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Indirect Payments: when the Mental Capacity Act interacts with the personalisation agenda.

Marcus Jepson. MSc PhD. School for Policy Studies/School of Social and Community Medicine, University of Bristol

Anne Laybourne, PhD. City University London.

Val Williams. BA (Hons) MEd PhD. Norah Fry Research Centre, School for Policy Studies, University of Bristol

Eva Cyhlarova, DPhil. Mental Health Foundation, London

Toby Williamson BSc (Hons) PGD. Mental Health Foundation, London

Daniel Robotham. BSc MSc PhD. Institute of Psychiatry, Kings College London

Correspondence may be addressed to Marcus Jepson, School for Policy Studies, University of Bristol. 8 Priory Road, Bristol BS8 1TZ. Marcus.jepson@bristol.ac.uk
Tel: (44) 0117 3313930

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Abstract

This paper reports findings from a study that aimed to explore how practitioners were bringing together the demands of the personalisation agenda, in particular the offer of direct payments, with the Mental Capacity Act, and to investigate current practices of offering and administering indirect payments for people who lack capacity to consent to them, including the use of 'suitable person' proxies under the new regulations (DH, 2009).

The study adopted a qualitative interview based design, participants were social work practitioners (67) and recipients of 'indirect' payments (18) in six local authorities in England in 2011-12. The paper reports on five key decision making points in the indirect payments process, the decision to take on an indirect payment, the assessment of mental capacity, the identification of a suitable person, the establishment of the care recipient's best interests, and the decisions about how to execute the indirect payment. We found that practitioners and suitable people had different experiences of the system, although in both cases there was overarching support for the benefits of enabling people who lack capacity to consent to a direct payment to receive their social care funding in the form of an 'indirect' payment via a proxy suitable person.

Keywords

Personalisation, direct payments, mental capacity, learning disabilities and dementia

What is known about this topic

- Since 2009, people who lack capacity to consent to a Direct Payment **may** still receive their social care funding in this way.
- Assessing a person's capacity to make a decision is not straightforward.

What this paper adds

- This paper defines a direct payment for a person who lacks capacity as an 'indirect' payment.
- It identifies and describes five key decision making stages in arranging an 'indirect' payment.
- Whilst understanding of how to apply the Mental Capacity Act guidelines to these decisions was well described, there appeared to be gaps in their application in practice.

Introduction

Since 1996, 'direct payments' (DPs) have been a central plank in the moves towards personalising social care in the UK, although the policy has met with mixed reactions (Glasby & Littlechild, 2006:19), being welcomed by disabled activists (Hasler et al, 1999), while being critiqued as the start of the erosion of the welfare state. This tension is reflected in the debates about personalisation generally (Houston, 2010) and has arguably been exacerbated by austerity measures and cuts in social care budgets (Williams et al 2014a). Therefore, a critical view of direct payments must always have an eye both to the benefits of independence, as well as the difficulties and the demands made on individuals.

In the context of English policy and forthcoming legislation (DH, 2014), direct payments are one option for adult social care users who have a 'personal budget' (Carr, 2009). They can also choose directly provided services from the local

authority, and can buy in support from an agency or organisation. This apparently simple system has however many complexities, since effectively a personal budget is a 'conditional resource entitlement' (Duffy *et al*, 2010). The state offers personal budgets to people who are entitled by virtue of their level of 'need' and who can plan how best to spend their budget to achieve outcomes that are approved by the state. There are therefore several tensions inherent in the rhetorical driver behind direct payments, which is the notion of 'choice and control' for the individual DP user:

There is solid evidence that care is less effective if people feel they are not in control.

A fundamental aim is to make the actions and choices of people who use services the drivers of improvement. (DH, 2006: 1.5).

As such, DP policy has depended on and assumed the notion of the individual user as an autonomous citizen (Beresford, 2001), and it is this same notion which now lies behind the wider personalisation agenda. Those in receipt of personal budgets should all experience 'choice and control' and one of those choices is whether to use their budget in the form of a direct payment. Commentary on the monitoring of personal budgets (Slasberg *et al.*, 2012) suggests that it is direct payments, rather than personal budgets themselves, that make a positive difference to people's outcomes. However, there are tensions, particularly since the proportion of disabled people in receipt of social care has been narrowed by eligibility criteria (DH, 2010) to those with the highest levels of 'need'. Questions then arise about the capacity of some individuals with cognitive limitations to take control for themselves (Dowse, 2009; Lymbery, 2012).

The apparent contradiction between 'capacity' and personalisation has become more prominent since the Mental Capacity Act (the MCA) that came into force in England and Wales in 2007. While the MCA promotes the principle that each person should

be assumed to have capacity, it also gives a legal framework for making a decision on behalf of an individual assessed as lacking capacity to do so (Boyle et al, 2012; Williams et al, 2014b). However, autonomy in making a decision should not be confused with the ability to implement that decision in action (Boyle, 2008). Leece and Peace (2010) helpfully unravel some of the conflicting ideas about independence and autonomy, focusing on a 'rational-voluntarist' view of autonomy, which they describe as 'control in principle'. As they argue:

Its explanation of autonomy encompasses people with cognitive disabilities who rely on the judgement of others to make decisions. (p. 1851)

It is this perception of control and autonomy which underpins the new provisions, reflected in the Health and Social Care Act in 2008, and in subsequent guidance (DH, 2009). If a disabled person is considered to lack capacity to *consent* to make a decision about a DP, then there is now the opportunity to appoint a 'suitable person' to receive and manage the payments on their behalf. Rather than deny groups of people the benefits of a DP, this legislation and guidance allows them to have the type of relational autonomy, where another person in their life can make the significant decisions about a DP for them.

This paper is based on a study that examined how these provisions were being put into practice in England during 2011-12. The aims of the study were:

- to find out how direct payments were being administered for people who lack capacity, by taking into account the views of various stakeholders including staff who influence decisions about direct payments (e.g. care managers,

brokers, advocates, finance managers) and suitable persons managing the direct payment of a person without capacity.

- to see how practitioners were bringing together the demands of the personalisation agenda, in particular the offer of direct payments, with the MCA
- to investigate current practices of offering and administering direct payments for people who lack capacity to consent to them, including the use of 'suitable person' proxies under the new regulations (DH, 2009).

Since the direct payments in this study were managed by a third party (the suitable person), this paper refers to them throughout as 'indirect payments'.

Method

The study employed a qualitative methodology, with data generated from semi structured interviews with social work practitioners and people who were in receipt of an indirect payment. The study purposively sampled six English local authorities, aiming to recruit a diverse sample with rural/urban and north/south distributions. We recruited one city, four county, and one borough council. Once an authority agreed to participate, an email was sent to all practitioners identified by the authority as having experience of direct payments. This email invited practitioners to contact a member of the research team directly if they were prepared to consider being interviewed. Those who responded to were provided with a copy of the project information leaflet, and asked to complete and return a consent form directly to the research team before an interview was arranged. Consequently, to preserve anonymity, authorities did not know which practitioners had consented to participate in the research.

In order to access people who received an indirect payments package on behalf of a person who lacked capacity, participating practitioners forwarded the research materials to relevant people, inviting them to contact the research team if they were prepared to consider participation. Those who responded were provided with a study information sheet and completed a consent form prior to being interviewed. The suitable people identified were not necessarily part of the identifying practitioner's caseload.

Interviews were undertaken face to face or by telephone. The study was reviewed and given formal approval by the Social Care Research Ethics committee (11/IEC08/0018, 15 June 2011), and the Association of Directors in Adult Social Services research group (RG11-007, 04 July 2011).

Interviews were audio-recorded and transcribed. Transcripts were read in full by the first two authors to gain an overall perspective of the data, and the team agreed an initial coding framework. Transcripts were uploaded to Nvivo 9 and categorised according to the role of respondent (practitioner or suitable person), the nature of impairment of the person lacking capacity and the local authority area. Categorising the data in this way made it possible to compare and contrast the viewpoints of different respondents. Following a line-by-line reading of each transcript the authors developed thematic codes which were discussed and agreed among the team. Several overarching themes cut across the coding framework, and it is one of those themes – decision making - that forms the basis for the current paper. In the subsequent section, analytic points are illustrated with quotes, labelled either 'P' if from social work practitioners, or 'SP' from suitable people.

Findings

This paper is structured around five decision-making moments in the indirect payments process. The chronology of these moments is far from clear, and in practice they do not necessarily need to happen in sequence. Therefore, we simply follow the 2009 Guidance, starting from the decision to take up a direct payment, and moving on through the assessment of capacity, selection of the suitable person, the consideration of best interests of the person who lacks capacity to consent and the execution of the indirect payment. Findings are based on interviews with 67 social work practitioners: a mixture of case-carrying, senior management and strategic level staff, from 6 local authorities in England, and a further 18 individuals (from 3 of the 6 authorities) who received an indirect payments package on behalf of a person who lacked capacity.

The decision to take up an indirect payment

Helping to achieve targets

Since 2001, practitioners have been required to offer a direct payment to every new social care recipient. Several of the practitioners we spoke to said that they felt pressure from their local authority to encourage people to choose a direct payment. This was typically perceived as being because of a need to achieve targets as this practitioner explained:

... our area's got one of the very, very lowest uptakes of direct payments...there's a massive amount of pressure on workers now ... you need push hard to get a direct payment, 'cos it's a performance indicator. (P15)

As a consequence, from the point of view of practitioners, indirect payments were

perceived as one way of increasing the numbers of people using direct payments.

Avoiding restrictive social care provision

Discussing this issue with the suitable people themselves, the picture appeared more complex. Although in two cases, suitable people acknowledged that a social worker had initially broached the subject of a direct payment, more commonly, suitable people perceived themselves as being proactive in seeking out the best solution from the local authority. Suitable people most commonly chose an indirect payment because of the outcome they wanted for their relative or friend. For instance, previous or alternative arrangements had been restrictive or inflexible, as this person explained:

Sometimes the [agency] carers'd come ten minutes late, they'd say, I'm sorry but I've had to get Mrs So-and-So ready to go into respite

(SP7)

The parent of a man with learning disabilities (SP9), described how services had been inadequate to meet her relative's needs, and that her priority was to take him out of residential care. As she understood it, the only way to achieve this aspiration was through an indirect payment. The daughter of a woman with dementia, similarly, said that her mother had been in a care home for ten months:

I felt so awful every time I left her, because she was put to bed at half-past three. And my Mum ... was a head teacher of a school. She's an author of books. she's a highly intelligent person, and she was being put to bed at, at half-past three.

(SP6)

Several other suitable people described how the only option previously available involved a move to residential care, an option that they all wished to avoid for their relative(s), and they believed that an indirect payment was the only way to do so. As one suitable person described, an indirect payment was *'the only game in town'* (SP5) with no viable alternative available.

Involving the social care recipient in the decision about an indirect payment

Although there is scant data about how the social care recipients themselves might have been involved in the decision about indirect payments, both the MCA's code of practice (DCA, 2007) and the 2009 regulations (DH, 2009) encourage practitioners to consult with the person lacking capacity. Where the involvement of the person was described, it was most commonly in situations when they had expressed a wish not to receive a direct payment in their own name. A suitable person, who receives an indirect payment on behalf of her daughter, a woman with a mild learning disability, described her attitude at the time she moved to adult services and thus became entitled to receive a direct payment:

But [name] is very, very clear that she doesn't want to go there, and wishes us to do it for her

(SP5)

As this woman is able to express a desire not to operate a direct payment herself, we may well question whether she actually does lack capacity to consent. This opens up the first area of difficulty in offering a direct payment to an individual, since there was a blurred distinction in this study between those who had a suitable person

'decide for them' about their indirect payment, and those who had simply consented and asked another person to manage their money for them.

Deciding that a person lacks capacity

A best interests decision can only be made for someone who lacks capacity to make that decision (MCA, 2005), so the second decision point we explore is that of the assessment of capacity to decide whether or not to take up a direct payment.

The language and principles of the MCA

Most of the practitioners interviewed apparently understood and adhered to the MCA's principles and were aware that assessing capacity was their responsibility. Many were very clear about the decision-specific nature of capacity. This practitioner understood the importance of seeing a person on more than one occasion:

Does the person have the ability to understand the information, in the format, is there a different format, is [capacity] fluctuating, could she understand it next week if we presented it in a different way?

(P1)

Practitioners also appeared to be aware of the second principle of the MCA, which requires that all possible support be given to help people make their own decisions. A practitioner described how a meeting with a man with learning disabilities took place in a familiar environment, it was: '*an informal meeting at home...with the parents*' (P38).

Assessing capacity to consent or to manage?

The 2009 regulations specify that the decision about which the person's capacity should be assessed is their ability to consent to a direct payment (distinct from their ability to manage it). As the guidance states:

Councils should not confuse whether somebody has the capability to manage direct payments with whether they have the mental capacity to consent to such payments.

(DH, 2009, p.26)

This was an area that appeared to cause confusion. A common theme reflected the challenges practitioners experienced in specifying *what* decision they were assessing capacity for. It was apparent that a lack of understanding about the micro-level of financial management was the most common reason for practitioners' assessing that people lacked capacity. One described how he showed a person '*...pictures of money, pictures of a bank [and] invoices...*' (P26). This lack of understanding of the detail led practitioners to assess that people may not have an understanding of '*what direct payments are all about*' (P32).

Suitable people's understanding of capacity assessment

According to the MCA, suitable people might expect to be consulted and involved at the point of any capacity assessment, as they would know the person well. However, most suitable people had not noticed a capacity assessment happening, exemplified by SP9. This parent recalled that the MCA had been mentioned in discussions with practitioners, but was uncertain whether or not her son's capacity to consent to a direct payment had been assessed.

In a small number of cases, practitioners expressed to the suitable person their judgement about the person's capacity. However, this appears to reinforce the

conflation between an assessment of a person's capacity to *consent* to a direct payment with their capacity to *manage* one, as in this case, of the parent of a man with a learning disability:

I mean they have said, you need to manage this on his behalf, because obviously he's not able to do it himself.

(SP10)

From the evidence we had from suitable people, their understanding of assessment of capacity was, at the least, confused. Many described assessments of need, when asked about capacity, and others described impairment assessments, such as dementia assessments. It would seem that this aspect of the MCA had not been explained clearly to most of the suitable people in our study.

Deciding whether an indirect payment is in the person's best interests

Each individual is different

Where a person is assessed as lacking capacity to make a decision, decisions made on their behalf must be made in their best interests (DCA, 2007). Therefore, at this stage of the process that we expected to see a decision about whether an indirect payment is in the best interests of the person. This manager summarised his exemplary understanding of when and how this principle should initially be followed:

before you even think about a suitable person you have to make a decision that making an indirect payment is in the best interests of this person. And when you're making a BI decision in favour of one option you have to be able to articulate why

you've ruled out other options ... then, having decided that it's appropriate, then you have to find a suitable person.

(P33)

Making a best interests decision should focus on the individual person's preferences, needs and values, and therefore a rounded picture has to be gained by consulting with a wide range of people. Another practitioner described the implication of this - that care managers do not always know best:

best interests ...it's a difficult concept isn't it? It varies from person to person. What I may feel is in someone's best interests may not be. So you've got to rely on a wider range of people, who would then maybe give you a more holistic picture

(P32)

Whose best interests?

Suitable people were rarely aware that a best interests decision had been made, nor that it was because of this process that they had the role of 'suitable person'.

However, several suitable people had used their personal knowledge of the needs and preferences of their relative, and reached the conclusion about an indirect payment because of those individual requirements. A more 'formalised' process was taken by the mother of a man with learning disabilities. She planned with his circle of support for when he left residential college, understanding the importance of his 'safety' and security within the community:

he needed to live where people knew him, where he knew people, where he felt safe and secure...so we started off with a circle of support.

(SP13)

Since suitable people often also acted as informal carers, the best interests of the disabled person were closely connected with the 'best interests' of the suitable

person. One indirect payment was being used to pay for a man with a learning disability to be supported to visit weekend activity sessions. Prior to receiving the indirect payment, his mother had accompanied him on these sessions. Therefore the outcome for the son was greater independence from his mother, and the outcome for the mother was that she had a break from her caring role.

Deciding who the suitable person will be

The family member

The DH 2009 Guidance acknowledges that:

direct payments in respect of someone who lacks the capacity to consent, [are] only possible if there is an appropriate and willing 'suitable person' to receive the direct payments on their behalf.

(DH, 2009, p.22)

Hence, for those lacking capacity, the decision to take an indirect payment depends on a suitable person being available. It may seem inevitable therefore, that these decision points will be conflated and this may partly explain the lack of awareness among suitable people that an 'official' best interests procedure had been followed. Almost universally practitioners described how they would pinpoint a suitable person on the basis of them being close to the person lacking capacity. This is in keeping with the message in the guidance:

in most cases the suitable person will be a family member or close friend already involved in the provision of care for the person concerned

(DH 2009, p.65)

In some instances, the parental role was assumed to be the key one: *'if it's at transition...then normally it'll be the parents'* (P4). Others were more robust in their

identification process, describing how they would spend time getting to know the circumstances of the person lacking capacity and finding out for example, who was *'consistent in their life'* (P9).

The only 'suitable person' available

The majority of suitable people here wholly agreed that they had been the most appropriate person to take on that role. None considered that there was any viable alternative available. In six cases, they had a Lasting Power of Attorney (LPA) for the person lacking capacity, and so equated their role with that power. This, of course is in keeping with the recommendation in the 2009 guidance which notes that if a person is a donee of lasting power of attorney, they are likely to fulfil the SP role (DH 2009).

Deciding on how the indirect payment will be used

The final decision stage is that at which the support plan has to be decided on; again, this stage may well happen simultaneously with others in this paper, but it is useful to consider it separately, since the best interests of the person lacking capacity should be central to decisions about how to spend the budget.

Confusion about the status of the support plan

There is an expectation that the suitable person will work with the person lacking capacity to make decisions about the type of support they want to have. In terms of the formal support planning process, the involvement of suitable people here was at times incongruent with policy. Around half of the suitable people spoke about support planning. They described bad practice, from support plans being provided by the

council practitioner after a needs assessment meeting and generic, 'cut and paste' plans without any assessment of the person lacking capacity, to a complete absence of a plan:

The social worker ...said, 'Oh don't worry with your fancy support plans, all we're interested in is the money bit at the back'

(SP7)

Making personalised decisions

Although there was limited awareness of 'official' support plans, suitable people had all developed packages based on their relative's specific needs and preferences. For instance, SP16 knew that her son was interested in maritime history, and so she engaged a personal assistant with similar interests. Another knew that her mother wished to continue smoking in her own home, so engaged personal assistants who understood this, and would be prepared to support the woman to continue to smoke.

Reviewing and monitoring the indirect payment

Despite the delegation of best interests decision making to the suitable person, the local authority retains the responsibility to monitor and review what is happening.

The guidance pays particular attention to the level of monitoring in these situations:

Adults lacking capacity are likely to need more frequent monitoring arrangements than other direct payment recipients... Councils should be satisfied at all times that the suitable person is using the direct payments in a way that protects the best interests of the service recipient.

(DH, 2009, p.82)

However, this overall review of best interests was not evident. Instead, we found that local authorities typically prioritised monitoring the financial execution of indirect

payments. In many cases, the only contact between the suitable person and a social work practitioner was in an annual review meeting. As this practitioner described, the annual review allowed for scrutiny of both financial and support elements of the package:

... we try to get the annual audit done just prior to the annual review due date. So that it is part of the review as to whether or not the package is running properly isn't it? And not only is it giving the financial picture, it actually tells us if they're having the support... it's another safeguard to inform the review...

(P2)

However, other practitioners described mechanisms in place for more regular review of indirect payments, particularly in the first months of suitable people taking that responsibility.

The perception among suitable people was that the only scrutiny of the indirect payment was financial. Whilst on the one hand they were happy to benefit from this 'arms length' approach to monitoring, they did also express concern that they had lost touch with social workers:

I would've said maybe three months in, or four months in. How are things going? Any problems? Is there anything you want to talk to us about?...you know just general health checks. ..So yeah I think there should be, but nobody's been in touch.

(SP4)

Discussion

Although this paper has separated out five 'key' decision points in setting up an indirect payment, in practice people moved back and forwards between the different

elements. For instance, the first discussion following an assessment of needs will often be with the 'suitable person', who takes on this role by accepting the offer of an indirect payment. Therefore, the identification of the suitable person is often carried out before the consideration of whether or not the indirect payment is in the best interests of the person lacking capacity. To some extent, this conflation of the processes is inevitable. However, our data revealed how easy it is to miss some of the essential elements of an indirect payment, particularly those which focus on the individual disabled person, such as the assessment of capacity and the identification of best interests.

There was often a discrepancy between what practitioners describe as happening (which in the main appeared to be well informed practice), and the descriptions from suitable people. Maybe this is simply due to lack of familiarity with the terminology of the MCA, and it is arguable how far one would wish suitable people to become micro-professionals. However, three years after the implementation of this legislation, it appears that there may still be a gap between rhetoric and practice. Previous research about the MCA (Williamson et al, 2012) has shown that capacity can seem a 'blurred' concept, and a difficult one for practitioners to approach. Since capacity has to be assessed on a 'decision specific' basis, perhaps the greatest difficulty in the current study lay in identifying what that specific decision was. How does one actually know if a person lacks capacity to 'consent', and conversely, what would a person have to demonstrate, to show that they *have* capacity to consent? This question was never answered clearly; instead, practitioners were veering towards assessing the ability of a person to 'manage', by testing whether they understood money. There was an unclear distinction made between appointing a

suitable person, and enabling someone to help and support with the management of a budget.

The question then arises about whether this lack of clarity matters. Returning to the key principles of the personalisation agenda, indirect payments are clearly now including those who lack capacity in various ways, and as such, are extending to them the ability to have personalised services that meet their individual needs. They are also, as suitable people in this study pointed out, keeping their relatives and friends away from services that they consider inflexible or undesirable. One of the hallmarks of personalisation has always been the call to reduce bureaucracy, (DH, 2008; 2012), and indirect payments processes perhaps do not need to re-introduce unnecessary trails of paperwork. Slasberg et al. (2013) question the efficacy of the systems introduced with personal budgets and self-directed support, claiming that the 'choice and control' experienced by those using adult social care is largely 'making use of the direct payment provisions of the 1990s' (2014: 93). The current study reinforces that point, showing how suitable people can manage the system in a straightforward, common-sense way.

The litmus test of indirect payments, however, should be the type of 'relational autonomy' described by Leece and Peace (2010), where a person relies on others to make big decisions in their life. Choice and control within the personalisation agenda seldom does mean total individual autonomy, as argued by Houston (2010).

However, where a suitable person is enabled to make decisions on a day-to-day basis for the person lacking capacity, there is a need to ensure that the individual's best interests remain at the centre of the support.

By way of caveat, we acknowledge here the limitations of this study. The majority of our sample comprised people who were already receiving social care funding and

were dissatisfied with provision. In discussions with practitioners, it was acknowledged that whilst they routinely made an offer of a direct payment to all new social care recipients, there existed a backlog of people who historically received care through a managed service and had not been offered the option of more personalised funding. Therefore, a bias that was introduced related to the knowledge and attitude of the suitable persons involved. They generally saw direct payments as a positive, and were prepared to defend the way it worked for them and for the person they supported.

Conclusion

The extension of direct payments to people who lack capacity must remain focused on their best interests, which generally includes the 'best interests' of their family members and friends. Without this, indirect payments can be seen as a cost-cutting exercise, where family members are being asked to perform the functions of the local authority without any formal recognition or recompense, which may not be sustainable in the longer term (Coles, 2013). Further, a system which devolves so much responsibility to individual family members and friends inevitably raises important questions about the balance between citizenship, welfare provision and family-led care. Maybe, as Dowse (2009) argues, there are some people who cannot manage to have an autonomous voice or to be full, economically active citizens. Moreover, the benefits of direct payments may be accruing chiefly to those who have a 'suitably' skilled enabler, potentially excluding vast numbers of people whose families do not have the necessary skills to manage a budget. This paper started with a critical question about the tension inherent in personalisation, heralded both as the answer to independent living, but also as eroding the welfare state. We must

remain vigilant about the place of indirect payments within this balance, and ensure not only that suitable people have a stronger voice, but also that the best interests and 'relational autonomy' of those receiving adult social care remains at the heart of the process.

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