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**CHALLENGES IN DELIVERING
PERSONALISED SUPPORT TO PEOPLE WITH
MULTIPLE AND COMPLEX NEEDS:
QUALITATIVE STUDY**

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KEYWORDS: Personalisation, person-centred support, personal budgets, multiple and complex needs, interprofessional collaboration, qualitative method

**CHALLENGES IN DELIVERING PERSONALISED SUPPORT TO PEOPLE WITH
MULTIPLE AND COMPLEX NEEDS: QUALITATIVE STUDY**

ABSTRACT

Personalisation involves placing service users at the centre of service provision to ensure that the support they receive meets their individual needs, hopes and goals. This paper focuses on a programme delivering personalised support to people with multiple and complex needs ('beneficiaries'). Each beneficiary received a tailored package of support and a £12,000 personal budget. Despite being well-resourced, the programme struggled to recruit and retain beneficiaries. The aim of this paper is to identify the challenges encountered and to share learning. Repeat semi-structured interviews (n=56) were conducted with beneficiaries, programme workers and external partners. Interviews were audio recorded, transcribed, coded and analysed via Iterative Categorization. Five categories of challenge were identified: 1. poor understanding of the programme; 2. the characteristics and needs of beneficiaries and programme workers; 3. lack of clarity regarding who owned and controlled the budget; 4. strained interprofessional relationships; and 5. excessive bureaucracy combined with difficulties establishing programme outcomes. Findings illustrate how the delivery of person-centred support is compromised by interacting individual, organisational, and system level factors, particularly poor interprofessional collaboration. The data also suggest that personal budgets may undermine personalisation for people with multiple and complex needs.

KEYWORDS: Personalisation, person-centred support, personal budgets, multiple and complex needs, interprofessional collaboration, qualitative method

CHALLENGES IN DELIVERING PERSONALISED SUPPORT TO PEOPLE WITH MULTIPLE AND COMPLEX NEEDS: QUALITATIVE STUDY

BACKGROUND

The terms ‘personalised support’, ‘person-centred support’ and ‘personalisation’ are difficult to define and often used inter-changeably. Together, they have played an increasingly central role in international social care policy and practice in recent years (Arksey & Baxter, 2012; Ferguson, 2007; Lymbery, 2012; Lymbery & Postle, 2010). All involve placing service users at the centre of service provision to ensure that the support they receive is individually tailored to meet their needs, hopes and goals (Carr, 2008; Department of Health, 2007; Glynn et al., 2008). This is achieved by promoting service user involvement, participation, choice, control, and empowerment; working with people holistically and flexibly; and fostering independent living (Needham & Glasby, 2014a). Service users are treated as partners in treatment planning and decision-making, with the aim of equalizing the balance of power between people receiving and providing support (Alakeson & Perkins, 2012; Veale, 2012).

Providing personalised or person-centred support can range from enabling someone to decide what they will wear to providing them with a personal budget or direct payment so that they can purchase the care and support they choose (Carr, 2008). In the United Kingdom (UK), personal budgets were piloted from 2003 to 2005, initially with people with learning disabilities. Since then they have been extended to many other groups using social care services (Glasby & Littlechild, 2009; Heslop & Williams, 2009). Personal budgets comprise an agreed sum of money that is allocated to an individual following an assessment of their

care and support needs. The money is provided by statutory bodies and/ or service providers and should be sufficient to meet the individual's assessed needs. The individual can manage their budget themselves (as a direct payment) or choose to allow others to manage it for them (or some combination of the two) (ibid.).

Although generally presented as a justice-based way of working with people using social care services, the concept of personalisation has been controversial (Needham & Glasby, 2014a). According to some, personalisation is underpinned by neo-liberal notions of individualism, consumerism and the market place, rather than citizenship (Lymbery, 2012). As such, personalisation has been described as being part of a drive to undermine the welfare state, reduce public sector services, deprofessionalise workers, and transfer state responsibility back to those already in need (Barnes, 2011; Ferguson, 2007; Lloyd, 2010; Needham & Glasby, 2014a). Critics have also claimed that the personalisation agenda has run ahead of the evidence base; and that advocates of personalisation have prioritised individual testimonies relating to the benefits of personalisation over formal evidence (Beresford, 2012; Needham & Glasby 2014b; Sullivan, 2001).

To date, research on personalisation has tended to focus on personal budgets or direct payments, rather than personalisation or person-centred support more broadly (Veale, 2012). In the UK, for example, national evaluations have considered the impact of personal budgets on people with long-term mental health problems (Clewett et al., 2015; Hamilton et al., 2015; Larsen et al., 2015); people with learning difficulties; older people; and people with physical and sensory impairments (Glendinning et al., 2008; Netten et al., 2012). Findings have been mixed, with some populations reporting increased control, flexibility, and improved treatment outcomes and others, particularly older people, reporting increased stress, lack of control, and

weak or poor treatment outcomes (Glendinning et al., 2008; Hamilton et al., 2015; Larsen et al., 2015; Netten et al., 2012). A systematic review of personalised care planning for adults with chronic or long-term health conditions found only small improvements in some indicators of people's health status and capability to self-manage their condition when compared to usual care (Coutler et al., 2015).

Although empirical data are limited, a number of studies and research reports suggest that personal, organisational and structural factors may be impeding the day-to-day delivery of personalised support. For example, service providers and carers may find it difficult not to make assumptions about what people want or need; unclear or variable eligibility criteria may make it difficult to decide who is entitled to a personal budget; and bureaucracy, regulations and a preoccupation with risk management may make services inflexible and unresponsive to personal choice (Glynn et al., 2008). In addition, entrenched organizational practices may be impossible to change (Moore et al., 2017); service users may lack the capacity or feel unable to make choices or manage personal budgets themselves (Lymbery, 2012; Veale, 2012); and staff may not have the time to work in a person-centred way (Glynn et al., 2008; Moore et al., 2017). Funding cuts may also have eroded the availability of local care and support that can be accessed (Glynn et al., 2008; Lymbery, 2012; Veale, 2012).

One population that has received little research attention in relation to personalised support are people with multiple and complex needs (also known as people experiencing 'severe and multiple disadvantage', 'complex needs', 'multiple needs', 'multiple disadvantage', and 'deep, chronic or extreme social exclusion') (Duncan & Corner, 2012; Rosengard et al., 2007). Multiple and complex needs implies both 'breadth of need' (more than one need, with multiple needs interconnected) and 'depth of need' (profound, severe, serious or intense

needs) (Rankin & Regan, 2004; Rosengard, Laing, Ridley, & Hunter, 2007). Types of need vary, but routinely include dependence on substances, homelessness, mental health problems, poverty, violence, abuse, offending and imprisonment. In an attempt to quantify the scale of multiple and complex needs, Bramley and Fitzpatrick (2015) reported that over a quarter of a million people in England are in contact with at least two out of three of the addiction, homelessness, and/or criminal justice systems each year.

Individuals experiencing multiple and complex needs often struggle to engage with everyday life, experience very poor quality of life, and feel socially isolated and on the margins of society (Bramley & Fitzpatrick, 2015; Department for Communities and Local Government, 2015). However, they also often fail to access the services they need, or end up in inappropriate, siloed or uncoordinated services (Bramley & Fitzpatrick, 2015; Cornes, Joly, Manthorpe, O'Halloran, & Smyth, 2011; Rosengard et al., 2007). In consequence, they repeatedly use public services in an unplanned way and rely on expensive crisis support, thus creating significant costs for the rest of society (Bramley & Fitzpatrick, 2015; Department for Communities and Local Government, 2015). The challenges of supporting people with multiple and complex needs have long been recognised and innovative solutions have been suggested. These include assertive outreach; early intervention; crisis resolution; creative approaches to resource pooling; as well as the provision of more personalised support via increased service user involvement in the design and delivery of services, individualised case management, and access to direct payments (Duncan & Corner, 2012; Rosengard et al., 2007).

The focus of this paper is a 'test and learn' programme delivering community-based personalised support to people with multiple and complex needs (referred to as

‘beneficiaries’). ‘Test and learn’ meant that the programme providers were expected to trial, assess and amend the programme as needed. The programme was established in 2014, funded by a non government public body, and delivered in London, UK, by a small team of frontline workers. The programme employed an ‘asset-based’ personalised approach to working which involved tapping into the beneficiaries’ own goals and ambitions in order to plan an individually tailored package of support for each of them. The objectives were to generate positive, manageable and sustainable outcomes at reduced costs to society and ultimately to enable the beneficiaries to live independently. To be eligible to join the programme, potential beneficiaries had to meet two criteria: i. they had to have cost public services £52,000 or more in the previous two years and ii. they had to have four areas of need (mental health, substance use, offending, and housing). After July 2015, this was reduced to three of the four areas of need.

Eligible individuals could be referred to the programme by any service in designated areas of London. Once accepted onto the programme, they were then allocated a named worker and a £12,000 personal budget which was meant to be theirs to spend how they chose. All workers had small caseloads and were expected to work intensively, on a one-to-one basis, with beneficiaries in the community. Despite having a £9.7 million budget to spend over eight years, the programme struggled to recruit and retain beneficiaries during its first two years of operation. By July 2016, the team had only worked with 30 beneficiaries (instead of the projected 90), and of those only 21 were still actively engaged with the programme team. The aim of this paper is to identify the challenges that were encountered in delivering this ambitious but well-resourced programme in order to share learning in relation to providing person-centred support to people with multiple and complex needs.

METHODS

Study design

We conducted a qualitative longitudinal study involving one-to-one semi-structured interviews with beneficiaries, programme workers and external professionals working with the programme. Qualitative methods were chosen to enable detailed insights into the delivery of the programme; beneficiaries, programme workers and external professionals were all interviewed to help us understand delivery from the perspective of the various stakeholder groups involved in the programme; and a longitudinal design was deployed to capture any changes in participants' perspectives over time. Although the programme and the study were theoretically grounded in personalisation and person-centred support, we were cognizant of the related concept of 'interprofessional collaboration' when interpreting our findings. Interprofessional collaboration occurs when professionals from different backgrounds work together to achieve common goals and deliver high quality patient-centred support and care across settings (Green & Johnson, 2015; World Health Organization, 2010).

Recruitment

First, a member of the research team (TP) briefed all current programme workers (n=8) about the study. All 8 agreed to participate themselves. Programme workers then asked all their current beneficiaries (n=21) if they would like to be involved. All 21 agreed and were

introduced to TP by their worker. After talking through the study with TP, all beneficiaries were still interested in participating and provided contact details so that TP could contact them again. The programme team also provided a list of external professionals (referred to as 'partners') working with the programme (n=13). TP reviewed the list to identify partners from a range of local services including housing, health, the police, and charities/ third sector services. He then contacted these individuals directly and six agreed to be involved. No exclusion criteria were deployed in recruiting programme workers, beneficiaries or partners.

Data collection and participants

In total, 56 face-to-face semi-structured qualitative interviews were conducted at two time points. Between May 2016 and October 2017, interviews were conducted with 21 beneficiaries, 8 programme workers, and 6 external partners (n=35). Follow-up interviews were then conducted approximately 9 months later with 8 of the beneficiaries, 7 programme workers, and all 6 external partners (n=21) (see Table 1 for additional participant details).

Table 1

Each interview was conducted by TP and lasted between 40 and 70 minutes. One person (TP) conducted all fieldwork for several reasons: first, we needed to establish a high level of trust with all participants (especially if we wanted to reassure them that they could be critical about the programme); second, we wanted all the interviews to be conducted in a consistent way to facilitate comparisons during data analyses; and third, the fieldwork arrangements were necessarily complicated and it was practically easier for one person to co-ordinate these.

Other members of the team supported TP throughout data collection, acting as sounding boards and providing reflections on both fieldwork progress and interview content.

All interviews followed a topic guide, with separate guides being used for each of the three participant groups. First and second interview guides varied slightly, with the latter focusing mostly on the period since the first interview. All of the guides covered the same core topics: participants' personal circumstances; views and experiences of the programme, with particular reference to personalisation/ person-centred support and personal budgets; and suggestions for improving the programme. None of the participants was paid for participating in the study.

Analysis

All interviews were audio recorded and transcribed verbatim by a professional transcriber. All transcribed data were then coded using the qualitative software programme MAXQDA (version 10). Six separate coding frames were used – one for each participant group at each time point. The coding frames comprised mainly deductive codes from the topic guide with some inductive codes emerging from the data. The coded data were then analysed via Iterative Categorization (Neale, 2016). To this end, all coded data were reviewed line by line to identify themes and patterns in the data. These were summarised in Microsoft Word documents (one document per code). Subsequently, all of the Word documents were reviewed to isolate the challenges experienced in delivering the programme. The challenges were then grouped, yielding five inductive categories. These five categories are presented below with anonymised quotations used to illustrate key points.

Ethical considerations

Ethical approval for the study was granted by a University Research Ethics Committee. Participation was voluntary and informed consent was obtained from all participants prior to each interview. At first interview, all participants gave consent for follow up. All interviews were conducted in private with only the participant and the study researcher (TP) present. Each participant was reassured that all information collected would be kept confidential and anonymous.

FINDINGS

1. Poor understanding of the programme

Beneficiaries, workers and external partners

Beneficiaries, workers and external partners at both initial and follow-up interviews reported that they did not really know what the programme 'did', who it was for, or what the personal budgets could be spent on. They were also confused by the programme's unconventional terminology (for example, 'beneficiary' rather than 'client' and 'nomination' rather than 'referral').

Beneficiaries

Notably, none of the beneficiaries knew what the term ‘personalisation’ meant and many did not understand why they were on the programme. As one beneficiary explained:

“Well I don’t know really... They [workers from the programme] came and saw us and said... ‘You’ve been allocated to us. We’ve been sent here to help you’.”

(Beneficiary 15, female, interview 1)

In addition, many beneficiaries did not know that their personal budget was worth £12,000; some thought that it was worth a different amount and others said that they did not know what it was worth at all. Moreover, being unexpectedly ‘given’ a large sum of money caused some beneficiaries to feel confused and even suspicious:

“I’m suspicious, still suspicious... Like this money. I’ve never had help like this before in my life... I still wonder ‘what’s this about?’” (Beneficiary 14, male, interview 1)

Workers

Several workers reported that uncertainty - particularly regarding their job roles, how they were supposed to work collaboratively with other services in helping beneficiaries, and the purpose of the budgets – had impeded delivery of the programme in the early months. Workers also stated that the lack of a written policy documenting the types of goods and services on which personal budgets could be spent created problems for them when trying to decide if the purchases beneficiaries wanted to make were appropriate. At their second

interviews, most workers said that clarity regarding the budgets had improved since purchasing guidelines - developed collaboratively with beneficiaries and other service users, workers and management - had been introduced in 2017. In addition, they explained that positive changes had now been made to ensure that all beneficiaries had better information about their budgets:

“They [beneficiaries] should be informed about how much money they have... I think it probably wasn't very clear between us if we should say something about it or not. We eventually discussed it and agreed that clients should be told about how much they have.” (Worker 5, interview 2)

External partners

External partners, meanwhile, repeatedly expressed confusion about the programme's remit, eligibility criteria, referral processes, duration of time working with beneficiaries, and procedures for ending relationships with beneficiaries. Some argued that this deterred them from referring people into the programme, but also confused clients whom they wanted to nominate:

“We were quite confused about what [the programme] did... And I know that the client we were working with, joint working, found it quite confusing as well. Because he didn't particularly understand the idea of personalisation.” (Partner 4, interview 1)

2. Beneficiary and worker characteristics and needs

Beneficiaries

Beneficiaries were generally very open about their needs and the high levels of support they felt that they required. For example, they described complex histories of mental health problems, substance use, housing problems, and offending (all criteria for entry to the programme). In addition, they spoke of past traumas, physical health problems, terminal illnesses, relationship problems, social isolation, lack of education, and worklessness etc. Some also said that their motivation to change was low or that they were difficult people to engage and work with: ‘I’m just one of them people as dosen’t listen’, ‘I’m a very, very, very difficult person’, ‘I’m not very reliable’. A few beneficiaries said that they were too irresponsible with money or poor at budgeting to be given a budget to manage. Others acknowledged that they had sold items bought from their budgets in order to purchase drugs:

“I’m disappointed in myself that I sold it [laptop computer bought from personal budget]. Because I said I would never sell it... I had always wanted a laptop. Yeah, even to this day, I’m still gutted that I sold it.” (Beneficiary 12, male, interview 1)

Workers

Workers at both interview stages similarly reported that beneficiaries often lacked motivation and needed a great deal of support. Furthermore, some workers were not convinced that all beneficiaries wanted to become independent:

“It’s about this whole becoming independent, coming out of the system, getting out of that loop. Some people really are quite happy being in the system and that’s the flaw in the plan... We thought we [the programme team] will march in on this white horse and everyone will... want to leave the system. But some people are quite happy, because it’s a nice cosy place.” (Worker 1, interview 1)

In relation to the budgets, workers sometimes emphasized that beneficiaries did not have the skills or ability to make purchases independently. Indeed, some argued that the £12,000 budget could overwhelm beneficiaries. Others explained that beneficiaries struggled to make ‘good’ decisions about how to spend their budget and to appreciate the value of items bought. Furthermore, several workers felt that beneficiaries did not have the cognitive capacity to think ahead and plan. Therefore, they tended to want to purchase goods for immediate use (such as phones or household items) rather than services (such as training or educational courses) that might help them in the longer-term:

“They [beneficiaries] want to focus on buying goods, not really services... They are focused on meeting their basic immediate needs. Like ‘OK... I’ve been given a room in a hostel... I need a telly [television] to spend my time, keep myself busy, watch some telly. I need bed sheets, I need a lamp, so I need goods’.” (Worker 5, interview 2)

Workers also explained that their own unmet training and support needs were undermining the programme. Specifically, they said that they required more guidance, supervision, and opportunities for team building and career development. Indeed, workers frequently expressed concerns and frustration that they did not know whether or not they were doing a

good job. In their second interviews, several workers voiced resentment at the stresses of their job, including the feeling that they had to be on call twenty-four hours a day, seven days a week. Furthermore, some stated that they struggled to maintain professional boundaries when beneficiaries made unacceptable demands:

“I don’t think it’s reasonable to be left a message at three o’clock in the morning... I’m not going to get back to you at three o’clock in the morning. I’m sleeping... It’s about being boundaried with clients as well.” (Worker 5, interview 2)

3. Contested ownership of the personal budget

Beneficiaries

At both initial and follow-up interviews, most beneficiaries emphasized that they did not feel that they ‘owned’ their budget or that it was ‘their money’; instead they believed that it belonged to the programme or to the programme funder:

“I feel like it’s their money... I don’t feel it’s my money to spend.” (Beneficiary 1, male, interview 1)

“It’s not my money, is it? They’re obviously giving it to me to help myself... It’s obviously not my money.” (Beneficiary 3, male, interview 1)

When asked why they felt this way, beneficiaries gave a range of reasons, including: their worker physically controlled the credit card; the budget was not held in their own bank accounts; the budget could only be spent if certain conditions were met (for example, the beneficiary had to stop drinking); they had been refused items they wanted; and their worker or the wider programme team often had the ‘final say’ on which items could or could not be purchased. Some beneficiaries additionally explained that they had wanted to buy a particular item (for example, a certain phone or pair of trainers), but their worker had encouraged them to go to a cheaper shop or to buy a second-hand item instead. In consequence, beneficiaries sometimes said that they had bought goods that they did not really want. Others expressed frustration at the fact that they urgently needed money for items that their budgets could not be spent on, such as food, bills, rent, or private residential drug treatment.

Most beneficiaries emphasised that having to ask their worker to use the budget and having things bought ‘for them’ by their worker was belittling and made them feel ‘awkward’, as if they ‘could not be trusted’, and as if they ‘were begging’. Reflecting on this, a few beneficiaries said that they were proud people who had never previously asked others for money:

“Every time we buy something, I say ‘please’ and I say ‘thank you’... I hate doing it... I’ve never done it before in my life... And I just don’t like the fact that I’ve got to come and ask.” (Beneficiary 5, male, interview 1)

By their second interviews, beneficiaries routinely described the budget as ‘pointless’ or ‘insulting’, and said that these feelings made them reluctant to purchase anything. Most expressed a desire for more control over what they could spend their budget on and how the

purchases were made (for example, by having their own credit card with a fixed sum of money pre-loaded onto it). Only a few stated that they preferred their worker to have control over the budget so that they did not ‘waste it’.

Workers

Programme workers had differing views on who actually owned the personal budget. Some believed it was co-owned by the beneficiary and their worker - so decisions on how it should be spent needed to be based on their joint conversations about meeting goals. Other workers reported that the budget belonged to the beneficiary, whilst one worker felt that it was owned by the worker. Some workers acknowledged that they had problems separating their own values and opinions from the purchases beneficiaries wanted to make. For example, they questioned purchases as being too expensive or too ‘risky’, and then said that they tried to remind themselves that the budget was not actually theirs. Workers also had mixed views on the acceptability of particular purchases and expenditures, particularly food and tobacco products:

“I think tobacco's a bit of a tricky subject... One of my beneficiaries is receiving tobacco at the moment because he has no recourse to public funds and, for him, that is the only thing that can keep him focused and settled and comfortable, is tobacco.”

(Worker 2, interview 1)

4. Strained interprofessional relationships

Beneficiaries

Beneficiaries only occasionally referred to difficult relationships with the programme workers, largely relating to workers giving them misleading information about their budget or preventing them from spending their money on specific items that they wanted to buy. In fact, beneficiaries were overwhelmingly positive about the relationships that they had with their programme workers. They repeatedly emphasised how much they liked their workers and valued the one-to-one intensive support they received from them, particularly when this was provided out of standard office hours:

“They [programme workers] would help you in any way. Housing, social [welfare benefits]... They help with my forms... even after hours, have a little chat, a coffee and a café. She [programme worker] will make her way just for a little chat, six o’clock in the evening.” (Beneficiary 6, female, interview 1)

Workers

Workers similarly tended not to report problems in the worker/beneficiary relationship; although, at their second interviews, some expressed concerns that beneficiaries might become dependent on them and so they wanted to create stronger professional boundaries for themselves. In contrast, workers often referred to difficult relationships between the programme team and other local service providers, noting how these impacted negatively on the delivery of the programme. Whilst workers acknowledged that other services were very busy, they also said that they were often inflexible and unco-operative. In attempting to account for this, workers worried that their relationships with external agencies had ‘got off

to a bad start' because the programme team had initially been overly-confident about their ability to help 'anyone' and 'boastful' about their large budget. With hindsight, they believed that this had been ill-judged since other local services were facing funding cuts, retendering, job losses and decommissioning:

"I think initially they [external service providers] thought... who were we coming in, swanning in with our big budgets, and telling them that they weren't doing things right?"
(Worker 4, interview 1)

"I think we had this kind of like 'we're new' kind of arrogance. 'We're going to come and sort everything out', pointing our fingers at people, 'actually what you're doing isn't right and we're going to come and fix it'." (Worker 6, interview 2)

External partners

External partners also identified problems in their relationships with programme workers and confirmed that the programme had originally been packaged and introduced to other services in a way that seemed 'arrogant'; a sentiment which they said had lingered. Furthermore, partners reported that the generous resourcing of the programme compared to other local services fuelled interprofessional tensions:

"It [the programme's approach] felt quite arrogant. It felt like, you know, 'we know better than all you guys do'... I think some people are quite jealous about the fact that they've got guaranteed funding for a long time as well... because everybody else is on three-year contracts that could be ended at the drop of a hat, and no one knows really

month-to-month whether they're going to have a job next month.” (Partner 3, interview 1)

Most partners additionally complained that the programme team did not communicate enough with other services; for example, they said that the programme team seldom reported individual client outcomes back to them, failed to explain when and why they were no longer working with beneficiaries, and did not clarify why they had not accepted nominated beneficiaries onto the programme. At the follow-up interviews, partners also said that the programme team and staff in other local services often had different and conflicting views on how best to help people with multiple and complex needs and this compounded already tense relationships. Specifically, programme workers were perceived as ‘wanting to use the budgets to solve problems’, whereas staff in other services were often committed to existing psycho-social interventions.

5. Bureaucracy and outcomes monitoring

Beneficiaries, workers and external partners

Beneficiaries, workers and external partners at both interview stages all agreed that the process of making purchases from the budget was overly bureaucratic, slow and frustrating. This was because beneficiaries had to ask workers who then often referred requests back to the wider team for discussion and decision; a process that could take two to three weeks.

Beneficiaries and workers

In addition, beneficiaries and workers reported limitations with the outcomes data being collected by the programme. For example, beneficiaries identified a range of goals for themselves that they did not feel were being addressed because the programme workers were too focused on the budgets. These included rebuilding family relationships, finding a supportive partner, having children, making new friends, helping others, going travelling, securing work, and passing their driving test:

“I want to sort out my life... stop offending, stop taking drugs, work every day, live a normal life.... No drugs, family, friends ... They [programme team] are just dealing with the budget, financial things, and support if I need it.” (Beneficiary 5, male, interview 1)

Workers, meanwhile, reported that the assessment scales used within the programme were problematic because they were too subjective, the team had not been trained in how to administer them, beneficiaries were not capable of completing them, and the outcomes captured did not appropriately reflect the ‘softer’ achievements made with clients (such as improved eye contact, reconnecting with family members, having someone to talk to, or generally feeling better). Workers also stated that in helping a beneficiary who was not accessing services to use services, they were potentially increasing that individual’s costs to ‘the public purse’, when a key outcome of the programme was to reduce individuals’ costs.

Workers and external partners

According to workers and partners at both initial and follow-up interviews, recruitment of beneficiaries to the programme was hindered by an unnecessarily complex recruitment

process that placed unreasonable demands on external services to provide detailed information that those services often did not hold or did not have the time or capacity to provide:

“By asking us how many hours you're spending with this [potential beneficiary]... to cost out [whether the potential beneficiary meets the eligibility threshold], it just doesn't make any sense to me. It's very time consuming.” (Partner 6, interview 1)

Furthermore, both workers and partners reported that initial expectations of what the programme would deliver had been unrealistically high. Both groups explained that the programme team did not have a ‘magic wand’ and it might take years for clients with such complex needs to achieve any sustained positive change. Nonetheless, partners wanted the programme team to be more collaborative when reporting any positive outcomes that were achieved. In particular, partners argued that the programme team needed to acknowledge the work of other services in helping beneficiaries because it was disingenuous to attribute positive outcomes in the beneficiaries’ lives solely to the work of the programme:

“They [programme workers] were saying ‘Oh, these are our outcomes’, and kind of owning all these outcomes. And keyworkers and managers [from other services] were saying ‘Well actually we were involved in that too’.” (Partner 2, interview 2)

DISCUSSION

The data presented derive from an innovative ‘test and learn’ programme designed to provide community-based personalised support, including a personal budget, to people with multiple and complex needs. The aims of this paper were to identify the challenges encountered in recruiting and retaining clients (known as ‘beneficiaries’) and to share learning. Personalisation and person-centred support, along with the allied concept of interprofessional collaboration, are now used to frame our discussion of the findings. The paper does not offer an evaluation of the programme or of the budgets; nor does it take into account changes made to the programme after data collection for the study had ended. These included simplification of the referral or ‘nominations’ process and the introduction of a new delivery model; both intended to increase beneficiary numbers and to help the programme team integrate more fully within local service delivery systems.

The analyses highlighted five broad categories of challenge: 1. poor understanding of the programme; 2. the characteristics and needs of both beneficiaries and programme workers; 3. lack of clarity regarding who owned and controlled the budget; 4. strained interprofessional relationships; and 5. excessive bureaucracy combined with difficulties establishing programme outcomes. The three participant groups emphasized slightly different challenges; for example beneficiaries and programme workers (but not external partners) discussed ownership of the budget, whereas programme workers and external partners (but not beneficiaries) identified difficult relationships between the programme team and other local service providers. Overall, however, there was considerable consistency across the three participant groups and at both interview stages, so supporting the trustworthiness of the findings (Nutt Williams & Morrow, 2009).

Various challenges identified were consistent with the extant literature on personalisation and personal budgets; for example, unclear programme eligibility criteria; concerns about clients' ability to manage a personal budget; bureaucracy and delays in making purchases; staff anxieties about risk; and the tendency of staff to make assumptions and decisions for people (Glynn et al., 2008; Lymbery, 2012; Moore et al., 2017; Veale, 2012). Other challenges were more unexpected; in particular, beneficiaries' suspicion, frustration and eventual hostility to, and reluctance to use, the budgets. Similar problems have, nonetheless, been identified in an evaluation of a novel contingency management-related intervention, which provided personal budgets to people receiving supervised injectable opioid treatment (Neale, Tompkins, & Strang, 2016). This evaluation also found that patients were confused by, and suspicious of, the budgets; angry with, and frustrated by, the bureaucracy and delays in making purchases; and in consequence often dismissed the intervention.

Although we found that practical, ethical and philosophical challenges undermined the personal budgets, considerably fewer problems were identified in relation to the delivery of personalised support. For example, participants expressed poor understanding of what the budget was, how much it was worth, how it could be spent, what it could be used for, who owned it, whether beneficiaries had the skills or ability to manage it, who made decisions about purchases, and who physically made the purchases. In contrast, challenges in delivering one-to-one support were largely confined to workers requiring more supervision and training, feeling stressed by their clients' demands, and needing assistance in setting professional boundaries. Indeed, beneficiaries were consistently positive about the individualised support received from the programme team whilst being negative about the budgets. Further exploration of the data is required, but this suggests that the personal budgets might be undermining, rather than enhancing, personalisation for this population.

Our findings support the assertion that the personalisation agenda is controversial (Needham & Glasby, 2014a) and has run ahead of the evidence base (Beresford, 2012; Needham & Glasby, 2014b; Sullivan, 2001). However, it would be unfair to claim that the programme was established to undermine the welfare state, reduce public sector services, deprofessionalise workers or transfer state responsibility back to those already in need (Barnes, 2011; Ferguson, 2007; Lloyd, 2010; Needham & Glasby, 2014a). More accurately, it was introduced in an era of austerity with the stated aims of generating positive, manageable and sustainable outcomes at reduce costs to society whilst also enabling the beneficiaries to live independently. Nonetheless, prioritization of the budgets over other aspects of personalisation clearly played to neo-liberal notions of individualism, consumerism and the market place and detracted from the wider need for personalised care and psycho-social support (including help with non-material difficulties such as addiction, past trauma, health problems, relationship difficulties, social isolation and lack of meaningful activity) that beneficiaries often wanted and needed to enable them to achieve greater autonomy (Lymbery, 2012).

‘Sharing’, ‘partnership’, ‘interdependency’, and ‘symmetry in power relationships’ have all been identified as central facets of interprofessional collaboration (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005). It is therefore concerning that our analyses revealed limited evidence of beneficiaries, workers and partners sharing responsibilities, decision-making, philosophy, data or planning; frequent poor communication and mistrust which undermined partnership working; and little evidence of professionals depending on, and supporting, each other to address the beneficiaries’ needs. Additionally, we found instances of imbalances in power, knowledge and control rather than beneficiaries, workers

and partners endeavouring to empower each other. For example, beneficiaries and partners did not have information about the programme and did not understand its terminology; workers purchased items ‘for’ beneficiaries and made assumptions about beneficiaries’ inability to manage their own budgets; and workers had significantly more resources (funding and time to spend with beneficiaries) than partners in other local services.

In line with other social care literature (Keene, 2001; Rankin & Regan, 2004; Rosengard et al., 2007), we also identified problems establishing and measuring appropriate outcomes for people with multiple and complex needs. As our participants explained, people with multiple and complex needs may lack skills, be dependent on welfare systems, and have low motivation. Consequently, they are unlikely to make transformational life changes in one or two years. Accordingly, there is a need for outcome measures that capture short-term and more nuanced achievements, particularly those that matter personally to people with multiple and complex needs. In a detailed evaluation of individual budgets, Netten et al. (2012) assessed personalisation using global measures of psychological well-being and quality of life plus a measure of social care related quality of life. However, an accessible, validated, self-report outcome measure of ‘recovery’ (the Substance Use Recovery Evaluator; SURE) has since been developed in conjunction with people reporting substance dependence, mental health problems, offending and homelessness (Neale et al., 2016). SURE measures five life areas (substance use, self-care, relationships, material resources, and outlook on life) and could potentially be used, or adapted for use, by programmes supporting people with multiple and complex needs.

Overall, our study highlighted how the delivery of personalised support was undermined by interacting ‘individual’, ‘organisational’, and ‘system’ level factors. These included

individual beneficiary and worker needs, comprehension, values, and preferences; programme terminology, decision-making processes, and provision of staff support and training; inter-agency working in terms of requests for information from other services, communications with other services, and how the programme was branded or ‘sold’ to other services; and the wider social care environment, including funding cuts, service retendering, job losses, and the need to demonstrate positive programme outcomes. This complexity reminds us that the concept of personalisation is not reducible to relationships between professionals and their clients within a single service. The delivery of person-centred support is inextricably linked to, and embedded within, the broader social, economic and political systems and structures within which people live and work. Personalisation fundamentally depends on good interprofessional collaboration but also requires an adequately funded public and social care sector (Needham, 2011; Netten et al., 2012; Slasberg, Beresford, & Schofield, 2012). Even a well-funded programme will not thrive if the rest of the system is under-resourced.

CONCLUDING COMMENTS

Our findings provide insights into how other programmes might avoid or overcome the kinds of challenges identified in providing personalised support to people with multiple and complex needs. Most obviously, there is a requirement for clear programme information regarding eligibility, referral processes, programme goals and content, workers’ roles, and anticipated outcomes; as well as the use of terminology that is familiar to other services. In addition, referral processes should be as straightforward as possible, with guidelines relating to any personal budgets ideally developed in collaboration with clients and other key

stakeholders. Workers are also likely to need appropriate training, support and supervision, including help in setting professional boundaries. Meanwhile, systems should be established to ensure that there is good communication with other services; for example offering feedback, managing expectations, sharing achievements, and being sensitive to the workloads and stresses of other professionals.

More intentional efforts to increase interprofessional collaboration – by, for example, providing opportunities for people from different professional backgrounds to meet and spend time together formally and informally - could also potentially improve programme outcomes. This is because interprofessional collaboration can create opportunities for workers from different sectors to learn from other, cross fertilize ideas, and progress beyond traditional ways of thinking (Green & Johnson, 2015). This can in turn lead to greater efficiency, improved skills mix, increased responsiveness, more holistic services, and ultimately more user-centred practice (Littlechild & Smith, 2013). Good collaborative practice is underpinned by two core competencies: i. understanding and appreciating each other's professional roles and responsibilities and ii. communicating effectively (Suter et al., 2009). Had more effort been invested in enabling the programme staff and external partners to recognise their complementary skills and functions and to develop good communication strategies at the outset of the programme, better outcomes might have been achieved subsequently.

Finally, offering people with very complex needs a significant personal budget to 'own' and spend 'as they choose' in practice did not seem to contribute to the personalisation of their care. Instead, the personal budgets created frustration. Providing clients with accessible information about the budget, engaging them as much as possible in discussions about how

personal budgets could and could not be used, and aiming for ‘joint-decision making’ (rather than client control) might actually have been more empowering than unworkable promises of ownership that resulted in resentment. Alternatively, the money invested in the personal budgets might have been better spent on providing beneficiaries with additional one-to-one support, particularly in the evenings and at weekends; on offering further training and supervision to the frontline workers; and/or on collaborative activities to build worker/external partner relationships. The latter might, for example, have included joint training for workers and external partners on topics of likely mutual interest, such as: service user needs; local funding arrangements; service remits and philosophies; information sharing and outcomes monitoring; substance use disorders; dual diagnosis; co-morbidity; trauma-informed working; and local supported employment and employability schemes. This is, however, easy to suggest with hindsight and would need to be tested in practice. The programme discussed in this paper took a brave step in terms of service delivery, but also in allowing us to study and report what happened so that others can now learn from, and potentially avoid, some of the challenges they encountered.

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Joanne Neale receives honoraria and some expenses from the journal *Addiction* in her role as Commissioning Editor and Senior Qualitative Editor. She has recently received unrelated research grants from pharmaceutical companies: Camurus AB and Mundipharma International Ltd. John Strang is a researcher and clinician who has worked with a range of types of treatment and rehabilitation service-providers. He has also worked with a range of governmental and non-governmental organizations, and with pharmaceutical companies to seek to identify new or improved treatments from whom he and his employer (King's College London) have received honoraria, travel costs and/or consultancy payments. None of these has any relationship to the area reported in this paper. For a fuller account, see John Strang's web-page at: <http://www.kcl.ac.uk/ioppn/depts/addictions/people/hod.aspx>. Tom Parkman has no disclosures to report.

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Table 1: Participant characteristics¹

Beneficiaries	<ul style="list-style-type: none"> • Of the 21 beneficiaries initially interviewed, 16 were male and 5 were female. They had a mean age of 41 years (range 22-54 years). Seventeen described themselves as White British, two as Mixed Race, one as Black British, and one as Asian British. At the point of referral to the programme, 20 had a history of offending, 16 had no formal qualifications, 15 had a problem with alcohol or other drugs, 13 had a diagnosed mental health disorder, and 8 were street homeless or living in a hostel. • Follow up interviews were completed with 8 of the 21 beneficiaries (6 males and 2 females). They had a mean age of 38 years (range 22-52 years). Six described themselves as White British, one as Mixed Race and one as Black British. Six were still actively working with the programme; the other two were interviewed in prison and were no longer engaged with the programme. Neither the research team nor the programme workers were able to establish contact with the remaining 13 beneficiaries.
Programme workers	<ul style="list-style-type: none"> • Of the 8 programme workers initially interviewed, 6 had been in their current role since the start of the programme and two had joined the team in 2016. They had all previously worked in the public sector (housing, criminal justice, addictions, mental health, social and family work, and service commissioning), although only one had previous work experience of personalisation and personal budgets. Three had a personal history of service use (although many years previously). • The 7 programme workers interviewed at the follow up stage included 6 workers who had been interviewed initially (one of whom had now left the programme) and one new staff member. Two other programme workers initially interviewed had since left the programme and could not be contacted.
External partners	<ul style="list-style-type: none"> • The six external partners initially interviewed were working in a range of local services, including housing, health, the police and the charity/third sector. All were currently working with people who had multiple and complex needs, and one had past personal experience of homelessness and alcohol dependence. • All six were interviewed at follow up.

¹ Only basic details are provided to protect participant anonymity