



**PERSONAL BUDGETS AND THE CARER- SERVICE USER
RELATIONSHIP: DEVELOPING THE KNOWLEDGE BASE ABOUT
CARERS AND PERSONALISATION**

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July 2013

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Registered office: 1 Beech Avenue, Sherwood Rise, Nottingham NG7 7LJ
Registered number 3123142
Registered charity number 1050779

Carers Federation Limited has achieved ISO9001: 2008 quality accreditation.



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Executive summary

Between September 2011 and January 2013 the Carers Federation Ltd funded a study with the objective of making a productive contribution to the emerging knowledge base about carers and personalisation by exploring a hitherto under-researched key issue - the carer-service user relationship. The focus was on developing better understandings of how a change in a service users' social care arrangements to a personal budget affects the carer-service user relationship. The rationale for this focus was:

- the centrality of this relationship to the delivery, quality and experience of care in general *and* within a personalised approach to service delivery
- the few studies that have been carried out indicate that personalisation can change this relationship . Given that this relationship is at the heart of the caring process, these changes require further exploration in order to ensure the successful implementation of personalisation
- personal budgets will impact on the lives of an increasing number of carers

The study was carried out in collaboration with De Montfort University, Leicester and was designed to address some of the limitations of existing studies about carers and personalisation in that it focused exclusively on exploring carers' perspectives and was carried out in several different local authorities. The first stage comprises 23 semi structured interviews with carers in 11 English local authorities who were in a long-term dyadic relationship with an adult in receipt of social care who had changed to a personal budget. These interviews were transcribed and thematically analysed using inductive coding. The second stage involved triangulation of the summaries of the themes in two forums; one was with the Carers Federation Trustees and another was at a meeting of a Local Authority Carers Lead Officers Network.

The themes that emerged centred around two main areas – the carer-service user relationship and carers themselves. These, together with their sub-themes are set out below:

1. The impact of the service user's personal budget on the carer–service user relationship

(a) Less control within the caring relationship

35 per cent said it was hard to cope with having less control within the caring relationship and talked about

- feelings of being 'pushed' out and 'redundant'
- worried that someone else does not know "what to look out for" and cannot cope with complex needs

However, these feelings did ease with time and if carers had confidence in the staff employed.

(b) *Enhanced personal relationship*

56 per cent felt that personal budgets had enhanced their personal relationship because they:

- were more relaxed with each other
- had more independence as individuals
- had more control over their lives

Those in spousal type relationships felt they "can be a couple" because they:

- have more time to do activities together
- can pursue interests together
- can socialize together

However, the age of the service user as well as or in addition to their illness or disability limited the extent to which the quality of the relationship improved.

2. Carer findings

(a) *Positive outcomes for carers*

78 per cent were happier because:

- they had more freedom and time to themselves
- they could pursue their own interests
- the person they cared for was also happier
- they felt healthier

(b) *Negative outcomes for carers*

56 per cent felt personal budgets were stressful to administer

- particularly at first
- paper work, recruitment and staff management were the most problematic
- 47 per cent reported inadequacies in the level and nature of support provided by their Local authority

BUT

- some of these difficulties had eased over time
- previous employment expertise helped
- 40 per cent used other services to support them with managing the personal budget e.g. Third Sector Organisations, broker services

This is the first study to focus exclusively on the carer - service user relationship and although it was relatively small-scale, analysis of its findings in relation to existing studies, showed it developed the evidence base about the impact of personal budgets on this relationship and on carers themselves, thereby simultaneously developing the knowledge base about carers and personalisation. It also led to recommendations for practice and further research which are included at the end of this report.

Background to the study

Carers are at the heart of the caring process, and their importance to successful implementation of personalisation has been consistently acknowledged (Newbronner *et al.*, 2011; SCIE, 2012; Welch *et al.*, 2012). With reference to personal budgets in particular, it has recently been argued that “carers play a central role in helping many personal budget holders to take up and manage their budgets”, and that “carers should be involved on all stages of the personal budget process” (Newbronner *et al.*, 2011: 66). However a review of the published research carried out since the strategic shift to personalisation shows that, until recently, carers have received relatively little attention compared to other groups affected by the changes introduced (Author’s own, 2011, Glendinning *et al.*, 2013). Furthermore, this body of research does have several limitations:

- *most of the studies have been carried out within a particular local authority and therefore only reflect carers’ experiences in one authority*
- *few studies have focused exclusively on carers and hence the findings about them tend to be incidental to or only part of a main study*

(Larkin and Dickinson, 2011; Jones *et al.*, 2012; Moran *et al.*, 2012; Mitchell *et al.*, 2013).

Nonetheless, the evidence from these studies does constitute a nascent knowledge base about carers and personalisation. For instance, it not only shows that overall, self-directed support has resulted in improved outcomes for carers, but has also identified some of the less positive outcomes. Examples of the positive outcomes are that carers are more likely to:

- be undertaking activities of their choice,
- have more time for themselves and for other family members (which in turn benefits other family members),
- have a social life
- feel in control of their daily lives.
- have a perceived higher quality of life
- to be enjoying caring,
- have a better relationship with the person for whom they care.
- have improved health and wellbeing

However, such outcomes do vary with the nature of the needs of the person they are supporting, the amount and quality of the information available to carers and ways different local authorities implement self-directed support.

(Hatton, and Waters, 2011; Office for Public Management, 2011; Forder *et al.*, 2012; Carers Trust 2012; Jones *et al.*, 2012; Moran *et al.*, 2012; Hatton *et al.*, 2013).

The less positive outcomes include the way that:

- many aspects of self-directed support can be stressful for carers.
- Carers have to take on additional administrative and managerial tasks
- carers can be faced with having to cope with several changes in their caring role which they may find challenging
- personal budgets do not improve carers' opportunities to undertake paid employment

(Breda *et al.*, 2006; Rosenthal *et al.*, 2007; Glendinning *et al.*, 2009; Duncan-Turnbull 2010, Hatton *et al.*, 2013).

Whilst these findings are useful there are other developments that point to the importance of continuing to progress understandings of the impact of different dimensions of personalisation on carers. There are:

- *more people will be carers and more of those who are carers will directly experience a personal budget of some sort, either as a result of the person they care for being in receipt of one or in their own right..* Estimates suggest 6.4 million people in the UK are currently carers and that this figure will rise to 9 million by 2037 (Buckner and Yeandle, 2011) and personal budgets for service users and their carers are to be a mandatory part of all care plans (HM Government, 2012) and from April 2014. In addition people who are already receiving NHS Continuing Healthcare will have a right to ask for a personal health budget (Department of Health, 2012).
- *policies are reflecting a commitment to improving the outcomes of personalisation for all carers* (ADASS, 2009; Department of Health, 2010a,b; Moran *et al.*, 2012).

Hence personalisation will not only impact on the lives of an increasing number of carers as it evolves but also on the lives of a growing number of people in our society who will become carers. Such a progressive impact, together with requirements to address carers' needs points to an ongoing need for *more* knowledge and further research about personalisation and carers.

This study addressed the need for more knowledge about personalisation and carers and was designed with the objectives of:

1. Making a productive contribution to the emerging knowledge base about carers and personalisation by exploring a hitherto under-researched key issue- the carer-service user relationship
2. Developing better understandings of changes in this relationship; this relationship is central to the delivery, quality and experience of care in general *and* within a personalised approach to service delivery. Therefore changes in this relationship that occur as a result of personalisation require further exploration in order to ensure the successful implementation of personalisation.

Methodology

The study was carried out by Carers Federation Ltd, and De Montfort University between 2011 and 2013. The methods used are as follows:

- 23 semi structured interviews with carers in 11 English local authorities who were in a long-term dyadic relationship with an adult in receipt of social care who had changed to a personal budget were carried out. *A dyadic relationship* is binding (this includes legally binding), usually continuous association between 2 individuals which involves commitment, often related. As most caring is embedded in a dyadic relationship (Larkin and Milne, 2013) the exclusion of carers in other types of relationships increased both the representativeness of the sample of carers who participated in the study and the generalisability of the findings. For the purposes of this study these relationships were defined as either partner relationships (married or civilly-partnered to, or co-habiting) or parent- adult child relationships. The decision to focus only on carers of those whose social care arrangements had changed to a personal budget was taken because the mainstreaming of this form of self directed support meant that the findings would be highly relevant to current and future developments within personalisation.
- the interview schedule was piloted with 4 carers
- 18 (78%) of those interviewed were in partner relationships and 5 (22%) in parent adult child relationships
- The interviews held either in the participants' homes or at a public venue, such as a local carers centre and lasted between 60 to 90 minutes They were digitally recorded, transcribed and thematically analysed using inductive coding primarily at a semantic level (Boyzatis, 1998; Braun and Clarke, 2006)
- The final stage of the data analysis involved triangulation of the summaries of the themes in two forums; one was a group of carers who had direct or indirect experience of personal budgets and another was at a meeting of a Local Authority Carers Lead Officers Network.

Key themes identified

Although the focus of the study was on how the receipt of a personal budget by service users affected the carer-service user relationship, all the carers interviewed talked about many other caring-related issues. This was reflected in the two main themes – one was the impact of the service user’s personal budget on the carer–service user relationship and the other was the impact of the service user’s personal budget on carers themselves. These themes and their sub-themes are discussed below. Quotations from the interview transcripts are used to support and illustrate the findings.

1. The impact of the service user’s personal budget on the carer–service user relationship

The two sub-themes within this theme centred around the way that personal budgets had reduced the amount of control carers had within the carer–service user relationship and the extent to which they enhanced the relationship.

Less control within the caring relationship

Just over a third (35 per cent) of the carers interviewed said it had been hard to cope with having less control within the caring relationship when the person they cared for became a personal budget holder. Feelings of being ‘pushed’ out and ‘redundant’ were amongst those expressed. As one said “Before, everything was funnelled through me, now that isn’t the case. I found that difficult at first”.

Some also found the loss of control challenging because they worried that someone else “does not know what to look out for” and that that “learning the job” can take a long time”. In some situations, others lack of expertise about the service user’s needs could even threaten the safety of the person for whom they are caring:

He’ll do things that he knows he hasn’t go to, that’ll be a danger to him, and sometimes people aren’t aware that he’s going to do them. Like taking the lawn mower to pieces, he could cut himself if he goes down to the shed, and they don’t follow him..... , so it’s difficult for me to leave him with people.....

However, such feelings did seem to ease over time; note the above carer's comment that he found not being in control "difficult at first". Other carers said they gradually felt "a bit more relaxed about it".

A key factor which reduced carers' concerns about their reduced levels of control was having confidence in the quality of the care provided by those now employed through the personal budget. As one of the parent carers explained, these people have to be "people that you trust" because:

.....they are taking your most precious thing out you need to be absolutely sure that they are what they say they are and that they are going to treat the young person properly

Consequently carers made comments such as "I've got to feel confident" and "it makes a terrific difference" if "I know I have got a carer that I can rely on". The following quote illustrates the relief carers experience when they have confidence in the care being provided:

They tend to anticipate, anticipate what he needs...., they will see areas where they see he is going to struggle, so they step in discretely and do it for him so he is able to function as best he can

It was stressful for carers when carers they felt the standard of care was inadequate, and made it harder to them to "let go"; even though the paid carers were supposed to wash his wife's hair Derek, found himself doing this for her because he "doesn't particularly trust these guys". Some carers also found themselves still taking overall responsibility anyhow because of the condition of the person they were caring for. For example, when talking about his partner's disabilities, one carer said:

because she has a brain injury , she doesn't understand what it's all about. She knows what the personal budget is, but she's not really able to take that kind of thing on board, so it's left for me to do.

Hence in these cases, there was little if any diminution in carers' control over the care for their partner or child as result of the personal budget.

Enhanced personal relationship.

Although there was no evidence that the carer- service users relationships had been crisis, several reported that these relationships were ‘strained’ and just over half (56 per cent) of the carers interviewed felt that personal budgets had effected improvements. This sentiment was expressed by Molly when she said that whilst it had not got to:

.... the point where Richard and I have discussed separating or divorce it has never been that bad but it has been hard work to a point, it is our silver wedding next year and we are renewing our vows so it is a really positive thing and I think the personal budget has got a lot to do with that because you know

Many different reasons were put forward for the improvements which had taken place. One male spousal carer admitted that he used to be ‘dominating’ and now that his wife now had more control meant their relationship had “improved, because I think she’s much happier in being able to take a greater part in running the home “

Others said they were more “relaxed” and “less snappy” with each other. Another reason given was that they had more control over their lives as a couple; Edith whose husband had Multiple Sclerosis said “we have no control over the MS and that is accepted but we have got control of how we live our life and that was a massive issue beforehand.” Interestingly, none of the four carers who were now employed by the service user felt that this contractual arrangement had changed their relationship. Instead, they focused on how they liked the flexibility to choose how much caring they did.

Carers also attributed their enhanced relationship with the person they cared for to the fact that they both had more independence as individuals and could therefore have “a break” from each other. As Bette explained “both of us like to be by ourselves and we couldn’t be on our own at all before and now we can be to some extent and that improves our relationship”. The exception was the carer who missed the time she used to spend with her husband in their pre-personal budget days; she said “I used to love taking him out and going out with him, but we don’t have time for that now very much”.

Whilst having more independence was valued, those in partner relationships specifically found that because the personal budget meant that they now had the “appropriate support”, they could undertake activities “individually and together”. It was clear that the opportunity for shared activities played an important role in enhancing these relationships; it was described as “opening up our vista” and there were comments such as “we can be a couple again” and “I’ve got my husband back”. Examples of shared activities were pursuing interests and socializing together. For instance John explained how he and his wife Joan were now:

...able to go out together and eat. Although I have to feed Joan it doesn't stop us going out and enjoying our lives and restaurants together, and going out with friends and so forth. All these things have become more evident I feel with the personal budget

Similarly, Robert talked about how “the (personal) budget .. it's encouraged us to get out and about and do things... like our cycling..... so we go out and meet other people.”

Three (13 per cent) commented on the fact that there had been no or little change in the quality of the relationship because of the age of the service user as well as or in addition to their illness or disability. For example, one of these carers said ‘ It hasn't changed an awful lot because of Keith's age and condition’ Another carer said that the personal budget had not changed the relationship with her husband as his disabilities meant that “there is not really a relationship; I'm here, and he's comfortable with what's happening. And while he's happy I just toddle along”. Furthermore, the point was made that a service user's condition can result in the carer-service user relationship “changing all the while” and hence enhancement through a personal budget may only be temporary.

2. Carer findings

The findings about carers themselves were categorised into positive and negative outcomes.

Positive outcomes for carers

Over three quarters of the carers (78 per cent) interviewed reported that personal budgets had resulted in positive outcomes for them. In general, they felt happier, mainly because they had “more freedom”. Comments included “it’s freed my life up” and “before I had to do it all, everything, I felt much more trapped and almost resented it and I don’t anymore.” Increased freedom meant they had more time to themselves and could pursue their own interests. One parent carer had picked up interests he had dropped because of the demands of caring for his son:

I used to go to the football with my brother and a couple of other guys a few years ago, and I’d stopped doing that because it was getting more difficult. And he offered me this year the opportunity of a season ticket, and my wife was saying ‘of course you can do it, we’ve got carers’ and I’m not only going, but enjoying it., I play golf a couple of times a week too

Some had started to pursue new interests. An example was June who had taken on an advisory role with a charity which she described as:

.....life changing I suppose in the sense that I have been invited to do things that I never thought I would be asked to dobeing interviewed for national news, sitting on advisory boards....., that wouldn’t have happened if we had not been given the opportunity of having Eric’s personal budget.

However a quarter of those in this group said their increased happiness levels was due to the fact that the person they cared for was also happier. This sentiment was summed up by the carer who said “Well, if he’s happy, I’m happy. It rubs off, doesn’t it?.”

The carers who talked about the positive effects of personal budgets on their lives also said they were feeling healthier. Having more free time enabled them to “do some exercise” and “keep fit”. Many commented on the fact they were healthier because they felt less “stressed”; they said the arrangements made through the personal budget had “taken stress off “ them and afforded them more “opportunities to relax”. As Jude explained having a personal assistant for her partner in the evening meant what she could “just completely relax for an hour, because I know I’m not going to get called, to do anything, or get anything, or move anything. I know for that one hour he’s not going to say ‘Jude’”.

Negative outcomes for carers

The most significant negative outcome for carers was the stress involved with the administration of the service users' personal budget. Indeed, over half (56 per cent) felt personal budgets were stressful to administer, particularly at first. Reference was frequently made to the lengthy and "complicated procedures" that had to be worked through to set up a personal budget.

Whilst the amount of time the day to day administration of personal budgets consumed was problematic, the paper work, recruitment and staff management were seen as the most problematic. With respect to staffing, several sources of stress were identified. The first was:

....finding the right people. Finding the way to get the right people... you really do get all sorts of people, with limited training and not necessarily the attributes of being a carer

Once they had overcome this hurdle, there was the issue of managing the staff and their relationship with them. Some focused on the stress of teaching staff about the care required when the service user had complex needs, how uncomfortable they felt having other people in the house and of the need to set "boundaries". Others found dealing with underperforming staff very challenging. An example was Harry. He said that the carers they now employed "will use any excuse to get out of anything, they really will, so we are really not happy with these guys at all" and found it upsetting that his wife "dreads them coming in". Keeping good staff also caused carers much anxiety. Concerns expressed included "We've always had problems with carers; the one we've got at the moment we get on really well with, and I'd be sorry if she left" and "I don't want to lose the one person I found after months and months of looking." When they were pleased with those employed it could reduce the stress of caring considerably. In some cases the personal assistants had "become friends of the family almost." which was "an incredible help".

A major source of stress was the problems they had experienced with their local authorities. Just under half (47 per cent) reported inadequacies in the level and nature of support provided by their local authority. The following shows the nature of some of these problems:

We contacted our local council and said I would like to get an assessment so we started going down this route. It took a long time for them to assign a Social Worker to our case and then we went through three Social Workers because they were leaving the department, retiring or other things they were doing instead. Yes, it is absolutely phenomenal, from the first person who came out who was phenomenally useless .I think it finally got signed off by the duty care worker because the worker she had been assigned last had moved departments again,

Others talked about lack of information and disputes with their local authorities. The fact that one carer said “the pressure I was under resulted in me virtually having a nervous breakdown” illustrates the extent of stress. Changes and the ever-present threat of reductions in funding also caused carers “constant worry” and led to them being “frightened to death”.

Some of the aforementioned difficulties had eased over time and several commented that their previous employment expertise helped them cope. Those who had managerial or commercial backgrounds were least likely to report difficulties with administering a personal budget. A typical comment from these carers was “I’ve worked in the commercial world myself. So I have some inkling in what to do..... I don’t find the admin too difficult”. Nonetheless nearly half (40 per cent) used other services to support them with managing the personal budget, such as, carers groups, Third Sector Organisations and broker services.

Discussion

Further analysis of the findings in relation to existing studies led to two main conclusions. One was that the study not only produced new findings about personal budgets and carer-service user relationships but it also validated, refuted and extended existing knowledge about these relationships within personalisation more generally. This is summarised in Table 1.

Table 1: Summary of findings in relation to existing knowledge on the carer - service user relationship within personalisation

Existing knowledge validated	Knowledge refuted	New knowledge added
improved relationship with the person for whom they care		ways personal budgets can be used to facilitate an improved relationship
service users needs can limit improvement in relationship		
	contractual relationship with the service user was challenging and does not necessarily reduce the level of care provided	a contractual relationship provides flexibility on the amount of caring provided
the reduction in their control within the caring relationship is challenging for carers		these feelings ease with time and if they have confidence in the staff employed

Similarly, the second main conclusion was the findings about carers themselves provided insights into both the impact of service users' personal budgets on carers

as well as validating and extending existing knowledge about the overall effects of personalisation on the carers. A summary is set out in Table 2.

Table 2: Summary of findings in relation to existing knowledge of the effects of personalisation on carers

Existing knowledge validated	New knowledge added
more in control of their time and their daily lives	
higher quality of life	
improved health and wellbeing	
stress associated with self directed support processes	<ul style="list-style-type: none"> • issues with LA processes and PBs specifically • worry about effects of continuing budget cuts
managerial and administrative responsibilities are burdensome but previous employment experience helps	<p>For PBs</p> <ul style="list-style-type: none"> • particularly at first • paper work, recruitment and staff management were the most problematic • many need additional support

Implications for practice

By validating existing knowledge, this study increased the robustness of the emerging evidence base about the impact of personalisation on carers. This simultaneously provides a firmer foundation on which to further develop practice and interventions in order to improve the outcomes of personalisation, for both carers and service users. Examples of good practice and effective interventions suggested by the analysis of the study's findings are discussed below.

- *support planning to include advice on the use of personal budgets to create the right environment to maintain and strengthen the carer – service user relationship*

The study indicates several ways of sustaining the carer-service user relationship in its role at the centre of the delivery and quality of social care. For instance, support planning could help carers cope with feelings of redundancy and adjust to any perceived reduction in control within the relationship. It could also ensure that personal budgets are used to create opportunities for service users and carers to have some independence as well as to pursue interests and socialise together.

- *more support and training for carers with paperwork, and employment and management of staff*

As well as providing information about where carers can get help with paperwork, and the employment and management of staff, consideration needs to be given to developing more support and training for carers around the areas of the management and administration of personal budgets that cause them the greatest problems.

- *review self-directed support processes*

The negative outcomes of local authority self-directed support processes for carers identified in this study is yet more evidence that evaluation and streamlining of these processes are essential, particularly as the number of carers of those in receipt of personal budgets increases. Moreover, as the demands on shrinking health and social care budgets continue to increase (Appleby, 2013) it is important that carers' fears about reductions in funding are addressed and that innovative practice at a local level are identified when

decisions are being made about meeting people's needs (Brookes *et al.*, 2013).

Implications for further research

- additional ways of strengthening the carer- service user relationship to enhance the experience and quality of care and to ensure that this relationship has the resilience to maintain the delivery of care in the face of the demands placed on it throughout the caring trajectory
- development of Third sector support for carers as personalisation evolves
- apart from empirical research, this study points to the need for regular and more formalised scoping of the existing research on carers and personalisation to secure the best outcomes for carers within personalisation.. Not only is an up-to-date and rigorous overview of the existing evidence base invaluable for the development of effective practice and interventions but it also brings benefits in terms of designing future research that makes productive and relevant contributions to knowledge

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