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Personalisation: Direct Payments and Mental Illness

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Abstract

Purpose: Since 2007 local authorities in the UK have been charged with implementing direct payments for people receiving social care. Direct payments allow people to make purchases to meet their needs. This study investigated the experiences of seeking to obtain and use direct payments of people who experience mental illness and their carers.
Design/methodology/approach: A qualitative methodology using telephone semi-structured interviews to collect the data from 12 people with experience of mental illness and 9 carers was employed.
Findings: Interviewees were motivated to seek direct payments to meet their needs not being met through current services. Knowledgeable and supportive carers and healthcare professionals were vital in helping many people who experience mental illness to achieve, manage and maintain direct payments. The process for direct payments can be complex, time consuming and stressful, requiring a high level of cognitive skills and assertiveness. Benefits of direct payments include: ability to improve social lives, reduce hospital admissions, raise standards of living, increase levels of empowerment, improve mental and physical health, and improve prospects for obtaining employment.
Conclusion: In general interviewees felt that the benefits of direct payments outweighed the difficulties. There is a need to simplify and improve the processes involved in obtaining and maintaining direct payments. If the direct payments process becomes further refined, established and uncertainness removed, it may result in a higher take-up of direct payments for people who experience mental illness.

Key words: direct payments, personalisation, mental illness, carers, empowerment

Introduction

Direct payments are monetary sums paid to individuals who have been assessed as eligible for a particular level of social care. These are intended to provide the individual with more choice and control in deciding how their care is arranged. In addition to facilitating care and support Taylor (2008, p. 44) stated that direct payments have enabled people: “to participate in many diverse activities from shopping trips to education and training courses and leisure activities, providing new interpersonal, vocational and lifestyle opportunities.”

Direct payments were introduced in relation to social care services for adults in England through the 1996

Community Care (Direct Payments) Act and are now governed by the 2012 Health and Social Care Act and the 1989 Children Act. From April 2003 it became a duty for councils to offer direct payments to people willing and able to manage or manage with assistance. On 9th November 2009 the 2001 act was extended to include people who lack capacity, as defined by the 2005 Mental Capacity Act, and to remove the exclusions which apply to people who are subject to various provisions of mental health legislation, particularly the Mental Health Act 1983, and to provisions of criminal justice legislation relating to mental disorder.

Direct payments take-up rates are lower for those who experience mental illness than they are for any other eligible group (Personal Social Services Research Unit, 2007). Despite such action as the Department of Health's (NIMHE, 2006) 'Direct payments for people with mental health problems: A guide to action' which sets out good practice in relation to making direct payments more accessible to people with mental health problems and the Department of Health funded 'Direct Payments Take Up Campaign' (Rethink Mental Illness, 2011), there is still a low take-up of direct payments by people who experience mental illness compared to other eligible groups. "Studies have shown that inadequate leadership, a lack of awareness about and promotion of direct payments, and staff concerns about people's ability to manage payments have hindered greater take-up" (Office of the Deputy Prime Minister 2004, p. 43).

A report funded by the National Institute for Mental Health in England suggested further reasons for low take up, including emphasis in the 1996 Community Care (Direct Payments) Act on the needs of people with physical disabilities, the tendency for people who experience mental illness to have contact with the NHS rather than with social services, tough eligibility criteria, and difficulties that people may have managing money when they are ill (Spandler & Vick 2004, cited in Personal Social Services Research Unit, 2007, p. 17). Taylor (2008) reviewed why the take-up of direct payments has been particularly slow compared to other service user groups and concluded that the confusion surrounding eligibility, impact of fluctuating needs, and reluctance of practitioners and care co-ordinators to offer this service provision were determining factors.
Having access to direct payments can bring many benefits. Direct payments can lead to a reported growth in self-worth (Johnstone, 2000) and can enable people to participate in activities and pursuits of their own choosing, for example attending a gym, which can promote social inclusion and participation by facilitating access to the kinds of opportunities of a normal life that people without the restrictions of mental illness may take for granted (Witcher, et al. 2000; Carmichael & Brown, 2002). Direct payments can enable the purchase of more flexible help, facilitate better continuity of care, allow greater control and an enhanced quality of life and well-being, compared with conventionally determined services (Glendinning, Halliwell, Jacobs, Rummery, & Tyrer (2000).

The value of empowerment, independence and the exercise of choice and control by people using services is a recurrent theme in care provision policy (Ridley & Jones, 2003). Using direct payments an individual can have the opportunity to decide what needs they have and seek to find effective solutions to meet those needs. It is intended to be an outcomes focused, proactive and empowering exercise, and encourage the individual to be responsible in managing their care; this kind of process can, in itself, result in mental health benefits (Taylor, 2008). The concept behind direct payments links with many of the principles of recovery, as described in Slade (2009), such as self-managing mental illness and developing a positive identity. Direct payments are intended to encompass a person centred and empowering concept (Spandler & Vick, 2006) but the reality of the experience of those seeking and using the payments has been fraught with difficulties (Taylor, 2008).

One use of direct payments by receiptants has been to employ a personal assistant. (PA). It is argued in the independent living movement that employing a PA is a very empowering way in which direct payments can be used (Spandler & Vick, 2006). Spandler (2004) and Glendinning et al. (2000) reported that employing PAs through direct payments offers many benefits for recipients but that it can also produce some difficulties.
This present study interviewed both people who experience mental illness and their carers on their experience of accessing and using direct payments. The study sought to investigate what are the self-reported barriers, fa-

cilitators, problems and successes, and to discover what recommendations could be made to those involved in seeking, using, assessing, supporting, supplying and reassessing direct payments. There was a particular focus on investigating the experience of seeking to employ and employing a personal assistant (PA) through direct payments.

Methods

Design

This study employed a qualitative methodology using telephone semi-structured interviews.

Sample

The inclusion criterion for the study was to have experience of trying to access direct payments, either successfully or unsuccessfully. The participants were recruited through advertising the opportunity to take part through third sector organisations such as the charity Rethink Mental Illness. A total of nine carers (three male and six female) and twelve people who experienced mental illness (four male and eight female) were interviewed. Seven participants stated that they had not been able to access direct payments. At the time of the interview, one participant was still waiting to hear whether or not he would be successful. Seventeen participants ascribed their ethnicity as white British (eight carers), one as East European, one as Greek Cypriot, one as Bangladeshi (carer) and one as Indian.

Research Measures

Two separate questionnaires, one for people with experience of mental illness and one for their carers were designed by the research team, which included a person with lived experience of mental illness. The questionnaire for people with experience of mental illness asked about availability and ease of access to direct payment related information. A care co-ordinator or key worker is often one of the most important care professionals in the life of a person who experiences mental illness and so they were questioned about awareness of their care coordinator's knowledge of and support in seeking direct payments. The people who experience mental illness were questioned about being offered direct payments information or if they had to take the initiative to request it. They were asked to share personal reflections on direct payments, as to whether they felt that the process was helpful, and whether they were satisfied with the choices on offer.

The participants with experience of mental illness were questioned about their experiences of the process of buying services. Information was gathered on what the interviewees spent money on, whether on PA services, or alternative modes of care, and how their choices impacted on their sense of wellbeing. 13. The participants were asked: 'What impact has using the DP had on you?' The interviewees' opinions were sought as to how the direct payments system could be improved, whether they had required additional support, whether they would recommend direct payments to someone else, and what advice they would give to that person. Those who had been refused a direct payment were asked about the appeal process, and about the ways in which they were supported if they decided to proceed. The interviewees were also asked about other options for care needs that they were presented with following refusal, and whether refusal had put them off applying again for direct payments in the future.
The carers were asked a similar set of questions to the individuals with experience of mental illness in relation to their involvement and role in the direct payment process.

Procedure

Participant information sheet and consent forms were posted out to participants prior to interview. Telephone interviews were conducted by a single researcher, ensuring consistency. Informed consent was obtained orally and digitally recorded. The interviews were digitally recorded. A semi-structured interview approach was employed, allowing key themes to be explored but providing an opportunity to examine issues raised by interviewees. This approach encouraged dialogue, enabling more comprehensive responses to be collected. All participants were offered a £10 voucher as a 'thank you' for their participation.

Analysis

Thematic analysis through the guidelines of Braun & Clarke (2006) was undertaken to identify key themes and deviant cases. Thematic analysis was employed here to identify and provide a detailed account of themes related to direct payments. This was undertaken through a number of phases: 1. data was coded into meaningful segments; 2. codes were sorted into potential themes; 3. a process of refining, separating and collapsing themes was undertaken; 4. the essence of what each theme is about was identified and the themes were named and quotes identified to support themes. Two coders worked separately and came together to agreed final themes.

Declarations

There are no known conflicts of interest. Both authors certify responsibility for the article as specified and required in the journal's author instructions.

Results and Discussion

The following results and discussion is divided into five sections which group together major themes in the data.

Motivators in applying for direct payments

A key motivator for individuals with experience of mental illness and their carers to apply for direct payments was the belief that direct payments offered the opportunity of more effective care provision and a more individually tailored model of care that could meet their needs to a greater extent. One of the reasons reported by both carers and service users for their involvement in the direct payments process was to widen social network and interests, factors which are seen as key in recovery, social inclusion and well-being. In addition, knowledge of rights to direct payments was reported as being a strong motivating force.

Another driving factor was dissatisfaction with existing care and services. Some interviewees described how they sought to meet their needs through the local authority and NHS but found that specific therapies (e.g. reflexology or counselling) or services (e.g. respite) that they felt that they required were not available; they then applied for direct payments in order to access these therapies and services.

Factors in direct payments application and success in application

The interview analysis revealed a range of factors in influencing whether a person with experience of mental illness applied for direct payments, as well as the chances of their application being successful. It was clear that having a supportive and proactive carer often played a vital role in the decision to seek to access direct payments, and in the potential success in doing so. It was often the carer who helped to identify how useful a direct payment could be. Also of vital importance in whether a person with experience of mental illness, or their carer, sought to access direct payments was a belief in the fundamental principles behind direct payments: choice, freedom, empowerment, control and better care, and the benefits that these factors could produce.

Having a supportive and proactive carer was reported as a key factor for many interview participants' success on their journey to acquire direct payments. There were however, some issues experienced by carers who took on the role of providing help in seeking direct payments for the person that they care for. One carer stated that they were told that they were unable to conduct the process by proxy, as confidential information was involved. Interview analysis also drew attention to the additional administrative workload that carers could face in providing support for the individuals they cared for in using direct payments. Nonetheless, all the carers interviewed stated that direct payments had made their lives easier.

Levels of self-confidence, self-efficacy and assertiveness were key factors in determining whether a person with experience of mental illness or their carer decided to try and access direct payments, and their chance of success. Many carers and people who experience mental illness are disempowered and socially excluded which can lead to lower levels of self-confidence and self-efficacy. This can stifle their motivation and ability to apply for, successfully navigate the process, and succeed in accessing direct payments, and this may contribute to low take up. This emphasises the need for high levels of support (information, guidance and encouragement) and having a system which is transparent, clear and simple. It highlights that the present system favours those who are empowered, socially included, and have high levels of self-confidence and self-efficacy, which further increases inequalities. It seems inequitable to have a system which can bring benefits in terms of choice, empowerment, control and better care which discriminates against those who are in greatest need.

Success in accessing direct payments also depended on the ability to make a strong case for direct payments; and this depends on, to some extent, having a high level of cognitive skills, for example, how articulate and organised they are. One interviewee stated: “the paperwork is very involved” (C03). The system can discriminate against those without a high level of cognitive ability. Although interviewees recommended that direct payments were worth fighting for, many people who experience mental illness may lack motivation and the cognitive skills to successfully apply for direct payments. One interviewee sated that they: “really went for it, because they [DPs] can make such a positive difference” (C06).

Many interviewees had a poor experience (for example, a lack of information or support) of trying to access and use direct payments. One carer assisting the person who they cared for stated that they had to: “bend over backwards because I haven’t had enough support” (C10). Such experience might deter future applications for the payments, both from individuals who have accessed them in the past, and others who have heard about the challenges of the system. A direct payments process which is disempowering goes against the core principles of the direct payments ethos.

The interviewees revealed the importance of health and social care professionals in the direct payments process. Key stories presented in the interviews described how healthcare professionals who were informed, and who provided information, support, guidance and encouragement in relation to direct payments, made a significant difference in the prospect of achieving direct payments. This highlights the value of training on all aspects of direct payments for health and social care professionals.

The need for this training was emphasised further as some interviewees revealed that care coordinators acted inappropriately as gatekeepers for direct payments. Rather than supporting the person to apply they decided whether they thought the person should apply and if they did not think that the person should apply they either did not provide information, support and assistance, or in some extreme cases, they actively blocked the application. Ridley & Jones (2003) also found evidence of prejudicial attitudes of some staff, and that some staff did not perceive people with experience of mental illness as able to manage direct payments. This can be a major barrier to direct payments if staff believe people are either: “not ill enough to have care needs, but if they do have care needs are too ill to meet the criteria to manage a direct payment” (Taylor, 2008, p.47). Other reasons identified by Taylor (2008) as to why staff might not support direct payments include a fear of change, a reluctance to share power, to take positive risks, to surrender control, to stand back to enable people to take their own decisions.

These issues could perhaps be addressed partially through more support for care coordinators, as some interviewees felt that there was a lack of support in relation to direct payments for frontline health and social care staff from their managers and the organisation that employed them. Dawson (2000) stated that good practice should be that care coordinators start by assuming capability rather than lack of capability.

The interviews revealed that if local authorities are flexible and innovative in what they allow direct payments to be used for it can be beneficial to the person who experiences mental illness and their carer. This aligns with the findings of Spandler & Vick (2006, p. 107) who found: “When given the opportunity, service users were able to use direct payments creatively to meet a range of needs in ways which increased their choice, control and independence.” The interview analysis presented an example in which a person with experience of mental illness was given real freedom of choice in deciding the best way to spend their direct payments. The interviewee stated that they had been provided with: “choice and control” (S08). This allowed the person with experience of mental illness to take ownership and be creative in deciding how to spend the money to best improve their health and wellbeing.

Support groups were also mentioned as being of great importance in the drive for direct payments, for example, the carer community with the links, support and advice that it can provide. Support groups can provide emotional support and practical aid, and access to information. The strength of interview participants’ social networks could be seen to determine access to information and support.

Ridley & Jones (2003) identified a key barrier to direct payments: a lack of knowledge and understanding of direct payments. Not having information about direct payments was found to be a fundamental obstacle to progress. One notable initiative is the Department of Health funded learning opportunity: 'Is it for me? A learning journey to direct payments’; which has been designed by NIACE (2006) to empower people to learn more and make informed decisions about direct payments. Hopefully this training will be made widely available. In this study, awareness, availability of, and ability to access information and advice emerged as a key theme in determining how accessible participants found the direct payments process. It was reported however, that local authorities did not take responsibility for providing sufficient information and advice.

Information and advice was accessed via other sources, for example, the internet (on sites such as direct.gov.uk) and from advisory services for example, those provided by Rethink Mental Illness and the Centre for Independent Living. The interviews highlighted that this kind of information and advice needs to be followed up with access to face to face support (from the local authority, healthcare professionals or the third sector) to facilitate the application process and access to direct payments. As Taylor (2008, p.46) stated: “Only through providing adequate support can local authorities enable mental health service users to make informed decisions…”. Spandler & Vick (2006) explained that having assistance to be able to pursue self-defined goals and aims is crucial for recovery.

The importance of personal assistants

One key aspect of the interviews was the importance of personal assistants (PAs) in the lives of people who experience mental illness and their carers. Previous experience of PAs was described by some as poor. Participants described a low quality service: PAs who were inadequately trained, and uncertainty about which PA might turn up on any given day (in one case, the participant described how this uncertainty caused considerable stress). Direct payments allowed people to choose a PA who matched their needs and who possibly had experience and training in working with people with experience of mental illness. People who used direct payments to employ a PA were able to take responsibility for quality control, employing someone who they felt that they could get on with, possibly of a similar age or with similar interests. This confirms the findings of Glendinning et al. (2000). As Glendinning et al. (2000) also found having a single PA who they had chosen enabled more consistent support, and the development of mutually beneficial ways of working. It also facilitated a stable relationship with the PA to develop, and allowed the PA to respond to their client on a more personal level, for example, to understand the effects of changes in mood and how to respond to these. The positive relationships with Pas and the benefits of this was also reported by Glendinning et al. (2000).

When direct payments were used to employ PAs, carers described how they experienced the benefits, citing reduced hours of care, less domestic work and so on, although in some cases, they described how helping to manage the direct payment led to an increase in their administrative workload. The potential of a reduced care load was described as a motivating factor for some. Others described how they thought that a PA hired through direct payments offered the opportunity for the person that they cared for to develop skills which would help improve independence, and reduce dependence on them as a carer. One carer interviewee stated: “it feel[s] like a huge burden has been taken away” and another stated that they feel: ‘less responsibility’ and ‘less drained’ (C03). This reduction in burden and responsibility could enable carers to take a holiday, get a job or engage in more social and leisure activities, all of which could be beneficial to their mental and physical health and their relationships with family, friends and the person that they provide care for.

Benefits of direct payments

Direct payments allow the creation of a bespoke care and support plan, and the funding resources to deliver this plan. Interviewees described a variety of benefits brought about by direct payments such as their ability to improve social lives, reduce hospital admissions, raise standards of living, increase levels of empowerment, improve mental and physical health, and improve prospects for obtaining employment. One interviewee described having direct payments as: ‘the best thing since sliced bread” (C07). Direct payments have the potential to enhance the lives of carers, people who experience mental illness, and their families. Another interviewee stated that direct payments: “...allows you to step out of that usual service user circle” (S18). Ridley & Jones (2003) reported that carers listed a range of benefits for themselves and the person that they cared for. Carer interviewees in this study described benefits that they derived through reduced care related responsibilities and time spent caring.

Ridley & Jones (2003, p. 647) found that people: “were frustrated with aspects of home support that did not meet their individual needs.” One of the key advantages of direct payments reported by interviewees in this study was that they can be a solution when the existing social and healthcare systems and provision are failing to meet their needs. A solution to social and healthcare needs is much more likely to be appropriate and effective when a person who experiences mental illness is engaged in and leads this process. Applying a solution that is more likely to be appropriate and effective can save money. There may however, remain a focus on: “providing adequate services at a minimum cost through offering packages of care which are easily available rather than evaluating what a mental health service user actually needs…” (Taylor, 2008, p. 50).

Issues of uncertainty

Although direct payments can bring benefits in terms of mental health for both people who experience mental illness and their carers (if they have one), they can also bring risks. The interviews revealed that the process itself can be stressful, and that disappointment in a rejected application can be harmful to mental health and leave people feeling disempowered, excluded, and with a sense of injustice. One interviewee stated that: “Direct payments are a fantastic concept, but the administration is actually really bad” (S17).

There are also new challenges associated with a successful bid for direct payments, which may result in difficulties for people. These include the increased responsibility of spending the money and, if a person is choosing to do so, challenges relating to hiring, employing and managing a PA. However, in general interviewees felt that the benefits of this positive risk taking outweighed the difficulties.

A major issue for some was the stress caused by the six month reassessment of direct payments that had previously been authorised. After the difficulties involved in securing direct payments, the prospect of losing them at the six month review was challenging. The outcomes focused nature of direct payments meant that when targets were met, and an individual’s mental wellbeing had improved, a review could determine that the direct payment was no longer necessary. Direct payments that enabled recovery could be removed and the person who experiences mental illness and their carer had little or no control over this. This caused a sense of uncertainty and powerlessness, and a fear of the reviewing process was reported by interviewees as having a negative effect on their mental health and well-being. A carer interviewee stated that direct payment stability was: 'incredibly important' for long term recovery.

The rules for direct payments were described as being subject to various changes which created problems, as the goal posts of achieving direct payments were moved. This made it difficult for health and social care staff to provide valid and up to date information. It also caused confusion and frustration for interviewees.

Another area of great frustration for some was the appeals process. The appeals process was one which was described as being fraught with problems and delays. Interviewees reported a significant problem in that their appeals were often not even processed, raising the need for this system to be examined for its effectiveness. One interviewee stated that: "the admin is lousy" (S18).

Some interviewees described a significant time lag between recognition of the need for direct payment provision and the process starting, citing the negative effects that this had in terms of their mental health. In some cases interviewees reported that direct payments did not automatically rise with increases in service costs, leaving the person short of money to pay for the services that they were accessing through direct payments.

Conclusion

Difficulties in obtaining and maintaining direct payments were reported by the interviewees, but many described how the benefits of the payments made the struggle to access them worthwhile. It is hoped that if the direct payments process becomes further refined and established, more people (practitioners, care coordinators, people who experience mental illness and their carers) will have greater knowledge of direct payments and the systems involved. If this is the case, there would be more effective support for people seeking to access the payment, and therefore a higher take-up and less apprehension about losing direct payments that have been provided.

This research has identified that dissatisfaction with existing care and support services and a belief that direct payments can more effectively meet needs are motivating forces in seeking direct payments. The analysis revealed the importance of supportive carers and healthcare professionals in achieving direct payments. It also illuminated the need to address inequalities in the direct payments system that discriminates against those in greatest need.

The research highlighted various benefits that could be derived from having direct payments (Glendinning et al. 2000; Johnstone, 2000; Witcher, et al. 2000; Carmichael & Brown, 2002) and, as previous research has identified (Spandler & Vicks 2006; Taylor, 2008) these benefits can only be achieved if people are made aware of their right to access direct payments, and are provided with the necessary information and support. Of paramount importance for care co-ordinators in providing support for direct payments should be the goals and aspirations of the person who may benefit from direct payments.

The research confirmed the advantages that having the power to choose and manage a PA through direct payments could have for people who experience mental illness (Glendinning et al. 2000). Having a PA through direct payments was also revealed as being beneficial to the carer of the person who employed the PA though reducing the hours of time spent on caring duties, and increasing the carer's independence, although many carers commented on increased administrative demands associated with helping the person they cared for to become an employer. Direct payments were reported as having the potential to benefit the mental health of the person receiving them, as well as that of their carer; nevertheless the six month reassessment process was reported as being damaging to mental health.

There should continue to be actions taken to improve the process of and take-up rates of direct payments for people who experience mental illness to facilitate benefits identified. There are a number of recommendations that emerge out of this study that build on previous recommendations such those made by Ridley & Jones (2003).

The recommendations from this study are:

1. Where possible, assurances should be communicated to people with mental illness around the security of direct payments funding.

2. Local authorities should engage with third sector organisations to work with them in providing information, guidance and support on direct payments.

3. Simplify the direct payments application process.

4. Provide training on direct payments for all frontline staff. This would need to include training on direct payments requirements, responsibilities, process and appeals system.

5. Ensure resources are dedicated to processing direct payments applications to reduce delays reported in this study.

6. Local authorities should ensure that high levels of individualised information, guidance, and support are provided to people with mental illness and their carers when they are going through the process of hiring PAs.

7. Provide 'working with people with mental illness' training for PAs.

8. Take measures to ensure that direct payments rise automatically with inflation or service costs.

9. Consult carers, people with mental illness, and the groups that represent them to identify problems in the direct payments systems and discuss possible solutions.

10. Enhance the efficiency of direct payments appeals process.

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