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Family carers managing personal budgets for adults with learning disabilities or autism

Agnes Turnpenny¹  | Stacey Rand²  | Beckie Whelton¹  | Julie Beadle-Brown¹  | Jacinta Babaian³ 

¹Tizard Centre, University of Kent, Canterbury, UK

²PSSRU, University of Kent, Canterbury, UK

³School of Psychology, University of Kent, Canterbury, UK

Correspondence

Agnes Turnpenny, Cornwallis, University of Kent, Canterbury, CT2 7NZ, UK.
Email: A.V.Turnpenny@kent.ac.uk

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Accessible summary

- Direct payments can help people with learning disabilities or autism to have good support. Often, family carers manage the direct payments for people who would find this very difficult.
- We asked family carers who managed direct payments to tell us why they decided to do this and what their experiences were.
- Family carers told us they found managing direct payments difficult and stressful at first, but this got easier over time.
- They also said that direct payments helped their family members to have more person-centred support.

Abstract

Background: There are a growing number of people with learning disabilities and autism who access personal budgets in the form of direct payments in England. Although they are often involved in decisions about their support, personal budgets are usually managed by someone else, typically a parent. This study examined the experiences of carers who manage personal budgets for adults with learning disabilities or autism with a particular focus on the challenges of securing suitable support and implications for their own well-being.

Methods: This was a qualitative study using a descriptive phenomenological approach to investigate the lived experiences of family carers who manage personal budgets. We conducted semi-structured interviews with 13 family carers. Interview transcripts were thematically analysed using the framework approach.

Results: Our analysis identified five main themes. The first theme relates to why carers decide to take up a personal budget in the first place and their initial expectations. The second theme, restricted choice, highlights the difficulties in securing adequate support and services in the context of what are often described as “complex needs.” The third and fourth themes relate to the tasks involved in managing a personal budget and the challenges associated with the dual role of the carer as a parent and a “professional.” The fifth and final theme, mixed emotions, describes the impact on the subjective well-being of carers.

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Conclusions: Family carers indicated that the benefits of personal budgets outweighed the difficulties and stress inherent in managing them. They need adequate support to ensure that personal budgets deliver personalised and self-directed support and greater well-being, and are sustainable arrangements.

KEYWORDS

adults with learning disabilities, complex needs, direct payments, family carers, personal budgets

1 | INTRODUCTION

Personalisation and self-directed support have been stated aims of English social care policy for over 25 years. The main delivery mechanisms have been various individual budget arrangements, primarily direct payments¹ and personal budgets. Since 2008, English local authorities with adult social care responsibilities have been required to offer personal budgets, either as direct payments or as managed budgets, to everyone eligible for adult social care support (Department of Health & Social Care, 2008).

Although the theoretical underpinnings of the broader personalisation and cash-for-care agenda are contested and the ambiguous nature of various policy narratives is highlighted (Scourfield, 2007; Needham, 2011, 2013; Needham & Dickinson, 2018), personal budgets have been a key part of the English social care and support system for over two decades. Whilst the majority of people with learning disabilities aged 18–64 years receive local authority-managed personal budgets (in 2016/17, 53%), a substantial minority (40%) access full or partial direct payments, managed with support from family (National Audit Office, 2018, p. 15).

In this context, family carers play a vital role in supporting people with disabilities to manage their direct payments (Hamilton et al., 2017; Mansell, 2010; Newbronner et al., 2011; Williams et al., 2014). Early implementation studies highlighted over-reliance on informal supporters willing and capable to manage support (Clark & Spafford, 2002; Ellis, 2007), and there have been concerns over equity of access and outcomes for people who do not have family support (Glasby, 2014). Where people are supported by family and friends, the role of carers can be ambiguous. Professionals reported that conflicts often arose between the needs of the individual with disabilities and the expectations of family carers when planning a personal budget, especially around the required level of support, management of risks and safety, promoting service user independence, and when or how carers were able to take a break from caregiving (Mitchell et al., 2015). Despite these inherent challenges and ambiguities, many service users depend on and value their carers' involvement in discussions related to personal budgets and carers often wish to be involved (Glendinning et al., 2015).

There is some evidence of positive impacts of personal budgets for carers, especially in terms of the flexibility afforded, allowing carers to be able to better balance caregiving with their other responsibilities and make employment decisions (Larkin, 2015; Woolham et al., 2018). Other studies found that personal budgets supported carers to have free time for their own social, leisure or essential activities (e.g. medical appointments), to feel healthier and less stressed, and to have a greater degree of choice and control over their daily lives (Jones et al., 2014; Larkin, 2015; Moran et al., 2012). However, there were also some negative aspects. Some carers report that managing personal budgets was stressful, even if this somewhat reduced over time (Larkin, 2015; Moran et al., 2012; Woolham et al., 2018). Carers also described that sometimes, they did not have enough confidence in those providing the support to be able to stand back from caregiving and feel less anxious (Larkin, 2015). Finally, there is evidence of a lack of support for carers to manage the personal budget (Glendinning et al., 2015; Mitchell et al., 2015; Woolham et al., 2018).

These issues are especially relevant for adults with learning disabilities. Informal carers, typically family, are often relied upon to support people to identify initial choices and manage the budgets where the person is unable to manage themselves (Manthorpe et al., 2011; Sims & Cabrita Gulyurtlu, 2014). While there has been a study of the role of carers of older and learning disabled people with cognitive or communication impairments (Glendinning et al., 2015), the study concentrated on the assessment and planning of personal budgets and only included personal budget holders who were able to also participate in an interview as part of a carer/care-recipient dyad. Therefore, there is a lack of evidence for those with more complex needs, who require significant support, including decision-making, and where the role of carers is the long-term management of personal budgets.

This is an important gap in the evidence. A growing number of people with learning disability access self-directed support, regardless of the severity of their disability or complexity of needs (National Audit Office, 2018, p. 15). Whilst people with learning disabilities can be involved to varying degrees in decision-making, they are not generally able to manage a personal budget without support. Therefore, someone else has to take on the responsibility for overseeing the budget on his or her behalf. There is no information on the source and type of support, but the primary source of support

¹Community Care (Direct Payments Act) 1996. Available: <https://www.legislation.gov.uk/ukpga/1996/30/contents>

is likely parental and, in some cases, from siblings, partners or other family members.

This study responded to this gap in the literature on the experiences of family carers managing personal budgets for people with learning disabilities or autism with higher levels of support needs (i.e. “complex needs”). The research aimed to explore the experiences of family carers managing personal budgets; in particular, the reasons why families decided to manage personal budgets; the perceived advantages and disadvantages by comparison with traditional service arrangements; and their experience of the process of planning and managing support.

2 | METHODS

2.1 | Study design

This was a qualitative study using a descriptive phenomenological approach to investigate the lived experiences of family carers who manage personal budgets on behalf of a person with learning disabilities or autism (Mapp, 2008).

2.2 | Participants

The study was conducted in four local authorities in South East England. Participants were recruited via social media and carers' organisations in these local authorities. Family carers were eligible to take part in the study if they were managing, or had managed in the past, any type of personal budget on behalf of an adult with learning disabilities or autism; or if they had been offered this, but did not take it up for any reason.

There were 24 expressions of interest in taking part in the research. Of these, nine people were not eligible, as follows: not managing personal budgets, but supporting individuals with disability-related benefits ($n = 4$); managing personal budgets for children aged under 16 years ($n = 3$); or lived out of the area the study covered ($n = 2$). In addition, two potential participants did not take part due to changing their mind or being unable to schedule the interview within the project timeline. In total, 13 interviews were conducted.

2.3 | Data collection

Interviews were carried out by the first three authors between December 2018 and March 2019. They lasted between 20 and 90 min. The interview topic guide, which was based on a review of the literature and previous research by authors (Richardson et al., 2019), included personal budget arrangements, including what the personal budget was used for; the background context and rationale for the decision to take up a personal budget; and experiences of managing personal budgets, including support from various sources. Interviews were concluded by asking participants if they

had anything else to add, allowing them to bring up any topics that they felt were important. Six interviews were conducted by telephone and there were seven face-to-face interviews, usually in the participant's home. Participants received a gift voucher as a recognition of their time and contribution to the research.

All interviews were conducted individually, except one, where both parents were present. Interviews were audio-recorded, transcribed verbatim, and then checked and anonymised by the first author.

Ethical approval for this study was granted by the Social Care Research Ethics Committee (REC reference: 18/IEC08/0025). Research governance approval was obtained from local authorities.

2.4 | Data analysis

The framework approach was used for data analysis (Ritchie et al., 2003). The first three authors developed a conceptual framework based on the topic guide and initial reading of the interview transcripts. Proposed codes were then discussed and consolidated into a code list, which was transferred to QSR NVivo 12 for coding. Transcripts were coded by the first three authors, also noting any new codes not covered by the initial framework in the process. Once all interviews have been coded, the team compared coding patterns and resolved any disagreements, agreed on any new codes, deleted codes that were not used and merged overlapping codes.

3 | FINDINGS

3.1 | Characteristics of participants

We interviewed 13 family carers from four local authority areas in the South East of England. All but two participants were managing personal budgets (either direct payments or personal health budgets) at the time of the interview. Most had done so for more than five years ($n = 7$; three participants were managing a PB for more than 10 years). One participant had been offered direct payment by their local authority, but could not take this up due to the lack of suitable support and services in the area. One participant had stopped using direct payments as the individual was now living in a supported living service.

All participants identified as white British. Over half ($n = 7$) were in part-time or full-time employment. Most participants were mothers of the people in receipt of a personal budget ($n = 9$) and lived with the individual for whom they managed the budget ($n = 10$).

3.2 | Characteristics of those in receipt of personal budget

Our study aimed to investigate the experiences of family carers managing personal budgets on behalf of people with complex needs.

“Complex needs” is generally used to indicate high levels of need for additional support; however, in this project we did not use this term prescriptively and allowed participants to self-identify as someone supporting someone with complex needs. To capture the range of needs, participants were asked to complete a checklist of eight activities of daily living (ADLs) alongside questions about disability for the person they support. This takes a narrower definition of “complex needs” from the perspective of the amount of physical support one requires. The characteristics are summarised in Table 1.

Only a minority of PB recipients in our study needed additional physical help in a range of activities of daily living (e.g. getting dressed). The complexity of needs was more likely to be associated with autism and/or mental health difficulties and included self-injurious behaviour, phobias and running away.

3.3 | Thematic analysis

Our analysis identified five themes, which are summarised in Table 2. The first theme, the hopes for personal budgets, relates to why carers decided to take up a personal budget in the first place and what their initial expectations were. The second theme, restricted choice, related to the reality the carers faced when it comes to personal budgets. Two themes related to the tasks of managing a personal budget: the complexity of managing a personal budget and managing a dual role: professional versus family carer. The fifth and final theme, mixed emotions, related to the impact on carers, who

TABLE 1 Characteristics of those in receipt of personal budgets

Characteristics	N = 12 (%) ^a
Disability (It was possible to select more than one category)	
Learning disability	10 (83%)
Autism	9 (75%)
Physical disability	4 (33%)
Mental health problems	7 (58%)
Communication difficulty	5 (42%)
Sensory disability	3 (25%)
Participants by number of ADLs they need help with	
1–2	6 (50%)
3–4	1 (8%)
5–6	4 (34%)
7–8	1 (8%)
Amount of support paid from PB	
4 daytime, less than 6 hr	6 (50%)
Daytime, 6–12 hr	3 (25%)
24 hr, sleeping nights	1 (8%)
Other	1 (8%)
Not receiving PB	1 (8%)

^aThe characteristics questionnaire was completed by 12 of the 13 participants.

TABLE 2 Carer’s experiences: The themes and sub-themes from the thematic analysis

Why opt for a personal budget	Restricted choice	The complexity of managing personal budgets	Managing a dual role: professional versus family carer	Impact on carers
Choice	Insufficient money	Sources of support	Managing and coordinating support	Positive personal outcomes
Possibility of better support	Restrictions on what can be purchased	Complicated and confusing at times	Underpinned by role as carer	Ease strain on relationships
	Lack of services and support to purchase	Insufficient or inaccessible guidance	Employing people and managing budgets	Emotional impact
		Can leave scope for creativity		

reported generally positive quality-of-life outcomes, but not without stress or burden.

3.4 | Why carers decide to manage personal budgets

Carers took up direct payments for a number of reasons. Most ($n = 10$) felt it would give them more choice and control over the delivery of support, with two-thirds ($n = 8$) reporting a perceived increase in the quality of life of the individual in receipt of the personal budget. Just over half ($n = 7$) talked about how personal budgets allowed support to be more person-centred.

The main advantage for us is having total control over his carers, over when we can use the hours. We're very flexible with carers. We choose them.

Participant 11 (father, managing son's direct payment)

There were also perceived benefits in terms of increased control and choice for the PB holder, and more flexibility compared to traditional services that were slow to respond to the person's changing needs and preferences:

We said we want [daughter] to have full control over her budget so that she decides and she changes what she wants to do. And so, we got control of the personal budget and now when [daughter] wants to change something she can do it very quickly.

Participant 2 (father, managing daughter's direct payment)

There was a belief that the support set up through a PB could be more personalised and relationship-focused. Personal budgets used to employ personal assistants (PAs) allowed people with learning disabilities and carers to take into account relational factors, such as the gender of the PA, their outlook, aspirations, and mutual interests and hobbies. When this worked well, PAs would become part of the individual's social network, in a way that was beyond that achieved within the structure, organisation and management of formal services.

He [son] goes on holiday one week, he takes two carers, two carers' husbands and their five children. He loves it, they love it, they get a free holiday. They go to the same place every time. He looks forward to it. They look forward to it, because they can't afford to take their own children on that. The work, in inverted commas, is looking after [son]. But because he's having such a good time, it works.

Participant 11 (father, managing son's direct payment)

The continuity and consistency of care were highlighted and contrasted to traditional services where staff changed often.

We've got consistency, we've got the carers and then we can employ the carers' friends if they recommend.

Participant 11

So that's the beauty for me about having the nurses at home. They will come into hospital too, and that is a continuation of care.

Participant 8 (mother, managing daughter's personal health budget)

Some carers employed extended family or friends with the personal budget. One carer spoke about how employing family gave a sense of safety and trust, as well as having the benefit of someone who already knows the individual well:

I've employed my parents to do this, purely because [son]'s non-verbal and I don't trust many people around him because he can't come home and tell me what's gone on.

Participant 4 (mother, managing son's direct payment)

Some interviewees spoke of how there had been *no choice* as to whether personal budgets were the right option for them. The carers' experience of the set-up of the personal budget was not as a decision to opt for a personal budget, because it was the only choice offered:

We didn't have a choice. It must have been when she turned 18, and I think we were just told that we were entitled to six hours a week, and we would have to look for a PA, and that social services would pay the money, we would have to open a bank account, a joint bank account and then the money would be paid to the PA.

Participant 7 (mother, managing daughter's direct payment)

3.5 | Restricted choice

Despite the stated policy aim of PBs to promote greater choice and control, many carers experienced a number of limitations on choice once they had opted for a personal budget. This included constraints due to the amount of money available via the personal budget and how it had to be spent (*budgets*), as well as what was available in the local area to purchase (*markets*).

In terms of budget-level constraints, two respondents expressed the view that the personal budget was insufficient to address the person's needs. In one case, this led to the eventual

decision to revert to a traditional service package. In the other, the carer relied on the goodwill of an informal arrangement to keep costs lower:

PA gets paid £8.40 an hour. Now because she's a friend and this is a bonus to her, she's happy with that, but to my mind that's not enough money. I'd rather pay her £10 an hour but if we paid her £10 an hour we then couldn't afford the payroll or the insurance out of the budget.

Participant 5 (wife, managing husband's direct payment)

The gap between PB allocation and the actual cost of services was also highlighted, which puts families in a difficult situation when trying to source support.

The difficulty is that the money you get for private respite is a lot less than you get for in-house respite [...] What we get for respite doesn't buy a lot of respite.

Participant 7 (mother, managing daughter's direct payment)

Some participants also talked about local authority-level constraints on the type of services that could be purchased or the limitation of services to approved providers.

We have to pay for her education courses; the budget doesn't pay for that. [...] In [area] you can only use services if they are CQC-registered and they are an approved provider. We'd have to pay for anything outside of that.

Participant 2 (father, managing daughter's direct payment)

Participants also expressed that their choice had been constrained by a lack of suitable, high-quality services able to meet the person's needs, and this did not only affect those with complex and intensive needs but sometimes also those needing low-level support.

To manage your own budget is only as good as if the services are out there to buy. And they're not.

Participant 4 (mother, managing son's direct payment)

3.6 | The complexity of managing a personal budget

Personal budget arrangements that our participants described were often complex with multiple roles managed by different individuals/organisations, often geographically dispersed. The role of oversight, coordination and communication fell on carers. The administrative

aspects of managing the budget were described as *complex and technical* particularly in the early stages or at transitions.

I phoned them a lot to start with because I have found the paperwork that comes through totally confusing.

Participant 5 (wife, managing husband's direct payment)

This was compounded by the perceived lack of transparency and insufficient or inaccessible guidance.

When you ask for a clear outline of how to use the direct payments they don't give you anything, they just say "oh it's down to the social worker".

Participant 1 (mother, managing son's direct payment)

For some participants, the lack of clear guidance was not necessarily a problem because it allowed them to be creative and make the case for particular activities or support.

I asked "can I use some of this money for him to go on holiday?" And the social worker wasn't really sure. I said, "Well, it's not going to cost any more, the budget is agreed how much a year for so many nights, so many hours, etc. So, to go on holiday, if that's taken out of the hours or nights--," and they agreed, and they still agree.

Participant 11 (father, managing son's direct payment)

Formal support in managing personal budgets was identified by most participants, even if the level of support varied. Some carers only had contact when the direct payment was reviewed or audited.

Quite often we have reviews twice a year, so that's fairly regular. [...] But I would say that is the only support we get with the personal budget.

Participant 2 (father, managing daughter's direct payment)

Other carers spoke of a lack of continuity and consistency of support due to restructuring and staff turnover in local authorities.

Until recently we had an allocated social worker and we went to her with any questions about anything [...]. Social services has overhauled their system, we now don't have an allocated case manager, they have a duty team and you phone a duty team who may or may not know about your case, with your question and they go away and find the answer and come back to you, which sometimes works and sometimes doesn't.

Participant 5 (wife, managing husband's direct payment)

Payroll companies were used by some carers to facilitate the administrative side of managing a personal budget. Nevertheless, they were not accessible for all:

I would love it if social services could've given us enough funding for the payroll company to manage itself. I wouldn't have to do it at all. I went back to them and asked if that's possible and they said sorry, there's not enough money in your budget to cover that... It wouldn't actually be a lot, I think we worked out it was about £100 more a year...[...] The stress this has caused me would all have been gone.

Participant 5

Carers also drew on informal sources of support, especially informal and community networks.

[A]ll these things are who you know and word of mouth, rather than anything official.

Participant 3 (mother, managing daughter's direct payment)

We're lucky enough we live in a small village so I literally asked the local vicar if she knew anyone using family friends or relatives as a PA or for respite.

Participant 7 (mother, managing daughter's direct payment)

3.7 | Managing a dual role: professional versus family carer

In the management of personal budgets, the carers referred to the ways in which they adopted a quasi-professional role. This was expressed in the day-to-day responsibilities that managing a budget entailed from managing finances, "commissioning" of services, recruitment and supervision of care staff, risk management and employer responsibilities:

The issue is managing the person [personal assistant]. What I've got is the equivalent of a Brownie leader. She is a lovely girl, who is taking my daughter swimming and horse riding and all those things, but has never handled a runaway... So the relationship is fragile and I suppose the responsibility on her is much greater than she knows even. So the worry rests with me and it's just the risk that you take.

Participant 6 (father, managing daughter's direct payment)

The presence of personal assistants in the family home meant that the distinction between home/workplace, private/public and formal/

informal could become blurred, which raised issues around privacy and boundaries:

The only thing that the downside is you've always got people in your house, [...] you say it to the PAs "you've got to remember this is your place of work, this is my house" [...] My husband says, "God, it's half past nine, we can go sit down in the lounge now," but we sit in the kitchen.

Participant 8 (mother, managing daughter's personal health budget)

Some carers spoke of how their professional training or background (e.g. in finance) gave them the required skills for budget management, which include researching options, understanding legislation and negotiating with stakeholders in the person's care. There was a recognition that taking on a personal budget was extra work and this would not be for everyone:

I think it does give the user or the person who manages the budget, which is me, quite a lot of extra work to do. I know I recognise it as a way of saving the local authority quite a lot of time and money because I am articulate and I can do it, but I think it must be awful for people who have to manage on their own.

Participant 3 (mother, managing daughter's direct payment)

A number of participants expressed that carers needed resilience and determination in order to navigate the system:

Yes, it was more up to me. All along, it's been more up to me to find out. I do feel quite--, very strongly about that. I've always been left to do it myself, really. [...] I had to make a big fuss and shout loudly. It's just he or she who shouts loudest gets there [...] But it is always a battle. It is a continual battle.

Participant 3

However, at the end of the day, the quasi-professional role of managing personal budgets is underpinned by their responsibility and identity as parents or family carers. One carer spoke of the balancing of these different identities as a combination of "organising and supporting" with "cuddling and all those things I would normally do as a mother" [Participant 8 (mother, managing daughter's personal health budget)].

3.8 | Positive outcomes for carers

Participants associated personal budgets with positive outcomes for themselves, such as staying in paid employment, having a better work-life balance or family life.

The personal health budget is fabulous, I've got my life back, you know [...] I was a single parent until last year when I got married, now there is something that says a personal health budget gave my daughter a life, but it gave me a life.

Participant 8 (mother, managing daughter's personal health budget)

Some carers described the peace of mind that came with having arrangements that they could trust and worked well for the disabled person:

I always say a good sign is when he goes out the door and I don't think about him, because I know he's safe.

Participant 4 (mother, managing son's direct payment)

The other side of this was anxiety over the future, when the parents were no longer able to manage the individual's personal budget:

I don't know what happens when he is in supported housing and we're dead and gone, would he be allowed to have a personal budget? How would he know about a personal budget? And who would manage it for him?

Participant 12 (mother, managing son's direct payment)

4 | DISCUSSION

The aim of this study was to respond to the knowledge gap related to the experiences of family carers managing personal budgets for people with learning disabilities or autism with support needs described as complex. Although a small-scale, qualitative study, the study provides some insight into these experiences. Most family carers reported that they opted to manage a personal budget in the expectation that it would allow greater choice and control, which would result in better support for their family member. These initial hopes were not always fulfilled in reality, although overall, most reported positive outcomes.

Personal budgets have the potential to promote consistency and continuity of care, and allow flexibility and a more person-centred and tailored support for the individual. Some families also expressed that personal budgets gave them peace of mind because they felt they could trust the person who supported their family member. Our findings also support previous research which demonstrated positive impacts in relation to flexibility and allowing carers to better balance caregiving with other responsibilities, including employment (Jones et al., 2014; Larkin, 2015; Moran et al., 2012; Woolham et al., 2018).

The findings of this study, however, indicate that there are some challenges faced by carers who manage personal budgets on behalf of someone with learning disabilities and autism, with complex

needs. Choice and control were not always forthcoming. There are constraints that relate to resources, either at the local authority level (e.g. amount of available funding, administrative rules) or at the national level (austerity, social care budgets). There are also constraints related to the lack of suitable services available to purchase in the local area.

Taking on a personal budget also carried with it a substantial mental and emotional load. Our participants spoke of the need for substantial resilience and determination in navigating the system. Our findings also highlighted the ambiguity of family carers' roles. Using Twigg's typology (1989), carers have been viewed by formal services as *resources* to be utilised, *co-workers* to work in partnership with services or as *co-clients* with a right to assessment and support to address their own needs. The findings of this study indicate that carers who manage a personal budget on behalf of someone are positioned as professionalised *co-workers*, even if it is perceived that PBs offer better outcomes for the person and their carer/family (*co-clients*). In fact, some carers acknowledged that they had accepted to undertake a task that would have previously been offered as part of formal support (i.e. as social work or care management) on the basis that it would have some benefit on personal outcomes, even if it also entailed additional tasks for themselves. The role of managing a personal budget on someone's behalf was experienced as a complex and demanding task, which required the acquisition or application of specialist knowledge (e.g. of employment and legal requirements) and skills (e.g. financial management, staff management). This may not be a feasible or desirable option for all family carers.

The findings of this study are also consistent with previous research, which found significant "operational ambiguity" and frontline discretion (Ellis, 2007), as well as fragmented practices and inconsistency in the administration of personal budgets by local authorities (Glendinning et al., 2015; Mitchell et al., 2015). In this study, there were differences between, as well as inconsistencies within, local authorities as to how the budgets could be spent. There was also a lack of clear guidance on managing personal budgets. The support that carers received was highly dependent on the individual professional liaising with them.

These findings also have implications for the provision of direct payments as part of the social care system for people with learning disabilities. There is a need for better availability and clarity of guidelines, and communication on the use of personal budgets to improve transparency and reduce inconsistency between and within local authorities. Training and bespoke support for carers in the early stages of managing a personal budget would be beneficial alongside more targeted assistance to carers with more complex or greater needs (e.g. those whose family members have complex needs and have limited resources).

Our study had various limitations. First, due to the small sample size, a focus on four, relatively similar local authority areas in the South East of England, and the lack of participants from minority ethnic backgrounds we might have missed important aspects of the experiences of managing personal budgets. Second, interviews were conducted using face-to-face and remote (telephone and Skype) interviewing

methods, which might have resulted in different dynamics and depth of information. The fact that most of our participants have had many years of experience in managing personal budgets and have acquired considerable skills can be seen as both an advantage and a limitation of the study. Limitation, in that we did not capture the experiences of those who might have given up and returned to more traditional arrangements, and an advantage because it provides a greater insight into the challenges of managing personal budgets.

The findings have highlighted some areas that would potentially benefit from further exploration. Over half of all personal assistants employed by individual employers in England are family or friends (Skills for Care, 2019), and a third of our participants employed relatives or extended family as personal assistants. Our research found that by employing family members, carers felt that they were getting “over and above” what they would get with a nonrelated personal assistant. There is little evidence of the impact of this in the UK (Larkin, 2015; Manthorpe et al., 2011); however, two studies in the Netherlands have suggested that it may affect the dynamics and boundaries within the caregiving relationship (Grootegoed et al., 2010; Kremer, 2006). Therefore, the impact on family dynamics and relationships would merit further exploration.

Second, flexibility was often mentioned by carers as one of the advantages of personal assistance, and this was due to being able to have less formal and more responsive arrangements. Some also commented that their PAs preferred working directly with families rather than via provider organisations. Skills for Care's PA survey (2019) indeed shows that employment conditions are somewhat more favourable (i.e. higher hourly pay) among PAs, and turnover and absence is lower than in the sector overall. Nevertheless, little is known about the experiences, motivations and satisfaction of PAs working in these roles, specifically with people with learning disabilities and autism, and the broader impact of self-directed support arrangements on the disability workforce (Macdonald & Charlesworth, 2016).

Finally, our study was conducted before the COVID-19 pandemic, which has had a major impact on individuals, their families and personal assistants. The implications and lessons for the management of direct payments must be explored and reflected in any future government guidance and local policies.

In conclusion, family carers in our study indicated that the benefits of personal budgets outweighed the difficulties and stress inherent in managing them; however, the tasks of managing a PB required substantial skill, resources, tenacity and resilience. They need adequate support to ensure that personal budgets deliver personalised and self-directed support and greater well-being, and are sustainable arrangements.

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DATA AVAILABILITY STATEMENT

Research data are not shared.

ORCID

Agnes Turnpenny  <https://orcid.org/0000-0003-4889-5993>
 Stacey Rand  <https://orcid.org/0000-0001-9071-2842>
 Beckie Whelton  <https://orcid.org/0000-0003-2792-7175>
 Julie Beadle-Brown  <https://orcid.org/0000-0003-2306-8801>
 Jacinta Babaian  <https://orcid.org/0000-0002-5256-9798>

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