of positive outreach were found, including:

- a user-led organisation which was facilitating peer support between existing PB holders with LGBT identities and potential PB holders from the same communities
- a user-led organisation targeting young people, and people with mental health problems and other needs such as substance misuse and/or HIV.

Overall, there does appear to be a need for more active outreach with marginalised communities, which works through trusted networks and groups. Such initiatives need to explain how PBs work and the scope they provide for setting up support which is in tune with people's relationships and cultural needs.

3.2 Deciding on a personal budget

3.2.1 Information about personal budgets

PB holders and carers emphasised the importance of people being given clear and understandable information about what a PB is, how it can be used and what is involved in holding one. However, it was clear that the process of getting this information was almost as important as the information itself.

Most PB holders and carers had been given some written information, and certainly all the case study LAs produced a range of written information about PBs. The panel below gives two examples of positive practice.

Positive practice example

Council C has developed a 'PB booklet' specifically for people who use services, which covers all the main aspects of PBs in a concise and easy to read form. It is given to anyone interested in having a PB and includes specific information about the different options people have for managing their PB. One PB holder explained: 'The booklet was excellent; it contained everything you need to know about personal budgets; it was available in braille and large print. It went through each process very clearly.'

Council E has produced a PB pack called *Living the life you choose* which is designed to be used by both PB holders and staff. The pack contains copies of the self-assessment questionnaire, a support planning toolkit and information about who to contact for further information.

Generally, PB holders and carers felt that the written information they had been given was helpful, but several found the amount of information daunting and said that it had taken them time to 'process it'. As one carer put it, 'it was a bit mind-boggling at first'. The PB holders and carers emphasised the importance of:

- leaflets/booklets being written in plain English with minimum use of jargon
- providing information about different aspects of PBs in 'bite-sized chunks'
- information being presented in a format that feels accessible and manageable
- offering alternatives to written information (e.g. DVDs, podcasts etc.)
- information tailored to the needs and interests of different groups of people who use services, with concrete examples of what the money might be spent on (following approval)
- information specifically designed for carers
- better information about the financial aspects of PBs (e.g. managing the money or flexibility in spending the money).

Overall, written information seemed to be most helpful when practitioners used it as a basis for a discussion about PBs and worked through it with the person using services (and their carer, if appropriate). While PB holders and carers valued having written information, it was usually the time spent discussing PBs with their social worker, community psychiatric nurse or provider organisation that helped them the most. Again, there were a number of factors which enhanced the experience of PB holders and carers, notably where:

- practitioners had a sound understanding of PBs and could talk about the process of taking up and managing a PB clearly and knowledgeably

- people felt they were being listened to and PBs were being discussed with them in relation to their lifestyles and circumstances
- there was adequate time for issues to be explained and explored, and questions followed up
- there was scope for more than one discussion, with people having time to read and digest written information in between discussions, with information being repeated if necessary.

These discussions were not simply about imparting factual information. People using services saw them as an important part of the process of deciding if a PB was the right choice, and if it was, working through what support they would need to manage it.

Personal story

Jenny cares for her mother who has Alzheimer's disease but is still able to live independently in her own home. Jenny feels that her mother was provided with very good verbal information, even though she is finding it more and more difficult to understand things. Her mother's social worker came to her home and explained to them both what a PB is and how it could improve her mother's quality of life. They also had a home visit from a worker from the local support provider organisation who explained the different ways of managing a PB. Jenny says that having the process explained verbally made it much easier to understand and made taking on a PB feel less daunting. She is however concerned that some people who might benefit from a PB do not know enough about them and are deterred by the fear of having a lot of paperwork to read. She said, 'I don't think people realise that you get as much back-up and assistance as you do… at any point if I've got a problem I can either ring somebody [at the provider organisation] if it is to do with the finance side, or if I've got problems with mum and her care I can ring social services.'

3.1.2 Sources of information

The main source of information for PB holders and carers was their social worker or community psychiatric nurse but a number of people had obtained information from their local support provider organisation, and a few had used other sources, such as the internet and local information workshops. Here PB holders and carers again felt that Las/trusts could do much more to facilitate the development of different information sources. They suggested:

- information sessions held in places such as day centres or drop-ins, which some older people and people with mental health problems go to regularly
- making information available through existing networks and community events, as well as through organisations working with older people, people with mental health problems and carers
- giving people the chance to think about taking on a PB by talking informally with existing PB holders or carers.

The information-giving role of the support provider organisations which contributed to the study varied significantly depending on their size, the nature of their funding, contract and 'history'. Some organisations only provided information about PBs to people who had been referred to them by the LA, while a few others actively marketed their services independently of the LA. Provider organisations and some PB holders felt that such organisations could have a much greater and clearer role in providing independent information about PBs. In particular, all support provider organisations felt that (prospective) PB holders should be offered the chance to discuss PBs with a worker from an independent organisation. Generally, user-led organisations saw themselves as having a wider and more experience-based information-giving role. A few PB holders felt that there could be conflicts of interest for provider organisations – on the one hand, if they are commissioned by the LA, they may feel they have to promote PBs in a certain way. On the other hand, if they were independent and had to charge PB holders for their services, they could be seen as having a vested interest in encouraging people to take up a PB and 'buy' support from them to manage it.

3.2.3 Expectations and concerns

As was noted above, the initial discussions people had with their regular social worker, community psychiatric nurse or provider organisation were very important, as they gave an opportunity to discuss expectations and concerns.

Many of the younger PB holders with mental health problems said that thinking about a PB had opened up new possibilities for them. One said that a PB enabled her 'to try new things I originally only dreamed about and hoped about'. It was often the prospect of being able to access different kinds of services and support, particularly those available to the community at large, which gave people the incentive to take up a PB. Most carers of people with mental health problems had initially focused on what the PB might do for the person they supported, again highlighting the scope for people to do things in the wider community, and through this to socialise and regain confidence and independence. However, they also hoped that this in turn would give *them* a break. It was the possibility of this 'dual benefit' that gave many carers the incentive to get involved in managing the PB.

For older people and carers, the prospect of being able to arrange care in a different way, to meet their individual needs and wishes or to better fit with family

life, was a big incentive for taking up a PB. Many older people said that they saw a PB as a way of improving the quality of care they received or of enabling them to stay living in their own home. Carers also highlighted quality and continuity of care issues, especially where they cared for a person with dementia, but they also believed that a PB would allow them to arrange care in a way that better fitted with their family and work commitments. Although the focus for many older people and their carers was on 'care provision', they also saw how a PB could help them regain independence, feel less socially isolated, and in some situations address the impact on the carer and/or the caring relationship. One carer explained: 'My husband was in a situation where he was doing everything for me and this was causing difficulties between us. I wanted to get out and be less isolated.'

All of the above were powerful drivers for people to take up a PB, and PB holders and carers felt strongly that the opportunities a PB could create should be presented to people at an early stage. Again this highlights the importance of practitioners having a thorough understanding of PBs and how they can be used, and conveying this to people who use services. It also reinforces the need for a number of sources of information about PBs so that if a person using services does not have a good relationship with their social worker or community nurse, or the practitioners working with them are poorly informed, they are not denied or put off considering a PB. Once again, PB holders and carers felt that being able to talk to other people who were already using a PB would be very valuable. As one service user put it: 'Maybe have a support group where people wanting to take up a PB can go and meet others who have done it and talk to them about their experiences with it, before they decide if they actually want to go through with it.'

Inevitably, PB holders and carers initially had some concerns about taking up a PB, although these were not as deep or insurmountable as might be imagined. The biggest concerns for older people and people with mental health problems were managing the money, keeping records and being clear about what the money could be spent on. Some were worried that that they would not manage the money 'properly' or might spend it on something that was not 'allowed'. Younger people with mental health problems were worried about not being able to control their spending, especially if they were given their PB as a lump sum, or were concerned that they might be tempted to 'misuse' their money in some way. However, in this study, as in the recent Audit Commission report (2010), such pitfalls rarely seem to have occurred in reality, and for many PB holders the sense of being 'trusted' to manage their budget more than outweighed their concerns.

Coping with paperwork was a particular concern for older people and older carers. Again, social workers, community nurses and support providers played a key role in encouraging and reassuring people. As one older carer who manages her husband's PB explained: 'The social worker I dealt with – she was fantastic. I said "Oh no, I don't think I could do that because I hate papers and things" but

she gave me every reason why I could. So I said I'd have a try… now it's working fantastically with me and I quite enjoy being responsible for it.'

4 Assessment and resource allocation

Assessment, whether self-assessment, supported self-assessment or an assessment carried out by a practitioner, clearly underpins the PB process. However, PB holders' and carers' experiences of the assessment often produced wider benefits in terms of building confidence or creating space to really think about needs and outcomes. This chapter looks at the assessment process for PB holders and the involvement of their carers. It also describes the resource allocation systems adopted by the case study sites and examines staff perceptions of assessment and resource allocation.

4.1 Being assessed for a personal budget

4.1.1 Assessment and self-assessment

The majority of PB holders with mental health problems completed a self-assessment questionnaire for their PB and had variable amounts of support in doing so. For some, filling in the questionnaire on their own was a positive experience, because completing it successfully had given them more control and boosted their confidence. Most, however, said they would have liked more help, at least to get started. Those who had support in the assessment process from their community psychiatric nurse felt that this had encouraged them to explore their needs more fully and helped them think more imaginatively about how best to meet those needs. It also gave them a greater sense of the assessment and the PB as a whole being about them as individuals and 'not just about ticking boxes'.

Personal story

Helen, who has mental health problems, lives by herself. Although she gets support from her mother and her niece, she wanted her community psychiatric nurse to help her through the PB process. She explained that she had been quite ill for some time and it was her nurse who suggested that a PB might help improve her quality of life. She described how she had felt before doing the assessment, saying she was 'filled with fear and anxiety' but that her nurse had been very supportive and the assessment process had actually proved to be straightforward. She recalled: 'I answered questions and ticked different boxes to say what help I needed. He [the nurse] ticked what he thought and I ticked what I thought… some questions we disagreed on and then we discussed them to understand the questions better…so I understood a bit more and it became clear.' She felt she had greatly benefited from doing her assessment with her nurse who was: ' with me all the way and discussed it at good length. The relationship is very important, when you do need support with everything.'

Some people with mental health problems raised concerns that the forms used for the questionnaire were not geared towards their needs so that they had to go through a lot of questions that were not relevant to them.

Several people with mental health problems did not recall a separate assessment stage but more or less felt (and appreciated) that information and assessment had been merged with support planning. Although technically support planning was a separate 'stage', assessments in effect included discussion about what could be incorporated in the support plan. This streamlined approach appealed to many people as it felt more natural and less bureaucratic.

Interestingly, in the two case study sites where mental health partnership trusts had been established and funding for social care was held or managed by the trusts, care co-ordinators/psychiatric nurses with an existing relationship with the person using services were co-ordinating the PB process and there appeared to be generally high levels of satisfaction with the assessment process. In the other two mental health sites, the PB process was co-ordinated by social workers and some PB holders were unhappy about the number of people involved.

The level of involvement of carers of people with mental health problems in the assessment process varied considerably. Where the person they supported was confident about speaking for themselves and there were no concerns about them understanding or remembering what was discussed, carers sometimes felt it was not appropriate for them to be directly involved in the assessment. Carers who had been involved felt this had been important, especially if there were implications for their own health and wellbeing or they were going to have an active role in helping to manage the PB. One carer in this situation explained: 'It's not only because he [the psychiatric nurse] feels I need to be involved but also

because he knows there's a great chance he [husband] will forget a lot of what has been said to him… so yes I've had a real good involvement with it.'

Many older PB holders found it difficult to recall the detail of the assessment process. The extent to which their single assessment and PB assessment were combined was often unclear and only a few mentioned self-assessment. All the carers of older people had been fully involved in the assessment process, which in part perhaps reflects the number of carers in the study who cared for someone with dementia who could not fully express their needs and wishes without their support. These carers also spoke positively about the assessment process, saying things like: 'the staff were patient and understanding – I could not have asked for better'. However, an older PB holder who had several years experience of holding a direct payment reported that the standardised form provided did not enable her to describe her fluctuating needs.

While emphasising the supportive relationship which many PB holders had previously formed with their community psychiatric nurse or social worker, some would have valued input from other people to 'gain their views about what I may need and what could be made available'.

Personal story

Derek, an older PB holder who is physically frail, needs a lot of support to enable him to live independently. While he was still being supported by the homecare reablement team, his social worker came to his home and went though the assessment with him and his wife Gillian. However, because his needs were quite complex, other practitioners and agencies were involved in assessing Derek's overall needs. An occupational therapist sorted out all his equipment needs, and the Fire Service ensured that smoke alarms were fitted. He and Gillian also had a visit from a financial assessor to discuss their personal contribution, and Age Concern (Age UK) made a home visit to give them information about care agencies. Although there were a lot of people involved in the process, the couple felt that it was all well co-ordinated and Derek said that 'the [PB] process had been explained quite clearly by the social worker'. Interestingly, he added that he had found it difficult to explain what his needs were because he had never previously had to consider or articulate them. His social worker helped him to think them through.

Even though people with mental health problems and older people and their carers appeared to have had different experiences of the PB assessment process, their ideas for how it could be improved were similar. In particular they wanted:

- the level of support and the forms provided in the assessment to be much more tailored to their individual needs (including fluctuating needs), without assumptions being made about what certain 'groups' of people could or could not do in terms of self-assessment
- a consistent contact person throughout the assessment process who knew their circumstances and whom they could get to know
- fewer people involved in the assessment process overall – but also having the opportunity to access and involve other people to obtain their input if required
- assessments to be outcomes-focused and to addresses aspirations as well as needs.

4.1.2 Assessing risk

Very few PB holders could recall risk and safety issues being explicitly discussed as part of the assessment process, although a few carers noted that the safety of the person they supported had been discussed with them (see panel below). The discussions with staff also revealed a mixed picture in terms of the consistency with which risk and safety issues were assessed. A number of the case study sites had produced written guidance for staff on risk management and in one site mental health staff noted that risk assessment was well managed. However, some staff said they did not explicitly talk to people using services about risks and were unsure about departmental guidance. It seemed that staff sometimes found it difficult to translate written guidance into practice, and/or that the guidance was linked to traditional care management systems and did not fit easily with the new PB systems being used.

Personal story

Joanne cares for her husband David, who suffers from depression and in the past has tried to harm himself. Thinking about his safety and finding ways to manage any risks was very important to her. She said that she was always concerned for his whereabouts – 'though he has never been a risk to anyone else, at times he has been a risk to himself' – and she was constantly worried about him 'disappearing'. The assessment identified that David required support to go out and socialise. His PB enabled him to join an indoor bowling club in the village where the couple live and he now goes there three afternoons a week. Joanne explained that at first she accompanied David to the club, but as he began to feel more confident and made friends she was happy to allow him to remain there without her. Eventually David felt able to tell people about his mental health problems and Joanne was reassured that his friends at the club would let her know if he was having problems. She reflected on how this approach had helped her: 'three times a week I get the freedom to do what I want to do knowing that he's with people that would contact me if anything were to go amiss with him. And I've got the confidence to know that I've got a couple of hours to myself and he's safe.'

For many staff it was not clear how they should include risks or safety issues in a self-assessment questionnaire if the person using services did not want them recorded in that document. This, in turn raised questions about 'ownership' of the questionnaire, especially if it was entirely self-completed. In most areas there did not appear to be clear protocols for linking risk assessment (at the assessment stage) and risk management (at the support planning stage). This was a particular concern where these stages of the PB process were being undertaken by different agencies. In the case study sites where PB assessments and support plans had to be approved by a panel, there appeared to be some confusion among staff about what was meant by 'risk', with some people using 'risks' to refer to financial or public relations risks to the LA, and others meaning risks to the safety of the PB holder and/or their carer. However, as the panel below highlights, councils were trying to address this.

Positive practice example

Council B has established a risk enablement panel which provides a monthly forum where staff at different levels in adult social services can share concerns about risks to a PB holder, and get advice and help in deciding how best to manage them.

Council E has also set up a risk enablement panel. If assessment reveals that there are undue risks associated with a PB holder's care and support, the support plan is considered by the panel and must be signed off by an adult social care assessor.

The feedback from PB holders and staff highlights the need for:

- clear guidance on how issues of risk and safety should be included in the assessment, including how to balance and record choice and safety concerns if PB holders and practitioners have a difference of view
- explicit separation in the PB process of the mechanisms used to judge the risks to the LA (e.g. financial risk) and those used to assess the safety of the PB holder and their carer (if appropriate)
- robust systems for linking risk assessment or safety issues raised at the assessment stage to risk management in the support planning stage, especially where these are undertaken by different agencies/staff.

4.1.3 Carers' assessments and carers' grants

The situation here was extremely mixed. Several had received a separate assessment, some knew what a carer's assessment was but did not recall having one, while others did not know about them at all or were unclear about the whole experience. A number of carers had received a one-off carer's grant, although they were not always clear that this was as a result of having had a carer's assessment. Carers did, however, understand that the grant was quite separate from the PB (and any provision for respite included in it) and that it was intended to support or assist the carer in some way. Carers had used their grants for a variety of purposes, most often to enable them to have a break or time to do something for themselves.

4.2 Staff perspectives on assessment

All the case study sites had introduced some form of self-assessment questionnaire, although implementation in practice varied considerably – not just

between sites but within sites. It was difficult to judge what the balance was between self-assessment, supported self-assessment and practitioner assessment. However, it was clear that some practitioners were far more comfortable than others in leaving the person using services to complete their own self-assessment questionnaire and, as was noted above, there was a tendency to assume that older people were less able to undertake self-assessment. Staff reported that assessment for PBs (especially outcomes-based assessment) demanded more time, with these pressures being particularly acute for older people's teams where there is normally higher 'throughput'.

There were a number of reasons for these additional time pressures. Where PBs were relatively new, staff were still learning about and adjusting to new systems, and in some areas they were having to complete or at least process two sets of assessment paperwork for new people using services – the 'single assessment' (or 'care programme approach' in mental health) and the PB assessment. However, several of the case study sites had involved frontline staff in designing PB paperwork and all were working towards integrated assessment paperwork, although none had completely achieved this. Information technology systems were often not geared up for PBs, which led to additional work (e.g. entering information into two systems or having to keep both paper- and computer-based records), a point echoed in the recent Audit Commission report (2010:16). A number of the LAs had commissioned changes to their main social services information system to accommodate the data collection and storage needed for PBs.

Positive practice example

In Council C, as well as the self-assessment questionnaire, the single assessment/care programme approach has to be completed for all PB holders with mental health problems. This used to mean that staff had to enter the same data on two information systems, but the introduction of an 'information warehouse' means that core information recorded on the mental health system (PARIS) can populate the social services system (CareFirst).

All the study sites had undertaken staff training as part of the introduction of PBs and some had provided specific training on outcomes-based assessment, which sometimes involved staff from local support provider organisations and in a few cases PB holders as well.

4.3 Resource allocation and the level of personal budgets

4.3.1 Resource allocation systems

Different resource allocation systems were used across the study sites. Two were using the In Control model. A third was working with In Control to modify a system originally developed while it was an individual budget pilot site, although the partner mental health trust in this case was continuing to use the original individual budget pilot allocation system. Another site, which had also been an individual budget pilot, had involved staff, people who use services and carers in modifying the allocation system used in the pilot and had then rolled the new version out across the county. The partner mental health trust in this instance was using the same 'new' resource allocation system. The remaining site was using an approach based on the In Control model for all client groups except people with mental health problems, where a system based on standard units of support was being used.

Two of the case study sites used the same single points-based resource allocation system for all client groups, while the other three had a generic allocation system and a mental health-specific system. Two sites had ceilings on the maximum budget for PB holders from different client groups and three had no ceilings. Most staff understood the philosophy behind a generic resource allocation system (and the use of ceilings), and welcomed the fact that it highlighted inequalities in resource allocation between client groups. As one practitioner said: 'You can clearly see the differences and then try to do something about it.' However, many felt that older people were disadvantaged by the system for calculating budgets and the ceilings set for different client groups. In particular, they felt that older PB holders with high care needs often only had enough funding to cover their personal care, with little left over for flexibility, social support or contingencies.

Some sites used 'inflators' (e.g. the need for specialist input) and 'deflators' (e.g. where support can be shared) to adjust resource allocation, but only one site had a 'carer neutral' allocation system (see panel below), an approach strongly supported by the recent Audit Commission report (2010: 16).

Positive practice example

In Council C the assessment is carried out initially assuming no informal carer support. Carer support is then factored in and the monetary allocation adjusted to take account of the support the carer is willing and able to provide. The points allocated for need are never amended regardless of carer support. This system means that if a PB holder's circumstances change and the carer is incapacitated or unable to provide care for a period, then the council can adjust the PB without the need for further assessment.

Interestingly, although carers did not talk in technical terms about resource allocation or carer neutral assessment, several carers of older people and staff working with them in the other sites felt that older PB holders who received a lot of family support were disadvantaged in the resource allocation process. As one carer put it: 'I do think that when families do so much, you're penalised for it and you probably don't get the same amount of money.'

In most of the case study sites, the information contained in the self-assessment questionnaire was used to determine an 'indicative budget'. For example, in one of the mental health partnership trusts, staff in the mental health teams were able to enter assessment information into a computer program which then calculated an 'indicative PB'. Although this figure could change as charges or personal contributions still had to be calculated, it provided a basis for early support planning discussions with the PB holder. However, budgets and accompanying support plans generally had to go through some process of 'sign off' or 'approval'. Levels of devolved responsibility and arrangements for 'signing off' PB allocations and related support plans varied across the study sites and between client groups. All the sites had some kind of 'approval panel' comprised of senior practitioners and managers, but its role and scope varied. Although staff understood that some complex or very costly PB support plans would always need to be considered at a higher level, most found the system of them all needing to be approved by a panel very frustrating. They felt that it devalued their professional judgement, made the system more bureaucratic and opaque to service users and, where there was pressure to save money, might lead to the level of individual PBs being influenced by financial constraints rather than needs. Some PB holders also expressed frustration with panel arrangements and the apparent slowness of decision-making associated with them. A few said they would like to be able to attend the panel meeting to present their 'case' and in one of the case study sites a system had been put in place to enable PB holders to do this. There were, however, a number of examples of more flexible systems. In three sites, all mental health PBs had to be approved by the panel but PBs for other client groups could be signed off in other ways.

Positive practice example

In Council A, care managers can agree PBs with support plans costing up to £250 per week and team managers can approve PBs up to £415 per week. PBs with higher cost support plans have to go to team meetings or an authority-wide practice development meeting for approval. Council C was moving to a similar system whereby PBs below a certain level could be signed off by team managers.

The mental health trust in Council E's area now has an arrangement whereby most PBs can be approved by mental health team mangers (although direct payment PBs have to be signed off financially by the social care budget holder within the trust, which sometimes causes delays).

4.3.2 Understanding how personal budgets were calculated and satisfaction with the budget received

Most PB holders with mental health problems said that they were not told how their PB was worked out, and those that had been told could not remember exactly how the process had worked. By contrast, the majority of mental health carers said that either they or the PB holder had been told how the PB had been calculated. The picture was much more mixed for older PB holders and their carers. Following assessment, most recalled having information about the level of their PB and broadly understood how the budget had been allocated. However, most talked about this in terms of how much money they had to spend on different aspects of their care (e.g. personal care, social support, mobility and transport), and knew little about how exactly the PB had been calculated.

For many PB holders and carers who are happy with the level of their PB, not being fully informed about how it was calculated may be of little concern. However, if a PB holder wishes to challenge the amount offered (and several older PB holders who contributed to the study had done this successfully) they, or someone acting on their behalf, needs to understand the mechanics of the resource allocation system or budget-setting process. Staff and providers also highlighted the importance of PB holders being able to challenge their allocations and the need for independent support or advocacy to do this.

The overwhelming majority of mental health PB holders and carers were very happy with the amount of money they had received in their PB. Satisfaction among older PB holders and their carers was much more variable. Most PB holders seemed reasonably happy with the amount they had received but a number of carers, especially those providing 'round the clock' support for a person with dementia, were less happy. As noted above, they felt PB holders who had a lot of family support were disadvantaged by the resource allocation system.

Once the overall PB has been set, some allocation systems gave PB holders more flexibility than others. The systems which 'segmented' the budget into areas of need/support highlighted in the assessment and the support plan required PB holders to spend their budget in line with these areas. This gave PB holders far less control and flexibility. For those whose care needs varied and/or who had fluctuating conditions, this created particular problems. PB holders generally favoured a system which gave them a global sum and then allowed them to use it flexibly to meet their needs.

4.3.3 Personal contributions

All the case study sites had moved away from the term 'charging', preferring to use 'personal contribution' as the way to describe the financial contribution PB holders made to their PB. This was reflected in the discussions with PB holders, who talked about 'their contribution' or how much they had to 'contribute'. This contribution was worked out by a separate financial assessment team after the assessment and resource allocation stages had been completed. These teams

were based in the LA but in the sites where a mental health partnership trust had been established, they worked with PB holders and staff from mental health services. In some areas the same teams were also responsible for the financial monitoring of PBs. Often a member of staff from the team came and met with the PB holder (and/or carer) to discuss their finances, and some used this meeting as an opportunity to provide additional benefits advice if this was appropriate.

Generally, PB holders and carers understood and accepted that this additional financial assessment was required. However, some PB holders with mental health problems felt that it had delayed them receiving their PB and had created extra anxiety, while some older PB holders found it confusing having additional people involved in the process of their accessing a PB.

Staff raised a number of interesting issues in relation to personal contributions. In mental health services, there were concerns that financial assessment teams did not fully understand the needs of people with mental health problems and this had led to problems in setting the level of personal contribution. For example, where a PB holder is incurring extra expenditure because of their mental health needs (e.g. a person with agoraphobia may have higher heating bills), this should be offset or discounted as disability-related expenditure against their personal contribution, thereby reducing it. However, mental health needs were often less obvious than physical needs and so there was a concern that mental health needs were not fully taken into account. In one area, mental health staff had been working with the LA finance and benefits team to improve their understanding, and this led to a number of PB holders being reassessed and their personal contributions reduced.

Staff also reported that some people using services had been put off having a PB because their contribution would have been quite large and they felt the additional money they would have gained from the PB was not worth the work involved in managing it. In some areas, staff from mental health and older people's services felt that the financial assessment team was struggling to cope with the volume of referrals. This may be in part because PBs are paid with personal contributions deducted and so the financial assessment has to be completed before any PB payments are made. With 'traditional' approaches to care management the timing of the financial assessment is less crucial because services can be put in place before charging arrangements are set up.

Staff in mental health services also raised concerns about charging PB holders for certain services such as daycare/drop-ins or support worker time, which might deter them from using such services. This was particularly a problem where practitioners felt that the PB holder was vulnerable and they needed to 'keep an eye on them'. One case study site had found ways of keeping some services free at the point of access to overcome this problem.

4.3.4 Contingency planning

The majority of PB holders and carers in mental health services said they had no provision in their PB for contingencies and they had not discussed or considered

planning for contingencies during their assessment. In part, this may be a reflection of the fact that most PB holders with mental health problems in the study had received their PB as a lump sum, and so setting aside money to cover unexpected ongoing support needs was less of a concern for them. However, contingency planning was of concern to their carers. Some had family who could provide back-up in an emergency (e.g. the main carer being ill) but others felt they would have to rely on mental health services stepping in.

Personal story

Hilary has mental health problems and physical impairments which mean that she needs a high level of support from personal assistants and other services. She felt quite strongly that the issue of risk and contingency planning needed to be addressed thoroughly. She explained that she discussed this with her social worker and they identified the potential risks to her, one of which was what would happen if her personal assistant or her husband was not able to provide care. She said: 'to ensure I was able to minimise this risk I was provided with £500 for emergency cover with Rapid Response. I also have alarm systems which I can use in the house in case of emergencies'. She said that discussing risks and making contingency plans for dealing with them was reassuring.

Older PB holders and their carers were more likely to have been advised to set aside a budget for contingencies, and indeed some had done so. Carers in particular found this reassuring but there was also a concern that if at the end of the PB year the contingency had not been spent, the PB holder would lose the right to that money for that year. Interestingly, many staff working with older people felt there was insufficient emphasis on contingency planning and inadequate systems for dealing with emergencies when they arose. In some areas this meant that assessment processes had to begin all over again and staff did not feel this was an efficient use of time or helpful to the PB holders and carers concerned. In one area, staff really valued the opportunity to talk to PB holders and carers about planning for an emergency or an unexpected problem, and often built an allowance for contingencies into the PB. However, as financial constraints increased within the LA, these contingency allowances were removed by approval panels to hold down the level of PBs.

PB holders, carers and staff felt that contingency planning should be strengthened and suggested a number of ways in which this could be achieved:

- ensure that contingency arrangements are discussed and recorded during assessment and, if appropriate, documented in the support plan

- allow PB holders who set aside part of their PB for contingencies to keep these funds if they are unspent at the end of the year
- when contingency arrangements have to be put in place, enable staff and carers to do this without a reassessment being required
- for PB holders with high care needs, whose contingency plans would be high cost, consider establishing an authority-wide contingency budget, which staff could draw on to set up additional support for a PB holder in a crisis.

5 Support planning and setting up services

This chapter focuses on support planning, including the role that support provider organisations and carers had in this process. It also describes how PB holders used their PBs and how they made the most of them. Lastly, it considers the factors which facilitated or hindered flexibility and choice. Although discussion and decisions about deployment options are often part of support planning, they are discussed in detail in Chapter 6, alongside our findings related to managing PBs.

5.1 Support planning

For most PB holders with mental health problems, the assessment and support planning stages seemed to be merged more or less into one continuous stage and for younger people in particular this worked well, as it kept a sense of momentum and 'things happening'. However, most PB holders with mental health problems clearly recalled how their support plan had been developed. Most had received support from their community psychiatric nurse or social worker and a few had help from a support provider organisation. As with the self-assessment process, some PB holders began by developing their ideas for their support plan themselves and then discussed them with their nurse or social worker. While most of the case study areas used a support planning template, other approaches were used. A few PB holders said that they found it liberating to use different forms of expression, such as essays and videos, to demonstrate what they wanted and why it would help them. While many PB holders with mental health problems were generally clear about what they wanted, a number highlighted how they had been encouraged to try and broaden their ideas about what the PB could be used for, and they welcomed this.

A very small number of PB holders with mental health problems could not remember how their support plans were developed or said they had felt daunted by what was expected of them. A few expressed frustration about how long it took to get their support plans approved and were unhappy about having to 'negotiate' the use of their PB. One young PB holder explained: 'It seemed to go on forever though I knew exactly what I wanted.'

Older PB holders had far more mixed experiences of support planning. Again the assessment and support planning stages often seemed to merge but the process was not always seen as being positive. A number of PB holders could not remember their support plan being discussed with them, and/or felt that they did not have much say in what was included (e.g. with previous packages of care simply being rolled over into their PB).

However, a significant proportion of older PB holders were very clear about what they wanted in their support plan and felt that this was respected, for example saying 'you can decide what's important to you' and 'I knew what I wanted and it all just fell into place.' Most older PB holders had developed their support plans with their social worker or with help from a local support provider organisation, and they found this extremely valuable, as again it encouraged them to consider different options and/or to explore ways in which support could be arranged to fit with their lifestyle or family circumstances.

A few older PB holders, who were taking up a PB following home care reablement or a major life event, such as a bereavement or moving to extra care housing, found it difficult to think about their long-term support needs and would have valued being able to agree a 'temporary' or short-term support plan, with a more substantial plan being developed at a later date when they felt clearer about what they wanted.

PB holders' experiences suggest that there are a number of ways to ensure that the support planning process is positive and flexible:

- the option of a 'fast track' from assessment to support plan, where it is clear what the PB holder wants to put in place and there are no major concerns about safety for the individual or financial risks for the LA
- the opportunity to agree a short-term or temporary support plan, which gives people time to think about what they want before their full support plan is developed
- although support planning 'templates' are clearly helpful, they need to be flexible and PB holders should be encouraged to use different ways to express their views, such as essays, or short audio or video recordings
- continuity in terms of the staff involved in the (self-)assessment and support planning processes
- offering the PB holder the opportunity to involve an support provider or user-led organisation in the support planning process, especially if the organisation concerned is likely to be supporting the PB holder in the management of their PB
- the active involvement of staff or support provider organisations in encouraging people to think beyond traditional service models and develop innovative ideas about how to meet their needs

- where service users are 'transferred' to a PB from a conventional package of care, and/or their care needs are relatively prescribed, the development of the support plan should still be used as an opportunity to give them maximum choice and control over how they are supported.

5.2 The role of external organisations in support planning

The interviews with support provider organisations working in each of the case study sites helped to provide a fuller picture of some of the support planning and PB management issues highlighted by PB holders. The majority of organisations were contracted under a service level agreement (typically stipulating the number of new referrals per month to be dealt with for a given number of meetings or hours). A few said that resources were getting tighter, with the recommended time for one organisation to deliver support planning and brokerage now being 'three hours on a one-to-one basis and seven hours for the rest'. Most organisations also marketed their services directly to PB holders and self-funders, and a number of them noted that this more 'user-directed' approach was likely to be the predominant model in the future.

Those organisations with service level agreements with their LA had usually been commissioned to undertake discrete tasks, particularly concerning brokerage and payroll services, but they often got involved informally in other aspects of the PB process, notably support planning and sometimes self-assessment. This ad hoc involvement could be beneficial for the PB holder but could also cause confusion – for example, if a PB holder was given conflicting information about appropriate expenditure.

None of the support provider organisations appeared to have clear referral protocols agreed with their LA and the majority estimated that across the various stages in the PB process they would only come into contact with about 30 per cent of all PB holders. Referral to a support organisation often seemed to depend on individual practitioners' views about who would benefit from this kind of input. As a result, providers felt that their particular skills in engaging with and advocating for PB holders were not being fully utilised. These organisations also felt that exclusively 'in-house' delivery of the PB process could result in significant delays due to approval panels rejecting support plans that did not show sufficient input from the prospective PB holder.

Overall, the discussions with the provider organisations suggested that the experience for PB holders could be considerably enhanced if there were:

- clear referral mechanisms and protocols to and from the LA with scope to expand the involvement of support provider organisations
- multiple referral routes to providers from all types of community organisations (e.g. via provider websites, third-sector organisations, GP practices, specialist clinics)

- outreach activity and 'warm-up' meetings facilitated or initiated by providers to enhance peer support
- stronger emphasis on the direct user accountability of providers when they tender for LA contracts for support planning services
- more joint training between providers and LA staff
- more opportunities for LAs and all local providers to exchange ideas and information, and so increase mutual understanding and trust
- a closer working relationship between providers and care managers to promote their role and encourage referrals
- an integrated support network from which PB holders could choose to get support at all stages of the PB process.

5.3 Involvement of carers in support planning

All the carers of PB holders with mental health problems who contributed to the study had had some involvement in the support planning process but the extent of this varied considerably. Some did not feel it was their place to shape the support plan, saying things like 'I mean the budget is for him, his needs, not mine', and they were happy that the PB holder worked with their community nurse or the support provider to devise the support plan. Others had been fully involved with the PB holder in drawing up the plan. This was most often the case where the PB holder was particularly unwell at the time, where there were specific safety issues to be considered or where the content of the support plan had implications for the carer.

The carers of older PB holders were all fully involved in the support planning process, which again may partially reflect the fact that many of them were caring for someone with dementia. Most reported that the support planning process had been largely positive, although there were mixed views about support planning templates, forms and the guidance provided.

5.4 Setting up services and support (brokerage)

For most PB holders, once their support plan had been approved, the services and support they wanted were put in place relatively quickly, and people used their PBs in a wide variety of ways. This section begins by briefly describing how people used their PBs and then goes on to consider what factors helped or hindered their ability to make the most of their PB.

5.4.1 How people used their personal budgets

Most, but not all, PB holders who had mental health problems had received their PB as a lump sum, and had used it in a variety of ways. Some had purchased one-off items to enable them to pursue a hobby. Others had bought computers which they used to help them keep in touch with friends and family, and also to learn new skills or undertake training which they hoped might eventually help them back into work. Many used their PB for social activities such as buying a football season ticket or attending a gym. Those who received their PB in instalments were more likely to use it to provide regular support to help them get out and about, either by employing a personal assistant or purchasing support worker time.

Older PB holders were much more likely to use their PB to pay for regular personal care or help with getting out and about. A significant proportion were employing personal assistants, usually with the help of a support provider organisation. A few PB holders employed family members (usually a son or daughter) or friends as personal assistants (see Section 6.2). Some held their PB in the form of a direct payment but then contracted directly with a care agency, while others had a managed account with a support provider.

In most of the case study sites, domestic tasks such as cleaning and gardening could be funded by a PB without a problem, but a few PB holders and carers said that they had needed to 'negotiate' in order to spend part of their PB on these services. Transport, especially the use of taxis, was another area of expenditure that PB holders often felt unsure about. This was particularly the case for older PB holders who sometimes viewed taxis as a luxury rather than a necessity. In rural areas particularly, for PB holders who could not drive and did not have access to a regular bus service, taxis were often the only way they could get out and about.

Where the level of PB allowed, older PB holders and their carers were using their PBs to fund a variety of support and services including residential respite, day services and warden call systems. In addition, some quite creative support arrangements had also been put in place. For example, several PB holders were using their funds to have a short break with their family rather than going into residential respite care. Although this had worked well, some carers almost felt 'guilty' that they were benefiting indirectly from the PB and needed reassurance that this was quite acceptable. One carer had purchased Sky Sport for her husband who had dementia, as he had always been a keen sports fan and while he was watching TV she could get on with jobs in the home or simply have some time to herself.

Personal story

Jim and his wife Christine care for Jim's mother-in-law (the PB holder), who is physically frail, and his father-in-law who has Alzheimer's. Jim explained that as a family they had been quite flexible and creative in using the PB to really improve his mother-in-law's quality of life. He described how she can now pay for certain household tasks that in the past he and his wife performed, and so the time they spend together is more enjoyable: 'The difference now is that instead of Christine and I spending two hours a week doing the gardening, or spending all the time cleaning the house, mum can afford for us to take her out for the day and that really recharges her batteries while dad's at the day centre.' Jim also explained how his mother-in-law was able to arrange some short breaks where they are able to go away as a family. They now go to a nearby Pontin's holiday centre a few times a year and because they go regularly they benefit from special offers, making this a form of 'cheap respite'. Jim also revealed that his mother-in-law's social worker had suggested incorporating a laptop and broadband in the support plan, with some lessons on how to use the machine and the internet. He remarked that this has been a huge, life enhancing change for her, providing 'a window to the world… it's a massive thing for her to be able to sit and do that… she's 80 odd.'

PB holders and carers often described how the way the PB was used had changed over time. One PB holder who used mental health services had been quite unwell when she first took up her PB and had used it to pay for a course of equine therapy. Her mother explained: 'The [equine therapy] was a very expensive course for about six months. She never would have been able to do it without the PB which paid for it all. You could see the change in her. At the time, with her health, that was about all she could cope with.' Then, as her mental health improved, this PB holder employed a personal assistant who helped her get out and socialise and supported her in moving to live independently in her own flat again.

Older PB holders and carers also described how their PB had been reviewed and the support they received adjusted, usually as their needs increased. They felt strongly that right from the outset PB holders needed to be reassured that the use of the PB could change as their needs changed, and they saw social workers, community nurses and provider workers as key to conveying this message. A carer who supported her husband with early dementia said: 'The social worker said "just because we've done it like this doesn't mean it has to stay like this. If you feel it is too little you can come back and we'll review it". I mean I was quite

amazed at what we were allocated but she said, "no that's very small compared to most people"… She's a very good advocate and she knows a lot about it … she's an excellent person.'

5.4.2 Enabling people to make the most of their personal budget

There were a number of factors which helped or hindered PB holders' abilities to make the most of their PB. One of the most important was clarity about what their PB could be spent on. As was noted in Section 4.3.1, resource allocation systems which gave PB holders a global sum and then allowed them to use it flexibly to meet their needs appeared to give people much more scope to make the most of their PBs than systems which required PB holders to spend their budget in proportion to the areas of care highlighted in their assessment. Concerns about spending PBs on the 'right' things were common to all PB holders and carers but the implications for them making the most of the PB were different for older PB holders and those with mental health problems. Those with mental health problems often had quite clear and innovative ideas about how they wanted to use their PBs and the main issue was ensuring that these ideas fitted the support plan, and then helping people to set up the support they wanted. Older PB holders and carers tended to be more cautious and some almost felt they needed 'permission' to spend their PB on certain things.

A number of provider organisations, particularly those that were user-led, were concerned that PB holders' choices were sometimes limited by what was presented to them by social workers and community nurses, while one provider felt that PB holders themselves could be limited by their own 'conservatism'. Providers emphasised that time was needed at the support planning stage to help people think about different options, and again they highlighted the importance of PB holders having a choice between support (planning) providers.

PB holders and practitioners suggested four things which they had found helpful:

- clear basic guidance on 'using your PB' which explains the link between PB expenditure and the PB holder's support plan
- a named member of staff (or team) who was familiar with the PB holder's circumstances, and whom they could contact for advice and guidance
- guidance (and training) for LA, trust and provider organisation staff on the use of PBs and scope for team managers to approve special requests
- the opportunity to exchange ideas with other PB holders about how they were using their PBs; some of the case study sites were also 'logging' examples of how PB holders had used their PBs creatively.

Availability of the service and support which people wanted was also an important issue. Sometimes this was related to local factors. For example, the recruitment and retention of personal assistants was sometimes difficult for PB holders living in very rural areas, especially if they only needed a few hours of support each day or week. They also found it more difficult to arrange holiday and

sickness cover. The use of day services in many areas also highlighted issues of choice and availability. Some mental health services had moved away from 'traditional' day services. Although PB holders were being encouraged and supported to set up other forms of support, several provider organisations and mental health staff felt that the PB process made it harder for people to pool funds and purchase or create an activity as a group. For older PB holders, the opposite problems appeared to exist in some areas – traditional day services were available but a number of PB holders did not want to use them. There was evidence, however, of staff working with older PB holders and carers to find alternatives which suited them. For example, one PB holder in his 90s, whose wife was in a care home, arranged 'daycare' for himself at the same home four days per week (even though the care home did not normally offer this service) so that he could be with his wife, have a cooked meal and get help with bathing.

Overall however, there was a sense that it was still too early in the implementation of PBs for them to have had a significant impact on the 'market'. Most managers and staff involved in the PB process felt that there had been only minimal change in the pattern of provider services and many acknowledged that the pressure of implementing PBs within their organisations had to date left little time to work with existing and potential providers. However, they recognised that this needed to change, a view echoed in recent work carried out by the National Market Development Forum (NMDF 2010). They suggested a number of things which LAs could do to encourage diversification and development of provider services:

- training and development work with existing providers (e.g. home care providers) to help them understand the principles and practice of PBs, and encourage them to adapt their services where appropriate
- creating an infrastructure which makes it easier for PB holders to pool their 'purchasing power' to jointly commission new services or support
- giving staff time to work with PB holders with unconventional or innovative ideas to help them source new types of support, and to share the learning from the experience.

As has been noted in previous sections, staff attitudes and knowledge were crucial in enabling people to make the most of their PBs. During support planning, social workers, community psychiatric nurses and support organisation workers were in a position to encourage people to think about different ways of meeting their needs, and they often played a vital role in setting up services and support. While a number of PB holders reported that social workers and community nurses had successfully 'argued' their case for different types of support, there were also instances of staff appearing to be restricted by 'traditional' notions of what social care should look like. LA and mental health trust staff themselves noted that there were still differing views among practitioners about what was 'appropriate' use of a PB. This, coupled with the fear of negative stories in the

press if a PB holder was 'allowed' to use their PB for something unusual, sometimes constrained practitioners' discussions with PB holders.

6 Managing the personal budget

This chapter begins by considering the options PB holders were offered and what they chose. However, it is important to note that in reality information and discussions about deployment options do and should feed into the whole PB process. In particular, how a person wishes to hold their PB may shape their support plan or may emerge as part of the process of developing the support plan. The chapter also describes the support PB holders received to manage their PB on an ongoing basis and looks at monitoring and review arrangements.

6.1 Deciding how to hold the personal budget (deployment options)

Across the case study sites PB holders were offered four ways of holding their PB:

- services directly commissioned and/or managed by the LA
- third-party managed accounts, usually held by a local support provider but sometimes by a care provider
- a direct payment held and managed by the PB holder, if necessary with support from a provider organisation (e.g. to employ personal assistants)
- a mixture of the above options.

All PB holders with mental health problems received their PB as a direct payment, many in the form of a one-off lump sum to pay for equipment and courses. The majority of older people also opted for a direct payment, but some had third-party managed accounts, and a few had services commissioned by the LA or a combination of a commissioned service and a direct payment or third-party managed account.

Decisions about how to manage the PB can have a powerful knock-on effect in terms of the ways in which people can exercise choice and control. PB holders emphasised the importance of ensuring people were able to make informed decisions about which deployment option would be best for them and the support they would need to make that option work. There was concern among provider organisations and some LA/trust staff that many PB holders, especially older people, were being steered away from direct payments and towards managed accounts or services commissioned by the LA. Certainly, some of the staff who contributed to the study felt that the primary concern of older people who are particularly frail and have very high care needs is being able to stay in their own home and having their care arranged for them. As one social worker put it:

'They're not thinking beyond "I want to be in my own home" – they don't want the additional responsibility of trying to recruit personal assistants or dealing with financial budgets.'

Some carers also echoed LA/trust staff concerns about very frail elderly people coping with a direct payment PB on their own. As one carer put it: 'It's quite good but not so good for the older person. I mean, I'm 75 but I've got all my marbles and everything, but the real elderly, it's a bit of a problem because you have to have a special bank account and everything.'

There were a number of issues underlying this view, which often did not seem to accommodate the possibility of a third-party arrangement with a local provider or a review of the PB at a later stage. Social workers helping older people, particularly those 'new' to the social care system, were often dealing with people at a very vulnerable time in their lives, perhaps after an illness or injury, or a major life event such as losing a partner or moving to supported housing. Some practitioners felt that they did not want to 'burden' people with thinking about different ways of managing their care and support and so perhaps made assumptions about what was right for them. Clearly, it also took time to discuss different options and many staff did not feel they had the time to do this properly because of workload pressures. However, there was also a view that either the PB processes were not sufficiently flexible or staff did not understand them well enough to know what to offer. PB holders, staff and provider organisations suggested a number of ways in which this problem was (or could be) addressed, including the following.

- Ensuring that staff have time to discuss different deployment options (fully, at an early stage and more than once) with potential PB holders.
- Using staff training, particularly training involving people who use services, to break down assumptions about which deployment option may 'suit' any particular group of people.
- Providing information about deployment options at different stages in the PB process.
- A much more flexible interface between reablement services and people taking up a PB. For example, enabling people to stay in reablement for longer, so that when they take up their PB they are well enough to make an informed choice about how to use and managed it.
- A much more flexible approach to reviews (see Section 6.7) so that people could initially opt to have services commissioned by the LA but move to other options offering a greater degree of direct control without having to be reassessed.
- Making it much easier for PB holders to move between management options as their needs change or their condition fluctuates. In this way people may feel more able to opt for a direct payment PB in the knowledge that they could

move to a managed account (permanently or for a period) if they wanted to take on less responsibility, or conversely move to a deployment option which gives them more control when they are well or confident enough.

- Proving clear information about the support available to people with managed accounts and direct payments, and allowing time for LA/trust staff or provider organisations to discuss this with PB holders.
- Providing opportunities for PB holders, particularly those who have opted to have their PB as a direct payment, to share their experiences with potential PB holders.

6.2 Choice and control

Those PB holders who received their PB as a direct payment clearly felt it had given them much greater choice and control over the services and support they received. For PB holders with mental health problems, this was not only about being able to choose support that matched their lifestyle and interests, but also about the sense of responsibility and increased confidence that managing their PB gave them. Support providers working with people with mental health problems echoed this view. As one put it: 'people are thrilled to pay out their own cheque and go rock-climbing'.

Older PB holders and carers who had opted for a direct payment were equally positive. They also highlighted the ways in which they had been able to shape the care and support they received to their needs and interests. Often this was linked to being able to choose their care provider and the scope this had given them to both organise care in a way that fitted with their routine and improve the quality of care their received. Many described how unhappy they had been with the care they had been receiving from care agencies and said the PB had enabled them to employ personal assistants. Although this had been a big step for many PB holders and their carers, it had generally worked well. One carer described how his mother had come to have a personal assistant: 'I'd never heard of it before. I was a bit wary of it at first because what we really needed was someone who was part of the family rather than someone coming in on a contract basis. I doubted it would work for us but they [the support provider] persuaded us to do it and it has worked really well. This lady is almost like a daughter to her [his mother].'

Another relatively young PB holder (67 years) with physical health difficulties explained how unhappy she had been with the care agency used in her supported housing: 'They were rough and had no respect for your home … I felt old and vulnerable.' With the help of an support provider she now employs two personal assistants and her quality of life has improved enormously.

Other PB holders in the study had used their PB to contract directly with a care agency and again felt this had given them more control over when and how their

care was provided. A few PB holders employed family members (usually a son or daughter) or friends as personal assistants. For some, particularly those with dementia or mental health problems, it was a way of getting support from someone they knew well and felt comfortable with. For other PB holders and carers, the PB enabled the family to organise care in a way that fitted in with their family life. In most cases the PB holder or carer used a support provider to handle issues such as payroll. This was partly to reduce the administrative burden, but it also created a 'firewall' between their role as a family member or friend and their role as a personal assistant.

Personal story

Rachel cares for her mother who has dementia and needs care day and night. She is the main carer but to enable her mother to stay living at home (over 50 miles away), her husband and daughter provide some care too. She explained that when her mum's PB first began, her care was provided by staff from a local third-sector care provider. After six months her mum's condition deteriorated and around the same time Rachel was made redundant. Although she was eventually offered another job, the new job had irregular hours which were incompatible with caring for her mum and so she decided to ask the county council if she could provide the paid care for mother. 'Life was getting very difficult for me so I said to them, we're paying all this money out on different care [workers], what would you do if I give up my job to look after my mum? … That's when the personal budget changed...now my mum pays me instead of [the care agency] and the county council gets more for their money.' Rachel explained that as she is now 'employed' to care for her mum she no longer gets Carer's Allowance but she felt fine about this as the PB pays her enough to be able to live on, which the Carer's Allowance did not. Rachel believes that being employed as her mum's personal assistant has helped provide the quality and consistency of care her mum needs and prevented her mum from having to go into a care home. 'At the end of the day it has enabled us to keep mum living in her own home which has always been her wish. If I hadn't been able to take some of the personal budget I don't know how I would have managed because of the amount of hours my mum needs.'

A few support provider organisations voiced concerns about family members being employed as personal assistants because they felt it could reduce the independence of the PB holder and might have a detrimental effect on family relationships, but there was no evidence of this in the research with people using services and their carers. A small number of PB holders reported that employing friends as personal assistants could be difficult because friends sometimes felt uncomfortable being paid or were reluctant to take time off. None of the LAs or

provider organisations appeared to have produced specific guidance for PB holders, carers or LA and provider staff on employing family members or friends as personal assistants, but there was a clear sense that people would find guidance on this matter helpful.

A number of older PB holders had taken their PB as directly commissioned services or a managed account, and there was evidence that this could work well. Here again, however, the attitude of their social worker and the flexibility and creativity of the support planning process was crucial. One PB holder in her 90s explained that in addition to personal care provided by an agency, her social worker had arranged a regular gardener and for transport for her to go and stay with her sons twice a month, which she really appreciated: 'I just think my social worker is always looking out for me. She really has been such a great help – I can ring her up and ask her anything.' However, this PB holder also said that she was not very happy with the care she was receiving from the care agency arranged by the LA: 'They are supposed to come at 8 a.m. for half and hour, 12 p.m. for an hour … [etc.] … but the problem is they hardly ever come at those times, so your routine is all disrupted. And they have lots of different carers so you don't get the same one each time.'

Other PB holders using managed accounts or directly commissioned services described similar experiences, suggesting that currently these deployment options often result in less choice and control than a direct payment. A few older people, who had simply had their existing services 'switched' to a PB, were unaware that they had a choice of provider. Others wanted to change their care provider but were anxious about doing this, fearing that there may be a 'break' in their care or that such a request might trigger a full review of their PB. Some had changed their care agency but often they had needed the help of a support provider or family carer to do this. Some were happy to remain with their care agency but clearly would have liked more control over how their care was provided. In a few cases, LA or provider organisation staff helped PB holders to shape their contract with the care agency so that the support they received was more personalised and flexible.

In one of the case study areas, a number of older people living in an extra care housing facility had been given PBs in the form of managed accounts held by the organisation running the housing complex. This approach offered real scope for people to have much more control over the care their received and even to pool budgets for other activities, but in practice a number of difficulties were encountered. These issues are discussed more fully in the panel below.

Positive practice example

An extra care facility located in Council C was established two years ago. It is a large complex with mixed tenure accommodation, developed and managed by a third-sector organisation. Council C's social services department provides the community care element of the support where required. Some residents are fully independent and do not require any community care support. Care workers are employed by the home and there is low staff turnover. A dedicated community care manager is responsible for the support needs assessed by the social services department and is on site full time. In addition, one of the social services teams responsible for ongoing case management/review is also based at the complex, which can aid comunication about individual residents. The 'package' of support that residents receive can be used flexibly. For example, if people want to reduce/adjust their personal care hours they can spend the 'time' saved on personal assistant support for shopping/external activities or other on site activities (e.g. the gym).

A number of residents had PBs in the form or managed accounts. While making PBs available to people living in extra care housing is a positive development, PB holders from the extra care facility suggested a number of things which would have enabled them to get more out of their PB, including:

- ensuring PB holders are fully informed about different deployment options and are supported to take their PB as a direct payment if they wish to
- giving PB holders with managed accounts more flexibly in the way they are used (e.g. providing 'monthly statements' so that people know what they have left to 'spend'; improving the range of activities available)
- changing thinking among practitioners to ensure that extra care housing is not seen as an end in itself and that support plans look beyond the move into extra care.

6.3 Ongoing management of the personal budget

Most PB holders with mental health problems felt able to manage their PB themselves with little or no support. Some noted that this was because they were able to draw on experience in their working lives, while others said it was because their PB was very straightforward or simply that they preferred to do it

on their own: 'I look after it myself – I'm OK with that'; 'I can cope with the money.' Where people did need some help in managing their PB, the main source of support was their community psychiatric nurse or social worker. Often this was quite informal and formed part of their regular meetings. A few had concerns about practitioners' understanding or knowledge of PBs but for most it worked well: 'Our social worker is really good … we've been lucky in getting the one we've got, you know she's a lovely approachable person and she knows all about it.'

Many PB holders with mental health problems also had significant support from family or friends. Carers of such people reported that their role in managing the PB ranged from managing it completely to supporting the PB holder as needed. Many were very conscious of trying to keep a balance between respecting the PB holder's independence while helping them keep things in order. For some, their main concern was the PB holder's ability to keep up with the 'administration' (e.g. keeping receipts etc.), especially where they had memory problems or found it difficult to stay organised. Carers often set up basic systems to help the PB holder, such as folders for receipts, notebooks to record expenditure, etc.: 'He'd end up with bits of it everywhere and he'd probably not have a clue about how it had been spent. One of his main problems is being organised, he does struggle with that so I have sorted out a system for managing it.'

Several carers also noted that the balance between their involvement and the PB holder's role in managing the budget changed over time. When the PB holder's mental health improved and they became more confident, the carer's role was reduced. Often, help from a psychiatric nurse or social worker had been important in achieving this shift. Similarly, one PB holder's condition worsened and her carer increased their role to compensate.

PB holders with mental health problems were less likely to use support from an provider organisation than older PB holders. However, a few, especially those employing personal assistants, did have regular support from a provider. Most used the provider to help them employ personal assistants but a few arranged for the provider to deal with all their payments. Others saw the provider organisation as a 'safety net'. One PB holder with quite high support needs explained: 'Because I have experience in business I don't need any help or support. However, if I do [ever need help] I know I can contact [the local support provider] – I have their contact details.'

Carers of PB holders who had mental health problems also greatly appreciated the backup offered by support providers. Most were very clear that if they had a problem or their circumstances changed, they would know who to ring and felt confident that the support organisation would respond. One carer explained that initially her daughter had taken on the responsibility for managing her PB but had found it difficult to cope and so she had taken it on. Eventually this became too much for her and she asked for more help: 'I phoned them up one day and I just said look … it was at a particular time when my other daughter wasn't that well and I just said this is actually making me quite stressed and ill. And there was no

problem ... now all the payments are dealt with direct and we don't have to worry about that.' This family's situation highlights the importance of reassuring both carers and PB holders that however they choose to manage their PB initially, this is not fixed and can be changed in line with their circumstances or needs.

Older PB holders were more likely to receive active support in managing their PB. A significant proportion had support from a provider organisation, and a number had a managed account with social services and/or support from their social worker. Interestingly, several PB holders and carers said that they had established a good relationship with the LA PB or direct payments finance team and felt able to contact them to discuss any questions or concerns. Many emphasised the importance of continuity and, as the personal story below illustrates, being able to contact someone who knew their situation.

Personal story

Don supports his mother to manage her PB. He explained that for the first 18 months they had been able to deal directly with their nominated social worker if they needed anything adjusting. He felt this had worked very well as the social worker, 'knew all the background, she'd visited the house, so she didn't have to keep coming and reassessing what the position was, she knew from her visit … so while we had that, the budget has worked brilliantly'. He explained that Council D now has a customer services centre which he has to call if he has any questions: 'I have to ring the general helpline, explain it to the operator, she puts it through to an appropriate person, and I tell them what expenditure I would like, they put it to a board and then they get back to say yes or no. The problem is now I never, ever, speak to anyone twice. It's okay if it's a very obvious thing but if it isn't obvious, they want to come and assess it.' He described the delays that this causes, commenting that he thought that, 'the point of the budget was that we could make a decision quickly and alleviate stress'.

Interestingly, Council D explained that as their workload was increasing generally and more and more people were taking up PBs they, like many councils, had to find ways of managing workload pressures. Now, once a PB has been in place for three months and there are no problems, it is classified as 'closed' or inactive. All new enquiries to social services and enquiries about 'inactive PBs' are routed through the new customer services centre. If an assessment is needed before a decision about PB expenditure is made, it is prioritised alongside all other assessment requests. This situation highlights the difficult balance to be struck between scaling up PBs while keeping 'the personal touch', especially when resources are inevitably limited.

Both older PB holders and carers were generally extremely positive about the service provided by support organisations. There was a strong sense that people not only valued the obvious practical support but also the psychological support that was provided. Many PB holders talked about feeling that they did not have to do it all on their own or were reassured that there would be back-up if a problem arose. As a PB holder noted: 'You feel secure if you've got someone behind you.' The level of support they were receiving varied, but this was mainly determined by people's needs and preferences. Some PB holders simply used the support provider for their payroll service, while others had an 'end to end' service,

including supporting the employment of personal assistants, setting up services through a managed account, making payments, providing ad hoc advice and information and facilitating peer support. One carer explained how support from a provider organisation had helped her cope: 'I mean the papers coming at you … I almost buckled under doing a full-time job, caring for my dad, so [the support provider] took over everything and we just do a direct debit and they run it all. All we do is sign the carer's timesheet.'

A PB holder also highlighted the importance of people understanding the level and range of support available: 'I don't think people realise that you get as much back-up and assistance as you do – at any point if I've got a problem I can ring someone [at the support provider] if it is to do with the finance side.'

A few older PB holders and carers were less happy with the service they had received from their support provider. The main criticisms concerned charging, but one PB holder felt that the staff lacked detailed knowledge about PBs and another had contacted her local provider but had not felt happy with their approach and attitude.

Many older PB holders were in fact self-reliant, explaining: 'I am pretty autonomous in managing my PB' or 'I've always been good at managing my money so I'm all right.' Others managed their PB with support from friends or carers. There was often a sense that the PB holders and carers saw this as a 'joint effort'. As one carer put it: 'We just potter along with it together.'

Where older PB holders were very frail or had dementia, carers had often taken full or substantial responsibility for managing the financial and administrative aspect of the PB. Although a few took this in their stride, perhaps helped by experience from their working lives, many were initially concerned about the responsibility. A carer who was supporting his very frail mother with a direct payment PB and employment of a personal assistant said: 'The only problem is you feel like you are taking on a business at a time when you don't want to take on a business. You don't want the responsibility of employing somebody.'

However, over time, like the PB holders themselves, most carers gained in confidence and began to find the process manageable or even rewarding, especially where they felt trusted to get on with it: 'It's just being trusted, I think, and being able to do this job – that's the thing … it's horrible when you keep having somebody on the phone querying everything, because then you feel they're not trusting you. Whereas if they leave you alone and let you carry on as you do, you feel lot better about it.'

A few older carers also had help from friends or family members and some felt that they would not have been able to cope without this informal support. One carer who found managing her husband's PB quite stressful explained that she now had help from a friend: 'I'm not the brightest of people … I get a bit muddley in my mind and they [social services] had to come back two or three times to show me, but now I've got a friend that helps me and she's very good.'

6.4 Support arrangements with providers

In all the case study sites there were providers offering PB holders support to manage their PBs, but as was noted in section 5.2, the number and nature of these organisations varied. In most sites there were just one or two organisations providing direct support but one area had taken the decision to allow the development of a number of support providers. Most providers had some grant funding (usually linked to their information and support planning roles) but all made a charge for some of their services (e.g. payroll).

Where providers have to charge PB holders directly for their services, there was a concern that some PB holders are reluctant to use them. However, most PB holders and carers viewed paying for support in the same way as paying for a service in any other area of their life, and had no problems with it. Some contributors even felt that if PB holders were choosing to spend part of their budget on support services this increased their purchasing power and ability to make choices. Generally, provider organisations offered a 'menu' of support and people chose the level of support they felt they needed or were willing to pay for. Charges were usually paid monthly and varied according to the level of support. Some providers had found ways of making it easier for PB holders to use their services – see the Positive practice example below.

Positive practice example

One user-led organisation which provided support to PB holders from all client groups offered them a choice between paying a monthly fee of £7 for their services or giving something else in return (e.g. acting as an occasional PA for another PB holder). This approach had the added advantage of increasing the PB holder's confidence and skills, which could in turn lead to longer-term positive outcomes for the PB holder and the community at large.

None of the provider organisations charged for more general support such as ad hoc advice over the telephone, providing information or peer support activities. PB holders and carers indicated that access to this 'free' informal support was important in terms of the sense of security it gave them, but also because it helped to build a positive relationship with the provider concerned.

6.5 Peer support

In all the case study areas, the main form of peer support offered was support groups. However, none of the PB holders with mental health problems had attended a peer support group. Some knew about them but did not want to get involved, either because they did not feel comfortable in a group or doubted the value of such a group. A small number of older PB holders had attended a peer support group organised by their local support provider but not all of them had found it helpful. Some carers had accessed peer support through their local carers' groups but this was not specifically linked to PBs.

A number of PB holders and carers said that they would have welcomed peer support, especially when they first received their PB. However, they felt this could be offered in a number of ways, not just in groups. Some would have liked to talk to an existing PB holder or carer about the experience of having a PB, while others felt that more 'experienced' PB holders would have been able to give them useful hints and tips about how to manage a PB. The idea of a 'PB buddy', who could provide informal advice and support to new PB holders, was also welcomed.

6.6 Monitoring arrangements

Monitoring and audit arrangements varied considerably between the case study sites and a number explained that their systems were still evolving. However, examples of positive practice were already emerging, as the panel below shows.

Positive practice example

Council A had a very clear monitoring hierarchy with payments in excess of £20,000 having full annual audit by the LA direct payments administration team. Payments in excess of £5,000, but less than £20,000, demand a detailed annual account but a number of previous checks have recently been removed to make the process more manageable. Payments of less than £5,000 have a 'light touch' review.

In Council D, monitoring is carried out through normal reviews, although frequency is dependent on the individual case. Any items of expenditure under £50 do not require a receipt. The council is currently reviewing its monitoring arrangements and may move to an even simpler system in the future.

The mental health trust in Council E also uses 'light touch' monitoring linked to routine reviews. At the 3-month review there is an initial check to ensure all is broadly in order, followed by a fuller monitoring process at the 12-month review.

In most of the case study sites the 'administration' element of monitoring PBs held as direct payments was carried out by a separate administration/finance team. For example, in one LA monitoring and audit is carried out by the direct payments team. However, if the PB was deployed through directly provided services, then the financial review would take place alongside the annual review. In the mental health trusts, community psychiatric nurses often had quite a hands-on role in monitoring PBs: 'It's monitored by my nurse every two weeks. He asks what I've done and it keeps the finance department happy.'

Generally, PB holders and carers understood the need for their PB to be monitored and had set up their own ways of recording and keeping the information required, ranging from simple systems for filing receipts and bank statements to logging expenditure and spreadsheets. One PB holder with mental health problems and physical impairments explained: 'I have a spreadsheet and this accounts for every penny I spend. There has to be a clear audit trail as this will be looked at annually. The spreadsheet covers all the wages paid to the personal assistants and the local authority can look at it any time.'

However, there were also aspects of the monitoring systems which people found onerous or impractical. For example, photocopying receipts was difficult and costly for some PB holders. Alternatively, taking receipts into the council offices was for some PB holders with complex care arrangements a major task, as their paperwork could fill several boxes which they then had to find a way of

transporting. Some of the case study sites were addressing this by offering home visits from their PB or direct payment teams.

A common area of concern for PB holders and carers was what they were allowed to do with unspent funds. Although most of the case study sites had rules or guidance about what proportion of a PB could be carried over to the next year and when money had to be given back, many PB holders felt unclear about what these 'rules' were. One PB holder with mental health problems said that he felt uneasy because he was not sure whether he should give money back or spend it quickly: 'I don't like waste… it makes me anxious.' A carer of an older person on a PB questioned why money that had not been spent could not be used for something else appropriate rather than given back: 'I rang the other day and said there's quite a lot of money left in the budget and I don't want to spend it for the sake of it, but there are three things that would make life easier for mum [carpet cleaning, a new vacuum cleaner and turning some steps into a slope] … I thought those things were reasonably straightforward but they said no – they'd have to refer it to an assessment team.'

Some PB holders and carers commented that it would be better to be able to carry over a small underspend to the following year, rather than be burdened with anxiety over what to do with the spare funds. In fact, as the panel below shows, some of the case study sites had clear systems for dealing with this.

Positive practice example

In Council A, the direct payment agreement only requires unspent funds above the equivalent of 10 weeks of direct payments to be repaid.

Council D has a more informal system. If there is a build-up of unused funds, they will contact the PB holder and, depending on the circumstances, may hold on to future payments or even 'claw back' money.

PB holders and carers suggested a number of things which had or could make monitoring easier for them:

- clear guidance about what is expected in terms of records and paperwork, including examples of systems other PB holders have found helpful
- optional training for PB holders and carers in 'managing your PB'
- having a nominated link person in the LA direct payments team who can be contacted in the event of difficulties and who has some knowledge of their case

- not having to keep receipts for small items of expenditure
- clear information about how underspends will be dealt with
- for those with high PBs who are required to have a full audit, different ways of carrying out the audit should be offered (e.g. an officer coming to the house to look at receipts and records)

6.7 Reviews and dealing with changing circumstances

Generally PB holders with mental health problems and their carers understood that their PB would be reviewed each year and most could recall having a review or, if they had only had their PB for a few months, knew roughly when their review was due to take place. For a number of PB holders, reviews were incorporated in their regular sessions with their nurse or social worker, so they did not see them as distinct.

The picture was less clear for older PB holders, with roughly half of those involved in the study saying that they had not had a formal review of their PB or could not recall having one. Carers had also had a somewhat mixed experience. Generally older PB holders and carers seemed unclear about when reviews should take place, and the division of responsibility between the LA and the support provider (if they used one) was not always clear to them. There was also anxiety about the practice of 'closing' cases because PB holders and carers wanted to be able to contact a social worker who knew their circumstances. This continuity was highly valued by many PB holders and carers, especially where they felt they had established a good relationship with their social worker or community nurse.

LA/trust staff often felt frustrated by the national requirement of a six-week and annual review. In mental health services, having to do a formal review at six weeks sometimes seemed unnecessary if staff were seeing the PB holder regularly anyway, and some PB holders found it irksome to have to 'fill in more forms'. There was also a view that because PB holders are usually given their PB for 12 months, it would be better to hold a formal review at 9 or 10 months, so that people are aware of what will happen to their PB well before the end of the year.

7 Key themes and issues

The research carried out in recent years into direct payments, individual budgets and now PBs clearly shows that these forms of self-directed support can enhance people's sense of control and satisfaction with services. However, significant barriers to taking up and making the most of PBs have also been highlighted, particularly for older people and people with mental health problems. This research has focused very strongly on learning from the experiences of PB holders and carers to identify ways in which practice can be improved to support

independence, choice and control. However, managers and practitioners from organisations across the case study sites often reinforced the points made by PB holders or shed light on the organisational barriers or 'successes' PB holders experienced as they moved through the PB process.

In this final chapter we draw together a number of key themes and issues, and where possible link these back to the findings from earlier research and policy. Some of these themes and issues relate to specific stages in the PB process, while others are more over-arching. They are primarily written to assist those 'in the field' who are implementing PBs, but some have wider policy implications.

7.1 'Promoting' personal budgets

A consistent theme in the earlier research into individual budgets and PBs has been the importance of people simply knowing about their existence, and linked to this, having access to clear information in different forms and from different sources. The PB holders in this study emphasised the importance of raising general awareness of PBs, so that more people could benefit from them at an early stage in their involvement with social services. Although LA staff are central to this, primary care and hospital staff involved in hospital discharge, care agencies and third-sector organisations also have a key role in signposting people to further information and advice about PBs. In particular, there is a need for more active outreach to marginalised communities, which works through trusted networks and groups to explain PBs and the scope they provide for setting up support which is in tune with people's relationships and cultural needs.

7.2 Strengthening risk assessment

Across the case study sites the LAs and trusts took the issue of risk assessment and the safety of PB holders very seriously, and there were clear examples of approaches which had worked well for PB holders and carers. However, there were also instances where guidance had not been translated into practice or where guidance linked to traditional care management systems did not fit easily with the new PB systems being used. The shift towards more self-assessment also raised questions about how to record safety concerns if the PB holder and practitioner had differing views. There is also a need for clear protocols for linking risk assessment and risk management in support planning, especially where stages of the PB process are being undertaken by different agencies. Risk management strategies in support plans should also take account of the central role that carers play in supporting many PB holders, and should include contingency plans. While training in risk assessment and risk management would need to incorporate local systems and procedures, there may be a place for nationally available training materials which would help staff think through the principles of risk assessment and management in relation to PBs.

7.3 Encouraging creativity in support planning

The IBSEN and In Control evaluations highlighted the importance of enabling older people and people with mental health problems to negotiate innovative support choices. This study revealed many examples of both older PB holders and those with mental health problems using their PB in creative and imaginative ways. Even where people needed high levels of care, which accounted for much of their PB, they had found modest ways of enabling their PB to change an aspect of their life. However, there was also a sense that support planning was still 'limited' in some cases. Sometimes this was due to staff having 'traditional' notions of what social care money should be spent on, however PB holders themselves sometimes found it hard to think beyond their immediate care needs. PB holders and staff suggested a number of ways in which support planning could be made more positive and flexible. In particular, PB holders would welcome the flexible use of templates and the opportunity to use different media to express their views. Here again, staff training is important in changing attitudes and opening up practitioners' thinking and all the case study sites provided this. There was also potential for a much stronger role for support provider organisations, giving PB holders greater choice in obtaining help to develop their support plan. The availability of services or the scope to 'create' new support options was also important and is discussed below.

7.4 Improving the supply of services

Across all the case study areas, even those which had a long history of direct payments, individual budgets and PBs, there was a strong view that the supply of services was not keeping up with the changing needs and preferences of PB holders. This finding is echoed in recent work by the NMDF (2010) and in the second report by the University of Kent Personal Social Services Research Unit on the implementation of personal health budgets (Jones et al. 2010). For those PB holders who needed personal care or support to enable them to get out and do things in the community, the employment of personal assistants often transformed their quality of life, but in many areas there were difficulties recruiting such assistants, arranging holiday/sickness cover and/or facilitating training. Even where people were happy to use a care agency, these agencies often did not understand the principles and practice of PBs. For PB holders with mental health problems in particular there appeared to be much greater scope for people to pool their purchasing power to commission new or different services. Alongside changing their internal systems, LAs and trusts do need to take a more active role in encouraging the development of provider services, so that PB holders have a range of services and support options to choose from.

7.5 Maximising control regardless of deployment option

A number of previous studies have highlighted the danger of a 'one size fits all' approach to self-directed support, and have emphasised the importance of people having a range of options for the management of their PB. Clearly, decisions about how to manage a PB can have a powerful knock-on effect on the ways in which PB holders can exercise choice and control. There was evidence that those PB holders who had managed accounts or directly commissioned services, rather than a direct payment, had less control over how the services and support they received were provided. Addressing this problem required a number of strategies. Staff training, particularly involving people using services, could be used to break down assumptions about which deployment options 'suit' different client groups, but PB holders themselves also need information and discussion about deployment options and support at different stages in the PB process to enable them to make an informed choice. For older PB holders in particular, there needs to be a much more flexible interface between reablement and take-up of a PB, and for all PB holders it should be made much easier to move between deployment options. Many user-led organisations would argue that the direct payment form of PB should be more actively promoted and this is most likely to result in people having maximum choice and control. However, there also needs to be recognition that some PB holders will at times be too unwell to cope with a deployment option or simply do not want the responsibility. Steps therefore need to be taken to ensure that, even with managed accounts and directly commissioned services, every effort is made to maximise PB holder choice and control. These deployment options should not be seen as 'second class', just different.

7.6 Offering choice of support to manage the personal budget

A strong theme to emerge from both the research and policy literature was the central importance of support for people in managing their PB. Many PB holders and carers in this study were able to manage their PBs with little or no support, but for others support from family and friends, social workers, community psychiatric nurses and/or support provider organisations was vital. If people using services are to feel confident taking up a PB, they need to know what support is available to them; they also need to feel confident that such support can be adjusted quickly and easily if their circumstances change and they must have a choice about who provides that support. Although there was broad acceptance among PB holders that support of this type had to be paid for, there is perhaps a need for more work to explore creative ways of PB holders offsetting the cost with a contribution 'in kind'.

7.7 Establishing manageable monitoring systems

The level of support needed to manage PBs is strongly linked to the monitoring arrangements LAs have in place. It was clear from the case study sites that, as they were rolling out PBs, they were recognising the need for and becoming more confident about using 'light touch' monitoring systems for small and less complex budgets. Some LAs were combining monitoring with reviews, which appeared to be a much better use of staff and PB holders' time. Given that the case study LAs appeared to have had few cases of deliberate misuse of PBs, there is perhaps an argument for simplifying monitoring arrangements further.

7.8 Recognising the central role of carers

Carers clearly play a central role in enabling many PB holders to take up and manage their PBs. This is particularly the case for people with dementia, but also for younger people with mental health problems who are especially unwell. Many practitioners were working well with carers and certainly the study showed that PBs could make a significant difference to carers' lives. However, there was still a sense that the role and contribution of carers was not fully recognised in the PB process. While respecting the independence and rights of the PB holder, carers should be involved in all stages of the PB process, if this is what they, and the PB holder, want. Resource allocation systems should also be 'carer neutral' – i.e. allocation should be based on no carer input and then adjusted to take account of the support a carer is willing and able to provide. This approach would also help to strengthen contingency planning and reduce the need for reassessments. It would also be helpful if LAs could provide guidance for PB holders and carers about employing family members as personal assistants.

8 Conclusion

As LAs gear up to make PBs available to more and more people who use services, they need to find ways to keep the PB process 'personal'. With high workloads and resource constraints this is easy to say and very difficult to do. There may, however, be a number of steps which can be taken to avoid PBs becoming 'bureaucratised'. Perhaps the first is acknowledging the very central place of the relationship between PB holders and their care manager or care co-ordinator. This human factor cannot be underestimated, and so giving staff support, training and time to work with PB holders properly is crucial. PB holders and carers do need the freedom to get information, advice and support from other sources, but this should not be at the expense of the continuity which practitioners often provide. As financial pressures bite, there may be a temptation to centralise in order to retain or increase financial control. However, devolving control of as many aspects of the PB process as possible to local teams and PB holders themselves has the potential to not only improve staff morale but also to

hold down administrative costs and provide a more flexible and responsive service for PB holders. Lastly, as many of the case study sites had recognised, a successful PB process isn't just about what the LA does; it requires a series of effective partnerships to be established between individuals and agencies, and this process inevitably takes time.

Appendix 1: Profile of study sites

Council A
Overview of Council A Council A is a unitary council with a population of 382,600 (2008), of which BME groups constitute 1.5 per cent. It is ranked in the least deprived quartile of councils in England (2007). It is Conservative controlled. The FACS (fair access to care services) threshold currently includes critical/substantial.
History of PB implementation The current system for PBs was launched in August 2009. PBs have been introduced across all client groups. The total number of PBs is currently in the region of 1,700, with 865 in the form of a direct payment. Person-centred planning is fundamental to the approach in relation to introducing PBs and is a key component of the support plan template.
Resource allocation system and payment methods The resource allocation system is made up of 'standard units of support', which describe a level of support equivalent to one hour delivered on a one-to-one basis by a paid carer. Half-hour units can also be made available. 'Specific alternative units' can be used – there are enhanced rates where specialist input is required and reduced rates where support can be shared or is less intensive. There are no cost ceilings for different client groups and in most cases PBs are permitted up to the need of a residential placement. Direct payments are the assumed method of payment – i.e. full control. If this is not feasible/desirable, a direct payment can be arranged via an agency that will provide the care. A further option is where funding stays with social services on a managed budget. Up-front annual payments can be made. For equipment, needs are assessed and then a 'prescription' will list the items to which people are entitled and cover their cost. People can go to a prescribed list of retailers and top up if they wish to have any additional features or a different brand.
Decision-making

The care manager can agree up to £250 per week and the team manager up to £415 per week. Discretionary payments above that level go to a practice development meeting or team meeting for approval.

Support with planning/brokerage/managing payments

Support planning is provided by either the care manager or a local support provider. There is a template for a person's support plan on the intranet.

A local support provider gives brokerage support to older people (including self-funders) and also offers a mentoring service, which is grant funded and allows a volunteer to help with paperwork once a week.

A local user-led organisation offers brokerage support to people under 65, and a managed account and payroll service for all ages. This organisation also provides training for personal assistants and keeps a personal assistant register.

Some agencies are also offering a managed account service. The LA funds independent advocacy.

Monitoring and review

Routine reviews are used as an opportunity to align with direct payment audit requirements.

Payments in excess of £20,000 have full annual audit by the LA direct payments administration team. Payments in excess of £5,000 but less than £20,000 demand a detailed annual account, but with a number of previous checks removed to streamline the process. Payments less than £5,000 have a 'light touch' review.

It is explicit in the direct payments agreement that unspent funds above the equivalent of 10 weeks direct payments will be required to be repaid.

The local user-led organisation offers a tiered risk-based approach to managing direct payment accounts.

Council B

Overview of Council B

Council B has a population of 249,500 (2008), of BME groups constitute 61 per cent. It is one of the most ethnically diverse LAs in the country and ranked in the most deprived quartile of councils in England (2007). It is Labour controlled. The FACS threshold currently includes critical/substantial.

History of PB implementation

Council B was originally an In Control pilot focusing on people with learning disabilities. After running a number of pilot schemes, PBs have now been rolled out across all groups of people who use services. The pilot schemes were evaluated internally.

Council B's focus has been on self-directed support, rather than a narrow focus on PBs. There has been dedicated project management support in place for delivering self-directed support. The aim is fully to mainstream individual budgets by the end of the 2010.

Current numbers on PBs are 837 across adult and children services:

- direct payments: 260
- commissioned service (individual service fund): 11
- managed account by council and other providers: 566.

Council B is to be a 'Right to Control Trailblazer' pilot site.

It is the care co-ordinator's role to undertake carer assessments. There is a dedicated carer support worker within the mental health team.

Carers are not able to access PBs in their own right in Council B but there are plans to introduce this.

PBs within mental health services

Within mental health services, Council B has been focusing PBs on people who have been using day services, and on people in contact with the early intervention team. Where possible PBs have been used to support people into employment. To date PBs have not been made available to people on adult placements because it largely meant that they would be worse off (as there is currently a payment ceiling of

Council B
£120 per week). In mental health PBs have tended to be time-limited rather than ongoing, in keeping with the recovery model. This system is now changing to align more with the centralised system, requiring completion of the core forms and recording/payment systems that are used for other client groups, but a resource allocation 'points' system is still not applied to mental health. Researchers were informed that the additional paperwork attached to the centralised system may be making some care co-ordinators more reticent to offer PBs, as there has recently been a dip in requests.
Assessments People have a 'supportive self-assessment' using a self-directed assessment questionnaire, with as much or as little support as they need. In mental health, the care co-ordinator (who can be a trained psychiatric nurse or social worker) provides support with the assessment. Mental health staff are also required to complete care programme approach documentation, which includes a risk assessment.
Resource allocation system and payment methods Centrally, Council B has adopted a points-based system, based on the In Control model and work done in Oldham, though as stated above this has not been employed within mental health. Until recently in mental health, payments were made by cheque, which could be authorised by the self-directed support co-ordinator, but this has now changed. Payments are made as a lump sum or split over regular intervals, depending on what the PB is being used for. There are different financial ceilings for different client groups. Exceptions are determined on a case-by-case basis in relation to individuals' assessed needs and required outcomes. The self-directed support team recoups any unspent individual budget funds in excess of an agreed contingency to be carried forward on a quarterly basis, following submission of financial monitoring returns, and alerts the allocated social work team to consider initiating a review. The finance team reallocate the recouped funds/'claw back' to

Council B
the appropriate budget code.
Decision-making All self assessment questionnaires (SAQs) and indicative individual budgets, and all support plans and individual budgets have to be approved by a panel and checks are made to see if the plan addresses outcomes/risks appropriately. This is an iterative process and support plans/levels of individual budgets can be adjusted in the light of feedback from the panel. In the case of mental health, the self-directed support co-ordinator is responsible for taking all the costed plans to the panel. The panel consists of a group manager (chair) and representatives from commissioning, finance, the adult social work team, the self-directed support team, mental health and quality. The panel meets three times a week – twice for budgets greater than £300 per week and once for budgets less than this. Decisions are made on the basis of individuals' assessed needs and required outcomes. Risks are considered according to decision-making capacity and needs. The risk enablement panel, which meets once a month, has been set up to provide a forum where staff at different levels within Council B's adult services can share risk decision-making when teams or individuals are concerned about managing the level of risk.

Council B
Support with planning/brokerage/managing payments Within mental health, help with support planning is largely provided by the care co-ordinators. Across client groups, external support has been commissioned from external organisations: • The Shaw Trust and Age Concern have been providing support planning and brokerage, largely with older people and those with physical and sensory impairment and learning disabilities. A tender has just been circulated for support/brokerage to put this on a clearer footing. • Payroll and accounting services are available via the Shaw Trust. • Internal and external 'self-directed support managed accounts' are also available as budget management options. • MIND was commissioned to provide help with support planning for mental health but this has not yet been embedded in practice (only one person had gone through this route during the time of this research). • MIND is one of 10 external support planning and brokerage providers within the framework contract. These providers will also provide a range of external information and advice and financial support services provision.
Commissioning Council B has in-house mental health day services, employment services, mental health support schemes, a limited amount of mental health residential care and a joint access and care management service providing support package co-ordination and commissioning.
Monitoring and review Council B's centralised system requires that people sign an agreement to submit quarterly returns showing how they have spent their individual budgets. This is checked by the self-directed support finance team to ensure it is in accordance with their support plan via the 'CareFirst' system – if there are any issues these are raised with the social worker. As stated previously, when this research was carried out the centralised system was in its infancy. Previously in mental health,

Council B
people received written information about the need to keep receipts etc. but in practice staff did not have a systematic means of monitoring and checking expenditure. Unlike other client groups, most mental health budget holders are not on ongoing PBs, and the timing of reviews related to short-term PBs is set on an individual basis.
Information The council has developed a self-directed support information pack and online information is available. Independent advocacy is available across client groups. There are also mental health-specific advocacy groups, such as Independent Mental Health Advocacy (IMHA) and Independent Mental Capacity Advocacy (IMCA).
Staff training Staff training has been delivered on concepts, values and processes. The council has also developed self-directed support resources on its intranet for staff, but researchers were informed that this has not been actively used within mental health services, initially because a different system of making PBs available grew up within that sector. Training in self-directed support has not been mandatory for mental health staff.

Council C
Overview of Council C Council C is a unitary authority with a population of 91,700 (2008) of which BME groups constitute 2.1 per cent. It is ranked in the most deprived quartile of councils in England (2007). Eleven wards in the borough are classified as among the most deprived fifth of areas in England. It is Labour controlled. The FACS threshold currently includes critical/substantial.

Council C
History of PB implementation Council C was an 'In Control Total Transformation' site. The council decided in the early stages not to pilot but to immediately mainstream PBs. PBs are available across all client groups. To support implementation, the council has used the Care Services Efficiency Delivery (CSED) self-assessment materials. Currently, 63 per cent of people who use social care services are in receipt of self-directed support/PBs. This represents 1,242 people out of a possible cohort of 1,970. In the last three years direct payments have increased by 10 per cent in relation to ongoing direct payments and by 45 per cent in relation to one-off payments (total figure September 2010: 651, of which 361 are ongoing). Some people receive a mixture of commissioned services and direct payments. If carers meet the criteria, they can receive a PB in their own right for their own needs. A new SAQ for carers is in the process of being developed.
Related activity Council C is currently a personal health budgets implementation pilot site. It is an intense evaluation site and is in the pilot with a neighbouring authority. Council C has very recently been awarded the power to give DPs for clients with fully-funded continuing health care funding. The council is also exploring children's PBs and has made progress towards having a system of self-directed support.

Council C

Assessments

The first point of contact for people seeking social care support is an assessment to ensure the right support is provided in relation to their current need. Where appropriate, people are provided with a reablement/intermediate service to stabilise their situation. Following the period of reablement/crisis intervention, if there is still a need for support, then a SDAQ is completed which informs the person of their indicative allocation and how they are able to use the resource/plan etc. Every new person using services is expected to go on to a PB after a period of reablement, which is generally six weeks, but this can be flexible.

The assessment is carried out initially assuming no informal carer support; then carer support is factored in and the monetary allocation is adjusted to take agreed carer/social support into account. The points allocated for need are never amended regardless of carer support. This system means that if circumstances change and the carer is incapacitated, then the council can adjust the PB as necessary without further assessment.

For mental health, a care programme approach also has to be completed and this used to mean double entry, but an 'information warehouse' has now been introduced so that core information gathered from Paris (an IT system) can populate CareFirst. People are not offered PBs if they are in crisis, only when their condition has stabilised. The SAQ is signed off by a social worker/community psychiatric nurse or, where any concerns have been presented, by the social worker at a panel meeting.

Resource allocation system and payment methods

Under Council C's policy individuals are required to contribute their personal income to the level of 75 per cent of the value of the support plan, up to the maximum value identified in their means test.

PBs can be offered in the form of:

- a direct payment
- an indirect payment via a representative (this can be a carer/agency)
- a commissioned service managed by the social worker – this limits choice as the social worker can only commission contracted

Council C
services, but the charging for the service is transparent • a mixture of direct payments and commissioned services (this is a popular choice in Council C). There are indicative financial ceilings for different client groups but these are flexible and can be adjusted according to individual needs. For mental health, some costs for professional support, or services which are integrated with health, do not form part of the indicative allocation and therefore an individual is not required to make a personal contribution to them. Some of these services are a helpful means of monitoring people potentially at risk and can be preventative/reablement-type services and are therefore effectively free. Currently PBs are not used to pay for assistive equipment. This falls outside the resource allocation system because some equipment such as telecare is not linked to the FACS eligibility system. Moreover, equipment to maintain people's independence and promote recovery is placed at the forefront of services, in order to provide the least intrusive, most effective response to need and only those with a longer-term need would have a PB.
Decision-making Most PB requests go to the risk enablement panel for approval, though the system is changing so that decisions about lower levels of funding can be made by team managers. The panel meets weekly and now only approves allocations where there is a disparity between current provision and proposed allocation. All mental health requests go to a panel as part of a drive to substantially increase the number of PBs in the next 12 months.
Support with planning/brokerage/managing payments Support planning is largely managed internally, although this is often with contributions from the person using services, their family and other agencies. There are now three independent agencies locally who provide brokerage support and/or technical support if required (e.g. payroll/help with employment), which serve all client groups. One of these is a user-led organisation which is looking to increase its support planning role (which currently majors in learning disability).

Council C
Council C has intentionally resisted building a partnership with just one or two external organisations for support with PBs, and has enabled a range of organisations to emerge in order to enable user choice.
Monitoring and review The support plan has to indicate review arrangements, with a date. Monitoring of PBs follows statutory review periods. However, Council C is increasingly reviewing on an individualised basis, rather than a generic one (i.e. the review should be proportionate). All direct payment financial monitoring is managed internally. For small amounts people are not required to open a bank account; they are just required to show receipts. This is in the case for all one-off direct payments regardless of size. If the direct payment is ongoing and regular then there needs to be an account and a risk assessment is undertaken in accordance with Chartered Institute of Public Finance and Accountancy (CIPFA) guidance on how to monitor payments and the use of resources in the long term. Review documentation is now more outcomes-focused, using six 'quality of life' questions, and this is still in the process of implementation.
Information Council C is now an information portal, kept up to date by the LA. It holds general/specialised information and service provider details (e.g. trusted handyman scheme). A user focus group is held twice a month and PBs/personalisation is a regular slot. Peer and independent mental health advocacy are available.
Hard-to-reach groups There is a BME forum (general, not social care specific) and personalisation has been raised as a topic here. Council C is promoting access to the 'Partners in Policy Making' course among this group. 'Making it Happen' discussions are also happening through a diverse MIND project (a community development project looking at mental wellbeing with BME communities).

Council D

Overview of Council D

Council D has a population of 850,800 (2008), of which BME groups constitute 1.5 per cent. It is ranked in the third least deprived quartile of councils in England (2007). It is Conservative controlled. The FACS threshold is currently critical/substantial.

History of PB implementation

Council D was an individual budget pilot focusing on mental health and learning disability. Following this, some of the council's social care transformation grant was used to initiate PBs among other groups. In older people's services the numbers on PBs are low compared to the number of older people they support. Although PBs are now county-wide, they initially had two pilot areas.

At the end of August 2010 there were 713 people on PBs: 450 were direct payment only, 97 commissioned service and 166 have a mix.

Resource allocation system and payment methods

Council D has a 'front door' service and if people come through that route they are linked into the teams and the PB forms are completed by them. If people come via the reablement service, the reablement staff use the PB questionnaire at around six to eight weeks (this is currently a pilot). Members of staff in the PB teams are encouraged to look at the scope for people to move to a PB when they undertake reviews. A pilot PB process started on 25 October 2010 to set up PBs in the council's Care Connect (Front Door) team.

Risk is assessed via a FACS assessment and the PB questionnaire in the 'keeping myself safe' and 'risks to others' sections. Risk areas are addressed in support plans which are all signed off by practitioners.

Previously, there was a single resource allocation system for all client groups, except mental health which has stayed with the version used in the individual budget pilot. A revised personal budget questionnaire /resource allocation system has now been developed which will include all client groups – this is currently in its testing phase. The allocation system is points-based and there is a different price per point dependent on client group. There are currently different ceilings

Council D
for different client groups. Council D has no carers on a PB at present but a carers' resource allocation system is in its development stage. If there is a build up of unused funds, the person using services will be contacted and depending on the circumstances the council may put a hold on future release of funds or potentially 'claw back'.
Decision-making All allocations are approved by either the local manager or a panel. This is currently under review. In future, once the resource allocation system is fully developed, this should not be required.
Support with planning/brokerage/managing payments For support planning there is a service-level agreement with the Coalition for Disabled People to provide both support planning (to around 100 people in 2009) and training to other third-sector organisations who want to offer support planning (e.g. Age UK). In addition to the support available from National Council of Disabled People (NCODP) practitioners, friends and family also help with support planning. Currently, 20 per cent of people manage their own budget, 10 per cent receive the payment but allow the support provider organisation do handle payment/tax of personal assistants etc. and 70 per cent allow the support provider to manage the whole budget. Only complex support planning requests are referred to the locality teams. Advocacy is supplied by Age Concern, DIAL and various learning disability and mental health groups (e.g. BUILD, People First etc.).
Monitoring and review Monitoring is carried out through reviews, which are generally after three months and annually thereafter, although frequency is dependent on the individual case. Financial monitoring is carried out after three months and receipts are checked against the support plan. This is then monitored annually.

Council D
Anything under £50 does not require a receipt. This is under review with a view to moving to 'light touch' monitoring.
Staff training PB implementation has involved a lot of staff training. There has been core training with over 300 practitioners, plus occupational therapists (OTs). A major part of PB development workers' training has been on the basics: process, costing, charging and support planning (including encouraging creativity). A new contingency policy is about to be launched for practitioners. There has been work regionally with the joint improvement team. PB development workers support the teams in their self-directed support work. There is an intranet page for staff with access to all the paperwork. Self-directed support is now linked to induction and basic training. E-learning on personalisation is being developed further. Additionally there has been awareness training for hospital staff and training for Care Connect (front door) staff began in October 2010.
Council D mental health trust The trust provides mental health and social care across the county. The Section 75 agreement means that all budgets are 'managed' by the trust but not 'owned' by it. The trust didn't want to take on the financial risk of budgets being overspent. Under a Section 75 grant, all social care staff working in mental health have been transferred to the trust. After the individual budgets pilot, the trust took the decision to target PBs at people in residential care (getting them out and preventing them going in) and so numbers stayed low. However, recently it was decided to roll out PBs to all groups in mental health, so numbers are gradually increasing. The trust follows social services policies and procedures. The budget is worked out/assessed by social services but the trust's care co-ordinator is included in the process. The template is completed by the trust and sent to Council D which determines the resource allocation and the trust then manages it. The trust is a personal health budget site and is one of the in-depth evaluated sites.

Council E

Overview of Council E

Council E is a county council with a population of 698,000 (2008), of which BME groups constitute 1.5 per cent. It is ranked in the third least deprived quartile of councils in England (2007). It is Conservative controlled. The FACS threshold currently includes moderate/critical/substantial.

History of PB implementation

Council E was an individual budget pilot site for all client groups from which a common resource allocation system was created. There were some problems with this and after some financial modelling a new allocation system was rolled out to the rest of Council E in January 2010. Since March 2010 anybody new to adult social care is automatically put onto a PB.

The total number on PBs as at July 2010 was 1,988, with 1,021 in the form of a direct payment. A project called 'Moving On' is being set up to look at supporting people to move from long-term residential settings into independent living, where health resources will be applied more flexibly and delivered through a support plan which will also draw in funds from other funding streams.

Resource allocation system and payment methods

During the individual budget pilot the In Control resource allocation model was used but since then Council E has consulted people who use services and their carers who were part of the individual budget pilot and created a new points-based model. At the end of reablement, an assessment is completed which identifies whether the person still meets FACS and requires ongoing support. The resource allocation is then completed and the support plan created.

Risks are assessed in the usual way through the adult social care assessor assessment process which includes reablement. The resource allocation system has a domain which deals specifically with risk. The support plan needs to be signed off if undue risk is identified, and there is a risk enablement process in place.

There are no different ceilings for different client groups. 'Claw back' from unspent funds is managed through the direct payment audit process.

Council E
Decision-making Decisions about the 'pounds per point' and the 'points per question' are made by adult social care finance in co-operation with adult social care operational heads of service and Putting People First. The resource allocation relates to eligible need, so would be confirmed by the practitioner. The manager then calculates the indicative amount. In theory, this is where budgetary control sits, as the manager is able to challenge the level of resource allocation against the assessment. Staff have to check that the resource allocation has been completed in accordance with assessed needs.
Support with planning/brokerage/managing payments People can use whoever they like to help them develop their support plan. Council E does not contract out support planning to any third-sector organisations at the moment but does have an individual budgets network (IBNL). The network has a website which is a directory. It has also been undertaking some research into brokerage funded by the council. Speaking Up has a contract with the council to provide advocacy across all service areas. There are other advocacy providers in the county but they do not have contracts with the authority.
Monitoring and review Monitoring is carried out through reviews, after three months and then annually. Council E intends to introduce the concept of self-review. If the PB is deployed through a direct payment, then the audit is done through the direct payment team. If it is deployed through a directly provided service, then financial review will take place alongside the annual review.

Council E
Staff training Conference-style awareness events were held in 2009 which all adult social care staff members attended. A further round was held to include managers of relevant organisations (e.g. health/providers/third sector etc). A staff training programme was rolled out with the new resource allocation system. Council E made a DVD of practitioners completing resource allocation with people using services (three vignettes – older person, person with a physical disability and person with a learning disability). The DVD is used in the staff training sessions. Both Council E and its mental health trust have 'Champions for PBs' who meet every month and are representatives from all the adult social care teams. They are now beginning to bring in speakers from other authorities so that they can learn from good practice in other areas.
Hard-to-reach groups An independent living guide has been published in Polish. There is no specific outreach work.

Appendix 2 - Profile of PB holders and carers involved in the study

The 'Basic information about you' part of the consent form enables us to understand the demographical profile of the users and carers involved in the study including gender, age, ethnicity and sexual orientation.

It was decided by the Advisory Group that the form should state clearly and in a prominent position that this section of the consent form was entirely optional and that those completing the form 'do not have to answer any questions you do not feel comfortable with'. Furthermore, six participants (included in the sample of 69 below) were not presented with the full consent form (because they were either involved in a focus group or contacted directly) and so did not have the opportunity to answer all questions in this particular section.

1. Profile of the PB Holders and Carers

Sixty nine users and carers were interviewed, 11 in focus groups and the remaining 58 as individual interviews. Forty nine of these individual interviews were conducted by telephone and nine in person.

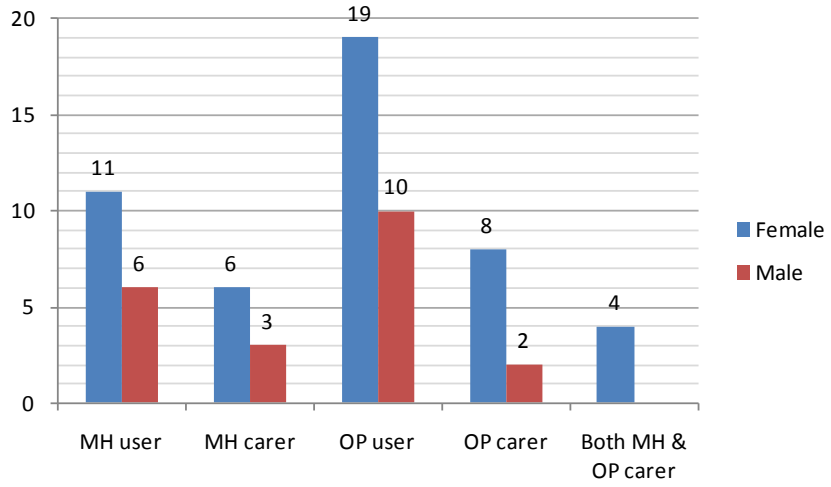
Of these 69, 17 were MH users, nine were MH carers, 29 were OP users, 10 were OP carers and four were both OP & MH carers (in each case this being one person who was both a MH and OP user).

Further to these 69, nine other users returned and three had an interview arranged but this was never completed (in one case because of illness and in the other two owing to not being contactable).

2. Gender

Forty-eight of those interviewed were female and 21 male with the specific breakdown shown in Graph 1 below.

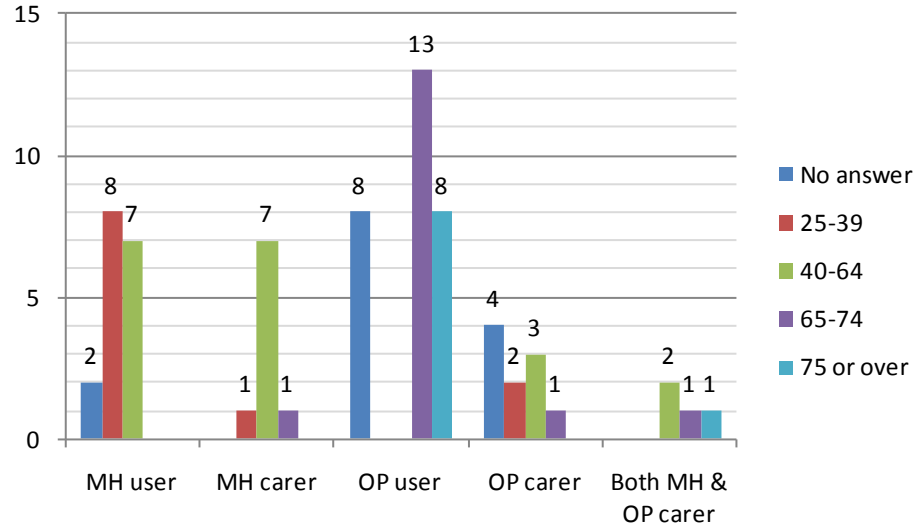
Graph 1 Gender



3. Age

Most MH users (n=15) were of working age (in the 25-39 and 40-64 age brackets) and the criteria for the OP users meant that all those involved were over 64 years of age. The MH carers were predominantly aged 40-64 and all but one cared for their spouse; the OP carers were spread amongst the age groups and generally cared for either their spouse or a parent. The only young adult aged between 18 and 24 was a MH user. Seven people did not disclose their age and nobody indicated they were aged between 18 and 24. The specific breakdown is demonstrated below in Graph 2 below.

Graph 2 Age



Of the 11 who did not answer, six were not presented with the full consent form (because they were either involved in a focus group or contacted directly) and so did not have the opportunity to answer this particular question.

4. Ethnicity

73 per cent of those interviewed (n=50) considered themselves 'White – British', four per cent (n=3) 'White – Irish' and 16 per cent (n=11) did not answer. The remaining 7 per cent (n=5) are distributed amongst the remaining ethnic groups as displayed in the Table 1 below.

Nobody indicated they belonged to any of the following ethnic groups: 'Chinese or other ethnic group – Chinese', 'Chinese or other ethnic group – Other', 'Asian or Asian British – Indian', 'Asian or Asian British – Pakistani', 'Asian or Asian British – Bangladeshi', 'Asian or Asian British – Any other Asian background', 'Mixed – White and Black Caribbean', 'Mixed – White and Black African' or 'Mixed – Any other mixed'.

Table 1: Ethnicity

Carer/User type	No answer	Black or Black British - African	Black or Black British - Any other Black background	Black or Black British - Caribbean	Mixed - White and Asian	White - Any other white background	White - British	White - Irish	Grand Total
MH user		1	1	1	1	1	12		17
MH carer							8	1	9
OP user	8						19	2	29
OP carer	3						7		10
Both MH & OP carer							4		4
Grand Total	11	1	1	1	1	1	50	3	69

There were 11 who did not answer, six were not presented with the full consent form (because they were either involved in a focus group or contacted directly) and so did not have the opportunity to answer this particular question.

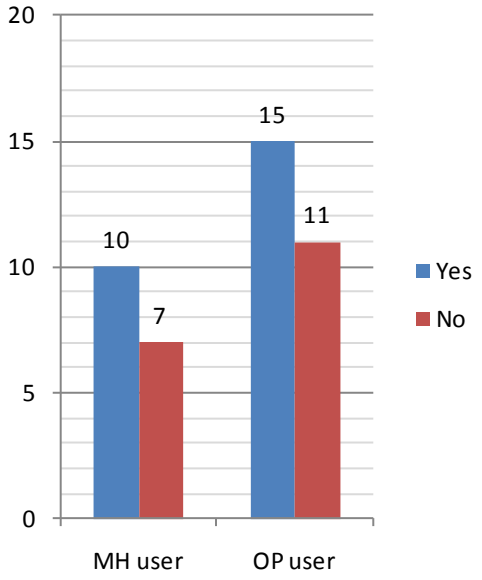
5. Sexual orientation

68 per cent of those interviewed (n=47) answered that they are 'Heterosexual/straight' and 30 per cent (n=21) did not answer, although, as mentioned above, this includes six participants who were not asked this question because they were involved in a focus group or contacted directly. Nobody indicated that they are 'Bisexual', 'Gay man' or 'Transgender'.

6. Carers of budget holders

58 per cent of PB holders had an unpaid carer (e.g. family member or friend).

Graph 4 Unpaid Carers



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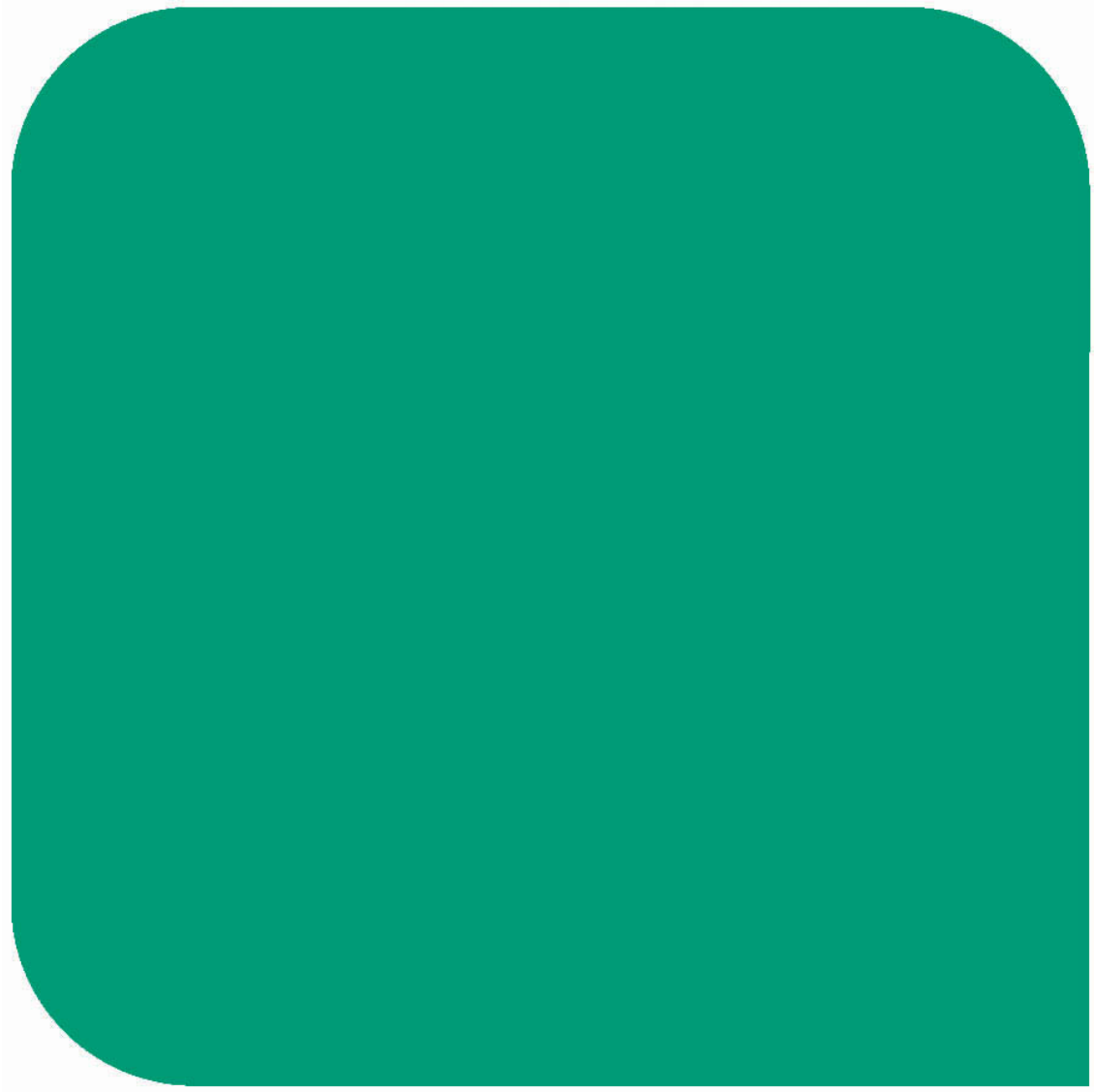

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