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Personal budgets briefing



February 2011

Learning from the experiences of people with mental health problems and their carers

Key messages

- Personal budgets can be held in several ways. Personal budget holders need clear information about what is involved – including information on risk and safety and help with assessment and planning. Knowledgeable staff are particularly important.
- Practitioner continuity, relationship-based working, staff training, peer support and allocated time to work with personal budget holders are all important factors for achieving good self-directed support. User-led and support provider organisations can also help with support planning.
- Services are not keeping up with the changing needs and preferences of personal budget holders. However, there seems to be some scope for people with mental health problems to pool budgets to collectively commission different services.
- Most people with mental health problems are able to manage their budgets themselves, but many would also welcome peer support.
- Carers play a central role in enabling many people to take up and manage their personal budget. Carers indicated that resource allocation should be worked out on the basis of no carer input and adjusted depending on how much support the carer can provide.
- Monitoring of personal budgets varies considerably. Clear guidance and flexible systems are needed.

Introduction

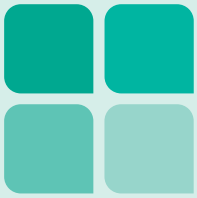
This At a glance briefing is a summary of people's experiences of using self-directed support and personal budgets. It focuses on people with mental health problems and their carers. It is based on a six month study, which also included older people. The research was commissioned from a joint team from Acton Shapiro, the National Centre for Independent Living (NCIL) and the Social Policy Research Unit (SPRU). The IBSEN national evaluation of the 13 Department of Health individual budgets pilot sites concluded that although individual budgets could give people a greater sense of control and satisfaction with services, there were differences in the uptake and outcomes for older people and people with mental health problems (Glendinning et al 2008).

This research provides more detailed evidence to inform good practice in personal budget processes for people with mental health problems and older people. It involved five local authorities and draws primarily on the experiences of personal budget holders and carers, supported by the views of practitioners and managers. Sixty-nine personal budget holders and carers, 40 practitioners and managers and 12 support provider organisations (including five user-led organisations) contributed to the research. For full details, see SCIE Report 40: *Keeping personal budgets personal* at www.scie.org.uk

Findings

Moving to a personal budget

Most personal budget holders with mental health problems and carers in the study had heard about personal budgets from their social worker or community psychiatric nurse (CPN). Many personal budget holders and carers would have liked earlier access to information about personal budgets and highlighted the importance of key groups of health care staff and service providers knowing about personal budgets.



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Deciding on a personal budget

Personal budget holders and carers emphasised the importance of having clear and understandable information about what a personal budget is, how it can be used and what is involved in holding one. They wanted to make well-informed decisions about their care and support.

While personal budget holders and carers value having written information, it was usually the time spent discussing personal budgets with their social worker, CPN, support provider organisation (SPO) or user-led organisation (ULO) worker that helped them the most.

The information-giving role of the SPOs (including ULOs) in the study varied widely. While a few actively marketed their services, some provided information about personal budgets only to people referred to them by the local authority. Generally, ULOs saw themselves as having a wider and more experience-based information and peer support role.

Being assessed for a personal budget

Most personal budget 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.

In particular they wanted:

- the support and the forms provided to be much more tailored to their individual (including fluctuating) needs, without assumptions being made about what certain 'groups' of service users could or could not do in terms of self-assessment
- a consistent contact person throughout the assessment process who knew their circumstances and who 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 outcomes-focused and to address individual strengths and aspirations as well as needs.

Very few personal budget 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 these issues were addressed. The feedback highlighted the need for:

- clear guidance on how issues of risk management should be included in the assessment, including how to balance (and record) choice and safeguarding issues
- explicit separation in the personal budget process of the mechanisms used to judge the risks to the local authority (e.g. financial risk) and those used to assess the safety of the personal budget holder and their carer.

Example

Hilary has mental health problems and physical impairments which means that she needs a high level of support from personal assistants (PAs) and other services. She felt strongly that the issue of risk and contingency planning needed to be addressed thoroughly when assessing her personal budget. She discussed this with her social worker and they identified the potential risks to her, one of which was what would happen if her PA 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.

Resource allocation

Different models of Resource Allocation System (RAS) were used across the sites. Where a generic RAS was used, it highlighted some inequalities in resource allocation between client groups.

Most mental health personal budget holders and carers were happy with the amount they had received in their personal budget. Often this was received as a lump sum which was used in a variety of innovative ways. However, the budget holders, carers and staff felt that contingency planning should be strengthened.



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Across all the case study areas, even those with a long history of self-directed support, there was a strong view that the supply of services was not keeping up with the changing needs and preferences of personal budget holders.

Despite this, for personal budget holders with mental health problems in particular, there appears to be much greater scope for people to pool their purchasing power to commission new or different services.

Support planning

Personal budget holders' experiences suggest that there are a number of ways to ensure that the support planning process is person-centred, enabling and flexible:

- a 'fast track' option from assessment to support plan, where the personal budget holder's wishes are clear and there are no major concerns about safeguarding or financial risks (there was some indication that mental health budgets had to be approved by a panel when personal budgets for other service users could be signed off in other ways)
- 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
- ensuring support planning 'templates' are flexible and that personal budget 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 an SPO/ULO in the support planning process, especially if the SPO is likely to support the personal budget holder in managing their budget
- active involvement of practitioners/SPOs in encouraging people to think beyond traditional service models and develop innovative ideas about how to meet their needs.

Deciding how to hold the personal budget

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

- services directly commissioned and/or managed by the local authority
- third-party managed accounts (usually an SPO)
- a direct payment held and managed by the personal budget holder
- a mixture of these options.

Decisions about how to manage the personal budget can have a powerful knock-on effect in terms of the ways in which people can exercise choice and control. Personal budget 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.

Personal budget holders, staff and SPOs suggested this could be addressed by:

- ensuring staff have time to discuss different options (fully, at an early stage and more than once) with potential personal budget holders
- using staff training to break down assumptions about which option may 'suit' any particular group of service users
- providing information about all options throughout the personal budget process
- making it much easier for personal budget holders to move between 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 the time for staff to discuss it with personal budget holders
- providing opportunities for personal budget holders, particularly those who have opted to have their personal budget as direct payments, to share their experiences with potential personal budget holders.

Personal budget holders using direct payments felt this had given them much greater choice and control. For personal budget holders with mental health problems the sense of responsibility increased their confidence.

Arranging and obtaining support

People used their personal budgets in a wide variety of ways. A number of factors helped or hindered personal budget holders' abilities to



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make the most of their budget. Personal budget holders and practitioners suggested four things they had found helpful:

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

The availability of the service and support people wanted was also an important issue. Managers and practitioners suggested things local authorities could do to encourage the diversity and development of services:

- training and development work with existing providers to help them understand the principles and practice of personal budgets and encourage them to adapt their services
- creating an infrastructure which makes it easier for personal budget holders to pool their 'purchasing power' to jointly commission the new services or support
- giving staff time to work with personal budget holders with unconventional or innovative ideas to help them develop their support, and share their learning.

The role of carers

Carers play a central role in enabling many personal budget holders to take up and manage their budgets. This is particularly for older people with dementia, but also younger people with more severe mental health problems. While respecting the independence and rights of the personal budget holder, carers can be involved in all stages of the personal budget process, if this is what they, and the budget holder, want. Resource Allocation Systems should also be 'carer neutral' – this means the RAS should be worked out on the basis of no carer input and then adjusted to take account of the support the carer is willing and able to provide.

Example

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. David's assessment identified that he required support to go out and socialise. His personal budget enabled him to join an indoor bowling club in his local village and he now goes there three afternoons a week. At first Joanne accompanied him, but as he began to feel more confident and made friends she was happy to leave him. 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. Joanne explains how this approach has helped her: 'I've got the confidence to know that I've got a couple of hours to myself and he's safe.'

Management of the personal budget

Most personal budget holders with mental health problems were able to manage their personal budgets themselves with little or no support. Where help was needed, the main source was their CPN or social worker. Some people also had support from family or friends. All sites had SPOs offering personal budget holders support, although not all of them were ULOs.

Generally SPOs offered a 'menu' of support. No SPO appeared to charge more for general support and advice. Personal budget holders and carers reported that access to this 'free' informal support was important, both for the sense of security it gave them and in building a positive relationship with the SPO.

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



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personal budget or to be linked up with a 'personal budget buddy'.

Example

Helen has mental health problems and lives by herself. Although she gets support from her mother and her niece, she wanted her CPN to help her through the personal budget process. She explained that she had been quite ill for a while and it was her CPN who had suggested that a personal budget 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 CPN 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 CPN] 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...' She felt she had greatly benefited from doing her assessment with her CPN 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'.

The role of external organisations

All the local authorities included in the research had a service level agreement with one or more SPOs (including ULOs), to undertake discrete tasks (particularly around support brokerage and payroll services for direct payment holders employing staff), but they often became involved informally in support planning. Discussions with the SPOs suggested that the experience for the personal budget holders could be enhanced if there were:

- clear referral mechanisms and protocols to and from the local authority with scope to expand the involvement of SPOs
- multiple referral routes to SPOs from all types of community organisations
- outreach activity/'warm-up' meetings set up by SPOs to enhance peer support
- more opportunities for local authorities and all local SPOs to exchange ideas and information, to increase mutual understanding and trust
- a closer working relationship between SPOs and social care practitioners to promote their role and encourage referrals
- an integrated support network available, from which personal budget holders could choose to get support at all stages.

Example

One ULO which provided support to personal budget holders from all client groups offered budget holders 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 personal budget holder). This approach had the added advantage of increasing the personal budget holder's confidence and skills, which could in turn lead to longer-term positive outcomes for the personal budget holder and the wider community.

Monitoring arrangements

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

- clear guidance about what is expected in terms of records and paperwork
- optional training for personal budget holders and carers in 'managing your personal budget'
- having a nominated link person in the local authority direct payment team whom personal budget holders and carers can contact, and who has some knowledge of their case
- not having to keep receipts for small items of expenditure
- clear information about how under-spends will be dealt with
- for those with high personal budgets who are required to have a full audit, different ways of carrying out the audit should be offered e.g. a home visit.



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Conclusion

Overall, the research highlighted a number of key themes and issues for the implementation of personal budgets:

- promoting personal budgets and access to clear information
- integrated working and information sharing with health
- active outreach to marginalised communities through trusted networks and groups
- clear protocols for linking risk assessment and risk management as part of the support planning process
- support plans accounting for carer role and including contingency plans for the individual
- encouraging creativity in support planning and recognising the role of SPOs and ULOs
- improving the supply of support and service providers to enable choice
- maximising control regardless of how the personal budget is managed
- offering choice in the support available to manage the personal budget
- establishing proportionate monitoring systems.
- Acknowledging the central importance of the relationship between personal budget holders and the practitioner who supports them to plan their care and support. Giving staff support, information, training and time to work properly with personal budget holders is crucial.
- Personal budget holders and carers need the freedom to get information, advice and support from other sources, but this should not be at the expense of the continuity that a practitioner can provide.
- Devolving as many aspects of the personal budget process as possible to local teams, SPOs and personal budget holders themselves has the potential to improve staff morale, reduce administrative costs and provide a more flexible and responsive service.
- A successful personal budget process requires a series of effective partnerships between both individuals and agencies, and these take time to establish.

The following advice can be taken to avoid personal budgets becoming too complex and to promote person-centred working:

Further reading

SCIE Report 40: *Keeping personal budgets personal* www.scie.org.uk (March 2011)

Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M., Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report* York: Social Policy Research Unit, University of York.

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