

Delivering personal budgets for adult social care: Reflections from Essex

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Contents

Background	1
Aims of this study	1
Positive outcomes are being achieved.....	2
Promoting confidence, capacity and creativity	4
Conclusions and next steps	8

Background

The government's 2006 White Paper *Our Health, Our Care, Our Say* proposed a new strategic vision for adult social care services where service users, as citizens, should be given more choice and control over their support and that care must enhance the independence of service users by giving them more control over how their support needs are met.¹

In December 2007, the government's vision was set out in the *Putting People First* concordant where central and local government, health and voluntary bodies agreed the need for 'a system focused on prevention, early intervention, re-ablement and tailored on-going support services'. Under the new system there is also an emphasis on achieving better outcomes for service users and for making better use of resources.²

Essex County Council (ECC) is at the forefront of such developments to transform adult services, being one of the first councils in the country to implement direct payments for disabled people. It now has more people in receipt of direct payments than anywhere else in the country³. As part of the overall transformation of adult social care, Essex has now introduced self-directed support (SDS) for service users and carers with assessed eligible needs. Since October 2008, instead of a package of support, service users have been offered a personal budget to spend on meeting their social care needs. Service users now have the choice of taking their personal budget either as cash payments in lieu of services, which are managed by themselves or by a third party, or as commissioned services managed by the council, or a combination of these two options.

Aims of this study

The Office for Public Management (OPM), working in partnership with the Essex Coalition of Disabled People (ECDP), has been commissioned by ECC to do a three-year study looking at the impact of personal budgets taken as cash payments by older and disabled people and their families (referred to in this paper as either 'cash payments' or 'self-managed personal budgets'). The study is also designed to gather evidence on the effectiveness of the practices and processes designed to deliver personal budgets across the county.

This paper reflects on some of the issues raised through face-to-face interviews conducted with 46 older and/or disabled people who are receiving cash payments and/or interviews with their relatives. These were conducted between November 2009 and January 2010.

The 46 service users who are participating in this study include:

- 25 older people
- 13 disabled people with physical and/or sensory impairments (PSI)
- eight service users with learning disabilities (LD).

¹ Cited in Self Directed Support Strategic Policy (SDS SP) 2008, ECC, p. 6.

² Cited in Self Directed Support Strategic Policy 2008, ECC, p. 7.

³ As noted by CSIP:

<http://www.kc.csip.org.uk/viewdocument.php?action=viewdox&pid=0&doc=34537&grp=601>

However, it is important to note that of the 46 interviews, only nine of these were conducted with the service user on their own. A total of 12 interviews were conducted with both the service user and at least one family member present, with questions answered by service users themselves and their relatives. But 25 interviews were conducted with relatives on their own where the service user was not present at the interview. As such, a number of the findings presented from these interviews are not the views of service users themselves, but are based on the views of the relatives who helped them to set up their personal budget and are now helping them with the ongoing management of their cash payments. This raises important questions about the types of people who choose to manage budgets or have budgets managed on their behalf, with attendant implications for experiences and/or reported outcomes. These are discussed in the sections below.

In addition to the interviews conducted with those who were managing their own cash payments, in August and September 2009, a further four interviews were conducted with older service users whose personal budgets were being managed by the council. These interviews were designed to find out whether older service users were consistently being offered the choice of whether or not to self-manage their personal budgets.

The following sections present findings and reflections primarily based on the 46 interviews with service users and/or their relatives, as well as a smaller number of findings from interviews with older service users whose personal budgets were being managed by the council.

Positive outcomes are being achieved

The majority of service users interviewed for this study had only been receiving cash payments from their personal budgets for a couple of months at the time of the interview, and a small number had not started receiving payments at all. For some service users it was, therefore, too early to identify any positive changes to the quality of their lives as a result of receiving their cash payments. Nevertheless, those who were purchasing services with their payments (both service users and their family members) tended to express satisfaction with the services they were purchasing and noted examples of positive impact as a result, including a feeling of being treated with greater dignity and feeling a reduced sense of loneliness as a result of increased opportunities for social interaction. Importantly, positive outcomes were reported by a range of service users, including older people, people with physical and sensory impairments and people with learning disabilities.

The level of support which service users received from their relatives varied from moral support to their relative taking on full day-to-day responsibility for setting up and managing the cash payments on their behalf. In these cases, some service users were unaware that they were receiving a personal budget and it was their relatives who had wanted to exercise greater choice and control by choosing cash payments on their behalf. Nevertheless, even where service users were unaware that they were receiving a personal budget, they could still identify positive outcomes as a result of the services being purchased by their relatives through their personal budget payments.

For a number of service users and family members, an important outcome of their cash payments was the fact that they – or their relatives – were receiving services at all. Where service users would have refused council-managed care, for example, because they did not want the types of services the council commissioned, they would have had no services at all.

In such cases, cash payments had enabled them to access support rather than them having to cope on their own.

Interviews suggest that self-managed personal budgets are helping service users and their families to purchase more tailored services, including being able to establish flexible arrangements with service providers. A number of service users reported being able to exert more control over their lives and do more of the things they wanted to do because they could decide when and how providers delivered services. Many interviewees explained that the services they were purchasing were based on their lives and needs. For service users who described this outcome, this was not simply a greater sense of control, but an important means of being able to retain – or in some cases regain – a sense of self and an ability to shape their lives around who they are and what they like to do. For some this was as simple as being able to choose what time they wanted to go to bed.

Furthermore, some service users said they felt they were being treated with greater dignity and respect because they could choose the individual who was providing them with intimate care. There were also examples where service users were purchasing services from agencies but could request specific people if they needed a particular type of care that week. This personalised service was described by service users as helping them to feel more in control – and to receive the type of support they needed.

Interviews also highlighted evidence of wider impact on families, in particular being able to choose providers and to change them if there was a problem, which gave relatives greater peace of mind, meaning that ‘respite really was respite’. Feeling more confident about the quality of the services being provided meant that a number of relatives said they could now relax and have more free time. Some of the family members interviewed also felt that they could now enjoy more time with their relative rather than just providing them with care.

In addition, some service users also felt that managing their own budgets had had a positive impact on the power dynamic in their relationships with service providers. Some service users believed they had greater leverage to negotiate with providers about when and how services were provided, and the ability to cancel services if they felt they were not delivering what they had promised. For example, a number of interviewees who were using their cash payments to purchase services from larger agencies felt that paying their provider directly had already affected the way their providers viewed them – and ultimately on the quality of the services they received. Some service users and their relatives explained that as managers of their own personal budgets they felt providers treated them more as private customers and had a sense of the loss of business they could incur should they under perform. This appeared to be the case even for a service user who had previously received services from the same provider under council-managed services and felt there had been a change in their provider’s attitudes and behaviour because the service user was now in control of payments.

However, it is important to note that some service users felt that although the ability to change providers might be there in principle, in reality the lack of affordable providers – or information on them – means that service users may have little option but to stay with a provider, regardless of the quality of the service they provide. For a number of people, even if they were currently happy with the provider they had found, they were conscious that if they had any problems they didn’t know where they would go to find an alternative provider.

Promoting confidence, capacity and creativity

Evidence of positive outcomes for service users who are receiving cash payments emphasises the need to consider how others can be encouraged to choose cash payments instead of council-managed services. Interviews for this study highlight the importance of service users having the confidence to opt for managing their budgets themselves, perceiving themselves to have the capacity to do so and having a sense of creativity to use their payments in innovative ways to maximise positive outcomes for themselves and their families. Interviews were used not only to explore reasons why people wanted cash payments, but also reasons why they felt confident in their ability to manage them. This revealed a number of factors that influenced people's initial decision to opt for cash payments and subsequent decisions about how their budgets should be spent.

Findings from interviews with service users and relatives who are managing cash payments suggest that a combination of personal resources, including skills and knowledge and support from social networks, as well as external factors, in particular, ideas and guidance from frontline staff, play an important role in shaping the degree of choice and control available to service users and their families, the practical decisions they make and ultimately the outcomes they achieve.

The following reflections are designed to contribute to discussions about the types of support people might need if they do not have access to the skills and social networks outlined below, and to discussions about the role of frontline workers in strengthening people's confidence in being able to manage their personal budgets themselves.

Relationships matter: family support and broader social networks

Interviews indicated that improving opportunities for social interaction was an important factor in motivating people to choose cash payments in the first place. Considerable emphasis was placed on being able to choose people with particular personalities and interests to provide services.

For many, this initial motivation is being achieved, with a number of interviewees illustrating the social benefits resulting from the fact they were managing their own budgets. This was most clearly illustrated by those who were employing personal assistants and had selected them partly on the basis of shared interests and personality types. However, service users and family members also highlighted the potential for even basic care services such as carers, cleaners and personal trainers to present opportunities for service users to engage with someone socially and to make new friends. A number of service users and relatives who were spending their payments on basic care services felt that by being able to choose their provider, visits by the provider had become opportunities for social interaction rather than just having service users' basic needs met. Service users and their families described the impact of this social engagement in terms of improved self confidence and greater independence, as well as a reduced sense of loneliness, particularly among older service users, as a result of having regular visits from someone they got on well with.

However, interviews also emphasised the two-way dynamic in the relationship between personal budgets and social networks: while on the one hand, personal budgets can be used to enhance social networks and increase opportunities for social interaction, on the other hand, interviews also highlighted the importance of existing networks and close family

relationships both in encouraging take-up of cash payments and influencing the way they are used.

In addition to the role played by a number of relatives in decision making on cash payments, interviews also suggest that confidence and perceived capacity to manage a personal budget was also influenced by whether service users (or their relatives) believed they had access to social networks through which they could identify people they could pay to provide services. Service users and their relatives tended to feel they had limited purchasing power within the market for social care services because the rates being charged by many companies were higher than their personal budget allocations enabled them to spend. Those who felt their only option was to purchase services from agencies tended to believe the issue of rates significantly undermined their ability to exercise choice and control in identifying ways to meet their needs. However, this was far less likely to be felt by those who were able to purchase services from individuals. While for some these individuals could be identified through advertising, many others had identified individuals by looking to their existing social networks.

In some cases, service users knew they wanted to employ a particular contact early on in the process of arranging their personal budget, but the majority had identified them once they started to let people know they were looking for someone. These were therefore not just close family or friends, but members of their extended social networks, who they identified through colleagues, neighbours and friends-of-friends. Those who had access to such networks to identify people they could employ were at a distinct advantage to those who did not, both in terms of the ease with which they could find providers, but also in terms of being able to think more creatively about ways to spend their personal budgets because they did not have to pay agency rates. As such, service users with strong social networks appear, in many cases, to be better placed to get more from their personal budgets than those who do not.

Furthermore, for service users and relatives who sought to identify a company to provide services, one of the major frustrations was their inability to judge the quality of the services until they were in place. Many service users had relied on professional or personal contacts to provide informal recommendations about which service providers they should use. This reliance on informal recommendations and advice, although seeming to work well for those who had access to it, again highlights the advantage people are at if they have access to social networks that can provide them with this type of information. It also raises important questions relating to safeguarding, with many of those who did not have access to this informal advice feeling they were taking a 'stab in the dark' and having to select providers based on very little information.

Skills, knowledge and a sense of rights

Overall, service users and/or their relatives tended to express a strong sense of rights and entitlements and often explained that they were used to being proactive, assertive and making complaints to get access to the services they needed in a range of sectors, not only adult social care. Importantly, almost all interviewees went on to explain that they felt they needed to be very confident and assertive during the process of arranging their personal budgets, with many feeling that the system had been designed with an implicit requirement for them to do so. Interviewees felt this was particularly the case in terms of articulating their needs and dealing with delays during the process of setting up their personal budgets, as well as on an ongoing basis in negotiating with service providers.

Interviewees also described the skills that they identified as having given them the confidence to believe they would be able to manage their budgets themselves. Again, this was a mixture of service users themselves and relatives who helped them manage their cash payments. In particular, many interviewees felt they had strong administrative and IT skills which they needed to draw on to manage their payments effectively. While many people felt they needed at least basic computer skills, for example, to keep spreadsheets and print invoices, by far the most common skill people said they needed was to be able to use the internet. For example, for those who did not have social networks they could use to identify service providers, the internet was viewed as an essential searching tool.

Many older and disabled people are now using the internet, but it is important to bear in mind existing evidence that not only are older and disabled people less likely to have access to the internet than younger and non-disabled people⁴, but also that a large number of websites are inaccessible⁵. It is therefore important to consider the potential choices realistically available to service users without computer skills or access to the internet – or friends or relatives who could help them with this.

Ideas and encouragement from frontline staff

The skills and personal support people have are clearly important in determining whether or not people choose cash payments in the first place and subsequent decisions about how they spend them. Interviews also highlighted the important role played by frontline staff, in particular social workers, not only in introducing the idea of cash payments to service users and relatives, but also providing them with support and encouragement to feel they could manage them themselves.

Unsurprisingly, the vast majority of the service users and family members we interviewed had been first introduced to the idea of personal budgets – and the option to manage cash payments – by council staff, most commonly by a social worker. However, a handful of people had heard about personal budgets through other sources, for example, a number of older people had initially been aware of direct payments, which they had heard about through friends or relatives.

In addition, a small number of people with physical or sensory impairments had been told about personal budgets by medical staff, for example, their district nurse. Although these represent only a small number of people in the overall sample, the fact that it was only younger disabled people who had heard about cash payments this way may reflect some of the preconceptions medical staff have about which groups of people are best suited to managing their own budgets.

⁴ For example, data from the British Social Attitudes Survey show that between 2005 and 2006, the proportion of households with access to the internet remained stable at 49 per cent among households where someone is disabled. At the same time, the figures increased from 66.8 per cent to 71 per cent among households where no one is disabled. For full discussion see <http://www.natcen.ac.uk/study/british-social-attitudes-26th-report/findings>

⁵ A formal investigation by the former Disability Rights Commission (DRC) in 2004 reported that 81 per cent of the 1,000 websites tested failed to satisfy the most basic Web Accessibility Initiative category. For full discussion see 'The Web: Access and Inclusion for Disabled People. A Formal Investigation Conducted by the Disability Rights Commission', DRC, London

The idea that the choices available to service users are mediated through the judgements and informal decisions made by professionals is also apparent through discussions with interviewees about the role of social workers. Many service users and relatives explained they had felt positively encouraged by their social worker to manage their own budget and were not only told it would be the best option for them, but also felt they had been encouraged to feel more confident in their ability to do it. This suggests that frontline staff such as social workers can play an important role not only in explaining personal budgets to service users and their families, but also in strengthening their confidence in their ability to self manage them. Reassurance is clearly an important part of social workers' role to encourage service users to imagine alternative ways of doing things.

But for almost a quarter of the service users and relatives interviewed, managing cash payments had not been an active choice - they had simply been told by their social worker that 'this is the new way of doing it' and that having services managed by the council was not an option. Half of those who said they had not been given a choice were relatives of service users with learning disabilities. A far smaller proportion of older people and service users with physical or sensory impairments said they had not been given a choice. While it is not possible to assert why this is the case with certainty, interviews with the families of service users with learning disabilities often highlighted that there was either a complete lack of age-appropriate services in their local area, or that the services which did exist were designed to meet the needs of people with very different types of impairment or different degrees of severity. Relatives of younger service users with learning disabilities also expressed a clear need for them to spend time with people their own age, doing 'normal things young people do'. It is possible, therefore, that in such cases, frontline workers may have decided that self-managed cash payments were the best or 'only' option for them, and therefore felt there was no need to explain alternatives.

Conversely, in all but one of the four interviews we conducted with older service users receiving council-managed personal budgets, service users and relatives had not been told that there was an option to receive their personal budgets as cash payments. This suggests that frontline staff may be making judgements about who to offer which choices to, using informal assessments of risk which are based on perceptions of needs and vulnerability about who they think will be more likely to benefit from - and be able to manage - cash payments.

Although frontline workers have not been interviewed as part of this study, interviews with service users and their families suggest that even for those who had been offered a choice - and had chosen cash payments - the amount of freedom they had to decide how they wanted their needs to be met varied considerably depending on the guidance and advice they received from frontline staff, most commonly their social worker. There were a number of service users and relatives who were managing cash payments but were spending them on traditional services and appeared to have exercised relatively little choice in selecting the types of services they wanted to purchase. In such cases, frontline workers had tended to present their support plan to them in terms of the number of hours of traditional care they could purchase, and had set fairly limited parameters for how payments were 'allowed' to be spent. Importantly, the perception of many of these service users and relatives was that the frontline staff they had contact with seemed unsure about the rules relating to cash payments and tended to place heavy emphasis on the risks associated with them.

Service users and family members explained that while in many cases frontline staff appeared confident in selling the initial idea of cash payments, they felt they often struggled

to explain the 'nuts and bolts' of how they work. It is possible that where frontline staff lack clear guidance, for example, about how cash payments can be used, they develop a heightened sense of risk which means they err on the side of caution – and stick to traditional ways of doing things – for example, conceptualising personal budgets in terms of numbers of hours of care and encouraging service users to stick to well-known providers of traditional services.

Conversely, where interviewees felt that frontline workers had displayed a clear understanding of how cash payments work and greater confidence in supporting them through the process, they had tended to play an active role in making innovative suggestions to service users about how their money could be spent. There were a number of examples where frontline workers had encouraged a sense of ownership and creativity among service users and their families during the support-planning process. In particular, where social workers had provided tangible examples from other people's support plans, service users and their relatives not only expressed greater clarity over how their payments could be spent, but had also developed support plans that included non-traditional services.

Conclusions and next steps

- Interviews so far suggest that contrary to much discussion among practitioners, researchers and policy makers to-date, the appropriateness of self-managed budgets cannot be determined by age or impairment type but that more accurate predictors of take-up of self-managed budgets may be the confidence of service users based on their own sense of rights, their skills and the support they have from close relatives and wider social networks
- For older service users and those with learning disabilities, family members often played a central role in making the initial decision of whether or not to opt for cash payments. This raises a number of practical implications, including the possible need to treat family members as one of the target audiences for awareness raising activities and support for managing cash payments. It also highlights the need for further reflection on the role being played by family members during the process of setting up and managing a personal budget and to explore the need for brokerage and on-going management support to service users who do not have this type of support available through personal relationships. In addition, the reliance on informal recommendations from wider social networks also emphasises the need to find ways of providing alternative support mechanisms and identifying reliable sources of advice for service users who do not have access to these informal sources
- The fact that the people who are among the first to embark on something as new as self-managed personal budgets appear to be confident and assertive is perhaps not surprising. But it is important to consider how well systems to deliver personal budgets – and the support mechanisms attached to them – would work for someone who was not assertive and confident, and did not have support from friends or relatives. Also, the perception among service users that certain skills – in particular IT and administrative skills - would be needed to manage their own budgets could deter those who feel they do not have such skills from choosing cash payments. This highlights the need for closer examination of what skills are actually needed in setting up and managing cash payments and how those who feel they do not currently have these skills can still realistically manage their personal budgets

- It also appears possible that service users are not the only ones making judgements about what they are capable of. Interviews suggest that frontline staff may be making implicit assumptions about which service users are capable of managing cash payments, which may influence not only the way they offer choices to service users, but in some cases whether they offer them certain choices at all. This has significant implications for the roll-out of personal budgets in terms of which people are offered cash payments and given the opportunity to access services that are not commissioned by the council. While there are issues about confidence, skills and family support that many service users say they need to manage their own budgets, if these are not explicitly recognised and addressed, it is likely that frontline staff will continue to make informal assessments of capacity and risk, taking on a gatekeeper role, possibly in an attempt to protect themselves and service users.
- 'Choice and control' is a term now widely used to explain personal budgets, but a lack of clarity over what it actually means in practice in terms of the decision-making power available to service users can leave it open to interpretation by individual frontline staff. To some extent, this is an issue of communicating information and clarifying processes to staff. However, it also has a 'hearts and minds' aspect, and relates to attitudes among staff and interpretations about what 'choice and control' means at a practical level. These attitudes and beliefs can then be passed on to service users, affecting the level of freedom they have to assess their own needs and identify the most effective ways they feel they can be met. As such, frontline workers who are helping people to develop their support plans can act as either barriers or enablers in terms of opening up or closing off the space service users have to think creatively about how best to use their personal budgets and maximise positive outcomes for themselves and their families. This emphasises the importance of ensuring frontline staff are not only confident in explaining the principles underpinning self-directed support, but that they are clear about what choice and control means at a practical level at each stage of the process of delivering cash payments. It also prompts reflection on the amount of face-to-face time frontline workers will need to spend with service users to encourage creativity in developing support plans that are designed to have a positive impact on their lives.

What next?

The second phase of interviews for this study will take place in September 2010, with subsequent interviews in the spring and autumn of 2011. Following each phase of interviews, findings are being captured and fed back to staff in Essex County Council to facilitate internal learning and improve their systems of delivering personal budgets.

Reflections will also be shared more widely, along with experiences of what it is like to receive cash payments over the longer term. Annual interviews are also being conducted with a range of service providers to capture evidence of whether – and in what ways – the market is evolving to meet the changing demands of service users as a result of cash payments.

More information

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