



## City Research Online

### City, University of London Institutional Repository

---

**Citation:** Laybourne, A. H., Jepson, M. J., Williamson, T., Robotham, D., Cyhlarova, E. & Williams, V. (2014). Beginning to explore the experience of managing a direct payment for someone with dementia: The perspectives of suitable people and adult social care practitioners. *Dementia*, 15(1), pp. 125-140. doi: 10.1177/1471301214553037

This is the accepted version of the paper.

This version of the publication may differ from the final published version.

---

**Permanent repository link:** <https://city-test.eprints-hosting.org/id/eprint/5212/>

**Link to published version:** <https://doi.org/10.1177/1471301214553037>

**Copyright:** City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.

**Reuse:** Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

---

City Research Online:

<http://openaccess.city.ac.uk/>

[publications@city.ac.uk](mailto:publications@city.ac.uk)

---

Beginning to explore the experience of managing a direct payment for someone with dementia: the perspectives of suitable people and adult social care practitioners

Anne H Laybourne<sup>1</sup>, Marcus J Jepson<sup>2</sup>, Toby Williamson<sup>1</sup>, Dan Robotham<sup>1</sup>, Eva Cyhlarova<sup>1</sup> and Val Williams<sup>2</sup>

This study was funded by a NIHR School for Social Care Research grant.

---

<sup>1</sup>The Mental Health Foundation, London, UK

<sup>2</sup>Norah Fry Research Centre, University of Bristol, UK

**Corresponding author:**

Anne Laybourne, City University London, School of Health Sciences, Northampton Square, EC1V 0HB

Email: [anne.laybourne.1@city.ac.uk](mailto:anne.laybourne.1@city.ac.uk)

**Abstract**

Following legal improvements made around mental capacity together with the Health and Social Care Act 2008, it is now possible for a direct payment to be paid to a 'Suitable Person' to manage on someone's behalf to purchase directly care and support services. People with dementia are a key group affected by this change in England of adult social care. We interviewed nine social care practitioners and seven Suitable People for people with dementia across five English local authorities to begin to examine their experiences of this new method of social care provision. Findings from thematic analyses suggest positive outcomes and multiple beneficiaries but some challenges: potentially inappropriate processes, support planning, divergence in attitudes towards care and support outcomes. Implications for practice include obfuscation of recipients' and Suitable People's best interests and supporting practitioners to explore fully clients' aspirations for care and support.

**Keywords**

Mental capacity, dementia, indirect payments, personalisation, social care, Suitable Person

## **Introduction**

There has been a move in recent decades towards a personalised social care system in England, with a central goal of 'choice and control'. Individuals are invited to make decisions about their own needs and organise their own support through self-directed support processes (Netten et al., 2012; Williams et al., 2012) and in the simplest terms, this is realised through personal budgets, a means-tested financial representation of how a local authority can meet the needs of individuals eligible for publicly funded social care. In 2013/2014, 648,000 people, 62% of all individuals eligible and receiving social care services, received self-directed support and 24% of this support was received in the form of a direct payment (Health and Social Care Information Centre, 2014). with local authorities making cash payments to individuals to pay for and manage their own support. Since the 1996 Community Care (Direct Payments) Act ("Community Care Act (Direct Payments)," 1996) when cash payments were offered to disabled people under the age of 65 years to meet their community care needs there has been a succession of Government initiatives and policies signalling a clear policy direction for a new type of social care provision ("Care Act," 2014; Department of Health, 2005a, 2005b, 2009a, 2009b). With a wider range of individuals eligible for direct payment, for example older people, people lacking mental capacity to consent to the payment, it is important to examine closely their experiences.

## **Background**

Older people are the group least likely to know about personal budgets and most likely to need help to plan support and manage the budget (Bartlett, 2009). In an early pilot of 14 individual budget sites, positive outcomes for those taking up budgets, as opposed to their

previous arrangements, were demonstrated (Glendinning et al., 2008) but older people tend to make less use of the more creative applications of their budget, particularly with respect to employing their own staff. Specifically, direct payments uptake has been patchy across the UK (Priestley et al., 2010) with older people again evidenced as a service user group facing particular barriers (Williams & Holman, 2006). Although known to potentially benefit from direct payments (Clark, 2006), attitudes of both social workers and older people themselves posed significant barriers (Ellis, 2007; Glendinning et al., 2008; Lakey & Saunders, 2011; Leece & Leece, 2006). Low uptake of direct payments has also been associated with poorly informed care managers, lack of direct payment support services, lack of enthusiasm among local authorities, poor public information, overly complicated monitoring systems, and difficulties with associated responsibilities (Davey et al., 2007).

An additional and central complication has always been the question of who is willing to consent to a direct payment and who is able to manage it. In practice, common law interpretations of best interests prevailed until the implementation in 2007 of the 2005 Mental Capacity Act ("Mental Capacity Act," 2005), which introduced a legal definition of capacity, and a process for assessing capacity and making best interests decisions. Following this, the Health and Social Care Act (2008) ("The Health and Social Care Act," 2008) extended direct payments to groups previously excluded on the grounds of incapacity by making it possible for a direct payment to be made to a 'Suitable Person' to manage on their behalf (Department of Health, 2009a). Local authorities must be confident that the Suitable Person is capable of managing the payments and will act in the best interests of the person, within the meaning of the 2005 Act. POhWER, one of the largest providers of advocacy services in the UK considers the terms and responsibilities that bind a service user receiving

a direct payment also bind the Suitable Person: (1) evidence that the direct payment is being properly managed and Returns completed as required by the local authority; (2) a direct payment account must contain the funds to make these payments and the invoices should reflect the amounts specified in the Support Plan; (3) any client contributions/third party top-ups must be paid into the direct payment account by Standing Order; and (4) the Care Manager or direct payment advisory service must be advised of any difficulties experienced managing the direct payment (POhWER, 2014).

People with dementia are among the key groups who can have high social care needs but may lack the capacity to consent to using a direct payment to pay for the appropriate care. With dementia currently affecting over 800,000 people living in the UK (Luengo-Fernandez, Leal, & Gray, 2012), there is considerable concern, but very little evidence, of how social care systems will cope with projected population increases in people with dementia in the coming decades (Kaplan & Berkman, 2011). Reflecting the wider older population's low use of personal budgets as direct payments, a survey of self-selected carers and people with dementia reported only one fifth of respondents using a personal budget or a direct payment arrangement (Lakey & Saunders, 2011). A further 15% had been offered a direct payment or personal budget but had declined. On the whole, where a direct payment was being used, it was to purchase care and support in the home, personal care, and respite services. In a similar vein to the problems perceived by older people with direct payments, people with dementia and their carers perceived the process of acquiring and using direct payments as stressful with a lack of information. Indeed, those who declined one cited additional burden, a lack of confidence, and a complicated or difficult process as three of the top four reasons for declining (Lakey & Saunders, 2011). From professionals, there has

been sustained concern about ensuring the minimisation of risks of harm in the move to personal budgets and in particular direct payments for people with dementia (Jill Manthorpe & Samsi, 2012).

In recognition of the impact that directly purchasing care could have on the carer of the person with social care needs, the IBSEN team developed a linked study of carers for people who paid for their care using a personal budget compared to previous arrangements (Jones et al., 2014). Overall, positive impacts on carers' quality of life, social care outcomes, and psychological wellbeing were associated with the individual budget group. Specifically, a person's individual budget could enable the carer to 'have a life of their own'. The IBSEN study pre-dates the legislation making available cash payments to people unable to consent to the payments. Within our wider study of direct payments in the context of the Mental Capacity Act (Cyhlarova, In peer review; Jepson et al., In review), we wanted to begin to examine the experiences of carers who took on the role of Suitable Person for a person with dementia, given the demography of this disease and the political will behind direct payments. This paper therefore reports on data collected between 2012 and 2013 from a group of social work practitioners self-identified as having a specialist interest or practice in older adults' social care and a group of Suitable People receiving and managing a direct payment for someone with dementia.

## **Methods**

The current paper examines the experiences of self-identified older adults' services practitioners and Suitable People managing an indirect payment for someone with dementia. Practitioners with a specialist interest in older people could not be identified in



one of the original study sites, therefore data presented here were collected from participants in five English Adults' Social Services (Funder: NIHR SSCR, in review).

*Recruitment of participants*

Recruitment of practitioners was a two-staged snowball process: First, following local research governance approval, the site contact was asked to identify or introduce to researchers appropriate adult social care team leaders, whose team had experience of direct payment cases where the user lacked the capacity to consent. This will be referred to as an indirect payment for the remainder of this paper. A contact at each site supplied team leaders with study materials including a study protocol. Second, team leaders were invited to identify individual social work practitioners with experience of direct payments for people who lack capacity to consent. It was not stipulated that the practitioner was case-carrying to maximise the breadth of experiences available to us. These identified practitioners were emailed an invitation to participate and a Participant Information Sheet.

Recruitment of Suitable People to the study followed identification by participating practitioners of any current indirect payment case within their team and obtain consent from the Suitable Person for their contact details to be passed to the research team.

Suitable People were supplied either by the practitioner or researcher study materials including a Participant Information Sheet. The Suitable People identified were not necessarily part of the identifying practitioner's caseload.

*Procedure*

The overall study was approved by the Social Care Research Ethics Committee (11/IEC08/0018, 15 June 2011). We also received support from the Association of Directors of Adult Social Services (ADASS) (RG11-007, 04 July 2011) and met local research governance requirements at each Local Authority study site. Data collection followed a qualitative methodology. Written informed consent was obtained from practitioners and Suitable People before interview following a full explanation of the study. Consenting practitioners were offered individual face-to-face or telephone interviews, while consenting Suitable People were offered a home visit or telephone interview. Interviews took on average 60 minutes.

*Data collection*

*Semi-structured interviews.* Interviewed practitioners were asked about indirect payment discussions with new clients, strategies for imparting information, best interests decision-making, capacity assessment, identification of a Suitable Person, support, and reviewing and monitoring practices. Suitable People were asked about the history behind the indirect payment, becoming a Suitable Person, the support planning process, support received, interaction with Local Authority departments, and impact of indirect payment on recipient. All interviews were audio recorded and with consent from the participant transcribed verbatim using an external transcription service. Interview topic guides were developed in consultation with an expert Research Advisory Group, members of the wider research team, and informed by the literature on direct payments.

## **Analysis**

Each interview transcript was checked and read in full by two researchers (AL, MJ) to gain an overall perspective of the data and to allow for a comparison of interpretations, enhancing reflexivity. An iterative process of analysis was employed, using the collection of data as an important phase of analysis, with early interviews informing future ones. The formal process of data analysis used the interview guides as a starting point and AL and MJ reread transcripts independently. Notes were made in the margins and discussed during research meetings. Using nVivo 9, open coding techniques generated codes which were organised into themes according to a framework agreed by consensus within the wider research team. Relationships between themes were identified through constant comparison of transcripts, codes and categories. AL and MJ reviewed the codes and their application and during wider group meetings discussed alternative interpretations until consensus was reached about the 'best fit' interpretation.

## **Findings**

### **Participants**

Nine practitioners self-identified as specialists in older adults' social care and seven Suitable People were managing an indirect payment for someone with dementia. The Suitable People included in this study represent the following relationship to the person with dementia: daughter-in-law, neighbour, sister-in-law, husband, son, and daughter and thus included examples of both familial and non-familial bonds. Five were female, three were over 65 years old. All Suitable People self-reported providing care to the indirect payment recipient.

Practitioners self-identified as having a specialist interest or practice in older people and were employed in a range of different areas of practice and position: finance, self-directed support, sourcing of services and both case-carrying and managerial.

In terms of outcomes for people with dementia following the care and support put in place using an indirect payment, this modest study of Suitable People's and practitioners' experiences broadly suggests that indirect payments can benefit this group in much the same way as they benefit the wider older population. Thus, people were able to remain in their homes, receive care tailored to their needs and lifestyle choices, receive stimulating support, access their local community, and maintain a flexible and dignified care routine. However, two main "mixed messages" themes emerged: carers benefitting on the one hand from the flexibility of a direct payment package but with concomitant struggles with the process on the other, and practitioners who are supportive of direct payments in this client group while exhibiting some reservations.

### ***Flexibility for carers but with some challenges***

#### **Flexibility and choice**

A recurring theme was that the flexibility of packages enabled through an indirect payment was commonly designed to benefit others, often informal carers, so that care work fitted better into their daily schedules. SP6 illustrates this by describing how local authority services did not suit her due to the stress of having to be present at the same time as staff to intervene when her sister-in-law became aggressive. Thus the care being provided did not actually relieve her of her caring duties; she was still *on duty*. She demonstrates here that

any care package provided should benefit her too by allowing her to purchase the care she wanted that would allow her some time off:

*We came to the point where I was having to stand guard like a policeman because [sister-in-law] was getting a bit handy. She was pinching and sometimes she'd kick ... making it very difficult for them to do their job. So I said, Well this is ridiculous. This is supposed to be helping me, and what I'm actually doing is standing, assisting you, because of her behaviour... If she pinches me and kicks me, well so what, she pinches me and kicks me. But at least if I had a direct payment I could have the help I wanted and I would therefore get time off (SP6)*

Managing a direct payment provided this Suitable Person with some free time. However, it was emphasised that the care must be commensurate with what she herself would provide as the primary carer and so any care purchased had to be meaningful, *what I really wanted was someone to come in and **do** things with [recipient]*. Using an example of a sitting service, she described that it was not enough to provide her with time off to the detriment of the recipient's care and support:

*What I wanted was some guilt-free time for myself, when I knew she was getting something that she wouldn't otherwise have got. Because she'd've just been sitting there in the chair. I couldn't see myself going out for an hour and a half for a swim and thinking was she just sitting there going to sleep? (SP6)*

We had examples of indirect payments being used for singing classes, accessing the local community, playing cards with old friends, going to the pub. These activities combine to demonstrate that meaningful activity, using what abilities the recipient has and building on

them, was often the objective being achieved by using an indirect payment. SP4 felt that the support suggested by the social worker would not be *support*, but would entail someone coming in to carry out tasks *for* her father-in-law, suggesting that he would lose what decision-making capacity he had through being passive.

SP5, retired and in his 70s, described how the indirect payment relieved him from informal caring roles and provided him with some flexibility in his life. Directly employing someone to care for his Mother gave him more control, removing the need to remain at home for frequently delayed agency care as had been his previous experience. He described two or three ‘free’ afternoons per week available to pursue his own interests. Indeed, in this case, the indirect payment seemed to benefit the Suitable Person more than the service user as his mother had not been previously distressed by different staff attending her, and despite having just one ‘Personal Assistant’ now, she failed to recognise her. A further example of an indirect payment arrangement benefitting someone other than the recipient was offered by SP14. This Suitable Person perceived that the care arrangements for her Father-in-law directly and positively impacted on her parents-in-law’s relationship, freeing her Mother-in-law from informal caring duties which were very draining and stressful:

*So really it was just having a balance where someone could ... which is what we’ve got now – someone comes in and sits with him three mornings a week, so that my mother-in-law can go out and do her shopping, she can go out and visit family, she can just go out and have a walk or a break. (SP14)*

Benefits and consequences of indirect payments, from the perspective of the Suitable People, were often constructed around how the arrangements related to the family carer in providing support. The indirect payment either offered a way to get involved when

previously they had not been, or to get some relief from providing all care, as in the cases of SP5 and SP14. Importantly, support had to be meaningful.

### Challenges of managing an indirect payment

Two main areas where Suitable People described particular challenges with their role of managing an indirect payment were the assessment process and practitioner information and knowledge in terms of indirect payment-appropriateness for this client group and type of support wanted.

#### Poorly fitting assessment processes

Although the indirect payment outcomes explored in this study provided benefits to people with dementia and very often others providing informal caring duties, there was evidence of challenging areas within the process. The range of assessments carried out was an element particularly prone to difficulties, specifically when these happened, who was present during, and how dementia-appropriate they were. One of the practitioners makes his feelings clear on the question of appropriateness through his comment “direct payments are not made for this client group”.

Suitable People were not always clear what assessment was being carried out and they considered timings of the day and their input to be imperative to any assessment due to symptoms of dementia and other comorbidities e.g. deafness. When questioned about an assessment of capacity, Suitable People often started to discuss a diagnostic assessment for dementia or described a needs assessment. This may be a function of practitioners making multiple assessments during one visit, that it was not always understood by the Suitable Person what the capacity assessment was, or that practitioners did not always adequately

describe the purpose of their visit in the interests of clarity. One Suitable Person was not convinced that the practitioner was very sensitive to the needs of someone with dementia or other age-related physical decline. In this case the indirect payment recipient had long-term hearing loss, due to industrial injury. His health situation was therefore quite complex and the Suitable Person did not feel the capacity assessment being carried out was done well in light of her father-in-law's challenges. She described her father-in-law's propensity to talk as if he were living through the war he had served in in 1956, making the assessment process a challenging one. Whilst acknowledging this, she did not consider the practitioner to have made the appropriate concessions for his behaviour nor to have disentangled the root causes of his difficulties. That is, were the assessments made based on poor hearing or cognitive impairment?

*My father-in-law was wandering all over 1956. And he's also very, very deaf, through industrial injury, in his youth. And ...[sighs]...I don't think, personally, that they tried hard enough, in any formal way, to measure his responses. Were they cognitive deficits? Or was it a hearing deficit? (SP4)*

Suitable People described challenges to assessments including capacity for the purposes of direct payment suitability due to the daily fluctuations of dementia or indeed rapid disease-related decline in health. For example, two respondents highlighted the fact that the time of day had to be taken into account because behaviours fluctuated over the course of the day, *my father-in-law's a sundowner* (SP4), and this made things difficult during assessments with practitioners. SP15 shows how she ensured she was present for the social worker's visit in order to be available to correct the recipient's answers, knowing her intimately through her informal caring role:



*And of course [name] would answer ... what she thought was her answer, but at least I was there to say, Well actually [name], you know, you sometimes used to get up, have some breakfast, go back to bed, then you'd get up, and you wouldn't know whether you'd had anything to eat or not, and ... except you saw the cup in the kitchen (SP15)*

SP15 was especially worried that an assessment for services, and any associated long term decision, might be made erroneously if the social worker saw the recipient on a day when she demonstrated her best cognitive ability and was not privy to how things really could be, 'So it was a case of demonstrating where she needed help, because sometimes ... up and down days, she doesn't always need the same help' (SP15). The Suitable Person explained how she had been present and contributed to the assessment to secure as big a care package as possible:

*So I ... it was quite involved at that time, setting up ... getting everything under way. Yes, it was very involved, in the early days. Social services, the investment, the assessment, the fighting to get the biggest, you know the best assessment (SP15)*

Indeed, from the perspective of the practitioners, one did not consider that the instruments within the system were designed for people lacking the capacity to consent:

*"All the tools that have been designed don't take into account people who lack mental capacity...you know, self-assessments and so forth. Even supported self-assessments...I think we perhaps need different tools that focus on best interest decision-making rather than pretend 'giving a voice' to someone who hasn't got one"*  
(P33)

While more specifically, P27 reported she and her colleagues did not consider direct payments to be appropriate for their clientele of older people with dementia:

*“everybody, every member of staff, all the different disciplines, don't really think it's for our clientele”.*

Poor knowledge and information from practitioners

Suitable People reported negative experiences of practice around indirect payments for older people with dementia. One suitable person raised a formal complaint against a practitioner after being misinformed about direct payments for people with dementia lacking capacity and the practitioner was removed from her case. This problem seemed to extend beyond individual cases; when one Suitable Person was complaining to her contact at her local Alzheimer's Society branch about the social services care being delivered and of her intention to ask her local authority for an indirect payment, she reported that her contact warned *don't let them talk you out of it*, tacitly saying that staff at this branch have not had positive experiences with local authorities on this topic. More directly, one Suitable Person reported hostility from a social worker when she approached them about an indirect payment:

*I found it tricky with our local authority. Although all the written literature that's available says that they are proactively encouraging direct payments for senior citizens, elderly people, there is no information available from his social worker. In fact his social worker got really quite angry and upset with me, which was ... interesting!...It was as if they didn't want it. Nothing positive was said about direct payments. (SP4)*

This Suitable Person was convinced that the attitude of the social worker delayed proceedings, meaning finances were not in place when needed. She attributed the low uptake of indirect payments among older people with dementia to this attitudinal problem:

*It took us from January to July ... to get the money. It could've all been done that much more quickly had the social worker been amenable, and any appearance of interest in this project... I can see now why it's in some regions not being taken up, because the social services teams aren't promoting it. And in fact the social worker we had appeared to be doing everything in his power to scupper it. (SP4)*

An area of poor practice in particular highlighted by four Suitable People here was a badly executed support planning process. SP17, who has experience of direct payments in the learning disability field, described how she was provided with a support plan, with no contribution from her or her mother, a plan which appeared to be an amalgamation of other service users' plans. Similarly, SP15 had never seen a support plan, although did describe what appeared to be a support planning meeting with a social worker. However, she had never been given a copy of the plan. Finally, SP6 knew through her background research what the requirement for a support plan was, understanding it to be an agreement and guide to how the indirect payment should be spent. She therefore expected to have to design one for the recipient. However, this had never been required of her:

*SP6: I understood actually that when we went for direct payments I would have to make out a plan of how I was going to spend the money.*

*I: Yes, that's what I'm talking about. Yes.*

*SP6: ...and needs they were going to make. That's from reading the booklet that I was given ages and ages ago at the very beginning.*

*I: And you've never done that, and that's never happened?*

*SP6: I've never done that, and never been asked to do that.*

### ***Supportive practitioners but with their own concerns***

The first contact for the Suitable Person in their management of the payment is the assigned social work practitioner or team of practitioners. From the perspective of these practitioners indirect payments are a way of offering the same opportunity of a personalised care package that they are able to for other groups. P14 reports that he can offer packages to people who would previously have been refused on the grounds of dementia-related capacity. He suggests increased equity of service as a result of indirect payments to Suitable People through his comparison to a direct payment for a learning disabled child in Child Services being carried over into Adult Services *because it was already up and running*:

*Because there is more scope now to give a direct payment, where in the past we probably would've turned it down. Especially on the dementia side. You know like this case I've discussed with you today, that probably wouldn't've gone ahead before, because of the capacity issue. Whereas the learning difficulty case, because the direct payment was already in place when the child became an adult, the chances are it may well have continued, because it was already up and running. (P14)*

There was some concern from practitioners about how the Suitable Person or the person who at first might be considered to take on that role for someone with dementia would cope when they were older themselves, sometimes with complex health needs. . It suggested that the health of an aged spouse or potential Suitable Person informed at least in part their decision about who would be suitable:

*I think the concern that I have is the amount of stress she is under. She very much wants to have that choice and control, and it I think it's very important to her... (P25)*

*The biggest problem is, I mean he's her carer, but he's not a particularly well man either. He's got heart problems etc. And they've had...sitting services for the night, because she tends to be wanting to get up and down to the toilet, so his sleep is very broken. And this doesn't help his health (P10)*

Despite this evidence of supportive views and considered selection about the appropriateness of a proposed Suitable Person around indirect payments for this client group, there was still concern expressed by these practitioners that this method is not always the right choice, expressing worries about them with regards people with dementia, exemplified here by P27: *'the personal budget, it wasn't really invented for our clientele'* (P27). This perceived mismatch was constructed around a lack of aspiration by people with dementia or their carers and the lack of services offering what practitioners considered this group would want to purchase. The idea of low aspiration for care and support services was posed through a direct comparison of people with dementia to younger and disabled recipients. P21 expressed the view that younger direct payment recipients have greater aspirations for choice or control while P40 suggested older people would not want anything other than regular personal care or a sitting service. P40 used this perceived lack of aspiration to explain smaller payments for this group:

*You would probably find with the transition people, the younger people coming through, I think you'll find a much higher uptake of personal budgets...because a lot*

*of those people...they've gone to residential, they've gone to college...[younger people] are really interested in that choice and control, 'cos they've experienced it more (P21)*

*How you allocate care, particularly in the community, for older people, is different to everybody else...the majority of our care is personal care for people who are elderly. And it goes in at slots, seven days a week, at the beginning and the end of the day. For younger adults it's very different, isn't it, and that's why people with physical disabilities have got access to bigger pots of money if they're eligible. Because their aspirations are different (P40)*

Similarly, P13 considered the provision of meals to be the predominant service required by this group. He justified his idea that indirect payments might not suit this group by constructing it round the fact that no business model could survive delivering home meals and so this group would have to use an agency anyway:

*The last thing [older people] want is this extra set of stuff. And very often, all they're gonna do is employ an agency anyway with the direct payment, because there's not many private support workers that are gonna do three calls a day...who's gonna make a living out of that? This mythical army of people, housewives able to drop everything and support the next-door neighbour, it's just mythical (P13)*

This idea held by some practitioners that older recipients have a lack of aspiration around their care and support needs manifests in the way they approach the provision of indirect payment information. All practitioners spoke of carers or family members of people with

dementia approaching the local authority at their lowest ebb or at a point of crisis, often following hospitalisation, and therefore wanting to be passive recipients of social services, rather than being offered an active role in their care and support:

*When you work with an older person who lacks capacity...they're only asking you for your help because they're at the very end, there's something going on and they really are really, really struggling. So to then ask them to say, I know you're at crisis, but you're gonna go and plan your own care now. They don't want that...they've come to you because they're at the point where they need help and they want you to sort it out for them (P12)*

## **Discussion**

Through this paper we sought to illuminate the experiences of Suitable People and the social work practitioners managing an indirect payment for someone with dementia who lacked the capacity to do it themselves. Briefly, with this small exploratory sample we found positive care and support outcomes in place as a result of an indirect payment where frequently there was more than one beneficiary from the arrangement. There was evidence of two mixed messages: Suitable People who rated the flexibility of the indirect payments system but encountered challenges working within it and practitioners who were supportive of this client group accessing indirect payments but with some reservation.

We place our first finding that good outcomes can be achieved for people with dementia using indirect payments within the evidence base for positive outcomes across others groups using direct payments (Clark, Gough, & MacFarlane, 2004; Glendinning et al., 2008;

Glendinning, Halliwell, Jacobs, Rummery, & Tyrer, 2000; Hatton & Waters, 2011; Lakey & Saunders, 2011). Broadening this idea further and mirroring the IBSEN carer study is our finding that the benefits of indirect payments can extend beyond the recipient alone. We consistently found that the type of service chosen or how that service was delivered was arranged to benefit either the Suitable Person, if they had a caring role, or someone close to the recipient, for example a spouse. Indeed, this finding is corroborated by the work by Hatton & Waters in the 2<sup>nd</sup> POET survey (Hatton & Waters, 2011). Although a limited study in terms of its sample, the POET work demonstrated more than half of surveyed carers who reported personal impact reported that the personal budget arrangement had a positive financial impact and positively influenced their ability to remain a carer. This was through improvements in quality of life and their physical and mental wellbeing. It is very appealing that indirect payments benefit individuals other than the recipient, with much literature demonstrating how beneficial it is to care for the carer and indeed, their interests are central to the new Care Act 2014, not yet implemented. However, we contest that as a secondary beneficiary, it may be difficult for the Suitable Person to be guided by the preferences of the recipient when purchasing services using the budget. As it stands, an indirect payment and the care and support bought provided must be in the best interests of the recipient and these may or may not be the same as those of the Suitable Person. It is important therefore that the various roles played by any 'third party' should be separated and support, including financial, should be received appropriately for each. For example, for any carer's role they perform, a Suitable Person is entitled to a carer assessment, and will sometimes receive support in their own right. Of course, the interdependence within the carer and caree dyad is not straight forward but the aim should be to meet the support needs for both as individuals. If meeting the needs of a caring Suitable Person and the



recipient is incompatible, it would raise questions as to the appropriateness of the Suitable Person. Processes used regularly in person-centred planning with people with learning disabilities may lend themselves to the field of dementia by supporting people to keep the focus on the recipient.

As with earlier studies (e.g. (Glendinning et al., 2008; Lakey & Saunders, 2011)), we also demonstrate that despite favourable outcomes, the indirect payments process can be a challenging one where Suitable People are not always clear about what is happening. In addition, we would cite our finding that standard direct payments assessment processes may not fit well this population. In particular the practice around support planning can be poor. These results echo those of the IBSEN carers study where dissatisfaction with assessment and support planning processes were evident in a substantial proportion of carers (Jones et al., 2014). The Suitable People in our study found it hard to recall or distinguish a mental capacity assessment of the person with dementia from other assessments such as dementia or needs assessments. The recent Social Care Institute for Excellence (SCIE) practice guide 63, albeit focusing on direct payment recipients, also demonstrated confusion among people with mental illness and older people's groups about what assessment was being conducted (Carr, 2013). Crucially, the Suitable People in this study expressed the need to be present and able to contextualise the recipient's responses within the fluctuations related to dementia or other comorbidities like deafness. Whether a miscommunication or misunderstanding between practitioner and Suitable Person or not, our findings suggest that Suitable People do not trust the assessment process to accurately represent the person with dementia's needs and capacities. Given this central position Suitable People have to recipients being represented within the system appropriately and

what responsibility the local authority is placing on them with public funds, it would be appropriate for them to be briefed clearly on the assessment being administered and for what purpose.

In addition to this opaque assessment process, we found further evidence of ambiguous practice around support planning. Evidence of poor practice ranged from Suitable People being provided a generic plan to not having one at all. This may be an artefact of direct payment practice where there is evidence that practitioners tend to think older people cannot complete self-assessments well (Carr, 2013). Indeed, older personal budgets users had mixed experiences of support planning. Although Suitable People for people with dementia are not necessarily older themselves, this attitude may pervade indirect payments practice with this group despite the intended empowering nature of support planning. Alternatively, poor support planning may be driven by beliefs held by some practitioners that people with dementia have static, basic needs that can be met by social care services without the challenge of an indirect payment. The SCIE practice guide demonstrated that practitioners made decisions based on a desire not to over-burden people with information and made assumptions on their behalf. It may be that some practitioners perceive that the crisis nature of dementia-related social work lends itself to providing templates or generic plans to ease the process.

However, the views of the practitioners contrasts starkly with the accounts here of Suitable People. Despite the absence of a formal support plan, they did in fact make support planning decisions about how they would spend the budget. They wanted flexible arrangements, chosen lifestyles to be possible, or meaningful therapeutic activity for the

recipient, often because they can provide basic needs within an informal care role. Although different methodologies have been used and sample sizes collected, it is useful to revisit the Alzheimer's Society report *Getting Personal? Making personal budgets work for people with dementia*; the preliminary and exploratory data collected from our Suitable People seem to slightly contradict the findings that 22% of direct payments are used to purchase personal care, 14% sitting services, and 21% respite care (Lakey & Saunders, 2011). However, evidence elsewhere does suggest older people received on average smaller budgets per person per week than other user groups (Information Centre for Health and Social Care, 2012) and this may be a limiting factor to what is purchased as discussed by Manthorpe and Moriarty in their study of day centres (J Manthorpe & Moriarty, 2013).

### **Implications of this study**

The study is limited; the results can only be considered as exploratory due to the low number of participants. Furthermore, it was outwith scope to access case records or to triangulate data. Finally, participants were self-selected and all were managing a direct payment for someone with dementia. It would be illuminating to interview individuals who declined an indirect payment.

Notwithstanding these limitations, we hope to have made an interesting contribution to the growing literature surrounding the practice of indirect payments for older people lacking the capacity to consent to this arrangement. Although a very modest study, there are potential implications for practice; first, that care and support put in place for people with dementia are arranged so that it might benefit others, for example carers. Thus, the best interests of both recipients and Suitable People are often intertwined. It is important to ensure the best interests of the recipient are always at the centre of indirect payment

arrangements, but if this cannot be achieved without overburdening a carer in a position to take on the Suitable Person role, we might argue this precludes the carer from the role. At the very least it suggests a requirement for considerable support for both the carer and Suitable Person roles. Second, our finding that practitioners assume types of care desired by this group and make decisions about the appropriateness of indirect payments based on this has implications for practice. It may be that some people with dementia are still not able to access direct payments and the prospect of increased choice and control due to well-intended but potentially misplaced 'gate keeping'. It is important that practitioners explore fully with clients what their aspirations and desires are for their care and support.

### **Future research**

In addition to exploring the decision-making process with people with dementia and their carers who decline a direct payment, it is our opinion following this research that future work should focus on developing further the usefulness and acceptability of Person-centred Planning to people with dementia and their family or carers. Helen Sanderson Associates have already begun working in this area, producing a guide to person-centred practice for people with dementia (Lindsay, 2012). Trialling whether the adoption of this technique can improve practice around support planning would make a useful contribution to social work practice.

### **Conclusion**

We conclude that as with the wider older population, the experience of managing a direct payment for someone lacking the capacity to consent to one can be a mixed one.

Improvements for this population in particular must focus on clarifying assessment and support planning practices.

## References

- Bartlett, J. (2009). *At Your Service. Navigating the future market in health and social care.* London: DEMOS.
- Care Act (2014).
- Carr, S. (2013). Improving personal budgets for older people: a research overview *Adults' Services Report* (Vol. 63). London: Social Care Institute for Excellence.
- Clark, H. (2006). "It's meant that, well, I'm living a life now": older people's experience of direct payments. In J. Leece & J. Bornat (Eds.), *Developments in Direct Payments.* Bristol: The Policy Press.
- Clark, H., Gough, H., & MacFarlane, A. (2004). 'It pays dividends': direct payments and older people. Bristol: The Policy Press.
- Community Care Act (Direct Payments), c. 30 (1996).
- Cyhlarová, E. (In peer review). How effectively does the direct payments system work for people who lack the mental capacity to consent? . London.
- Davey, V., Fernandez, J., Knapp, M., Vick, N., Jolly, D., Swift, P., . . . Priestly, M. (2007). *Direct Payments: A national survey of direct payments policy and practice.* London: London School of Economics and Political Science.
- Department of Health. (2005a). *Improving the life chance of disabled people.* London: Department of Health.
- Department of Health. (2005b). *Independence, well being and choice: our vision for the future of social care for adults in England.* London: Department of Health.
- Department of Health. (2009a). *Guidance on direct payments: for community care, services for carers and children's services.* London: Department of Health.
- Department of Health. (2009b). *Living Well With Dementia: a national dementia strategy.* London: Department of Health.
- Ellis, K. (2007). Direct Payments and Social Work Practice: The Significance of 'Street-Level Bureaucracy' in Determining Eligibility. *British Journal of Social Work*, 37(3), 405-422. doi: 10.1093/bjsw/bcm013
- Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., . . . Wilberforce, M. (2008). *Evaluation of the individual budgets pilot programme: final report.* York: Social Policy Research Unit, University of York.
- Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K., & Tyrer, J. (2000). Bridging the gap: using direct payments to purchase integrated care. *Health & Social Care in the Community*, 8(3), 192-200.
- Hatton, C., & Waters, J. (2011). *National Personal Budget Survey 2013. Summary of main findings and next steps.* London: Think Local Act Personal.
- The Health and Social Care Act, c.14 (2008).
- Information Centre for Health and Social Care. (2012). *Personal social services: expenditure and unit costs - England 2010-11 - Final release: Information Centre for Health and Social Care.*
- Jepson, M., Laybourne, A., Williams, V., Cyhlarová, E., Williamson, T., & Robotham, D. (In review). Indirect payments: when the Mental Capacity Act interacts with the personalisation agenda. *Health and Social Care in the Community.*
- Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H., & Moran, N. (2014). Can individual budgets have an impact on carers and the caring role? *Ageing and Society*, 34(1), 157-175.
- Kaplan, D. B., & Berkman, B. (2011). Dementia care: A global concern and social work challenge. *International social work*, 54(3), 361-373.
- Lahey, L., & Saunders, T. (2011). Getting personal? Making personal budgets work for people with dementia. [www.alzheimers.org.uk/personalbudgets](http://www.alzheimers.org.uk/personalbudgets).
- Leece, D., & Leece, J. (2006). Direct payments: creating a two-tiered system in social care? *British Journal of Social Work*, 36(8), 1379-1393.

- Lindsay, M. E. (2012). A Practical Guide to Delivering Personalisation: Person-centered Practice in Health and Social Care, (Sanderson, H. & Lewis, J). London: Jessica Kingsley Publishers, 2011. ISBN 978-1-84905-194-1. *International Journal of Person Centered Medicine*, 2(2), 320-322.
- Luengo-Fernandez, R., Leal, J., & Gray, A. (2012). UK research expenditure on dementia, heart disease, stroke and cancer: are levels of spending related to disease burden? *European journal of Neurology*, 19(1), 149-154.
- Manthorpe, J., & Moriarty, J. (2013). Examining day centre provision for older people in the UK using the Equality Act 2010: findings of a scoping review. *Health and Social Care in the Community*, 22(4), 352-360. doi: DOI: 10.1111/hsc.12065
- Manthorpe, J., & Samsi, K. (2012). 'Inherently Risky?': Personal Budgets for People with Dementia and the Risks of Financial Abuse: Findings from an Interview-Based Study with Adult Safeguarding Coordinators. *British Journal of Social Work*. doi: 10.1093/bjsw/bcs023
- Mental Capacity Act, c.9 (2005).
- Netten, A., Jones, K., Knapp, M., Fernandez, J., Challis, D., Glendinning, C., . . . Stevens, M. (2012). Personalisation through individual budgets: Does it work and for whom? *British Journal of Social Work*, 42(8), 1556-1573.
- POhWER. (2014) Retrieved 01/06/2014, 2014, from [www.pohwer.net/self-help-tools/direct-payments](http://www.pohwer.net/self-help-tools/direct-payments)
- Priestley, M., Riddell, S., Jolly, D., Pearson, C., Williams, V., Barnes, C., & Mercer, G. (2010). Cultures of welfare at the front line: implementing direct payments for disabled people in the UK. *Policy & Politics*, 38(2), 307-324.
- Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T., & Heslop, P. (2012). Making Best Interest Decisions: people and processes. London: The Mental Health Foundation.
- Williams, V., & Holman, A. (2006). Direct payments and autonomy: issues for people with learning disabilities. In J. Leece & J. Bornat (Eds.), *Developments in Direct Payments*. Bristol: The Policy Press.