Learning from the experiences of older people and their carers

Key messages

- Many older people see personal budgets as offering them more independence, as well as choice and control. The biggest concerns are managing the money and understanding what it can be spent on.
- Personal budgets can be held in several ways. Personal budget holders need clear information about what is involved – including risk and safety and help with assessment and planning. Knowledgeable staff are particularly important.
- Even with managed accounts and directly commissioned services, every effort should be made to maximise choice and control for the personal budget holder.
- Older people need to have flexible support plans that can change if their circumstances change. Assumptions should not be made about what care and support older people need and want.
- Practitioner continuity, relationship-based working, staff training, peer support and allocated time to work with personal budget holders are important for achieving good self-directed support. User-led and support provider organisations can help with support planning.
- Carers play a central role in enabling many older people to take up and manage a personal budget. Resource allocation should be worked out on the basis of no carer input and adjusted depending on how much support the carer can provide.

Introduction

This At a glance briefing is a summary of older people’s and carers’ experiences of using self-directed support and personal budgets. It is based on a six month study, which also included people with mental health problems. 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). Previous evaluation of individual budgets showed that they could give people a greater sense of control and satisfaction with services, but there were differences in the uptake and outcomes for older people and people with mental health difficulties (Glendinning et al 2008).

The aim of this research was to provide more detailed evidence to inform good practice in personal budget processes. For full details, see SCIE Report 40: Keeping personal budgets personal at www.scie.org.uk

Findings

Moving to a personal budget

Most older people in the study had learned about personal budgets through friends who already had a personal budget, or knew someone who had. Some had heard about them for the first time when they were discharged from hospital to a home care reablement service. For older people in particular, there needs to be a clearer path between reablement and take-up of a personal budget.

Many personal budget holders and carers would have liked earlier information about personal budgets. Key groups of health care staff and service providers should know about personal budgets.

Deciding on a personal budget

A big incentive for older people and carers is being able to arrange care to meet their individual needs and circumstances.
Risk and safety issues are not always addressed during the assessment process. This highlights the need for:

- clear guidance on how issues of risk management are to be included in assessment and support planning
- explicit separation in the personal budget process of assessment of risks to the local authority (e.g. financial risk) and risks to the safety of the personal budget holder and their carer.

Some practitioners are far more comfortable than others in leaving older people to complete their own self-assessment questionnaire. Staff also reported that assessment for personal budgets (especially outcomes-based assessment) demands more time, particularly for older people’s teams where there is normally higher ‘throughput’.

Resource allocation

Different models of Resource Allocation System (RAS) were used across the study sites. Where a generic RAS was used it highlighted some inequalities, particularly for older people. Some staff from older people’s services felt that the financial assessment team was struggling to cope with the volume of referrals.

Most older people were reasonably happy with the amount they had received in their personal budget, but didn’t always understand how this had been calculated. A number of carers (especially those providing ‘round the clock’ support for a person with dementia) were less happy. Several carers and staff members felt that budget holders who received a lot of family support were disadvantaged.

Older people and their carers were likely to have been advised to set aside a budget for contingencies. However, financial constraints in some areas removed contingency allowances. Those with high care needs often only had enough funding to cover their personal care, with little left over for flexibility and social support.

Staff and providers highlight the importance of personal budget holders being able to challenge their budget allocations and the need for independent support or advocacy to do this.
Support planning
Assessment and support planning stages often merge and this is not always seen as positive. A number of personal budget holders did not feel that they had much say in what was included (e.g. with previous packages of care simply being rolled over into their personal budgets). Ensuring support planning ‘templates’ are flexible and that personal budget holders are encouraged to use different ways to express their views is important.

However, a significant proportion of older people were clear about what they wanted in their support plan and felt that this was respected. Most had developed their support plans with their social worker or with help from a local SPO. They found this valuable as it encouraged them to consider different options and to explore ways in which support could be arranged to fit with their circumstances.

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

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
- the opportunity to agree a short-term or temporary support plan
- 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 it is likely to support the personal budget holder in managing their budget
- involvement of practitioners/SPOs in encouraging people to think beyond traditional service models and develop innovative ideas to meet their needs.

Deciding how to hold the personal budget
There are four ways of holding a personal 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 influence the ways in which people can exercise choice and control’

Decisions about how to manage the personal budget can influence the ways in which people can exercise choice and control. The attitude of the person’s social worker and flexibility and creativity in support planning is crucial.

Social workers are often dealing with older people at a vulnerable time in their lives, and many older people may be new to the social care system. Some practitioners do not want to ‘burden’ people with thinking about different ways of managing their care and support and so may make assumptions about what is right for them. However, it may be that personal budget processes are not sufficiently flexible or staff do not understand them well enough to know what to offer.

There is concern that many older personal budget holders are being steered away from direct payments and towards managed accounts or services commissioned by the local authority. Some staff feel 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. Carers may also have concerns about very frail elderly people coping with direct payments on their own. These views often do not take into account the possibility of a third-party
arrangement with a local provider or a review of the personal budget at a later stage.

Decision-making that promotes choice and control can be achieved 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’ older people
- providing information about all options throughout the personal budget process
- making it much easier for personal budget holders to move between budget management options as their needs change or their condition fluctuates
- 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.

Arranging and obtaining support

Older budget holders are more likely than other groups to use their personal budget to pay for regular personal care or help with getting out and about. Many employ personal assistants – usually family members. This is a big step for many but generally works well.

In most of the study sites, domestic tasks such as cleaning and gardening could be funded without a problem, but a few personal budget holders and carers said that they had to negotiate in order to spend part of their budget on these services. Transport, especially the use of taxis, was another area of expenditure that older budget holders often felt unsure about. They were generally cautious about what they spent the money on.

Where there is enough money in the budget, older people and their carers are purchasing a variety of support and services, including residential respite, day services and warden call systems. Some quite creative support arrangements have been put in place, for example, budget holders using funds to have a short break with their family rather than going into residential respite care.

A few older people, who had simply had their existing services 'switched' to a personal budget, 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 personal budget.

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 is not keeping up with people’s changing needs and preferences. There are a number of things which 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
- making it easier for personal budget holders to pool their ‘purchasing power’ to jointly commission 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.

Example: Personal story

Derek, an older personal budget 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 through 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. 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 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.
The role of carers

Carers play a central role in enabling many older people to take up and manage personal budgets. 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 that 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.

Where older personal budget holders are very frail or have dementia, carers often take full or substantial responsibility for managing the financial and administrative aspects of the budget. Many carers were initially concerned about this responsibility. 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.

Management of the personal budget

Many older personal budget holders receive support from a provider organisation, and a number have a managed account with social services and/or support from their social worker. Older people and carers are generally positive about the service provided by support organisations. Where people are less happy, the main reason concerns charging.

People value psychological as well as practical support. Many personal budget 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. They also emphasised the importance of continuity and being able to contact someone who knew their situation.

A number of personal budget holders and carers said that they would have welcomed peer support, especially when they first got their personal budget. The main form of peer support offered is groups. However, budget holders felt this could be offered in a number of ways, including the opportunity to talk to an existing personal budget holder or carer or to be linked up with a ‘personal budget buddy’.

The role of external organisations

All of the local authorities included in the research had a service level agreement with one or more SPOs (including ULOs), to undertake tasks around support brokerage and payroll services for direct payment holders employing staff. However, they often also became involved informally in support planning. The experience for 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 care managers 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.

Monitoring arrangements

Systems for monitoring and audit vary considerably from ‘light-touch’ time-based reviews to systems linked to the size of payment. Personal budget holders and carers suggest a number of things which had or could make monitoring easier:

- clear guidance about what is expected in terms of records, paperwork and how to manage under-spend
- 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
- 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.
Conclusion

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 the 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.

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

- Acknowledging the importance of the relationship between personal budget holders and the practitioner who supports them and giving staff support, information, training and time to work properly with people.
- 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.
- A successful personal budget process isn’t just about what the local authority does. It requires a series of effective partnerships between individuals and agencies, which take time to establish.
- Even with managed accounts and directly commissioned services, every effort should be made to maximise choice and control.

Further reading

SCIE report 40: Keeping personal budgets personal
www.scie.org.uk