Briefing paper 1: Positive impacts of cash payments for service users and their families

Findings from the second round of a three-year longitudinal study in Essex

ecdp

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Introduction

In 2008 Essex County Council (ECC) commissioned OPM and ecdp to do a longitudinal study of people receiving cash payments for adult social care within Essex. The study provides a unique opportunity to fully understand the experiences of people living with a personal budget over a three-year period, and also to engage with stakeholders from the council and the wider service market who are working to facilitate self-directed support within the local area.

The study has two main objectives:

1. To capture the **impact of self-managed cash payments** on the lives of people who use them, including evidence of how and why impact is being achieved over time
2. To assess the **effectiveness of practices and processes** being used by ECC and its partners to support the delivery of cash payments, including evidence of how the market is evolving over the study period

This is one of a series of briefing papers containing findings from the second annual round of research with service users, frontline practitioners and providers in Essex. These brief papers have been produced to share key findings with audiences involved in personalising social care, including practitioners, managers, commissioners, service providers and policy makers.

Other papers in this series include:

- Briefing paper 2: Understanding demand
- Briefing paper 3: Developing the service provider market
- Briefing paper 4: Attitudes to risk in spending personal budgets
- Briefing paper 5: ‘In our own words’ – the impact of cash payments on service users and their families

For copies of any of the above or for a copy of the full report, which contains details of our findings, please email Sarah Holloway at OPM. ([sholloway@opm.co.uk](mailto:sholloway@opm.co.uk))
Key points

- Service users are experiencing a greater number of positive outcomes after a year on their personal budget, including an improved quality of care, an increased sense of control and increased opportunities for social interaction.
- In accessing support through personal budgets, service users report they can gain a higher quality of care than has traditionally been available via council-funded services. Support is also more flexible and tailored.
- Some service users find that cash payments incentivise providers to give a better level of service, and that this can hold for both small and micro enterprises and some larger agencies, though there remain some that are not delivering a personalised service.
- A number of service users reported that, since the introduction of their personal budget, they have experienced a greater level of control over their lives, leading to additional positive impacts on their emotional health and well-being.
- Particular types of service accessed through a cash payment support greater independence for service users, which is associated with a string of further positive impacts for confidence and self-esteem.
- Among all groups of service users there is evidence that services purchased via cash payments are helping to reduce loneliness and isolation. This is particularly strongly evidenced where service users have employed personal assistants, but is also notable in general that cash payments provide a greater chance of a personal relationship emerging between service user and carer and therefore of decreased isolation.
- A number of those interviewed for the study, primarily those with physical and sensory impairments (PSI) and older service users and their carers, noted that family relationships had improved since the introduction of cash payments.
- For all of our findings, it is also important to note at the outset that there is evidence of older service users, service users with learning disabilities and with physical and sensory impairments experiencing positive impacts in all outcome areas.

Overview

In our first round of interviews for this three-year longitudinal study, conducted in late 2009, service users had only been receiving their cash payments for a few months, yet some positive outcomes were already being experienced. One year on, we can evidence a greater number of positive outcomes.

While these outcomes vary from person to person, they can be grouped into the following five areas:

1. Improved quality of care
2. Increased sense of control
3. Improved emotional well-being
4. Increased opportunities for social interaction
5. Improved family relationships.
These areas are interlinked in several ways, with some outcome areas being consequences of others. They are discussed in turn below to emphasise the breadth of impacts.

It is also important to note at the outset that there is evidence of each user group – older service users, service users with learning disabilities (LD) and with physical and sensory impairments (PSI) – experiencing positive impacts in all five of these areas. As such, these positive impacts are not limited to a specific user group. We have indicated where a particular user group is strongly associated with a particular impact.

1. Improved quality of care

Service users are reporting they can gain access to a higher quality of care through the cash payment system than has traditionally been delivered via council-funded services.

More flexible and tailored support

Using cash payments, service users can access support that is flexible, and better tailored to their individual needs, both physical and emotional. A key benefit of purchasing services via cash payments is the flexibility that this arrangement can offer. Purchasing, rather than simply receiving services, enables individuals to set a routine which suits them, and their families’ lives, rather than having a routine imposed on them. In some cases, where a service user has a fluctuating condition, individuals can choose to do away with care routines altogether and opt for highly flexible arrangements, only accessing care on an ad hoc basis.

The quote below, from a PSI service user who uses the budget to pay for respite care to relieve her husband (and primary carer), is a powerful illustration of the value of a cash payment, and its ability to respond to fluctuating circumstances:

‘I can just say to her [carer]: OK, why don't you come round here an extra couple of hours this week? I can see something's getting to him and something's bothering him. So just come round here an extra day this week, you know?’ (PSI service user)

Positive relationship with providers

Some of the service users and families in our study report receiving better levels of care, which is attributed to having a direct relationship with providers. Some of those interviewed believe that the cash payments system incentivises providers to give a better level of service to keep their custom. For example, some reported that they were less likely to have to put up with ‘no-shows’ from care providers. Similarly, they were more likely to receive services from the same individual, allowing a more personal relationship to emerge between carer and service user. In other cases, service users report instances where carers have acted beyond the call of duty. Carers have offered to make emergency visits to individuals, e.g. on Sunday, outside of their normal working hours, and to run impromptu errands, e.g. taking a service user’s pet to the vet.

‘The manager will even help out when things are tough, like at the weekend. One time we couldn’t get mum off the commode – she was too heavy. And she came out at eight in the morning.’ (Daughter of older service user)

In one instance, where a service user was taken into hospital, the carer offered to drive the service user’s husband to hospital to visit her. This was a paid for service, but recalling this incident, the daughter of the service user remarked that it was above the level of what she
would have expected from a care agency, and a council ‘bank’ carer would not have had the flexibility to offer this.

There may be an assumption that personalised care is best provided by individuals who know the service users already or who are contracted by small and micro enterprises. But there is some evidence that the larger agencies are equally capable of offering a personalised relationship and service to individuals. The quotation below refers to one service user’s experience of Essex’s largest care agencies:

‘I mean you can’t say they’re friends because they are professionals but really, they make you feel so comfortable. I mean they’re lovely to me as well, you know.’ (Husband of older service user)

But it should be noted that there are also a number of agencies that will fail to meet these standards. The mother of one LD service user feels as though the agency she is currently contracting knows that that there is little local competition, and as such they do not make the effort to provide a good quality or tailored offer.

2. Increased sense of control

A number of service users and their families report that since the introduction of their personal budget, they experience a greater level of control over their lives, which in turn can lead to additional positive impacts on emotional health and well-being – explored in section 3 below.

Control over their own lives

When asked to identify the key points about personal budgets which they would want to advertise to other service users, many service users single out ‘control’ ‘autonomy’ and ‘independence’.

For some individuals just knowing that they are in the driving seat and can control their own care is a positive thing. Indeed, becoming dependent on care services is often associated with a loss of control and autonomy for both the service user and their family, and so there is particular value in transitioning to personal budgets, which can bring back an element of control to individuals who feel it has been lost to them:

‘Oh yeah, it gives you a sense of freedom, just from a psychological point of view. It definitely has a ripple effect. It’s about not being dictated to, and having the ability to change, should the wish arrive.’ (PSI service user)

In more practical terms, cash payments can enable families to make important decisions for themselves, which would otherwise be decided for them. For example, can an older relative stay at home or will they have to enter residential care? Can a young person with learning disabilities move out of the home to live independently or will they have to stay in the family home? Having access to tailored and high quality care and personalised respite services opens options that would otherwise be out of reach to services users and families:

‘We wouldn’t have been able to cope with it and she would have had to have gone in to care so it’s made an enormous difference to her and … us.’ (Son of older service user)

However, it is important to consider that some service users may not experience an increased sense of control, as they may be subject to the decisions of the family member who is managing their budget. It is difficult to draw conclusions on this from our study, given
that in cases where the budget is managed by a family member it was not always possible to capture the views of the service user independently.

Practitioners responsible for introducing cash payments need to take a view on the best way to ensure service user control for those not directly managing their own budget. Furthermore, the sense of control experienced by service users can be limited if decisions made by commissioners or practitioners as to what is considered legitimate in terms of spend are unclear or inconsistent. Should service users feel their support plan choices are unreasonably denied, the sense of control will be quickly eliminated.

**Control over types of services, providers and individual carers**

Service users and carers are making informed choices about the types of services being purchased. The cash payment system allows them to, if appropriate, select non-traditional options, such as live-in PA support and access to leisure activities over traditional residential care and day care. Similarly, service users are able to exercise control, both in choosing the provider and/or individual with whom they work. In a number of cases service users and families have exercised their ability to request a different member of staff, to ensure they receive the best possible care for an individual in question:

‘I've been able to have the carers that I want for my son and that I'm happy with, because when I've spoken to people before that are in the system, that are on the old style then there's carers that have been sent that they weren't happy with and they didn't like at all.’

(Mother of LD service user)

But it’s important to underline that the potential of the cash payment to provide control to service users can again be severely undermined where there is an underdeveloped market of service providers. If the market is not sufficiently diverse, service users can feel forced to accept poor standards of service to not upset their relationship with a provider on which they depend.

**3. Improved emotional well-being**

**Self confidence and self-esteem**

Particular services can support greater independence for service users. This is perhaps most clearly illustrated by those receiving PA services who are supported to do things, such as errands, or even leisure and socialising, without relying on family or primary carers. Indeed, for younger LD service users, this independence is felt to be critical to their personal development, to give them the opportunities to experience life in ways that other young people do. The following quotation underlines the value of the PA service purchased via a cash payment in terms of boosting independence for a young woman with learning disabilities:

‘I think it's made her a lot more independent. It's done her brilliantly going out with the PAs hasn't it? Yeah, it gives her much, much, much more confidence and self-esteem.’

(Mother of LD service user)

As suggested in the quotation above, the ability to act more independently, and to make individual choices, is associated with a string of further positive impacts for confidence and self-esteem. Service users and their families note improvements in levels of self-esteem before and after receiving tailored services via cash payments. Again, this outcome is most obviously evidenced for young LD service users, as in the example below:
‘She is more outgoing, which she wasn’t before… confident is the word I was looking for. She’s more confident in lots of things. Where before she wouldn’t sort of say anything, she would just obviously sit it out you know, now she give her own views. So it’s really positive.’ (Mother of LD service user)

That is not to say that this outcome is limited to LD service users. The quotation below is from an older service user who opted to take a personal budget to be able to choose carers of her own age, with whom she could develop a personal and supportive relationship. For this individual the relationship has improved her confidence and appetite for independence:

‘They give me a lot of confidence to do things on my own.’ (Older service user)

Dignity and respect

Where individuals are able to pay for services that they otherwise had to rely on friends and family to provide for free, this can lead to a revival in terms of their own self-respect and sense of dignity.

This outcome is particularly well-evidenced among PSI service users. Individuals feel less of a burden on friends and families, either because they are actually able to rely on them (and instead purchase trusted services from external providers), or else because they are able to pay friends and families, which legitimises the arrangement and introduces more equity. The quotation below is from an individual who uses the personal budget to pay friends and family to provide care support:

‘Not sort of being a burden is the bottom line of it. Otherwise, you do feel like a burden and now with the budget, I think that’s taken that away. You can instruct, shall we say. It gives you that power doesn’t it?’ (PSI service user)

Greater sense of self

Cash payments can help service users to pursue their own interests, and can operate as a platform from they can access opportunities which help them to develop a stronger and more positive sense of themselves. The cash payment works to support service users’ sense of self in a way that council services are less likely to be able to do, since they can be infinitely responsive to individual needs.

‘This budget gives her some interests and some fun. There are things to look forward to. It gives people the ability to do what’s important for them as individuals. The council traditionally supply care, but they don’t supply wellbeing’ (Son of older service user)

And positive impacts around emotional well-being can also extend to family members, particularly where the personal budget can pay for them to take respite from caring duties and pursue personal interests and occupations.

‘Believe you me, it's surprising, it's made a difference to me, more than anything. I can actually then do things like I used to. I'm a very helpful person, I fix cars and I do building work and stuff like that. I love working with my hands and that's my relax time. So I've been able to actually have a bit of that time.’ (Husband of PSI service user)

4. Increased opportunities for social interaction

Among all groups of service users there is evidence that services purchased via cash payments are helping to reduce loneliness and isolation. This is particularly strongly
evidenced where service users have employed PAs, but is also notable as an impact of domiciliary care and general home help. Even if the primary aim of the service is not befriending or socialising, the fact that the service user has the ability to choose the individual giving the care means that there is a greater chance of a personal relationship emerging and therefore of decreased isolation.

One service user employs a range of three or four live-in PAs, who provide him with not only physical support but valuable companionship. He values being able to choose the PAs he works with, and he believes compatible personalities/interests have been the basis for their positive relationship.

‘For me someone with mutual interests is useful so you’ve got some level of conversation or mutual interest, mutual tolerance. Personally I like to eat with my companion so preferably a similar palate, although my palate is pretty broad.’ (PSI service user)

And there is also evidence of service users gaining access to social networks that extend beyond just the PA. In one case an LD service user also socialises with the family of her PA. And in another case, the PA of a PSI service user will often bring their friends back to the house, offering further opportunities for socialising with a wider social network.

5. Improved family relationships

A number of those interviewed for the study, primarily PSI and older service users, and their carers, noted that family relationships had improved since the introduction of cash payments.

In cases where the personal budget allows for an increased amount of care, family members are freed up to take more ‘time off’. In this context, it is particularly important that the care being provided is known and trusted, so that individuals feel able to leave their family members in safe hands.

In one instance, the partner of a disabled service user has been able to return to work since the personal budget has been in place. This obviously has knock-on implications in terms of the household income, as well as the partner’s sense of self. Further, a parent with a reduced burden of care is freed up to look after other siblings and pays more attention to other relationships within the family that may have suffered.